

**Acceptability of and adherence to a
Tai Chi exercise intervention to prevent falls
among older people living with dementia**

A thesis submitted in fulfilment of the requirements of Bournemouth University
for the degree of Doctor of Philosophy

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Abstract

Acceptability of and adherence to a Tai Chi exercise intervention to prevent falls among older people living with dementia

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Exercise interventions are effective in preventing falls, however, few have involved people living with dementia and explored their experiences. The aim of this PhD thesis was to fill this gap by exploring the experiences of dyads (formed of a person living with mild-to-moderate dementia and their informal carer) taking part in a Tai Chi intervention program, including class and home-practice. Participants' acceptability of and adherence to the Tai Chi intervention was studied alongside the Intervention Pilot Phase (3/4 weeks long) and the Randomised Controlled Trial Phase (20 weeks long) of the TAI CHI for people with demenTia (TACIT) Trial respectively, to inform how to enable their sustained participation in this exercise intervention.

Participants recruited from localities in the South of England's experiences were explored using qualitative methods. These included field notes (at both phases) to record researchers' observations during the classes and participants (n = 10 dyads and n = 22 dyads, respectively) and instructors' feedback at the end of each class, 2 focus groups (n = 7 dyads, 1 at each site in the Pilot Intervention Phase) and 15 dyadic interviews (in the Randomised Controlled Trial Phase). Thematic analysis was used to inductively code the field notes and transcripts, which were then deductively linked to theory.

Findings suggest that a dementia friendly approach to the design of the intervention based on repetition and individualised support enacted participants' enjoyment and mastery of Tai Chi. Dyads discovered a new common activity and valued the importance of incorporating home-practice into their routines. Facilitators of adherence to the intervention point towards participants' enjoyment, perceived impact on well-being, social interactions with people in a similar situation and qualities of the instructor. Main adherence barriers to the intervention were difficulty following the booklet provided to support their home-practice, as well as unexpected or recurrent health problems and competing commitments.

In conclusion, people living with dementia and their informal carers could benefit from getting involved in a Tai Chi exercise program. Programmes that provide opportunities for practising Tai Chi in class and at home could provide a normalised shared interest to support communication, well-being, and quality of life.

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List of Accompanying Material

One paper was published online before this thesis' submission. This is a reduced version of contents reported in (and mostly directly extracted from) Chapter 4:

- Barrado-Martín, Y., Heward, M., Polman, R., & Nyman, S. R. (2018). Acceptability of a dyadic Tai Chi intervention for older people living with dementia and their informal carers. *Journal of Aging and Physical Activity*, published online 30 August 2018, DOI: <https://doi.org/10.1123/japa.2017-0267>.

At least two more papers are expected to be published from chapters 5-7.

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Author's Declaration

This dissertation is submitted for the degree of Doctor of Philosophy at Bournemouth University. The research described here was conducted under the supervision of Dr Samuel Nyman, Professor Remco Polman and Dr Michelle Heward, between January 2016 and January 2019.

This work is, to the best of my knowledge, original except where acknowledgements and references are made to the previous work. As this work is embedded in the TACIT Trial, a detailed description has been made in Chapter 1 (section 1.5.) and in Appendix A of my individual contribution through this thesis.

Further to what is reported in the List of Accompanying Material section, a summary of the Pilot Intervention and RCT Phases' findings have been presented in national and international conferences both through oral and poster presentations.

1. Introduction

This opening chapter aims to provide the reader with an overall picture of the elements integrating this thesis in the context of an ageing population, as well as its structure. Hence, the first four subsections define and contextualise: 1.1 Dementia; 1.2 Falls; 1.3 Physical activity and exercise; and 1.4 Acceptability and adherence. Whereas the last subsection (1.5) describes this thesis in terms of its: 1.5.1 Aims and research questions; and 1.5.2 Structure.

1.1. Dementia

One of the greatest successes of the last century has been the increase in life expectancy rates, however, it has arrived with a new challenge given population is ageing globally (UK Parliament, 2015; United Nations, 2017). As people age, the chances of accumulating two or more health chronic conditions (or experiencing comorbidity) increase (WHO, 2015), which is related to the increased risk of mobility disabilities (Fried, Ferrucci, Darer, Williamson, & Anderson, 2004).

One of the chronic conditions that can occur with age is dementia. Dementia is a condition that is estimated being currently affecting 46.8 million people around the world, and a rising tendency leading towards 131.5 million people living with dementia by 2050 has been projected (Alzheimer's Disease International, 2015). In the UK context, there seems to be a similar tendency. At the moment, it is calculated that 850,000 people (representing approximately 7.14% of those 65 years old and over (Alzheimer's Society, 2014a)) are living with dementia and by 2025 it is projected that this figure could grow up to 1 million (Alzheimer's Society, 2014b). However, a recent study comparing the incidence of dementia across two decades in the UK identified, in fact, a reduction of its incidence (Matthews et al., 2016). This study highlighted also the fact that even in the context of an ageing population, estimations around the amount of people who have developed dementia every year has not increased at the same speed. On the contrary, it seems that this amount has remained stable (Matthews et al., 2016).

Dementia has been medically described as a major neurocognitive disorder in the 5th Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) where one or more cognitive domains (i.e., attention, executive function, learning and memory, language, perceptual-motor function and social cognition) are significantly impaired. Such impairments may impact on individuals' independent performance of daily activities. Hence, dementia is different from Mild Cognitive Impairment (MCI), where similar cognitive domains can experience

a moderate decline, but that does not affect the individual's independent performance of daily activities. Accordingly, MCI has been described as a mild neurocognitive disorder in the DSM-5. An additional difference is that cognitive decline in MCI occasionally progresses to the characteristic decline of dementia, but it can also stabilise or even improve. Whereas the cognitive decline in dementia cannot be avoided, as there is no cure yet (Robinson, Tang, & Taylor, 2015). Dementia has also been characterised clinically as a syndrome, that is as an umbrella term that amalgamates different symptoms depending of the areas of the brain affected and the corresponding affectation on the cognitive domains (Bundy & Minihane, 2018). Different brain region's affectations give way to the different types of dementia (listed according to their prevalence - going from 63% to 2%): Alzheimer's disease (AD), vascular dementia, mixed dementia (Alzheimer's and vascular), Lewy body dementia, frontotemporal dementia, dementia in Parkinson's disease and other types of dementia (Alzheimer's Society, 2014c). Biologically then, dementia symptoms are the manifestation of the gradual damage in the structure of the brain. The origin of such damage will depend on the type of dementia, but frequently will be due to the abnormal presence of proteins that interfere the normal chemical exchanges between neurons or the lack of oxygenation of the brain (Alzheimer's Society, 2017).

Given the described impact of dementia, it has become a public health priority, with policies such as Challenge 2020 looking to make England the best place to live with dementia and to do research in dementia (Department of Health, 2015). However, more globally, the World Health Organization is also looking for more countries to develop their dementia policies (WHO, 2018).

1.1.1. Psychosocial interventions

In the absence of a cure for dementia, research has focused on ways of improving the quality of life (QoL)¹ of those living with dementia and their families. Psychosocial (or non-pharmacological) (Van't Leven et al., 2013) interventions led by professionals from different disciplines (such as Psychology, Nursing, Occupational Therapy, Social Education, Music, Arts) can be understood as tertiary prevention strategies that are aimed to reduce the impact of dementia on people's lives. Where possible, they are also intended to diminish the impact or the progress of this condition into more advanced stages.

Psychosocial interventions in the context of dementia have used diverse interventions such as sensory stimulation, cognitive training, social support or physical activity. However, a recent overview of systematic reviews has found more interventions

¹ QoL is a broad concept which comprehends the result of the interaction "between social, health, economic and environmental" spheres impacting on "human and social development" (WHO, 2004, p. 48).

targeting participants living in residential settings than in the community, and a lack of evidence to support such interventions due to its heterogeneity (Clarkson et al., 2017). Apart from the type of intervention, the setting where these are conducted, or the group versus individual approaches used, there are also differences in the target of these interventions. Amongst psychosocial studies in the community, most target the person living with dementia and the carer separately, whereas only a few incorporate them in the intervention as a dyad (Rausch, Caljouw, & van der Ploeg, 2017). In the later review by Rausch et al. (2017), authors highlight they surprisingly found more randomised controlled trial (RCT) studies targeting carers than people living with dementia (70% versus 30%). This might point a trend to still focus research on proxies rather than in the individual living with dementia or highlight the scarce involvement of people living with dementia in research (Nygård, 2006). Despite the increase in participation of people living with dementia in research in the recent decades (Hubbard, Downs, & Tester, 2003), only approximately 4% of people living with the diagnosis are included in research studies (Department of Health, 2012).

The need to focus dementia research on those living with the condition is clear. Similarly, the under use of joint dyadic interventions despite the importance of relationships in the context of dementia is disappointing (Rausch et al., 2017). This is particularly important in light of another systematic review finding dyadic interventions being more effective in delaying dementia progression than pharmacological interventions (Laver, Dyer, Whitehead, Clemson, & Crotty, 2016). Finally, when looking at the psychosocial interventions conducted amongst people living with dementia (excluding formal or informal carers), little research seems to make use of qualitative methods to explore what works or could be improved from such interventions (Dugmore, Orrell, & Spector, 2015). This points towards the underuse of qualitative methods to understand how interventions work for people living with dementia and how to improve them; whereas the focus of psychosocial research remains on the quantitative assessment of QoL improvement. This has continued to be assessed this way despite the lack of consensus regarding the definition of QoL, and the lack of involvement of people living with dementia in developing such measures (Bowling et al., 2015).

1.2. Falls

Apart from dementia, another challenge of an ageing population are falls. Falls are the second most common cause of accidental death around the globe and occur more

frequently amongst those over 65 years and who are frailer² (WHO, 2007). The definition of a fall has been controversial as different people might define it in slightly different ways making reporting or study comparisons difficult (Gillespie et al., 2012). However, a consensus was reached in 2005 to define a fall as “an unexpected event in which the participants come to rest on the ground, floor, or lower level.” (Lamb, Jørstad-Stein, Hauer, Becker, & on behalf of the Prevention of Falls Network Europe and Outcomes Consensus, 2005, p. 1619).

The incidence of falls per year in older people seems to be around 30% (Gillespie et al., 2012), representing around 5% of the Accident and Emergency patients (Rubenstein, Powers, & MacLean, 2001). Such events have a direct impact on individual’s autonomy and QoL (National Institute for Health and Care Excellence, 2013). In fact, falls amongst older adults have been identified to be a strong predictor of their access to residential care (Tinetti & Williams, 1997). Similarly, experience of falls could affect their willingness to partake in activities they used to, due to the fear of losing independence and damage their personal identity (Yardley & Smith, 2002). However, as in the case of dementia, falls do not only have an impact on the individual and his or her closer social network and environment, but also in the social and health care systems (WHO, 2007).

Falls have been associated to occur more likely amongst older adults due to the biological decline attributed to the ageing process, as well as the highest chances to experience comorbidity (Samaras, Chevalley, Samaras, & Gold, 2010). However, not only biological causes have been identified behind falls, but also behavioural (i.e., lack of exercise), environmental (i.e., lack of lighting), and socioeconomic factors (i.e., difficulties to access healthcare) (Sousa et al., 2017; WHO, 2007) that could be potentially modified. Hence, falls are described as multifactorial.

Due to the impact of falls on the individual and the cost to society of looking after people after a fall, a variety of interventions have been attempted to reduce the risk factors for falls amongst those living in the community (Gillespie et al., 2012).

Nevertheless, participants’ adherence to falls prevention interventions remains to be a challenge (Osho, Owoeye, & Armijo-Olivo, 2018). In most of these studies, moreover, people living with dementia have been excluded even when they are between two and three times more likely to experience a fall, at higher risk of getting injured, and face a

² Frailty has been described as “a state of increased vulnerability to poor resolution of homeostasis after a stressor event, which increases the risk of adverse outcomes, including falls, delirium, and disability.” (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013, p. 752). That is a disorder where the individual’s health status changes radically due to a minor illness, and does not fully recover its previous functional level, leaving the individual more vulnerable to other adverse events. Frailty has also been interrelated to sarcopenia, which refers to the muscle mass loss associated to the aging process (Nascimento et al., 2018).

more difficult recovery including greater risk of mortality (Aizen, 2015; Allan, Ballard, Rowan, & Kenny, 2009; Fernando, Fraser, Hendriksen, Kim, & Muir-Hunter, 2017; Shaw, 2003). This could be because the risk factors for falls in older people with and without dementia have been shown to have similarities and differences. For instance, age and gender has been identified as a risk factor amongst older adults without dementia, whilst there seems to be no such difference in the context of dementia; whereas in the context of dementia, performance in daily living activities and dementia severity can be more relevant factors (Fernando et al., 2017). Furthermore, people living with dementia could experience more negative consequences from a fall such as a loss of confidence, and an actual higher chance of experiencing future falls (Allan et al., 2009). It has been argued that people living with dementia might be at a greater risk of falls as:

“They are more likely to experience problems with mobility, balance and muscle weakness; Can have difficulties with their memory and finding their way around; Can have difficulties processing what they see and reacting to situations; May take medicines that make them drowsy, dizzy or lower their blood pressure; Are at greater risk of feeling depressed; and May find it difficult to communicate their worries, needs or feelings” (The Scottish Government, 2018).

A recent systematic review only supported balance alterations, specific drugs intake, depression, carer’s distress, orthostatic hypertension and the history of falls as the risk factors for falls amongst people living with dementia (Fernando et al., 2017). As risk factors are particular for people living with dementia, falls prevention interventions that work among community-dwelling do not necessarily work in residential care settings (Cameron et al., 2018; Gillespie et al., 2012). Likewise, interventions that work in the general older adult population have not been found to work among those with dementia. In community-dwelling people living with dementia, physical activity has been attributed a protective effect against falls (Allan et al., 2009). In this line, when falls prevention interventions targeting people living with dementia in the community have been studied, exercise has been found to be potentially useful for this purpose (Burton et al., 2015).

1.3. Physical Activity and Exercise

In the literature, “exercise” and “physical activity” have been frequently used interchangeably. However, a useful differential definition was suggested over thirty years ago where exercise was defined as only a part of physical activity. Hence, physical activity is a broader term that includes any action that burns calories (apart from basal metabolic consumption) such as our movements when we are at work or in

our leisure time. Whereas exercise is defined as the “physical activity that is planned, structured, repetitive, and purposive in the sense that improvement or maintenance of one or more components of physical fitness³ is an objective.” (Caspersen et al., 1985, p. 128). Having made this distinction, this thesis will focus on exercise rather than physical activity. This is due to the type of intervention under study and its aim: An exercise intervention (Tai Chi) looking to improve an aspect of physical fitness (balance). There is an abundance of evidence which has indicated that regular exercise participation protects against age related decline, although “adherence issues” have been less studied (Lam & Cheng, 2013, p. 171).

1.4. Acceptability and Adherence

By studying the acceptability of and adherence to an intervention it is possible to identify aspects of the intervention that would need refinement to facilitate participation and maximise its impact. Despite being different concepts, there is a relationship between acceptability and adherence in practice, as the acceptability of the intervention will facilitate participants’ adherence to it (Sekhon, Cartwright, & Francis, 2017). The acceptability of an intervention reflects to what extent the intervention is perceived as adequate by the target population and has been described as a “multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention.” (Sekhon et al., 2017, p. 8). It has also been postulated to be a difference between the acceptability and the satisfaction with an intervention. Whereas the former can be studied at different time-points: before joining an intervention, during and after being involved in the intervention; satisfaction can only be assessed *a posteriori* (Sekhon et al., 2017).

In contrast, adherence to the intervention shows to what extent the target population participated in the intervention. There is an important difference between adherence and compliance. Whilst adherence assumes a joint agreement reached between the intervention’s deliverer and the individual target of the intervention (i.e., when the gym instructor and client agree the weekly exercise routine). Compliance infers that the individual target of the intervention does not take an active role in deciding its involvement in the intervention, which is imposed by the intervention’s deliverer (i.e., when the doctor prescribes medication to treat an infection).

³ Physical fitness includes a series of aspects people try to improve through exercise such as muscle strength and endurance, flexibility, balance or speed (Caspersen, Powell, & Christenson, 1985).

One thing is clear though, studying the acceptability and adherence of an intervention it is key when delivering innovative interventions or implementing known interventions in a new population. Studying acceptability and adherence might explain why elements that worked in previously tested contexts, do not necessarily translate to successful results in other settings. Similarly, the study of both aspects can contribute to explain if what worked or did not work was the intervention or the way it was implemented (Craig et al., 2008; Oakley et al., 2006). Hence, the assessment of the ways an intervention is implemented, received, and the context where it takes place (or a process evaluation) it is fundamental to understanding an intervention's positive or negative outcomes, as well as the different results obtained in different settings (Craig et al., 2008; Oakley et al., 2006).

In the face of complex healthcare interventions, the combined use of quantitative and qualitative methods has been advised to facilitate its reproducibility (Campbell et al., 2000) and acceptability (O'Cathain et al., 2015). The use of qualitative methods, especially in the context of dementia, is of interest as can keep researchers and the research process sensitive to the participants involved. Qualitative methods can generate knowledge which could be used in future trials to make interventions more effective for this population (Gibson, Timlin, Curran, & Wattis, 2004; O'Cathain, Thomas, Drabble, Rudolph, & Hewison, 2013). Predominantly RCTs focus on the use of quantitative methods to assess the effectiveness of interventions, to the detriment of qualitative methods (Lewin, Glenton, & Oxman, 2009). More recently, a trend towards using qualitative methods at pretrial phases has been noted (O'Cathain et al., 2013). However, reporting of qualitative methods in RCT protocols is still lacking (Drabble, O'Cathain, Thomas, Rudolph, & Hewison, 2014). A final point has been made on the importance of integrating quantitative and qualitative results (Lewin et al., 2009) to create an enriched picture.

1.5. This PhD Research Project

This thesis is embedded in a larger three-year project, The TACIT Trial: TAI CHI for people with demenTia⁴, funded by the National Institute for Health Research (NIHR) through a Career Development Fellowship awarded to Dr Samuel Nyman. The TACIT Trial, as well as the idea of integrating a process evaluation as part of the Trial was developed by Dr Samuel Nyman, prior to the start of this thesis.

⁴ The TACIT Trial's primary objective was to assess the impact of Tai Chi in improving people living with dementia's dynamic balance. The secondary objectives of the TACIT Trial include the assessment of further areas that could be potentially benefited because of Tai Chi practice. These areas include global cognitive functioning, QoL or fear of falling, amongst others described in the trial protocol (Nyman et al., 2018).

A process evaluation is described as an integral part of the TACIT Trial Protocol. This thesis represents an important part of the process evaluation and shadowing The TACIT Trial's design comprises two main studies: The Pilot Intervention Phase, and the Randomised Controlled Trial (RCT) Phase. In the TACIT Trial, participants living with dementia are recruited in dyads, formed by the person living with mild-to-moderate dementia and an informal carer⁵. At both stages, participants taking part in the intervention are invited to weekly Tai Chi classes and encouraged to practise at home.

Tai Chi is an exercise that shows promise for preventing falls among people living with dementia. However, there is a lack of high-quality studies investigating the potential benefits of Tai Chi for community-dwelling older people living with dementia and their carers (see Chapter 2). There is, furthermore, a lack of studies focusing on the experiences of people living with dementia taking part in exercise interventions. For this reason, an evaluation that covers the intervention process, providing a complete description of the context from the beginning to the end of their participation, including participant's experiences is needed. In this thesis, the acceptability of (in the Pilot Intervention Phase) and adherence to (in the RCT Phase) a Tai Chi exercise intervention delivered to community-dwelling participants living with dementia and their carers is examined using qualitative methods (as outlined in Chapter 3).

Given the complex setting of the TACIT Trial, together with the author of this thesis there was a second PhD student looking at the role of Behaviour Change Techniques and adherence using quantitative methods. Both PhD students' work made up the process evaluation of the TACIT Trial. Similarly, both PhD students oversaw TACIT's data collection and good part of its management (further details on tasks performed by the author are provided in Appendix A). It needs to be added, that PhD 2's role in the TACIT Trial was as a blind researcher, unaware of participants randomisation's outcome, unlike PhD 1 (author). Hence, this thesis author's contributions are related to the recruitment stage and the 6 months study time between baseline and follow-up assessments. This way, the objectivity of baseline and follow-up is ensured, being conducted by PhD 2 (blinded to participants allocation). This thesis author's role in the Pilot Intervention Phase was to assess the acceptability of the Tai Chi and data collection process amongst people living with dementia and their carers. Results from this first phase informed refinements for the following (RCT) Phase. Author's contributions to make this thesis her own included: a) Choosing the approach to the literature review; b) Tailoring the research questions following the gaps identified through the literature review; c) Choosing the theoretical approach of this thesis (Self-Determination Theory); d) Liaising with the patient and public involvement (PPI) group

⁵ Informal carers or caregivers are those who provide unpaid support to people living with dementia. They can be family members, friends, neighbours or volunteers; who are not necessarily trained to provide this assistance.

to discuss the appropriateness of qualitative methods chosen and planned questions; and e) Choosing the analytical approach (thematic analysis).

1.5.1. Aims and research questions

Following the gaps identified in the previous subsections of this chapter as well as from the literature review (see Chapter 2). This thesis examined three main questions (for research sub-questions see Appendix B):

- 1) What influences participants' acceptability of a Tai Chi exercise intervention?
- 2) What prompts or mitigates participants' adherence to a Tai Chi exercise intervention?
- 3) How do people living with dementia and their informal carers experience their joint participation in a Tai Chi exercise intervention?

The aim of this research was to understand the experiences of people living with dementia and their carers taking part together in a Tai Chi intervention designed to prevent falls amongst people living with dementia. Specific objectives sought to:

- 1) Identify practical issues of the Tai Chi intervention and research process that may reduce participant's acceptability of the intervention.
- 2) Enhance knowledge and understanding on what aspects of the Tai Chi exercise intervention are influencing participants' engagement. Such understanding will inform on ways of facilitating their adherence to the intervention and potentially increase future exercise's research impact.
- 3) Understand how people living with dementia and their carers experience their joint participation in a Tai Chi exercise intervention, allowing identification of potential advantages and disadvantages.

1.5.2. Structure

Having contextualised this thesis in terms of its main elements, its aims and approach, it is finally time to introduce its structure. To better understand the needs of people living with dementia and their carers at the two stages of the TACIT Trial this thesis has been structured in the following way:

- Chapter 1. Introduction: Has introduced the different terms and elements involved in this thesis (i.e., dementia, falls, exercise, acceptability and adherence) highlighting its rationale, and described its aims and research questions.
- Chapter 2. Literature Review: Provides in-depth view on the research conducted around the main elements of this thesis and strengthen its rationale and unique contribution.

- Chapter 3. Methodology and Research Design: Describes and justifies this thesis' methodology, the methods chosen, as well as the ethical approach and the planned analysis. It also captures the initial research design for each phase, including its time-frame, and the one actually implemented.
- Chapter 4. Pilot Intervention Phase: Illustrates the lessons learnt from the Pilot Intervention Phase's implementation and participants' experiences impacting on their acceptability of Tai Chi. Later it discusses the findings and identifies strengths and weaknesses of this first study and suggests areas of future work.
- Chapter 5. Randomised Controlled Trial Phase: Participants and Study Setting. Depicts in-depth the intervention context, including the recruitment and implementation process, and the characteristics of venues, participants, and instructors. This chapter sets the scene of the findings related to the second study of this thesis (and RCT Phase of the TACIT Trial), that are then presented in Chapters 6 and 7.
- Chapter 6. RCT Phase: Experiences of the Classes. Explains the findings relative to participants' experiences of the classes and how these impact on their sustained attendance. Later, relates these back to previous research and theory and suggests future areas of research.
- Chapter 7. RCT Phase: Experiences of Home-Practice. Reports on participants' experiences of home-practice and the benefits or harms attributed to their participation which could affect their sustained practice at home. Findings are then discussed, strengths and weaknesses are identified and future areas of research are recommended.
- Chapter 8. Epilogue: Provides a summary of the main findings of this thesis, as well as the take home messages for future research and practitioners delivering exercise interventions for people living with dementia in the community.

2. Literature Review

This chapter provides a review of exercise interventions conducted amongst people living with dementia. The focus is on the literature related to interventions conducted in dyads (formed by people living with dementia and informal carers, henceforth “carers”) living in the community, where Tai Chi is the intervention delivered, and falls prevention or balance improvement as the main outcome(s). However, due to the lack of research in this specific area, neighbouring exercise literature has also been reviewed.

The chapter includes four main sections: 2.1 Introduces the aims of this literature review; 2.2 Reports the method followed to search for relevant literature; 2.3 Presents the literature reviewed; 2.4. Provides a theoretical background and a justification of the theoretical approach chosen for this thesis; and 2.5 Summarises the content of this literature review.

2.1. Aim

This literature review critically analyses exercise interventions for people living with dementia and their carers. The aim is to answer three specific questions:

- What are the methods used in previous (process) evaluations of exercise interventions for people living with dementia?
- How have these methods been reported in research publications?
- Which factors influence people living with dementia and their carers’ uptake and adherence to exercise interventions?

2.2. Search Strategy

This thesis is embedded in a larger randomised controlled trial (the TACIT Trial). The approach to this literature review is based on the Population, Intervention, Control and Outcome (PICO) model (see Figure 1 and Appendix C) which has been used extensively to generate research questions in clinical research (Aslam & Emmanuel, 2010). In fact, in clinical research, this approach has been used to conduct “thorough literature search [es]” (Aslam & Emmanuel, 2010, p. 50) facilitating the identification of gaps in previous research and, in turn, the development of relevant research questions for the population under investigation.

The acronym PICO has also been used to generate search questions (Willson, 2007). It provides an orientation to the relevant literature around a given topic by asking the researcher about the target population of the study, previous interventions the researcher can learn about and their purpose, allowing enhancement of the new project.

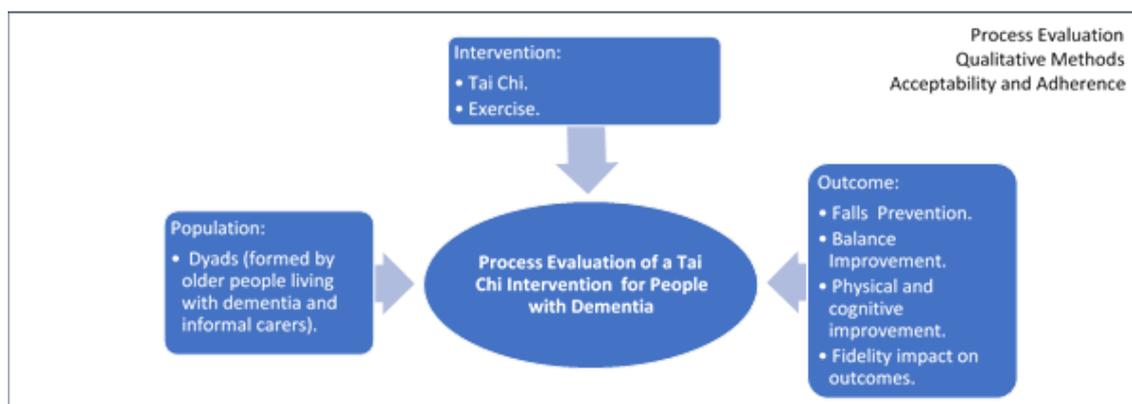


Figure 1. Representation of the PI(C)O model applied to the TACIT Trial.

To identify more precisely the relevant literature and its gaps, the PICO approach was used to inform the literature searches (Schardt, Adams, Owens, Keitz, & Fontelo, 2007), including three of its elements (PIO) as described in Appendix C. The innovative component of the TACIT Trial was highlighted across preliminary searches on dyadic Tai Chi interventions targeting an improvement in community-dwelling people living with dementia's balance. For this reason, neighbouring literature including interventions conducted in similar populations (i.e., only people living with dementia or only carers), with similar interventions (i.e., exercise interventions) or outcomes (i.e., mainly physical and cognitive) were included in this literature review. Accordingly, search strategy (see example in Appendix D) and reporting of each section of this chapter have been conducted from a specific (and more similar to the TACIT Trial's design) to a broader perspective, including neighbouring literature.

2.3. Results

2.3.1. Population

The population included under this subsection were people living with dementia in the community and their informal carers, who provide support in activities of daily living (ADLs)⁶. This support frequently involves a long-term commitment and its duration or

⁶ These ADLs comprise a variety of activities, which have been divided in two types: Basic ADLs and Instrumental ADLs (also IADLs). Basic ADLs are those fundamental for individual's survival, such as personal hygiene, mobility, feeding and dressing (Lawton & Brody, 1969; Mahoney & Barthel, 1965). IADLs are those which help the individual to interact with his/her environment and the community (i.e., cooking, taking medications, phoning, housekeeping, travelling, dealing with finances) (Lawton & Brody, 1969). Informal caregivers generally start providing support in IADLs and with the progression of dementia become more involved in the person living with dementia's Basic ADLs.

intensity tends to increase as the dementia progresses and the person living with dementia becomes increasingly more dependent on them (Lamotte, Shah, Lazarov, & Corcos, 2016). This increase in dependency does not only impact on the person but also on the carer, and wider family and friends; affecting social, health, and financial circumstances. As carers need to become more active in supporting the person living with dementia, as well as keeping up with their previous responsibilities, carer burden is more likely to occur (Canonici et al., 2012). Accordingly, dementia progression has been associated with a gradual increase on its care and health costs (Joling et al., 2015). This highlights the interdependence (Moon & Adams, 2013) and mutual influence (Van't Leven et al., 2013) between both members, where the (in)dependence and (ill or) well-being level of one member impacts on the other. The uniqueness of the dyadic relationship justifies the focus of this section on interventions involving both the informal carer and the person living with dementia as members of a dyad.

2.3.1.1. Dyads

Interventions targeting together people living with dementia and their informal carers are relatively recent in the literature around psychosocial interventions (Van't Leven et al., 2013) as traditionally they have been targeted separately (Moon & Adams, 2013). However, dyadic interventions have proved to be well received and feasible amongst community-dwelling people living with dementia (Moon & Adams, 2013). In these interventions, participants were satisfied with the intervention and improvements in their well-being were reported (Moon & Adams, 2013).

Several kinds of psychosocial interventions⁷ have used this dyadic approach, according to systematic (Van't Leven et al., 2013) and critical reviews (Moon & Adams, 2013). The significant benefits (i.e., delay in time to access long-term care settings⁸, decrease in carers' burden and improvement in mood, cognitive function, or QoL; the lack of effect in carers' depression; and, when reported, adherence facilitators (i.e., instructors characteristics, enjoyment and socialising component) are summarised in Table 1.

Despite the positive findings identified by Van't Leven et al. (2013), a recent systematic review of systematic reviews, which included Van't Leven et al.'s (2013), identified inconsistencies amongst studies' findings and risk of bias in those dyadic interventions (Laver, Dyer, Whitehead, Clemson, & Crotty, 2016). Furthermore, both reviews (Moon & Adams, 2013; Van't Leven et al., 2013) focused on the study outcomes for the

⁷ Psychosocial interventions in the context of dementia refer to non-pharmacological interventions designed to support people living with dementia and their carers preserving their well-being after the diagnosis (Guss et al., 2014; Van't Leven, de Lange, Prick, & Pot, 2016).

⁸ Long-term care settings include a variety of services offered to older people where they are supported in their ADLs and IADLs.

person with dementia or the carer separately and not the dyad together. Similarly, adverse events, the lack of effect on primary outcomes, and the evaluation of the implementation process seems not to be a priority. This could reflect the underuse of process evaluations and qualitative methodology along dyadic psychosocial interventions in dementia. This thesis will fill this gap by targeting dyads' experiences and explaining the impact of Tai Chi on both members.

Table 1. *Benefits and Adverse Events Reported in Two Reviews of Dyadic Psychosocial Interventions*

Psychosocial intervention	Benefits for people living with dementia and their carers reported	Adverse events/lack of effect reported for carers or people living with dementia	Barriers and facilitators for acceptability and adherence
Psychoeducational and care/ caregiver training programs	For the person living with dementia: delay in time to access long-term care settings (Van't Leven et al., 2013). For the carer: Reduce burden, increase competence and promote better QoL (Van't Leven et al., 2013).	Not reported.	Not reported.
Environmental adaptations in their own home	For the person living with dementia: delay in time to access long-term care settings (Van't Leven et al., 2013). For the carer: promote better QoL (Van't Leven et al., 2013).	Not reported.	Not reported.
Exercise, activity and occupational programs	For the person living with dementia: delay in time to access long-term care settings (Van't Leven et al., 2013). For the carer: Reduce burden, increase competence (Van't Leven et al., 2013).	Not reported.	Not reported.
Cognitive stimulation	For the person living with dementia: improvement in the cognitive function (Moon & Adams, 2013) and delay in time to access long-term care settings (Van't Leven et al., 2013). For the carer: reduction of depression symptoms (Moon & Adams, 2013). For both: maintenance in the quality of the spousal relationship.	Not reported.	Facilitators: Group leaders support, information provided during the intervention, opportunity for socialising with people in a similar situation and for spending time with the other member of the dyad (Moon & Adams, 2013).
Dyadic counselling and support groups	For the person living with dementia: delay in time to access long-term care settings (Van't Leven et al., 2013). For both members: maintenance of their QoL and improvement in their communication (Moon & Adams, 2013).	No impact on depression levels of carers or people living with dementia (Moon & Adams, 2013).	Facilitators: Satisfaction with the intervention, feeling less isolated and value the emotional and social support. Characteristics of the counsellor (i.e., caring style and knowledgeable).

2.3.1.2. *Process evaluations in dyadic interventions*

A complementary search for dyadic interventions to update the previous reviews was made. However, the aim on this occasion was to identify studies reporting adverse events, or barriers and facilitators along these interventions. Through this process, four studies were retrieved, two reporting dyadic exercise interventions (Dal Bello-Haas, O'Connell, Morgan, & Crossley, 2014; Prick, de Lange, van 't Leven, & Pot, 2014)

(which will be commented in following subsections 2.3.1.3 Dyadic exercise interventions and 2.3.2.2.2 Adherence to exercise interventions of this chapter), plus a cognitive stimulation intervention program based on reminiscence (Woods et al., 2016) and a protocol for case management interventions (MacNeil Vroomen et al., 2012).

In the dyadic reminiscence study, authors defined compliance in terms of attendance to 50% of the weekly sessions conducted for 3 months (Woods et al., 2016), which 70% of the dyads accomplished. However, the intervention consisted of 7 further monthly maintenance sessions, making the intervention last for a total of 10 months. During this second part compliance was considered when dyads attended at least 3/7 sessions (42.86% of them). Despite the percentage of sessions considered for compliance being slightly lower in the second phase of the study, adherence dropped from 70% to 57%. Factors influencing attendance rates involved those related to the dyad (i.e., health issues) but also some related exclusively to the carer. These factors included carer's dissatisfaction with the group-based format of the intervention or a lack of perceived benefits. Sometimes these carer-related factors contributed also to dyads' drop outs. In this study, they also used qualitative methodology, but only to study carers' experiences of taking part in this dyadic reminiscence intervention (Melunsky et al., 2015). This focus on carer's experiences, did not examine the experiences of the person living with dementia, nor the construction of their joint experiences as will be the objective of this thesis. Carers were mostly satisfied with the intervention and perceived several benefits like the support obtained from people in a similar situation, the opportunity to share a pleasant activity with their family member and learn from other carers, or felt reassured for their own coping strategies. However, a few of them pointed some weaknesses of the intervention, including missing the opportunity to have a break from caring and expressed more feelings of burden because of taking part together. Others would have liked more time to talk with other carers about their issues or would have rather not seen people living with dementia in more advanced stages. Some of those who could see a benefit from the intervention, felt guilty when they could not implement it in the home-environment, where they had no time due to competing roles. In the TACIT trial, dyads will receive a home-visit from the Tai Chi instructor to facilitate the implementation of the intervention at home and ensure the exercise is conducted in a safe environment. Moreover, time has been allocated at the end of each group-based session for dyads to resolve any doubts regarding the Tai Chi practice at home. The appropriateness of this continued support for the dyads will be assessed as part of this thesis.

In the protocol for the study comparing two case management interventions (MacNeil Vroomen et al., 2012), a process evaluation was planned to identify strengths and

weaknesses from each program. MacNeil Vroomen et al. (2012) planned to follow-up dyads allocated to usual care or one of the two interventions for two years in order to identify differences in terms of impact and cost-effectiveness. However, the use of qualitative methods seemed to be more focused on the professionals (Van Mierlo, Meiland, Van Hout, & Dröes, 2014) than dyads themselves.

A dyadic approach has been able to satisfy both members of the dyad and improve the relationship and communication between them in most cases (Moon & Adams, 2013). However, heterogeneity of the interventions' characteristics and participants (Van't Leven et al., 2013), together with a lack of high-quality study designs (Moon & Adams, 2013), require caution in interpreting findings. Caution is particularly necessary as interventions included in previous systematic reviews around dyadic interventions have included interventions (i.e. reminiscence) very different to Tai Chi. Similarly, dyadic interventions have focused on the effectiveness of these interventions (Moon & Adams, 2013), but less importance has been given to the barriers and facilitators surrounding the implementation process. Moreover, this relatively new approach has not been used regularly in RCTs, which underpins the importance of piloting them and studying its feasibility (Moon & Adams, 2013) as this thesis does.

2.3.1.3. Dyadic exercise interventions

The involvement of both, the person living with dementia and their carer, has been found relevant in exercise interventions (Dal Bello-Haas et al., 2014; Suttanon, Hill, Said, Byrne, & Dodd, 2012), particularly to ensure safety and promote enjoyment (Logsdon, McCurry, & Teri, 2005). In some cases, however, people living with dementia have taken part in exercise interventions without their carers. In these interventions, carers have supported people with dementia's attendance to the sessions by reminding the person to attend the activity or helping with transport (Frederiksen, Sobol, Beyer, Hasselbalch, & Waldemar, 2014; Yu et al., 2015). In these studies, carers have appreciated the respite time, but also valued other outcomes of the intervention in terms of their family member's changes. When carers did not attend the group sessions with the person with dementia, they had around ten hours of respite per week (Farran et al., 2008; Yu et al., 2015). However, there are many more examples of interventions where people living with dementia took part with the carer who provided support in data collection (i.e., completing falls reports) and supervised their exercise practice (Close et al., 2014; Dal Bello-Haas et al., 2014; McCurry et al., 2010; McCurry et al., 2011; Steinberg, Leoutsakos, Podewils, & Lyketsos, 2009; Yao, Giordani, Algase, You, & Alexander, 2012). In some studies, the role of the carer has been particularly active, as they were taught to conduct a home-based exercise intervention (Teri et al., 2003). Whereas in other interventions, a more flexible

approach was taken, where participants with certain level of baseline performance were allowed to participate on their own by the research team, or they were able to do so when a member of the dyad preferred this approach (Wesson et al., 2013).

It has been suggested that carers involvement could be particularly relevant in people with higher levels of cognitive impairment (Teri, Logsdon, & McCurry, 2008), as they might need additional support (i.e., to perform the exercises in the way they were taught and in a safe manner) (Yao et al., 2012). Student's involvement as pairs and supervisors of people living with dementia taking part in an exercise intervention has also been found a feasible way of motivating participants to adhere in the long-term (Arkin, 1999, 2003). According to this, when reporting intervention's outcomes, apart from acknowledging that a dyadic approach has been used, it would be relevant to describe other factors that could impact on the provision of this support. For instance, the nature of dyad's relationship (i.e., friends, children or spouse) (Yao et al., 2012) or intervention's impact on the carer (i.e., burden) (McCurry et al., 2010). In line with this, one of the studies (Forbes et al., 2015) suggested the involvement of the carer as a supervisor could reduce their burden. This has also been supported in a review of four RCT dyadic exercise interventions that were tested in people living with dementia and their carers (Lamotte et al., 2016). These authors highlighted the need of more RCTs investigating further the impact of exercise interventions delivered in dyads.

Even when not providing an explicit justification, some studies have attached a temporal criterion to the carer's inclusion in research. This temporal criterion has been based on the length of face-to-face contact with the person living with dementia. This is the case of studies where 3.5 (Close et al., 2014; Wesson et al., 2013) or 10 hours per week (Yao et al., 2012) of relationship between both members was required. This criterion has probably been used to ensure the availability of the carer to provide support during the exercise intervention, however, little has been commented on its importance. Similarly, and according to the lessons learnt by researchers who have conducted research in dyads, there is a need to explore the "physical, environmental and interpersonal characteristics" of people living with dementia and their carers (McCurry et al., 2011). These, in turn, could have an impact on participants' adherence to the study protocol.

A recently published systematic review of 23 systematic reviews of interventions aiming to delay cognitive impairment in people living with dementia, has also highlighted both the value of exercise interventions and the use of a dyadic approach (Laver et al., 2016). This review included a total of 14 reviews around exercise and dyadic interventions –involving a total of 1277 participants. These interventions seem to have

more positive effects, including higher QoL and a reduction in the speed progression of functional decline, compared to pharmacological approaches.

When reviewing the literature around exercise interventions conducted in dyads, qualitative and quantitative studies have been identified, with the latter approach being more common (35.7% versus 64.3%, according to papers reviewed and included in Appendix F). Amongst qualitative studies, semi-structured interviews have frequently been used to gather instructors' (Hawley-Hague, Horne, Skelton, & Todd, 2016a) and dyads' views (Suttanon et al., 2012) on the intervention. However, focus groups have also been used (Yu & Swartwood, 2012) to understand factors facilitating and mitigating their adherence (see subsections on "Acceptability of exercise interventions" and "Adherence to exercise interventions" of this chapter). Nevertheless, when dyads' opinions were included, their perspectives were gathered separately (Yu & Swartwood, 2012). When theory informing the study has been reported, the theory of planned behaviour (Hawley-Hague et al., 2016a), and phenomenological theoretical framework (Suttanon et al., 2012) have been used. Similarly, when the type of analysis has been stated, content (Hawley-Hague et al., 2016a; Yu & Swartwood, 2012) and thematic analysis (Suttanon et al., 2012) have been used.

Quantitative studies, on the other hand, included cycling (Yu et al., 2015) and balance and strengthening exercises (Pitkälä, Pöysti, et al., 2013; Suttanon et al., 2013). The aim of these studies was to improve cognitive function, reduce carers distress and reduce behavioural symptoms (Yu et al., 2015), but also improve physical functioning and reduce the use and cost of social and healthcare services (Pitkälä, Pöysti, et al., 2013).

The format used in RCTs and non-RCTs studies recruiting dyads included group-based (Yu et al., 2015), home-based (Suttanon et al., 2013) or a mixture of both intervention types (Pitkälä, Pöysti, et al., 2013). Dosage varied from 2 to 5 days a week, between 45- and 60-minutes duration per session, over 6 to 12 months. This heterogeneity in the characteristics of the interventions is consistent with the conclusions of Forbes et al. (2015)'s systematic review. Forbes et al. (2015) also identified a lack of measurement of intervention's impact on the carer which is consistent with the studies reviewed here where only one measured carer's QoL (Suttanon et al., 2013) and two analysed carer's burden/distress (Suttanon et al., 2013; Yu et al., 2015).

Methods used to measure adherence were mainly activity logs or attendance registers. Measures in place to facilitate adherence, explicitly reported or not, were: rapport establishment between delivers and members of the dyads, exercise logs to register achievements, attendance reminders, assistance with transportation, timing flexibility (Yu et al., 2015), telephone contact (Suttanon et al., 2013; Yu et al., 2015), home-

visits, booklet with pictures and explanations, and provision of professional's contact to facilitate an ongoing problem solving (Suttanon et al., 2013).

Assessments of the adherence to research protocols have been rarely reported, although occasionally fidelity checks have been conducted (Yu et al., 2015). Fidelity checks are fundamental to assess the intervention's dosage received by participants as well as the principles followed during its implementation, which could have an impact on its effectiveness. Participant's adherence has predominantly been assessed quantitatively. Adherence to the home-based interventions (around 84%) was slightly higher than to group-based ones (around 81%). However, home-based interventions registered higher attrition rates (i.e., 42.11%) over six months (Suttanon et al., 2013) in comparison with group-based ones (around 21%) (Yu et al., 2015). In the TACIT Trial participants will be asked to engage in both, group and home-based Tai Chi. A quantitative record of their participation in both settings will be kept, by Tai Chi instructors along the Tai Chi classes and by the people living with dementia and their carers in the home-based practice. However, this thesis will additionally investigate the impact of settings in the Tai Chi intervention, by enquiring participants around the barriers and facilitators mediating in their adherence to Tai Chi in both settings. This could help to explain which setting was preferred by participants and how to facilitate their adherence to Tai Chi interventions conducted in any of the two settings.

In summary, the use of a dyadic approach in interventions to support people living with dementia and their carers is relatively recent (Van't Leven et al., 2013). To date, interventions using this approach have shown its feasibility and acceptability (Lamotte et al., 2016). In exercise interventions, particularly, this approach has improved people living with dementia's adherence and ensured their safety participation during the intervention. However, more research is needed to understand dyads experiences on new interventions, particularly in the context of RCTs, where this approach has been underused. Future research needs to address this gap by including the use of qualitative methods to gather the views of both the person with dementia and the carer and clarify whether their joint participation is perceived as a gain or a barrier for their adherence to potentially beneficial interventions.

2.3.2. Intervention

2.3.2.1. *Tai Chi*

Tai Chi was originally a martial art. Nowadays it is frequently practised as a gentle form of exercise, training aspects of physical fitness (i.e., flexibility, balance, coordination), cognitive performance (i.e., attention, memory) (Lam et al., 2012; Wayne et al., 2015), as well as relaxation. For this reason, it has also been described as a mind-body

exercise and there has been an interest in studying its impact on both physical and psychological outcomes.

Tai Chi originated from China and is based on the Taoist Philosophy (Lam, 2007). Alternative types of Tai Chi derived from it (i.e., Chen, Yang, Sun, Wu, Hao) keep most of the essential principles, but adopting different characteristics (i.e., intensity) (Lam, 2007). Regular participation in Tai Chi has been shown to have a variety of benefits for older adults (see Table 2):

Table 2. *Benefits Attributed to Tai Chi in Individual Studies Conducted Amongst Older Adults Without Cognitive Impairment*

Physical improvements in:	Psychological benefits in:
<ul style="list-style-type: none"> - Blood pressure reduction (Wolf et al., 1996)*. - Grip strength (left hand) (Wolf et al., 1996)*. - Walking speed (Sun et al., 2015)*. - Gait (Wayne et al., 2015)⁻. - Balance (Lam et al., 2012; Li et al., 2005; Voukelatos, Cumming, Lord, & Rissel, 2007) ^{-**}. - Risk of falling (Li et al., 2005)*. - Number of falls (Li et al., 2005; Voukelatos et al., 2007; Wolf et al., 1996)^{**}. 	<ul style="list-style-type: none"> - Cognitive function (Lam et al., 2012; Sun et al., 2015; Walsh et al., 2015) ^{-**} in participants with questionable (CDR=0.5) or no cognitive impairment (MMSE \geq 24). - Fear of falling (Li et al., 2005; Wolf et al., 1996)^{**}.

*: Studies that found a significant difference attributable to Tai Chi practice.

⁻: Studies that did not find a significant difference attributable to Tai Chi practice.

Tai Chi has been considered as a physical activity (PA) with potential to prevent cognitive decline in adults with questionable⁹ dementia or Mild Cognitive Impairment (CDR=0.5) (Lam et al., 2012). It has also been widely categorised as a form of exercise in intervention studies (Chen et al., 2008; Day et al., 2012; Fogarty et al., 2015; Logghe et al., 2011; Walsh et al., 2015; Wayne et al., 2015; Yao et al., 2012; Zheng et al., 2015) and systematic reviews (Hu et al., 2016; Lomas-Vega, Obrero-Gaitán, Molina-Ortega, & Del-Pino-Casado, 2017). Accordingly, these interventions have been included in systematic reviews around the effectiveness of exercise interventions (Cameron et al., 2012; Forbes et al., 2015; Gillespie et al., 2012; Kelly et al., 2014). However, other studies have classified Tai Chi as a leisure activity (Cheng et al., 2014). A possible explanation for this alternative view is the familiarity of Chinese/Asian participants with this activity. Similarly, other studies have classified Tai Chi as a sport activity because of its association with martial art (Ballesteros, Kraft, Santana, & Tziraki, 2015). In this thesis Tai Chi has been categorised as an exercise activity, according to the definition provided in Chapter 1.

⁹ Questionable dementia is the term used to designate people scoring 0.5 in the CDR scale, however, under this umbrella term, people diagnosed with Mild Cognitive Impairment and Probable AD can be found (Petersen, 2000).

Studies on the effectiveness of Tai Chi have frequently excluded people living with dementia (Chen et al., 2008; Fogarty et al., 2015; Sun et al., 2015; Walsh et al., 2015; Wayne et al., 2015; Wolf et al., 1996; Zheng et al., 2015). Consequently, systematic reviews around this group of participants have not been found. Instead, studies including people living with dementia practising Tai Chi, have been reported in wider reviews analysing the effects of exercise in this condition (Cameron et al., 2012; Forbes et al., 2015) or the effects of different interventions seeking to prevent falls amongst those living in long-term care settings (Cameron et al., 2012). These reviews have found promising effects. However, both systematic reviews have also reported inconsistencies (Cameron et al., 2012) and large heterogeneity (Forbes et al., 2015) amongst study results or participants' characteristics, respectively. On the other hand, systematic reviews focusing on the impact of Tai Chi (Wayne et al., 2014; Zheng et al., 2015) or exercise interventions -including Tai Chi- (Kelly et al., 2014) have been conducted on older adults' cognition. Reviews that have included a number of studies which included people living with dementia (5 out of 20), have reported the positive impact of Tai Chi in global cognitive function (but not on specific domains) (Wayne et al., 2014). Tai Chi studies conducted amongst people living with dementia and in the general population have reported both cognitive and physical benefits (Burgener et al., 2008; Yao et al., 2012). Most of these studies including people living with dementia have been conducted in long-term care setting environments (Cheng et al., 2014; Choi, Moon, & Song, 2005; Nowalk, Prendergast, Bayles, D'Amico, & Colvin, 2001; Saravanakumar, Higgins, Van Der Riet, Marquez, & Sibbritt, 2014; Tsai et al., 2015) and it is unclear whether similar benefits are achieved for community-dwelling older adults (Barnes et al., 2015; Burgener et al., 2008; Day et al., 2015; Yao et al., 2012). In particular, it has been suggested that differences in the effects of Tai Chi could be due to the characteristics of participants living in both settings, the environment where these interventions are delivered and the characteristics of the intervention itself (Hill et al., 2015; McCurry et al., 2010) (see Table 3).

In this section, due to the limited number of published studies around Tai Chi involving community-dwelling participants (see Appendix G), studies based in both community and long-term care settings have been reviewed (see Appendix F). As reflected in Appendix F, only one study (Yao et al., 2012) has been identified where Tai Chi was delivered alone in the community and its results have been published. An additional RCT protocol has been identified where a seated version of Tai Chi will be explored for its potential beneficial effect on carer's depression (Chan et al., 2016). As participants will be recruited in dyads, authors expect there might be a benefit for them as well, however, results of this study are not yet available.

Table 3. *Differences Between Interventions Conducted Amongst People Living in the Community and Those Living in Care Settings*

Differential aspect	Examples
The characteristics of the participants living in both settings	Generally, those living in long-term care settings are frailer and have greater dependency (Cameron et al., 2012; Hill et al., 2015; Saravanakumar et al., 2014). They have an increased risk for falls compared to people living in the community (WHO, 2007).
The environment	The availability of a carer to support their participation in the intervention. This can be more difficult in a care setting where staff need to allocate time for these activities, whereas in the community the same carer can provide one-to-one support in a group and home-based setting (Saravanakumar et al., 2014; Yao et al., 2012).
The dosage and format required to meet the needs of people living with dementia in different settings (Forbes et al., 2015)	Those living in the community will have more opportunities to engage in home-based -individualised- but also in group-based – standardised- interventions (Yao et al., 2012). Those living in long-term care settings, however, will tend to be only provided with group-based interventions (Saravanakumar et al., 2014). The characteristics of these participants (i.e., frailty and cognitive functioning), in turn, will have an impact on their needs.

All other studies included complementary interventions in parallel (i.e., other types of exercise, a cognitive-behavioural intervention and support group) (Barnes et al., 2015; Burgener et al., 2008) which cloud inference of Tai Chi's effectiveness. When two or more different interventions are delivered together, it is not possible to determine which is causing an impact on study results, it might be that only one of the various interventions is (in)effective, or that the conjunction of various interventions explains its (in)effectiveness. In long-term care settings, however, this has been less common, as only one of the papers included a therapeutic intervention delivered at the same time (Nowalk et al., 2001). This could be due to community interventions aiming to address various elements (i.e., behavioural, physical and cognitive functioning) in the person living with dementia to, in turn, help reducing carer's burden and indirectly delay the person living with dementia's move to long-term care settings.

Tai Chi prescription in terms of length of the sessions, frequency and duration of the intervention has been mostly described across papers. Only one of the studies in Appendix F failed to provide the duration of each session (Nowalk et al., 2001). This is in line with Wu, MacDonald and Pescatello (2016)'s systematic review around the ways of reporting dosage and session's content in Tai Chi interventions designed to improve balance amongst older people in general. Also consistent with the results of this

systematic review (Wu et al., 2016), a number of papers failed to provide information on their instructional methods (i.e., style of Tai Chi) (Barnes et al., 2015; Nowalk et al., 2001), others describe the style as “traditional” (Burgener et al., 2008) or “modified” (Saravanakumar et al., 2014) which according with the authors of this systematic review (Wu et al., 2016) should be equally considered as absent. These papers did not point to a dose-response of the Tai Chi intervention nor reflected (when specified) on the most suitable style of Tai Chi, which is again in line with Wu et al. (2016)’s review. Moreover, a lack of guidelines to adapt these interventions preserving their effectiveness was identified. However, a meta-analysis around exercise interventions to prevent falls in older adults recommended a minimum dosage of 50 hours of exercise; approximately 2h a week, over 6-months (Sherrington, Tiedemann, Fairhall, Close, & Lord, 2011). This has informed the 50 hours dosage of Tai Chi targeted by the TACIT trial over a 5-month period. Accordingly, this thesis focuses on participant’s acceptability of this recommended dosage, as well as the barriers and facilitators influencing adherence levels.

Only one study reported having used a dyadic approach in a community (Yao et al., 2012). This approach, combined with the use of behavioural techniques to facilitate motivation, was found beneficial to enhance participants’ motivation, attention, and adherence to the intervention (Yao et al., 2012). No challenges related to this approach were reported, although authors admit the high level of motivation of carers taking part in the intervention could have had a positive effect on their results (Yao et al., 2012). For this reason, they recommended further research into the different “types of caregiver interaction” established amongst different type of carers (i.e., relatives, friends, neighbours, volunteers) (Yao et al., 2012, p. 293). Another study did report recruitment in dyads, but carers were not actually involved in supporting people living with dementia during the class (Barnes et al., 2015). Most studies did not report a dyadic approach at any stage (Cheng et al., 2014; Choi et al., 2005; Nowalk et al., 2001; Tsai et al., 2015), or provided insufficient information to assess if support was provided one-to-one by volunteers (Saravanakumar et al., 2014). In the TACIT Trial carers will be asked to take part in the Tai Chi intervention together with the person living with dementia, so their role will be clearly defined as a fundamental part of the intervention. Complementarily, in this thesis, the relationship between the members of the dyad will be described, and opinions from dyads with different types of relationship will be sought to fill the gap in the literature identified by Yao et al. (2012).

As previously mentioned, Yao et al. (2012)’s is the most similar to the TACIT Trial (see Appendix G) as this trial delivered only Tai Chi and used a combination of home and class-based approaches in a community setting. However, Yao et al. (2012)’s study

was not part of an RCT, which makes generalization of findings to older adults living with dementia problematic. Community studies have aimed to improve both physical and cognitive functioning (Barnes et al., 2015; Burgener et al., 2008), whereas Tai Chi interventions conducted in long-term care settings seek to improve physical aspects (Choi et al., 2005; Nowalk et al., 2001; Saravanakumar et al., 2014), particularly determinants related to falls. This could be explained by the amount of people falling in care settings, which is three times higher than those living in the community (Care Inspectorate and NHS Scotland, 2016). Similarly, there are some differences amongst the aims of studies and primary and secondary outcomes. Some are targeting the prevention of falls itself (Choi et al., 2005; Nowalk et al., 2001; Saravanakumar et al., 2014; Yao et al., 2012) and focus on incidence of falls and balance outcomes, whereas others target the reduction of pain (i.e., in participants' knee) amongst participants with dementia (Tsai et al., 2015). Probably because Tai Chi has been described as a mind body exercise, some authors have focused on its potential to improve cognitive functioning of participants (Cheng et al., 2014). In this case, the common standing position to challenge balance was replaced by a seated version of Tai Chi. When reported, attrition and adherence rates are difficult to compare amongst studies included in Appendix F. There are several reasons for this:

- ✓ The cognitive decline of participants varies from early stages up to moderate.
- ✓ The length of the studies varies from 3 months to 2 years.
- ✓ The number of participants ranged from 11 to 55.
- ✓ The lack of agreement around a definition of adherence previously reported in the literature around older adults' adherence to exercise interventions (Hawley-Hague, Horne, Skelton, & Todd, 2016b). In papers reviewed in Appendix F, adherence was reported mostly as an average of sessions attended (from 72.22% to 100%), which does not allow to analyse the differences amongst participants who adhered more or less to the intervention. Other authors, on the other hand, established a cut-off point to consider participants' adherence to the intervention. This cut-off point varied from attendance to 67% of the sessions (Nowalk et al., 2001) up to 100% of prescribed minutes for home-based practice (Yao et al., 2012). According to the studies in Appendix F, main reasons for attrition in participants living in the community were health issues (i.e., illness or changes in medical conditions unrelated to the study) or feeling that they did not need the intervention; whereas for those living in long-term care settings, death and moving to another care setting were more frequent.

Lessons learnt about facilitators to enhance participant's adherence to interventions will inform future research. However, subsequent studies have not always acted on findings which enhance implementation. For example, although transport is a key issue for participants to attend sessions, Yao et al. (2012) argued that this would hinder future sustainability, whereas Yu et al. (2015) provided participants with transportation. In the TACIT Trial, a similar approach to Yao et al. (2012)'s was used initially to assess the acceptability of the intervention and strengthen the ecological validity of its results, as participants are unlikely to be offered this alternative if the intervention was established in the community and funded by the NHS.

Assessment of fidelity to the intervention protocol has been rarely reported. Only two of the studies in Appendix F reported the principal investigator or a researcher were responsible for conducting fidelity checks (Barnes et al., 2015; Yao et al., 2012). Searches were conducted in order to find the protocol papers published for all the studies included, however, only one was found (Yao et al., 2012). To avoid this, any publication related to the TACIT Trial will provide the reader with the Trial number to facilitate the identification of the protocol.

In studies where Tai Chi did not significantly reduce the incidence of falls (Day et al., 2015; Nowalk et al., 2001), low intensity and low adherence rates (Day et al., 2015), together with the need for tailoring the intervention to participant's needs (Nowalk et al., 2001) have been suggested as possible explanations. In neighbouring literature, where a Taoist form of Tai Chi was examined in people with Mild Cognitive Impairment (MCI), findings showed no impact on cognition or mobility. The type of Tai Chi used, the level of frailty of participants, dosage (including intensity and frequency), participants' sceptical attitudes and low adherence, have been pointed as possible explanations of their results and differences with previous research (Fogarty et al., 2015).

The number of papers found reporting qualitative findings in Tai Chi based trials were limited, which is in line with the underuse of qualitative methodologies along RCTs (see Chapter 3). Only one (Barnes et al., 2015) reported a change in their study protocol to implement a qualitative data analysis. This paper did also include some integration of qualitative and quantitative results in its discussion section (Wu et al., 2015). By doing this, the authors were able to explain the importance of making exercise movements relevant to participants to facilitate their engagement and enhance intervention outcomes. These techniques could have been relevant to overcome some participants' initial scepticism towards the intervention or exercise in general, as some of them thought "movements seemed unusual or silly" (Wu et al., 2015, p. 358), but this ceased during the intervention when a participant admitted "maybe it's not worthless" (Wu et al., 2015, p. 359). Another two papers unexpectedly reported an exit interview in their

discussion (Burgener et al., 2008; Yao et al., 2012) to highlight participants enjoyment of the intervention or carers' suggestion to have more group-based sessions. However, they did not provide any methodological information nor referred to further publications.

Considering the nature of this thesis (involving a dyadic intervention and a process evaluation) and after reviewing papers around the use of Tai Chi in older population living with dementia, a more specific search was conducted (see Appendix D). This time the purpose was to identify papers more closely related to the TACIT Trial and this thesis.

In the first two searches, and according to the previous search on papers around dementia and Tai Chi, only one published study referred to a Tai Chi intervention using a dyadic approach (Yao et al., 2012). Authors reported that this approach, complemented by a "Positive-Emotion-Motivation"¹⁰ (Yao et al., 2008) and a physical contact between members of the dyad practising Tai Chi together, facilitated attention and motivation of those living with dementia. However, in this case, no measurements were taken from carers. Accordingly, it is not possible to estimate the impact of this intervention on their QoL or their physical performance.

In the last two searches, no papers were found reporting process evaluations of Tai Chi interventions conducted amongst people living with dementia. When broadening the search to process evaluations conducted in the context of tai chi interventions, only one paper was identified (Logghe et al., 2011). This paper analysed the possible factors influencing Tai Chi Chuan's lack of effectiveness in reducing the incidence of falls amongst 138 community-dwelling older adults (Logghe et al., 2011). This intervention had been delivered for thirteen weeks, in sixty-minute sessions, twice a week. Authors collected quantitative and qualitative data (using questionnaires and forms) from participants and instructors. Both were satisfied with the intervention; however, authors reported a 21% attrition rate, and amongst attendants less than half of them (47%) adhered to the intervention (and attended 80% or more of the sessions). In this case, aspects assessed by the process evaluation were the fidelity to the protocol, attendance and adherence to the sessions, and the views of participants and instructors about the program (see Appendix E). Suggestions made by the authors to improve adherence included the use of supporting materials to facilitate Tai Chi practice at home and tailor the intervention to individual needs (Logghe et al., 2011). These recommendations have been considered in the TACIT Trial and, for this thesis, people living with dementia, their carers, and the Tai Chi instructors' opinions will be sought following completion of the trial to improve the intervention. Informal

¹⁰ This technique refers to the use of incentives/rewards or pleasurable moments (Yao et al., 2012) to enhance memory (Yao, Giordani, & Alexander, 2008).

conversations with Tai Chi instructors will inform on their opinions about the implementation of the intervention (during the classes and the home-visits that they will be doing) and the impact perceived on participants.

2.3.2.1.1. Acceptability of Tai Chi interventions

The number of papers found reporting qualitative findings in Tai Chi based trials was limited and supports previous research findings that report the underuse of qualitative methodologies alongside RCTs of healthcare interventions (Gibson, Timlin, Curran, & Wattis, 2004; Lewin, Glenton, & Oxman, 2009). Studies delivering only Tai Chi and including people living with dementia have not reported the use of qualitative methods. In these studies, acceptability was reported by authors following their perceptions about participants' satisfaction with the intervention. Some authors, despite not having reported the use of qualitative methods in their studies, however, have pointed the need for listening to participants' opinions and perceptions regarding their involvement in Tai Chi interventions. For example: "The high level of interest for yoga and tai chi amongst the older participants needs to be explored. What were the perceptions and experiences of the older participants?" (Saravanakumar et al., 2014, p. 85).

2.3.2.1.2. Adherence to Tai Chi interventions

When barriers and facilitators for participant's adherence have been reported, these came mainly from lessons learnt by authors or their recommendations for future research. These included the use of dyadic approaches and behaviour change techniques to improve participants' adherence (Yao et al., 2012), and the creation of a motivational and friendly environment that allow social interaction (Barnes et al., 2015) in interventions conducted in the community. If these were based in long-term care settings, then the decision of carrying out the whole intervention at the same setting (Nowalk et al., 2001) was also perceived as a facilitator. On the other hand, care routines in long-term care settings, together with professional carers not facilitating participant's attendance to the sessions were perceived as barriers (Saravanakumar et al., 2014).

Only on a few occasions, carers or people living with dementia's opinions have been reported, but only as anecdotal comments (Burgener et al., 2008; Yao et al., 2012) gathered in interventions conducted in the community. On these occasions, a demand of more group-based sessions by carers has been interpreted as a possible facilitator of adherence (Yao et al., 2012). Also, people living with dementia could adhere more to the intervention when feeling their improvement or enjoying the social interactions in group-based interventions (Burgener et al., 2008). In the TACIT Trial, the group-based component will be present for the duration of the intervention. In this thesis, the views

of people living with dementia and their carers will be sought after every observation session, not as anecdotal comments but as the focus of this thesis. Also, participants will be asked about the group-based component of the intervention in a focus group or dyadic interviews to weight its importance in facilitating their adherence to Tai Chi.

In older participants in general, perceived benefits have been identified as facilitators of adherence to a Tai Chi intervention (Logghe et al., 2011). However, having difficulties to remember the forms practised was identified as a barrier. This barrier could be of particular interest when a Tai Chi intervention is delivered to people living with AD at a mild or moderate stage. In this context, the role of the carer, together with the use of adequate supporting visual materials, as in the TACIT trial, could be particularly relevant.

Tai Chi interventions have proven to be beneficial for older people. However, there is a lack of high-quality interventions supporting its effectiveness to prevent falls amongst people living with dementia in the community. Only one non-RCT study has been identified where Tai Chi was the only intervention delivered. This study recruited dyads of participants (formed by highly motivated spouses or family carers and people living with dementia). Further research is required to understand the impact of different dyadic relationships and levels of motivation of participants in their adherence to Tai Chi interventions. So far it is known that perceived benefits, memory aids, supporting materials, the use of behaviour change techniques, and friendly environments facilitate participants' adherence to these interventions. Future research should place participants' views at the centre of attention to understand the barriers and facilitators modifying their adherence to Tai Chi.

2.3.2.2. Exercise Interventions

Besides Tai Chi, several exercise interventions -also considered behavioural interventions (Yu et al., 2015)- have been studied in people living with dementia with the potential to "improve health, mood and quality of life" (Logsdon et al., 2005, p. 90). A systematic review including 30 trials –involving a total of 2020 older participants experiencing cognitive impairment and dementia- supported the positive effects of exercise on health-related physical fitness and cognitive functioning (Heyn, Abreu, & Ottenbacher, 2004). A potential to delay this functional decline was also supported in a recent systematic review of systematic reviews (Laver et al., 2016).

Although some of the interventions designed for people living with cognitive impairment in the community have reported only the use of exercise (Frederiksen et al., 2014), frequently they have also applied behaviour change techniques with the aim of enhancing benefits on physical and psychological functioning. For instance, exercise

interventions have commonly been accompanied by: a) Problem solving interventions (Farran et al., 2008; Logsdon, McCurry, Pike, & Teri, 2009; Logsdon et al., 2005); b) Goal setting techniques (Haas, Mason, & Haines, 2014; Logsdon et al., 2009); and c) Self-monitoring (i.e., using pedometers), feedback, and reinforcement procedures (Logsdon et al., 2009).

When goal setting techniques have been used with older people (including those living with dementia), several difficulties have been identified. Elements like participants' ability to establish health behaviour related goals and the use of inadequate tools to assess their achievement or procedures to review such goals have been found to be detrimental (Haas et al., 2014). In these multicomponent interventions, improvements in physical and psychological functioning have been shown. In addition, these interventions improved QoL in people living with dementia and their carers (Logsdon, McCurry, & Teri, 2007).

Existing reports of exercise research involving people living with dementia has aimed to study its impact on cognitive and physical function, or on their mood and any behavioural challenges associated (i.e., agitation, aggression, sundowning, restlessness, shouting and screaming, and loosing inhibitions (Alzheimer's Society, 2013, 2015)). Lowery et al. (2014) reported no effects on mood in a walking intervention conducted in a clinical trial context, although carers' burden was reduced. This negative result could have been influenced by low intervention adherence and dosage, as other research has found a positive impact on behavioural outcomes. Nascimento, Teixeira, Gobbi, Gobbi and Stella (2012), for instance, who only analysed data coming from high adherent participants - with a minimum attendance to 75% of the exercise sessions- found a reduction in most of the scores on the Neuropsychiatric Inventory (NPI) (Cummings, 1997). Similar results were found in Stella et al. (2011), although authors warn that such positive results would need to be taken with caution as researchers assessing the study were not blinded to participant's allocation. Other exercise interventions have included social interaction as one of the key elements, together with memory training and body awareness (Wu et al., 2015). In their intervention Wu et al. (2015) included eleven people living with mild –to-moderate AD attending a day centre, who were asked to take part in an integrative intervention consisting of conventional and complementary types of exercise (such as Tai Chi). Feedback from instructors, carers, and the study team revealed positive changes in the functional (i.e., “during a class activity involving patting the legs, Doris looked at her legs and said ‘you’re waking up!’” (Wu et al., 2015, p. 357)), emotional (“She often smiled, breathed deeply and commented about feeling ‘more peaceful’” (Wu et al., 2015, p. 358)), and social (“Well, I never thought so when younger, so I didn’t speak

up, but now, I've started to speak up more here, and I plan to more” (Wu et al., 2015, p. 359)) spheres; which were observable in terms of reduced anxiety and friendship development during the sessions.

The variability in exercise frequency, duration, and intensity (McCurry et al., 2010), as well as the additional component delivered (i.e., psychoeducational) during the intervention period, makes it difficult to establish which is the effective component in such interventions. Similarly, in dual task interventions, it is not feasible to distinguish which is the effective task in the intervention, if both are having an impact on the research outcomes, or whether the combination of both tasks is what makes these interventions effective. Andrade et al. (2013), for instance, explored the positive impact of a multimodal exercise in postural control and frontal lobe cognitive functions; however, they used a dual-task intervention to test their hypothesis which involved cognitive tasks.

Exercise interventions designed for people living with dementia have also employed different approaches (i.e., dyadic and non-dyadic). Frequently, quantitative studies have included exercise interventions targeting the person living with dementia (Schwenk et al., 2014) or the carer (Connell & Janevic, 2009; Farran et al., 2008) separately. Interventions for people living with dementia tend to deliver only the exercise component, aim to improve gait performance, and use a group setting. In contrast, exercise programs targeting carers are frequently multicomponent (including different types of intervention such as support and increase of exercise practice) and delivered individually through the telephone.

Qualitative studies around non-dyadic exercise interventions have been conducted mainly amongst older people without cognitive decline living in the community aiming to prevent falls. When people living with cognitive impairment have been included in interventions targeting the wider older population, challenges have been identified by deliverers (Day, Trotter, Donaldson, Hill, & Finch, 2016). In this context, qualitative methods used have comprised telephone interviews with older adults without cognitive decline (McPhate et al., 2016), semi-structured interviews with program leaders (Day et al., 2016), or surveys with older adults without significant cognitive impairment (Haines, Day, Hill, Clemson, & Finch, 2014). When theory or analysis approach were reported, diffusions of innovations theory (Day et al., 2016) and framework approach has been used (McPhate et al., 2016).

In older adults without a significant impairment, it has been suggested that participants might value more the short-term benefits of an intervention (i.e., practising the exercises and engaging in social interaction) instead of the long-term ones (i.e., falls

prevention) (McPhate et al., 2016) as it has been described for general health interventions (West, Walia, Hyder, Shahab, & Michie, 2010). Perceived benefits of an intervention (i.e., improvements in health and mobility) have been described as facilitators for participants' adherence to interventions when these have been appreciated during the intervention (see Table H 2). In general older population, these qualitative studies have shown older people are not aware of their higher risk for falls (Haines et al., 2014). This, although applicable to the general older population, could be of importance in participants living with dementia due to self-awareness changes¹¹. Moreover, finding the intervention more suitable for other people than for themselves has been identified as a barrier to engage in exercise interventions for older adults (Hawley-Hague et al., 2016a). This, in turn, could also have an impact not only on people living with dementia but also on their carers.

2.3.2.2.1. *Acceptability of exercise interventions*

Initially, a specific search around acceptability of exercise interventions retrieved 29 original papers involving people living with dementia. Most of them were excluded for being based in care settings, excluding people with cognitive impairment, or analysing the impact of exercise in cognitively healthy older adults. In this and the following subsections, papers based on people living in care settings were excluded due to the differences amongst settings reflected in Table 3 (i.e., in participant's needs, interventions' format, involvement of formal or informal carers), which can impact on the participant's acceptability and adherence to an intervention. These differences were evident when reviewing papers around Tai Chi interventions (see subsection 2.3.2.1.1). After this screening, three papers were reviewed (see Table F 3) and limitations were identified related to:

- a) A lack of description around the qualitative methods used: The first paper included (Dal Bello-Haas et al., 2014) used thematic analysis of the interviews, which revealed dyads liked taking part together in the intervention and that the group-based intervention was found beneficial by participants: "I feel very pleased to be with other people who have the same problem" (Dal Bello-Haas et al., 2014, p. 7). However, they provide no further information on how these dyads took part in interviews together, the reasons for interviewing them jointly, which questions they were asked, or when exactly these took place. However, more detail is provided on the quantitative methods used. On the other hand, apart from the baseline health state measures, no more information on intervention's

¹¹ Self-awareness changes reflect the loss of insight associated to Frontotemporal Dementias (FTD), however, it is also a characteristic of AD that people are not aware of their disease (Rankin, Baldwin, Pace-Savitsky, Kramer, & Miller, 2005).

impact on carers was obtained. The second paper (Frederiksen et al., 2014), did not provide information on why focus group were conducted separately (carers and people living with dementia), why this approach was chosen or, more specifically, how many or where focus groups were organized. For this thesis, qualitative methods used as well as its rationale will be provided in research publications. Additionally, description of any difficulties encountered when using these methods in dyads and in people living with dementia will be reported to provide future researchers with information on the (in)adequacy of these methods in this specific context.

b) A lack of qualitative methodologies in studies: The final publication (Wesson et al., 2013) includes a reflective comment by the authors in their discussion admitting qualitative methodology could have been useful to explore in-depth participants' perceived benefits. The study was limited in reporting participants living with dementia and their carers' (un)fulfilled needs. Authors used field notes to record this, however, they did not specify if they requested participants' feedback or took note on their spontaneous comments. This publication only reported an acceptable level of participant satisfaction and the need for some participants to take part in a more intense exercise. Another lesson learnt by the authors was that carers' needs (i.e., need for training in communication skills) must be taken also into account when designing falls prevention interventions. This could be particularly important when they reported carer burden was almost two times bigger in the intervention group (compared to control). To avoid this adverse effect, providing the person with dementia with another person to practise with (different from the primary informal carer and more motivated towards exercise), has been suggested as a possible alternative which, in turn, could facilitate the person living with dementia's adherence to the intervention (McCurry et al., 2011). In the TACIT Trial context, dyads will not be required to be formed by an alternative carer. However, flexibility for the type of informal carer to get involved in the intervention will allow that not only the primary carer can take part in the study. In turn, for this thesis, the experiences of dyads formed by other than primary carers will be sought were possible.

Adherence to the intervention, interconnected with its acceptability, has frequently been reported along these studies in terms of attendance rates (Dal Bello-Haas et al., 2014; Frederiksen et al., 2014; Wesson et al., 2013) and number of exercises practised (Wesson et al., 2013). However, a clear distinction between acceptability and feasibility or adherence, has been missing consistently in these papers. Even when the three papers commented here were identified through the acceptability search, they tended

to report adherence factors, related to the continuity practising exercise, instead of acceptability issues or facilitators. In summary, exercise interventions seem to be acceptable and feasible for people living with dementia and their carers (Farran et al., 2008; Suttanon et al., 2013; Yao et al., 2012; Yu & Swartwood, 2012; Yu et al., 2015). While carers' involvement on these studies varies, they are always described as an element of support for the person living with dementia. On the other hand, there has been limited use of qualitative methods and, when they have been used, how they were implemented has been underreported.

2.3.2.2.2. *Adherence to exercise interventions*

As commented previously, exercise has shown potential benefits for people living with dementia. However, as for the older population in general (Hawley-Hague et al., 2016a; Hill et al., 2015; Lam et al., 2012; Suttanon et al., 2012), people living with dementia's adherence to these interventions is a challenge (Yao et al., 2012). A systematic review around exercise interventions targeting people living with dementia to prevent falls in the community (Burton et al., 2015) pointed that attrition rates varied from 4.5 to 50% depending on the study and length of follow-up. This highlights that not only adherence to the intervention is a challenge, but also participants' retention in the research process. The most common reasons for dropping out amongst these community-dwelling participants were: Admission to care settings, poor health and not willing to complete the program, and in some cases death. Reasons for missing sessions were: The lack of an exercise habit before starting the intervention, need of support while practising, temporary illnesses, or holiday periods (Wesson et al., 2013).

The impact of intervention's format (home or group-based) on adherence has been considered in exercise interventions. However, a lack of a standardised method to report adherence (Simek et al., 2012) does not allow comparisons. An exercise intervention conducted amongst people living with dementia showed that 92.9% of participants allocated to the home-based exercise arm participated in 50% or more sessions, compared to 78.6% of participants in the group-based intervention over 12 months (Pitkälä, Pöysti, et al., 2013). However, the duration, intensity and modality of exercise were not necessarily the same for both groups, as the home-based intervention was tailored to everyone's needs. On the other hand, two systematic reviews of studies conducted amongst older people in general have provided different measures of adherence such as average of classes attended or average of full attending participants. Whereas a systematic review around home-based exercise interventions reported an average full attendance of 21% (Simek et al., 2012); another systematic review of group-based exercise interventions reported an average attendance to the total amount of sessions of 74% (McPhate, Simek, & Haines, 2013).

An additional systematic review of interventions to prevent falls amongst older adults living in the community (Nyman & Victor, 2012) found a higher median adherence to class-based (73.2%) than to home-based (52%) interventions over 12 months.

After replicating the search strategy (and exclusion criteria) to find papers around people living with dementia's acceptability of exercise interventions, 12 papers were retrieved (see Table F 4 for data extracted) around people living with dementia's adherence to these interventions. A number of lessons were learnt which informed the TACIT Trial:

- a) The need for tailoring home-based exercises: Tailoring exercises to participants' needs is not only important to facilitate their adherence to the intervention (Close et al., 2014; Teri et al., 1998) but also to ensure a safe practice. In the TACIT Trial, as advised by the Research Ethics Committee, participants will receive a visit from the Tai Chi instructor in their homes to conduct a safety assessment and then instruct participants on how to practise the exercises at home. In parallel, participants will receive continued support at the end of each group-based session on their home-based practice.
- b) The inclusion of diverse informal carers: The inclusion of other carers different from the primary carer, who could prefer to take the intervention time as respite or be less motivated to the exercise practice than other carers, has been suggested as a gap in research (McCurry et al., 2011). In the TACIT Trial, a flexible approach will be taken, where people living with dementia will be allowed to get involved in the intervention with any informal carer (spouse, family member, friend or neighbour) available to attend the sessions and provide support at least a couple of days a week for the home-based practice. If necessary, this carer could change during the intervention period.
- c) The use of behaviour change techniques: Goal setting techniques (Connell & Janevic, 2009), in form of action plans (Brown et al., 2015), have been frequently used to encourage participants adherence to the intervention. In the TACIT Trial, Tai Chi instructors will agree on a joint action plan with both members of the dyad during the home-visit. During the intervention, Tai Chi instructors will be available to participants to solve any problems that could experience during their involvement in the intervention and participants will be asked to record their actual adherence to the home-based component using exercise logs (Suttanon et al., 2012). In this thesis, action plans will be used as prompts in the semi-structured interviews to allow participants' reflection on their expected and real adherence to Tai Chi.

d) A continuous telephone follow-up during the intervention period: A continuous contact with participants during the intervention has been used in previous studies (Brown et al., 2015; Connell & Janevic, 2009) to encourage participants' engagement in trials. In the TACIT Trial, these phone calls will be used for safety monitoring purposes (Close et al., 2014), but also to check if participants agree to continue taking part in the study. Additionally, these calls will be used as reminders when participants do not attend two sessions consecutively without letting know to the instructor.

Apart from the lessons learnt from previous research, a number of limitations were identified through this review:

a) Underreport and misreport of qualitative methods: Although the use of qualitative methods (apart from progress reports) was not reported by Teri et al. (1998), in their discussion section they unexpectedly report comments from carers. However, this limitation appeared also in other papers retrieved by this search. Yao et al. (2012) hypothesise in their discussion about the possible higher time investment of carers of people living with AD to support these participants. Connell and Janevic (2009) also report adherence limitations in their discussion. McCurry et al. (2011) do the same when exploring the particularities of participants' experiences in any of the group conditions. In this case, authors commented on feedback requested to participants after the 6-months follow-up. This feedback provides information about barriers to maintain adherence during and after the intervention took place. For instance, they found spousal carers facilitated people living with dementia's adherence to the intervention. In this thesis, the impact of the relationship between members of the dyad and particular situations that participants might be experiencing (McCurry et al., 2010) along their participation in the trial will be explored to understand its impact on their adherence to the intervention.

Methods used have sometimes not been clearly explained. Suttanon et al. (2012), for instance, do not state if the interviews they conducted with people living with dementia were actually dyadic or not. They report a slightly different interview schedule for carers and people living with dementia, but also comment "only the interviewers, the participant with AD and, where relevant, their caregiver were present during interviews to minimize distraction or influence over participants' responses" (2012, p. 1175). However, they do not describe in what - or how many- cases this approach was used. On the other hand, as they interviewed only participants who adhered to the intervention, they stated that opinions from those who withdrew could be different. A lack of detail on how

qualitative data was analysed has been observed previously (Farran et al., 2008). For this thesis and related publications, not only a dyadic approach will be reported, but the method and its adaptations will be described.

b) Lack of agreement in defining adherence: Another paper was based on a study analysing adoption of a strength and balance intervention. However, adoption of this intervention was considered synonym of attending the gym once (Aartolahti et al., 2014). This definition of adherence did not consider the maintenance or duration component (Hawley-Hague et al., 2016b). In fact, previous publications seem to use a 6 months cut-off point (van Stralen, De Vries, Mudde, Bolman, & Lechner, 2009) to consider the establishment of a behavioural intervention (Hawley-Hague et al., 2016a). Perhaps then Aartolahti et al. (2014) should have considered using the concept of acceptability instead. This lack of consensus on the measurement of adherence is consistent with Hawley-Hague et al. (2016b). In studies included in this literature review, adherence has been sometimes reported in terms of classes attended (Burgener et al., 2008; Choi et al., 2005; Saravanakumar et al., 2014; Yao et al., 2012), exercises practised in these classes (Barnes et al., 2015; Yao et al., 2012), or individual exercise logs sent back to the research team (Yao et al., 2012). However, as reported by Hawley-Hague et al. (2016b) and previously reported for Tai Chi interventions (in section 2.3.2.1), different cut-off points have been used to assess participants adherence to interventions. Such variability will likely affect intervention's outcomes as participants will not receive the recommended dosage. When reporting interventions' impact on health the use of "completion (i.e., retention), attendance, duration and intensity adherence" measurements has been advised (Hawley-Hague et al., 2016b, p. 4) to clarify their possible impact on research outcomes. Particularly, adherence to the exercise intensity (apart from attendance) has been found to have a key impact on health outcomes (Miller et al., 2014). In the TACIT trial, data will be collected regarding participants' retention, attendance to the Tai Chi classes, and home-based Tai Chi practice (frequency and duration). Additionally, adherence to the protocol will also be reported.

In this thesis, participants' adherence will represent their attendance to the class-based sessions and Tai Chi practice at home. Given the difficulties that might appear when including people with cognitive impairment in interventions, programs specifically designed for them have been advised (Yao et al., 2008). However, a systematic review published around home-based exercises for older people living in the community seems not to have considered this aspect (Hill et

al., 2015). Even when the importance of intervention's differences according to the setting (care-home versus community) and delivery format (group or individual) it is clearly pointed by the authors, they included only one study on people living with AD, when the rest of them considered only participants without cognitive impairment. Moreover, in terms of reporting adherence, they report that 4 different methods had been used to report this in the studies reviewed but did not describe them. The TACIT Trial has been particularly designed for people living with dementia and their carers. This thesis will examine their joint experiences of taking part in the intervention, to help defining the different aspects promoting or challenging their adherence to the intervention in both settings.

c) Lack of detail on carer's characteristics and roles: Some studies have provided very little or no information on carers' demographics or relationship with the person living with dementia (Steinberg et al., 2009). The role of the carers is not always described either (Schwenk et al., 2014), possibly suggesting that these were not involved. However, it seems quite unlikely that outpatients living with dementia attending (or having attended) a hospital/care setting can take part in the intervention totally independently. In the TACIT Trial, not only demographic data from carers will be collected, but also about their physical performance. In this thesis, carers' role and their relationship with the person living with dementia will be described to explain the purposive sampling used. The impact of carers' characteristics and their relationship with people living with dementia on their adherence and experiences will be analysed.

d) Lack of description about the consent process followed: Information about the way consent has been gathered from participants seems to be a critical point when studying participants with dementia. However, sometimes this process has been under reported. For instance, Schwenk et al. (2014) stated that informed consent was gathered, but no information from who or how this consent was obtained is available. Similarly, these authors do not provide information about the initial level of motivation of participants or the environment where this intervention was conducted. However, this study did report on the lack of association between adherence and training response. In the TACIT Trial and this thesis, informed consent will be obtained from both members of the dyad along their participation in the study. Participants will be asked for their willingness to continue taking part in the study at every contact with the research team.

e) Lack of fidelity checks to ensure adherence to the intervention protocol:

Requirements used to recruit participants such as having an interest in “increasing their physical activity” (Connell & Janevic, 2009, p. 174) could have an impact on adherence levels and the generalizability of results. Intervention’s format could also have an impact on adherence. For instance, the fact that the exercise was supported by telephone, without direct contact with professionals or researchers, makes it difficult to assess the intervention’s implementation fidelity. Similarly, adherence to the program is not assessed and difficulties during the exercise practice (even when authors report the use of problem-solving strategies) are not reported (Connell & Janevic, 2009). In other occasions it is not clear if the intervention was conducted individually or in groups, even when the community is defined as the study setting (Yu et al., 2015). The TACIT Trial will combine home and class-based approaches and this thesis will analyse barriers and facilitators in both settings. Adherence to the suggested dosage will be measured by instructors (attendance to the classes) and also by participants themselves at home. This thesis will also incorporate fidelity checks to assess the adherence to the intervention protocol.

Two of the papers identified were study protocols. In one of them (Brown et al., 2015), the role of the carer was not clearly defined, it was just mentioned that they would be invited to the baseline measurements. There was also a lack of description on how participants will provide consent to take part in research. The other study stated that adherence would be recorded (Close et al., 2014) but authors do not provide much details on the way this would be done. They only state that a logbook will be provided to record exercises practised and any adverse event experienced. As they point this information will be analysed statistically, it does not seem that qualitative methods will be used. However, it seems particularly relevant to provide more detailed information on how this adherence will be checked by the research team in a 12 months long intervention.

A systematic review about exercise interventions conducted with older adults living in the community found more quantitative ($n = 5$) than qualitative ($n = 3$) papers studying participants’ adherence (Farrance et al., 2016). Authors initially performed a qualitative synthesis where six factors influencing older adults’ adherence to group-based interventions emerged: “social connectedness, participant perceived benefits, instructor behaviour, programme design, empowering /energising effects and individual behaviour” (Farrance et al., 2016, p. 162). These are likely to be common factors with participants living with dementia taking part in exercise interventions.

2.3.2.2.3. *Process evaluations in exercise interventions*

The use of process evaluations to study factors such as participants' acceptability and adherence along exercise interventions designed for people living with dementia has not been frequent. In fact, there has been only one such evaluations in the context of an intervention using a dyadic approach (Prick et al., 2014) and planned from the beginning of the study as reported in their protocol (Prick, de Lange, Scherder, & Pot, 2011), which highlights a gap in research this thesis will seek to address.

Prick et al. (2014) conducted a process evaluation of a multicomponent intervention for dyads (people living with dementia and family carers) delivered at home. Apart from being able to report factors acting as barriers and facilitators of participants' adherence to the intervention (as reported in Appendix H) they could also identify strengths and weaknesses in their intervention. Amongst their strengths, dyads were able to discover a new activity to practise together and improve their relationship by increasing their mutual confidence (Prick et al., 2014). Weaknesses included that the exercises confronted people living with dementia with their physical and mental inabilities, and that strengthening and balance exercises were difficult to perform for some people living with dementia (Prick et al., 2014). At a later stage, authors have reported a lack of impact in mood, behaviour, physical health outcomes, and cognitive functioning (amongst their sample, $n = 111$ dyads). Such lack of impact could potentially be explained by the home-work being perceived as a burden and time consuming by participants, by the ceiling effect (considering half of their sample was attending day care centres), or the lack of effect of the intervention (Prick, de Lange, Scherder, Twisk, & Pot, 2017; Prick, de Lange, Scherder, Twisk, & Pot, 2016). Considering these aspects in future research with dyads including people living with dementia will potentially facilitate participants' adherence to the intervention. Similarly, it would be useful to understand if some exercises are more suitable for people living with dementia than others (i.e., easier to practise and more appropriated to their preserved abilities) or explore alternative ways to help participants to adhere to the intervention when the participant it is not able to perform the exercises.

Two additional protocols have been published very recently about interventions containing an exercise component and planning to perform a mix-methods process evaluation (Allan et al., 2018; Harwood et al., 2018). In one of them, qualitative methods have been used to develop the intervention and will be used in the feasibility RCT Phase as part of the process evaluation (Booth et al., 2018; Harwood et al., 2018). According to the protocol, the intervention will target people diagnosed with MCI and mild dementia, aim to preserve activity levels through the inclusion of home-exercise, and use a dyadic approach where carers are available. The other study is

also looking to develop a tailored home-based intervention for people living with dementia and will involve carers to support participation in the study (Allan et al., 2018). The aim of the study in this case will be to improve falls' outcomes in the person living with dementia tailoring the exercises (including strength and balance) and functional activities.

The value of such evaluations has also been proven in the context of an RCT trying to replicate a successful psycho-social intervention in a different country (Voigt-Radloff et al., 2011). In this case, however, a process evaluation helped to understand the unsuccessful results found in the study replica.

The positive impact of exercise on people living with dementia's physical and mental health has been well recognised. The use of behaviour change techniques, as well as the socialising component and perceived benefits of the interventions, have helped enhancing their adherence to interventions. Exercise interventions in the context of dementia have tended to target people living with dementia and their carers separately. However, when a dyadic approach has been used, qualitative methods have been underused and the role of the carers has been poorly described. Future research needs to address this to further understand the impact of their joint participation in adherence and, in turn, in research outcomes in both members. Similarly, there is a lack of process evaluations conducted along RCTs testing exercise interventions in people living with dementia. Only one study has been identified, where participants were recruited in dyads and asked to identify strengths and weaknesses of the intervention. There is a need to understand the views of participants involved in exercise interventions and explore their views in complex interventions such as the TACIT Trial.

2.3.3. Outcomes

2.3.3.1. *Impact of Tai Chi interventions on balance and falls prevention*

Tai Chi interventions have frequently been assessed for its impact on postural balance, due to this being identified as a risk factor for falls amongst older adults living in the community (Vieira, Palmer, & Chaves, 2016). Tai Chi interventions conducted amongst people living with dementia (see Appendix F) have frequently targeted an improvement in balance or the reduction of falls (62.5%). Only one of these studies did not measure balance (Nowalk et al., 2001) but merely the number of falls. When balance was measured, the Berg Balance Scale (BBS) (Berg, Wood-Dauphinee, Williams, & Maki, 1992) was used alone in two studies (Burgener et al., 2008; Saravanakumar et al., 2014); the Unipedal Stance Test (UST) (Hurvitz, Richardson, Werner, Ruhl, & Dixon, 2000) and Time Up & Go (TUG) (Podsiadlo & Richardson, 1991) were used together in

one study (Yao et al., 2012); and, in the last study, the description of the measure used is similar to the UST (Choi et al., 2005). These measures were both used in community and long-term care settings; however, whereas BBS measures functional balance, the UST assesses static balance and the TUG dynamic balance. In this case (as shown in Appendix F), studies using BBS did not report improvements in balance, but a maintenance (Burgener et al., 2008) or a reduction similar to the control group (Saravanakumar et al., 2014). However, those using UST (or UST and TUG) reported an improvement in participants' balance (Choi et al., 2005; Yao et al., 2012); which suggest that not only intervention characteristics, but measures chosen could have an impact in trials' findings. It is possible that certain measures are more sensitive to balance improvements or that only specific types of balance can be enhanced by Tai Chi. In the TACIT Trial, postural balance will be the main outcome (measured with TUG), but secondary measures will include functional (measured by BBS) and static balance (measured using a postural sway test). The use of additional measures of balance could help to determine which measures are more appropriated and sensitive when used in people living with dementia.

According to the studies summarised in Appendix F, Tai Chi had a positive impact on participant's physical performance –including balance- in most of the studies based in community-dwelling participants (Barnes et al., 2015; Yao et al., 2012), even when attendance to the sessions was quite low (52.1% on average) (Barnes et al., 2015). Other interventions in this setting showed an improvement in balance performance during the first part of the intervention (1-20 weeks) and maintenance in the second half of the intervention (20-40 weeks) compared with participants in the control group (whose performance declined during the first 20 weeks (Burgener et al., 2008)). Considering the progressive nature of dementia, a maintenance in physical performance compared to the control group should be taken as a positive result (Burgener et al., 2008). However, in studies conducted in long-term care settings, the impact on balance has been equivocal. Choi et al. (2005) found an improvement in balance whereas Saravanakumar et al. (2014) and Nowalk et al. (2001) did not. Difference in findings could be due to variation in the level of cognitive impairment of participants (Choi et al. (2005) do not provide an average of the MMSE performances of their participants). In addition, a number of participants practising seated Tai Chi in Saravanakumar et al. (2014)'s study and a difference in the Tai Chi dose offered (21hrs in Choi et al. (2005)'s versus 14hrs in Saravanakumar et al. (2014)'s studies) could be feasible explanations for these varied findings. This dose-response relationship would be supported by the Sherrington et al. (2011) systematic review's results where higher dosages of exercise (≥ 50 hrs) had greater impact on falls outcomes. Nowalk et al. (2001), on the other hand, did not state the length of sessions, which makes it difficult

to estimate the Tai Chi dosage offered, as could be particularly heterogeneous in a 24 months intervention.

Although older people living with dementia are more likely to fall than their peers without dementia (Shaw, 2003), they have been frequently excluded from falls prevention interventions (Hasselmann, Oesch, Fernandez-Luque, & Bachmann, 2015). When widening the search, studies conducted amongst general older people at risk of cognitive decline living in the community trying to analyse the influence of exercise in balance have found positive results (Lam et al., 2012). It has been suggested that its impact on cognition's preservation would require more long-term adherence, similarly as the improvement in balance was found to be clearer after a year of practice. This is consistent with the need of maintaining adherence to exercise interventions to reach its long-term benefits. Longer interventions that provide support to their participants, in turn, are more likely to produce a behaviour change. Moreover, Lam et al. (2012)'s results, pointed Tai Chi's positive impact on balance could be higher than other exercises like stretching which do not challenge balance.

In older adults who had previously experienced progressive modifications in their mobility as a result of a chronic disease (Fried, Young, Rubin, & Bandeen-Roche, 2001), no impact on balance (Day et al., 2012) or falls (Day et al., 2015) was identified when comparing Tai Chi with a chair-based exercise. Authors suggested participants "at an increased risk of [mobility] disability" (Day et al., 2015, p. 421) would need to reduce their amount of standing practice and, in turn, the balance challenge, which could help explaining these results. This is in line with Nyman and Skelton (2017)'s commentary which suggested that adapted versions of Tai Chi for frailer participants using more seated practice could lose their falls prevention effectiveness.

On the other hand, in healthy older adults Tai Chi studies have supported a positive impact on balance (Howe, Rochester, Neil, Skelton, & Ballinger, 2011; Sherrington et al., 2008) and fear of falling (Kendrick et al., 2014) at least immediately after completing the intervention. Its potential as a falls' prevention intervention (Wayne et al., 2015) seeking to address only one risk factor for falls (i.e. balance or muscle strength) was stressed by Gillespie et al. (2012). Such positive results could highlight the power, acceptability, and cost-effectiveness of Tai Chi as a falls prevention strategy. It must be noted, however, that its effectiveness amongst participants at higher risk¹² was questioned. This potential limitation was also identified in a systematic

¹² High risk of falling was defined as having history of a fall or having various risk factors for falls (Gillespie et al., 2012). Risk factors for falls according to the Centers for Disease Control and Prevention (n.d.) are: advanced age, previous falls, muscle weakness, gait and balance problems, poor vision, postural hypotension, chronic conditions including arthritis, diabetes, stroke, Parkinson's, incontinence, dementia, fear of falling, psychoactive medications, and other external factors as poor adaptations in the house.

review including a variety of exercise interventions conducted amongst older people in general (Sherrington et al., 2008).

2.3.3.2. *Impact of exercise intervention on falls prevention*

Apart from Tai Chi, other exercises interventions have been found to have promising effects on preventing falls amongst people living with dementia (Burton et al., 2015; Wesson et al., 2013). However, as with Tai Chi, people living with dementia have frequently been excluded from primary research studies and, this has been reflected in systematic reviews analysing the effectiveness of falls prevention interventions in older people (Gillespie et al., 2012; Howe et al., 2011). When a systematic review has been published around the effectiveness of exercise in people living with dementia, a positive impact on ADL but not on falls outcomes was reported by Forbes et al. (2015). However, this review only included two studies conducted amongst community-dwelling participants. In contrast, a systematic review on the effectiveness of exercise interventions in people living with cognitive impairment found a positive effect on the prevention of falls (Chan et al., 2015) even when it also mixed long-term care and community study settings. Similarly, when a review focused on those living in the community (Burton et al., 2015), and taking necessary caution in interpreting these results, a promising impact on falls has been identified. Such encouraging results have been found as well after conducting a more inclusive systematic review including older people living in both (community and care) settings (Sherrington et al., 2008).

A Cochrane review (Gillespie et al., 2012) included 159 randomised or quasi-randomised controlled trials aiming to prevent falls amongst community-dwelling older people. 59 Of these (37.11%) tested the effect of exercise on falls. Most of them were delivered in a group basis, with only 12 being home-based. Heterogeneity was again identified as a limitation. Whilst some of them were delivered as a single component (to impact one risk factor) other were delivered as part of a multicomponent (targeting the reduction of various risk factors for falls) intervention. Similarly, some interventions provided the same (standard) intervention to all its participants, whereas others provided a tailored intervention. Having acknowledged this, authors found strong evidence in favour of some exercise programmes as being effective to prevent falls and reduce recovery periods. In that respect, the format of the intervention, delivered in group or individually at home, seemed not to have an impact on reducing the rate of falls or the risk of falling.

There are contrasting versions regarding the suitability of home-based or group-based interventions when involving people living with dementia across the literature. Papers reporting home-based interventions (Farran et al., 2008) argue and refer to aligned

literature were participants prefer individual tailored interventions delivered in their own homes. In contrast, group-based interventions highlight the role of the social component as a facilitator for participants' engagement in the intervention (Dal Bello-Haas et al., 2014). Despite these differences, Farran et al. (2008) report the case of one of their participants who was not able to increase PA until engaged in a group-based PA program. However, as reported for Tai Chi interventions, not only people should be offered different types of cost-effective interventions to fit their varied needs (Nyman & Skelton, 2017), but these will need to be offered in different formats (i.e., home and class-based) which meet their preferences.

A systematic review of interventions for preventing falls in older people in care facilities and hospitals (Cameron et al., 2012) suggests exercise in sub-acute hospital settings appears effective, but its effectiveness in care facilities is less clear. However, in these settings exercise is frequently done seated. It has been argued that the level of limitations (or disability) could be negatively mediating its effectiveness, whereas vitamin D supplementation or interventions targeting multiple individual risk factors seems to work better for participants living in those environments.

The impact of exercise interventions in the prevention of falls could be influenced by improvements in the physical and cognitive functioning. In AD, for instance, deterioration in frontal cognition could increase the risk of falling (Andrade et al., 2013). Similarly, Kemoun et al. (2010) found a significant correlation amongst walking and gait variables and cognitive performance.

2.3.3.3. *Impact of exercise on cognitive function*

Exercise research based on people living with dementia has typically studied its effects on cognition. A recent meta-analysis on the effects of PA –used by the authors as synonym of exercise- on cognition of individuals living with dementia included 6 out of 18 RCTs based on community-dwelling participants (Groot et al., 2016). Results suggested that PA interventions involving aerobic (or a combination between aerobic and non-aerobic exercise) could have a positive impact on people living with dementia's cognition. The authors reported that exercise could be used as an alternative or complement to traditional pharmacological therapies. These results are consistent with a previous systematic review comparing the effects of exercise and drug interventions, which found exercise to be more effective (Ströhle et al., 2015). There is a lack of clear evidence informing on optimal frequency, duration and modality of exercise (Forbes et al., 2015), which makes it difficult to provide recommendations on its dosage. Other systematic reviews (Forbes et al., 2015; Littbrand, Stenvall, & Rosendahl, 2011; Öhman, Savikko, Strandberg, & Pitkälä, 2014) have not been so

positive about the potential influence of exercise on cognitive functioning. These reviews have identified numerous methodological problems as well as heterogeneity in findings. The differences in findings are also due to the inclusion and exclusion criteria used in the various systematic reviews. For example, the review by Littbrand et al. (2011) was mainly based on interventions in individuals living in care facilities whereas the review by Öhman et al. (2014) included individuals with dementia and MCI. Similarly, a variety of interventions –from walking to Tai Chi- have been analysed together (Öhman et al., 2014).

2.3.3.4. Impact of exercise on physical functioning

The physical performance of people living with dementia and their ability to perform ADLs has been improved through participating in exercise interventions (Forbes et al., 2015). According to the conclusions of the systematic review and meta-analysis conducted by Hill et al. (2015) on individualized home-based exercise programs for older people –which included only one study based on people with AD-, these interventions appear to be effective. The authors also reported a few strengths and weaknesses in comparison with similar interventions conducted following a group-based format. Amongst the strengths they identified the possibility of tailoring the intervention to meet individuals' needs, as well as reducing intervention costs. Weaknesses were related to the lack of social interaction and reduced adherence.

2.3.3.5. Impact of fidelity, acceptability and adherence on research outcomes

As balance has consistently emerged in the literature as a key element in any falls' prevention intervention, including Tai Chi or other types of exercise; adherence has also been identified (Sherrington et al., 2008) as a key factor in these interventions. Monitoring participants' adherence and needs fulfillment have become necessary to assess their impact on attaining improvements in physical functioning (Pitkälä, Pöysti, et al., 2013).

When it has been measured, only in isolated occasions adherence has not predicted an impact on treatment outcomes (Schwenk et al., 2014). In this case, authors measured adherence as an average of sessions successfully performed per participant (not reported) and stated participants' average adherence was 91.9%. However, adherence ranges were not provided, information on how adherence predictability was calculated was not provided and could be that most participants in the intervention arm received an acceptable dosage. Sherrington et al. (2008), on the other hand, did not find an adherence effect, but they used a 50% cut-off point which indicates participants were far from the recommended dosage. However, in most of the cases authors have reported low adherence and high attrition rates as a mediating factor of

the weak effectiveness of their interventions (Day et al., 2012; Day et al., 2015; Logghe et al., 2011; Pitkälä, Pöysti, et al., 2013). Voukelatos et al. (2007), for instance, reported a causal relationship amongst higher adherence to a Tai Chi intervention and a lower register of falls in older adults. In this context, not only the number of sessions attended is important, but also Tai Chi dose received. For example, Day et al. (2015) reported their participants received on average half the exercise dose recommended. The optimal exercise dosage and mode (FxDxIxM), however, does still need further investigation (Chan et al., 2015).

In the studies reviewed here about Tai Chi interventions conducted in people living with dementia, when an impact of Tai Chi on balance (and falls) has not been found (particularly in the long-term care setting context), authors have suggested adherence level (Nowalk et al., 2001) and level of dependency (Saravanakumar et al., 2014) as the possible causes. In this respect, research studying the effectiveness of treatments amongst participants with cognitive impairment could be more challenging than those conducted amongst general older population. This is due to cognitive impairment being identified not just as a risk for falls but also as a potential interference for adherence to interventions (Vieira et al., 2016).

In falls prevention interventions conducted in the older population in general, low adherence has been described as a matter of concern in the literature (Day et al., 2016; Haines et al., 2014; McPhate et al., 2016; Nyman & Victor, 2014). Two systematic reviews revealed around 75% of older adults living in the community agreed to take part in fall prevention interventions when offered (Nyman & Victor, 2012), compared to 50% of those living in long-term care settings (Nyman & Victor, 2011). However, in both settings their adherence fell notably over a year. Reasons for such low adherence rates have been linked to a lack of perceived benefits for older adults themselves than a lack of perceived effectiveness of the intervention itself (Haines et al., 2014). However, not only the lack of effect has been attributed to low adherence rates, but also positive health outcomes (i.e., in cognitive performance, mobility and risk of falls) have been attributed to high adherence rates (Burgener et al., 2008; Suttanon et al., 2013; Yao et al., 2012). The impact of adherence in research outcomes has highlighted the importance of monitoring and reporting participants' involvement in research.

Exercise interventions, in general, and Tai Chi in particular, have shown a positive impact both on the physical and psychological outcomes of older adults. Particularly, its impact on postural balance and the reduction of falls events in people living with dementia has been promising. Often the effect of these interventions has been reduced by low adherence and high attrition rates. The tendency to use quantitative methods to

assess the effectiveness of these interventions has possibly limited our understanding of participants' experiences. This, in turn, has left a gap in research to identify ways of improving sustained adherence to exercise interventions in older people living with dementia. Future research needs to study these outcomes in high-quality studies where participants are given the opportunity to express their views on these interventions. Exploring participants' characteristics together with their views will facilitate making recommendations of which interventions are more likely to have a significant impact on participants.

Despite not being the focus of this literature review (approaching exercise behaviour as a source of health and wellbeing far from competition), in the sports domain a similar trend has been identified where the main focus of research is on the effectiveness rather than the participation process (Coalter, 2008). However, both disciplines face the challenges of contradictory findings due to interventions' heterogeneity, as well as methodological and quality issues, which makes it harder to produce an evidence-based message required to inform policy (Coalter, 2008; Oja et al., 2015). As in exercise, the sport domain would benefit from understanding the experiences of participants with different health conditions that might influence their sustained participation. UK sports policy has highlighted the need to include these under-represented collectives who are less active than their peers (HM Government, 2015). To fill this gap, Sports England funding has been allocated to support their inclusion in physical activity or sport. Hence, this thesis will work towards this aim and its results might be of interest to understand what processes might be interfering with measured outcomes in sports and physical activity contexts.

2.4. Theoretical Background

After reviewing empirical studies, only a few provided a theoretical background. Nevertheless, there is a need to link research findings (as in this thesis) to a theoretical approach as this would help explaining and understanding the phenomenon under study. Participants' acceptability and adherence to a 20-week exercise intervention could be studied from different theoretical approaches from a health psychology perspective.

A recent systematic review, for instance, identified five main thematic categories where diverse theoretical approaches to the initiation and maintenance of behaviour change could be allocated (Kwasnicka, Dombrowski, White, & Sniehotta, 2016):

- a) Maintenance motives, that is theories that have explained the sustainment of exercise behaviour by keeping at least one motive to exercise over time. Self-Determination Theory (Deci & Ryan, 2000), for instance, postulates the well-

being of the individual is enhanced when his or her behaviour (i.e., Tai Chi practice) is driven by their enjoyment of the exercise (or intrinsic motivation). This theory's relevance in the TACIT Trial will be further discussed later (in section 2.4.1). Another example could be Protection Motivation Theory (Rogers, 1975) where the individual would take part in exercise driven by their willingness to protect him or herself from a negative outcome (i.e., to prevent health issues) after the individual's evaluation of its seriousness, likeliness to happen, and chances to effectively act and avoid the negative outcome. However, in the context of the TACIT Trial, Protection Motivation Theory might not be useful as participants would have already made the decision to join the Tai Chi classes and the falls prevention would be less stressed than its potential positive outcomes (i.e., well-being).

- b) Self-regulation, where maintenance of exercise behaviour is mainly based in adjusting to the new exercise behaviour and being able to overcome difficulties. It might be relevant in the context of the TACIT, as barriers to participation are likely to be identified and participants' adherence could be challenged. Relapse Prevention Model (Marlatt & George, 1984) was initially proposed to explain how to refrain addictive behaviours, though over time, it has also been used to prevent lapse (interrupting the health behaviour for a short time) and relapse (for long time) in exercise interventions. The development of coping plans to use in face of a high-risk situations, would help individuals to avoid the relapse (Buckey & Hughes, 2008). Coping, but also action plans, have also been suggested under the Health Action Process Approach, which attempts to overcome the intention-behaviour gap. To do this, it explains behaviour change as a process of two stages, where the first one focus on the processes involved in the formation of the intention (i.e., action self-efficacy, outcome expectancies and risk perception) and the second one (volitional) leads to the actual behaviour (maintenance self-efficacy, recovery self-efficacy, and action and coping planning) (Schwarzer, 2008). However, the Health Action Process Approach does not consider the role of motivation and outcome expectancies to plan and sustain participation in exercise interventions; which could be explained better by motives theory in the TACIT Trial.
- c) Resources, or having enough physical and psychological reserves required to perform the exercise behaviour would facilitate behaviour maintenance. Self-Control Model postulates that "Self-control enables a person to restrain or override one response, thereby making a different response possible." (Baumeister, Vohs, & Tice, 2007, p. 351). However, self-control is presented as

a limited resource, where its use in a certain environment can translate into a poorer performance in another aspect of life. Additionally, there are modulator factors that could help to counterbalance the scarcity of this self-control resource such as motivations, incentives or positive emotions. In the TACIT Trial, the exploration of these modulator factors would be more feasible through observation and interviews, whereas the impact of lack (or abundance) of resources in other areas of participants' life will not be explored in depth.

- d) Habit or having incorporated exercise to life routines would promote exercise maintenance. Habit Theory would describe the habit as a purposeful response to a given situation that has become automatic after the successful reiteration of a past behaviour (Verplanken & Aarts, 1999). In this line, it takes past behaviour as predictor of future behaviour e.g., previous exercise experience would facilitate future exercise engagement. This might be useful in the TACIT Trial, as participants will be asked about their previous exercise experience when collecting their feedback at the end of the classes.
- e) Environmental and social influences, where having a supportive environment (including social support) helps to carry on practising. In Social Cognitive Theory (Bandura, 2002) the dynamic and reciprocal interactions amongst environment, behaviour and the individual are central. Individuals can learn from peers how to perform behaviours through modelling, however internal and external reinforcements will impact on the likelihood of this behaviour to reoccur. Similarly, expectations regarding the outcome of certain behaviour, often influenced by previous experiences, will impact on behaviour. Lastly, environmental and individual's factors will have an impact on individuals' self-efficacy level. Self-Efficacy (SE) Theory (Bandura, 1977) describes the perceptions that individuals have regarding their potential success in performing the exercise behaviour considering their abilities but also the situation or context where they find themselves at that specific time-point. Past exercise performance accomplishments, viewing relevant others exercising (i.e., famous people acting as models), relevant others' persuasion (i.e., the other member of the dyad or the instructor), and the physiological and affective state will influence the individual's SE level. However, SE's impact on behaviour seems to decrease once the individual becomes familiar with the exercise. This seems to make SE theory more useful to explain exercise adoption at the initial stages of exercise practice than adherence to exercise in the long-term (Lox, Martin Ginis, & Petruzzello, 2010). Hence, it might be partly useful to explain the findings in the TACIT Trial's context.

Other theories seem to have been categorised into different themes amongst experts consulted for the systematic review (Kwasnicka et al., 2016). This is the case of the Theory of Planned Behaviour, which proposes three elements (attitudes towards the behaviour, subjective norm and behavioural control) as having an impact on behavioural intention. Behavioural intention is assumed to be a predictor, as well as Perceived Behavioural Control, of actual behaviour. Other factors such as biological or environmental ones would be mediated by the former three elements. This theory has been frequently criticised due to the intention-behaviour gap that rests unaddressed (Sniehotta, Pesseau, & Araújo-Soares, 2014). The Transtheoretical Model (Prochaska & DiClemente, 1982), on the other hand, differentiates between five stages (pre-contemplation, contemplation, preparation, action and maintenance). However, stages models have been criticised for not being able to predict the direction of the individuals' movements through these stages or explain why some individuals would skip some stages or regress to previous stages (Lox et al., 2010). This would also be a limitation in this thesis' context, as its aim would be to determine what makes participants (not) accepting or adhering to the exercise intervention.

Having acknowledged the contributions of different theories to explain behaviour change and maintenance, there is one that seems more useful to explain the experiences of participants in TACIT Trial: Self-Determination Theory (SDT). SDT focuses on the individual and its well-being. It considers the impact of the environment as Social Cognitive Theory (Bandura, 2002), but not only as a source of learning, but as a facilitator of the fulfilment of basic needs which have an impact on its well-being. Habit theory (Verplanken & Aarts, 1999), on the other hand, can be useful to explain long-term adherence, however, SDT allows understanding what happens with those who do not develop a habit and the process individuals undergo to (not) develop such habit. As previously mentioned, theories around resources (Baumeister et al., 2007), have a difficult application in this thesis which focus is in one aspect of participant's life (participation in Tai Chi). Finally, self-regulation theories (Marlatt & George, 1984; Schwarzer, 2008) do not explain the role of motivation or outcome expectations in sustaining participation.

2.4.1. Self-Determination Theory

SDT has been widely used in the exercise context, where different types of motivation have been associated with maintenance or discontinuation of practice. SDT fits well with this thesis' research questions and aim (stated in Chapter 1), which look to explore participants' drives to sustain their participation in Tai Chi. When looking to understand the experiences of people living with dementia, as well as ways to facilitate their

acceptability and adherence to an intervention, it is important to keep the focus on individual's preferences and needs.

Self-Determination's focus on the individual (and its autonomy) is particularly relevant in a dyadic intervention as both members might initiate the exercise practice with different levels and types of motivation. In the context of dementia, individuals' self-identity could be affected by their perceptions and awareness of their own decline, which can have an impact on their well-being (Windle, Woods, & Markland, 2010). However, the environment's reaction to the diagnosis is also critical. There is still a stigma (or double stigma as more frequent in older people) around people living with dementia, which contributes to the depersonalisation of individuals that have been diagnosed and makes some of them feel that life is no longer worth living (Robbins & Bernat, 2017; Wolverson, Clarke, & Moniz-Cook, 2010). This is the reason why a person-centred approach¹³, where personhood and individuals' self-determination are protected is so necessary (Reed, Carson, & Gibb, 2017). Self-Determination Theory, contributes to this focus on individuals making decisions around their engagement in Tai Chi.

Other theories might be useful to partially explain this thesis' findings (i.e., in case of practice's lapses or if repeated practice develops into a habit). However, Self-Determination Theory (SDT) has been chosen as the main theoretical approach for this thesis, providing its broad scope, not only focused on motivation, but also on well-being and personality. SDT is a macro-theory, which is formed of five mini-theories (Vansteenkiste, Niemiec, & Soenens, 2010):

1. Cognitive Evaluation Theory (CET): Suggests that individuals have an innate, intrinsic motivation that drives them to explore their environment and engage in new experiences without the need for external reinforcements. As a result of trying new activities, individuals find some of them enjoyable, which facilitate its long-term practice and enhance their well-being. Hence, CET posits a classic distinction between extrinsic and intrinsic motivation, giving intrinsic motivation a central role (see types of motivation in Figure 2). Extrinsic motivations are perceived as controlling and external pressures.
2. Organismic Integration Theory (OIT): Evolves from CET theory and suggests that there are different types of external regulation. These go from external to integrated regulation (see types of regulation in Figure 2) and are characterised by the extent to which are perceived as autonomous (versus controlled) and the

¹³ Initially developed by Carl Rogers and then brought by Thomas Kitwood into the dementia care field, the person-care approach puts the individual in the centre of attention. Under this approach, it is accepted that the way the environment (i.e., carers) treats the person living with dementia when becomes increasingly dependent on their carers, has an impact on his or her preservation of self (Fazio, Pace, Flinner, & Kallmyer, 2018).

reasons leading to the behaviour. By a process of internalization (also represented in Figure 2) the individual can adopt external demands (i.e., social norms), opt for following them, and integrate them in their values (and end up applying them in absence of controlling agents). Hence, the growth of the individual will be possible, through the adoption of behaviours that are aligned with their values or perceived as important. The individual might not find an enjoyment in such behaviours but feel them as relevant for them and hence feel some autonomy in their performance.

3. Causality Orientations Theory (COT): As reflected in Figure 2, posits that individuals' motivational pulse or the reason to act comes from the individual's values and interests (autonomous orientation), from their tendency to act according to internal or external pressures (control orientation), or from their feeling that their lives are out of their control (impersonal orientation).
4. Basic Needs Theory (BNT): Suggests that autonomy, competence and relatedness are three innate needs the individuals need to fulfil to ensure their well-being. There are three characteristics of the environment that will support meeting those needs: autonomy supportive (through the acknowledgment of other's needs, providing a rationale in absence of choice), structure (so individuals know what is expected from them) and interpersonal support (involving empathy, a warm environment, and connection with others). These characteristics of the environment are supposed to be contributors to the satisfaction of the three basic needs and translate into more autonomous forms of motivation and well-being.
5. Goal Content Theory (GCT): Accounts the different aspirations individuals have, which could be internal (i.e., personal growth) or external (i.e., fame). Pursuing health was in principle considered as an internal goal, however, due to the messages sent by media nowadays it could be more difficult to differentiate if health goal responds to an internal goal (reduce pain or promote health generally) or an external goal (achieve a better body image).

Self-Determination Theory's focus on motivation, on its own, is of interest in this thesis as apathy has been identified as a symptom of dementia (Brodaty & Burns, 2012). That is, people living with dementia frequently experience a lack of motivation in engaging in activities, which could interfere in their willingness to participate in Tai Chi. This lowered motivation in the context of dementia it is difficult to differentiate if it is due to not willing to engage in activities per se, to the cognitive decline associated to dementia or, even, to the secondary effects of medication (Brodaty & Burns, 2012).

It is widely accepted, however, that motivation plays a key role in sustaining exercise behaviour (Teixeira, Carraça, Markland, Silva, & Ryan, 2012). A classic distinction has been established between intrinsic and extrinsic motivations, based on the origin and purposes of our drive to act. Whereas intrinsic motivation emerges from the individual will to do something essentially interesting for him or herself; extrinsic motivation involves an outer stimulus which facilitates reaching a goal (Ryan & Deci, 2000). In SDT, these two classical types of motivation are part of a self-determination continuum that involves from non-self- to self-determined behaviours (amotivation- extrinsic motivation- intrinsic motivation). Such behaviours are informed by different types of regulation, which reflect the level of autonomy in the individual’s motivation. Hence, following Figure 2, types of regulation increase in autonomous motivation as they reach the right end (i.e., external regulation implies the lowest autonomous motivation, and intrinsic regulation represents the highest autonomous motivation). Similarly, the locus of causality or individuals’ reasons to act (Ryan & Connell, 1989) can be internal (to please themselves), external (to please others) or impersonal (when individuals’ feel a lack of competence and control).

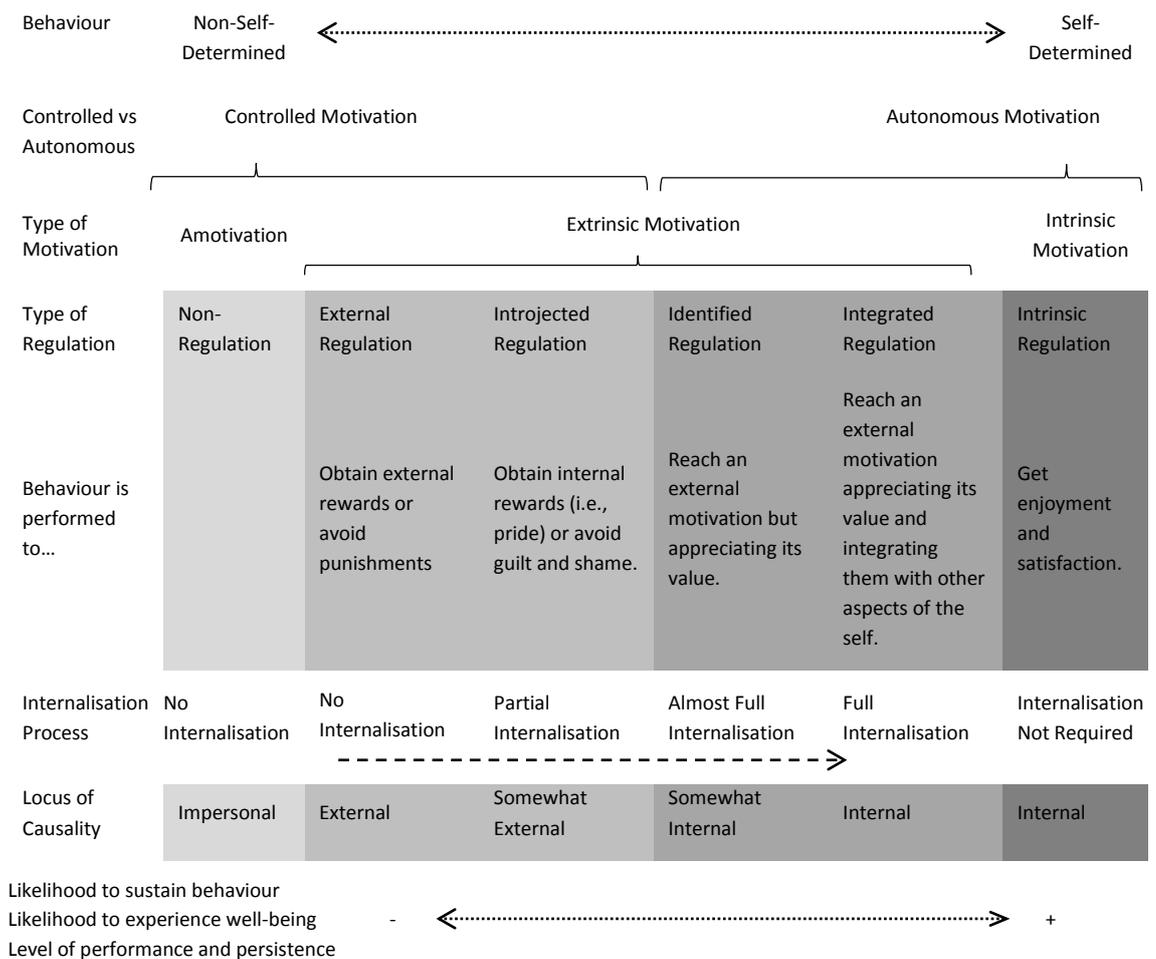


Figure 2. Self-determination continuum, adapted from Deci & Ryan (2000, pp. 236-237) and Vansteenkiste et al. (2010, p 115).

As suggested by SDT a progress towards an integrated regulation (hence, to more self-determined behaviours) is likely to happen as the social context's values tend to be internalised, provided individuals' basic needs are fulfilled (Deci & Ryan, 2000).

According to SDT, these basic psychological needs are innate and need to be addressed by the intervention to enhance participants' self-motivation and psychological well-being (Deci & Ryan, 2000):

- ✓ Competence: This need is satisfied when the individual feels in control and succeeds in an activity. However, this need could also be satisfied through positive feedback; which would enhance intrinsic motivation. SE theory (Bandura, 1977) relates to competence, however, does not differentiate between the type of regulations described in SDT (Deci & Ryan, 2000).
- ✓ Relatedness: This need is satisfied when the individual feels connected with other members taking part in an activity. This connection is experienced by interacting with others but also when the individual feels that belongs to a group and that others care of them. In an intervention were participants will take part together with a family member or a friend, relatedness might apply to their relationships with the other member of the dyad, the other participant dyads, and the instructor.
- ✓ Autonomy: This need is satisfied when the individual performs an activity freely, without external pressures or rewards. Hence, autonomy does not limit to the individual acting independently. Autonomy can be supported by providing alternatives to the individual and accepting their feelings. In the context of the TACIT Trial, in the absence of a provision of alternatives, the importance of Tai Chi and its potential benefits will be explained to the participants. This could contribute to the internalisation process if participants perceive them as valuable and relevant. Hence, participants might feel progressively more autonomous in their decision to join an activity that is well-internalised and aligned with their values.

This thesis feeds back on the usefulness of SDT in explaining dyad's sustained participation in a Tai Chi exercise and what contextual factors appear to be linked with adherence over the course of the intervention. For instance, it is explored whether dyads' reasons to keep attending classes (or to adhere to the home-based component) are related to the fulfilment of the three basic needs. It is also explored whether more adherent participants keep doing so merely to enjoy, and/or whether other aspects such as the social context (in dyads and in a group setting) and the characteristics of the intervention can explain their sustained participation better.

2.5. Summary

From reviewing the literature, one can detect a growing body of evidence over the last two decades focusing on the impact of exercise on people living with dementia.

However, there are still gaps to be addressed, which this thesis will seek to address and disseminate in three publications:

- 1st There is a lack of research projects studying the acceptability of Tai Chi exercise interventions in older people living with dementia in the community. Acceptability studies are key in novel interventions to assess their appropriateness and relevance for the target population. This thesis will inform on the adequacy of the Tai Chi intervention for people living with dementia in the community, taking part together with an informal carer. Participants' experiences of getting involved in research and research procedures will also be explained. These findings will help the TACIT Trial's team to adapt the intervention as appropriate to enhance its impact on research outcomes. A first publication will help future exercise research to develop more adequate intervention designs.
- 2nd Only one process evaluation conducted alongside an RCT delivering a Tai Chi intervention has been identified through this literature review. However, it was not targeting people living with dementia. As no intervention fits all, it is likely that people living with dementia have different needs which should be met to increase their adherence to Tai Chi interventions and potential benefits. This thesis will report a process evaluation, including implementation fidelity checks, conducted alongside the TACIT Trial. A second publication will inform future research on barriers, facilitators, and areas of improvement to facilitate participants' adherence to Tai Chi or similar exercise classes.
- 3rd Only one process evaluation conducted alongside a dyadic exercise intervention targeting people living with dementia has been identified. However, Tai Chi was not the intervention delivered and only included family carers. The intervention delivered and the person supporting the person living with dementia it is likely to have an impact on their adherence to the intervention. This thesis will seek to include the views of dyads of participants with different dyadic relationships, levels of motivation to take part in Tai Chi, age, gender and levels of adherence to the home and class-based intervention. A third publication will contribute to research with an exploration of barriers, facilitators, and areas of improvement to facilitate participants' adherence to the home-based exercise component.

Targeting these gaps in the literature, this thesis will contribute to the understanding of dyads' experiences of taking part in a Tai Chi exercise intervention, something that has not been previously explored. Likewise, linking back this thesis' findings to SDT, will contribute to explain to what extent SDT is useful to explain people living with dementia (and their carers)'s adherence to exercise. Participants' experiences will, in turn, reveal specific needs, which could be of general guidance when involving people living with dementia in RCTs or designing similar interventions to prevent falls and / or promote physical activity. This is particularly relevant when sustained adherence to exercise interventions has been identified as a challenge both for older people living with and without dementia in the community. Nevertheless, it is likely that older people with a diagnosis of dementia, which are more prone to experience falls (Shaw, 2003) and often frailer (Kulmala, Nykanen, Manty, & Hartikainen, 2014), will benefit to a broader extent from such interventions (Hauer et al., 2012). Successful falls prevention interventions would benefit people living with dementia, their carers, but also the wider society. People living with dementia would be able to stay independent for longer and the current spent in dementia care (£26.3 billion per year in the UK (Prince et al., 2014)) would be reduced.

Finally, this thesis will also indirectly contribute to the exploration of the adequacy of qualitative methods in research involving people living with dementia, particularly in using a joint dyadic approach. The following chapter provides further information on the methods chosen and its implementation process.

3. Methodology and Research Design

This chapter provides an account of the research design followed in this thesis. The aim is to provide the reader with a rich description of the different steps guiding the approach to the research questions. In this chapter the different aspects related to the research design are described in three main sections: 3.1 Presents the methodology used in this study; 3.2 Describes the data collection process as originally designed and what was implemented; and 3.3 Reflects on the data analysis process.

Given the gaps identified through the literature review, three main research questions were formulated (see Table 4, and Appendix B for detailed sub-research questions). An exploratory qualitative approach was required to understand the experiences of people living with dementia and their carers taking part in the TACIT Trial.

Table 4. *Gaps in Research to Be Filled by Responding to This Thesis's Research Question*

Gaps in research	Research questions
1. There is a lack of studies assessing the relevance and appropriateness of Tai Chi for people living with dementia	1. What is influencing participants' acceptability of a Tai Chi exercise intervention?
2. There is a lack of process evaluations conducted along RCTs testing Tai Chi exercise interventions in people living with dementia	2. What is prompting or mitigating participants' adherence to a Tai Chi exercise?
3. There is a scarcity of process evaluations in RCTs studying the effects of exercise in dyads formed by a person living with dementia and an informal carer	3. How do people living with dementia and their informal carers experience their joint participation in a Tai Chi exercise intervention?

More specifically, an experiential approach was chosen to put the focus of research on reporting the opinions of dyads taking part in Tai Chi, instead of imposing the perceptions and interpretations of the researcher on participants' discourse (Braun & Clarke, 2013). The use of an experiential approach is aligned with the goal of preserving the meaning participants attached to their feedback to, in turn, facilitate the *Verstehen*¹⁴ (Hennink, Hutter, & Bailey, 2011). Certain subjectivity in interpreting and understanding participants' experiences is accepted as unavoidable because this is conducted by a researcher (see subsection 3.1.6). In this thesis, however, an "empathic neutrality" (Ormston et al., 2013, p. 22) was sought, and a space was provided for researcher's reflexivity through her research diary. Additionally, different measures were in place (see subsection 3.1.5) to enhance trustworthiness of the findings reported through Chapters 4-7. Lastly, even when results from this thesis cannot be generalised in terms of prevalence, by including a variety of participant's experiences, it is expected that its findings could represent the perspectives of several people living with dementia and their carers in a similar situation.

¹⁴ *Verstehen* has been translated in terms of the "understanding" of the experiences of subjects under research from their positions and taking into account their social contexts (Ormston, Spencer, Barnard, & Snape, 2013).

To understand participant's opinions about the TACIT Trial, a combination of inductive and deductive approaches was used. Whereas previous research informed the research questions (corresponding with gaps identified in Chapter 2), chosen methods, sampling strategy and analysis; an inductive approach was used to understand participant's opinions, which could be different or complementary to those reported in previous research. Lastly, findings were linked back to previous research and theory (particularly self-determination theory, which had a good fit with the research questions).

Due to the novelty of the intervention, Patient and Public Involvement (PPI) meetings took place before funding and throughout both phases of the TACIT Trial. An active involvement from members of the public to enrich research and make it more relevant to the public has been highly encouraged (Bergold, 2012; National Institute for Health Research, 2016). In relation to this thesis, one of the PPI sessions (see APPENDIX I) was used to check the appropriateness of the methods and questions to be used in focus groups and interviews. Participants in the PPI group supported this thesis' approaches, methods, and contents. The use of a dyadic approach in the intervention context but also in the evaluation had been found to be useful for understanding participants' experiences constructed jointly by both members (Radcliffe, Lowton, & Morgan, 2013). This approach has sometimes been avoided, possibly due to the belief that participants' responses would be modified in front of the other member of the dyad (Caldwell, 2014). The impact of one member of the dyad can have a "silencing and domination" effect over the other or the presence of the two members could conduct to "desirability bias"; however, similar effects could be observed in individual interviews with less engaging participants or due to the presence of the researcher (Morgan, 2016, p. 27). Nevertheless, examples can be found where people with dementia and their carer preferred to participate together, acknowledging that they do not have secrets with the other member of the dyad (Nyman, Innes, & Heward, in press; Prick, de Lange, van 't Leven, & Pot, 2014). This approach had been previously used to facilitate inclusion of people living with cognitive impairment in research (Chong et al., 2014). This was also consistent with the responses of most of the members of the PPI advisory group meeting. Following the PPI advisory meetings, and after gaining approval from the Research Ethics Committee (REC) and the Health Research Authority (HRA), the TACIT Trial and this thesis' data collection started.

3.1. Methodology

The TACIT Trial can be defined as a psychosocial complex intervention, testing the effectiveness of a Tai Chi exercise intervention to improve dynamic balance amongst

people living with dementia. Its complexity resides in the multiple components (Campbell et al., 2000; Craig et al., 2008) involved in the intervention (including an intervention based in two different settings –class and home-, which seeks a behavioural change and requires measurement of diverse outcomes -from postural balance to QoL-, and the inclusion of participants with two roles – people living with dementia and their carers-). To understand the impact of these components, as well as the way the intervention was delivered, a rich detailed description of the implementation process was needed.

As previously mentioned, in the context of RCTs and complex interventions a process evaluation (Moore et al., 2015) has been advised (Oakley et al., 2006) over other evaluation frameworks (see Appendix J). This approach allows the use of quantitative and qualitative methodologies complementarily (Campbell et al., 2000) although qualitative research has been more frequently used to understand the research process (Golafshani, 2003).

3.1.1. Process evaluation

A process evaluation involves an assessment of factors and mechanisms which take place during the intervention delivery phase and can have an impact on its outcomes (Moore et al., 2015; Oakley et al., 2006). It covers the whole intervention, from the first participant recruited until the last measurements are taken. It compiles the elements that can make a theoretically driven and potentially successful intervention to be (not) effective in practice.

In complex evaluations, process evaluations are particularly important to understand which elements are likely to modify its effectiveness and, in turn, be critical in terms of study and outcomes replicability (Moore et al., 2015). The Medical Research Council (MRC) has supported process evaluations and provided guidance around the way of conducting and reporting them (Moore et al., 2015).

This thesis, embedded in an RCT of a complex intervention (see Figure 3), has focused on the “Mechanisms of impact: how does the delivered intervention produce change?” (Moore et al., 2015, p. 2) of a process evaluation. This evaluation included the barriers and facilitators mediating on participants’ acceptability and adherence to the intervention. Complementary data on the way of delivering the intervention (implementation fidelity) and the context where the intervention was delivered was also obtained as this could have a direct impact on participants’ acceptability of and adherence to the intervention.

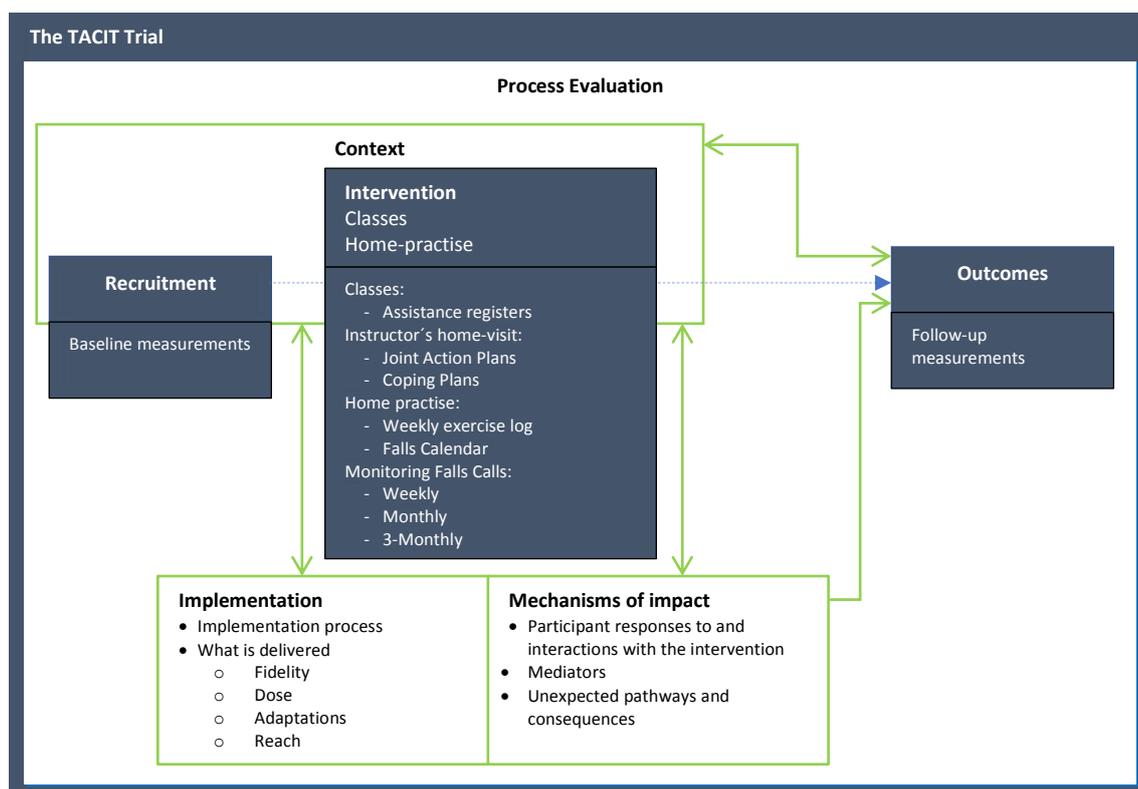


Figure 3. Process evaluation embedded in the TACIT trial. Boxes in blue/shaded represent the TACIT Trial's design and the blue/discontinuous arrow its direction. Boxes framed in green/unshaded and green/continuous arrows represent the key elements of a process evaluation as presented by Moore et al. (2015).

Qualitative methods have been commonly used (Moore et al., 2015) to assess these mechanisms of impact, the implementation process and the context where the intervention is taking place. Although various components of the process evaluation are part of this thesis, the aim was not to conduct a full process evaluation; accordingly, some aspects (i.e., dose, adaptation, reach, training, resources) were not included. Particularly, behaviour change techniques (BCTs) will be quantitatively evaluated in a parallel thesis as announced in Chapter 1.

3.1.2. Approach

3.1.2.1. Philosophical

The ontological position adopted for this thesis is critical realism, where a reality exists behind the social context we live in, but we can just have access to a fragment of it (Braun & Clarke, 2013). It is not that a basic reality does not exist, but our social context interacts with this reality and can alter it. In this case, the reality of taking part in the intervention is shared by participants in the same group and described by the researcher through field notes along the Tai Chi classes observed. However, it is expected that every participant would experience those classes and the home-based activities in a different way. This is due to motivations towards the exercise, previous

experiences, interaction with other members of the group and many other factors that can impact on individuals' experiences of the same activity.

In line with this ontological position, contextualism is the epistemological assumption adopted for the study where the knowledge gained through this study was considered true for this specific context (Braun & Clarke, 2013) or similar contexts to the one described by the author through the field notes. This is aligned with the aim of qualitative research, not being the generalisation of results to any context, but the understanding of a phenomenon in context. Hence, a thick description of the intervention context it is critical for this thesis' findings being of use for researchers and practitioners working with people living with dementia in a similar context (i.e., delivering or studying exercise interventions).

Methods chosen for this thesis align with its philosophical position as explained in section 3.1.3, accepting that participants' experiences of the same intervention might be different, and offering opportunities for participants to share their views individually, in dyads, or in a group context.

3.1.2.2. *Personal*

As the author of this thesis, I need to acknowledge the impact I might have had on its results given my academic and professional background and personal approach to the research topic (see Appendix U). My background has helped me to be more aware of participants' needs, which can largely vary from individual to individual but also within the individual; and present the data collection process in an informal, flexible, and relaxed manner. During data collection I kept in mind that all participants can make a valuable contribution (independently of its length or quantity) if they feel comfortable. This positive and empowering mindset has also accompanied me during the analysis, where I have made an effort to present the views of each participant (differentiating between carers and people living with dementia) and providing quotes of them all.

3.1.3. Qualitative methods

Several reasons made the use of qualitative methods most suitable for this thesis. Firstly, qualitative methods have been particularly recommended in dementia research to gather participants' opinions, as quantitative measures can fail to report particular opinions (i.e., around what works well or what does not work well in an intervention) (Gibson, Timlin, Curran, & Wattis, 2004), especially in relatively new interventions. In this line, qualitative approaches have been frequently underused in dementia research compared to quantitative approaches, which highlights the need to develop a better understanding of people living with dementia and their carers' experiences (Carmody,

Traynor, & Marchetti, 2015). Secondly, a process evaluation to understand participants' acceptability and adherence to Tai Chi required a qualitative approach (Moore et al., 2015), which at the same time could complement the quantitative RCT conducted amongst people living with dementia. Thirdly, qualitative methods allow more flexibility and adaptation to participants needs compared to standardised methods used under quantitative approaches. When using semi-structured schedules, for instance, it is up to the researcher to decide whether it is appropriate to formulate a certain question, when to do this, or place the focus in another aspect instead to understand participant's views (Kallio, Pietilä, Johnson, & Kangasniemi, 2016). Finally, it is likely that the cognitive effort required would have been higher responding to quantitative measures (i.e., rating their level of satisfaction would require considering the different options to then make a choice, instead of directly expressing their views in their own words) around participants' views about different aspects of the intervention (i.e., group and home-based components). When asking participants about their experiences, episodic memory (Gold & Budson, 2008) is required to recall their Tai Chi practice at home or in class. However, quantitative measures would have required not only the activation of this memory, but also the working memory to understand the alternatives they would have been given, and make a decision taking into account their past experiences. This would have not been adequate when it is known working memory it is also affected in AD (Stopford, Thompson, Neary, Richardson, & Snowden, 2012), the most common type of dementia. All in all, the use of qualitative methods will allow responding to this thesis' research questions which are intrinsically linked to participant's experiences.

Thesis's structure

As part of the TACIT Trial, this thesis consisted of two interrelated phases (see Appendix K):

- a) Pilot Intervention Phase (see Chapter 4): The study started on 19th October 2016 and finished on 14th December 2016.
- b) RCT Phase (see Chapters 5 to 7): Recruitment started in April 2017 and finished in July 2018 (eight months after the expected date, due to the extensions). The first class took place on 02/08/2017 and the last class was on 26/11/2018. RCT Phase's data collection (including Follow-Up) finished on 30th November 2018.

In both phases, participants taking part in the Tai Chi intervention were asked to attend 45-minute sessions of Tai Chi (plus additional 45 minutes were allocated to socialise and support dyads with the home-based Tai Chi practice) once a week and practise Tai Chi at home for 20 minutes every day (after the Tai Chi instructor's home-visit) during

their involvement in the TACIT Trial. As the aim of this thesis was to understand the experiences of those taking part in Tai Chi, those in the control group (in the RCT Phase) were excluded. In the Pilot Intervention Phase all participants were invited to the classes and included in this thesis, whereas in the RCT Phase, due to time constraints, only some participants were included in this thesis' observations. Among them, only 15 dyads took part in a dyadic home-interview. Similar qualitative methods were used in both phases of the study (observations, focus groups and interviews) (see Figure 4), complemented by researcher's reflections kept in a research diary.

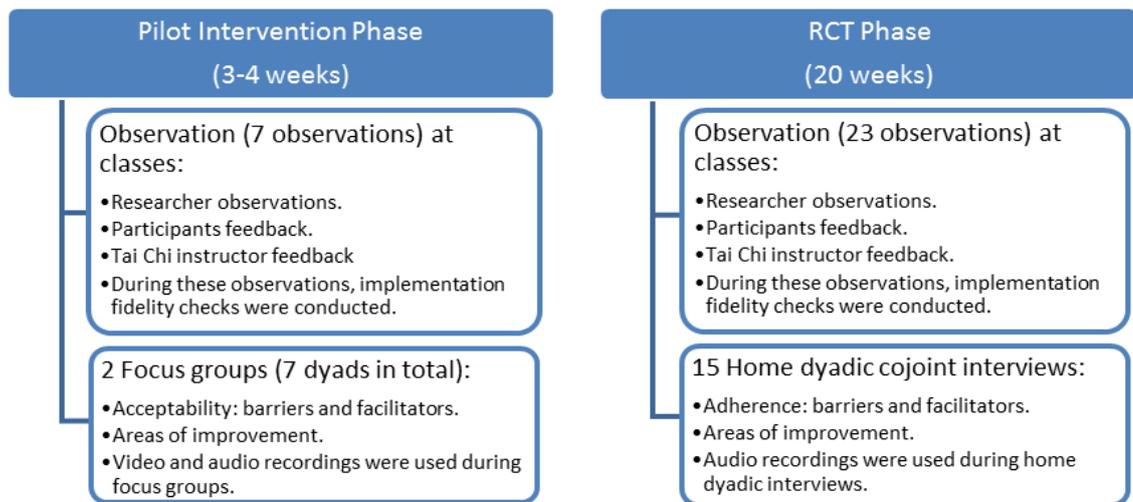


Figure 4. Qualitative methods used in the Pilot Intervention and the RCT Phases.

The combination of qualitative methods (using methodological triangulation within qualitative methodology) and involving different perspectives (from instructors, people living with dementia, their informal carers and the researcher) was used to have a broader picture (360° perspective) of the elements impacting on acceptability and adherence to the intervention (Bekhet & Zauszniewski, 2012; Logghe et al., 2011; Ravelin, Isola, & Kylmä, 2013). This combination of methods and techniques were aligned with the philosophical underpinning of this thesis and allowed, in turn, a reflection on the research process itself, including perspectives from all the parts involved in the TACIT Trial.

A dyadic approach was used in focus groups and interviews, to explore their joint experiences, help the person living with dementia feel secure, and facilitate their recall (Cridland, Phillipson, Brennan-Horley, & Swaffer, 2016; Morgan, Ataie, Carder, & Hoffman, 2013; Torgé, 2013). These methods were useful to deeply explore participants' experiences and are described in the following subsections.

3.1.3.1. *Field notes*

Field notes are commonly used to describe the situations the researcher observes in the research context (Austin & Sutton, 2014; Patton, 2013). In this thesis, field notes were used to describe the development of the sessions and to report feedback collected from participants and Tai Chi instructors at the end of the sessions. Field notes in this thesis were based on “observation”, which has also been described as a research method where “the investigator systematically watches, listens and records the phenomena of interest” (McNaughton Nicholls, Mills, & Kotecha, 2013, p. 267). These observations did not follow an ethnographic approach, which would have required longer observations and the intention to understand participants’ culture (Spradley, 1980) in a more naturalistic environment (Ballinger, Yardley, & Payne, 2004). Ethnographers base their field notes on “participant observation”, which implies the immersion of the researcher in participants’ culture (Crowley-Henry, 2009). However, under the critical realism the purpose of these notes were to reflect as transparently as possible what was being observed by the author in the field and what participants and instructors reported within this context, rather than incorporating her views.

The use of techniques where participants are asked to report their experiences and opinions (i.e., interviews, focus groups, self-report questionnaires) have been extensively employed in qualitative research (Austin & Sutton, 2014; Drabble, O’Cathain, Thomas, Rudolph, & Hewison, 2014; O’Cathain et al., 2014; Rapport et al., 2013). However, frequently, participants might be unaware, unable or unwilling to report certain behaviours (Ballinger et al., 2004). In these occasions, observations made by a third person can help illuminate these behaviours (Windle et al., 2016). In this thesis, its author was the third person conducting these observations and recording them by using field notes. The purpose of these observations, however, was to enhance and complement the data reported by participants and instructors not to impose the researcher’s view, since each individual might perceive the same reality differently.

All field notes were based on semi-structured observations to ensure minimum data collection (see Appendix L) in a consistent way throughout research sites and observations (McNaughton Nicholls et al., 2013). At the same time, this approach allowed the inclusion of unstructured and spontaneous annotations about participants’ reactions to the intervention context (Mulhall, 2003). A qualitative observation coding manual (see Appendix L) was developed to allow a second researcher (lead supervisor) to code along the author during three observation sessions in the Pilot Intervention Phase. After each observation, notes from both researchers were

compared (see subsection 3.1.5.1) “to be aware of how their own interpretation may influence what they record” (McNaughton Nicholls et al., 2013, p. 260).

Researchers’ observations (see Appendix L) included firstly, a description of the venue (layout of the room) and the location of the participants in the room. Secondly, notes were taken around participants’ relationships (with other members of the dyad, the group or the instructor), their level of engagement with the activity, their attitudes towards the Tai Chi intervention, their mood before and along the intervention, their verbal and non-verbal communication, and any comments regarding the fulfilment or non-fulfilment of their psychological needs (according to self-determination theory). In the RCT phase, the observation template was simplified as shown in Appendix L.

These observations were descriptive and grounded in the context where they were taking place (Braun & Clarke, 2013). This procedure was chosen to facilitate reporting results from a perspective closer to participants’ experiences. During these observation sessions, the researcher took notes from a complete observer (Mulhall, 2003) position during the session, she did not take part in the Tai Chi classes, nor was interacting with participants during the classes. However, participants were made aware of the researcher’s role and, if asked, the researcher explained again the purpose of her presence in the class. To avoid the Hawthorne effect (Roethlisberger, Dickson, Wright, Pforzheimer, & Western Electric, 1939) which would make participants likely to change their behaviour for feeling observed, the researcher chose a discrete location (to the side or behind participants) in the room. From this location she was able to observe participants and make corresponding annotations without putting them off the Tai Chi.

At the end of the classes, however, the researcher adopted a more active role in order to gather participants’ feedback about the session (see Appendix M). Participants were asked on their level of enjoyment of the class, and the barriers and facilitators they might have been experiencing when taking part in Tai Chi in the class or at home. Additionally, they were also encouraged to provide comments on areas of improvement in the intervention.

Instructors’ feedback (see Appendix M) was similarly sought at the end of each class. An overall impression of how the intervention had developed, the level of engagement appreciated by participants, and their social interaction was collected. Information about the development of the home-visits, as well as barriers and facilitators identified along the implementation of the Tai Chi intervention were also gathered to improve the intervention at both stages of the TACIT Trial.

All these field notes were manually recorded during the classes (or when feedback was provided) and transcribed as soon as possible thereafter to further develop these notes in a trustworthy manner (Spradley, 1980) to avoid losing details. Most of these notes

were taken immediately, however, when this was not possible, these notes were taken as soon as possible and preferably on the same day, following previous recommendations (Ballinger et al., 2004; Saldaña, 2016).

3.1.3.2. Video and audio recordings

Initially, each observation session was going to be video-recorded for the Pilot Intervention and the RCT Phase, to support field notes taken by the researcher, facilitate implementation fidelity checks, and peer-reviewed assessments of the intervention. However, the lead Tai Chi instructor did not consent for the classes to be recorded under any circumstances. Video and audio recordings were used only when seeking participants' feedback at the end or towards the end of their participation in the Trial (during focus groups and dyadic interviews) to capture their reports (realities) accurately and facilitate a transparent data collection process. Two audio recorders were used to minimise the risk of losing data due to technical factors (i.e., unexpected stop of recordings, low batteries and coverage).

3.1.3.3. Research diary

The use of a research diary has been described as a good practice in qualitative research (Braun & Clarke, 2013) to register researchers' impressions about the research process. This is independent of the qualitative method(s) used, as its objective is to gather the researcher's subjective opinions along the research project. It should facilitate reflexivity about the research process, the impact of the researcher on it and help enrich reports during the data analysis stage.

An entry to the research diary was made after each contact with participants at observation sessions, focus groups or interviews (using the templates provided in Appendix N). This method was particularly useful to preserve researcher's observations during sessions based on a rich description of actual behaviours (influenced by the "realist tradition" (Ballinger et al., 2004, p. 109) of the RCT).

3.1.3.4. Focus groups

In the Pilot Intervention Phase a group discussion¹⁵ was held at each intervention site (a total of 2 focus groups were organised). All the participants taking part in the Pilot Intervention Phase were invited to take part. This way, participants were able to share their views with the rest of the group members they had been sharing sessions with and, possibly, benefit from their interaction. In line with this thesis philosophical approach, it was accepted that participants might have different experiences of the

¹⁵ "Group discussion" is used in this thesis as a synonym of "focus group" to denote the informal environment where these discussions took place, and the occasional active role of the author (as moderator) to ensure all participants had the opportunity to contribute to the conversation.

same classes, and that they might want to share their views to different extents from participant to participant given the group context. A total of 14 participants per focus group were initially expected (according to the recruitment target of seven dyads per group, however, this number was smaller in practice as shown in section 3.2.). The ideal number of participants taking part on this kind of group has been a matter of discussion in the literature and various factors have been recommended to be taken into account (Ayala & Elder, 2011; Tang & Davis, 1995) (i.e. time available for the focus group and number of questions to be asked). However, in this case, the aims of the study (Tang & Davis, 1995), the characteristics of the participants and the time limitations were considered to include all the participants of each group. For practical reasons, focus group were organised after the last intervention session in order to reduce the efforts of the participants and avoid missing some participant's views. But more importantly, this strategy was chosen to facilitate participants' living with dementia's participation, as the context could play an important role in recalling the activity they would have been taking part in. However, this strategy also limited its length to make it manageable and avoid participant exploitation.

After considering the suitability of using focus groups, a schedule of questions was arranged (see Appendix O) inspired by the groups of questions suggested by Leung and Savithiri (2009): opening questions, introductory questions, transition questions, key questions, and concluding questions. Complementarily, three pre-group discussion questions had been prepared in order to facilitate participants' reflection on the topic of the discussion. These questions were related to the strengths and weaknesses of the intervention, which could be impacting on their acceptability of the intervention and possible improvements. These preliminary questions could guide participants through the conversation, allow those less willing to share their views in a social context to express their views, and particularly help those living with dementia to remember their points in the discussion. At the end of the intervention, people living with dementia and their carers were asked to hand these anonymous preliminary questions back to the research team, to support their statements in the discussion. The fact that those comments were asked to be anonymous, carers were only asked to write a "C" on their sheets, was to facilitate the collection of their honest opinions, even if they had not felt comfortable sharing some aspects with the group.

During the group discussion participants wore name badges, so the researcher moderating the discussion could ask participants' views using their preferred titles and/or names. Similarly, name badges also helped participants to remember other participant's names. This strategy also facilitated the other researcher assisting during the focus group could take notes on their participation and contributions to the group.

To facilitate recall of the questions, these were printed out in large font (Chong et al., 2014) on A4 sheets.

3.1.3.5. Dyadic interviews

Towards the end of the Tai Chi intervention (around week 16), in the RCT Phase, joint semi-structured interviews with 15 dyads were conducted to wider explore barriers and facilitators for participants' adherence to Tai Chi and any benefits or harms appreciated.

Dyadic interviews are an innovative approach to understanding the experiences of people living with dementia (Morgan, Eliot, Lowe, & Gorman, 2015). According to Morgan, Ataie, Carder and Hoffman (2013) dyadic interviews were originally used in family research. This dyadic approach made sense in this study as it was consistent with the way participants were involved in the intervention: jointly (as a dyad). Their joint participation would have likely had an impact on their experience taking part in the TACIT Trial and this interview format facilitated a space to share and reflect on it (Arksey, 1996; Eisikovits & Koren, 2010).

Joint interventions created for people living with dementia and their carers are not very frequent in the literature compared to those targeting both of them separately (Moon & Adams, 2013). There are a few examples where this has been done in an exercise related intervention for people living with dementia, however, the use of a dyadic interviews in this context had only been reported in one study (Prick et al., 2014). However, authors had not planned this approach but acceded to participants' requests (Prick et al., 2014). Similarly, dyads' motivation was not considered as part of the purposive sampling strategy. In this thesis, this was incorporated into the sampling criteria to assess its impact on dyads' adherence. The dyadic approach could lead to participants' concealment of certain opinions. However, particularly for those living with dementia carer's presence has been suggested as a possible facilitator of their engagement and participation in the interview (Suttanon et al., 2012).

Participants were asked in the first instance to be interviewed in their own homes, although they were given the alternative to conduct them in another appropriate venue for them. Participants' home should facilitate their comfort during the interview (i.e., feeling in a familiar, convenient, and secure location), avoid financial costs on transportation to reach any venue, and make their participation in this study less time-consuming.

After considering the suitability of using dyadic semi-structured interviews a schedule of questions was arranged (see Appendix P). Additionally, a series of prompts were shown during the conversation to facilitate recall. The time-frame used to gain

participants' experiences at the end of the last Tai Chi session (in the Pilot Intervention Phase) or towards the end of their participation (in the RCT Phase) was chosen to facilitate people living with dementia's recall. Previous research has suggested that after 6 months of exercise practice participants living with dementia seemed to have no issues in recalling their participation in the study a month after the intervention had finished (Suttanon et al., 2012). However, this risk was avoided in this thesis, to ensure data collection and adapt to thesis time-frame.

3.1.3.6. Fidelity checks

Fidelity checks of the intervention were conducted to enhance the study impact. These checks were required to assess to what extent the intervention was delivered according to the protocol, so its outcomes would be due to the intervention being delivered as per design, and not to other factors (i.e., deviations from the protocol). In case these deviations had happened, their potential impact on results could be hypothesised. These assessments "ensure that internal validity of the study is maintained, and external validity is enhanced" (Horner, Rew, & Torres, 2006, p. 80). That is, not only ensures that outcomes are due to the intervention, but also that this intervention conducted in a similar environment will replicate its outcomes.

Fidelity checks in the TACIT Trial were conducted in all the classes during the Pilot Intervention Phase and in at least 10% of the sessions in the RCT Phase. These checks were conducted by the author during observation sessions. Initially, sessions were going to be video recorded and the researcher would assess fidelity to the intervention protocol when double checking these recordings. However, with the impossibility of recording the sessions (due to lack of consent from the instructor), the researcher had to do these assessments during or just after finishing the session. These assessments were conducted following a checklist, based on the principles of the TACIT Trial (see Appendix Q).

3.1.4. Demographic data

Despite not being collected in the context of this thesis (nor by its author), demographic quantitative data was incorporated into this thesis as additional information to describe the participants involved in both stages of the TACIT Trial. This would contribute, together with the observational data, to provide a rich description of the intervention setting. Demographic data collected from participants at baseline home-visit (by the other PhD student involved in the TACIT Trial, PhD 2), as well as quantitative data regarding participants' intention and confidence to adhere to the intervention during their participation in the study, and their score in the cognitive test (M-ACE), was reported in this thesis. This data was to be used to select the purposive sampling,

however, after the slow recruitment process it was less relevant as most dyads observed in the classes were later interviewed. When the author had to choose amongst participants in two groups, this was based on their dyadic relationship and the adherence to the classes and home-based component; which had been found out during the classes or gathered from participants and instructors through class registers and self-report exercises logs managed by the author.

3.1.5. Ethical approval

As stated by Hellström, Nolan, Nordenfelt and Lundh (2007), in relation to research involving people living with dementia, both methodological and ethical issues are often interlinked. For this reason, the Declaration of Helsinki (World Medical Association, 2013) was adopted in this research project as it has been done world-wide in medical research involving human participants. Before gaining ethical approval, the author completed a series of trainings and considered different ethical issues in handling research data and working with older people living with dementia (see Appendix R).

This study received ethical approval from NHS REC on 01/08/2016 and HRA on 14/09/2016 together with the rest of the TACIT Trial and was recorded with the Bournemouth University Research Ethics Committee on 15/09/2016 (see Appendix S). No amendments were required for any of the documents related to this thesis. However, a delay in receiving the green light from the Sponsor (on 18/10/2016) impeded to start the Pilot Phase on the scheduled date (03/10/2016). A short time space was allowed in between both phases of the Trial to submit amendments to be approved by ethics committee.

After the Pilot Intervention Phase, amendments were submitted for ethical approval. The green light to start the RCT Phase was received in April 2017.

3.1.6. Process consent

People living with dementia have not been traditionally active participants in research, with ethical difficulties often being cited as the reason for this (Hellström et al., 2007). There was a tendency in research that relied on proxies to understand the reality of the person living with dementia through the carer to protect people living with dementia's rights (Hellström et al., 2007). However, relying on proxies did not necessarily protect the rights of those who live with dementia, but provide a version of their experiences which may not be accurate with their feelings and experiences (Dewing, 2002). Carers' point of view can be equally valuable and necessary, but attention must be paid to understand both realities without imposing one over the other. Giving more importance to the carers' opinion leads to a bigger disempowerment of the person living with

dementia and promotes dependency. Respecting the five general ethical principles for psychologists of beneficence, non-maleficence, justice, autonomy and integrity (American Psychological Association, 2010); working under a person-centred care approach (Kitwood, 1997; Kitwood & Bredin, 1992); and understanding the process consent as an ongoing procedure along people living with dementia's participation in research should allow their participation in research (McKeown, Clarke, Ingleton, & Repper, 2010; McKillop & Wilkinson, 2004).

Process consent has been accepted as a valid means for obtaining informed consent "even when capacity is said to no longer exist" (Dewing, 2008, p. 59). Correspondingly, consent was sought from people living with dementia along the research process, considering the progressive nature of dementia and through their verbal and non-verbal expressions. These continued checks of consent took place at every contact with participants, in line with Good Clinical Practice guidelines instructed by the National Institute for Health Research (NIHR), where consent is defined as an "ongoing process". Apart from written and verbal consent, non-verbal communication was checked before and during focus groups and home interviews. In this line, Hellström (2007) alluded that the objective should be ensure a 'maximally informed consent' from participants living with dementia. Additionally, people living with dementia were asked a few questions in order to verify their understanding of the information provided following the example of previous research (Close et al., 2014). This process consent included permission for image and audio-recordings to be taken. Only people with capacity according to the Mental Capacity Act (Department of Department of Health, 2005) and mild/moderate dementia were recruited for the TACIT Trial and therefore into this thesis.

Written informed consent was sought from both members of the dyad (Prick et al., 2014) at both phases of the trial but at different time points. In the Pilot Intervention Phase, consent to take part in the focus group was checked as part of the eligibility criteria at the point of screening. Participants consenting to participate were accepting to take part in the focus group and verbally confirmed before starting the group discussion. In the RCT Phase, however, an independent Participant Information Sheet was provided to selected participants and written consent was collected (see Appendix T) just before conducting the interviews. Such difference was coherent with the different sampling strategy guiding each phase of the trial (all versus selected participants).

In this thesis, an inclusive approach was used to allow participants living with dementia's opinions to be at the centre. Their opinions, together with those coming from their carers, highlighted areas in the intervention that needed improvement. This

inclusion allowed amending the intervention to make it more attractive, reassuring, valuable and overall a positive experience for people in a similar situation. This approach was used, as the involvement of people living with dementia in previous research had been defined as an enriching and enjoyable process (McKillop, 2002).

3.2. Data Collection

3.2.1. Pilot intervention phase

3.2.1.1. Sampling strategy

No specific data sampling strategy was used in the pilot intervention phase. All the participants recruited were included in the data collection process of this study to gather the overall impression of the group about the intervention.

3.1.1.1. Timing (data collection points –planned versus real)

Data collection for the Pilot Intervention Phase was planned before the TACIT Trial underwent the ethics committees. For this reason, Table 5 reflects the differences between expected (shadowed) and real timing reflecting the delays accumulated (dotted) during the research process.

Table 5. Pilot Intervention Phase: Data Collection Points Expected Versus Real

Task	2016				2017				
	9	10	11	12	13	14	15	16	17
	S	O	N	D	J	F	M	A	M
Recruitment (10 dyads: 4 in Southampton, 6 in Bournemouth)									
Observations 2 groups (3-4 weeks, 1 observation session per week per group)									
Field notes (participants and instructor's feedback)									
1 Focus group in Bournemouth, 1 Focus group in Southampton									
Transcriptions of focus groups									
Transcriptions anonymization, analysis and writing									
Analysis and writing for Publication 1 (Acceptability of the Tai Chi intervention)									

3.1.1.2. Qualitative data collected (planned versus obtained)

Table 6 shows the amount of data expected to be collected before the study started.

Table 6. *Pilot Intervention Phase: Volume of Data Expected*

Pilot Intervention Phase N = 28 14 dyads 2 groups 4 weeks intervention 1 class per week	Field notes	2 groups (7 dyads, N = 14 each group) 4 classes to observe per group. Data is generated from a total of 8 sessions, involving a total of 28 people.
	Research Diary	8 entries (1 per session observed)
	Fidelity Checks	8 fidelity checks (1 per session observed).
	Focus group (Video-recordings and audiorecordings)	Two focus groups conducted at the end of each intervention group. 2 video recordings and 2 audiorecordings, one from each focus group were expected. Data from a total of 28 people is expected to be gathered.

However, despite the efforts made, it was not possible to recruit 14 dyads for this Pilot Intervention Phase. The first class in Site 1 was cancelled due to a lack of participants recruited for this date. A total of 10 dyads were recruited instead, 4 dyads in Site 1 and 6 dyads in Site 2. A comment on the data finally obtained through each method is provided in the following subsections, together with a description of the sessions observed and the number of participants involved in each.

3.1.1.2.1. Field notes

After the cancellation of the first class in Site 1, a total of 7 sessions were observed for this thesis (as pointed in Table 7). During these sessions both researchers' observations (lead supervisor –in Site 1- and author), feedback from dyads, and from the instructor were collected.

Table 7. *Pilot Intervention Phase: Sessions Observed*

Site 1		Site 2	
Sessions observed	Participants involved	Sessions observed	Participants involved
1 st 18/11/2016	Session cancelled	1 st 24/11/2016	10 (5 dyads)
2 nd 25/11/016	8 (4 dyads)	2 nd 01/12/2016	12 (6 dyads)
3 rd 02/12/2016	4 (2 dyads)	3 rd 08/12/2016	10 (5 dyads)
4 th 09/12/2016	6 (3 dyads)	4 th 15/12/2016	8 (4 dyads)

Observations generated more volume of data, as the researcher was taking notes during most of the time. Despite this, during the classes, most participants in Site 2's group (as reported in the focus group) were unaware of the author's presence taking notes ("I didn't even know you were there" (02004C)) even when her role was explained to the participants during the first class and when asked during the classes.

Getting participants' feedback was slightly difficult at the beginning provided they were engaging in conversation with their peers, some of them were curious about the author, and she was initially involved in preparing drinks for participants. Obtaining the views of the instructor at the end of the classes was also challenging, as the author focused on

participants and the instructor had to engage in conversation with participants as well. Despite this, some feedback was obtained from participants and instructor.

3.1.1.2.2. Video and audio recordings

Only one video recording was finally obtained from focus group in Site 2. In Site 1, even when the video recorder was in place, it did not record the group discussion. In this case, however, participants' voices were easily recognisable, as only 6 participants attended the last class and joined the focus group.

Two stereo recorders were used to record both groups; the second recorder was used as back up, but also in case more participants had attended the groups. The use of two audio recorders, oriented in opposite positions, was useful to check the professional transcriptions obtained from both focus groups. Due to the number of participants taking part in both groups, and the familiarity of the researcher with the participants, it was possible to recognise their voices over the discussion. The quality of the recordings varied, however, depending on participants' respect of the ground rules about respecting turns. Whereas in Site 1 professional transcriptions were accurate and comprehensive because participants respected their turns; in Site 2 overlapped conversations made several points of the audio-recording difficult to hear. This, in turn, implied that some words were missing from participants' contributing to the main conversation.

3.1.1.2.3. Research diary

The research diary contained 7 entries –one per session observed. Additionally, feedback about the research process provided by PhD 2 (conducting the home-visits) was included. This research diary allowed the author to keep track of the thoughts of the researcher, complement the recommendations to be made before starting the RCT Phase, and enrich the analysis process keeping a clear separation between researcher and participants' thoughts.

3.1.1.2.4. Focus groups

Two focus group (one at each site) were organised as expected. The dynamics of both focus groups, however, were slightly different. Whereas in Site 1, the CI (Researcher 2 & Lead Supervisor) of the TACIT Trial was there to support the moderator (author); in Site 2, an independent researcher to the trial (Researcher 3, also Supervisor) took on this role. This could have made participants more reluctant to contribute to the conversation in Site 1. However, knowing the role of the CI in the project, participants took this opportunity to discuss the project with the CI and challenge some of his decisions regarding the study's design; mostly respecting their turns. Probably because of this reason, and in order to give the conversation a more informal flow, the CI took a

more active role in the conversation than the actual moderator (the author) and ended up contributing more than any of the participants individually. In Site 2, however, the role of the moderator (assisted by Researcher 3, Supervisor) was held by the author of this thesis who was less active during the conversation. Although participants' living with dementia in this group tended to require more prompting to engage in conversation, this role was spontaneously supported by carers.

People living with dementia's contribution was irregular amongst focus groups (as reflected in Table 8), being higher in Site 1, where two out of the three participants living with dementia were particularly talkative. In Site 2, however, only one out of four participants living with dementia was spontaneously contributing to the conversation, which made the participation of the rest more dependent on direct prompts from the carer or the moderator. Consequently, people living with dementia's contribution was more balanced with those of their carers in Site 1, whereas in Site 2, this equilibrium was not reached due to people living with dementia's engaging less in the conversation and carers overtaking. The later imbalance influenced the overall contribution in the two focus groups of people living with dementia (31%) and their carers (69%).

Table 8. *People Living with Dementia and Carers' Contribution to the Focus Groups*

Focus group	Dyads contributing	People living with dementia's contribution	Carer's contribution
Site 1	3	44%	56%
Site 2	4	20%	80%

Additionally, one dyad in Site 2 provided their final feedback over the phone, first the person living with dementia and then the carer. During this conversation the person living with dementia was fully aware of who the researcher was and her role in the project. The focus group guide was used for this purpose, and the conversation lasted for 20 minutes.

The expected duration of both focus groups was 90 minutes each, however in Site 1 took around 1 hour and in Site 2 around one hour and ten minutes. This was probably due to both groups' involvement of fewer participants than initially expected (7 dyads each) and to none of them requiring a comfort break.

Major incidents did not take place during the focus groups. Only one participant in Site 1 got emotional when preliminary questions were handed to them. She was probably frustrated by confronting her difficulty to find the right words. She was able to recover and actively engage in the conversation later and, by the end of the focus group, to respond one of the questions in the preliminary questions sheet. However, to avoid the risk of raising negative feelings in participants and given that the other two participants

were not able or not willing to write down their answers, these preliminary questions were not used in Site 2.

3.1.1.2.5. *Fidelity data*

A total of 7 fidelity checklists were filled – one per session attended by the author. Fidelity checks were made during the session and complemented with additional qualitative comments soon after the end of each session. Sessions in Site 1 were observed both by the author of this thesis and the CI of the TACIT Trial, and both completed the fidelity checks. After the first session, differences between researchers were discussed and an agreement was reached. Agreement was found during the second and third sessions. Fidelity checks were used to inform the instructor on aspects that should be reinforced in future sessions, although the instructor did not necessarily reinforce those aspects.

3.2.2. RCT phase

3.1.1.3. ***Sampling strategy (planned versus obtained)***

Field notes were taken from observation sessions and feedback from all participants attending these sessions was sought. However, for the dyadic home-interviews a purposive sample of 15 dyads was targeted amongst the 75 dyads expected to be recruited and allocated to the intervention arm. The sample size was decided before starting recruitment and data collection in order to be time and resources realistic, in line with previous research projects, and obtain a rich but manageable amount of data to analyse.

As participants in the intervention arm had already been randomly assigned to their condition in the TACIT Trial, a non-probability sampling was used to select participants in this study. A commonly used sampling strategy, purposive sampling, was implemented. This strategy has been defined as one of the most useful when qualitative perspectives are sought in clinical studies (Luborsky & Rubinstein, 1995).

The objective of using a purposive sample was obtaining views from as varied participants as possible (see Figure 5), to examine common trends in data sets, but also gain understanding of participants particularities. This is one of the strengths of using a qualitative approach, which allows the appreciation of people's perspectives, as rich as complex human beings are (Atieno, 2009). To recruit this purposive sample the following criteria were considered: gender, age, relationship between members of the dyad, level of adherence to the intervention along the first half of the intervention and initial motivation to take part in the intervention. Demographic data was obtained from baseline information requested for participants' inclusion in the TACIT trial. Initial

motivation was ascertained by participants' intention and confidence scores (rating from 1 -true/likely- to 7 -false/unlikely-), which were obtained also during the baseline home-visit. Level of adherence was checked from weekly exercise logs handed back by dyads to the Tai Chi instructors, and from the registers of attendance completed by the instructors at each class. The purposive sampling strategy reflected in Figure 5, however, did not pretend to recruit participants responding to different combinations of the chosen criteria but ensuring variety amongst participant's characteristics (i.e., to avoid interviewing only very motivated or only younger participants in the trial). Participants were to be recruited according to only one of these criteria.

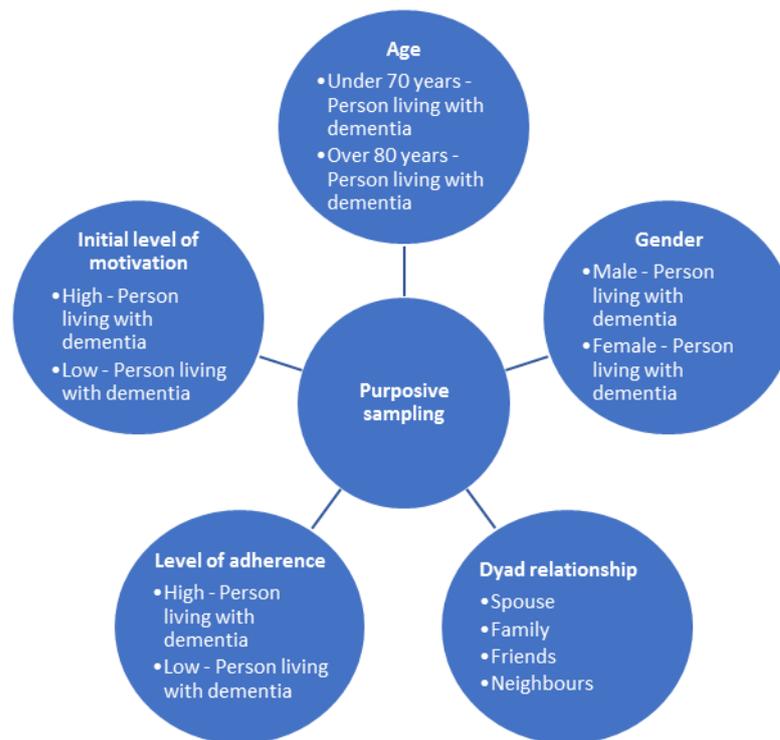


Figure 5. Characteristics of participants living with dementia included in the purposive sampling strategy.

In practice, however, a slow recruitment and the consequent extension of the recruitment period, required to adopt exceptional measures. Initially the plan was to use such purposive sampling from the start of the RCT Phase, however, this had to wait until the last 2 groups included in this thesis (groups 5 and 6). It was not until that point when there was some certainty that enough participants would be recruited and retained in the study at around week 16 (when they were invited to interview). Hence, participants in groups 1 to 4 were all given the opportunity to take part in a joint dyadic home-interview, to ensure data collection would finish on time to then allow analysis and write-up period for this thesis. This meant that groups 7 to 10 were not observed nor included in this thesis analysis. However, data saturation had been reached by the end of the 15 interviews, and participants included in groups 1 to 6 naturally

represented the variety of characteristics sought by the initial purposive sampling strategy (see Chapter 5).

3.1.1.4. Timing (data collection points – planned versus real)

Data collection for the RCT Phase was planned in advance as in the case of the Pilot Intervention Phase. For this reason, Table 9 reflects the differences between expected and real timing according to the delays accumulated during the research process (a dotted line indicates an extension further to the initial plan).

Table 9. RCT Phase: Expected Data Collection Points Versus Real

Task	2017												2018											
	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36		
	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D		
Trial Phase RCT Recruitment	[Solid Blue]												[Dotted Blue]											
Trial Phase RCT Delivery: Observations (Fieldnotes)	[Solid Blue]												[Dotted Blue]											
Analysis and writing for Publication 2 (Adherence-Fieldnotes)	[Solid Blue]												[Dotted Blue]											
Trial Phase RCT: Home Interviews	[Solid Blue]												[Dotted Blue]											
Analysis and writing for Publication 3 (Adherence-Home Interviews)	[Solid Blue]												[Dotted Blue]											

3.1.1.5. Qualitative data collected (planned versus obtained)

Table 10 shows the amount of data expected to be collected during the one-year long RCT Phase.

Table 10. RCT Phase: Volume of Data Expected

Trial Phase (RCT)	Field notes	11 groups (maximum 10 dyads, N = 20 each group) 2 sessions to observe per group , one of the firsts sessions (session 2-7) and one towards the end of the intervention (session 14-19) . Data generated from a total of 22 classes involving a total of 150 people (75 dyads).
N = 300	Research Diary	22 entries (1 per session observed)
75 dyads in the intervention arm	Fidelity Checks	22 fidelity checks (1 per session observed).
11 groups	Dyadic home interviews	Semi-structured home-interviews conducted with a purposive sample of 15 dyads (n = 30), towards the end of the intervention (around session 16). 15 audiorecordings from dyadic home-interviews.
20 weeks intervention	Audiorecordings	Interviews were to be conducted in dyads, having together the person living with dementia and the informal carer involved in the intervention, unless participants objected.
1 class per week		

As for the Pilot Intervention Phase, a comment on the data finally obtained through each method is provided below, together with a description of the sessions observed and the number of participants involved in each one.

3.1.1.5.1. Field notes

The amount of sessions observed was 23, from the 6 first groups, which meant each group was observed more than 2 times (initially planned). Instead, provided the time-constraints 4-5 observations per group were made, depending if any of the classes to

be observed were cancelled last minute and if data saturation had been reached. In Chapter 5 a detailed account of the sessions observed is provided, however, as a summary, two classes were observed in Site 1, 12 in Site 2, and 9 in Site 3. Despite the differences in the number of observations, this was proportional to the number of classes organised per Site in the whole RCT Phase. The 23rd observation (1 more than expected) was due to the author attending two classes to collect half-way through data for the TACIT Trial and observations were made in case any last-minute cancellation of an observation session occurred. In one case it happened, and in the other not, but data was equally included in analysis, as it had already been collected. Feedback from instructors and participants was collected following the semi-structured templates used in the Pilot Intervention Phase (see Appendix M).

3.1.1.5.2. Audio recordings

A total of 15 dyadic interviews took place, hence 30 recordings were obtained (two per interview). Two recorders were used during interviews as planned to ensure good quality of the audio recording and in case one of the recorders failed. All of them had a good quality and one per interview was sent for professional transcription. Once the transcription was returned these audios were used to double-check transcriptions' accuracy. During the interviews one recorder was placed close to each participant.

3.1.1.5.3. Research diary

An entry to the research diary was produced after each observation session (n = 23) using a semi-structured template (see Appendix N) and after each interview free notes (n = 15) contained the author's impressions of the data collection process and observations. A total of 38 entries were recorded. Entries related to the observations were kept in separate files (one per observation), whereas a unique document with different entries was used in the case of those related to the dyadic home-interviews. Using this sole document allowed the author to reflect on the interviews previously conducted and try to improve her technique before attending the next one.

3.1.1.5.4. Dyadic interviews

Following the semi-structured design of the interviews, the author adapted the order of the conversation to the participants' choice. For instance, talkative dyads who would start discussing about later topics in the interview schedule, were asked earlier on, whereas those who were waiting for the author to ask, the order initially established was followed. Generally, moderation was used to keep the conversation on, introducing new questions only. Nevertheless, occasionally a more active moderation was used in a non-verbal way (i.e., looking to the person living with dementia) to, for instance, invite them to join in the conversation and regulate the carer's contribution. All participants

invited to interview accepted to take part. An additional (16th) dyad was invited after withdrawing from the intervention only, who did not respond to the invite after saying they would think about it. Later in the study, they ended up fully withdrawing from the TACIT Trial due to the person living with dementia not wanting to undergo the follow-up assessment. Home-interviews flowed with no incidents, and participants were happy with their contributions at the end of the interview. Although they were given the chance to add further comments after the interview day, none was in touch to provide further data. Further details of the dyadic home-interview's environment are provided in Chapter 5.

3.1.1.5.5. *Fidelity data*

Fidelity checks were conducted either during the session or as soon as possible thereafter. Conducting these checks was not challenging, however, there might be differences when these were conducted by different researchers. For instance, the author did not consider an item had been implemented if a part of the statement had not been accomplished, which triggered a further qualitative note. A practical example would be the item 6 of the fidelity checklist "Home-practice is key: All were encouraged to do Tai Chi at home 20mins daily, and the importance of this was emphasised", where the author would not say it was accomplished if no explicit mention to the 20 minutes practice a day was made. Occasional research assistants supporting the study might have coded this differently (positively) if a general encouragement of home-practice had taken place.

3.3. Data Analysis

Data analysis in qualitative research is frequently conducted in parallel to the data collection process, when the researcher is in touch for the first time with participants' views (Bradley, Curry, & Devers, 2007). In this thesis, the use of a research diary facilitated the commencement of this analytic process, keeping a separation between participants' direct manifestations and the inferences raised by the researcher.

Two different approaches were used for data analysis in the Pilot Intervention Phase and the RCT Phase. Whereas in the Pilot Intervention Phase data collected through observations, feedback and focus groups were analysed together; in the RCT Phase data from observations and feedback were analysed before dyadic interviews' data were obtained. This difference in the analytical approach was due to the participants involved in each phase. In the Pilot Intervention Phase all participants were contributing with their experiences during the classes and at the focus groups. However, in the RCT Phase all participants were included in the observations and feedback at the end of the

classes, but only 15 dyads were included in the dyadic interviews. Additionally, this approach to analysis was chosen according to the purpose of each phase. Whereas the Pilot Intervention Phase was studying the acceptability of the intervention; the RCT Phase was seeking to study participants' adherence to the intervention (where data from observations and feedback could be used to further explore particular barriers and facilitators to participants' adherence to the intervention). In the following subsections, steps and decisions made around data analysis are presented.

3.3.1. Anonymising process

Before starting the second round of analysis (after data had been collected) data were prepared to detach any information which could disclose participants' identity, as well as to prepare electronic textual data for analysis with a qualitative data analysis software. An anonymising process is fundamental to ensure participants' identity is not disclosed. In this process, however, it is also necessary to preserve the "maximum content" (UK Data Archive, N. D.), so the data remains useful for research purposes. In this thesis, good practice guidelines provided by the UK data archive were used to ensure data quality and anonymity at the same time (UK Data Archive, N. D.):

- a) An anonymisation log was kept for all data sets. This file contained focus group or interview identifier, original word and anonymised phrase. This was kept separated from focus group or interview transcription and password-protected.
- b) Focus groups or interview transcriptions anonymised, contained symbols <seg> to indicate anonymised words.
- c) Original versions of the transcriptions were kept password protected electronically and hardcopies were locked in the unblended researcher's cabinet. However, these would never be used for this thesis or its outcomes.

Video and audio recordings were only used as a support for transcription and participant identification, so no anonymisation process was required in this data, which was securely stored as with the original transcriptions.

3.3.2. Thematic analysis

Qualitative data obtained for this thesis was thematically analysed. This approach had been extensively used in qualitative research and advised to novice researchers in qualitative methods (Braun & Clarke, 2013). Thematic analysis was useful to describe participants' experiences of taking part in the intervention together with a family member or a friend, identifying strengths and weaknesses of the Tai Chi exercise intervention proposed and to detect areas of improvement. By using this type of analysis not only common patterns across different participants were reported, but also

distinctive aspects pointed by individuals. Themes were defined and, when possible, relationships amongst them were identified and described.

Thematic analysis is more suitable for addressing the research question than other qualitative analysis as it allows keeping the analysis closer to the experiences expressed by participants, avoiding purely interpretive approaches where the researcher would have a more active role in giving sense to their experiences. Similarly, thematic analysis allows searching for patterns across interviews and focus groups with different participants, but also linking this with the perspectives of the instructors and the observations made by the researcher during the sessions. However, the choice of a thematic analysis instead of alternative analysis implies accepting the limitations of not being able to follow the evolution of a particular participant or experiencing difficulties in focussing the analysis as already pointed by Braun and Clarke (2013).

3.1.1.6. **Six steps (Braun & Clarke, 2006)**

Thematic analysis was implemented on qualitative data collected, following the six steps described by Braun and Clarke (2013, p. 202):

- a) Transcription. Focus group and interview data were sent for professional verbatim transcription. Every professionally transcribed file was double checked by the researcher, comparing audio-recordings and writing transcriptions obtained. When mistakes were identified, or data was missing, the researcher added this data. Once transcriptions had been checked, the researcher anonymised the data set.
- b) Reading and getting familiar with the data. When transcriptions had been anonymised, the documents were imported into NVivo 11. Then the researcher went through the files and started taking notes on potentially interesting elements (recording these as annotations).
- c) Coding or the “the process of identifying aspects of the data that relate to your research question” (Braun & Clarke, 2013, p. 206). More specifically a code has been defined as “a word or short phrase that symbolically assigns a summative salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data” (Saldaña, 2016, p. 4).

A hybrid coding approach (combining inductive and deductive aspects) was used in both stages of this thesis. In the Pilot Intervention Phase the inductive approach to the data was used first and afterwards a deductive approach took place. Initially an inductive (Hennink et al., 2011) or “data-derived” coding (Braun & Clarke, 2013, p. 207) approach was used to code aspects pointed by

participants in the entire data set using a “complete coding” (Braun & Clarke, 2013, p. 206). Afterwards participants’ contributions were analysed to identify themes (as described in the next point: Searching for themes) which could relate to the research questions illuminating factors influencing participants’ acceptability and experience of taking part together in a Tai Chi exercise intervention. This process has also been described as using a “researcher-derived” coding (Braun & Clarke, 2013, p. 206) and being more “selective” (Braun & Clarke, 2013, p. 206) and looking for specific themes in the data. Some of these themes changed their names to be aligned with previous knowledge. The use of a deductive approach (Hennink et al., 2011) after the inductive approach facilitated the relation of the findings from this thesis with previous research without imposing previous knowledge and allowing exploration of new themes.

In the RCT Phase, however, the deductive approach was attempted to be used first (coding against broader themes identified in the Pilot Intervention Phase and self-determination theory¹⁶, which could explain the role of motivation in sustaining or discontinuing their Tai Chi practice). However, agreement between coders (author and a Supervisor) was very low as themes were too few and broad and allowed very diverse interpretations from researchers when using an inclusive coding (see Appendix V). Hence, analysis was re-started using an inductive approach to later check against previous findings and theory. Following Hennink et al. (2011)’s steps, the researcher first reread the data sets annotating reflexions on possible codes and creating links between the information provided by participants. The researcher examined the repetitions, topic changes, potential “*in vivo*” codes (those which could correspond with participant’s words), analysing the meaning of participant’s verbalizations and examining underlying ideas. During this process a codebook was developed where the name of the code, together with its description were stated (Hennink et al., 2011, p. 241), which was used by the second coder when the analysis was more advanced, and themes had been identified (see Appendix W).

- d) Searching for themes. This step implied a revision of codes and the quotes gathered under these codes searching for patterns in the data. Some of these codes referred to similar issues which were merged to create a theme, whereas other codes were broad enough to constitute a theme by themselves. At this stage, themes were still closely representing the raw data, but links between

¹⁶ Self-determination theory (Deci & Ryan, 2000) is based in the classical distinction between intrinsic and extrinsic motivations, where those driven by the self tend to promote greater well-being in the individual. However, a high level of integration and internalization of extrinsic motivation can lead to these positive results as well. In parallel, this theory describes three basic psychological needs which need to be fulfilled in the first instance: autonomy, competence and relatedness.

codes were established, searching for common aspects amongst those. At this point a hierarchy was established, where some themes had subthemes and even codes underlying that theme.

- e) Reviewing themes. This stage represented an auditory of the themes established to date, to make sure each theme was “distinctive” and “fit together to form the overall analysis” (Braun & Clarke, 2013, p. 231). To do this, Braun and Clarke (2013) advised to go back to the themes and re-read the data coded under them to make sure these codes are correctly classified under each theme. Then, it was necessary to go back to the raw data again and double check that those themes represented what participants said regarding the research questions. This process served to re-examine the themes and make adjustments or deletions to make sense of the data to start constructing a story.
- f) Defining and naming themes. A description of the overarching themes was developed where the role and relationships amongst themes, subthemes and codes were explained. This final stage helped to develop an understanding around relevant factors influencing older people living with dementia’s acceptability and adherence to Tai Chi.

At this stage cross-groups “comparisons” (Hennink et al., 2011, p. 244) took place in the RCT Phase, to understand the impact of the group characteristics on the findings, but also of participants’ motivations or the nature of the dyadic relationship. These cross-group comparisons were facilitated by using Nvivo 11, which allowed the visualization of codes attributed to the data from different sources.

3.3.3. Enhancing rigour of qualitative research

The quality of qualitative research needs to be assessed. However, commonly and extensively used terms in quantitative research are not applicable in qualitative research, due to the different philosophical traditions behind them (Noble & Smith, 2015). Whereas quantitative studies are examined independently in terms of validity and reliability, this separation is not possible in qualitative research (Golafshani, 2003). However, beyond the terminological differences there are parallel criteria which are applied to qualitative research: credibility (internal validity), transferability (generalisation or external validity), dependability (reliability) and conformability (objectivity) (Golafshani, 2003; Leung, 2015):

- ✓ Credibility refers the extent to which results reflect participants’ views (Hannes, 2011) and in this thesis was enhanced by: a) Including verbatim quotes from dyads and instructors; b) Presenting dissenting views amongst participants and paying attention to weaknesses of the intervention pointed by participants; and

- c) An additional researcher coded 10% of the transcripts at both stages of the trial, following a coding manual created by the author of this thesis. The consistency in the coding process (Hennink et al., 2011, p. 229) was checked to ensure results could be confirmed by other researchers relying on the data.
- ✓ Transferability relates to the outcomes' applicability or the replicability of the results in similar settings (Hannes, 2011). To facilitate transferability assessments, description of the intervention context as well as the demographic characteristics of the participants were provided in detail (Hannes, 2011; Noble & Smith, 2015).
 - ✓ Dependability refers to the potential impact of methods used, and decisions made during the research process on the qualitative outcomes; and confirmability to "the extent to which findings are qualitatively confirmable through the analysis being grounded in the data and through examination of the audit trail" (Hannes, 2011, p. 4). To improve the evaluation of both dependability and confirmability various strategies were used in this thesis: a) A space for reflexivity was ensured to keep track of the decisions taken during the research process, the own researcher's reflections during the research and the potential impact of the researcher on results (Lietz & Zayas, 2010; Noble & Smith, 2015); b) Audio-recordings were used when formal feedback was sought from participants (in focus groups and home-interviews) to allow transcription and a transparent verbatim analysis (Noble & Smith, 2015); c) Members of the supervisory team were available for debriefing and quality checks during the data collection process -regular meetings were hold and data from observations was sent to the supervisory team as soon as had been entered in the computer and anonymised (Noble & Smith, 2015); d) Participant triangulation (using different methods and different informants –people living with dementia, informal carers, instructors and researchers) (Lietz & Zayas, 2010); e) Inter-coder agreement was calculated and reported (Hannes, 2011); and f) Researcher's background was described (Hannes, 2011).

Additionally, Nvivo11 was used to facilitate a transparent audit trail to reinforce the rigour of this thesis' qualitative findings. NVivo 11 is one of the qualitative data analysis software (QDAS) available to support the management, visual representation and analysis of qualitative data. QDAS are increasingly used in successful research published in scientific journals (Woods, Paulus, Atkins, & Macklin, 2016).

NVivo 11 was preferred instead of manual analysis for a series of advantages: a) Facilitated a transparent analytic process where codes and themes are defined, refined and supported by participants' quotes; b) Enabled inter-coder analysis, as various

researchers can code the same file and it is still possible to recognise who contributed to each code; c) Made possible the audit track of decisions made during the analytic process, by using memos, as well as establishing links within the data; d) Simplified and efficient management of numerous and large data sets in a unified project, where all data was easily accessible and compared amongst different sources of data; and e) Allowed importing analytic data to standard formats (i.e., word and PDF), making it accessible to the supervisory team. NVivo 11 was also chosen amongst other similar QDAS due to pragmatic reasons: this software was available to the researcher for free at Bournemouth University and training and support service was also available free of charge. In parallel, NVivo is well-known and understood in qualitative research.

As any tool, this software has also some limitations that have been reported in the literature: a) Entails a time-consuming learning process (Welsh, 2002); and b) As other QDAS (i.e. ATLAS, Open Code, The Ethnograph), this software facilitates the analytic process, however, it is not able to replace the researcher in conducting the analysis (Zamawe, 2015).

3.4. Summary

The qualitative analysis sought to reflect the patterns identified amongst participants' experiences of taking part in the TACIT trial, respecting their anonymity and the meaning they attributed to their contributions. The role of the researcher, however, must be acknowledged, as she was the one who decided what to observe, when collecting the data, and how to analyse the data obtained from participants. The engagement with other researchers during this process, nevertheless, ensured that this process was trustworthy, and that participants' views were faithfully represented in this thesis. The following chapters will provide a description of the implementation process of the TACIT Trial and reflect on the findings obtained by using the methods described within this chapter. The next chapter will summarise the lessons learnt from the first stage of this thesis (Pilot Intervention Phase) that informed the RCT Phase of the TACIT Trial.

4. Pilot Intervention Phase

The aim of this section is to provide an answer to the first research question targeted by this thesis: What influences people living with dementia and their carers' acceptability of a Tai Chi exercise intervention? This overarching research question, however, contains a series of sub-questions which were pursued at this stage (see Appendix B) regarding the characteristics of the intervention, participants' reaction to the intervention, perceived difficulties and benefits of Tai Chi as well as the impact of the research process on participants' acceptability of the intervention.

To respond to these questions, section: 4.1. Provides a description of the recruitment process, participants' characteristics, intervention's context, and the themes identified through participants' experiences; 4.2. Discusses this chapter's findings; 4.3. Reflects on the strengths and weaknesses of this study, its practical implications and future areas of research; and 4.4. Summarises this chapter.

4.1. Findings

4.1.1. Recruitment and retention

The 'green light' to commence recruitment was received from the Sponsor on 18/10/2016 and recruitment activity ceased on 08/12/2016. As reflected in Table 11, a total of 320 (potentially eligible) people living with dementia were approached by three NHS Trusts in the South of England by letter, telephone or in person. A total of 53 people (8%) reported to one of the NHS Trusts that were interested in taking part, expressed their interest in getting involved in research through Join Dementia Research (JDR) website, or contacted the BU team after accessing to a TACIT flyer in their local community. All these potential participants were referred to the BU team¹⁷ or contacted by them for screening. Of those screened by the BU Team, 12 (23%) were ineligible, 18 (34%) declined to take part and 12 (23%) could not be contacted. A home visit to confirm eligibility and conduct baseline assessment was undertaken for the remaining eleven dyads. One dyad was found to be ineligible at the home visit (person living with dementia was categorised as 'severe dementia' on the M-ACE) and the remaining 10 dyads were eligible and consented to participate in the study (3% of those initially approached by NHS Trust South of England 1, 2 and 3 teams).

¹⁷ BU Team was comprised by two Postgraduate Researchers who were mainly in touch with participants from screening up until the end of their participation in the study: PhD 2 was involved in participant recruitment (telephone screening with participants referred by NHS Trusts South of England 1, 2 and 3 and baseline data collection in home-visits). PhD 1, the author of this thesis, was involved in participant recruitment (telephone screening only, of participants from Join Dementia Research (JDR) website and publicity), weekly falls phone calls, qualitative data collection and fidelity checks during sessions and focus groups at the end of the Pilot Intervention Phase.

Eleven home visits were undertaken by PhD 2 between 07/11/2016 and 30/11/2016. Typically, home visits took about 2.5 hours to complete and involved participants completing questions to collect demographics and the various assessments which make up the different study outcome measures. The first dyad of participants was recruited on 15/11/2016, as the first dyad visited was found not eligible for the study. Ten dyads were recruited (6 dyads at Site 2 and 4 at Site 1); the target was 14 dyads in total.

Table 11. *Pilot Intervention Phase: Recruitment Numbers*

Source	Participants retrieved from databases		NHS Trust South of England 1, 2 and 3 team referrals		BU Team activity								Conversion rates	
	JDR Website	NHS Trust South of England 1 database	Participants Approached	Referred to BU Team for eligibility	Screened	Not eligible at screening	Refused to take part	No response to contact	Home Visits	Not eligible -at home visit	Not willing to take part - at home visit	Consented and Recruited	2 nd – To recruited ³	1 st – To referrals ⁴
NHS Trust South of England 1	0	521	121	19	19	0	13	1	5	1	0	4	21%	14%
Site 1 JDR	32	N/A	17											
Site 1 Publicity	N/D	N/D	N/D	N/D	N/D	N/D	N/D	N/D	N/D	N/D	N/D	N/D	N/D	N/D
NHS Trust South of England 2	N/A	N/A	112 ¹	5	5	1	1	0	3	0	0	3	60%	4%
NHS Trust South of England 3	N/A	N/A	70 ²	3	3	2	0	0	1	0	0	1	33%	4%
Site 2 JDR	27	N/A	N/A	N/A	21	6	3	11	1	0	0	1	5%	N/A
Site 2 Publicity	N/A	N/A	N/A	N/A	5	3	1	0	1	0	0	1	20%	N/A
Subtotal (Site 1)	32	521	138	19	19	0	13	1	5	1	0	4	21%	14%
Subtotal (Site 2)	27	N/A	182	8	34	12	5	11	5	0	0	6	18%	4%
TOTAL	59	521	320	27	53	13	17	12	11	1	0	10		
													Percentage 37%	Percentage 8%

¹Estimated from number of patients potentially contacted weekly (16 over 7 weeks), assuming all were approached.

²Estimated from number of people potentially contacted weekly (10 over 7 weeks), assuming all were approached.

³Second conversion rates: Percentage of potential participants who were recruited into the study after the BU team's screening.

⁴First conversion rates: Percentage of people referred by NHS Trust South of England 1, 2 and 3 to BU after their initial approach.

Reasons for ineligibility and refusal are summarised as a CONSORT diagram in Figure 6. A high percentage of the potentially eligible participants who were initially contacted by the three NHS Trusts (approximately 83%) declined to take part in the study. There were several reasons for declining participation including: the study was not of interest, they did not meet the eligibility criteria, or they felt it was not relevant for them as they had not previously experienced balance or falls issues.

Recruitment was particularly challenging initially, as participants who initially consented to having their details passed to the BU team, later declined to take part (see Figure 6 for reasons). To overcome these challenges the recruitment strategy was adapted by advertising the study locally (i.e., distributing flyers to organizations in contact with people living with dementia and/or their carers) as additional source of recruitment and relaxing the recruitment criteria in terms of availability to attend the sessions (some instead of all of them) and to support transport costs.

Participants' retention

During the Pilot Intervention Phase, one dyad from each area withdrew from the intervention (20% withdrawal rate): After session 1 in Site 1 due to previous health issues and after session 2 in Site 2 due to planned holiday. Both dyads, however, decided to carry on providing research data. As recruitment continued whilst the classes had started, one dyad was recruited after the first class in the Site 2 area. This dyad, however, was not able to attend the last class due to illness. Another dyad in Site 1 was able to attend only two of the classes due to a traffic accident which made it impossible for them to reach the venue for the second class. As reflected in Table 12, six dyads attended all the classes offered and only one dyad attended less than 50% of the classes (33%).

Table 12. *Pilot Intervention Phase: Dyads' Attendance to the Classes*

Dyads	Class number				Totals		
	1st	2nd	3rd	4th	Classes attended per dyad	Dyads' average attendance	Groups' average attendance
01001 ¹	Yes	Withdrawn	Withdrawn	N/A	1	33%	75%
01002	Yes	No - Traffic accident	Yes	N/A	2	67%	
01003	Yes	Yes	Yes	N/A	3	100%	
01004	Yes	Yes	Yes	N/A	3	100%	
02001	Yes	Yes	Yes	Yes	4	100%	83%
02002	Yes	Yes	Yes	Yes	4	100%	
02003	Yes	Yes	Yes	Yes	4	100%	
02004	Yes	Yes	Yes	Yes	4	100%	
02005	Yes	Yes	Withdrawn	Withdrawn	2	50%	
02006	Not recruited	Yes	Yes	No - Illness	2	50%	
Dyads attending	9	8	8	4			

¹ Dyads' Identification Numbers: The first two digits refer to the site, and the last three to the number assigned to each dyad in the group. Individual members of the dyad can be identified in the rest of the document by a letter "C" (carer) or "P" (person living with dementia) added at the end of their dyad number.

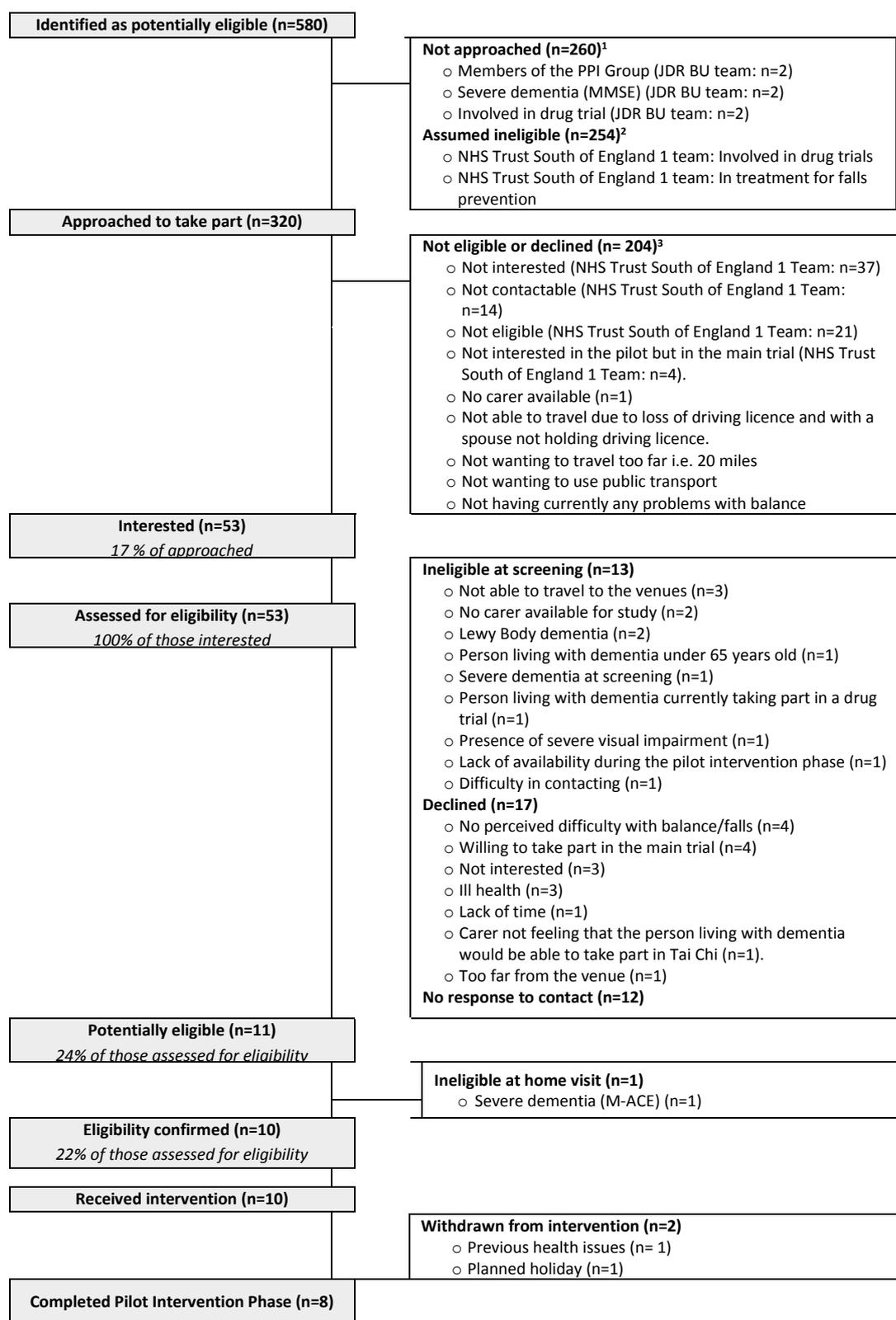


Figure 6. CONSORT Diagram for the Pilot Intervention Phase of the TACIT Trial.

¹ We do not have the reasons (and corresponding number of people) for participants not approached by NHS Trust South of England 1.

² Based on the estimates, but we do not have the number of people declining for each reason or a detailed list of reasons.

³ We made the assumptions based on estimates that everyone was approached but this may have not been the case.

4.1.2. Participants' demographic characteristics

All 10 dyads recruited were from a white ethnicity, stated they had no previous experience practising Tai Chi and had the intention and confidence to be able to practise Tai Chi during the classes and at home (measured on a 7-points Likert scale). Gender was balanced amongst people living with dementia (5 male, 5 female), whereas there were 4 male and 6 female carers (for further details on participant's demographics see Appendix X). Members of these dyads were living together, all but one (relatives) were married or partners. Most of participants ($n = 7$) had reached secondary or higher education. Carers were aged between 69 and 74 years old (mean = 72.4, SD = 5.28) and people living with dementia between 73 and 88 years old (mean = 78.2, SD = 5.39). Amongst those living with dementia, all had a diagnosis of AD ($n = 9$) or mixed Alzheimer's and vascular dementia ($n = 1$). Scores on the M-ACE cognitive test ranged from 13 to 26 (mean = 16.8, SD = 3.99). Seven out of ten participants living with dementia had other chronic conditions, though none of them prevented their engagement in Tai Chi. None stated that they needed to use walking aids, and only one person reported having had falls the year before engaging in the Pilot Intervention Phase. Most participants living with dementia ($n = 8$) reported that they undertook moderate physical activity on a weekly basis (everyday ($n = 3$), three times per week ($n = 1$), two times per week ($n = 3$) or weekly ($n = 1$)), and the remaining participants ($n = 2$) reported rarely or never undertaking moderate physical activity. One reported doing vigorous physical activity fortnightly; and the remaining participants reported not doing or rarely doing vigorous physical activity ($n = 9$).

Participants living with dementia were to be excluded if their scores in the M-ACE screening tests were under 15 indicating a more severe stage of dementia. However, after finishing the Pilot intervention Phase, it was revealed that three participants (highlighted in Table 13) included in this phase of the study did not meet this criterion, which was reported to the Sponsor.

Table 13. *Pilot Intervention Phase: Participants Living with Dementia's M-ACE Scores*

Participants	M-ACE Scores
01001P	13
01002P	26
01003P	14
01004P	15
02001P	15
02002P	22
02003P	14
02004P	19
02005P	15
02006P	15

It must be noted, however, that all of the participants were able to take part in the class, contribute with their feedback, and that no one was put at risk from participating in the study. A request was then sent to the Research Ethics Committee (REC) to lower the threshold to 10 for the RCT Phase.

4.1.3. Context

Initial difficulties with recruitment meant that the first class in Site 1 had to be cancelled. Consequently, the two pilot groups organised ran for 3 weeks (Site 1) and 4 weeks (Site 2). Classes were delivered during working days (Thursdays and Fridays) around midday (starting at 11.30 am or 11am) on a weekly basis, following advice from the PPI group. Participants were asked to arrive 10 minutes before the scheduled time of the class and take part in 45-minute Tai Chi classes. There was also an opportunity for them to engage in conversation (over a cup of tea/coffee and cake) for 45 minutes after the Tai Chi class. Every session therefore required participants' involvement for up to 90 minutes. Participants were expected to stand for the duration of the class to challenge their balance, but they were free to sit before and at the end of the class. Additionally, dyads were asked to practise Tai Chi at home for 20 minutes a day after the first class. Three out of six expected exercise logs were returned in Site 1, and 12 out of 15 on Site 2. Amongst dyads who reported their home-practice, their average weekly home-practice was 76 minutes. It is not possible to report accurate minimum and maximum minutes of weekly practice as some dyads provided only one exercise log after two weeks of practice (with no reason provided for this). Accordingly, data regarding the minimum and maximum practice could have been altered by dyads using a single exercise logs for two or more weeks of practice.

Classes were led by a professionally trained Tai Chi instructor. The instructor had experience of working with older participants living with and without dementia in community and care-home settings. Both pilot groups were led by the same instructor.

Venues were chosen after checking their suitability against various criteria: size (able to accommodate between 14-20 people), maintenance conditions (i.e., well maintained floors), accessibility by car (free onsite parking or public parking available close by) and/or public transport, time slots availability, flexible booking, availability of onsite cooking facilities, and general accessibility within the venue (i.e., lifts and toilets). The chosen venues were big enough for the group size and left sufficient space for participants to move around the room while practising the exercises. Both were bright, used a combination of natural and artificial lighting, and had well maintained wooden floors. Heating was available, and the sessions took place generally in a warm environment -with some differences between sessions, as the Tai Chi instructor tried to

find the most comfortable temperature for participants. Both venues were accessible by car and public transport.

4.1.4. Acceptability of the intervention and participants' experience of involvement in the TACIT trial

Findings in this Pilot Intervention Phase are reported in terms of participants' acceptability of the Tai Chi intervention and the research process that they participated in. Both the intervention and research procedures were well received by most participants (9 out of 10 dyads) who continued to take part in Tai Chi classes in the context of research. The remaining dyad was unable to continue participating in the pilot and withdrew after the first class due to health issues, they were also unwilling to attend the focus group organised at the end of the study. Participants were generally disappointed that they were not eligible to participate in the RCT phase of the TACIT Trial.

Three main themes were identified that represented their views on participation in the Pilot Intervention Phase of the TACIT Trial (as reported in Table 14): intervention's characteristics, participants' reactions to the intervention, and their experience of getting involved in the research process. These three themes are presented and described within this subsection.

Table 14. *Pilot Intervention Phase's Hierarchy of Overarching Themes and Subthemes Around Dyad's Experiences of Taking Part in Tai Chi and Getting Involved in Research*

	Overarching themes	Themes	Subthemes	Examples of quotes
Dyads' experiences in the Pilot Intervention Phase	Taking part in the Tai Chi exercise intervention	Intervention's characteristics	Instructional methods	"The instructor says in the next class it was planned to introduce something new, but comments he'll not do this, to adapt the class to the group's needs."
			Class-based practice	"you practice over and over again...I mean it's much better than you saying, well, do this and then, and then the next minute you've forgotten all about it..."
			Home-based practice	"The very first weeks participants felt home-practice was difficult as they could not remember what they had been doing in class".
	Participants' reactions to the intervention	Participants' reactions to the intervention	Feelings towards the intervention and their dyadic participation	"I thought it was quite nice"
			(Dis) engagement	"Comments after 3 classes, he's felt more "getting into it", he was "flowing more"".
			Perceived benefits	"I think the exercises ultimately with people with dementia could help with balance".
			Interactions with others	"When participants laugh at the instructor's jokes they look at each other."
	Getting involved in research	Research process	Participants' involvement in research	"We're happy to partake in that if it, er, if it helps you keep a record".
			Participants' expectations	"That's a shame. I was hoping [laughs] it would continue."

4.1.1.1. *Intervention's characteristics*

All subthemes contained by this overarching theme relate to the way the intervention was: a) Delivered by the instructor, including the way he engaged with participants, built rapport, reassured participants, and tailored the intervention to meet participant's needs; and b) Practised by participants, in terms of class- and home-based Tai Chi practice.

4.1.1.1.1. *Instructional methods*

All participants very positively valued the instructor. Both people living with dementia and their carers stated that they were able to understand him, as he was using clear speech and an adequate calm tone of voice, appropriate also for a participant with hearing aids:

He's a very, very warm, delightful man and I felt at ease immediately with...with him. (02004P).

He makes it really interesting. He's got a very nice manner (...) He's right at the top of his field in what he's doing, so, I mean, you're very lucky to be working with him. (01004C).

During the classes, the instructor made use of examples from his private life to create rapport with participants (i.e., sharing comments made by his daughter), but also used examples from everyday life to describe the movements during the classes. He regularly provided positive feedback during the classes to encourage participants' engagement in the activity and reassured the participants when they verbalised difficulties while doing Tai Chi at home or during classes:

Is like drinking a cup of tea.

Excellent... that's good... that's perfect... wonderful.

Tai Chi is a journey, it is perfectly normal that your brain says how is that?

Sometimes this positive feedback was given also when some participants were struggling to perform the movements or doing them incorrectly. This approach was chosen by the instructor for this initial stage (Pilot Intervention Phase) to facilitate their engagement. This positive feedback was positively perceived by one of the carers during a focus group:

When he's doing the exercises, he says, oh, that's good, yes, that's right, you're doing it right there, but...you know they're not really but... he's just encouraging. (02001C).

Corrections, however, were mostly made as a general comment not directed to individual participants (i.e., “*golden rule: your knees very slightly bent go forward and your heels stay in the ground*”), unless participants had expressed a particular difficulty in performing a movement. The instructor reinforced participants’ home-practice by providing positive feedback (i.e., “*I can see some of you have been practising*”).

The instructor adapted the intervention to participants’ needs and responded to their requests (i.e., introducing breathing while practising one movement, as requested by a carer during the class) to make the intervention accessible for both people living with dementia and their carers. He emphasised the need of participants to focus only on their own performance:

Tai Chi is about you, this is your Tai Chi (...) everybody has different flexibility, different hips. Please don't worry about looking as anybody else.

4.1.1.1.2. Class-based Tai Chi practice

Classes had a common structure formed by warm-ups, patterns, relaxation and socialising. Classes consisted of copying the instructor’s movements. Each pattern (formed by several movements) was slowly repeated two or three times by the instructor whilst participants mirrored him. Occasionally, participants performed better in the second attempt of practice. However, more frequently, participants (mostly people living with dementia) carried on practising the movement in the opposite direction, bending too much forward or pausing their engagement in the activity.

During the classes, participants moved around the room while practising and tended to go back to their start positions after each pattern. In Site 2, participants took different positions from the first class. During the first class participants living with dementia were practising closer to their carers, however, in the classes that followed, three of the carers practised in the first line, leaving the person living with dementia to work individually (behind).

As shown in Table 15, participants positively valued the classes’ settings (venues, timing and group size) as well as the role of repetition. Only the amounts of contents delivered were a matter of concern for two carers and the instructor (“*they’ll only grasp so much*” (02004C)), particularly thinking of those participants with more difficulties who might struggle memorising or performing the movements.

Table 15. *Strengths and Weaknesses of Class-Based Tai Chi Practice*

Perceived as a...	Aspects	Example quotes
Strength	Accessibility of the venues and not having to travel more than 35-45 minutes.	<i>we could have accommodated a few more participants (01004C). it's been ideal as a small group I think (...) you don't want 30 odd people (01002C).</i>
	Group size	<i>45 minutes for me personally was enough, it's a good time, and mostly (...) for us it's very easy (01002P).</i>
	Length of the classes	<i>you practice over and over again...I mean it's much better than you saying, well, do this and then, and then the next minute you've forgotten all about it (01004P).</i>
	The role and importance of repetition	<i>it's the repetition that's the important (01002P).</i>
Weakness	Amount of contents delivered.	<i>They can't help it, but they'll only grasp so much. And I think to concentrate on a few movements every week would benefit them far more (...) you have to realise everyone's got their own limitations (...) if you're gonna go for the few that probably do grasp it there's gonna be a lot that don't. The ones that can't are the ones that really need the help (02004C) balance is challenged in one pattern already (Instructor)</i>

4.1.1.1.3. Home-based Tai Chi practice

Eight out of ten dyads reported that they had managed to practise at home. Dyads who did not report any practice were the dyad who withdrew after the first class and another dyad that attended all the classes but was not able to practise due to an unexpected lack of time (*"when the lady asked me [during baseline home-visit] and I said, oh, that'll be fine. But it's been so hectic"* (02001C)).

As reported in Table 16, barriers and facilitators to home-based Tai Chi practice were identified by participants. Two carers verbalised their difficulties motivating the person living with dementia to do things (02001C, 02006C), which had an impact on their home-practice meaning that they did not manage to do any practice or not more than 20 minutes for one week. However, most dyads willing to practise for 20 minutes reported no problems in doing so. Only one participant living with dementia struggling to practise at home had experienced difficulties following the classes, and decided to focus their home-practice around the warm ups:

You do get quite a bit of benefit in that. (02004C).

But our warm-ups is Tai Chi in my mind. (02004P).

The lack of guidance and confidence when practising at home, however, was the main issue raised by participant dyads. Particularly carers felt like the "blind leading the blind" (01002C, 02003C), which led one of the carers to stop practising at home whilst the person living with dementia carried on alone, convinced that any practice would be positive for her. The booklet in all the cases was perceived as not useful, unclear and

with inconsistent (picture-description) instructions which failed to show the progression of the movements. An instructional DVD was the most repeated request raised by dyads. In absence of the DVD, however, a crib-sheet (as suggested by the instructor) with bullet points indicating how to start home-practice, together with a clear booklet divided into smaller sections, was perceived by the dyads as an improvement.

Table 16. *Barriers and Facilitators to Home-Based Tai Chi Practice*

Perceived as...	Aspect	Example quotes
Facilitators	Incorporating Tai Chi into their routines	
	Participants' determination to get the benefits of Tai Chi.	<i>I think for the main course it would be good to instruct the people on it to have a time to do it (01002P).</i>
	Perceived growing confidence over sessions.	<i>We don't have a lot of routine (...) we found it far better to do the Tai Chi in the mornings after breakfast (...) if we had a shopping day (...) we might have given it a miss (01004C)</i>
	Ability to allocate some time for home practice (action plans)	<i>I found that beneficial (...) I do forget whether you should be going up there or down there (...) But then somehow it doesn't really seem to matter all that much (01004P).</i>
Barriers	No insuperable barriers were identified and ability to provide solutions to overcome their difficulties (coping plans)	
	Lack of guidance and confidence -booklet and starting home practice after the first class.	Carers describe the booklet as "overwhelming" (01002C), "confusing" (01003C), "not self-explanatory" (02006C).
	Instructor's difficulties to schedule home-visits (only six dyads received those, but some just before the last class).	<i>I'm not as good as I was at reading and the book was difficult for me to comprehend (01002P).</i>
	Lack of time.	<i>I think you want all three [classes] before you start it [practising] at home (...) your confidence is a bit better. (01002C).</i>
	Difficulties to motivate the person living with dementia or sustain practice for 20 minutes (attention or health issues).	<i>we didn't manage very often more than 15 minutes because <02004P> used to get so tired. And of course, she had a problem with her arms (02004C).</i>
Alarm clock was not used as memory aid.	<i>I found this business of not being able to concentrate for too long (02003C).</i>	

4.1.1.2. **Participants' reactions to the intervention**

All subthemes contained by this overarching theme relate to the way participants responded to the intervention in terms of their: a) Feelings toward the intervention and their dyadic participation; b) (Dis) engagement with Tai Chi; c) Perceived benefits; and d) Interaction with others.

4.1.1.2.1. *Feelings towards the intervention and their dyadic participation*

Before starting the classes and after the first class half of the dyads (01002, 01004, 02003, 02005, 02004) were particularly passionate and enthusiastic about the opportunity of taking part in Tai Chi, whereas the rest were more neutral in their behaviours and expressions. In subsequent sessions, participants arrived in the session with a neutral or smiling face. Generally, participants had neutral and positive feelings towards the intervention ("a good addition to my life" (02005P). All participants

shared their enjoyment of the intervention and the socialising component, when providing feedback. However, only occasionally they verbalised this satisfaction during the class (i.e., “*I like it!*” (01002P)). In site 2, participants expressed their content non-verbally at the end of the class by clapping the instructor.

Tai Chi was perceived as a different activity that participants were not familiar with, however, this perception had no impact on participants’ enjoyment and engagement in the activity. On the contrary, participants valued the benefits of taking part in Tai Chi, both in terms of well-being and physical condition.

Well, I've never done anything like it... very hard to take in, just quick, you know... and a good experience to look. (02001P).

It's strange from another tasters that I went to, but I like it. (02003P).

de-stressing and relaxing (...) particularly the breathing. (02006C).

Tai Chi would be good for people with dementia (...) particularly good for people with balance problems. (01002P).

Only one participant living with dementia seemed to react negatively towards the intervention, feeling “*distressed before going*” to the sessions as reported by the carer (02006C). This participant failed to attend one of the classes due to a previous health condition which the carer described as a frequent way of expressing “*anxiety*”.

Tai Chi is an activity that carers see themselves doing with their partners to improve or maintain their physical condition unlike other types of exercise:

They keep...all these people, they sort of say, oh, you've got to do about sixty minutes a day of something.....energetic, get your heart moving and all that. But, you know, I couldn't do that, but.....as I say, I like this movement. (02001C).

Well, this sort of exercise gives you exactly that [“slow movement”, “it's ideal for people, it's so smooth and easy”], doesn't it? (02004C).

I think it's absolutely perfect, I really do. (02003C).

Two carers, however, questioned the appropriateness and benefits of Tai Chi for people living with dementia in more advanced stages, although these views were not shared by one participant living with dementia as the following conversation shows:

Don't think is an activity for people living with dementia in very advanced stages, as it requires sustaining attention for a long period of time, and this is something people at more advanced stages would struggle with. (02002C).

Some people are more, unfortunately, afflicted by this dementia (...) So they're not gonna respond quite so well (...) So whether anyone with quite bad dementia could really benefit from it, I don't know, er. (02004C).

I think they can, <02004C>. (02004P).

Both people living with dementia and their carers enjoyed the dyadic component of the intervention as this gave them an opportunity to discover a new activity to practise together:

I know that's perhaps not the way to describe Tai Chi but it's lovely, we found anyway that we could do this together and I had no problem getting him to do it. (02003C).

thoroughly delighted and enjoyed the experience (...) I have got my carer at home and he's so updated and he's now able to do Tai Chi every single day (...) he's getting better (...) I love doing the exercises with <02004C>. (02004P).

Their dyadic practice, moreover, allowed at least two participants living with dementia to engage in the intervention as otherwise they would have not engaged alone according to their reports (01004P, 01003P). The value of the carer's role was highlighted by people living with dementia and carers in the context of supporting the implementation of the intervention and in providing data in the context of research:

...it needs someone with competence to be the partner of the person with dementia because, believe me, it's not like a drug trial which is very easy, this needs competence on behalf...of the partner or carer, in my opinion. (01002P).

...we need to be with them when you're talking to them, to give you the right idea and the right side of the story. (02001C).

Carers did not find their joint participation to be a burden, only one expressed it had been hard as a carer although he would keep going for the person living with dementia and the possibility of meeting with other carers (02002C).

It's not difficult to accommodate because you're doing it with everything else in your life. (01004C).

4.1.1.2.2. (Dis) engagement with Tai Chi

During the classes, all participants were focused in the session, looking at the instructor and copying his movements. Dyads were mostly practising independently. Only two carers (01003C and 02002C-during the first class-) approached the person living with dementia for repeating or supporting instructor's instructions. In these cases, however, the person living with dementia tended to freely carry on practising the same way, with no further comments from carers.

Three participants expressed they had experienced difficulties following the classes after the first session due to their fear of falling (02004P) or because they got lost during sessions when copying more complicated patterns (01004P, 02006P). It was clearly observed, however, that an additional participant, who did not report any difficulties (01003P), got lost copying some of the movements. One of the participants living with dementia (02002P), on the contrary, according to the instructor and the author's observations got more into the intervention and was able to follow the class without verbal prompting from the carer. Carers engaged in the intervention reported no difficulties in copying the movements during the classes. Only two participants, a carer and a person living with dementia (one from each group) verbalised they were not able to perform well. Generally, participants enhanced their perceptions of competence during sessions. In addition, the participants start to realize that more practice enhanced their perceptions of competence, feelings of the "flow" and getting other benefits of the intervention. Participants' progress was already noticeable in the second class when half participants living with dementia and carers anticipated the movements taught by the instructor.

Three people living with dementia stopped their practice at some point during the classes and this was because they needed the toilet, were coughing, or afraid of falling. Participants coughing stopped their practice and observed the class for a while. The participant with fear of falling, according to her feedback, was able to perform the movements in a familiar environment with the availability of an armchair (02004P):

It's been familiarity, I have a problem with my feet, something to do with my balance after I had a stroke. And here I'm terrified to move my feet, but I do it, I can really do it at home (02004P).

This participant never expressed the need of taking a seat or having a chair close by during the classes. However, she was never offered these alternatives nor was asked during the classes if she was feeling ok.

Finally, three adverse events experienced by participants were rated as definitely/probably/possibly related to the intervention: dizziness (reported by two participants living with dementia) and pain (reported by a carer and attributed to previous conditions). However, none of them was serious and all were expected as possible reactions to the intervention. The two participants living with dementia experiencing dizziness, however, did not stop practising. The carer experiencing knee pain stopped practising because the person living with dementia was not feeling well and due to a lack of time, but expressed her willingness to carry on practising Tai Chi.

4.1.1.2.3. *Perceived benefits*

The most important facilitators of participants' engagement in the intervention were the benefits perceived by both members of the dyad after taking part in the intervention: a) Relaxation; b) Exercise for health benefits –increasing activity levels, keeping muscle supple; c) Body awareness– “*it makes you think about what's going on in your body while you're doing this*” (01004P); d) Brain stimulation; and e) Balance improvement. Taking part in the intervention was perceived as a source of pride and conversation in itself:

It's something to be kind of proud of and, yeah, makes you feel better... you know, that you're doing something good for yourself. (...) I have to say we've almost been quite, um, proud to, to tell our friends we've been doing Tai Chi. (01004C).

Participants' perceived benefits and enjoyment of Tai Chi helped participants struggling with practice to carry on:

May I say the one thing I have noticed, I love to do my bit of gardening and I rather love to go out and inspect everything daily. And to go into my greenhouse, for instance, I'm very much more careful with my legs. And I have said quietly to myself, um, thank you Tai Chi, because it has helped me so much with balance. (02004P).

4.1.1.2.4. *Interactions with others*

Participants in Site 2 were more interactive, where participants naturally tended to return to their original seats after the class to chat with the other participants and enjoy their refreshments. During the classes, most of the interactions were initiated by the instructor as he was the one leading the session. However, some participants developed interactions with the instructor in a verbal and non-verbal way. Particularly, participants reacted to the instructor's comments frequently with smiles and laughs. Mainly non-verbal interactions with other dyads took place in Site 2 during the classes.

In both sites, only occasionally, there was an interaction between members of the same dyad, for instance, in the form of non-verbal interactions expressing mutual understanding. When the carers started a verbal interaction, this was always in a soft and comfortable way to ensure the person living with dementia was all right or to support the instructions provided by the instructor. At the end of the class participants were able to engage in informal conversation with other dyads and the instructor, not necessarily about Tai Chi, but about their experiences of caring for or being supported by their loved ones, their past experiences, and daily life. In these interactions at the end of the class, camaraderie was most present in Site 2 which was also observable during the focus group, where participants engaged in overlapped conversations exchanging impressions on their caring role or commenting on things they did in the past. At the end of this focus group, at least 3 dyads exchanged their contact details. Lastly, a positive unexpected discovery was made by the author who found two less verbally active participants exhibiting non-verbal social behaviours. One of them ended up collecting tea cups from the rest of participants during the socialising component (02002C) and, the other one, being the only one taking the initiative to shake hands with the rest of participants at the end of the class (02001P).

4.1.1.3. Research process

All subthemes contained by this overarching theme relate to: a) Participants' involvement in research, including PhD 2's experiences over recruitment and delivery of the intervention, participants' experiences of taking part in data collection procedures, and the impact of implementation fidelity on their experiences; and b) Participant's expectations regarding their engagement in the Pilot Intervention Phase of the TACIT trial.

4.1.1.3.1. Participants' involvement in research

Home-visits scheduled for informed consent and baseline data collection were successfully completed and developed in a friendly and relaxed environment in the presence of carers facilitating the smooth development of the assessments. Only two recruited participants (01003P and 01004P) were apprehensive, one of them during the whole visit, and the other one during the cognitive tests only. A third participant, the one who was found not eligible to take part in the study was confused and irritated since the arrival of the researcher. The BU team reacted calmly, explaining the purpose of the home-visit to the person living with dementia and the carer, ensuring there were no time constraints and offering breaks to the participant where required.

When asked about home-visits as an ice-breaking conversation during the first class, participants reported positive feedback to the researcher. During the focus groups only

two areas of improvement were highlighted: the length of the home-visits (“*on the long side*” (01004C)) and the point where carers are asked to leave the room. Carers in Site 2 expressed they would have liked to be all the time with the person living with dementia. They made their point regarding the importance of people living with dementia’s difficulty to respond to certain questions and to provide accurate responses:

We need to be with them when you're talking to them, to give you the right idea and the right side of the story. It's no use taking...putting us apart because we have to be there to tell you how it really is. It might be one thing in their minds but it's a different thing in other ways. And I felt I didn't like that, they were making me go somewhere else whilst they was talking to him about certain things. They...not just your people, the doctors do it as well. When he's been on the...when he's had his dementia care thing, they've took him away, they've spoke to him and not spoke to me. And...but you have to be...we're...we're a couple, we're a team... and you have to do it together. (02001C).

I totally agree that they should be allowed to have their voice as far as they're able... but as you say, it's not necessarily...they don't necessarily say or have the words to say what they really mean. (...) I think it is difficult to find a balance because in the early days, um, you don't want them sitting there like a little puppet. I think it's nice when people do look them straight, you know, in their face...and talk to them. (02003C).

Two carers also commented on their partners’ difficulties to talk over the phone:

I don't know if you noticed, well, you obviously must have done, um, I don't know how other people have reacted. But it's quite I think in the early stages that people talk...talk directly to them. But <02003P> was unwell really and when I said who was on the phone, he would have no idea really who it was. I'd say it was Tai...he'd know it was Tai Chi classes. And the questions you were asking him were difficult, not difficult questions but difficult for him anyway to answer the phone. Um, it's just that I want to be aware, because if you're not...we're all in a big learning curve here. (02003C).

<02002P> passes...lifts the phone up but she doesn't know. And sometimes she... puts the phone down and she don't give it to me. (02002C).

However, one of the carers was not accurate providing data, as the only fall registered was not reported during the weekly falls’ calls sustained with him the day after the fall (according to the data he provided through the falls calendar) but during the focus

group, the last day of the intervention. Similarly, at least two carers mentioned the person living with dementia's difficulties with writing which made it impossible for them to complete the exercise logs. Accordingly, carers took over this task and provided the responses. Some of them, however, did not complete these documents correctly (i.e., filled two exercise logs, one for the carer and one for the person living with dementia).

4.1.1.4. Summary: What is influencing participants' acceptability of a Tai Chi exercise intervention?

The Pilot Intervention phase of the study has been generally positively received by most of the dyads (9 out of 10) who also expressed their willingness to carry on practising Tai Chi and getting involved in the main study. The main area of improvement pointed out by participants was the home-exercise booklet provided to support their practice at home (see Appendix Y for other suggestions to increase participants' acceptability). This was not perceived as a useful tool to guide their practice at home, nor to trigger memories of the movements performed in class, as they could not get the progression of the movements from one picture to another. Accordingly, such alternative forms of assisting with home exercise would be required. The use of DVD's was suggested by the participants.

Implementation fidelity was generally high, although the importance of home-practice and the invitation to chat with other participants at the end of the class would need more emphasis in the RCT Phase. These limitations in the delivery of the intervention, however, did not impact on participants' acceptability of the intervention as they carried on attending the classes and practising at home.

Enjoyment, the opportunity to socialise with others, the discovery of a new pleasurable activity to practise together, and perceived benefits (relaxation, physical performance and brain stimulation) of practising Tai Chi were key in participants' acceptability and adherence to the three- or four-weeks intervention. These were particularly important for participants experiencing difficulties in copying the instructor's movements, but who persisted practising Tai Chi. Participants did not report any injuries whilst taking part in the trial apart from pain in their knees which they attributed to previous conditions. Dyadic participation was positively valued, some participants living with dementia commented they would have not engaged without their carers and carers seemed to be missing an activity where they could both engage and enjoy doing.

Home-practice was facilitated by participants' incorporation of Tai Chi into their daily routines and the perceived benefits of their practice. The main barriers for practising at home were the lack of time to practise due to other commitments (i.e. Christmas time,

looking after grandchildren, or being busy) as well as the lack of confidence when practising at home, given the booklet was not seen as helpful in guiding their practice.

Participants reported that they were happy to take part in the research process, providing data during home-visits, sessions, by phone, and in the final focus group. However, improvements in terms of reducing the length of the initial assessments to around one hour and a half, allowing dyads to be together during the whole home-visit, and talking with the carer as well during weekly falls calls would be appreciated by carers.

4.2. Discussion

The aim of this Pilot Intervention Phase was to identify the elements of the TACIT Trial impacting on dyads' acceptability of the Tai Chi intervention. Participants' experiences helped to illuminate strengths and weaknesses of the intervention's design and the research process.

Findings suggest that the TACIT Trial is acceptable by the target population. It has shown that Tai Chi is perceived as an adequate exercise for people living with dementia in mild-to-moderate stages and their carers. Although not including qualitative analysis, Yao et al. (2012) also reported that Tai Chi is acceptable in community-dwelling people with dementia in the USA. However, caution is required in supporting the acceptability of Tai Chi as a falls' prevention intervention, as recruitment was challenging. Several participants declined before or after reading the study's information. An important reason for this is that eligible participants felt that they were not at risk of falls (Hawley-Hague et al., 2016a) and as such that a falls prevention program was not for them. This has been a common problem in that participants rate exercise intervention designed to reduce falls as important but for other people (Haines, Day, Hill, Clemson, & Finch, 2014). In this study there were also participants who did not feel at risk of falls, which is consistent with Yardley et al. (2006)'s finding in older population. Some participants, for instance, found weekly falls phone calls acceptable but "*possibly a little over the top for the particular people in this group*" (01004C) as they were not expecting any fall amongst them. Amendments to the study leaflets and participant information sheets to be used in the RCT Phase will seek to describe the aims of the TACIT Trial focusing on studying the wider benefits of Tai Chi for people living with dementia (i.e., impact on well-being) apart from its effects on balance. The impact of this change in the study presentation will be checked in the RCT Phase where participants will be again invited to provide reasons for declining taking part. On this occasion, the proportion of participants rejecting because of not experiencing falls issues should be reduced.

Amongst dyads who accepted taking part in the study, both people living with dementia and their carers reported on a Likert scale to have the intention and confidence to be able to practise Tai Chi before starting the intervention. However, it was already known that people engaging in exercise interventions in the context of RCTs tend to be highly motivated (Connell & Janevic, 2009; Prick, de Lange, van 't Leven, & Pot, 2014). In the context of the TACIT Trial, nevertheless, participants are requested to take part in dyads where there might be a discrepancy in motivation to take part. Therefore, in the RCT Phase the impact one member of the dyad has on the other will be examined. Although most of the participants seemed to have taken a joint decision there were also two exceptions. One carer openly commented having been the one who made the decision to join in the study, whereas in the other dyad the person living with dementia was the one convincing her partner to take part. The person who makes the decision of taking part in the intervention could make a difference in dyad's adherence to home-practice. Whilst the dyad where the carer made the decision to join the study never practised at home; the other dyad not only practised at home, but the person living with dementia practised alone when the carer was not feeling confident during home-practice. This example leads to a future research question on what ultimately affects who makes the final decision to join in research in dyadic exercise interventions. It is likely that factors such as previous exercise experience, the level of cognitive impairment or the level of empowerment of the person living with dementia influence the uptake.

4.2.1. Class-based practice

The intervention was widely accepted by participants who particularly adhered to the class-based component. Participants were motivated by the instructor who received only positive feedback from participants as did the classes' setting. Instructor's choices of specific instructional methods (i.e., the use of repetition instead of personalised corrections at the early stages of the intervention) could have influenced participants' engagement with the intervention. Consistent with previous exercise research, the qualities of the instructor (Hawley-Hague et al., 2016a), the creation of a warm and failure free environment (Barnes et al., 2015) and the importance of the socialising component (Wu et al., 2015) have been positively valued by participants and influenced their adherence to the Pilot Intervention Phase. Moreover, unexpected non-verbal behaviours (i.e., collecting cups or shaking hands) from two less interactive participants living with dementia could be highlighting their comfort in the social context and their willingness to fit in.

Participants' enjoyment and engagement with Tai Chi could be more relevant for participants' acceptability of the intervention than their accuracy performing the movements. There were participants living with dementia who at some point struggled in copying the instructor and did not report any difficulties copying the instructor but only their enjoyment of Tai Chi. This could be partially supported by previous research suggesting that participants' enjoyment of the intervention could be critical for their sustained participation in falls prevention interventions (McPhate et al., 2016). Similarly, previous studies have also found apathy in participants with lack of insight to their dementia symptoms (Aalten et al., 2006), which could explain their lack of awareness about their performance during the classes and their tendency to not to communicate their difficulties in this study. However, participants' enjoyment of the socialising component could have impacted more positively on their acceptability of the intervention, as the satisfaction of the social need seem to be crucial for people living with dementia (Maki, Amari, Yamaguchi, Nakaaki, & Yamaguchi, 2012).

Missing the first class may have had a negative impact on one participant's (02006P) acceptability of the intervention by feeling their performance was not as good as the rest of the group. Verbalised perceived incompetence to perform the movements by the carer (01001C) or the person living with dementia (02006P) could also have an impact on participant's willingness to carry on taking part in the intervention. In this Pilot Intervention Phase, both dyads who expressed this lack of competence ended up not willing (or not being able, due to health issues) to attend further sessions. In light of these results, and consistent with previous research, tailored support from the instructor (Chong et al., 2014; Day, Trotter, Donaldson, Hill, & Finch, 2016; Pitkälä et al., 2013) in becoming aware of these perceptions could facilitate their adherence to the exercise intervention. Moreover, in the RCT Phase, the reduction of the content to be delivered could facilitate participants' reengagement if they miss a class due to unexpected commitments.

On the other hand, participants who withdrew from the intervention did not necessarily find the intervention inappropriate. One of them reported he was having a health issue, though the participant living with dementia seemed to be sceptical about the intervention; whilst the other dyad went on holidays. When participants did not attend a session, this was due to health issues or not being able to reach the venue due to a traffic accident. All these reasons, except the unexpected traffic accident, are consistent with those reported in previous studies as common reasons to skip a session or dropping out of exercise interventions (Burton et al., 2015; Wesson et al., 2013). Except for the sceptical approach or unwillingness to carry on with the

intervention, little could have been done to avoid unexpected, or expected but inevitable, dropouts and participants' occasional discontinued participation.

4.2.2. Home-based practice

The home-based component was generally well perceived by participants who included Tai Chi practice in their routines. However, their acceptability was challenged due to their difficulties remembering the Tai Chi movements at home, which was not improved by the use of the home-exercise booklet. Such difficulties could have potentially impacted on participants' adherence to the home-based component, particularly those dyads with an unmotivated (02001P) or frailer (02002P) person living with dementia. These results expand on previous research findings suggesting the use of memory aids such as exercise booklets with images and explanations to support home-practice (Connell & Janevic, 2009; Logghe et al., 2011; Logsdon et al., 2009; Prick et al., 2014; Suttanon et al., 2013). Following the difficulties experienced by both members of the dyads, especially in getting the progression of the movements, it is suggested that not only home-exercises booklets are required to support this practice.

Difficulties to sustain attention have not been previously identified in exercise interventions for people living with dementia (Dal Bello-Haas, O'Connell, Morgan, & Crossley, 2014; Prick et al., 2014). However, in this study, difficulties reported by two carers (02004C, 02003C) trying to get the attention of the person living with dementia for 20 minutes in a row could be motivated by the home environment and the level of confidence of the carer supporting this practice. Previous research suggested that instructions provided by the instructor could have a higher impact on the person living with dementia than the ones offered by the carer (Prick et al., 2014), which could be influenced by the instructional methods and qualities of the instructor.

4.2.3. Dyadic approach

The dyadic approach has been openly accepted by both –people living with dementia and their carers. This finding concurs with previous studies where a dyadic approach had been used to facilitate people living with dementia's adherence to exercise interventions (Teri et al., 2003; Yao et al., 2012). Results from the current study suggest that this dyadic approach could not only facilitate their adherence to the intervention, but enable people living with dementia's inclusion in these interventions. It might be that some people living with dementia would not have agreed to join the study alone (01003P, 01004P, 02001P, 02002P) or that some carers would not have given a go to Tai Chi if it were not because of the potential benefit for the person living with dementia (01004C, 02002C). In the same way, feedback from carers reinforce the use

of this dyadic approach in the context of dementia as it gives them the opportunity to discover enjoyable activities which could evolve to shared interests. Moreover, carers in this study seem to point towards a lack of suitable activities in the community where they both can engage together. These would be of particular relevance when these common activities could be helpful for carers (to experience their role more positively) and the person living with dementia (to feel competent and empowered) (DiLauro, Pereira, Carr, Chiu, & Wesson, 2015; Lamotte, Shah, Lazarov, & Corcos, 2016). The fact that carers miss activities in the community where to take part with the person living with dementia, together people living with dementia's willingness to get involved only with the carer might point towards the strength of their dyadic relationship. The strength of this relationship might be beneficial not only for their uptake of the Tai Chi but also for their sustained participation in the study. Another strength of this dyadic approach highlighted by carers is that not only the person living with dementia but also them could feel the benefits of taking part in Tai Chi. This perceived benefit could potentially help carers to be willing to carry on practising after their involvement in the trial, which would be of benefit for the person living with dementia (Lamotte et al., 2016). In contrast to some reports in the literature (Wesson et al., 2013; Woods et al., 2016), carers involvement in this study was not referred as a source of burden.

4.2.4. Research process

Participants' involvement in research was positively valued which is broadly consistent with previous people living with dementia's experiences (McKillop, 2002). Carers' suggestion to be present during the whole home-visit could refer to carer's willingness to supervise what the person living with dementia has to report, as they refer to people living with dementia's difficulties to provide valid or accurate responses. This could be reflecting these carers' tendency to overprotect the person living with dementia or wrongly assuming that people living with dementia are not able to provide accurate responses due to their condition. Such beliefs, in turn, could be linked with the "malignant social psychology" described by Kitwood (1997, p. 46), which does not necessarily refer to intentional behaviours but those that contribute to the depersonalization of the individual living with dementia.

People living with dementia should be able to speak on the phone to be included in the study, as per TACIT protocol researchers will talk with both members of the dyad before arranging a baseline home-visit. However, considering the possible progression of dementia and the presence of good and bad moments during the day, the impact of this data collection method will need to be monitored (McGovern, 2016).

Finally, in the RCT Phase the role of randomisation to the control and intervention conditions will be clearly and repeatedly explained at the point of recruitment to avoid participants' confusion. This, in turn, could facilitate recruitment in the first instance as studies where participants are not informed about the condition they are allocated to (i.e., placebo versus drug) can jeopardise the recruitment process (Caldwell, Hamilton, Tan, & Craig, 2010; Treweek et al., 2013). In this study, however, the risk is to incur in higher attrition rates due to participants not feeling satisfied with the condition they have been assigned to (Caldwell et al., 2010).

4.3. Strengths and Weaknesses of this Study and Future Research

These results describe for the first time how people living with dementia and their carers respond to a Tai Chi exercise intervention. This study has been the first to the author's knowledge using qualitative methods to enhance the acceptability assessment of a Tai Chi only intervention for people living with dementia and their carers.

4.3.1. Strengths

Amongst the strengths of this study is the inclusion of people living with dementia and their carers' views that are rarely captured in previous exercise studies (Teri et al., 1998; Yao et al., 2012). More importantly, this study has included the views of dyads, instructors, and researchers offering a much richer understanding than those exercise studies reporting anecdotal comments to summarise participants' experiences (Burgener et al., 2008; Day et al., 2016; Yao et al., 2012). This strategy has facilitated a transparent report, not only based on strengths but also weaknesses of the intervention. The use of a joint dyadic approach to gather the views of participants living with dementia and their carers, has enabled quiet or less verbally fluent people living with dementia's expression of their views. In this study, carers have successfully helped the researcher, rephrasing questions and inviting the person living with dementia to provide their views during the focus groups organised. Similarly, this joint dyadic approach has been able to correspond with requests to be interviewed together in previous research (Nyman, Innes, & Heward, 2016; Prick et al., 2014) and in our PPI advisory group. Additionally, the combination of both individual (at the end of the sessions) and group feedback (at the end of the intervention) has afforded getting the benefits from both approaches: Whereas individual feedback facilitates reporting of personal and controversial opinions and capturing experiences of the moment (recent); group feedback makes possible a joint and overall reflection on participants' experiences (Leung & Savithiri, 2009; Morgan, 1997).

4.3.2. Limitations

This study has several limitations. First, classes were not video-recorded as initially planned as the instructor did not consent for him or participants to be recorded during classes. This could have impacted on the quality of the observations, as whilst the researcher was taking notes particular participants' reactions could have been missed. These videos could have helped the researcher to complement her observations and a possible second coder to go through these videos. Second, feedback from the two dyads who withdrew from the intervention was limited because one did not agree to take part in the final focus group, and the other dyad was not feeling good after their holiday period. An interview with the dyad who withdrew and was sceptical during the first class could have enlightened ways of facilitating their acceptability of the intervention. Third, time to collect participants' views at the end of the class was also limited, particularly when the researcher got involved in refreshment preparation at the end of the sessions. Getting the views of about 10 people in a group, trying to respect their socialising time, and engaging in more individual or small groups conversation might be quite time consuming. It must be acknowledged that with some participants it might be easier to engage initially in informal conversation with them, to then comment on their experiences of the classes; whilst other participants, on the other hand, might need extra time to elaborate their responses. Regardless of these difficulties, however, capturing how people feel in that specific moment (after practising Tai Chi) could be particularly relevant in the context of dementia as recall could be facilitated by interviewing participants in the natural environment where they were taking part in the activity (Nygård, 2006). Additionally, a short interview before and after their participation in the study could have helped to illuminate the (lack of) change of their attitudes towards Tai Chi. Likewise, it could have contributed to understand the impact of previous exercise experience and motivations to take part in the study in their acceptability of the intervention. Lastly, during one of the focus group participants living with dementia could have felt uncomfortable by hearing their carers commenting they are not always able to provide accurate responses. Although people living with dementia did not seem to respond verbally or non-verbally to this, this could have silenced their voices.

4.3.3. Future research

Future research investigating the acceptability of Tai Chi should consider the inclusion of participants from different ethnic backgrounds and with different relationships with the person living with dementia. In this study, informal carers were sought to be recruited independently of their relationship with the person living with dementia. However, only one dyad was not formed by a couple and in all cases the person living

with dementia was living with the informal carer, which could have influenced their acceptability of the intervention and particularly their availability to take part in home-based practice. Similarly, the impact of the size of the group on dyads' acceptability was only explored in two small groups, which could be less cost effective in community settings. The acceptability of larger groups formed by dyads rests unexplored in the context of exercise interventions for people living with dementia and their informal carers.

Further studies are required to assess the impact of using DVDs versus booklets in home-based Tai Chi exercise interventions for people living with dementia and their carers. In the TACIT Trial, due to Intellectual Property restrictions, a crib sheet will be used and assessed in the RCT Phase instead. In home-based exercise interventions, it would be interesting to capture how participants' living with dementia and their carers are feeling during their engagement in the study. In the RCT Phase of this study, weekly phone calls will be used to monitor participants' falls and their experience's progression over their participation in the study. However, future studies could monitor this adding open ended questions to home-exercise registers, so that dyads could comment weekly on the barriers they experienced to practise Tai Chi and the solutions they found (if any) to overcome these.

4.3.4. Novel contributions

The novel contributions made through this chapter relate to the population and methods used. This is the first time the experiences of those living with mild-to-moderate dementia and their carers taking part in a class- and home-based Tai Chi exercise intervention are qualitatively explored. Such exploration it is critical to adapt exercise interventions in a way that are better received by participants and to enhance adherence. Dyadic focus groups have been used for the first time in the context of an exercise intervention for people living with dementia and found useful. This is then the first Tai Chi study for people living with dementia using the views of participants in the Pilot Intervention Phase to inform further development of the intervention and making recommendations to future exercise studies.

4.3.5. Practical implications

This study highlights three main aspects which should be considered in designing future exercise programs. First, the use of a dyadic approach in exercise interventions could be beneficial for both the person living with dementia and the carer at an individual level; but also facilitate their uptake of the intervention, as this would provide them with a potential common interest. Second, the combination of class- and home-

based practice could be advantageous to reinforce participants' social support networks as well as strengthen dyadic relationships and facilitate the acceptability of the intervention by feeling an increased competence. Third, instructors' awareness of dementia and adapted instructional methods facilitates participants' acceptability of the classes, as the supporting materials should do at home. For this reason, it must be taken into account that booklets with images and descriptions might be insufficient for people living with dementia and their carers when facing unfamiliar movements such as those of Tai Chi. In this case, simple, clear and when possible, dynamic prompts (i.e., DVD) are advised.

4.4. Summary

People living with dementia had been rarely included in studies where the effectiveness of Tai Chi to prevent falls has been tested. However, when studies about Tai Chi had involved general older people, the acceptability of the intervention had been scarcely explored. This study conducted over the Pilot Intervention Phase of the TACIT Trial has allowed assessing the acceptability of Tai Chi by exploring the experiences of people living with dementia and their carers. Such experiences suggest that intervention's characteristics, participants' reactions to the intervention, and aspects of the research process itself might impact on the acceptability of this exercise intervention. A series of improvements have been suggested by participants, instructor, and the research team to facilitate the engagement of people living with dementia with different levels of performance (i.e., reducing the amount of contents to be delivered), support home-practice (i.e., adjusting materials and including a crib sheet), and enable an accurate data collection where both members of the dyad can get involved (i.e., clarifying reporting materials). These improvements should facilitate, in turn, the acceptability of the intervention for participants in the RCT Phase of the TACIT Trial, where the adherence of participants in the intervention group will be studied over their 5-months involvement in the study. The next chapter introduces the second study of this thesis by providing a thick description of the RCT Phase's study setting.

5. RCT Phase: Participants and Study Setting

The aim of this section is to provide an overall descriptive picture of the Randomised Controlled Trial (RCT) phase from the recruitment process and its challenges to the day-to-day running of the study. Apart from the recruitment process, the rest of its subsections are based on the author's field-notes to provide the reader with a rich description of the participants and the study setting. Such description will contribute to understand the whole picture depicted by participants' experiences in the following chapters (Chapters 6 and 7).

To give context to participants' experiences described in further chapters, section: 5.1. Provides a description of the RCT phase recruitment process, 5.2. Details the characteristics of the participants recruited; 5.3. Provides participants' adherence levels to the class and home-based component; 5.4. Describes the characteristics of the study setting; 5.5. Reports on the implementation fidelity checks performed during some of the classes; and 5.6. Summarises this chapter's contents.

5.1. Recruitment and Retention

The 'green light' to commence recruitment was received from the Sponsor on 06/04/2017 and recruitment activity ceased on 17/07/2018. Recruitment sources included 3 NHS Trusts and 15 GP Participant Identification Centres (GP PICs) in the South of England, Join Dementia Research Website (JDR), The Alzheimer's Society, and publicity (via flyers or face-to-face events attended by BU Team) across the different research sites. A total of 359 participants approached or were referred to and screened by the BU Team. Of those, as reflected in Figure 7, 80 (22%, similarly as in the Pilot Intervention Phase) were ineligible, 139 (39%, similarly as in the Pilot Intervention Phase) declined to take part, 36 (10%, half than in the Pilot Intervention Phase) could not be contacted and 4 (1%) were not contacted 3 times or did not provide an answer to their willingness or unwillingness to take part in the study prior to the end of the recruitment time (17/07/2018). Amongst the 100 dyads lined up for baseline home-visit, 85 were randomised. Reasons for not being recruited and/or randomised are provided in the CONSORT diagram.

The recruitment target in this RCT phase was 150 dyads, and despite extending by 6 months the initially planned recruitment period, 86 dyads recruited fulfilled the 57% of such target. At first recruitment was particularly challenging, as many participants who initially consented to having their details passed to the BU team, later declined to take part (see Figure 7 for reasons). Approximately half-way through the recruitment period,

the recruitment strategy was adapted by incorporating three changes: 1) A monetary incentive for those ending up in the control arm (£50 to cover costs of a few Tai Chi classes in their local community after their participation in the study and after completing the 6-months after recruitment follow-up visit); 2) Allowing participants under 65 and over 18 years old to join the study; and 3) Refunding all willing participants for their travel costs to attend the classes. In parallel, the number of GP PICs involved in the study was also increased and the TACIT Trial was locally advertised on TV and radio through local news programmes. These strategies seemed to help, and a momentum was reached when more participants seemed to be willing to join the study.



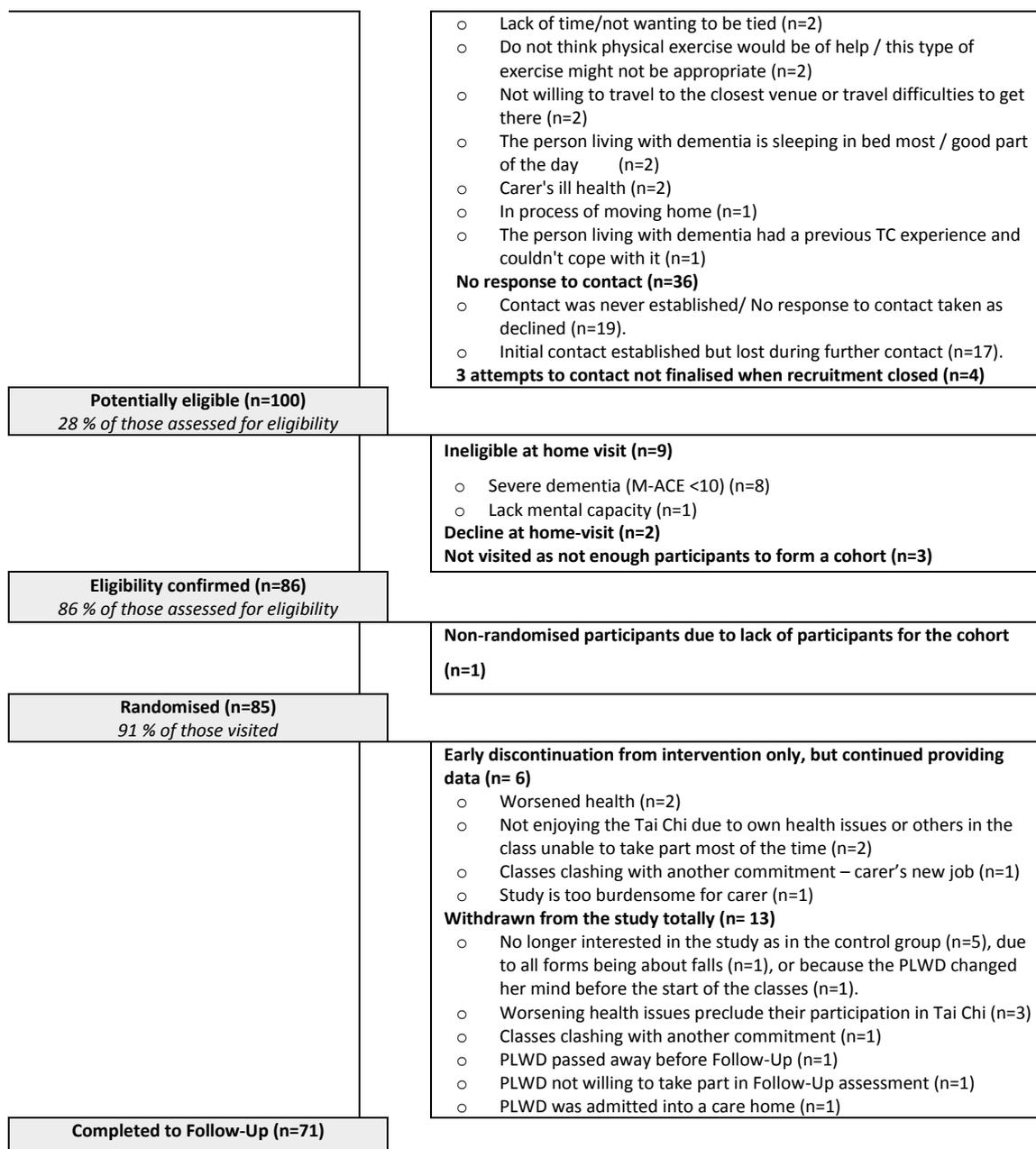


Figure 7. CONSORT Diagram for the RCT Phase of the TACIT Trial.

Overall participants' retention

During the RCT Phase, 12 dyads from the intervention group and 7 dyads from the control group withdrew or discontinued their participation in the study (a total of 19 dyads withdrew, 22% overall withdrawal rate). However, from the dyads withdrawn from the intervention group, six agreed to keep providing falls data and take part in the 6 months follow-up. This meant that data from 13 dyads was missed at follow-up. Reasons to withdraw or early discontinue participants' involvement in the classes are provided in Figure 7. However, whereas the control group's main reason to withdraw was not being able to attend the Tai Chi classes; for the intervention group, worsened

physical health and Tai Chi clashing with other commitments (i.e., carer's new job or another Alzheimer's group) were the most common reasons to withdraw.

5.2. Participants Characteristics

From this point onwards, data reporting will focus on participants who contributed to this thesis. This is because the TACIT Trial involved a total of 10 groups throughout 3 different sites; however, for this study only 6 of these groups were included. As announced in Chapter 3, this was due to the initial slow recruitment and the corresponding extension of the recruitment and study period, which did not match this PhD's time-frame. Hence, to allow enough time for data collection, data analysis and write up, the last data collection point for this thesis was 16/07/2018, which matched with around week 16 for Tai Chi groups 5 and 6. This was followed then by data entry, transcription and data analysis. A total of 25 participants had been allocated to these 6 groups, however, not all of them managed to attend a first class due to withdrawing after randomisation and before the start of the classes ($n = 1$; 01043) or due to health issues that impeded the person living with dementia to get involved in the classes ($n = 1$; 03007).

Participants living with dementia and their carers' demographic characteristics obtained at baseline home-visit are summarised in Table 17 (for detailed information on each participant see tables provided in Appendix Z). All participants allocated to the intervention group (in groups 1 to 6) were from a white British ethnicity and dyads were formed of the person with dementia and a family member, despite the study being open to people from all ethnicities and all informal carers including friends and neighbours.

Table 17. RCT Phase: Participants' Characteristics

Participant	Item	Total (SD)	
People Living with Dementia	Gender	Male	13
		Female	12
	Mean age (SD)		77.60 (7.67)
	Relationship status	Married / Civil partnership	21
		Single	2
		Divorced	1
		Widowed	1
	Current living situation	Living with family/friends	23
		Alone	2
	Level of education	None	1
		Primary	1
		Secondary	15
		Higher education college / university	6
		Further education / professional qualification	2
	Ethnicity	White	25
	Dementia type	Alzheimer's	18
		Mixed Alzheimer's & Vascular	6
		Other (Frontal Lobe)	1
	Mean number of months diagnosed with dementia (SD)		20.96 (21.7)
	Other chronic conditions	Yes	19
No		6	
Existing injuries or health injuries to be	Yes	5	

Participant	Item	Total (SD)	
Participant	considered to do Tai Chi	No	20
	Uses a walking aid?	Yes	7
		No	18
	Mean prescribed daily medications (SD)		5.52 (3.62)
	Falls in the last year?	Yes	10
		No	15
	Falls in the last month?	Yes	4
		No	21
	Frequency of moderate PA practice	Everyday	13
		3 times per week	3
		2 times per week	1
		Weekly	1
		Rarely/never	7
	Frequency of vigorous PA practice	Everyday	1
		Weekly	2
Rarely/never		22	
Previous experience practising Tai Chi?	Yes	4	
	No	21	
Mean confidence about being able to practise Tai Chi for at least 20 minutes per day (SD)		1.96 (1.17) ¹	
Mean intention to practise Tai Chi for at least 20 minutes per day (SD)		1.44 (0.92) ²	
Mean M-ACE Score (SD)		15.76 (4.95)	
Carers'	Gender	Male	7
		Female	18
	Mean age (SD)		71.64 (9.25)
	Relationship with the person living with dementia	Spouse/partner	20
		Son/daughter	2
		Brother/sister	3
	Live with the person living with dementia	Yes	21
		No	4
	Relationship status	Married / Civil partnership	22
		Single	2
		With partner	1
	Current living situation	Living with family/friends	24
		Living alone	1
	Level of education	Primary	2
		Secondary	13
		Higher education college/university	6
		Further education/professional qualification	3
		Missing data	1
	Ethnicity	White	25
	Previous experience practising Tai Chi?	Yes	3
No		22	
Mean confidence about being able to practise Tai Chi for at least 20 minutes per day (SD)		1.72 (1.14) ¹	
Mean intention to practise Tai Chi for at least 20 minutes per day (SD)		1.72 (1.21) ²	

¹ Participants were asked to rate their confidence using a Likert scale from 1 (true) to 7 (false), where 1 was the best score –showing participants' confidence about being able to practise for 20 minutes per day.

² Participants were asked to rate their intention using a Likert scale from 1 (likely) to 7 (unlikely), where 1 was the best score –showing participants' intention to practise for at least 20 minutes per day.

Additionally, most participants reported when providing feedback or during the interviews having previous exercise experience (i.e., playing football, rugby bowls or golf, swimming, going to the gym, dancing, walking or doing exercise routines at home). Amongst them only a few had practised also Tai Chi (03006P) or a similar exercise such a Yoga or Pilates (01002C, 01021C) or different martial arts like Karate or Kung Fu (03008C, 01002P). Nine participants reported having no previous exercise experience (03003C, 03006C, 03005P, 03005C, 01009C, 01023C, 01025C, 01036).

5.3. Development of the Classes and Participants' Adherence

Levels

Attendance to the classes varied as well as the time-points when participants withdrew, for this reason, additional tables per group are provided in Appendix AA. Dyad's attendance to the classes varied widely amongst groups 1-6 of the TACIT Trial. Only three dyads attended 100% (20/20 class offered), one additional dyad attended all the classes offered since their recruitment (16 classes), and 10 dyads attended at least 50% of the classes. Reasons for missing classes are provided in Table 18, these were mainly health issues experienced by the person living with dementia or the carer and that were frequently sustained over weeks (i.e., Unrelated Serious Adverse event including strokes, injurious falls occurred when not practising Tai Chi and requiring surgery, chest infection, incapacitating back pains, need to rest after programmed surgeries, flu and colds) but also doctors' appointments and planned holidays. Less frequently, having visitors at home, other carer's commitments (i.e., a job interview), or the dogs being unwell impacted as well on participants' attendance to the classes.

Table 18. RCT Phase: Reasons for Missing Classes

	PLWD's health	Carer's health	PLWD's SAE	Holiday	Carer's SAE	PLWD's doctor appointment	Carer's doctor appointment	Dogs unwell	Interview	Visitors	Had not received invitation letter
Times reported	53	17	10	9	6	6	2	1	1	1	1
Average	50%	16%	9%	8%	6%	6%	2%	1%	1%	1%	1%

Occasionally, however, classes were also cancelled and postponed due to the instructor being ill (4 classes), having other commitments (1 class), or being stuck in traffic (1 class). Two additional classes were cancelled and postponed as no participants would be able to attend, four more classes were cancelled and postponed last minute as no participants turned up and had not alerted the team or the instructor, one class was cancelled due to adverse weather (snow), and a last class was cancelled because the only dyad able to attend preferred to postpone the class so they would participate with another dyad. To clarify when the classes took place, as well as the classes delivered, cancelled (dotted), and postponed (session number over 20), a summary is provided in Table 19. In this table, dates of planned classes observed by the author (in blue/ shadowed boxes), but also of unplanned classes observed (in red/ shadowed boxed), and the time-points when home-interviews (in orange/ shadowed boxes) took place are also provided. Additionally, information is provided about when

participants were asked to provide feedback on their participation in the study for purposes of the TACIT Trial (in green/ shadowed boxes). Finally, thick vertical lines (in red), reflect that there was a week when classes did not take place due to bank holidays or unavailability of the instructor or the venue.

Amongst the dyads willing and able to attend groups 1 to 6, that is, dyads that had been recruited and had not withdrawn from the intervention or from the whole study, overall participants' attendance per session is provided in Table 20. In this table, decimals appear when a member of the dyad attended a class on their own. Figure 8 is the visual representation of Table 20 and highlights the higher number of participants attending early sessions compared to the later ones. Figure 8 also shows that at week 8 there is a low peak despite the higher number of participants recruited and allocated to the intervention arm.

In Appendix BB, further details about participants adherence to the classes and home-based component can be found. In both cases (home- and class-practice), the fact that some dyads joined the intervention after a few classes (as shown in Table 20 and Figure 8) needs to be accounted as this would impact on their overall adherence levels in both settings (see also Figure 9), and their overall adherence. Hence, Table BB 1 reflects adherence averages in terms of absolute adherence (out of the 20 weeks planned to be offered per study design) and relative adherence (out of the number of weeks offered to each participant if recruited later).

In summary, people living with dementia attended an average of 11.4 (ranging 0-20) sessions and carers, 11.6 (ranging 0-20) sessions. This was assuming all had been recruited to start the classes from the very first session. However, as this was not the case, considering the number of sessions they were able to attend since their recruitment, people living with dementia attended 58.1% of the sessions available since their recruitment (ranging from 0 to 100%). Similarly, carers attended 59.1% (ranging from 0 to 100%) of them. These values do not consider that some participants decided to withdraw before the termination of the study, since classes were still available to them had they not wished to withdraw.

Table 19. RCT Phase: List of Classes Delivered, Dates and Data Collection Time-Points¹⁸

Group Number	Site	Weekday	Start time	End time	Classes																											
					1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	Postponed 1	Postponed 2	Postponed 3	Postponed 4				
1	3	Dates	Wednesday	11:30hrs	13hrs	02/08/2017	09/08/2017	16/08/2017	23/08/2017	30/08/2017	06/09/2017	13/09/2017	20/09/2017	27/09/2017	04/10/2017	11/10/2017	18/10/2017	25/10/2017	01/11/2017	08/11/2017	15/11/2017	22/11/2017	29/11/2017	06/12/2017	13/12/2017	20/12/2017	17/01/2018					
		Observation Sessions																														
		Half-way through data collection																														
2	2	Dates	Wednesday	16:00hrs	17:30hrs	23/08/2017	30/08/2017	06/09/2017	13/09/2017	20/09/2017	27/09/2017	04/10/2017	11/10/2017	18/10/2017	25/10/2017	01/11/2017	08/11/2017	15/11/2017	22/11/2017	29/11/2017	06/12/2017	13/12/2017	20/12/2017	03/01/2018	10/01/2018	17/01/2018	24/01/2018					
		Observation Sessions																														
		Half-way through data collection																														
3	3	Dates	Wednesday	13:15hrs	14:45hrs	04/10/2017	11/10/2017	18/10/2017	25/10/2017	01/11/2017	08/11/2017	15/11/2017	22/11/2017	29/11/2017	06/12/2017	13/12/2017	20/12/2017	03/01/2018	10/01/2018	17/01/2018	24/01/2018	31/01/2018	07/02/2018	14/02/2018	21/02/2018	28/02/2018	07/03/2018	14/03/2018				
		Observation Sessions																														
		Half-way through data collection																														
4	2	Dates	Thursday	11:30hrs	13hrs	16/11/2017	23/11/2017	30/11/2017	07/12/2017	14/12/2017	21/12/2017	28/12/2017	04/01/2018	11/01/2018	18/01/2018	25/01/2018	01/02/2018	08/02/2018	15/02/2018	22/02/2018	01/03/2018	08/03/2018	15/03/2018	22/03/2018	29/03/2018	05/04/2018	12/04/2018					
		Observation Sessions																														
		Half-way through data collection																														
5	1	Dates	Monday	11:30hrs	13hrs	12/03/2018	19/03/2018	26/03/2018	02/04/2018	09/04/2018	16/04/2018	23/04/2018	30/04/2018	14/05/2018	21/05/2018	04/06/2018	11/06/2018	18/06/2018	25/06/2018	02/07/2018	09/07/2018	16/07/2018	23/07/2018	30/07/2018	06/08/2018	13/08/2018	20/08/2018	03/09/2018	10/09/2018	17/09/2018		
		Observation Sessions																														
		Half-way through data collection																														
6	2	Dates	Wednesday	11:30hrs	13hrs	04/04/2018	11/04/2018	18/04/2018	25/04/2018	02/05/2018	09/05/2018	16/05/2018	23/05/2018	30/05/2018	06/06/2018	13/06/2018	20/06/2018	27/06/2018	04/07/2018	11/07/2018	18/07/2018	25/07/2018	01/08/2018	08/08/2018	15/08/2018							
		Observation Sessions																														
		Half-way through data collection																														
7	2	Dates	Thursday	11:30hrs	13hrs	19/04/2018	26/04/2018	03/05/2018	10/05/2018	17/05/2018	24/05/2018	31/05/2018	07/06/2018	14/06/2018	21/06/2018	28/06/2018	05/07/2018	12/07/2018	19/07/2018	26/07/2018	02/08/2018	09/08/2018	16/08/2018	23/08/2018	30/08/2018							
		Half-way through data collection																														
8	2	Dates	Thursday	14:30hrs	16hrs	03/05/2018	10/05/2018	17/05/2018	24/05/2018	31/05/2018	07/06/2018	14/06/2018	21/06/2018	28/06/2018	05/07/2018	12/07/2018	19/07/2018	26/07/2018	02/08/2018	09/08/2018	16/08/2018	23/08/2018	30/08/2018	06/09/2018	13/09/2018	20/09/2018						
		Half-way through data collection																														
9	2	Dates	Wednesday	16:00hrs	17:30hrs	06/06/2018	13/06/2018	20/06/2018	27/06/2018	04/07/2018	11/07/2018	18/07/2018	25/07/2018	01/08/2018	08/08/2018	15/08/2018	22/08/2018	29/08/2018	05/09/2018	12/09/2018	19/09/2018	26/09/2018	03/10/2018	10/10/2018	17/10/2018	24/10/2018	31/10/2018					
		Half-way through data collection																														
10	3	Dates	Wednesday	11:30hrs	13hrs	20/06/2018	27/06/2018	04/07/2018	11/07/2018	18/07/2018	25/07/2018	01/08/2018	08/08/2018	15/08/2018	22/08/2018	29/08/2018	05/09/2018	12/09/2018	19/09/2018	26/09/2018	03/10/2018	10/10/2018	17/10/2018	24/10/2018	31/10/2018							
		Cancelled after 4th session.																														

¹⁸ Table's coding explanation: Date boxes filled with dots are those of classes that had to be cancelled either for lack of participants able to attend or due to the instructors not being able to attend for personal reasons or due to dense traffic. The final group (highlighted/in red) that was cancelled only after four sessions due to the unavailability of Instructor 1 to carry on delivering the classes, and Instructor 2's unavailability to take up these classes. This group (number 10) was left with only one participant dyad (01081) attending at the point of its cancellation. This dyad was offered to join another group (number 5) being run by Instructor 2 in a different location and taxi travel costs were covered to facilitate their continuation in the study.

Table 20. Dyads Attending Each RCT Session Amongst Those in the Intervention Arm

	Session Number																				Totals	Average Attendance
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20		
Total able dyads	20	22	22	22	23	23	23	23	23	23	23	21	18	18	18	18	18	18	18	18	412	
Total dyads attending	17	17	20	18	19	19,5	16,5	12,5	15	14,5	14	13	12	11	12	11	11,5	10,5	11	12	287	
% dyads attending each session amongst those able	85%	77%	91%	82%	83%	85%	72%	54%	65%	63%	61%	62%	67%	61%	67%	61%	64%	58%	61%	67%		69%

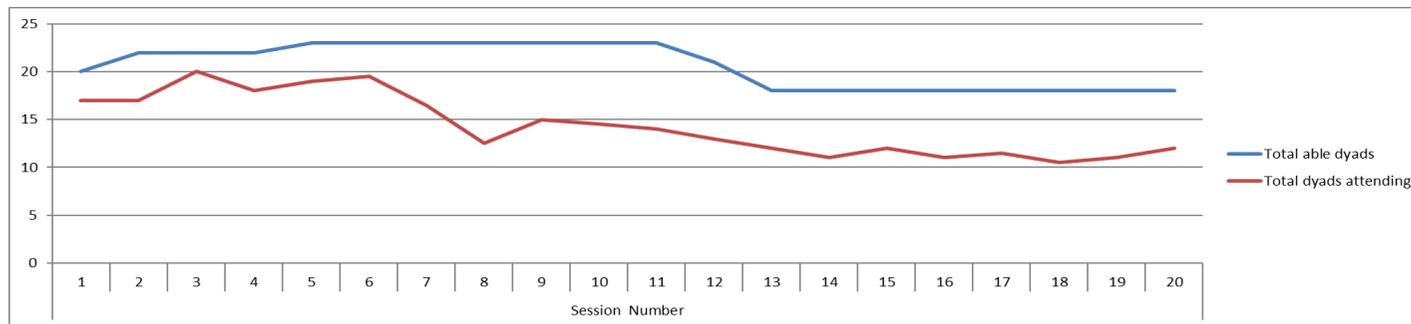


Figure 8. Visual representation of dyads attending RCT classes amongst those in the intervention arm each week.

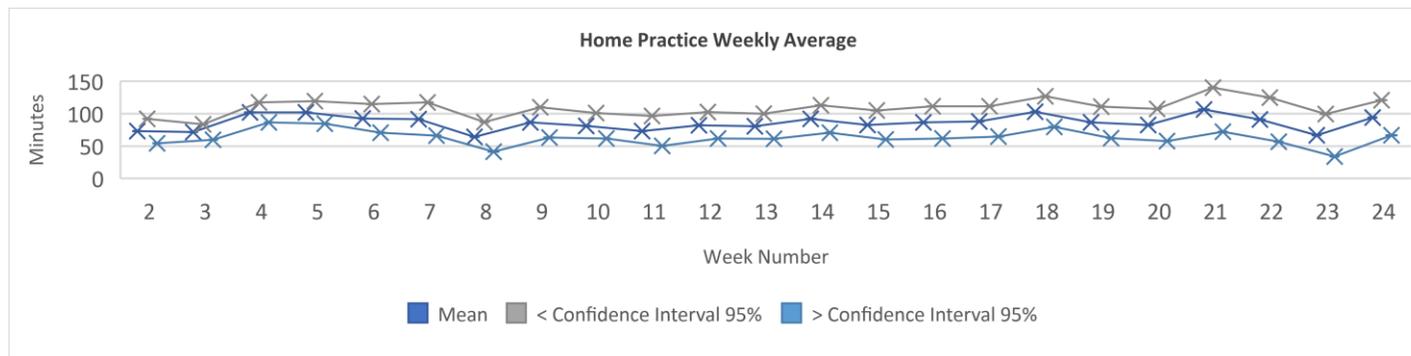


Figure 9. Visual representation of mean RCT participants' adherence to home-practice (minutes/week) with the 95% confidence interval.

With regards to home-practice, participants living with dementia practised an average of 965.3 minutes throughout their participation in the study (ranging from 0-3650minutes). That is, people living with dementia received an average of 54% (ranging from 0 to 179%) of the recommended dosage since their recruitment. Carers practised at home an average of 1073.8 minutes (ranging from 0-3650minutes), achieving the 60% (ranging from 0 to 179%) of the recommended dosage since they received the instructor's visit.

Figure BB 1 adds further detail on the adherence to home- and class-based component taking into account the time participants stayed in the study. That is, this figure represents their adherence taking into account when they were recruited, but also if they withdrew early from the study. Additionally, in Figure BB 2 reflects individual participants or dyads depending of their practice pattern at home, if they practised exactly the same number of minutes every week, their practice is presented as a dyad. However, if their practice was separate or one member practised more than the other one at any week, their practice time is presented as separate individuals.

With regards to the home-practice data accuracy might have a relevant impact as some participants returned only a few exercise logs whereas others who handed them regularly forgot to do so occasionally, particularly when they missed a class. Looking at Figure 9's visual representation, however, on average each dyad undertook approximately 86 minutes (CI 95%, 63 to 109) practice per week. In Appendix BB, further data is provided in Table BB 1 to detail the number of minutes practised in class and at home by each participant as well as the average of the recommended dosage received. Similarly, there is also a representation of each participant's home-practice over the intervention period in Figure BB 2, showing a high difference between practice patterns. Additionally, an overall visual representation of the total dosage of Tai Chi (class plus home-practice) is visually represented as well in Figure BB 3 and Figure BB 4, where a slight difference can be found between participants under instructors 1 and 2's supervision. Such difference might well be due to the difference in the amount of participants under both instructors and those who kept attending classes over time, as those with instructor 1 seem to either withdraw or carry on producing two different patterns after half-way through the intervention. However, amongst adherent participants with instructor 1 there seems to be a common overall dosage received overtime, whereas participants with instructor 2 seem to adhere more differently throughout weeks.

5.4. Study Setting

5.4.1. Venues

As in the Pilot Intervention Phase, venues were assessed for suitability against various criteria including accessibility, size and maintenance (described in Chapter 4). As this time there were several venues involved, with different characteristics, a summary has been provided in Appendix CC. The six venues were easily accessible by car and public transport and had enough room to accommodate the groups' size.

5.4.2. Instructors

In the context of an RCT, the intervention delivered and the way it is delivered should be as similar as possible when running different groups. However, as the Tai Chi classes were delivered by two different instructors some differences in their teaching styles were observed by the author and are described next.

5.4.2.1. *Instructor 1*

Instructor 1 is a white female, aged between 45-55, with no experience teaching Tai Chi to people living with dementia but with experience (as a practitioner) working with people with different type of needs. Teaching Tai Chi is not Instructor's 1 main job. Potentially due to her experience as Alternative Practitioner seems quite interested in knowing about the health conditions of participants.

When participants arrived in the initial classes, Instructor 1 welcomed them and engaged in conversation with them, asked them about their previous exercise practice experience, and about the health conditions that could affect their Tai Chi practice. In the following classes, Instructor 1 welcomed the participants with a hug, asked them about their week, and established an informal chat with them. Participants seemed to appreciate this welcome. Once instructor 1 arrived in the venues, she arranged a few chairs, so that participants could take a seat before starting the class if they were early and involved them in conversation.

During the classes Instructor 1 provided lots of instructions during the movements' practice and rarely related them with daily life movements. Movements and patterns were introduced by their numbers (i.e., "this is pattern 1") and there was no history/tale behind each of them but a description of the physical moves. Instructor 1 did not share informal comments about her private life or personal experience learning Tai Chi during the class. Generally, Instructor 1 demonstrated the participants first and requested them to watch before start copying her movements. Frequently, Instructor 1 needed to repeat the participants to watch her, so they could get an idea of the movements first,

and actively requested them not to start copying the movements yet. When participants started practising the movements, Instructor 1 corrected them when they were not doing the movement right from the very first classes. Occasionally, Instructor 1 provided only a general correction - pointing at what was not correctly being done; however, if the participant did not amend or did not realise, Instructor 1 addressed the correction comments to the participant that was not performing the movement correctly. Frequently, Instructor 1 approached the participant so she could show him or her how to perform the movement correctly, by doing the movement together with this participant and physically guiding them where required so the participant replicated the movement correctly. Instructor 1 frequently asked participants to repeat the movements two or three times until they were able to copy them right.

During the classes Instructor 1 seemed a bit tense and focused in keeping a look on the participants possibly due to her worry about participants' conditions, which contributed to the overall external feeling of tension. At the end of the classes, participants tended to go back to their chairs and keep on chatting with Instructor 1 and with other participants.

5.4.2.2. Instructor 2

Instructor 2 (lead instructor) is a white male aged between 40-50 with experience of teaching Tai Chi to people living with dementia. Teaching Tai Chi is his main full-time job. Instructor 2 has experience working in community and residential settings; and was the one delivering the Pilot Intervention Phase classes.

When arrived in the classes he tended to talk less with the participants, possibly due to him arriving to the classes closer to its start time. During the classes, the instructor explained the movements and repeated them a couple or three times, taking into account the participants needs. Instructor 2 used a regular tone of voice, audible and relaxed. Participants doing the movements wrong or in the opposite direction were frequently uncorrected. When a participant was struggling or getting lost in copying one of the movements, generally correction was not made unless participant requested it. Instructor 2 provided, however, frequent general positive feedback and punctual positive feedback to specific participants, particularly to those struggling. Only general corrections were made by Instructor 2. Positive feedback was also provided once participants (or a particular participant) amended the movement after general correction or spontaneously during one of the repetitions. The importance of "your" Tai Chi was stressed by the instructor to avoid participants' comparing themselves with others.

Instructor 2 incorporated some jokes and personal anecdotes that helped creating rapport with participants and contributed to the external perception of relaxation. Instructor 2 told the participants about the story behind each of the movements, provided a name for each movement (i.e., “hugging your grandmother”), and linked these movements to familiar movements of participants’ life. This might have helped participants to see a purpose of doing this intervention and feel that they could apply what they learnt in the classes to their daily lives.

At the end of the classes sometimes instructor 2 engaged in conversation with participants, providing positive feedback (particularly on the aspects that each person living with dementia is doing better) or telling them about when he started practising Tai Chi, but not necessarily creating a group conversation as instructor 1 did.

5.4.2.3. *Instructors’ differences*

Despite the differences in their teaching styles, both instructors seemed to develop a good relationship with participants. Both instructors seemed to have different strengths and weaknesses. Whereas Instructor 1’s strength was the interaction with participants before and after the class, showing an interest in participants’ lives; during the class she was stricter in terms of performing the movements correctly and safely. Instructor 2, on the other hand, had a more calming and informal (but professional) way of delivering the classes; however, he did not seem to get to know as much the participants as he interacted less with participants before and after the classes observed and to a less personal level. This could be related as well with the amount and the type of feedback provided by both instructors at the end of the classes.

After Instructor 2 (senior and lead instructor) visited one of Instructor 1’s classes, some constructive feedback and advice was given to Instructor 1 to facilitate a more similar approach to the delivery of the classes and on line with Instructor 2’s course. A change was appreciated after this, as i.e., Instructor 1 stopped providing verbal guidance at certain intervals. After a second observation made by Instructor 2, further feedback was provided to Instructor 1. Similarly, after the author observed some of the classes, feedback was provided by CI to Instructor 2 to ensure one of the participants safe practice (01012P). This participant was provided then with two instead of only one chair to hold on to during the classes as the author had observed the participant was still unsteady on her feet and compromising her posture during the classes by trying to hold to the back of the chair provided whilst moving forward during her practice.

5.4.3. Groups 1 to 6

A brief description of the 6 groups observed, and where home-interviewed dyads were selected, is provided at this stage to facilitate the depiction of the research context. All these groups experienced a loss of participants either because of their withdrawal or because of their interruption of practice mainly due to health reasons. This variation in attendance numbers (also shown in Appendix AA), taking into account that most groups started running with minimum participant dyads, it is likely to have had an impact on participants' experiences.

5.4.3.1. Group 1

Group one started with 3 dyads, however, soon the health of one of the participants living with dementia (suffering from chest infections) together with the distance to the venue, and later a health condition of the carer (back pain) hindered their (03003) participation in the classes and at home. Their reported adherence to the home-based component was only 10% of the recommended dosage.

Similarly, after week 7, 03005P experienced a Serious Adverse Event (stroke), followed by a second one. Hospitalisation and recovery time took a good part of the classes' period, but also the later tiredness experienced by 03005P allowed them to attend the classes only very occasionally and sometimes only to have a chat with the other dyad attending and Instructor 1. Given the tiredness experienced by participant 03005P the dyad stopped their home-practice as well, where they only managed to take 21% of the recommended dosage. They were very willing to re-join the classes as soon as possible after the first and the second stroke.

The last dyad managed to attend most (19/20) of the sessions, despite 03006P's numerous health conditions. In most of the classes (10/19) this dyad was on their own as the other participants were unable to attend. This dyad was the one who adhered higher to the home-based component amongst those in groups 1 to 6, they actually exceeded the recommended dosage (they reported through their exercise logs having done 174% of the recommended dosage). 03006P Had previous experience practising Tai Chi and despite 03006C's initial embarrassment feelings, she ended up overcoming those to facilitate 03006P's participation in the study and enjoying it.

5.4.3.2. Group 2

Group two started with 4 dyads. One of the participants living with dementia (02002P) stopped attending only after week 3 due to a previous back pain that was not relieved with injections and that made him stop during the Tai Chi classes. The carer kept attending, but half-way through the intervention was advised by her doctor to stop her

practice as her knee's problems had worsened, and a week after discontinuing their participation in the intervention she suffered a Serious Adverse Event (stroke). At home, the discomfort of the person living with dementia persisted so only managed to take 3% of the recommended dosage. The carer kept doing the exercises whilst taking part in the classes and achieved a 30% of the recommended dosage. Despite their withdrawal they were happy to keep providing research data and agreed to take part in a dyadic home-interview.

Dyad 02004 ended up withdrawing from the study in the second half of the intervention after not being able to attend 7 consecutive weeks as the carer had had a Serious Adverse Event (fall unrelated to Tai Chi where she broke her hip and fractured her arm). At the time of the Serious Adverse Event they were looking forward to resuming the classes as soon as the carer would have recovered from surgery but when the person living with dementia's health conditions started worsening, they decided to withdraw fully from the study. Their home-practice was interrupted by the Serious Adverse Event, so they only managed to take around 7-9% of the advised dosage.

The other two dyads kept practising and attending classes as much as possible, as 01008P also had a Serious Adverse Event (was knocked over and fractured her arm) and interrupted their practice for 3 weeks for recovery and missed a class to attend medical appointments. Despite the accident, dyad 01008 were looking forward to resuming the classes and 01008P ended up attending still with the plaster on. Similarly, they decided to carry on with the home-practice as much as possible and their home-practice adherence was quite high (75-79% of the recommended dosage). Dyad 01002 only missed a couple of classes when going on holiday or an additional week due to having guests at home. For dyad 01002 these other commitments seemed not to impact much on their home-practice, however, as managed to exceed the recommended dosage (107-112%).

5.4.3.3. Group 3

Group three started with 2 participant dyads and ended up with 4. However, one of the dyads (03007) never managed to attend classes due to the person living with dementia's breathing difficulties. One other dyad only attended one class (01015) and then totally withdrew from the study as another commitment clashed with the classes (another Alzheimer's group) and preferred to leave the Tai Chi classes and stop providing research data.

Dyad 03008 withdrew from the classes' half-way through as the carer changed her job and reported 03008P would not be able to carry on attending on her own. They, however, did practise very little at home according to their exercise logs (reporting only

7% of the recommended dosage) and much preferred attending classes, where carer used to provide corrections to 03008P. They only missed a couple of classes, due to the carer not feeling well and having a job interview. Despite not being able to attend any more classes, they agreed to keep providing research data and getting involved in a home-interview.

Last dyad (01021) joined the intervention later but was the one who carried on attending until the end of the intervention period. They started later but really committed to attending all the classes since then to the end of their involvement in the study. They did not miss any of the classes even when they attended most of them on their own (11/16). They were also committed to home-practice, where they reached 67% of the recommended dosage despite joining the intervention part-way through the 20-weeks course, at week 8.

5.4.3.4. Group 4

Group four started with three participant dyads and ended up with four. However, one of the dyads (01006) stopped attending after week seven and later ended up withdrawing fully from the study due to the person living with dementia's pain in his head and dizziness. They did not manage to hand back any exercise log reporting on their adherence to the home-based component, so their home-based adherence was assumed to be 0%.

The rest of dyads kept attending only missing classes if they had a cold/flu (01022 missed 5 classes for this reason) or if any of them had a medical appointment (01009, missed 2 classes for this reason). However, their home-practice adherence was not as high, around 59% of the recommended dosage for 01022 and between 69-79% for dyad 01009.

The only dyad from groups 1 to 4 that attended 100% of the classes (20/20) was 01012, however, they did not hand back most of the exercise logs and those handed back reflected a low adherence (around 19-24% to the recommended dosage) to the home-practice component.

5.4.3.5. Group 5

Group five started with two dyads and only at the last quarter of the intervention incorporated an additional dyad from the cancelled group 10. For this reason, the last dyad was never observed in the class context or interviewed; and their demographic details or adherence levels have neither been provided within this thesis. However, the incorporation of this last dyad (01081) might have been important for one of the two dyads attending classes in this group (01023). Once the other former dyad (01025)

interrupted their attendance for health reasons concerning the person living with dementia, dyad 01023 did not seem to enjoy as much the classes on their own. Until such health issue concerning 01025P appeared, both dyads' attendance to the classes was full, and 01023's attendance kept being very high until the end (only missing one class for health reasons).

Until the interruption of classes attendance from dyad 01025, both dyads seemed to find time to practise at home. Throughout the 13 initial weeks of home-practice 01025 managed to do 65% of the recommended dosage at home. In 01023's case, the carer practised over the total recommended dosage, whereas the person living with dementia only managed half of the carer's dosage, which was reflecting their weekly practice pattern (every week the carer was doubling the dosage of the person living with dementia). The home-practice involvement per day of the week was the same throughout 01023's participation in the study, which meant their participation looked linear and parallel.

5.4.3.6. Group 6

Group six started with seven dyads, responding to the initial research design's plan, and an additional dyad joined the group from the third class (01055). Two dyads withdrew from this group, one before the start of the classes because of the person living with dementia changing her mind (01043) and the second one after week 12 because the person living with dementia was getting anxious of not being able to remember the movements (01031). Two additional dyads interrupted their attendance due to health reasons and missed a large number of classes (01055, 01034). However, the other three dyads kept attending as much as possible and made the class feel as a group.

Home-practice time amongst those highly attending the classes was irregular i.e., whereas a dyad attending all the classes managed to go over the recommended dosage at home, another dyad only managed to practise amongst 42-57% of the recommended dosage.

5.4.4. Data collection process

Data collection during the classes in terms of observations and feedback flowed well. Participants were approachable and willing to share their views at the end of the class. During the classes the author sat in one side of the classes and generally avoided eye contact with participants when they were performing the movements towards her side. This was done to avoid them feeling observed and avoid distracting them from the class as they were generally focused on the instructor. There was no verbal interaction

with the researcher during the classes and only rarely there was a smile when the instructors made a joke and the participant looked towards the author. None of the participants expressed discomfort and, when asked, they knew it was part of the tasks to be done by the author as part of the research team or reported they had not realised the author was observing the class.

Participants' feedback, however, was somehow limited and they mostly reported their enjoyment of the classes and the home-based component. This limited feedback might be the result of the context, as the author opted by not interrupting the dynamics with the instructors at the end of the class (when they engaged in conversation with participants). Similarly, the author was also in charge of collecting half-way through data for the TACIT Trial from each dyad and, something new in the RCT phase was that very often participants had to leave after the class. This time constraint was also present when collecting data from the Instructors, however, Instructor 1 frequently was asked about feedback when the author travelled with her to the venues. A difference between instructors was observed when providing feedback, as Instructor 1 seemed more inclined to provide feedback spontaneously and willing to write a few notes after each class about participants' engagement in the register, however, Instructor 2 generally needed more prompting.

Regarding home-interviews all dyads invited in first instance agreed to take part in the home-interviews (15/15). Only one dyad who was invited later, after discontinuing their attendance to the classes due to the person living with dementia getting stressed about not being able to remember the movements. This dyad (01031) never confirmed their willingness to take part in the interview after telling the author that they would inform her if they decided to take part. Hence, this was taken as a decline to the interview, perhaps because the conversation would have brought back difficult moments to the person living with dementia was part of their reason to withdraw.

All interviews performed developed in a friendly and warm environment, with a good rapport between researcher and interviewees. Depending on the dyads' time availability, the home-visit lasted from around 50 to 120 minutes, which included longer or shorter informal conversation before and after the interview. Interviews itself lasted between 35 and 72 minutes (average 56 minutes, as shown in Table 21). The shorter interview was due to the dyad having arranged an appointment for the person living with dementia. In most of the cases the interview took place in the person living with dementia's home, but for 01012 whose preferred location was the carer's as the interview took place after one of the classes and is where they routinely went afterwards.

Table 21. *RCT Phase: Participants' Contributions to the Interviews*

Reporting Element	References Coded		References Average Contribution		Number of Words Coded		Words Average Contribution		Transcribed Interviews Length (Min)
	Living with Dementia	Carer	Living with Dementia	Carer	Living with Dementia	Carer	Living with Dementia	Carer	
01002	87	211	29,19%	70,81%	896	4628	16,22%	83,78%	52
01008	307	332	48,04%	51,96%	2873	5612	33,86%	66,14%	64
01009	228	281	44,79%	55,21%	2458	3802	39,27%	60,73%	52
01012	327	275	54,32%	45,68%	3573	4650	43,45%	56,55%	66
01021	188	338	35,74%	64,26%	1435	6392	18,33%	81,67%	55
01022	138	270	33,82%	66,18%	1058	4778	18,13%	81,87%	50
01025	211	385	35,40%	64,60%	1942	6100	24,15%	75,85%	71
01036	372	321	53,68%	46,32%	3534	3723	48,70%	51,30%	59
01039	194	226	46,19%	53,81%	3867	2961	56,63%	43,37%	49
01055	459	467	49,57%	50,43%	6616	4342	60,38%	39,62%	72
02002	152	283	34,94%	65,06%	1507	2810	34,91%	65,09%	41
03003	289	323	47,22%	52,78%	2936	3031	49,20%	50,80%	54
03005	149	132	53,02%	46,98%	1916	1177	61,95%	38,05%	35
03006	290	312	48,17%	51,83%	2947	4492	39,62%	60,38%	57
03008	411	468	46,76%	53,24%	4367	6422	40,48%	59,52%	67
Totals	3802	4624			41925	64920			844
Averages			45,12%	54,88%			39,24%	60,76%	56

The participation of the person living with dementia and the carer varied from interview to interview, as summarised in Table 21. Although overall carers' word count was higher than those of people living with dementia, both people living with dementia and their carers had a more similar amount of participations throughout the interviews (a detailed contribution per themes per member of the dyad is provided in Chapter 6).

These proportions are important as it can reflect that either the carers sometimes overtook in the conversation as contributed with 61% of the word count; but it could also show participants living with dementia's differences in their ability and willingness to make long verbal contributions to the conversation as they were the ones contributing to the conversation in 45% of occasions. Contribution differences seem not to be related to the number of months since diagnosis as 01055P and 03006P were participants who had been diagnosed longer ago and were not amongst those with lower contributions either in terms of amount of references or words coded (see Table 21).

Higher differences between members of the dyads, however, were observed when the person living with dementia was less verbal both throughout the classes and in the interview (01002P, 01021P, 01022P, 01025P) or when the person living with dementia had hardly attended a few classes due to his health issues (02002P). In cases where the participant living with dementia shared less during the classes (and generally contributed less during the interviews), which seemed to reflect their behaviour in their daily lives, the interview context might have provided the carer with an opportunity to know more about the person living with dementia's thoughts:

You're saying things that I've never heard you say so it's quite nice to hear it. (...). Well you keep a lot to yourself, it would be quite nice if you shared it a bit more... (01002C-I).

Only in one case it was noted, moreover, that the carer tended to interrupt when the person living with dementia was talking (01021C). Very occasionally carers talked as if the person living with dementia was not present (i.e., 01002C).

01021C-I¹⁹

Because you remember that...right, right, the...the first, second, third, what are...what are we at? Five/six?

01021P-I

And there's...there are times when I'm...

01021C-I

I mean, at...at the moment at home, I'm doing it too fast for him, but it's me trying to remember the sequence, to be honest.

01002C-I

When I say to you, come on let's do our Tai Chi you're always quite happy to do it aren't you?

01002P-I

Yes, anything for a quiet life.

01002C-I

I think that's probably the most you're going to get out of him.

However, more frequently it was the carer encouraging the person living with dementia to provide his or her views or helping to rephrase or repeat the question to facilitate the person living with dementia's contribution to the conversation (01008C, 01039C, 01002C, 01012C, 03008C, 03006C, 01055C). Generally, dyad's members agreed on their opinions about the interviews, but there were very occasional points some expressed disagreement:

01008P-I

I've just got to work that out. [pause] Um, can you rephrase it because my brain can't cope with that?

01008C-I

¹⁹ Participants' ID numbers are provided before their quotes when an extract of the interview is provided instead of a single quote. Participant number ending in C identifies the carer whereas P identifies the participant living with dementia. An additional letter identifies the source of the quote (i.e., "I" means the quote was provided in the context of an interview.).

Put it this way, do you feel that doing the Tai Chi exercises has worn you out or, um, made you feel better...

Researcher 1 (Author)-I

What...what made it, err, what...was it any useful to have the instructor coming to your place and telling you how to do the...the tai chi at home?

03003C-I

Yes.

03003P-I

Do you think so? I don't think it was.

5.5. Implementation Fidelity

A total of 34 fidelity check forms (representing nearly 20% of the RCT classes) were filled for groups 1-6, 23 of them by the author and the rest by student research assistants helping with the TACIT Trial and one by its Chief Investigator. Generally, all the aspects checked were met. However, two main weaknesses were identified across groups. The first weakness was that occasionally refreshments were not offered to the participants during the socialising time (in at least 7 sessions, 21% those observed). In a couple of occasions, however, this was because the kitchen facilities were closed or because the venue did not provide them as agreed. After further enquiries about this, this lack of refreshments and a scarce socialising time was usual in groups 2 and 4. According to the feedback from the instructor and the observations of the author, this could be due to the time of the classes in case of group 2, where the classes were finishing around 5pm in winter periods, and participants were looking forward to getting home and preparing their dinner. Similarly, in group 4, this could have been due to participants' worrying about parking ticket running out and having other commitments to attend.

The second weakness identified was the lack of instructors highlighting the recommendation of practising for 20 minutes (in at least 14 sessions, 41% of those observed) at home. Whereas home-practice was encouraged and positively reinforced, the dosage was not highlighted.

5.6. Summary

Despite the recruitment efforts and the momentum latterly reached with recruitment, the number of participants recruited and consented into the TACIT Trial has had an impact on the configuration of the six groups presented. An initial small size of the group had an impact on the dyads who adhered higher to the classes and kept

attending (or mostly) on their own for several weeks. At least two of the groups introduced ended up delivering classes in a one-to-one basis, unlike the study design. Similarly, the weaknesses identified through the implementation fidelity checks (including a lack or reduced socialising time) have also had an impact on the participants' experiences.

This chapter has provided the context on which participants' experiences of the RCT Phase are based, considering their individual characteristics and those of the study setting. A detailed description has been provided to frame as best as possible participants' experiences that will be presented in the following chapters (Chapters 6 and 7). The next chapter will provide a description of participants' experiences of the classes, followed by their experiences practising Tai Chi at home (in Chapter 7).

6. RCT Phase: Experiences of the Classes

The aim of this section is to provide an answer to the second research question targeted by this thesis in regards with participants' class practice: What is prompting or mitigating participants' adherence to Tai Chi exercise? This overarching research question, however, contains a series of sub-questions which were pursued at this stage (see Appendix B) and includes: (1) the characteristics of the intervention and the factors that contribute or hinder adherence to Tai Chi, (2) the differences with the Pilot Intervention Phase, (3) the implementation fidelity and its impact on participants' experiences.

To respond to these questions, section: 6.1. Provides an overall description of the themes identified when analysing the qualitative data from the RCT phase; 6.2. Focuses on experiences of class practice; 6.3. Highlights the differences with the Pilot Intervention Phase of this study; 6.4. Discusses this chapter's findings; 6.5. Reflects on the strengths and weaknesses of this study, its practical implications and future areas of research; and 6.6. Summarises this chapter.

6.1. Randomised Controlled Trial Themes

After analysing the data provided by participants, instructors, and the author three main themes were identified, with the subthemes identified in Table 22:

1st) Taking part in the Tai Chi intervention: Which included references to participants' experiences whilst taking part in the Tai Chi classes or the Tai Chi practice at home and their reactions to the characteristics of the intervention; the barriers and facilitators to their adherence to practise in class and at home; and the ways the intervention could be enhanced in both settings.

2nd) Motivation and impact: Which included references to previous and current exercise experience (or lack of experience); motivation to join the Tai Chi study and willingness to carry on during and at the end of the study; and the impact of the Tai Chi intervention on dyads' relationships, and broadly the benefits or harms experienced by taking part in Tai Chi.

3rd) Getting involved in research: Which included references to participants' experiences taking part in the study, particularly in terms of their experience with data collection. As this theme is not responding to any of the research questions targeted by this thesis, further details will not be provided on this theme.

Table 22. RCT Phase: List of Themes and Subthemes

Theme/Subtheme	Chapter where themes will be presented
1. Taking Part in the Tai Chi Exercise Intervention	
1.1. Experiences of the Classes	Chapter 6
1.1.1. Practicalities of the Classes	
1.1.2. Instructors' Characteristics	
1.1.3. Participants' Reactions	
1.1.4. Class Barriers	
1.1.5. Class Facilitators	
1.1.6. Classes' Suggested Improvements	
1.2. Experiences of the Home-Practice	Chapter 7
1.2.1. Crib Sheets and Booklets	
1.2.2. Behavioural Change Elements	
1.2.3. Ways of Practising	
1.2.4. Home Barriers	
1.2.5. Home Facilitators	
1.2.6. Home-Practice's Suggested Improvements	
2. Motivation and Impact	
2.1. Previous Exercise Experience	Chapter 7
2.1.1. No Exercise Experience	
2.2. Motivations to Take Part	
2.3. Motivations to Carry On	
2.4. Interventions' Impact	
2.4.1. Dyadic participation	
2.4.2. Tai Chi Benefits	
2.4.3. Tai Chi Harms	
3. Getting Involved in Research	This theme will not be discussed within this thesis.

This and the next chapter will focus on the first and second main themes identified. To make the description of the results clearer, the first theme will mark the division of Chapters 6 and 7 (class- versus home-practice experiences) and the second theme will be presented at the end of Chapter 7. This will allow to present first classes experiences, then home-practice experiences, and finally the impact and motivations related to both class- and home-practice's experiences (and in many ways also the result of such experiences).

Table 23 shows the average contribution of participants, instructors, and researcher (the author of this thesis) to each theme/subtheme. This table shows instructors' feedback and researcher's observations are mainly contributing to the classes' experience, whereas carers and people living with dementia are the ones contributing to the wider range of sub-themes, which highlight their central role in this study. A more detailed table can be found in Appendix DD where average contributions per member of each dyad to each theme/subtheme has been provided. Dyads who did not attend any classes can clearly be identified as making no contributions, and those making a

reduced contribution were also those who provided feedback at the end of the classes but where not invited for interview.

Table 23. Participants, Instructors and Researcher's Contributions per Theme/Subtheme

Contributor	Participants				Instructors			Researcher (Author)
Sources	Feedback and Dyadic Interviews				Feedback			Observations
Theme/Subtheme	Average contribution Carers vs PLWD		Average contribution amongst Carers and PLWD		Average contribution Instructor 1 vs Instructor 2		Overall average contribution	Average contribution to each theme/subtheme
	Carer	PLWD	Carer	PLWD	Instructor 1	Instructor 2		
1. Taking Part in the Tai Chi Exercise Intervention								
1.1. Experiences of the Classes								
1.1.1. Practicalities of the Classes	62%	38%	17%	17%	1%	8%	5%	13%
1.1.2. Instructors' Characteristics	54%	46%	4%	6%	0%	7%	4%	48%
1.1.3. Participants' Reactions	58%	42%	6%	7%	66%	34%	46%	39%
1.1.4. Class Barriers	64%	36%	5%	4%	21%	16%	18%	0%
1.1.5. Class Facilitators	51%	49%	4%	7%	10%	13%	12%	0%
1.1.6. Classes' Suggested Improvements	69%	31%	4%	3%	0%	0%	0%	0%
1.2. Experiences of the Home-Practice								
1.2.1. - Booklet	76%	24%	4%	2%	0%	0%	0%	0%
1.2.1. + Booklet	47%	53%	1%	1%	0%	0%	0%	0%
1.2.2. Behaviour Change Elements	76%	24%	6%	3%	0%	8%	5%	0%
1.2.3. Ways of Practicing	68%	32%	7%	5%	0%	2%	1%	0%
1.2.4. Home Barriers	72%	28%	6%	4%	1%	7%	5%	0%
1.2.5. Home Facilitators	61%	39%	3%	3%	0%	0%	0%	0%
1.2.6. Home-Practice's Suggested Improvements	84%	16%	0%	0%	0%	2%	1%	0%
2. Motivation and Impact								
2.1. Previous Exercise Experience	49%	51%	2%	3%	0%	0%	0%	0%
2.1.1. No Exercise Experience	65%	35%	0%	0%	0%	0%	0%	0%
2.2. Motivations to Take Part	63%	37%	5%	5%	0%	0%	0%	0%
2.3. Motivations to Carry On	55%	45%	13%	17%	1%	2%	1%	0%
2.4. Interventions' Impact	77%	23%	0%	0%	0%	3%	2%	0%
2.4.1. Dyadic participation	62%	38%	3%	3%	0%	0%	0%	0%
2.4.2. Tai Chi Benefits	57%	43%	5%	6%	0%	0%	0%	0%
2.4.3. Tai Chi Harms	65%	35%	2%	2%	0%	0%	0%	0%
3. Getting Involved in Research	72%	28%	2%	1%	0%	0%	0%	0%
Miscellaneous	81%	19%	1%	0%	0%	0%	0%	0%

As coding was not exclusive, some overlap was found between codes assigned to different themes subthemes. This might reflect an initial relationship between themes as reflected in Figure 10. For instance, the impact of the intervention was related to reports on the experiences of the classes and the home-practice, and motivations to carry on seemed to be related with the perceived impact of the intervention.

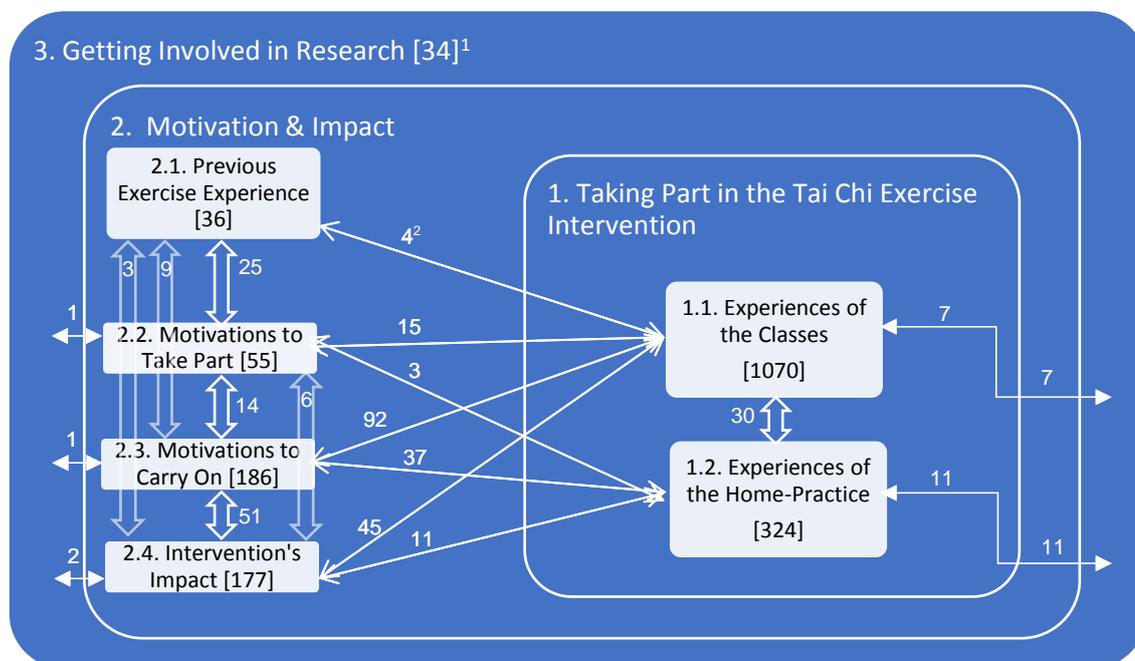


Figure 10. Relationships between themes and subthemes.

¹Between brackets are provided the amount of references coded per theme/ subtheme.

² Outside brackets (accompanying the arrows) are the number of references in common between themes/subthemes pointed by the arrows.

6.2. Experiences of the Classes

Overall, participants interviewed (n = 15 dyads) enjoyed their participation in the classes, both people living with dementia and their carers. Only one dyad (01022) described Tai Chi as a “boring” activity and would opt to meet the rest of participants and benefit from the social gathering aside from the Tai Chi classes if this was possible. They admitted, their previous exercise history might have impacted on their experience of Tai Chi, as both the person living with dementia and the carer were used to higher intensity exercises (i.e., personal trainer and cardio exercises). Their continued attendance to the classes was motivated by the slight chance of benefiting from Tai Chi and their commitment to the study. One carer (03008C), perceived Tai Chi not to be a suitable activity for her in a dyadic setting as she did not feel able to relax or gain benefits. She might have continued for the benefit of her mother living with dementia but would have preferred to continue in a separate group (i.e., Tai Chi carers group).

The other dyads interviewed (n = 13) described the Tai Chi classes generally as a positive experience which was consistent with the observations from the instructors and the author.

I thoroughly enjoyed doing the exercises. I enjoy going. (...) we have a bit of laugh...a bit of a laugh over things. I don't...it's just quite a jolly, jolly place to be. (01008P-I)²⁰.

Four participants living with dementia were less enthusiastic in expressing their enjoyment of the classes. Paradoxically, they reassured they would not be attending classes should they not be enjoying them. All of them faced different circumstances that did not allow them to participate in the study in full (i.e., due to health reasons (03003P and 02002P)), because they were recruited into the study after the classes had started (01021P) or the carer changed her job (03008C).

I wouldn't say I enjoyed it (TC) but it was...wasn't unpleasant, shall we say. (03008P-I).

During the observations, however, these participants also struggled either for health reasons (02002P) or difficulties to copy the movements. Furthermore, Instructor 1 tended to more actively correct these participants during the classes, although this was accepted by participants and perceived to be the point of being taught a new activity.

Additionally, some participants living with dementia (01002P, 03006P, and 01025P) pointed they might not remember the day of the week they do their practice, or the exact movements performed during the classes, but reported this did not impede them enjoying the classes. Similarly, it was observed and later confirmed in the interviews that a couple of participants living with dementia attending the same class had difficulties recalling why they were at the venue before the start of the class. Once the carer explained (01025C) or the classes started (01023P), participants living with dementia were willing and able to follow instructions.

I have...I have one problem that's incurable about so that I don't, well, sort of continue...consider it much, and that's that my memory's not very good. So, I love to go to the lessons and go through the practice, but about three days later I can't remember what they were. (Laughs). But I like the lesson, like, you know? (03006P-I).

²⁰ In chapters 6 and 7 again, source quotes specify the participant number, plus a P if provided by the person living with dementia or C for the carer; and a letter O (Observation), F (Feedback), or I (Interview), reflecting the environment where it was collected. When a participant number is not followed by P or C it represents the dyad (i.e., when both expressed the same opinion). Participants' identifiers are presented before the quote and without brackets, when an extract of the conversation is presented.

In some cases, one member of the dyad felt they had enjoyed the Tai Chi more than the other member (03003C) or joined the practice only for the other member of the dyad's benefit and ended up discovering that Tai Chi is an enjoyable activity (03008C and 01036C). Three carers with an age gap with the person living with dementia (>10 years) (01002C, 03008C, and 01012C) expressed some surprise towards the person living with dementia's enjoyment of Tai Chi (01002C, 03008C, 01012C). The last two carers were daughters of the person living with dementia (living together or not) but who appreciated the difficulty in finding a suitable activity for the person living with dementia.

I've been quite pleased at how happy <01002P> is to do it and how enthusiastically he actually, you know, given that it's <01002P>...relatively enthusiastically, he embraces it. (01002C-I).

You don't tend to join in [usually with activities], so you obviously enjoyed it [Tai Chi]. You never went oh, I don't want to go. (...) She...I mean, you...you could say...mum would be quite obstinate if she wanted to and she didn't want to go to something like that... (03008C-I).

Mum always enjoys it, she always looks forward to going to it, and she doesn't always enjoy going to places. Erm, you're always bright and breezy on a Thursday, aren't you? (01012C-I).

6.2.1. Practicalities of the classes

6.2.1.1. Duration

In terms of the classes, participants were happy with the duration, frequency, intensity or difficulty/challenge of the classes, timing, and venue. The duration of the classes (45 minutes, once a week) was adequate for all 15 dyads interviewed. Classes were long enough to "try hard" (03003P), "feel like they have done something" (01012C), and not too long as for people living with dementia to start thinking that they are not feeling well even if they were not feeling great on one of the class days (03006P). Whereas some participants stated that they could probably continue longer i.e., an hour (01002, 01021, 03008, 01025P, 01036), for some of them time went fast (01021C, 03008, 01025, 01012) others, on the other hand, specified that this was their limit.

Yeah. But, err...it's, err...it's...it's a good... [class duration] it's a really good... It is, because...and you don't have to worry, you know? If...if you weren't feeling as good as you did last week, it's not long enough to sort of get to your mind and think, oh, I don't feel very well. It's one of these things, oh, well, I did it last

week, I can do it this week, and that's how it goes, you know? It's...it's pleasant that, you know... (03006P-I).

I don't think I could have done a longer class. Because, um, you're concentrating so much for that length of time. So, um, no, I don't think I could have done a longer one. I was ready to say right can we dress now. Have a cup of tea. (03005P-I).

I think after the forty-five minutes, I... especially the, the last piece, which I find a strain on my upper knees and legs, actually, it's, erm...but I think... Yeah, but I, I think it is...long enough. (01009C-I).

6.2.1.2. Frequency

The frequency of the classes was right for participants. Only participants in the group taking part on Mondays (which clashed with several bank holidays) highlighted in their feedback that continuity would be preferable (01025C, 01023C). Additionally, some dyads indicated they would have preferred more classes i.e., twice a week or a second optional class if delivered in their local area (01012, 03003C, 01021C, 01036, 01039, 01025) as this could facilitate their learning process. Other dyads, on the other hand, reported they would not be willing to attend more weekly classes (03003P, 03006P, 01022C) or would have been willing but not able due to other commitments or appointments (03005, 02002C). They all seemed to agree that less frequent classes would not help their learning process or to create a routine and they would feel the Tai Chi would lose its impact (01022C).

They...to come back to the same...to the original point, I think the more you practice it the better it is. And the easier it is, you know. If you, if you're not, if you've got the time to deal with it, and of course er, we, we are, we are retired and er, it's a question that you must make time for what you want to do, mustn't you, really? (01055P-I).

6.2.1.3. Intensity or Difficulty/Challenge

Participants were happy with the intensity and challenge provided in the classes (“not too challenging” (01012C)). New exercises were worth doing. Although difficult and challenging this was perceived as necessary to enhance their competency.

Four carers expressed some frustration/impatience (01002C, 03008C, 01021C, 01012C) due to the repetitive nature of the classes and its slow progression but acknowledged that they were aware the classes had been designed for people living with dementia and this was beneficial for this population.

Um, as I said I personally find it slightly frustrating the speed that it goes at, but I know that it's not aimed at me. But, you know, I would just love to extend it all a bit and what I would really like to do is do it...she [Instructor 1] goes through a pattern at a time and I'd like to do it from the beginning all the way through [laughs]. But, yeah, I mean, I do appreciate that's me and it's not aimed at me necessarily. (01002C-I).

It's all the same for the first 6 weeks [explaining how the course works to the new dyad 01055 and pointing they will be able to catch up]. (01035C-FB).

In his feedback, Instructor 2 mentioned that finding the right balance in terms of content and challenge was difficult. What could be perceived as the appropriate challenge for some could be perceived as too difficult or easy by others. The Pilot intervention Phase was crucial in reducing the number of patterns from 10 to 5 by instructor 2 and he indicated that this worked a lot better. Instructor 2 pointed out the sessions where he introduced new content were critical in terms of the reactions of the participants to a new challenge. After these sessions and going over the practice of the patterns repeatedly he noted that participants familiarised and were more relaxed during movement execution. Such difficulties were not so much observed during the classes, although observations did not necessarily match the sessions when the new content was introduced. Nevertheless, it was observed that Instructor 2 provided reassurance to the participants, neutralizing the fact that they felt they did not know where to go with their movements and explaining their cognitive reactions were totally normal and just a reflection of their brain learning something new.

Instructor 2: "It's perfectly acceptable in the early days of Tai Chi for your brain to say, 'what way are you going?' It still happens to me" (and explains about his experience after 17 years when his instructor shows him a new movement. He also adds that this means that the brain is developing new neurological pathways. (Observation - Group 6, Session 3).

6.2.1.4. Timing

The timing of the classes suited most of the participants well. They were generally able to arrange their commitments around the classes. The notion that classes were on the same day of each week was helpful to build a routine in the person living with dementia. Only one dyad clearly expressed that if they had the choice, they would have preferred a morning class instead of a late afternoon (16-17.30hrs) as going back home in the winter meant reaching home in the darkness (01008). This was, however, no reason to stop attending. In the same group, there was another dyad with a very

different view, pointing that late afternoon class was good for them as they could respond to their other commitments before the class. Regarding the morning classes, a couple of participants mentioned that they would not actually set the class any earlier than half past ten (01025C) or half past eleven (03005P), reflecting on the fact that people living with dementia might need some extra time in the morning.

6.2.1.5. Venue

The venues were generally perceived as suitable. Only a few participants mentioned possible improvements in terms of floor conditions (“a bit tacky” (03006C)), parking availability (01021C), or brightness (01039P). Two dyads valued the community setting of the venue, gathering people from different ages, and the friendliness of the staff (01008 and 03008); whereas participants in group 6 stated that the caretaker tended to arrive at the start time of the class, so they had no time to air the venue and that he was particular about how to use the facilities in the venue (i.e., telling participants how they should operate the curtains). Two carers in a venue with a big mirror at the end of the class valued this element (01002C, 01008C), whereas a participant living with dementia in a class without mirror missed it (01021P). When asked, Instructor 2 also thought that in an ideal situation, a mirror in the class could be helpful.

6.2.1.6. Session Structure

Every session had the same structure across groups: warm-up, patterns, and relaxation. Whereas some participants had preference for the warm-ups (i.e., 01009, 01012P) because they felt they could perform them better, others were more excited about putting the arms and footwork together (i.e., 01002C, 01021C). Before (when participants were early to the classes) and after the classes, participants were able to engage in conversation with other participants.

6.2.1.7. Social Side of the Classes

Instructor 1 frequently promoted conversation asking participants informal questions about their week or responding to their queries about Tai Chi whilst they enjoyed their refreshments or were seated at the end of the classes. For participants with Instructor 2, when they stayed for some socialising at the end of the classes, the conversations sometimes were based on informal chat amongst participants and others included the instructor chatting about Tai Chi or demonstrating them i.e., the martial arts side of the movements practised during the classes.

Overall, the socialising component of the classes was highly valued, and frequently perceived as one of the strengths of the intervention. Participants positively described their relationships with other participants and the instructors and felt this socialising

was important for their well-being. The fact that they all shared a common condition might have helped to create a comfortable group environment as they were empathic to each other's needs. However, some participants missed the chance to relate to others and develop a relationship either because they discontinued their class attendance due to Adverse or Serious Adverse Events (SAEs) (03003, 03005, 01008, 02002P), they were the only (or one of the only) dyad(s) who kept attending the classes consistently (01021, 03008, 03006, 01002, 02002C), or because the refreshments time at the end of the practice was mostly not implemented (for groups number 2 and 4). According to participants' accounts, a combination of factors might have been behind this lack of socialising time at the end of which some participants attributed to the need of responding to other commitments (01002C), being late (01008), being tired after work or the hall not being the place where they would have a social gathering after the class (03008C, 01025C) or them being worried about the car parking ticket running out (01009, 01022). 01002C Also mentioned they did not attend the Tai Chi classes with the aim of making friends and they found that participants in this group were not similar to the people they tend to socialise with (i.e., 01002C pointed the participants seemed older and less active than the people they are used to meet with).

Well there's not a lot of time for that now because we have to get out of the room and there's the opportunity, as you know, to go and have a cup of tea. But we've all opted to, kind of, get home because we've all got dinners to cook and, you know, to be honest I want to get home...to be honest [laughs]. (01002C-I).

(...) to start with, we were offered tea and then they didn't...they couldn't find tea or whatever. And that's not applied and it's at a slightly awkward time, because we do our shopping before the class and therefore the car park is running out by the time that...the...the...the thing finishes, so, um, we don't want to hang around too much longer. (01022C-I).

I think, erm, there is a problem because people, er, they might come by bus or they might come by whatever, so they're ready to get away quickly or...you know, I think, it's really difficult, it's a really difficult one...'cause often, I mean, <Instructor 2> has said would you like a drink and we've gone no, no, no, we're off, we're going to do such...and so has the other couple, no, no, no, we're going to catch a bus. So, I think that you've...you just start off with saying that you probably will need to stay and have a drink, or you need to...'cause I think it would do a lot of people some good. Say there was a little cafeteria added on to it, or, you know, you probably...probably would stay. You might even stop and have your lunch. (01025C-I).

Despite the decision not to stay for refreshments at the end of classes being made by participants in the group, some did still report during the interviews that they missed having such dedicated time (01022, 02002C, 01025C).

Participants who did have the opportunity to share this socialising time greatly valued the opportunity to share some time and informal conversation with people “in the same boat” (03003, 03005, 03006, 01039). Learning with other participants in a similar situation was of importance to one of the dyads (03005) who also enquired about the possibility of the research team to provide advice in terms of continuity in the Tai Chi groups for similar people.

Well doing it with the others and realising that, that, you know, you're all in the same boat, that it was something that you all had to learn through. And had the same difficulties, you know, the short-term memory, the, um, oh, the stumbling, lack of balance sometimes. You know, and it was fine. And that you didn't necessarily understand what was being asked of you, but she would...yes, she [Instructor 1] would go...do it with us until we did understand, yeah. (03005P-I).

Four dyads highlighted the importance of the socialising component as older people in general, and people living with dementia in particular, are at risk of isolation (03008C, 01008). This provided an opportunity to have a conversation with a different group of people to talk with instead of family members or neighbours (01012C, 03008C, 01008, 01025). One of the dyads emphasised that people living with dementia seem to be talked to differently following diagnosis and that activities such as Tai Chi should be offered just after diagnosis as this is a crucial time when they try to find alternative activities (01025). Another two dyads from group 6 stressed the benefits of exchanging information about their diagnoses and treatments and receiving information from peers about other activities they were unaware of. This would allow other people attending their Tai Chi class discovering other activities in their community (01036 and 01039).

Yes, rather, rather than just say somebody from an organisation said, well you want to do this, this and this, er, when you've got a group of people then you can get a better idea of what other people's experiences have been. So er, er, and like <01039C> said, you know, you, you pick up all sorts of bits and pieces of information, it's that way round that don't seem to, well not, they probably are available but you, we've never seen them before. (01039P-I).

Er, funnily enough, <01055P> is not very good with new situations, and new you know, people and everything else. And, actually, you fitted in quite well there...(01055C-I).

[Explaining the new dyad 01055 how the Tai Chi classes work] It's easy [Tai Chi] (...) It's nice, you know, to chat with other people (...) you might make a mistake [doing Tai Chi in the class], so what? (01045P-FB).

Some dyads were willing to maintain their relationships with others in the group after the 20 weeks (03003, 03006, 03005, 01008, 01036, 01039,01025). Reasons for not continuing relationship included having little conversation before or after the class (02002, 01022, 03008), a significant age gap, different lifestyles (01002C, 03008C), living far from each other (03005, 01009) or not continuing with the classes.

6.2.1.8. Group Size

Although, in some instances, dyads were provided with one-to-one tuition they preferred to practise in the company of others (03003C, 03008, 01012, 03006, 03005,01009, 01023C, 01025C). If anything, some dyads expressed concern of practising when number were low. These concerns related to the potential negative consequences on the study or the instructor (travel to only teach one dyad) (01012P, 01022C, 01009P, 03006C, 01023C). One dyad expressed their desire to have other dyads present and not to do classes on a one-to-one basis (01023).

Four participants indicated to be apprehensive prior to starting the trial (03003C, 01009P, 01009C, 01039C) because they did not know other group members. One carer also anticipated some embarrassment in this setting (03006C). However, in all cases participants felt comfortable after their first session:

01039C-I

To begin with yeah, we were probably a little bit um nervous that everybody was watching up, but nobody is watching you because they're all concentrating...

01039P-I

Well, but not...they're all trying to concentrate of what we're supposed to be doing.

01039C-I

Doing their own thing, mm...

01039P-I

And I think that's you can see that with, with the people themselves, you know, they're more confident about doing it in the right way. But as he says, you know, it...it isn't always the way to do it, but this is just, he's showing us how it started and where it came from and er, er, how it's developed that way round. Um, so, er I sort of get a lot of information that way round as well. So, yes, it's, I think it's worked out all right.

When asked, participants pointed towards an ideal number of dyads per class being over four (01008C, 01012P, 01012C), five (03006C, 03005P, 01021P, 03008C), six (03003C), seven or eight (01039P); always depending of the size of the room and the instructor's ability to monitor the individuals in the group. The only participants who did not express concerns about the size of the group were those in Group 6, the largest group organised.

Regarding the group size, both instructors agreed that small groups were a challenge as the impact on dyads missing a class or withdrawing was higher on the other participants. This situation could leave a dyad practising alone or the need to cancel classes at the last minute due to none of the participants turning up without prior notice.

6.2.2. Instructors' characteristics

Both instructors received positive feedback from the participants despite the differences in their teaching and communication styles and personalities.

6.2.2.1. Instructor 1

Participants described Instructor 1's strengths in terms of her ability to focus on the individuals in the group (03003P), have a caring and attentive manner (03006C, 02002C, 03008P), responding to personal needs of the participants (i.e., placing a chair close by if a participant does not seem to feel well at the beginning of the session), providing clear and detailed explanations (03003C, 03006P, 01008C), be patient (03003C, 03006C, 03005, 01008C, 02002P, 03008C), being authentic, being pleasant and welcoming (03003C, 03005, 01008, 02002, 03008C), having the ability to create cohesion in the group (01008P), encourage the participants (03005C, 01008C), keep the socialising time at the end and without eating into the Tai Chi class at the beginning (01002C), and provide corrections in an acceptable way (01008, 01021C, 03008C). Only one carer made an improvement suggestion regarding Instructor 1 related to her speaking louder for participants with hearing aids (01002C).

<Instructor 1>, she's been very good. Very, very good. (...) ...she takes time to stop and have individuals, not just a group. (03003P-I)

So, if she's, sort of, saying, you know, that's good then you can believe that at that stage, at that moment that's good. (03005P-I)

(...) people who, um, make mistakes, um, you know, she puts them right nicely, it...it's caring in a caring fashion. (01008P-I).

During the classes observed, Instructor 1 started providing a lot of verbal guidance through the movements without telling the story behind them but describing them

physically. Instructor 1 kept correcting participants' postures (i.e., pelvis position) and the way they were performing the movements, including its direction. Frequently corrections were provided in such a way that individuals were not directly targeted but by emphasising correct form (i.e., in the interest of safety). Generally, Instructor 1 tried first with verbal corrections and then, if a participant was still struggling, approached them and physically guided the movement. Over the sessions, and after receiving a supervisory visit by Instructor 2, Instructor 1 slightly changed her way of delivering verbal guidance throughout the classes. This resulted in reduced verbal corrections. Throughout sessions, Instructor 1 used more general corrections, but kept correcting participants at an individual level. Instructor 1 also provided plenty of general positive feedback throughout the sessions and positive feedback once the individual participants had amended their movements following verbal feedback.

"Left hand over right" (x2 repetitions) – 01002C approaches and helps 01002P correcting this. Instructor 1 "keeping four hands down" and approaches 01002P to correct this. (Instructor 1 -O).

"No, no, no" (to 01021P) and repeats instructions to 01021P - 01021P responds " oh, no" (and he amends his movement following the instructions) - instructor 1 adds " don't ever cross your legs like that otherwise you're going to lose your balance". (Instructor 1 -O).

"Keep your shoulders down (looking and smiling at 03006P), it's really important" – 03006P nods and smiles to the instructor. (Instructor 1 -O).

"Brilliant, well done everyone, fantastic". (Instructor 1 -O).

"If it's painful [the movement], if it's not comfortable, just reduce it. If you're in pain, you can get injured and we don't want you to get injured." (Instructor 1 -O).

6.2.2.2. Instructor 2

Participants guided by Instructor 2 described him as an excellent instructor (01012, 01025,01036,01039,01055), patient (01012C), the right person to have involved with people living with dementia (01012C, 01009P, 01025C), providing good explanations which were easy to follow (01009P, 01036, 01025P), a down to earth person (01009P), with the ability to focus on the individual (01012C, 01025P), being thorough in his approach to the classes (01012P, 01009P), that makes you feel relaxed (01025P, 01036,01055P) that uses several repetitions for people living with dementia (010012C), and creates a failure free environment (01012C, 01039, 01025C, 01055P). Participants felt encouraged by him (01009P), that his feedback was genuine (01009, 01055P), boosted participants up and gave them confidence through positive feedback (01009,

01025), explained the tales behind the movements which made the classes interesting (01009C, 01039, 01036), introduced a little humour and personal anecdotes which helped them to feel at ease, approachable and like them (01036, 01039), corrected participants gently (01009C), felt he was a caring person that anticipates participant's difficulties (01009C), pleasant (01022, 01025, 01036), who never criticises (01022C), professional (01025C, 01055P), believed in what he was doing (01055P), and fairly well organised (01022C). Participants did not report any suggestions on how his teaching style could be improved.

He [Instructor 2] does seem to have the ability to see what each person is doing. He obviously picks out each person at one... (...) <Instructor 2> always says, it's your Tai Chi. As long as she's [01012P] doing the movements it doesn't matter if she's not doing them quite the same as he's doing them, or slower, or quicker. (01012C-I).

01039P-I

It's when you're going that way and that way and... but er, um, he makes it easier. Because he doesn't tell you, no, don't do it that way. He sort of is very clever because he moves it on to something else and says, well if we did this or that then, then you don't feel like you've made a complete mess of it, you know.

01039C-I

He says your best interpretation, that's what I like...

01039P-I

So, so yes...

01039C-I

...because we all do interpret things differently don't we and you, sometimes you feel, oh, am I doing this right? And, er, yeah, he's very good that way.

01039P-I

Yeah.

01039C-I

Yeah, puts you at your ease, which is lovely.

During the classes observed of Instructor 2, in line with participants' report, verbal guidelines were provided in a relaxed manner, frequently making use of analogies (i.e., describing some of the movements as "hugging your grandmother", "leaving the pencil back on the shelf"). The initial demonstration of the movements was generally accompanied by a description of the tale behind it or personal anecdotes around the movement (i.e., his daughter calling a movement "a teapot"), which frequently made the participants laugh. Corrections made were generally presented as general

rectifications, without naming the actual participants doing it wrong, and frequently explained as something Instructor 2 himself struggled with when he started practising Tai Chi. Instructor 2 frequently added some personal experiences about his difficulties learning Tai Chi and anecdotes about how his teacher used to teach him, which again frequently caused participants' laughs. Instructor 2 reported to the author that the strategy of leaving participants to practise on their own, whilst he goes around checking and correcting their practice would not work with this population, as he did attempt this in the past with a private class.

Provides general positive feedback "your coordination is getting better" and reminds participants about their reactions the first week he showed them the patterns. Participants laugh to his explanations about their reactions in the early days of practice. (Instructor 2-O).

Keeps providing positive feedback "perfect, perfect, excellent, good...relax (once they complete the form)". (Instructor 2-O).

Provides general positive feedback "that's it – up and down in the one side" and with this last general prompt 01012P corrects (as she was lifting both arms). Instructor 2 provides then personalised positive feedback "that's it <01012P>". (Instructor 2-O).

"I get quite excited with good Tai Chi" – and mentions again about their initial difficulties (i.e., not knowing where to bring their arms) and their improvements. (Instructor 2-O).

During the classes observed both instructors positively reinforced participants' practice at home, acknowledging their progress from class to class. Similarly, they both emphasised with practice the movements would get easier.

6.2.3. Participants' reactions

Participants reported through feedback and interviews (03006, 03005, 01002, 01008, 02002C, 01012) that they were looking forward to attending the class on the day (except for 01022). Though this might mean for some of them having to rush in the morning or before attending the class, to meet their other commitments (01002C, 01008). One of the participants living with dementia used to wake up asking if there was a Tai Chi class on the day (i.e., "Every day he'll wake up in the morning, now what's on today? And if I say tai chi, oh, it's like Christmas to him." 03006C). Four participants living with dementia were not so enthusiastic about the classes (03003P, 03008P, 01021P). One of the carers found she was too tired during the Tai Chi classes as she had been working before them (03008C) and a last dyad kept attending the

classes as considered Tai Chi an activity to attend given it had been marked on their diaries following their commitment to the study (01022).

6.2.3.1. Participants' distribution

Once in the venue, participants generally kept the same position in the classroom throughout sessions, with carers practising in front, behind, by the side of the person living with dementia, or at the other end of the room occasionally (01012). During the classes, participants moved through the room, advancing towards the instructor. Generally, the whole class moved backwards to their initial positions after finishing each movement. Occasionally, it was the carer or the instructors reminding participants to do so to avoid clashing, to facilitate their copy of the movements, or to ensure their safety when practising by a chair to give more confidence to the person living with dementia.

Instructor 2-O: "Can I make a suggestion...?" – Instructor 2 suggests 01012P and 01009 to move slightly so they form "a square nice shape with the rest of participants", so they are looking at him whilst they look to the front, instead of one sided as they are asked to mirror him, but from a sided position it might be more difficult to copy.

6.2.3.2. Participants' interactions

Participants kept focused on the instructor during the classes and had little interaction with other participants or the instructor. In the instance of an interaction with the instructor this was either non-verbal (i.e., generally laughing or smiling after instructor's comments) or verbal to clarify the performance of one of the movements (i.e., 03005P), respond to the instructor's corrections, requesting a break (i.e., 01023P), asking a question about the importance of the way of performing the movements, or replying to the instructors comments (i.e., sharing their impression on the difficulty of the exercise or keeping the joke started by the instructor). Some participants (i.e., 01036P, 03008P) tended to spontaneously comment more during the classes and where acknowledged by instructors with a reassuring response.

03008P-O: "in what way?" - Instructor 1 replies "circle in and then out, onto the heel" (Instructor 1 corrects this approaching the participant and practising in the same direction as her). Instructor 1 repeats this instruction twice at the time that she shows the participant how to do it and then adds "okay, well done".

01036P-O: asks why their outbreath must be longer - Instructor 2 replies "good question" and explains this is to enhance the "parasympathetic system".

01055C-O: “oh!” after Instructor 2 mentions that they are going to put arm and footwork together. -Instructor 2 acknowledges her reaction and mentions that sometime people feel scared when they are going to put it all together.

03008C-O: says “That’s weird doing it without instructions” and mentions that at home they do it with instructions “I talk all the time” (laughing). Instructor 1 explains that they “get the benefits from talking less and relax whilst doing it”.

Conversation between members of the dyad or with other participants during the classes was mostly non-existent except when one of the participants needed occasional carer’s support in executing the movements (i.e., 01002P, 01021P, 01008P) or if there had been a joke between participants and the instructor (i.e., 01036P and 01031P). Participants frequently looked at others in the class to copy their movements when the instructor was not facing the participants and when no mirror was available, as some struggled to copy the movements.

03005C-O: approaches 03005P to correct her softly (physical support).

01021C-O: corrects 01021P’s arm position “Bring it down love”.

01006P-O: looks at 01009 (smiling) and moves backwards a little bit (it seems like they were going to touch otherwise). 01006P might have said something to 01009P and 01009C (possibly joking and all 3 are smiling/laughing).

6.2.3.3. Participants’ performance

During the classes observed, participants were able to follow and copy the movements of the instructor. In instructor 1’s classes it was common that the carer would support the participant living with dementia to perform the movements correctly. This was something encouraged by Instructor 1, as she thought this would create a habit to provide such corrections at home as well. This was not observed in the groups guided by Instructor 2. In these classes, participants practised more independently and were less corrected throughout the sessions. This difference between instructors did not seem to impact on participants’ feeling of achievement or surprise of their own performance when they were able to complete the Tai Chi forms (03003, 03006, 03008, 01025, 01039, 01036).

6.2.3.3.1. Reactions to the corrections

Participants seemed to welcome both direct and indirect corrections (03006P, 03005P, 01002P, 01008, 01021C, 03008, 01009P, 01039P, 01036P). Two participants living with dementia expressed their willingness “to do it [Tai Chi], the way it’s got to be done” (01002P, 03003P).

You...you come away thinking, oh yeah, I've managed this today and I managed this today, and, you know, it's.....it's...it's a...it's a marvellous thing, you know? (03006P-I).

Participants felt instructors were polite when providing corrections. On one occasion, Instructor 1 had the impression that 01021C was not happy with her correction (01021P). This initial perception might have changed once 01021C became more involved also in correcting 01021P's movements. During the home-interview with dyad 01021, it appeared that the person living with dementia did not understand why it should have been so relevant to do the movements in a particular direction (something that Instructor 2 would have probably not corrected as much as Instructor 1) and might have felt that the instructor was telling him off at times despite their positive view of him:

I thought, well what difference does it make. Er, if...if...if I'm going to go that way...and instead of going that way, sort of, thing, so what. I've still...I've still done the same exercise, haven't I. (01021P).

One carer felt physical support and corrections were crucial for the person living with dementia to learn the movements the right way and achieve the expected benefits.

I think if...one of the things he quite often does wrong when you do this one and come up under your arm, he's got his arm, hand there and if she comes and shows him it's better because it's all about muscle memory isn't it. And I am finding that he is developing muscle memory, so it's important that it's the right memory and not the wrong one. (01002C).

One carer and one person living with dementia reported some potentially negative feelings around corrections. However, these were only initial feelings that did not impacted on their enjoyment of the classes or their impressions about Instructor 1:

There's one particular exercise I'm useless at, and <Instructor 1> always laughs at me, but, err, no, I think it's...it's ideal. (03006C).

(...) oh, my word not again but that didn't come from <Instructor 1> at all. You know she just said no it's fine let's, you know, we'll do it again. (03005P).

One carer expressed she felt some pressure when practising alone in front of the instructor, when the person living with dementia had to interrupt his practice during a class when they were the only ones attending (i.e., "You talk about vulnerable, I was the only one she could look at. (Laughs)." (03006C-I)). This carer had expressed she joined the intervention only for the benefit of the person living with dementia and had

she been given the opportunity not to get involved in the classes, she would have opted for the latter as she initially felt some embarrassment having to practise in front of other people. Such initial embarrassment was overcome in this group setting, but she did feel the pressure when she was the sole focus of attention during practice.

6.2.3.3.2. *Performance expectations*

Participants reported at the end of the classes their expectation that movement execution would get easier over time. Interviews confirmed this notion. Both people living with dementia and their carers appreciated that the more repetition, the more they could feel the flow when engaging in Tai Chi. Repetition provided feelings of improvement in their performance over sessions, which was supported by instructors.

(...) gradually improving the...the things that you perform, it's...it gets better and better and better. (...) think we got to the stage now where anything is...anything you're capable of is use...is...is useful. (Laughs). (03006P-I).

I think the more you go to the classes, the more you learn, so the more easier it becomes (...) I noticed that the, erm, especially with, like, Mum's obviously got mobility, and memory issues. And each week, as we get in (...) as we get into the class, erm, she kind of gets the move a bit quicker than the week before. (01012C-I).

6.2.3.3.3. *Progress self-evaluation*

Four participants perceived their ability to perform the movements was worse than others (03003P, 03006C, 01002P, 01012P), that they struggled with some part of the practice such as a particular movement or part of their practice (i.e., 01009C, 01012P, 01036, 01055P, 01039P), or their ability had worsened after suffering a Serious Adverse Event (SAE) (01008P). Two participants living with dementia referred themselves as “stupid” either for their age (03008P) or because of feeling the rest were able to pick the movements quicker and better than them (01012P) even when the instructor emphasised to avoid comparisons and that everyone has a different body and execute movements differently (01012C). Another participant living with dementia experienced a pre-existing health issue worsening after being recruited into the study and before starting his Tai Chi practice (unrelated to his Tai Chi practice), which impacted on his participation in the few classes attended having to stop and sit down. This finally resulted in his inability to continue with the classes (02002P). Hence, despite the efforts of the instructors to tailor the intervention and create a failure free (inclusive) environment (focusing their attention in their own performance and taking into account that each body is different and hence the resultant performance is slightly

different in each individual), comparisons between participants or with the other member of the dyad occurred. At least on one occasion this resulted into a dyad withdrawing from the intervention as the person living with dementia (01031P), described by Instructor 2 as a perfectionist compared with i.e., 01036P (who also struggled occasionally), felt she was not able to remember the movements and feeling anxious for this reason. Hence, this dyad decided that keeping up with Tai Chi was being more detrimental for the person living with dementia than beneficial.

You look at the other people seeing how they are doing it and you think that's better than the way that I do it. (01002P).

Most participants were able to identify their own strengths and weaknesses during their practice and were confident their performance could improve with further practice. This encouraged them to keep practising Tai Chi and willing to continue with the classes as 01012 who joined Instructor 2's private lessons once their participation in the study finished.

As far as I'm concerned, it's my footwork that's a, a problem. But, erm, I'm getting there with it. (...) I love starting it and getting the first few actions (warm-ups) ...but it's when I get to the foot work, and this, erm, it's, erm...I'll shut myself into a silent room and practice. (...) I am trying hard to become perfect, but...not with great, great results at the moment. (01012P-I).

Some participants living with dementia described their learning process as a natural process. Something they were learning from the instructor during the classes implicitly (03006P, 01002P, 01012P). One of the participants living with dementia who experienced two Serious Adverse Events (strokes) during her participation in the study and had to discontinue her practice reported she was still capable of remembering the movements when back practising. Similarly, 01008P and 01008C were able to resume and catch up with the classes after missing several sessions when recovering from another Serious Adverse Event.

I was talking to <Instructor 1> about it this last time and I said I can't remember it visually, but I do find that I'm automatically doing the moves that I really had learnt [before Serious Adverse Event]. (03005P-I).

6.2.4. Class barriers

None of the participants reported any reluctance to attend classes. On the contrary, the potential benefits were perceived to be more important than potential difficulties to

attend (i.e., time of the classes) and that they would miss the Tai Chi classes once their participation in the study would be finished.

No, not...not reluctant, because...it gets...it gets a habit and if you wake up in the morning and you weren't feeling up to it, you'd very likely still go. (...) You'd still go because...because you think it might be getting rid of what's...what's...in your mind in the morning. (Laughs). (03006P-I).

Yes, mornings are better than late afternoons, half...er, four o'clock, to turn out to go for four o'clock on a dark winter's day is not what we would choose to do. But the benefits of going outweigh the fact the time's not...not particularly, um, conducive to good spirits. Is that right? I think the timing is the thing we...we...we dislike about it. (01008C-I).

One carer particularly missed the classes when there was a bank holiday. Several bank holidays clashed with the classes in group 5, or Instructor 2 was not able to deliver the classes on other occasions. This, according to the carer was a limitation, and something that should be avoided as weekly classes allowed them to check if they were doing their home-practice right and facilitate their learning process. This carer also commented that such interruptions did not make it difficult to catch up with the classes after the break.

01025C-I

Especially if we had the week like when there was [bank] holidays and that week, that was a bit harder, you did need to get back to <Instructor 2>. (...) I felt that it was harder, 'cause you were losing... a bit. Once you get back to Monday again then you're back on track again, aren't you? You know? (...) You needed that continuity.

(...)

Researcher 1-I

Did you feel that it was any more difficult when you went back after a bank holiday when you missed a class?

01025C-I

Erm, no. Funny enough, you soon get into the swing of it once <Instructor 2> starts to...you might feel it when you're there and you think, oh gosh, but once you've done... you've done it again...

01025P-I

Mm hmm.

01025C-I

...it comes back, doesn't it?

01025P-I

Yes.

01025C-I

Once he's shown you and it...there's a couple of bits where, especially when we had to do hands and feet, that became a bit...but, no, once he shows you then you're okay again. You're definitely back on top, yeah, yeah. But I just feel that you've got to have the continuity though.

Some participants were unable to attend due to health issues (i.e., from a cold or a flu to some Serious Adverse Events unrelated to Tai Chi or Non-Serious Adverse Events) affecting several dyads (03003, 03006, 03008, 03005, 01008, 02002, 01022, 01055, 01025, 01034, 01055), doctors' appointments (03006, 01009, 01023), and planned holidays or having visitors (01002, 01036P, 01039, 01034). Only one dyad (03003) reported difficulties to attend classes due to location issues. Attending classes required this dyad to take multiple forms of public transport which was not helped by adverse weather conditions (cold/rain).

A limitation of Tai Chi pointed out by one person living with dementia was that it took them a while to familiarise themselves with the movements. This was probably increased in this dyad's case as they joined the intervention later and the person living with dementia struggled with getting used to the mirroring.

Not really, no (reluctance to attend the classes). (...) Oh, largely it's...it's just getting used to it (Tai Chi), isn't it? 'Cause we're get...we're getting used to it. But it's, er...it's...it takes longer than you think, put it that way. (01021P-I).

01021P-I

The problem with the...the mirror (mirroring)...(...) what I'm...was going to say was, how...[cough], like she'd [Instructor 1] say, um...er, left foot...and...and...and...so she gets the right foot and...and I...That...that...Well it...it does confuse you.

01021C-I

It [mirroring] really confused him at the beginning. (...) ...she [Instructor 1] goes...she goes...it's mirror image, so goes...she's leaning the left and telling you to go to the right. Use your right foot, so you're leaning the same way as her. But he...his brain's telling him, but you're...you've moved your right foot and you're telling me to move my left foot.

The slow speed and relatively low intensity of Tai Chi might also have impacted negatively on participants' assessment when considering their previous exercise

history (01021P, 01022). One of the carers pointed out that she preferred the instructor providing further verbal guidance during the classes making it easier for people living with dementia to follow the exercises. This was also reported by 03008P's.

I preferred it when she was talking. I think it's probably way more useful when she was talking than when...because I don't think this Tai Chi's is gonna be like Tai Chi, if you know what I mean, like where you...they've done it for years and years and years, because it's too late in their life. You know, so...you know, the memory...not too late, I don't mean that, but the...you need to know it before you have to...you forget things...I think for it to be a natural thing. And I think talking, probably verbal for people is easier than just...you never...I don't think some people are ever gonna remember all those moves...because it's just...too much. You know, but take three or four moves, yeah. But when they start putting the hands and da-da-da, so the verbal thing helped where, you know...like moving my arm down...underneath your elbow, you know (...) or end up here and things like that, instead of, you know. So, if she can do it, I think it's better. (03008C-I).

6.2.4.1. Performance Difficulties

Several participants living with dementia (n=12: 03003P, 03006P, 02002P, 01012P, 03008P, 01008P, 01023P, 01055P, 01021P, 01036P, 01034P, 01008P) reported a health issue that interfered with their class Tai Chi practice at some point (i.e., not allowing participants to copy the movements or feeling discomfort when doing it – as lifting arms when they have a shoulder issue- even when the instructor advised not to lift the arms in that case). Less than half of them had to sit for a little while because of diabetes, low blood pressure, feeling wobbly, dizzy spells, balance difficulties, back pain, or shoulder problems. They joined the class following a short break. This rarely ended up in dyad's withdrawing from the intervention (only in 02002's case and was motivated by the carer being advised to stop her practice by the doctor). Previous health conditions of both members of the dyad and surgeries from these serious conditions ended up impacting some dyads' adherence rates (i.e., 03003, 01055, 01034, 03007).

01021P-I

I...I have shoulder problem...which...which doesn't...doesn't help things, does it.

01021C-I

But, I mean, she's [Instructor 1] told us he's [01021P] to keep his arms down. But he'll try and do it, 'cause he's such a stubborn little toe rag. He likes to do the same as everybody else.

In other occasions, when participants' health conditions made them feel afraid of having a fall whilst practising (i.e., whilst practising the footwork if they had had several surgeries on their leg), this was overcome by providing a chair or couple of chairs close by to where they were practising. Carers also had some physical conditions (i.e., arthritis) which might have caused some discomfort whilst doing Tai Chi as with other activities of their daily living (01036C, 01055C).

But I have had a problem on my legs, you see, I've had two operations on my leg. And I, I think, subconsciously, I'm a little bit nervous about falling again, but, erm... (...) Yeah, erm, <Instructor 2>puts the chairs in where he thinks I should be standing for some of the, erm, operations. So, erm, and I, I, to be quite honest, there's nothing I could really fault the system on. (01012P-I).

Both participants and instructors reported Tai Chi specific difficulties. This included left right differentiation (03003P, 01023P, 01021P), getting relaxed (03008, 03006P), copying the movements (03003P), remembering the movements (03008P, 03006P, 01031P), doing the footwork (01012P, 03008P, 01009C, 01055C, 01039C), mirroring (01021P), or practising with little verbal guidance (03008P).

Finally, some participants were able to re-join the class after a break due to experiencing a Serious Adverse Event (i.e., 01008P and 03005P) and felt able to catch up with the content and remember what they had previously practised. Uncertainty about their ability to catch up with classes after missing some sessions or their lack of confidence might have impacted on two carers: one that decided to withdraw with the person living with dementia after finding a new job (03008C, as she could only attend a few classes) and another one that never returned to classes after the person living with dementia underwent a surgery with a difficult recovery:

You know, it's, er...but yes, probably [could have attended the odd class]. But then, you see, that's it, you've got to go to all of them, you can't just go to some and not the others because then you're always behind. And I think that's quite hard as well, because people are doing one...so you're holding up somebody else who's done that bit and it's...er, you've got to be able to go to most of them anyway (...). (03008C-I).

01055C-I

This is the problem [that they joined late] that because...we, we actually started in I think it was week three, and it was absolutely superb. What I'm concerned about now is because we've missed about five, I think, it might be even six, is will we be able to pick up as quickly when...if and when we go back, as to when we did it then you see? That was the, the thing. Yeah. 'Cos I was saying to <01055P>, I think we need to do a little bit at home before...

01055P-I

I think, I think we will because erm...like, like er, like he said, the, the, the instructor said, the erm, you start with the...all, all the key, all the key movements, and then it's a question of er, practice. And we keep on, we keep on doing the exercises, and er, it's simply a case of er, persevering with them. They don't...it's not going to...it doesn't seem to be that they're going to keep on introducing new stuff all the time and all the time.

6.2.5. Class facilitators

Enjoyment and socialising opportunities were reported by all as two of the main factors associated with adherence (03003, 03006, 03005, 01008, 02002P, 03008P, 01012P, 01009, 01022, 01025, 01036, 01039, 01055, 01045, 01023). Some also liked the helpful environment (03003C, 01008C) and the instructors were also acknowledged for their motivational qualities (02002C, 01025, 01055, 01039).

The exercise itself (03003C, 03006, 03005P, 01008P, 01008C, 01021P, 03008P, 01025, 01039, 01055P), the potential benefits (i.e., helping to keep fit, feeling well afterwards), the habit of attending classes and its environment characteristics (i.e., failure free), and the enjoyment of specific parts of the session such as the warm-ups or the integration between foot and arm work, when they felt were “actually doing the Tai Chi”, helped the participants to keep attending the classes.

I would say the middle part where you're actually learning the Tai Chi. I mean, fair enough, the warm ups and...I mean, what she does, she does the warm ups first, which is...obviously you should do that with any exercise. And then she'll do the arm movements, right through the sequence. And then she'll do the feet movement, right through the sequence. And then she'll put them together. We prefer it when they're both together, so we're actually learning the both...at the one time. That bit I do enjoy, when we're actually doing the Tai Chi itself. (01021C-I).

I love starting it and getting the first few actions (warm-ups) ...(01012P-I).

Um, I can see that there is a possibility that it might help <01022P>... (...) Um, and as I say, we're...there's a question mark over how useful it is but we'll try anything. (01022C-I).

People living with dementia's ability to remember and perform the movements could have acted as a facilitator to their adherence to the Tai Chi classes. In addition, their progress in movement execution and their enhanced physical self-perceptions can help explain willingness to keep practising.

It sticks in the mind sometimes, so I can remember it. (01002P-I).

I think, this I think is huge, he got in... because he's saying he doesn't remember going and all the rest of it but last week he got in the car and said, oh that gets easier every week. Which I thought was, yeah, important. (...) ... when we're practising, he remembers what we're doing. If, you know, if I say to him right start here, we're going to do this one he does remember. (01002C -I).

The position is, you're willing to learn on, and press on. (...) Well, erm, it's, it's my toe work, erm, footwork that's a problem. If I can conquer that, I'm okay, I'm...but, erm, yeah, I'll keep practising. It'll come. (...) I don't want to give up and say, oh that's enough, I can't cope anymore. I will press on regardless [laughing]. Erm, I think at the present stage, if I could carry, continue for a few more weeks, I'm sure I, I can meet, meet the system, you know. (01012P-I).

An additional motivator was the fact that Tai Chi gave the participants the possibility of practising exercise together, which for some participants was a must or an incentive (i.e., "It's always nicer if you've got someone to go with." 01009P). The Tai Chi was described as potentially beneficial for both members, though carers understood the target of the Tai Chi classes were those living with dementia (01012C, 01002C, 01008C).

And for me, yeah, it's, it's great to be able to do something with Mum...but something that I think I, I genuinely think, is helping her. That's why, I mean, we haven't missed a single class, be...because of that. Well, because I wouldn't anyway, you sign up to something, you do it. (01012C).

Lastly, more altruistic motivations such as helping people living with dementia (01021C, 03008C) and a firm commitment to the study (01012, 01022, 01021) were also mentioned as facilitators of classes' attendance.

...it's in the diary...and we'll go to the class. We're...we're...we're okay. There's...there's nothing that's...says, this is rubbish, we'll stop. We're happy

to go along with it. As I say, it's a bit boring. Um, happy to go along with it because there's a...a very slim chance that it just might help. Um, and there's...there's nothing to indicate that it definitely won't help, so we'll go along with it. But we're not enthusiastic, put it that way. (...) Well we're always...always interested in taking part in anything that might help...as I told you. We're both bored with it, but we keep...we'll keep going because we're committed to the exercise and we'll...we'll continue to do it. But, um, it's a little bit boring. (...)Um, but we made the commitment, we said we'd do it, so we should carry on and...carry...see it through. (01022C-I).

6.2.6. Classes' suggested improvements

Most dyads were happy with the classes (03003, 03006, 02002, 01021, 01012). Some suggested the following improvements: a) Possibly increase the number of dyads per class (03003C, 03008, 01012, 03006, 03005,01009) recruiting younger people living with dementia (01002C) or participants at earlier stages of dementia progression (03008C, 01025C); b) Set up a morning class instead of late afternoon class as getting home when it is dark might be off-putting for older people (01008); c) Offer another class for carers with less pausing (03008C) or give the option for the person living with dementia to attend on their own so the carer can take some respite (01025C); d) Offer an outside practice in the summer (03008C, 01039); e) Keep verbal guidance throughout the classes (03008); and f) Enhance the socialising component by:

1. Allocating 10/15/20 minutes for socialising (in groups were this did not happen) and presenting it as part of the class (01039, 01022, 01002, 02002C);

Well you have...you include that as a coffee break...um, and it seemed to...it...that's the hour. Instead of committing three quarters of an hour, you're there for an hour. (01022C-I).

So, I think that you've...you just start off with saying that you probably will need to stay and have a drink, or you need to...'cause I think it would do a lot of people some good. (01025C-I).

2. Staying in the same room for socialising in the case of group 2 where they were required to move to another room on a different floor (01002C, however, another participant in this group thought this would have not been a difficulty);

Well I think if we didn't have to move. If there were...say there was, um, a drinks...machine, thank you [laughs] there was a drinks machine there and we could all go and get a coffee maybe we'd sit round for another fifteen-twenty minutes and have a chat. But the fact that we've all got to pack up

and walk up to that room upstairs and then the kettle has to go on makes it all a bit time-consuming. (01002C-I).

3. And, on the contrary, choose a different room environment inviting to socialise in a more natural way (as reported in group 3 and 5 where refreshments were offered in the same venue).

I mean, the <Venue 3> Centre is not exactly designed for sitting around and having a chat is it, you know, it wasn't very comfortable in that giant room or anything. (...) ...that place is not as...it just wasn't as...you know, like a sit down and socialise sort of looking place. (03008C-I).

Say there was a little cafeteria added on to it, or, you know, you probably...probably would stay. You might even stop and have your lunch. (01025C-I).

6.3. Differences with the Pilot Intervention Phase

The main change introduced since the Pilot Intervention Phase with regards to the classes was the content delivered. The content was reduced from 10 to 5 movements. Participants reported that the amount of content and the difficulty of the classes was adequate. Instructors agreed and reported occasional difficulties by specific participants that were overcome throughout sessions.

The second difference with the Pilot Intervention Phase was the presence of two instructors, with different teaching styles. This difference was less noticeable in terms of participants' reports regarding satisfaction with the instructor. Three participants mentioned their reactions to Instructor 1's more active corrections, however, these could have been explained not only by the teaching style but also because of the small numbers i.e., Instructor 1 often had sessions where only one dyad could attend and so the focus was centred on them. Despite this, participants kept attending; whereas one of the classes with Instructor 2 was cancelled (in group 5) because of one dyad preferring to wait for the second dyad to be able to attend and seemed not to feel comfortable during a class they did alone.

Regarding Instructor 2, a slight change was noticed in his teaching style in this RCT Phase. He seemed to pay more attention to participants' balance, providing participants with a chair when required. Similarly, he introduced the two sides practice (first practising facing the participants and later with his back to them), which was not implemented by Instructor 1. Hence, Instructor 2 ended up guiding participants looking at them and, after the initial sessions, combining this with practising with his back to them. This new strategy seemed to work better with those having difficulties with the

mirroring (and this was the intention of Instructor 2), but at the same time did not work so well with those that could not remember the arms movements and were left with less visual prompts on the upper body movements.

Finally, the last difference introduced in this RCT Phase was the fact that instructors were generally in charge of providing refreshments at the end of the classes. In some groups there was a Research Assistant supporting the instructor in organising the social component. Research Assistant 1 was present in most of the classes of group one, and in some of the classes of group three. For group three the venue provided refreshments. In the first few classes of group four, Research Assistant 2 was also providing support. However, for most of the sessions and groups, it was the instructors' in charge of providing refreshments, which might have reduced their socialising opportunities with participants (or their promotion of such socialisation amongst participants) at the end of session.

6.4. Discussion

The aim of this chapter was to evaluate the second research question: What is prompting or mitigating participants adherence to the classes? The RCT Phase of the TACIT Trial has confirmed the acceptability of the Tai Chi classes by people living with dementia and their carers. This chapter's findings around participants' adherence will be discussed first in the context of previous empirical studies reporting adherence barriers and facilitators, and later according to the theoretical framework of this thesis.

6.4.1. Adherence facilitators

Several aspects of the classes have contributed to participants' adherence to the 20-week class practice in line with previous research's findings: a) The enjoyment of the classes (Frederiksen et al., 2014; McPhate et al., 2016; Wesson et al., 2013; Yu & Swartwood, 2012); b) The group-based setting with its inherent socialising component with similar others (Burgener et al., 2008; Dal Bello-Haas, O'Connell, Morgan, & Crossley, 2014; Frederiksen, Sobol, Beyer, Hasselbalch, & Waldemar, 2014; Yao, Giordani, Algase, You, & Alexander, 2012); c) The friendly and task-oriented environment of the classes where improvement resulted from repetition and effort, and where instructors invited participants to avoid comparing themselves with others (Barnes et al., 2015); d) Their dyadic participation (Yao et al., 2012) and potentially the strength of their relationship particularly if living together and having a balanced relationship despite the diagnosis of dementia; and e) The perceived benefits of Tai Chi (Logghe et al., 2011). Additionally, weekly monitoring calls were perceived by some individuals as an encouragement for their attendance to the classes. Despite not being

the purpose of these calls, this could have acted as a facilitator (Frederiksen et al., 2014; Hawley-Hague et al., 2016a; Lam et al., 2012).

Although not often examined, the characteristics of instructors have been shown to influence engagement and adherence to exercise programs (Hawley-Hague et al., 2014). The present study provides support for this notion. The instructors in the TACIT trial, although exhibiting different instructional styles, provided participants with confidence in their capabilities to execute movements. The quality and quantity of feedback provided by the instructors was also deemed suitable, which was mainly related to instruction and positive feedback. Sport studies have indicated that these types of feedback are preferred (Smith, Smoll, & Cumming, 2007).

At the individual level, some participants' attitudes towards Tai Chi changed during their participation in the trial (Wu et al., 2015). Those who were more sceptical about Tai Chi as an activity expressed that they regarded Tai Chi as a suitable exercise for them, which they enjoyed and involved learning of new physical skills. Importantly, participants were able to sustain attention for the duration of the classes (45 minutes) supporting previous research (Dal Bello-Haas et al., 2014).

6.4.2. Adherence barriers

Reasons for participants being unable to attend sessions are aligned to those reported in the literature. Amongst them, changes in health or worsening health conditions affecting the person living with dementia or the carer (including adverse and serious adverse events, of which both were unrelated to Tai Chi participation) (Chong et al., 2014; Farran et al., 2008; Prick, de Lange, van 't Leven, & Pot, 2014; Suttanon, Hill, Said, Byrne, & Dodd, 2012; Wesson et al., 2013), competing commitments (Suttanon et al., 2012), or holiday periods (Wesson et al., 2013) were the most common.

Consistent with previous research, in-class barriers such as occasional dizziness or physical discomfort (i.e., back pain) (Teri et al., 1998) led to a brief interruption of the Tai Chi practice. Similarly, difficulties to remember the Tai Chi moves (i.e., when the instructor was standing with their back to the participants) previously found amongst older adults in the community (Logghe et al., 2011), triggered one of the dyads to drop out.

Lastly, research has indicated that opportunities for socialising are important facilitators of adherence (Farran et al., 2008; Frederiksen et al., 2014; Hawley-Hague et al., 2014). The lack of implementation of the socialising component at the end of the classes in some of the groups matched with some participants' unmet social need. In the future, there is a need to ensure this component takes place for those who wish to join in. This could mean reducing the time for socialising to 15 minutes, actively involving

participants in refreshments' preparation, or offering them in the same room where the exercise class takes place.

6.4.3. Self-Determination Theory

Participants joined the study aspiring to get a health benefit from their participation in Tai Chi. According to SDT, taking part in exercise for health benefit is considered an external form of behavioural regulation. It is not uncommon that during the adoption phase of a more active lifestyle participants are more motivated by such external motives. However, following continued participation behaviour becomes more internalized and intrinsic motives (i.e. enjoyment) can come to dominate motivation for continued engagement in the activity (Ingledeu, Markland, & Medley, 1998). This process was facilitated by the class environment and the instructors' behaviour that generated a task-oriented motivational climate (Eys et al., 2013; Farrance, Tsofliou, & Clark, 2016). That is, class environment was geared towards competence development. At the same time, the provision of socialisation opportunities assisted in developing relatedness (Annesi, Unruh, Marti, Gorjala, & Tennant, 2011; Farrance et al., 2016).

6.4.3.1. Competence

The task-oriented motivational climate provided by the instructors was indexed by their clear instructions of how participants were expected to execute the movements, the provision of positive feedback and requests to focus on one's own performance (avoiding comparisons with others) (Deci & Ryan, 2008; Silva et al., 2010; Su & Reeve, 2011). This, together with participants' perception of their learning process during classes helped to meet their competence perceptions (Leyton, Batista, Lobato, Aspano, & Jiménez, 2017; Podlog & Dionigi, 2009; Rahman, Hudson, Thøgersen-Ntoumani, & Doust, 2015; Teixeira, Carraça, Markland, Silva, & Ryan, 2012).

In the exercise context, competence need satisfaction has been found to be key in the prediction of continued exercise behaviour (Edmunds, Ntoumanis, & Duda, 2006; Teixeira et al., 2012). This might have been the case with the Tai Chi classes as participants kept focused on the instructor and there were few opportunities for comparisons with others. Furthermore, in the RCT Phase, the reduction of contents (limited to 5 patterns over the 20 weeks), helped participants to perceive these as challenging but achievable, contributing to their adherence to the classes. Providing an optimal challenge has been shown to be a facilitator of competence need satisfaction (Teixeira et al., 2012) and would have been strengthened by participants' confidence in that they could carry on practising on their own after the end of the classes (Podlog & Dionigi, 2009).

6.4.3.2. Relatedness

The need for relatedness was supported in the current study by exercising with a partner in a group setting and providing opportunities for post-exercise socialising. Participants developed a sense of camaraderie and liked having a group for people “on the same boat”. Furthermore, instructors spent time before and after the classes, engaging in informal conversation, sometimes about Tai Chi, but also showing their interest in participants’ well-being. Although not measured explicitly, several participants pointed to this need being fulfilled. For example, there was concern for those who missed classes and participants expressed they valued their relationship with the instructors.

Some people living with dementia and their carers reported having felt some embarrassment before the start of the classes, linking this to their performance in front of others and their uncertainties about how comfortable they would feel in the new group. However, these anxieties were successfully overcome once they started the classes, got to know each other, and practised alongside other people in a similar situation. Recent systematic reviews have pointed group-based interventions were a desired option by participants and a potential facilitator of adherence although further research is required (Farrance et al., 2016; van der Wardt et al., 2017). Such preference could highlight the important role of relatedness need satisfaction when starting a new activity (Wilson, Longley, Muon, Rodgers, & Murray, 2007) and in sustaining practice once participants get familiarised with the exercise (Edmunds, Ntoumanis, & Duda, 2007).

6.4.3.3. Autonomy

The Tai Chi classes were not designed to provide a great choice to the participants; however, there was room for tailoring the intervention to participants’ needs and explaining them the importance behind the movements they were asked to perform. The fact that the instructors were not overly prescriptive and allowed participants to use a chair for support or rest, when required, created a task-oriented motivational climate in which participants had some level of autonomy. Instructors explained participants the potential benefits of Tai Chi and acknowledged their verbal and non-verbal reactions.

This autonomy-supportive environment might have not been enough to totally fulfil participants’ autonomy need; however, it has been found to be a predictor of all three basic needs’ satisfaction (competence, autonomy and relatedness) (Edmunds, Ntoumanis, & Duda, 2008). Furthermore, participants interviewed and those who provided feedback at the end of the classes often verbalised their willingness to attend the following sessions and continue, if possible, outside of the trial. Similarly, they

reported no avoidable barriers impacting on their attendance or that made them feel unwilling to attend the classes. Such expressions stress their volitional choice throughout and beyond their participation in the study, which would not be expected if this need had been thwarted.

Overall, it appears that the Tai Chi intervention was successful in developing higher levels of competence and relatedness within the participants. It is unclear if this allowed them to be more autonomous in aspects of their daily life. SDT appears to be an appropriate theoretical framework to describe: a) Changes in motivational orientation over time (from extrinsic to intrinsic motivations, or at least well-internalised forms of extrinsic motivation); and b) The role of a motivational climate to assist in this and how basic needs might be fulfilled. The latter is important, because fulfilment of basic needs, according to SDT is associated with an enhanced well-being and QoL (Deci & Ryan, 2000).

6.4.4. Additional theories

Participants' adherence to the classes can be complementarily explained by the concept of self-efficacy from Social Cognitive Theory (Bandura, 1977, 2002). Self-efficacy (SE) expectations are developed through four elements (Bandura, 1977): 1) Performance accomplishments, which are "based on personal mastery experiences" (p.195) such as participants' previous experiences succeeding at difficult tasks; 2) Vicarious experiences, where a relevant model (i.e., instructor or another participant)'s success, contribute to the feeling that one will also be able to succeed; 3) Verbal persuasion (i.e. "you can do it" messages or feedback) or encouragement of the individual through highlighting his or her abilities to succeed and providing guidance on how to do it; and 4) Emotional arousal, where relaxing environments (that are not perceived as stressful or threatening) and positive feelings promote efficacy feelings.

This study findings suggest that performance accomplishments (Neupert, Lachman, & Whitbourne, 2009), verbal persuasion from professional instructors (Burton, Shapiro, & German, 1999) and vicarious experiences (Lee, Avis, & Arthur, 2007) might have been key during the classes. Over the sessions, participants perceived their own improvement and realised they were able to perform the movements they initially found challenging. This way participants experienced mastery and developed their self-efficacy beliefs. By the time a new pattern was introduced they had successful experiences themselves and saw others succeed. As such they would have been confident to learn new movements. Participants were supported by constructive and informative feedback from the instructor who provided a task-oriented learning climate

in which comparisons with others was discouraged. These factors would have assisted in participants' continued participation in the classes (Lee, Arthur, & Avis, 2008).

In summary, participants mostly described the class setting as a facilitator to their attendance, where barriers appeared to be occasional and frequently unavoidable (i.e., health issues, doctors' appointments). Self-Determination and self-efficacy are partially useful in explaining adherence to Tai Chi classes. Competence and relatedness need satisfaction, together with high self-efficacy perceptions are likely to have contributed to participants' adherence to the classes. Overall, Tai Chi might be less suitable for those preferring more vigorous activity but challenging enough for those with less exercise experience. An optimal challenge was offered to participants in the TACIT Trial as were able to develop their Tai Chi skill (Guadagnoli & Lee, 2004).

6.5. Strengths and Weaknesses of This Study and Future Research

6.5.1. Strengths

An important strength of the current study was the use of field notes to collect "*in situ*" feedback from participants living with dementia, which enabled capturing comments from participants (i.e., describing the relaxed environment of the classes and encouraging themselves to give a go to Tai Chi). These details might or might not have come up in the context of the interview, which were generally scheduled within sessions (on average 3 days after the most recent session). Secondly, the qualitative approach allowed an examination of the data as it was being generated (using reflexivity) to then assess when saturation was reached and to prompt further questions during the dyadic interviews. This helped to consider, for instance, if trying to attend another session when one had been cancelled last minute was going to contribute further to the data. Thirdly, being in touch with participants to collect data for the TACIT Trial has contributed to a natural development of rapport with the author (and interviewer). This continuous relationship with participants and triangulation enabled the author to determine the consistency of the data collected during the classes and the interviews (enhancing credibility and dependability). An additional advantage of small intervention groups was that observations of the classes were easier and field notes were potentially more accurate (considering these were not video-recorded). Finally, focusing on people living with dementia's experiences is to be applauded. Participants living with dementia were able to contribute, happy with their participation and contributions made to the interview, which challenges negative stereotypes and supports future interventions to include this group. The dyadic setting facilitated the data collection process as carers were able to make clarifications and dyadic interviews developed in a familiar and relaxed environment.

6.5.2. Limitations

This study is not without limitations. Because of slow recruitment into the RCT phase, the groups observed, and dyads approached to participate in interviews were from the first six Tai Chi groups rather than representative of all 10 groups organised. Purposive sampling was only used amongst dyads in the last two groups as until then all attending dyads were observed and invited for interview to ensure that enough qualitative data would be collected to demonstrate a range of participant's experiences. As in the Pilot Intervention Phase, observations of the classes could not be video-recorded which might have enhanced the quality of the data collected. This weakness might have been particularly relevant with the larger group (group 6), where more people needed to be observed at the same time. Measures of in-class participation were not used, which does not allow a precise evaluation of their adherence (e.g., in terms of intensity) during the classes. During observations, a note was made stating that the person stopped and later re-joined, however, notes were not taken on the exact duration of these pauses. This limitation could have also been overcome by video-recording the classes. Furthermore, the fact that participants living with dementia were invited to take part in dyadic interviews some time (on average 3 days after the most recent session) after one of the latest classes (on average around week 16) could be seen as a limitation. This is because for some participants it may have been difficult to recall the barriers and facilitators of their adherence due to the symptoms of some types of dementia. For participants who discontinued their participation this time window could have been for several weeks (i.e., 5 dyads had not attended classes for 6 consecutive weeks on average, ranging from 1 to 9, prior to that). Hence, future research might benefit from scheduling these visits as soon as possible after early discontinuation or after the classes (i.e., if not immediately after the class, to avoid fatigue, then the next day), to facilitate recall. Similarly, the dyadic format of interviews might have impacted on dyads' willingness to share the weaknesses of taking part together in the intervention to avoid upsetting the other person. On the other hand, for those living with dementia, their willingness to share their views might have been altered if the conversation was led by the carer.

6.5.3. Future research

Future research could benefit from ensuring classes are video-recorded, with prior agreement from the instructor. This would enrich observations and allow for systematic qualitative observations to be compared or complemented with quantitative measures (completed during or after the classes). Additionally, quantitative measures could be incorporated to the classes (i.e., heart-rate monitors), which would contribute to know how hard participants worked during the session, useful measures for the study but

also for the participants themselves to track their progress over time. Future exercise research based on people living with dementia might benefit from pre- and post-assessment of the three basic needs (i.e., using the Basic Psychological Needs Scale). This approach might help to ascertain the impact of exercise on people living with dementia's need satisfaction.

Similarly, future exercise research could more actively include instructors' views, for instance, by asking them to complete diaries about their impressions on dyad's progression and their on-going reflections. This might be useful to keep a more systematic record of their impressions since the space provided for notes in the class registers was not always equally used by instructors. Getting feedback from instructors and participants at the end of the classes was frequently harder as they engaged in conversation, hence instructor's views could be less represented. Towards the end of the classes, it could be interesting to gather all instructors in a focus group to facilitate a discussion of their experiences during the trial. They could be invited to share their views on the strengths and weaknesses of the classes and the barriers and facilitators for participants adherence to this (and the home-based) component.

6.5.4. Novel contributions

The novel contributions made through this chapter relate to the evidence produced as well as the methods and theoretical approach used. This is the first study to explore the experiences of those living with mild-to-moderate dementia and their carers taking part in Tai Chi classes for 20 weeks. Such exploration it is key to understand the adherence barriers and facilitators identified by dyads with different adherence levels (and different dyadic relationships) throughout the study period. Furthermore, this is one of the few exercise studies including people living with dementia focused on their experiences and using dyadic interviews. This focus is required when they are the target of the intervention and adherence is often reported as a challenge in exercise research. Finally, this has been the first study to interpret people living with dementia and their carers' experiences and adherence to an exercise intervention under Self-Determination Theory. This has allowed to connect this study's findings with previous knowledge, highlighting its gaps and suggesting areas of future research.

6.5.5. Practical implications

Findings of this study suggest that community-based interventions for individuals with mild-to-moderate dementia are successful when conducted with a significant other (dyadic approach) (Moon & Adams, 2013). However, giving people living with dementia the choice to join on their own could facilitate access, particularly to those living alone (Rollin-Sillaire et al., 2013). The provision of normalised exercise (i.e., Tai Chi) (Nyman

& Skelton, 2017) for a group of people living with the same diagnosis (i.e., dementia) in the community is preferred. A Tai Chi program could benefit from multiple sessions per week on similar days and times to contribute to adherence and learning. Alternatively, offering additional support materials for the home-based practice (as will be explained in Chapter 7) could help increase adherence to the recommended dose, making the intervention financially sustainable and facilitating continuation after the trial. Exercise interventions for people living with dementia should include substantial repetition of movements to facilitate such learning (Fenney & Lee, 2010; van Halteren-van Tilborg, Scherder, & Hulstijn, 2007). It is also important to have instructors who create a task-oriented motivational climate through instruction and positive feedback. Providing opportunities for socialising post-exercise also enhances participants' enjoyment and likelihood of continued participation in the activity (Farran et al., 2008; Frederiksen et al., 2014; Hawley-Hague et al., 2016a; Lam & Cheng, 2013). As indicated in the literature, and observed in the present study, venues characteristics and accessibility (Dal Bello-Haas et al., 2014) are important for participants to initiate and continue the exercise behaviour.

6.6. Summary

This chapter provides a rich description of participants' experiences of the classes and highlights the barriers and facilitators to participants' attendance to them. Amongst the most common barriers to class attendance and continued engagement are participants' health issues unrelated to the study (including Serious Adverse Events). Amongst the most common facilitators are the enjoyment of the classes and the socialising component. The following chapter will report the experiences of participants practising Tai Chi at home as per study design, as well as the impact of the intervention in terms of perceived harms and benefits of their overall involvement in Tai Chi.

7. RCT Phase: Experiences of the Home-Practice

The aim of this section is to provide an answer to the second and third research questions of this thesis: a) What is prompting or mitigating participants' adherence to Tai Chi exercise's home-practice? and b) How do people living with dementia and their informal carers experience their joint participation in a Tai Chi exercise intervention? These two overarching research questions contain a series of sub-questions which were pursued at this stage (see Appendix B) which include: (1) the characteristics of the intervention and factors that contribute or hinder adherence to Tai Chi, (2) the differences with the Pilot Intervention Phase, and (3) intervention's impact on participants' dyadic relationship.

To respond to these questions, section: 7.1. Focuses on experiences around home-practice; 7.2. Depicts the impact of Tai Chi in participants' dyadic relationships and well-being; 7.3. Describes the differences with the Pilot Intervention Phase; 7.4. Discusses this chapter's results; 7.5. Reflects on the strengths and weaknesses of this study, its practical implications, and future areas of research; and 7.6. Summarises this chapter.

7.1. Participants' Experiences of Home-Practice

Generally, participants found time to practise Tai Chi at home, however, this time did not necessarily reach the recommended dosage of 50hrs over the 5 months intervention period. Adherence to the classes was better than home-practice, and home-practice was higher among those that attended more classes (except for 01012). Participants living with dementia and carers did not always practise at home for the same amount of time, as shown in Appendix BB.

Those who adhered better to the home-based practice, or who returned their exercises logs back as requested, reported they enjoyed it and had no major difficulties in finding time to practise at home (01039, 01045, 01002, 01008, 01055, 02002C, 03005,03006, 01021, 01009, 01055, 01045, 01035, 01031). This was an opportunity to work together on practising the movements to become familiar with them and work on the weak points identified by the instructor during the class (03006). Some reported that at the beginning of their practice they had to develop a routine for their home-practice (01025, 01039, 01055). Others reported less enjoyment to home-based practice because of finding Tai Chi boring (01022). Additional commitments (03008,01012, 03003) included preferring to attend the classes and doing it with the group or seemed generally less enthusiastic about home-practice (01036,03003, 01023).

7.1.1. Crib sheets and booklets

Participants were provided with a total of three booklets throughout the classes, as well as nine crib sheets designed to point participants towards the exercises they were due to practise at home according to the week number, with some crib sheets covering several weeks.

Only a few people reported on these crib sheets (03003,03006, 01002, 01021, 01025) which were either not used if the participants did not manage to do much practice or used and found generally useful to know the exercises they had to work on. However, a few carers (01002C, 01021C) realised that the contents would not fit a 20 minutes practice.

I mean, there's no way, there's absolutely no way you could do all that in twenty minutes [laughs]. Yeah, I mean, if, you know, if obviously I've altered it, but it says warm up eight times, we only do it four times because warm up eight times would probably take about fifteen minutes [laughs]. (01002C-I).

I mean, it's telling you...maybe once we know the whole sequence, we'll go on to it, 'cause they're telling you to do eight times...in each sequence. And that's...that's the warm ups. So, there's...I think they're on to six. We do never six...we never do eight. We've done eight...the...the first two, we usually do the eight but by that time, I get fed up with the warm ups...which is naughty, 'cause that's supposed to lubricate your body, kind of, thing. But they're not...we're too interested getting the...the full Tai Chi done right, you know, so we're too anxious to go on to that...yeah. (01021C-I).

Much more feedback was provided about the booklets (henceforth “booklet”). Some participants found the booklet worked well for them and would not be requiring any further information or additional home-practice support elements (03006, 01012P,01009, 01036C); others reported some improvement in regard to the booklet would be required and/or additional support such as a DVD to facilitate their practice. Additional support was particularly missed at the early stages of home-practice, as once participants were familiar with the movements some felt the booklet was not needed anymore. Others reported it was good for reminding them about the movements but felt that attending more sessions and getting more familiar with the movements would be more beneficial.

Um, it's okay now because I think I'm not actually using the books I think I can remember it all. (01002C-I).

As I said, when you first, erm, read it [the booklet] and you're going like that, I don't get it, I don't get...and then another week or two would go by and then you'd feel really silly because that was quite easy. (01025C-I).

Most dyads interviewed reported that it was the carer who mainly used the booklet and the person living with dementia relied on the carer for home-practice (03006C,01002C, 01008C, 01002C, 02002C, 01021C, 01022P,01055). One of the participants living with dementia attributed this to getting muddled up when reading:

Because I've got dementia, I don't follow the book. <01008C> tells me what to do. Because it would be too...take up too much time for me to follow the book. And I get, um, [pause] muddled...sometimes about reading. So, it's easier to learn from <Instructor 1>, <01008C> tells me what to do. (01008P-I).

Some participants checked the booklet together or people living with dementia checked theirs if practising separately. The booklets were used more intensively early in their home-practice. Most of the younger carers (<65 years old) reported practising from memory since the beginning because they had no booklet (01012C) or they memorised all the patterns (01002C). One dyad tried to work out the movements without checking the booklet as a way of stimulating their brains:

03005C comments at the end of session 7 that the booklet is good as a reminder of how to do it, but they are not following it too much when they are doing the practice. He mentions they are trying to do an effort to remember the movements, as he wants to stimulate 03005P. (03005C-FB).

Overall, the participants appreciated the booklet and it was used regularly when practising at home. A few participants could not make any suggestions for further improvements (01009P, 01012P, 03003, 03006). Others reported that the booklet provided a useful guide but that the instruction during the classes were the main source of their improvement in practising Tai Chi (01008, 02002C, 03005, 01021C, 01022, 01039, 01036, 01025). In addition, some reported that the pictures and description of the movements in the booklet were insufficient and that additional information (e.g., DVD or diagrams) would have facilitated home-practice. Finally, a few participants reported that some of the movements described in the booklet were different from the instructions provided by Instructor 1 (03005C, 02002C, 01002C, 01021C), which was reported to the instructor by one carer (01002C) during one of the classes observed.

Because it's like a, it's like a film, er, in stills [the booklet]. (...) You er... They start with... Back in the silent movies and the stills they had separate frames,

didn't they?(...) Then they started to put them altogether and the...it made a continuous movement.(...) Now when it goes in the book it's just showing you one instant of the movement.(...) And how...you can't really show how it got there and how it's going to go on. So, it's really difficult to portray movement in a, in a stationary picture. (01055P-I).

It's just the book, yeah, I do find um, just the stances, it's not, it doesn't always make it plain how the footwork, um, goes. You know, you can see the...certain stances but you can't see the flow of the movement. I think that's, unless you could do a little diagram with the...footwork. I don't know, could you do that? (...) ...so, I think yeah, a bit more explanation um about the movement between the stances. You're seeing the photograph of the stances is good, but you just miss that flow in between. (01039C-I).

It was just as I say, trying to read the book and trying to make sure you were doing it right, 'cause it felt...I felt as if what she's taught us and what...the way the book goes is slightly different. (01021C-I).

The booklet was also more difficult to use whilst doing the movements (01009C, 01036) and some had difficulties understanding or interpreting the information (01039, 01021C, 01002C, 01022C). A couple of dyads mentioned they had discussed how the movements were correctly performed during their home-practice, trying to remember the way they did it in class (03005, 01025).

Well, easy, when you were looking at it, but not so easy when you were trying to do it at the same time as looking at it [laughing]. (01009C-I).

Not as helpful as I would have liked. (...) Well simply because I couldn't interpret it easily. But that was me and my brain. (03005P-I).

Not as helpful as [sigh]...I didn't think it was, um, as well written as it could have been. I thought the descriptions were a little bit lacking. (...) Um, because we're...we're still not properly coordinating our foot movements with our hand movements in our practice sessions. Um, we pick it up...we pick up a bit more every time we go to the class, so it...it's improving but it's not there yet. (01022C-I).

The font used in the booklet was adequate for normal reading but more difficult when practising from a distance (01002C, 03008C). Finally, one dyad reported that the potential benefits were too good to be true:

There was...we...we had a laugh over this because there's one of the warm up exercises that says, this is beneficial to the liver, the spleen and one or two other things. And that caused a laugh because it seemed to have no...I mean, moving your arms very slowly in one or two directions, how is it going to benefit your liver, your spleen and one or two other things? Um, so as I say, we...we've got no [sigh]...I suppose we don't really believe that it's going to be of serious benefit. (01022C-I).

Difficulties to follow the booklet, which could be due to the way the movements were described or the need to have more pictures to show the development of the movements (01021C, 01055C, 01039), would be reduced if video material would be available. Participants also indicated that such video material would be most beneficial if it would include their regular instructor.

7.1.2. Behavioural change elements

At the end of the initial home-visit from their instructor, a copy of the action and coping plan completed with the instructor was provided to the participants, together with a copy of the first booklet, an alarm clock and several exercise logs. At this point, participants were invited to start practising at home. Participants were due to complete a weekly exercise log and return this at each subsequent session.

7.1.2.1. Instructors' home-visit

Instructors found the home-visits useful to explain to participants the relevance of home-practice, make sure they practised safely, get to know the participants a bit more, and perceive their willingness to get involved in home-practice.

Participants appreciated the home-visit and felt that this meant that the instructor showed a genuine interest in them and ensured safe practice. One participant (02002C) was "very impressed" by the instructor visiting all participants in the group, and thought it was a good opportunity to know the instructor better (02002C, 01039). However, a few carers (03003C, 01023C) did not see the value of the instructors' home-visit and suggested that safe practice information could have been provided at the baseline home-visit (01023C). Despite the mixed reaction to the home-visit, none of the participants suggested any improvements to these home-visits to make them more useful to them and their practice.

Um, well she...it was just the explanation and what it was all about and what we were going to be doing. And it sounded really interesting and...we're game for anything really. And it's all in a good cause... (01021C-I).

I think they're excellent. [Instructor's home visit] I really do. Because he can, whoever it is, can get a proper view of, of who you are, and where you are. And they can usually pick up, if they visit you at home, erm...how it is with you. (01009P-I).

I don't think it was [useful]. (...) Well, no, because they're gonna show me at...at the hall. Like I would at home. Umm...no, I...I...yeah, I...I can't see, to be honest, why there would be any advantage, although really it should be, shouldn't it, if they're coming home...(03003C-I).

7.1.2.2. Action and Coping Plans

When asked during the interviews 14 out of 15 dyads reported that they had not used the action and coping plans. Although one pointed out that the coping plan was useful as they could think about what to do when they did not feel well (01055C). Some participants reported that they had not faced any difficulty to find the time to practise (03006), or that they did not practise when they plan to do it (01022), or need to adapt their practice to their other commitments (03008C, 01009C, 01012C).

Something I've filed and... [laughs]. I didn't file it under 'b' for bin I filed it in 'bag' [laughs]. (01002C-I)

Oh, we never do it at the time we say...because we might be doing something else. We might be out. But we'll...we'll fit in a time during the day. [re. action plan: 5 minutes each evening] (...) A...a bit simplistic I thought, but... [re. coping plan] (01022C-I).

I don't [use them], because I just have to, erm, play it by ear, really...as to when we can fit in the, erm, the...[practice] (01009C-I).

I haven't particularly checked them [coping and action plans] have I? Have I? (...) But...it's a good idea to talk it through um to begin with because, you know, there are all sorts of things that can get in the way, can't they? And er, so yeah, it's a good, good thing to think about. (01039C-I).

During the interviews it was common that participants confused the action plan with the weekly exercise logs (01002C, 02002C, 01021C, 03008C, 01036P). Not checking these forms or confusing them did not necessarily translate into a lack of home-practice. Some realised that they had not done as much practice as they initially planned but managed to do as much as they could instead (01012C), or experienced unexpected difficulties (including Adverse Events and Serious Adverse Events) at the time of completing the exercise logs (01008P, 03005P, 01055P, 02002C, 02004C). Other participants, who did not check the initial plan, managed to practise longer and

exceeded the recommended dosage (03006); or practised at different times than reported, and with different patterns, as they saw this worked better for them in practice and were considering extending their practice time once they mastered the patterns.

Well, er, [cough] we do our best, but circumstances [Serious Adverse Events, appointments due to Serious Adverse Events rehab and others described by 01008P] perhaps reduce what we...the time we spend as we should, but we do as much as we can. (01008C-I).

We haven't found any difficulties [finding time to practise at home, as per coping plan]. You know, everything changed with the <Serious Adverse Event 1>, up to then and that's the period we should really look at... (...) Yeah, well we were going to do it with <Formal carer of 03005P> so that was the time, yeah. And over the weekend we did it...fitted it in whenever... (03005C-I).

I think maybe once we get the full sequence and we know what we're doing properly, we'd probably extend the...the...even the times, the...the time we're doing it. (01021C-I).

7.1.2.3. Clock

Only a few dyads commented on the use of the clock provided. None of them used it as an alarm clock to remind them when they were due to do their practice (i.e., to set a time for their practice). Merely having the clock around their home helped some to remind them of their practice (01009P) or was used to check the length of their practice (03006C, 01002C, 01036C). 01002C Added that it would be disturbing to have an alarm reminding her of doing their home-practice. Additionally, a couple of participants reported that their alarm was not functioning (03003P, 01036C).

7.1.2.4. Home-Exercise Logs

Out of the 25 dyads allocated to intervention groups 1 to 6, three either withdrew before starting the classes (01043), before receiving the instructor's home-visit (01015), or did not attend any classes (03007) and hence were not due to return any home-exercise logs. Amongst the rest of dyads ($n = 22$), return rate was 70% (266 received/368 expected).

Most interviewed dyads commented on the home-exercise logs (13/15). It was mainly the carers who completed the logs. One carer suggested that the person living with dementia would struggle to remember to do so (01009C) whereas another could not see its value (03003C). In addition, participants who experienced a Serious Adverse Event and missed a class, frequently forgot to hand in their exercise logs at the following class. Those who regularly completed logs reported that it was beneficial in

raising awareness of their practice and increased motivation to attend upcoming sessions (01002C, 01012C, 01022C, 01025, 01036, 01039, 01008C, 01022C). Others considered completion of the logs as part of the research and of no use to them (03008C, 03005, 01021C, 02002C) and for a few it was “a bit of a bind” (i.e., 02002C).

No, it is quite useful, it is...because you look at it and you think, oh, didn't do any maybe we ought to do some [laughs]. Or we only did fifteen minutes, so we'll do a bit more today. (...) Well it's quite nice, it's like doing the job and ticking it off isn't it, you know how satisfying that is. So, at the end of it I write down twenty minutes and then this little halo comes here, and I go off and do other stuff [laughs]. (...) Yeah, and then I have to say we were away over the weekend I couldn't [laughs] miss, couldn't do my homework at the weekend sorry...Dog ate it? [laughs]. (01002C-I).

Well...ah. If the form wasn't there and we didn't have to report, it's quite possible that we would have done it less. It's possible. Um, because if we don't keep a record, it...I mean, it's helpful for us in a way to have a record of what we've done. You know, we've done it there and then hand it in. I think...there would be...if we didn't have to hand the form in, I think there would be no incentive at all for doing the exercises. So, um, if you...if...the course instructor or you had said, go home and do the exercises and then come back next week and do the next class with no forms, then I think we would probably have done it a lot less. So, the form is there which...helps us along. (01022C-I).

Instructor 2 was not checking the exercise logs in the classes because he did not want to pressure participants. In that regards, two participants wondered during the interview if other participants would be reporting their honest time of practice in the forms and whether the instructor would be able to pick up on this, and they stated that they had been honest (01009C, 01036). However, during another interview, the person living with dementia unexpectedly shared that she had lied in one of the forms, and she was not ashamed of it:

I'm not ashamed that I did, because I thought, 'cause I look like I'm just ignoring it, so I just put twenty minutes, five minutes. (...) Not in that hot weather, I didn't, no. (01036P-I).

Participants did not report any possible improvement for the exercises log. One of the participants living with dementia reported that it needs to be simple as it is, as asking many things or requiring electronic transfers would “put people off” (01039P).

7.1.3. Ways of practising

7.1.3.1. Preferences

Dyads had different preferences in terms of how to implement their home-practice. Some preferred mornings around breakfast (i.e., 01039) whilst others ended up practising quite late in the evening (i.e., 01022). Similarly, according to their needs, some practised in 10-minute blocks (i.e., 01036C) whereas others practised 20 minutes or more continuously (i.e., 01036P). Participants reported practising between 20-30 min/day (03006, 01002C, 01022C, 01036C) or 30-40 min/day (03005C). They tried to fit Tai Chi in where possible. For some, this was done at a regular time slot of similar duration, whereas for others the timing and duration varied. Some participants reported exceeding the advised daily practising duration (20 minutes) because of their willingness to improve a certain movement, to fit in the content in the crib sheets, or because with practice they felt they could handle longer periods.

...quite often we go over (20 minutes) to be honest because of what I've said all the warm up exercises...take up a lot of time. What does tend to get squeezed a bit is the breathing at the end I have to say, because sometimes I'm thinking really you ought to go and get the dinner on [laughs]. You're trying to relax and thinking dinner, dinner [laughs]. But, um, no, I mean, we normally take at least twenty minutes don't we, sometimes...as I say sometimes it's a bit more. (01002C-I).

I actually did forty minutes yesterday, and I didn't, it just went...because I was trying to do that new one, you know. And I kept thinking, I'll do that again, I'll do that one more time. (01036C-I).

A potential weakness of the implementation of the home-practice as per study design was identified by Instructor 2 after having talked with participants in group 8 (not observed as part of this thesis) who seemed not to be necessarily doing the arm work and footwork together at home as planned. Instructor 2 was unsure if this could be due to a time limitation or to the fact that, during the classes, participants were taught first the upper and lower body movements, to later put them together. However, when he was stressing the importance of doing both together at home to the different groups, he had the impression (by the reaction of the participants) that other participants in other groups might have been doing their practice separate as well. This, in turn, could have had an impact on the study's outcomes as some participants might have stressed more the arms or footwork depending of their time availability, preferences, or overall have invested half of their home-practice in each (instead of the full time).

Most participants developed a routine for their home-based practice. However, this was interrupted by visitors, travel, or competing commitments. Participants realised that a routine was beneficial to avoid procrastination and ensure daily practice.

But I, I do it any time. Sometimes morning, sometimes afternoon, sometimes in the evening, so, that's, that's how I am, yeah. (01036P-I).

I think you have to really, because I also think that if you didn't have that piece of paper you would fall by the wayside [laugh]. (...) So I think really it is quite important that you do that and to me it's quite important that you say every day, because then if you miss a day at least you...that's really naughty, but you just think, oh well, you as the...think, well, we have got x amount of time out of them...(...) ...so that's good, yeah. (01025C-I).

We've done eight...the...the first two, we usually do the eight but by that time, I get fed up with the warms up...which is naughty, 'cause that's supposed to lubricate your body, kind of, thing. But they're not...we're too interested getting the...the full Tai Chi done right, you know, so we're too anxious to go on to that...yeah. And <01021P>...the bit when you slow down at the end and the bit where you're doing the...just the breathing like that, <01021P> can't do it because his shoulders...we keep telling him to put it down like that. He doesn't like that one. (01021C-I).

Participants adapted home-practice to their diverse needs. Some developed strategies to make home-practice easier by involving a formal carer, family members (i.e., granddaughter, grandson), or friends when they were together during the Tai Chi practice time (03005, 01012, 01025,01039, 01036). Others used a mirror to facilitate home-practice (01021, 01008), or used music to keep their practice more relaxed and focused and their movements slower (01039).

01039C-I

Um, but sometimes, I mean we've been away a couple of times recently so that's sometimes difficult. But we did get to, in <01039's holiday destination> we did it on somebody's balcony [laughs] and we showed the people we were on holiday with. They watched us didn't they...

01039P-I

They were quite happy with it...

01039C-I

...were really impressed [and joined in].

And granddaughter would join in sometimes. But she's four so you can imagine. But, um, if we said to the family, you know, we're going to practise our Tai Chi then they left us to practise the Tai Chi and then <Granddaughter of 03005> decided that she was going to join in. (03005P-I).

7.1.3.2. Progress over practice

In some cases, both members of the dyad reported having difficulties in remembering the movements at home (03003). In others, it was agreed that the carer started leading home-practice as they could remember more of the movement patterns (03005C, 01025, 01039, 01055).

Progressively, after practice, they felt like they had learnt a lot (03006C) or that the person living with dementia was able to remember the movements at home (01002C, 01021C, 01025, 01036, 01055). One of the dyads even did a demonstration of their knowledge during the interview and the carer added that on a few occasions during home-practice, the participant living with dementia had remembered how to do a movement when the carer was stuck.

01025C-I

Some of the bits, your ball and then going up in the air and then coming down. You could do that, could you?

01025P-I

Mm hmm, yeah, is a ball.

01025C-I

Then you go up above the head.

01025P-I

Then you...let's not get technical.

[Laugh]

01025P-I

The ball. It was up.

01025C-I

Yes.

01025P-I

You bring it down.

Difficulties in remembering movements whilst practising at home might have impacted one dyad. This dyad ended up doing the movements faster than in the classes to avoid forgetting the sequences of movements after reading them in the booklet, which did not allow them to keep their "heads up" and get the benefits of relaxation. Instructor 1 also

noticed during the classes that this was happening as she frequently had to request them to perform their movements slower. However, the carer was confident once they had learnt the sequences by heart, they would be able to adapt their speed and get additional benefits from the Tai Chi:

...so, he can see he's beginning to remember it. So, I think doing it at home really helps that way. But I just need to get...make sure I'm doing the right sequences that follow it. Once I've got them mastered, we'll be fine. (01021C-I).

Participants that described in detail the way they had been doing their home-practice (03006, 03005, 01021, 01008, 01002, 01025, 01039, 01055) generally were the ones who handed back more exercise logs and reported a higher adherence to home-practice (at least until 03005P had a Serious Adverse Event, 01055P underwent a surgery, and considering dyad 01021 joined the intervention later). Participants who practised less at home, also reported less details about their practice.

01055C-I

...to refresh myself, when we'd learnt something in the class and everything, if it was fairly new, what, what we did was we'd built up with what, what we knew, and, and then I sort of...I'd introduce whatever new part, er, <Instructor 2> had taught us, and then we'd practise that. Er, and then sort of, you know...and we continued with that and then we went along. And er, but I...all the time I had the booklet to make sure I was doing it correctly and everything...

01055P-I

That's 'right.

01055C-I

...you know. Yeah.

01055P-I

We remember things a bit, a bit at a time.

01055C-I

Yeah.

01055P-I

And then we'd practise it together.

7.1.3.3. The role of routine

Participants acknowledged the importance of developing a routine to fit Tai Chi into their daily life. Whereas one group incorporated Tai Chi as a daily routine to enhance its mastery and enjoy it for its intrinsic value (03006, 03005, 01002, 01008, 02002,

01012, 01021, 01009, 01025, 01039, 01055), another group was driven by external motives. Although they incorporated Tai Chi in their daily life, it was to get it over and done with (03008C).

It's almost another chore to be done, isn't it? (01022P-I).

It's...it's nothing to like about it. Um, it's part of the, um...the experiment, if you like...and we've committed to doing the experiment, so we'll do what's necessary. But, um, if you said today, oh you don't need to do that any longer, I'd be delighted [laugh]. (01022C-I).

Whereas for a few participants home-practice was motivated by external factors, others carried on even when on holiday or not at their home. Moreover, despite their reported initial embarrassment about practising in front of others (01039C), this dyad opted to practise in public on different occasions:

01039P-I

And we have been out on the heath a couple of times as well so, which is...

01039C-I

Yes, doing it in the fresh air, which is lovely isn't it?

01039P-I

Trying not to scare the people who are on there but...

01039C-I

People don't, they just ignore us. [laughs]

01039P-I

Actually no, they didn't, there was two or three and they just walked past us as if we weren't there.

01039C-I

Which is good yeah.

01039P-I

[laughs] They probably, they maybe thought, oh God, I'm not stopping here.

[laughs]

7.1.4. Home barriers

Despite most participants being able to find time to practise at home, some reported different reasons that might have reduced their practice. Reasons included: a) Not enjoying the home-based exercise, describing it as a "chore" (i.e., 01022, 03008); b) Competing commitments (i.e., 01012C, 02002C); c) Experiencing the consequences of previous or unexpected and unrelated health issues that impacted on both their class attendance and home-practice (i.e., 03005, 01008, 02002P, 03003, 01055) or

occasionally not feeling well (03006, 01022); d) Occasional forgetfulness or procrastination, when saying “We will do it later” and then “the later never comes” (i.e., 01025, 01055, 01039); e) Having a busy day, with family and friends over; f) travelling or holiday; and g) Dyad’s members not living together (01009, 01012, 01036).

No, I don't...I...I...I don't think so, not for me. I think if I was actually doing Tai Chi and getting into it, it might be a different thing and I would do it at home no problem. But I'm not... (03008C-I).

The, the only...as I say, we absolutely loved it, and in fact we were...you know, erm, even after <01055P> had had his operation and everything I was...he did, did a little bit of, err, seated Tai Chi. (...) But he found this [home-practice] a little bit difficult. So, in the end unfortunately he had to stop doing that. (01055C-I).

No, only if you...you were busy, and you've got a lot going on and that sort of thing, then that could take over [home-practice], if you weren't careful, so you do have to be very strict with yourself. (01025C-I).

Some participants clearly expressed a preference for group practice rather than home-practice due to the socialising component “we really enjoyed it when we were with a crowd, you know, with all of us doing the same thing, rather than doing it alone.” (03003C-I; 03008, 01036). Participants found more difficulties to adhere to the home-based compared to the class-based Tai Chi session. The most common reason for this discrepancy was non-spousal carers (i.e., 03008C, 01009C, 01012C, 01036C) with competing responsibilities. The home-based component was designed to become a daily dyadic task and more reliant on participants’ personal commitment. However, for non-spousal carers it was frequently more difficult to find time to practise together; perhaps clashing commitments did not allow them to meet as frequently as desired, hence practice was more commonly done separately or over the phone (01036, 01012, 01009).

I had massive intentions at the start [to practise together at home]. Erm, because, you know, we always spend Thursday together, well we go to the class, Friday evenings, and Sunday afternoons. But... [ended up practising mostly separately] (...) I, yeah, I mean, I just grab, I do practise most days. I mean, there's, I wouldn't say every single day, but most days. And I would think it probably averages, over the week, ten minutes a day. Probably not more, if I'm honest. But, but some days, it's thirty, and then maybe, only, I just do the warm-ups, or the standing still, another day. (...) Yeah, erm, likewise [as the

person living with dementia]. I get a little or a lot, so, put it that way. (...) Yeah, but it, it probably would be better if you said, right, fifteen minutes every day. But life doesn't work like that. (01012C-I).

Dyads practising separately left their practice unsupervised, uncorrected (01009P, 01012P, 01036P) and unguided (01012P, 01036P). In addition, strategies such as practising over the phone, would not necessarily allow the carer to do their practice in full (i.e., “And I can't do the footwork, there's no way over the phone I could manage footwork” 01009C-I) or know if the person living with dementia was actually doing the practice as reported to Instructor 2 at the end of one of the classes (01009C). Hence, two of the non-spousal carers mentioned that such difficulties would not have appeared had they been the spouse, and one of them actively recommended to focus the intervention on spouses (03008C).

That's what I say about maybe, you know, some...some carers are older with their parents and live at home on their own, without family [laugh] but, you know, I find it just, er [voices overlap] and it's like we'll do ten, fifteen minutes here and there, it's like oh, okay [laugh]. Yeah, that was more a chore. (...) It's...it's time as well, you know, I mean, you know, you've got your own life. Whereas obviously, it's another extra bit onto the top of what else you do. I think if you live with someone as in partner, you, you know, do it all together anyway, don't you...(03008C-I).

I think with the target audience, the practice at home is probably the big...biggest issue. Because it's all very well if it's a husband and wife, you know, where the partner is the husband or the wife. (...) I have to say, [home-practice] has been the hardest part...of it. But in order to be better next week from this week, you've got to practise, I understand that. It's just, it is the most difficult part of...but I, I don't, I don't think, there's not a way round that, it's just bad luck that, you know, we're mother and daughter, rather than husband and wife, or whatever. (01012C-I).

A few carers (03006C, 01021C) that attended classes with instructor 1 reported struggling doing the mirror image at home “...the only difficulty is facing each other you're back to front, like mirror image, you know, so I've got to remember the opposite way, but, no, it's fine.” (03006C-I). In contrast, one of the participants under instructor 2's supervision mentioned they were encouraged to practise in parallel by the instructor, to facilitate their home-practice.

Despite the barriers and weaknesses identified and faced by participants throughout their home-practice, one participant living with dementia summarised that it was a matter of willingness to find the time to do the home-practice:

You've got to make time for what you want to do...really. Yes, you have. Yes. You can always find the time if you want to, I reckon. And you can always make an excuse if you don't want to. (01055P-I).

7.1.5. Home facilitators

Despite the barriers and weaknesses identified in the previous subsection, participants also pointed towards different factors as facilitators or strengths of the home-practice: a) The enjoyment of their home-practice and having a laugh whilst practising at home (03005, 01039, 01025, 01055, 01021); b) The expectations of getting better at or achieving benefits of Tai Chi through repeated practice (01036C, 01055, 01008,01009, 03006, 01021C, 02002C); c) The development of a habit and Tai Chi being included in their daily routines (01009, 01022, 03006, 01002, 01021, 01039,01025); d) Doing it together, where the carer provides support and reminds about practice time (03006P,01002, 01021, 01025, 01055, 01039) and with the possibility of involving other family members or formal carers (03005, 01036C); e) Having reminders around the house such as the exercise booklets (03006P) and clock (03006C, 01009P); f) Feeling that if any difficulty was identified it could be clarified with instructor in the following class (02002C); g) Feeling committed to the study (01021P, 01022, 01039) which in one of the dyads translated into the person living with dementia encouraging carer to practise at home; and i) The possibility of carrying the booklets when they go on holiday or do their practice somewhere else (01039, 01002C).

He [01021P]'s more enthusiastic at home. He'll be saying, right come on. Only you call it the dance. The dance, come on, we're dancing now. (...) So, it's him that's dragging me up for it. Not me dragging him up. (...) And I'll say, are we having the night off? No. Come on. Your programme will be on in half an hour. You've got half an hour. You can do it for half an hour. Him that drags me up. (01021C-I).

Well, we...it's...it's nothing...once we...we've considered...if...if it's doing you some good, even if...even if you...you get a bit tired of it after a couple of weeks or something, the fact it's doing you some good, you think, oh, I'll keep this going and then eventually you...you...You're happy with it. (03006P-I).

I've realised that it...that that was Tai Chi. I said it's something you can do it anywhere. Anyway, in a park, on a, on a, on a beach, wherever you want. Yes,

it's, it's... It's a universal thing. You can't say that about everything, 'cos certain things you sort of need set patterns and set equipment and... You don't... With Tai Chi, the only equipment you need is yourself, and that's the beauty of it. (...) If you... It's all about you. That's the art of it. Once you've realised that, you're, you're, you're halfway there I reckon. (01055P-I).

7.1.6. Home-practice's suggested improvements

When participants were asked about ways their home-practice could be facilitated, they either reported no suggestions or improvements to the booklet. The most popular request that came up in participants' feedback and during the interviews was the need to produce a video or DVD complementing the books (as some might not have access to a DVD player), so they could have "someone showing them all the time" (03003, 03008, 01012P, 01022C). Some mentioned having had initial difficulties remembering the movements at home or feeling confident about being practising correctly (01025, 02004, 01021); whereas for others, having a video would avoid them having to stop and check the home-exercises booklet regularly (i.e., 01009, 03008, 01021). Only a few mentioned that a DVD would not be required because the booklet was sufficient (01036C,01012P) or they had no DVD player (01009P, 01055). Some felt that a DVD would be a better alternative to guide their practice and overcome their initial insecurities when practising at home (01021, 01002, 03005, 01025, 01039); others point that this would make home-practice more attractive to those who are not so eager (03008) and that it could make it easier for them to practise longer periods (i.e., 45 minutes) like they did in class (03005). One of the carers suggested to record the instructor during a class with her tablet, so she could feel confident showing the person living with dementia at home; and was also willing to pay for a DVD. However, there was no agreement between dyads with regards to the format of the video; whereas some would only need to have visual cues, others felt they would benefit also from having verbal cues.

That's what we really need. (...) I would make...I thought I'd make a note of that because it's... (...) And it...and at the moment, we're...really, we...we really need somebody there doing it, er, and we follow that, don't we. (01021P-I).

I think a DVD or something, if you're doing it along to something, I think that would be good. You know, like <Instructor 1> there, you...you're, like, in...in something, so you're doing it, rather than standing looking at a book and looking at your wall. It's harder, it's...it's not as enjoyable, obviously. But that's, you know. Unless...unless you're sort of like completely addicted to Tai Chi, which obviously some people are...and that's what they do all the time [laugh], people

I know, um, then they will just meditate and do their Tai Chi, whereas we're looking at the wall. (03008C-I).

Failure to meet such need to further support their home-practice might translate into dyads seeking alternative support without consultation with the instructors. For instance, two dyads admitted having looked at YouTube videos to support their practice realising the movements shown were not exactly the same as the ones they were practising (01039, 01021). For this reason, one of the carers decided to wait and postpone the use of these videos until their participation in the study had finished. One carer reported having bought a beginners Tai Chi DVD to continue their practice after the study period.

Alternatively, those who did not use a DVD or unwilling to use the booklet when away made suggestions to improve the booklet. More pictures or providing diagrams showing the progression of the movements (01039, 01021, 01008, 01002), providing more accurate and detailed explanations as for someone who does not know how to do it, and improving the grammar (01008C, 01022C, 01002). An additional suggestion was to transform the booklets in A3 size flips that could stand on their own, so participants could look at them easily when performing the movements.

Finally, when asked, participants did not know in which ways classes could be improved to facilitate home-practice amongst participants. In fact, their perception was that this was quite an individual decision and that only perseverance could help them to develop a practice habit. Only two dyads suggested a way of promoting home-practice amongst dyads attending the classes by: a) Meeting with other participants to have a coffee at their place and practise together if living close to each other or; b) Ensuring socialising time takes part at the end of the session as per study design.

I don't know, really, I wouldn't know this. Unless they invite each other to do it all together, you know? To practise at home and say are you coming for a cup of coffee and we do some tai chi? (03003C-I).

Well you could...if you added on the...these fifteen minutes where you sat down with a cup of coffee and had a general chat, then that would...you could find out if they do their home exercises and...and encourage them to do it or whatever. Um, and I think it...it does boil down to this...this extra social contact...because while we're doing our exercises, there's no social contact at all. So, it's just the few minutes before and the few minutes after. (01022C-I).

7.2. Impact of the Tai Chi Practice

The last important theme identified through participants' accounts was the perceived impact of their involvement in Tai Chi. This theme includes their feelings before and after joining the study, as well as their reactions to the dyadic component of the intervention and the perceived benefits and harms from getting involved in Tai Chi.

7.2.1. Feelings before and after joining the Tai Chi programme

Motivations to take part in the study included: a) Filling an exercise gap they had had for years since ceased practising other activities such as dancing or swimming due to health reasons (01008), they felt had to be more physically active (01009P), a willingness to try Tai Chi that had never been fulfilled (03005) or a tendency to be open to practise exercise (01022P, 01008P, 01009); b) The potential benefit for people living with dementia (03003P, 03003C, 03006P, 01021C, 03008C, 01025, 01039, 01055, 01022); c) Keeping active and mobile (01002P, 01002C); d) Satisfying the person living with dementia's willingness to take part (03006C); e) Being a gentle exercise (02002C, 01008P); f) Willingness to get involved in anything (i.e., research) that might help the person living with dementia or that might be good for both (01012C, 01009C, 01022C, 01036, 01039); and g) Being somehow familiar with Tai Chi through a friend or family member (03008C, 01009C, 01008P).

Most participants either had no expectations about Tai Chi because they had never practised it before or the Tai Chi turned out to be as they expected, and their perception of Tai Chi had not changed over the trial (03003C, 03003P, 03006C). One of the carers had no initial preconceptions of Tai Chi but after reading information about it had become enthusiastic (01002C). One of the participants living with dementia reported Tai Chi was an adequate and enjoyable exercise for someone of her age, unlike other exercises she had practised and not enjoyed in her childhood (03008P). Some carers felt that Tai Chi could be more relevant for younger people living with dementia, or those at early stages when, in their case, had not been pointed towards exercises or studies involving Tai Chi even if they were looking for them (01002C, 03008C, 01025C). One of the carers reflected that the younger the carer, the more likely is that they will have more energy to be willing to go to the classes and do the home-practice.

Overall participants felt the time they had invested in Tai Chi was worth it, some described it as a valuable time and something that "will last" (03005P), useful (02002C), good (01002P, 01008P), enjoyable (01021P, 01021C), and that Tai Chi should be promoted from youth or early stages of dementia to be able to keep practising throughout the life course (01008C, 01009C, 01025, 01039, 01055P). One of

the carers particularly valued that Tai Chi was a beneficial activity different from the most commonly offered amongst older people living with dementia like painting (03008C).

Only a few people were unsure about continuing their participation in Tai Chi at the end of the study due to the lack of enjoyment of Tai Chi and perceived short-term benefits (01022), competing commitments (01009C), and worsened health condition (02002P). Most reported that they would choose to carry on if offered or that they would choose to carry on practising at home if that would fit their needs better (03006, 03005, 01002, 01008, 02002C, 01021, 03008, 01012, 01025, 01036, 01039, 01055, 01009). Some participants expressed they would be sorry when the classes would be finished (03003P, 03006C, 03005P, 01002C, 01008P, 01012C) and that they would like to be pointed towards similar groups in the community to allow their continued participation (03005).

Some participants were determined to carry on with their practice on their own after their involvement in the study (03006, 01008, 01021, 01002, 01012, 01039). Some with a DVD that they bought or with the videos they found on the Internet. Another dyad (01012) kept practising with the same instructor but in private classes.

...if there's nothing to follow, I think we'll have to find...something similar...to Tai Chi actually, because it's... (...) I certainly wouldn't want to give up, but I think we...we'd hopefully look for a...a morning class or early afternoon. (...) Yes. Yeah, definitely. There's no question about that. (...) Um, there's no way I'm giving up. (01008P-I).

Erm, but hopefully, we can speak to <Instructor 2>and get Mum in on a class to carry on, because it, it, you know, if down the line it is proved that Tai Chi does... (...) Because I believe it is a useful addition to, to Mum's life. (01012C-I).

Participants' involvement in the Tai Chi classes and home-practice did not facilitate nor hindered their participation in other activities.

7.2.2. Impact of a dyadic participation

Most people living with dementia and their carers agreed that taking part together in the Tai Chi classes had been an enjoyable and positive experience. Some people living with dementia pointed that they were used to be supported by the carer, so this was also perceived as a natural approach in the context of their participation in the study (01008P, 01002P) or as a necessary requirement for their willingness to participate (01021P, 01012, 03006).

Well I, I think it's key that, erm, someone in Mum's position has someone who's going through it with them, if you like. Because, you know, it, it's all very well telling her what she should be doing, but actually being part of it, and understanding what the process is, and what the learning curve is. Because of the nature of Mum's difficulties with memory and mobility, erm, having someone who is doing the same thing, who can help, I think is...because even though we don't do it together, we often talk, I mean, we talk about it all the time, because it's some...and it's just something that stimulates her mind and body, that we, we can actually do together. I know that's a bit cheesy, but there's not a lot...(...)...well I think, I think it's really important that, that people, people go with a partner. (01012C-I).

This dyadic approach was also perceived as a good option to support practice at home (when the instructor is not providing guidance) (03003P, 01025C) or to facilitate participation in the Tai Chi in general (i.e., to act as an incentive to continue practising (01009P, 01022P)). One of the carers admitted she would not have chosen to join the study if it had not been required for the person living with dementia to be able to take part in the study. However, at the same time she was aware the person living with dementia would have not been able to take part on his own due to an existing chronic health condition (03006).

Carers did not perceive their dyadic participation as a burden but as an extension of their normal tasks (01021C, 01008C, 03008C, 01009C, 01022C, 01039C) and appreciated it was positive to start a new activity together (03006C, 01012C, 01039C, 01009C, 01036C). One carer wondered whether it might have been good to have had the choice to take respite time instead of attending the classes with the person living with dementia (01025C). A few carers emphasised that even when it was not the aim of the study, Tai Chi had benefitted them as well (02002C, 01008C, 01002C, 01025C, 01039C), though this caused one of the carers to feel guilty when the person living with dementia was not able to join in the practice (02002C).

Whereas most participants reported no changes in their dyadic relationship since they started practising Tai Chi because they had been married for many years or been family members (03006, 03005, 01002, 01008, 02002, 01021, 03008, 01012, 01009, 01022, 01025, 01036, 01039, 01055), several reported it had become a source of conversation between both members (03005, 01009, 01012, 03003) or competition between them (01012P). Attending together to the class led a few of them to do something else together before or after the class (i.e., having lunch (01012), shopping (01022)).

7.2.3. Benefits and harms from practising Tai Chi

Only a few participants reported no benefits from taking part in Tai Chi (02002P, 03008C, 01022, 03006C). They mentioned this was probably because they did not engage in sufficient practice (02002P), were not able to relax whilst practising (03008C), did not appreciate any immediate effects (01022), or having always felt well anyway (03006C).

Not really. Not really, but I'm one of those lucky people that's...touch wood...been well all my life. I don't have any pills, I've...I've all...I don't feel any different to now to when I was sixteen, you know? (03006C-I).

Most participants, however, identified at least one specific benefit from practising Tai Chi either in terms of: a) Physical improvement or maintenance such as feeling fitter, stronger, steadier, more mobile, with a better balance, more aware of and with a better posture (in general and when walking), and needless use of a walking stick (03006P, 03005, 01021, 01002, 01009, 01008, 01012P, 01036, 01025, 01039); b) Mental condition's improvement in form of relaxation and focusing on the moment, or feeling that their brain was functioning better (01036, 03003C, 02002C, 01012C, 01036, 01055, 01025P, 03006P, 03005, 01008); c) A combination of mental and physical enhancement (01002C, 01012C, 01009C, 01055P, 01036); d) Getting out of the house and meeting other people (03003C, 01008C, 03006C, 01021C, 03008P, 01009P, 01039, 01025, 01036); and e) Personal satisfaction and learning a new skill (03003P, 01055, 01036, 01039, 01025).

I think I'm gaining, um, mobility with it, so I'll continue. (...) I feel easier doing it and easier after it. I don't get so many aches and pains as I used to get. So, it's helping in that respect. (01002P-I).

I'm trying to translate it into when we're walking because sometimes, he (01002P) shuffles with his head down and now I'm able to say, remember your Tai Chi head up, heel, toe, heel, toe. So, yeah, it's been useful for that. (01002C-I).

I've got to the stage now, where I don't seem to need to walk, with, with a stick, or, erm. But, erm, I can't guarantee that's forever the same, erm, day in, day out, sort of thing. (01012P-I).

Well, [my previous exercise experience was] physiotherapy and things like that, because I've had, because of my back, and that. But I mean, I never really enjoyed that [laughing]. I used to have to make myself do it. Erm, physiotherapy that I've had for my shoulder, and my back, you know. They give you exercises,

and a lot of them I had to stop, because it did hurt me, the physio. But this [Tai Chi] hasn't. (01036C-I).

Some referred also to the wider benefit of Tai Chi: "Doing us good" (03003C, 03006P, 03005C, 01008C) or "I feel good afterwards" (03006C, 01025, 01036, 01039, 01055). These benefits were achieved implicitly (i.e., "I think you benefit almost without realising. You know, you do all these exercises, and it's doing you the, the benefit." (01009P-I)). Four dyads (01002, 01022, 03003, 03008, 01021) suggested that there would be a long-term benefit if they continued their Tai Chi practice.

None of the dyads reported any harm from taking part in Tai Chi, apart from some stiffness the day after practising (03003P) or hurting joints sometimes, though this was often not attributed to the Tai Chi practice, but to previous conditions and felt "it's better to move than not to move" (01039).

7.3. Differences with the Pilot Intervention Phase

A series of changes were introduced since the Pilot Intervention Phase with regards to the home-practice. For instance, participants were invited to start practising at home after receiving the visit of the instructor from session 2. This allowed participants to become more familiar with Tai Chi before the start of the practice on their own. Despite this improvement in the RCT phase, participants (particularly those carers who were more actively taking in the role of guiding the home-practice) kept feeling uncertain about their correct practice at home, mostly at the early stages of practice.

Having learnt from the experiences of the Pilot Intervention Phase the booklet was subdivided into 3 booklets to avoid overwhelming participants. Also, crib sheets were provided alongside to guide practice each week. In the RCT phase there was no mention of the booklet or its contents being overwhelming, and participants were able to start the movements following the crib sheets. Some difficulties persisted such as getting the progression of the movements from the pictures, which had not been modified after the Pilot Intervention Phase. At this point, most reported having difficulties getting the progression of the movements from the booklet, without the addition of a DVD.

An additional improvement made was providing participants with a copy of the action and copying plans. Despite the efforts to provide the participants with a copy they could have access to, participants did not check these pages once the instructor left their homes. The fact that participants received the home-visit and reflected about the contents of the coping and action plans might have had a positive impact on their

adherence to the intervention as some participants were aware of the answers provided to the instructor when asked towards the end of the intervention.

Finally, detailed instructions were provided with the exercise log, describing the correct way to complete it. This assisted in accurate completion of the logs with only occasional mistakes (i.e., missing writing a 0 when there had been no practice).

7.4. Discussion

The aim of this chapter was to examine two research questions: What is prompting or mitigating participants' adherence to Tai Chi home-practice? And how do people living with dementia and their informal carers experience their joint participation in a Tai Chi exercise intervention? The RCT Phase of the TACIT Trial has highlighted barriers and facilitators to participants' adherence to the home-based component. As in the previous chapter, findings will be discussed here in the context of previous empirical studies around adherence barriers and facilitators, and according to the theoretical approach of this thesis.

7.4.1. Adherence facilitators

Enjoyment of the home-based component (Gonçalves, Cruz, Marques, Demain, & Samuel, 2017), together with participants self-efficacy beliefs, and feeling the benefit of the intervention (Escolar-Reina et al., 2010) facilitated adherence. In spousal dyads, one member's mastery beliefs not only impacted on their own exercise behaviour but spilled over to the other member's (Drewelies, Chopik, Hoppmann, Smith, & Gerstorf, 2018), which would have contributed to their overall adherence.

Home-practice allowed people living with dementia to have more individualised support from carers (acting as role models) to develop motor memory whilst practising the movements they found more difficult during the classes (Barnes et al., 2015; Day, Trotter, Donaldson, Hill, & Finch, 2016a; Suttanon, Hill, Said, Byrne, & Dodd, 2012). Despite not feeling very competent at the early stages, those who were able to practise in dyads shared a laugh, in a more relaxed environment. As the weeks passed, participants become aware of their progress, enhancing their self-efficacy beliefs (Campbell et al., 2001; Essery, Geraghty, Kirby, & Yardley, 2017; Pozehl, Duncan, Hertzog, & Norman, 2010).

Whilst most participants managed to find some time to practice at home, tailoring home-practice to participants' needs and environment to facilitate adherence following previous research's recommendations might have had an impact on the dosage received (Day, Trotter, Donaldson, Hill, & Finch, 2016b; Pitkälä et al., 2013). For

instance, participants not living together or carers with competing roles might end up practising for less time than the advised dosage (20 minutes a day). In comparison with previous research, this study's findings show it was not so much carers' health or lack of commitment (Suttanon et al., 2012; Wesson et al., 2013) that hindered practice but other commitments (such as caring for another family member).

Carers' support facilitated people living with dementia's adherence to home-practice and the lack of a practice companion has been shown to be a barrier for people living with dementia's adherence to exercise at home (Suttanon et al., 2012). In the present study participants practised individually when not living together or having additional caring responsibilities (Connell & Janevic, 2009; Farran et al., 2008). Despite the efforts to recruit dyads who reported meeting at least two days a week, members of the dyad that were not living together reported not being able to practise together for two days a week but on the odd occasion. The flexible schedule might have helped busier dyads to manage to practise either by phone or on their own at different times. Some spousal dyads developed a routine following the instructors' home-visit although practice days and times varied from the action plans. In this study, the carer's role has been particularly relevant in supporting the person living with dementia's practice when there was a spousal relationship. In these spousal dyads the carer often took the lead role, practising the exercises with the person living with dementia (Lam & Cheng, 2013). In this situation, it was the carer who checked the booklet and provided the instructions for the person living with dementia to copy. Regardless of the time spent in joint practice and the different communication styles observed amongst dyads, no changes were reported in their relationships since participation in the study. However, the strength of their relationship at baseline might have influenced their level of participation particularly at home where the routine was to be presented by one of the members of the dyad instead of a more neutral figure (i.e., instructor). Future research would benefit from exploring relationship strength and quality of communication before engaging in the intervention to be able to assess its impact on adherence.

7.4.2. Adherence barriers

Participants' adherence to the home-based component was varied, with some participants practising the required dosage, whereas others hardly practised at all. Reasons for this variation in home-based adherence included, competing commitments, activities, or generally a lack of time (Meyer, Williams, Batchelor, & Hill, 2016). Additionally, regardless of using written materials as memory aids, following previous research's recommendations (Logsdon et al., 2009; Prick, de Lange, van 't Leven, & Pot, 2014), only a few dyads reported feeling confident during their practice following the booklets and crib sheets provided. Challenges of using written materials

with pictures only for home-practice can lead to participants not doing the exercises correctly, as has been previously reported in studies with older adults (Friedrich, Cermak, & Maderbacher, 1996; Meyer et al., 2016). One of the main limitations was the lack of additional visual instruction material. Although some participants might not have had the technological capabilities, future studies should include video material to support the home learning process. This could be provided in different formats depending on the preference of the individual and could include video, DVD, or online material. This would enhance the confidence of executing movements correctly and as such enhance the learning process. Hence, modelling of desired behaviour is an important component of the development of self-efficacy beliefs (Hoogerheide, van Wermeskerken, van Nassau, & van Gog, 2018; van Gog & Rummel, 2010). The provision of additional visual material is also in line with previous studies which have found it was effective to increase self-efficacy and increase the reach of the intervention in older people (Awick et al., 2017). However, the provision of additional materials such as a previous Tai Chi intervention in older adults suggested, would need to incorporate a social component (via community or telematic interventions) to facilitate adherence (Wu, Keyes, Callas, Ren, & Bookchin, 2010).

Despite following the recommendation to use behaviour change techniques to facilitate adherence (i.e., alarm clock, action and coping plan, exercise logs) (Nyman, Adamczewska, & Howlett, 2017), participants did not always use such techniques as intended. The alarm clock, for instance, was used to monitor the amount of practice time instead of using the alarm to remind participants of their practice time. The action and coping plans were completed during the initial home-visit performed by instructors but not checked by participants throughout the study. Some participants pointed out that it was a good strategy to start the home-practice by planning how to overcome possible difficulties. This might reflect the usefulness of the action and coping plans as suggested in the context of the Health Action Process Approach (HAPA), helping in the process of creating more considered plans. That is, considering the beliefs of the individual about his or her chances to succeed in their Tai Chi practice (self-efficacy), and the difficulties that might encounter. This, in turn, highlights the importance of an intermediate step between intention and behaviour, which is lacking in the theory of planned behaviour (Schwarzer, 2016; Sniehotta, Penseau, & Araújo-Soares, 2014). Future studies might benefit from following up the use of action and coping plans. Recording the reasons of any changes appreciated in their practice patterns and encouraging participants to use these forms might help explain to what extent they are useful. Although exercise logs were considered to be helpful by participants (Suttanon et al., 2012) some were unclear about its function. The role of instructors might facilitate its use in future studies. This could be achieved by instructors regularly

checking the logs for completion (as per protocol) and to assist the participants with clarifying its role.

7.4.3. Self-Determination Theory

As with their class-practice, participants started practising at home after the instructor's home visit, to improve their performance and get the benefits of their practice.

According to Self-Determination Theory (SDT), taking part in exercise for health reasons, to avoid shame (i.e., for not being able to show a progress in the next class) or deceiving others (i.e., instructor) are considered to be an external form of behavioural regulation. Such external forms of regulation are common when adopting a new behaviour such as Tai Chi. However, self-efficacy and perseverance at this initial stage helped some participants to progressively internalise their practice. Continued practice allowed the development of intrinsic motives (i.e., enjoyment) which ended up dominating motivation and resulted in participants sustaining their home-practice (Ingledeu, Markland, & Medley, 1998). Additionally, feeling the benefits of practice (i.e., such as a reduction in stress levels or feeling well after practising) seem to be related with well-internalised or even intrinsic forms of motivation as had been found in younger populations (Ednie & Stibor, 2017). The internalisation process was facilitated by enhancing their perceived competence and self-efficacy through the progressive nature of the learning process and receiving positive feedback from the instructor during the classes (acknowledging their hard-work at home). This also resulted in participants finding solutions to barriers including visitors or going away (Sebire et al., 2018).

Nevertheless, some participants seemed not to internalise their home-practice and remained driven by extrinsic motives (i.e., their commitment to the study). This might explain to some extent their poor adherence to home-practice. In addition, these participants might have missed the socialising part (relatedness), maybe felt less competent when practising at home (for not having a professional to model and feedback on the movements), struggled to find time to practise, or just lacked the motivation (Wu et al., 2010). To this end some evidence suggest that professional feedback enhances adherence (Room, Hannink, Dawes, & Barker, 2017), hence further support from the instructor after each class might have been beneficial. As indicated, these participants described their drive to practise at home was based on their willingness to comply with the commitment they agreed on when joining the study. Hence, they ended up describing home-practice as a "chore" (Lamb et al., 2018), which seemed to reflect a less autonomous form of extrinsic motivation.

7.4.3.1. Competence

Whereas the classes provided a task oriented-motivational climate through clear instruction and positive feedback from the instructors it is unclear how carers assisted in developing a similar environment at home. The fact that some carers felt less competent in the execution of movements might point to providing insufficient instructions and feedback to develop a home-practice climate conducive for continuous participation (Room et al., 2017). This could be overcome in future research by introducing additional instructor's home-visits at the initial stages, so participants receive feedback and support regarding their home-practice (Meyer et al., 2016).

Competence perception might have been enhanced by carers who were determined to persevere and less worried about interpreting the booklet wrongly at the initial stages. This time might have given them the opportunity to get more familiar with the movements and build up their competence perceptions. By appreciating the participant living with dementia and their own's improvement, such competence need might have been supported. Their competence perception might have translated into a higher feeling of control of the Tai Chi movements and a better position to overcome any other barriers to practise, which might have reflected a greater autonomy in their practice (Russell & Bray, 2009).

7.4.3.2. Autonomy

Participants would have been fully autonomous at home, where they could do as much or less practice as they chose despite the recommended dose, to match their goals (Mehra et al., 2016). Determining the autonomy of those with difficulties to remember about their home-practice might be hard in the context of this study as no observation of the home-practice was performed. However, their comments reflect the carer was frequently prompting their joint practice. Autonomy need might have been indirectly supported through participants' involvement in Tai Chi when their participation had an impact on other aspects of their life. For instance, some perceived an improvement in their posture when walking or their confidence, to the extent that one of them opted to walk without stick.

7.4.3.3. Relatedness

The encouragement to conduct home-practice together might have resulted in meeting relatedness needs. However, participants did not report the Tai Chi intervention nor home-practice had led to any changes in their relationship. That said, participants seem to prefer the classes and the social interactions associated with this. Previous

research has indicated that social activities are important to be included in exercise programmes to enhance enjoyment and adherence (Mehra et al., 2016).

7.4.4. Additional theories

Apart from SDT, self-efficacy (from Social Cognitive Theory) (Bandura, 1977, 2002) might help to explain why home adherence is problematic. Hence, an important driver of self-efficacy is a reliable model. Previous studies have indicated that this is a limitation of home-based exercise interventions albeit in heart failure patients (Rajati et al., 2014). That said, high self-efficacy believes, together with a more self-determined motivation towards exercise developed over classes might have spilled over to home-based practice in those who adhered higher ((Russell & Bray, 2009). In turn, adherent participants might have progressively developed their self-efficacy at home by perceiving their improvements and the physical feedback (relaxation) (Lee, Avis, & Arthur, 2007).

Habit theory (Verplanken & Aarts, 1999) might also contribute to explaining the impact of repetition on participants' adherence. This is because repetition was a key component of the classes and home-practice but also of habit development (Gardner, de Bruijn, & Lally, 2011). Some dyads acknowledged having made an initial effort to turn their home-practice into a habit, however, those who kept practising regularly at home might have developed it. In fact, dyads with better adherence mentioned having progressively incorporated Tai Chi into their daily routines or created a habit (Jansons, Robins, Haines, & O'Brien, 2018; Meyer et al., 2016), and did not need to plan their practice ahead. However, although adherent participants in the present study reported to have developed such habit, previous research has also indicated that reliance on self-report might result in overestimation of its effect (Gardner et al., 2011), which would require these findings to be taken with caution.

7.5. Strengths and Weaknesses of This Study and Future Research

7.5.1. Strengths

This study has some strengths, such as the inclusion of participants with very different adherence levels to the home-based component, including participants who withdrew from the classes. Despite all participants being of the same ethnic background, there is a diversity of levels of adherence and barriers and facilitators captured. Another strength was the use of dyadic interviews over other methods to explore their experiences. Perhaps a group format of data collection would have refrained their free expression (i.e., might have avoided to say openly that it was a chore or boring for

them). Additionally, the dyadic approach of the interviews allowed both members of the dyad to contribute (Morgan, Eliot, Lowe, & Gorman, 2015) and sometimes the carer provided support (Suttanon et al., 2012) by clarifying questions. Their answers seemed honest, in line with previous reports during the classes, and hence not necessarily affected by the presence of the other member of the dyad. As with the class-based data, to ensure the trustworthiness of the qualitative findings a series of strategies were used (Noble & Smith, 2015). For instance, participants were asked at different stages and using different methods (fieldnotes and interviews) about their home-practice and dyadic participation experiences. Later, data was triangulated (Leung, 2015), and it was found consistent throughout reports.

7.5.2. Limitations

Among the limitations of this study, the main one would be that opinions were not captured whilst or just after doing their home-practice, which might have facilitated the task of reporting the difficulties and strengths of the intervention. Furthermore, as adherence to the home-based component was not objectively measured, there is always the risk of participants reporting more than what they did (as one of the participants admitted) (Gardner et al., 2011) to avoid feeling bad when handing the exercise logs to the instructor. If this had been a common case, which some spontaneously reported it was not, it could have an unknown effect on TACIT Trial's outcomes but also on participants' accounts. After all, it is not the same having been practising regularly than not. Similarly, it is difficult to tell, unless they explicitly mentioned during the interview, if they did all parts of the practice (warm-up, Tai Chi patterns, cool down). Hence it would have been better perhaps to ask directly the participants some questions such as if they completed all these parts or if they would have preferred to attend more classes instead of being asked to practise at home.

7.5.3. Future research

Future research could try to understand better how dyads take part at home by including a home-visit of the instructor e.g. half-way through their practice. This visit could be used to make notes on how they practice (fidelity of the home-practice) and perhaps to conduct an interview with the dyads. This would help identifying any difficulties they might be facing, both remembering the moves or finding the time to practise, which could be addressed by the instructor. Similarly, it could be explored to what extent the instructor having a look at the exercise diaries during classes would have a positive or negative effect on their practice. Hence, this might have been perceived as an external pressure for dyad's to practise; or, on the other hand, perceived as an interest in their well-being and practice allowing for early detection of

difficulties. Both strategies would be less intrusive than asking participants to video record themselves but could potentially help to detect barriers. Additionally, and even less invasive, exercise logs could contain an open box for participants' comments on their difficulties to reach their target practice weekly. In the context of dyadic interventions, it could be interesting to add a few qualitative questions to the baseline data collection. This way, dyads could be asked openly about their motivations to take part in the study and about their dyadic relationship (i.e., what activities they practise together or how they get on e.g. if one is "bossy" over the other one or have quite a balanced relationship). Later, when exploring their experiences towards the end of their participation in the intervention, they could be asked to describe their relationships again, to then see whether there are any changes. Most dyads in this study reported no changes to their dyadic relationship, however, small changes in their daily lives could go unnoticed. Finally, the introduction of a DVD/video to their home-practice needs to be studied in terms of its impact on their adherence.

7.5.4. Novel contributions

The novel contributions made through this chapter relate to the evidence produced as well as the methods used. This is the first study to explore the experiences of those living with mild-to-moderate dementia and their carers practising Tai Chi at home for around 18 weeks. This exploration is relevant in the context of exercise research for people living with dementia as home-practice might support the development of a habit, as well as the maintenance of practice beyond the study period, and reduce the costs of delivering an intervention in person. Similarly, this is one of the few studies using qualitative methods to explore participants living with dementia and their carers' experiences of taking part in an exercise intervention. This qualitative exploration, and particularly the use of semi-structured dyadic home-interviews, have been found useful to create a comfortable environment where the person living with dementia could freely contribute.

7.5.5. Practical implications

The practical implications of this study point towards the need of participants living with dementia and their carers to have more support (namely a DVD, in absence of a private tutor) at least at the early stages. Whereas most enjoyed the class-based component, home-based practice was only enjoyed by some. Considering the importance of developing exercise routines, any strategy that might be perceived as attractive should be implemented. Similarly, more objective monitoring of home-practice (i.e., through home-practice observations) might help with early identification of barriers to adherence and, in turn, an early intervention or support. The socialising time

at the end of the classes could be used to prompt participants to talk about their home-practice experience. This, in turn, could contribute to learn new strategies from peers to enhance adherence to home-practice.

7.6. Summary

This chapter provides an overview of participants' experiences regarding home-practice and points the main barriers and facilitators to participants' adherence to Tai Chi for a period of around five months. Amongst the most common barriers to adherence were participants' concomitant commitments and the booklet that was not easy for them to follow due to a lack of illustrations/DVD. Amongst the most common facilitators were the enjoyment of the practice and the development of a habit, which was supported by their commitment to the study and their willingness to benefit from Tai Chi.

8. Epilogue

The aim of this chapter is to provide a closure to this thesis, summarising its key findings through its different sub-sections: 8.1. Addresses how the thesis has met the aims and objectives; 8.2. Reflects on the impact of the Pilot Intervention Phase on the RCT Phase; 8.3. Highlights the qualitative rigour of this thesis; 8.4. Recapitulates on this thesis' findings; 8.5. Highlights this thesis' contribution to knowledge; 8.6. Considers the strengths and weaknesses of this thesis, reflecting on the practical implications; and identifying future research gaps and directions; and 8.7. Highlights this thesis' closing remarks and novel contributions.

8.1. Aims and Objectives

The main aim of this thesis was to provide an insight into participants living with mild-to-moderate dementia and their informal carers' needs and preferences influencing their acceptability of and adherence to a Tai Chi exercise intervention. Sustained adherence to exercise interventions is challenging across the life course (see Chapter 1), hence this thesis' objectives were focused on understanding participants' experiences and needs to facilitate their engagement.

In the literature review (see Chapter 2) few studies were found to involve community-dwelling people living with dementia in Tai Chi interventions. This despite there being some evidence for its effectiveness in falls prevention amongst older adults. The review of the literature identified a need for the formal exploration of participants living with dementia's experiences of participating in Tai Chi, and more broadly in exercise interventions to prevent falls (Meyer, Hill, Dow, Synnot, & Hill, 2015; Peek et al., 2018). Therefore, this thesis examined three specific objectives seeking to:

1. Identify practical issues of the Tai Chi intervention and research process that are interfering in participant's acceptability of the intervention.
2. Enhance knowledge and understanding on what aspects of the Tai Chi exercise intervention influence participants' engagement in order to increase their adherence to the intervention and potentially increase its impact in future research.
3. Understand how people living with dementia and their carers experience their joint participation in a Tai Chi exercise intervention.

Qualitative methods (see Chapter 3) were used to collect data from dyads of participants (formed of those living with dementia and their informal carers), instructors,

and the researcher (author) throughout the two phases of the TACIT Trial, where this thesis was embedded. In the Pilot Intervention Phase (see Chapter 4), the first objective was met by observing participants attending the three or four sessions offered and collecting their feedback at the end of the classes (n = 10 dyads), collecting feedback from the senior instructor at the end of the classes, and through two dyadic focus groups organised (one at each site) involving seven dyads in total.

The second and third objectives were fulfilled in the RCT Phase of the TACIT Trial (see Chapters 5 to 7), after observing participants and getting their feedback at the end of the classes (n = 22 dyads), collecting feedback from both instructors involved, and interviewing dyads at home (n = 15 dyads).

8.2. Pilot Intervention Phase and RCT Phase

As planned, the Pilot Intervention Phase's findings informed further adjustments to the TACIT Trial's design to facilitate dyad's adherence to the Tai Chi exercise intervention. The acceptability of the intervention was initially established in the Pilot Intervention Phase and later confirmed in the RCT Phase. Improvements made after the lessons learnt from the Pilot Intervention Phase, had a positive impact on RCT participants' experiences (i.e., the content was found appropriate by carers and people living with dementia, the booklet was not perceived as overwhelming, and the exercise logs were not found to be complicated). Similarly, what remained unchanged (i.e., booklet's explanations and pictures, and the absence of a DVD) was again reported as a weakness in the RCT Phase. These findings demonstrate a strength of using qualitative methods alongside RCT studies (O'Cathain et al., 2014; O'Cathain et al., 2015; Rapport et al., 2013). This thesis stresses the value of piloting interventions before running full RCT studies; particularly in populations where interventions have not been widely tested before (Moore et al., 2015). Similarly, the Pilot Intervention Phase was equally valuable to establish the feasibility to recruit the number of participants targeted at the RCT Phase, as the conversion rates (from referred to recruited) was similar in both phases (22% versus 24% respectively). The estimations about the time required to reach the required number of referred participants was the same as if no changes had been introduced in terms of recruitment sites from the Pilot Intervention to the RCT Phase (26 months). In brief, the Pilot Intervention Phase's findings contributed to the refinement of the RCT Phase but also to produce evidence-based recommendations summarised in a published paper (Barrado-Martín, Heward, Polman, & Nyman, 2018) that will be useful to facilitate the acceptability of future exercise interventions/programmes targeting people living with dementia and their carers. In this line, two further publications (under development) will contribute to

understand how better design and deliver class and home-based exercise interventions to facilitate people living with dementia and their carers' adherence.

8.3. Qualitative Rigour

Throughout both phases of the study (see Chapters 4 to 7) qualitative rigour was ensured through reflexivity and by introducing strategies to enhance the following aspects (Daniel, 2018; Noble & Smith, 2015; Noreña, Alcaraz-Moreno, Rojas, & Rebolledo-Malpica, 2012):

a) Credibility:

- Presenting verbatim quotes from participants as well as dissenting views (see Chapters 4, 6 and 7).
- Observing participants and having a continued relationship with them over their involvement in the study, rapport was progressively developed with the author.
- Having 10% of the data double coded by another researcher, and supervisor of this thesis, following a codebook (that included a "set of firm coding rules" (Smith & McGannon, 2018, p. 11)) developed by the author of this thesis (see the one developed for the RCT Phase in Appendix W).

b) Transferability:

- Providing a thick description of the intervention context and participants' demographics (see Chapters 4 and 5).
- Acknowledging strengths and weaknesses of the data collection processes, as well as describing how data collection took place.

c) Dependability and conformability:

- Filling a research diary, keeping this thesis author's reflective notes and impressions separate from field notes (describing what was being directly observed or what was being feedbacked by participants and instructors). Hence, this helped to provide an accurate report of findings accounting the origin of the data.
- Audio-recording and getting verbatim transcriptions of the interviews and focus groups.
- Having quality checks performed by thesis' supervisors checking codes and its contents.
- Using triangulation at the participant and method level. That is, the views of individuals with different roles in the intervention context were accounted to enrich the analysis (people living with dementia and their carers, as participants, instructors and the researcher). Similarly, different methods of

data collection (dyadic interviews or group discussions, observations, and feedback provided at the end of the classes) were used to collect participants' views. Reports throughout methods and participants were found consistent at both stages of the study.

- Checking inter-coder agreement levels (MacPhail, Khoza, Abler, & Ranganathan, 2016) and calculating the Kappa value (i.e., in the Pilot Kappa value was .71, showing a moderate level of agreement, and in the RCT Phase it was .90 showing a strong level of agreement, and that most quotes were coded to the same codes by both researchers).
- Describing author's background, acknowledging its potential impact on data collection and analysis.
- Using NVivo 11 to keep together the different data sets and facilitate an audit trail; but also, to support the processes of coding, extracting and performing data checks during the analytical process.

Throughout this thesis the author was committed to capture the views of those living with dementia and their carers, with an emphasis on the first ones, who had received less opportunities previously in the literature. The provision of varied quotes from both members of the dyads (in Chapters 4, 6 and 7) highlight people living with dementia's ability to successfully report on their experiences and make contributions as valuable as their carers'.

8.4. Thesis Summary

This thesis confirms the appropriateness of Tai Chi for community-dwelling people living with dementia and their informal carers. The RCT Phase's findings suggest that Tai Chi was well received amongst participants in the mid-term (up to 20 weeks). Furthermore, findings suggest Tai Chi could be sustained in the long-term with most participants willing to extend their participation in Tai Chi at the end of the study. Some participants would have liked to be given the opportunity to join a Tai Chi class at an earlier stage after their diagnosis. They thought this would have allowed them, or their loved ones, to have a better physical condition when their dementia was advancing. Others would have liked to have the option to decide whether to take part in dyads or independently, which would have provided carers with the chance to have respite. Similarly, people living with dementia's ability to join the intervention on their own would have facilitated recruitment of those living more independent in the community or with no informal carer available. Unavailability of a carer has been reported as a barrier for people living with dementia's inclusion in trials (representing nearly 40% of the exclusion reasons) (Rollin-Sillaire et al., 2013). The dyadic approach, however, was

welcomed by participants recruited at both stages of the study and was a factor that appears to have contributed to their participation in this trial.

Adherence to class-practice was better than home-practice. This is best explained by differences in enjoyment between the two forms of exercise and the ability to socialise during classes. The role of enjoyment or pleasure has been frequently forgotten when studying behaviour maintenance in health research (Phoenix & Orr, 2014). However, frequently the pleasure of feeling the flow of the moves, of recording and reporting adherence to the agreed practice, of rehearsing the movements over and over again, and the focus in one's own body and mind has a relevant impact on behaviour maintenance (Phoenix & Orr, 2014). In addition, the absence of a qualified instructor, an unclear booklet, and the absence of video material to support movement execution might also have played a role in differences in adherence between class- and home-based exercise. Finally, differences in motivational orientation might also have played a role. For example, some carers participated because the intervention might be beneficial for the person with dementia. Research has suggested that those who engage in exercise programs for extrinsic motives are less likely to continue the behaviour in the future (Ingledeu & Markland, 2008).

Class-based practice received positive feedback at both stages of the study, both in terms of its characteristics and participants' reactions to it. Contrary to previous research, this thesis' findings do not support that cognitive impairment or decline, memory difficulties, mood, nor behavioural challenges were a barrier for people living with dementia's participation and adherence to the Tai Chi exercise intervention (Day, Trotter, Donaldson, Hill, & Finch, 2016; Lam & Cheng, 2013; McCurry et al., 2011; Teri et al., 1998). In fact, the later (mood and behavioural challenges) were mostly absent during the sessions. Instead, it was found that people living with dementia were generally able to copy the instructor's movements and follow the class with none or little help from carers. The task oriented motivational climate during the classes, which was indexed by tailored support and positive feedback provided by instructors, might have contributed to participants' enjoyment and willingness to keep improving in their practice (Yao, Giordani, & Alexander, 2008).

Home-based practice seemed to be more challenging in both the Pilot Intervention and RCT Phases. Important reasons, as indicated previously, were the lack of a qualified instructor, unclear booklet and absence of additional video material. At home, carers were frequently providing support, although there were some exceptions. Carers' attitudes towards Tai Chi and their lack of confidence (in the Pilot Intervention Phase) and different dyadic relationships (in the RCT Phase), together with competing

commitments, and time constraints (in both phases) had a higher impact on their adherence to the home-based component (Prick, de Lange, van 't Leven, & Pot, 2014).

Previous research has suggested that tailored home-exercise (Close et al., 2014; Teri et al., 1998), the use of behaviour change techniques (action and coping plans) (Brown et al., 2015; Connell & Janevic, 2009), and exercise logs (Suttanon, Hill, Said, Byrne, & Dodd, 2012) can help in improving adherence rates. However, in this study, most participants did not check the coping plans or thought they would need to make room for practice on the go (Warner, Wolff, Ziegelmann, Schwarzer, & Wurm, 2016) and perceived the exercise logs as merely part of the research. Perhaps an explanation about the usefulness of these action and coping, both for research but also to facilitate their adherence could help participants to understand their purpose, as well as the importance of returning their exercise logs. This would be important to enhance self-monitoring, but also for research purposes (improving data completion) and for the instructors to be able to provide further support. Additionally, the weekly falls calls made for safety monitoring purposes (Close et al., 2014) were occasionally perceived as an encouragement to participants' adherence to the intervention (Brown et al., 2015; Connell & Janevic, 2009), which might have contributed to enhanced adherence rates.

Having previous exercise experience might have helped some dyads with adhering to the program (Burton et al., 2015; Day et al., 2016; Suttanon et al., 2012); although some individuals with previous exercise experience might have found Tai Chi not as intense as they would have expected (i.e., with a personal trainer or going to the gym). However, the enjoyment of the classes and the socialising component seemed to help both people living with dementia and their carers to accept and adhere to the classes (McPhate et al., 2016; Yu & Swartwood, 2012). Perceived benefits such as physical improvement (i.e., in strength and balance), cognitive (i.e., concentration) or mood and relaxation have also contributed to their sustained practice (Day et al., 2016; Frederiksen, Sobol, Beyer, Hasselbalch, & Waldemar, 2014; Lo et al., 2018; Yu & Swartwood, 2012).

Research in older people, including people living with dementia, has found that previous health conditions are the main reason to withdraw from studies. This was also the case in the present study (Burton et al., 2015; Chong et al., 2014; Connell & Janevic, 2009; Farran et al., 2008; Hawley-Hague et al., 2016a; Lam & Cheng, 2013; McCurry et al., 2011; Prick et al., 2014; Suttanon et al., 2012; Wesson et al., 2013).

Overall, people living with dementia's involvement in Tai Chi was feasible, not only because participants were able to copy, but also because they were able to learn and perceive their improvement through practice (through the development of perceptions of competence and/or self-efficacy). Several participants living with dementia were able

at both phases to the study to recall and reproduce verbally or physically instructions provided by the instructor (i.e., regarding body posture or movement's explanations, during focus groups and dyadic home-interviews), even when they reported to have memory difficulties (Ullén et al., 2012). These findings point towards' people living with dementia's ability to learn cognitively (and recalling instructions, that had been repeated over sessions) in some cases and, particularly, in a more tacit and less conscious way, through motor learning (Fenney & Lee, 2010; van Halteren-van Tilborg, Scherder, & Hulstijn, 2007).

8.5. Contributions to Knowledge

This section provides a summary of this thesis's contribution to theory, practice and data collection methods.

8.5.1. Contributions to theory

In this study, self-determination theory (SDT) (Deci & Ryan, 2000) helped to explain how participants' different types of motivation and regulatory styles have impacted on their adherence to the class- and home-based component. This is in line with previous studies suggesting that SDT is a useful theory to explain the influence of motivational orientation on exercise behaviour (Hagger & Chatzisarantis, 2008; Slovinec D'Angelo, Pelletier, Reid, & Huta, 2014). Both members of the dyads who valued the intervention appeared more autonomously motivated and excited about taking part in the classes and home-practice, which translated into higher levels of adherence (Fortier, Duda, Guerin, & Teixeira, 2012; Weman-Josefsson, Lindwall, & Ivarsson, 2015). Perceptions of personal importance also resulted in better adherence. This finding would support the suggestion that varied forms of autonomous regulation besides intrinsic motivation are relevant to adherence (Edmunds, Ntoumanis, & Duda, 2006; Mullan & Markland, 1997; Teixeira, Carraça, Markland, Silva, & Ryan, 2012). Despite being motivated (and express intention to practise when joining the study), adherence was influenced by adverse health events and closeness of the dyad (living together or not). Regarding the latter, dyads not living together might have greater difficulty to engage in home-based practice (e.g., because of competing commitments such as caring for another member of the family).

The gap between intention and behaviour, which has been a criticism of the intention-based theories such as the theory of planned behaviour (Sniehotta, Pesseau, & Araújo-Soares, 2014), has appeared once more in the TACIT Trial. Participants generally expressed their intention and confidence to be able to attend classes and practise for twenty minutes a day (when joining the study). Nevertheless, their

adherence to the class- and home-based component varied in practice, which highlights the intention-behaviour gap. Such gap seems to be better filled by SDT, and the role of motivation in sustaining behaviour.

Whereas participants were driven by extrinsic motives for participation when enrolling in the RCT overtime this shifted to intrinsic motives to continue the behaviour (Eynon, O'Donnell, & Williams, 2018; Slovinec D'Angelo et al., 2014). Motives became internalised following participation in the trial. Tai Chi became a more self-determined activity and a routine in participants' life. For example, some joined the TACIT Trial because they valued the potential of the intervention to benefit the person living with dementia and the carer and felt it was worth trying. Following involvement in the classes, they moved to a more intrinsic regulation as they found they wanted to carry on practising for their inherent satisfaction and enjoyment of the activity (Eynon et al., 2018). The fact that participants felt good after practice (Ednie & Stibor, 2017) might have helped in the internalisation from an external to a more intrinsic regulation of the Tai Chi. It would therefore be important in future settings and interventions to facilitate the internalisation process by supporting basic needs and contributing to the development of self-determined behaviours.

Supporting previous findings in cardiovascular patients, participants who seemed intrinsically motivated to attend classes (i.e., reporting on their enjoyment of their practice) were also more likely to be motivated and engage in motivation to the home-practice (Russell & Bray, 2009). They practised to improve and sustain the enjoyment of the intervention. These participants seemed less focused on obstacles like the weaknesses of the booklet and considered this sufficient.

Self-Determination Theory (Deci & Ryan, 2000) also suggests individuals require their three basic needs to be fulfilled to ensure their well-being and continue the exercise behaviours. As in previous studies, findings of the present thesis suggested that higher levels of competence need satisfaction was associated with higher levels of adherence. All three needs were not satisfied in the same manner across class- and home-practice. Whereas relatedness was an important aspect of class-practice this was not the case for home-practice. Findings regarding autonomy were equivocal. It appeared that participants had more autonomy during home- compared to class-practice. Importantly, however, none of the needs was thwarted (Bartholomew, Ntoumanis, Ryan, & Thogersen-Ntoumani, 2011). As suggested by Fortier et al. (2012), needs are not always satisfied directly through a need supportive environment but can be mediated by the social environments and the characteristics of the individual (Fortier et al., 2012). Participants who withdrew from the study might have had higher expectations on the outcomes of their performance. However, this could also be the

result of social comparisons (feeling that they were not able to do what other participants could) and a perceived lack of competence. Despite the connection with others in the group existed (relatedness), seem not to be enough to retain these dyads, which might explain the mixed results reported by a systematic review (Teixeira et al., 2012).

Generally, participants who were struggling with the exercises kept believing that they would be able to improve progressively to one day master Tai Chi (highlighting the importance of self-efficacy (Bandura, 1977)) (Ball, Bice, & Maljak, 2017). Participants progressively perceived an increase in competence that boosted their confidence and self-efficacy levels; which is in line with previous studies finding the later to be related to attendance to exercise classes (Selzler et al., 2018). This increase in their perceived competence, would have contributed to their internalisation process and to transform their regular practice into a daily habit (Verplanken & Aarts, 1999).

8.5.2. Contributions to practice

This thesis provides information regarding the experiences of people living with dementia and their carers involved in a Tai Chi exercise intervention. Its findings provided important information on the barriers (i.e., booklet) and facilitators (i.e., perceived benefits) identified by people living with dementia and their carers. Such barriers and facilitators would have had an impact on their acceptability and adherence to this exercise intervention and should be considered by those planning to design or deliver similar exercise interventions/programs in the community.

In terms of the contents of the classes, these need to be adapted to participants' needs and capabilities. Findings showed that learning five patterns over twenty weeks was appropriate. People living with dementia and their carers appreciated and were aware of the need for repetition to both facilitate their learning process and improve their practice. This supports the idea that setting achievable goals is important for the success of an intervention targeting people living with dementia (Jennings et al., 2017).

Instructors familiarisation with participants and their motivations to join exercise interventions can be relevant to facilitate adherence. This can be promoted before and after the classes, or during the context of a home-visit if one is to be scheduled to promote practice at home. Instructors' awareness of the motivations of their participants/clients can help them tailoring their feedback and support their internalisation process better. This, in turn, might contribute to participants' greater adherence.

Generally, dyads reported that class-practice was easier than home-practice. However, the role of home-practice in sustaining behaviour through its incorporation in daily

routines needs to be acknowledged. An adequate balance between both, to benefit from the social interaction and the habit formation, might be key. For instance, those dyads not living together might find it easier to commit to more weekly classes instead of arranging their dyadic practice at home; whereas dyads that live together might prefer attending one class per week and do the rest at home to fit the recommended dosage around their other responsibilities.

For home-practice, providing participants with a video additionally to the booklet is necessary for people living with dementia and their carers who feel unsure when practising on their own. Alternatively, the introduction of other forms of materials (i.e., visual graphs with arrows) that help people living with dementia and their carers to perceive the progression of the movements might be helpful.

The dyadic approach, which had been scarcely used in exercise interventions for people living with dementia, has been successful in the TACIT Trial context and beneficial for both members of the dyad (Yu & Swartwood, 2012). This finding contrast with a previous process evaluation of a dyadic exercise study where carer's burden was reported as a barrier for adherence (Prick et al., 2014). Such difference could be due to the intensity of Prick et al. (2014)'s intervention in the context of an already intensive usual care (consisting of attending 1-2 times per week a day-care centre plus receiving regular home-visits from a counsellor). Participants in Prick et al. (2014)'s study received eight further 60-minutes home-visits where exercises were progressively introduced, however, these were perceived as "too complicated" (Prick et al., 2014, p. 12). This contrasts with carers' in the TACIT Trial reporting the appropriateness of Tai Chi compared to other types of exercise (i.e., swimming if the person living with dementia did not know how to swim) or activities (i.e., painting) offered in the community. Although the dyadic approach was successful in the current trial, in the future exercise programs could leave the choice to take part together with the dyad. This would allow some time-out for willing carers and facilitate the inclusion of people living with dementia without a carer.

8.5.3. Data collection methods

This thesis used qualitative methods for the first time to gather the views of people living with dementia and their carers taking part in a Tai Chi exercise intervention. The strengths and limitations derived from the use of qualitative methods are summarised next according to the experiences implementing each method.

A weakness is that sessions could not be video recorded and instead the researcher made field notes of observations of the classes. This might have led to missed details from the session setting and its development. Similarly, the time allocated to collect

feedback at the end of the classes was limited as participants were either engaging in conversation with others or leaving the venues soon after the classes' ended. This was also the case for collecting feedback from the instructors. At the end of the classes it was frequently difficult to find the space or time for individualised feedback collection, and often participants were in front of others (sometimes also with instructors around), which might have affected their feedback. However, the strength of field notes is that occasionally instructors were willing to provide this feedback through the class registers, which provided a continuous picture of the classes' progress. Similarly, being in touch with participants on a weekly basis over the telephone allowed them to share any additional and more personal feedback (with the author) over the phone if they wanted to.

Regarding dyadic focus groups, where the carer and the person living with dementia were together providing feedback, the main weakness was carers overtaking in the conversation. Nevertheless, people living with dementia were also encouraged by some carers and the researcher (taking occasionally a more directive approach) to provide their feedback. The group setting might have been less comfortable for some participants though it did not seem the case in the Pilot Intervention Phase. On the contrary, some participants living with dementia were quite active and those who were quieter had also been like this during their participation in the study. The strength of the focus group was that it provided space for discussion of participants thoughts and was an effective way of collecting views, while feeling they could contribute to improve the intervention. An important lesson learnt in the first focus group conducted was that giving participants the chance to write their individual thoughts on paper before starting the group conversation (responding to 3 preliminary questions, so they do not forget about their individual views during the conversation) is not necessarily a good approach for people living with dementia. Asking people living with dementia in a group to write their thoughts down might be an adequate approach for some of the participants, but not for others who might feel stressed in the group context. At that point, some might struggle to understand the task, find their answers, or simply write their answers down. Hence, this technique was abandoned during the first group's conversation and did not seem to have a negative impact on the second group as the conversation was guided, and participants had time to think about their answers and respond to other's views.

Finally, dyadic home-interviews offered selected dyads the chance to tell the author about their experiences of the classes. One of the weaknesses was again the chance of the carer to overtake in the conversation. However, this might be down to the characteristics of the person living with dementia (i.e., if generally less engaging in

conversation) or their dyadic communication style, as there was not a clear pattern of carers overtaking, but different levels of contribution throughout dyads. Similarly, taking part together might have contributed to dyads' members agreement on their accounts. Additionally, as with any interview, participants might have wanted to provide only positive feedback about the intervention to express gratitude. Such dyadic approach has also smoothed the conversation at times, as the carers contributed to clarify or simplify questions to the person living with dementia. Some carers occasionally also invited the person living with dementia to engage in the conversation or develop their explanations. In addition, the fact that interviews took part in a familiar environment for the person living with dementia (i.e., mostly their home) could have facilitated the conversational flow as they felt secure and comfortable.

Considering the experiences from using qualitative methods in the Pilot and the RCT Phase, future research might find it useful to use focus groups to collect feedback from as many participants as possible. This is because each group might experience the intervention slightly differently depending on the number of participants involved (and their relationships) and it would help giving closure to the group. In parallel, purposive sampling could be used to interview a few dyads during different time points of the study, to explore more in-depth their experiences and any changes derived from their participation. This allows for information to be gathered closer to when it happened and reducing recall bias (Althubaiti, 2016).

The experience of using qualitative methods was very positive, as these allow time for those who require it to provide their responses, are flexible and accept any answer that could then trigger a clarification question. More importantly, it provides the person living with dementia with the freedom to provide any answer without questioning their response. Unlike quantitative methods which do not accept a "good" but require the person living with dementia to give a value within a restricted scale as a response, qualitative methods allow more flexibility. Furthermore, the use of a semi-structured approach has ensured systematisation in the data collection process and scope to adapt to people living with dementia's needs. Similarly, the use of a process consent has been proved to be useful to allow people living with dementia's involvement in this research. It has allowed them to opt in taking part in the qualitative component, but also following up their consent during and after finishing the data collection process.

8.6. This Thesis and Future Research

In this section the strengths and weaknesses, as well as the practical implications of this thesis's findings are discussed. After considering these, a reflection about future research gaps and directions is provided.

8.6.1. Strengths

The main strength of this study is that it placed people living with dementia (Wilkinson, 2002), whose involvement in research is still limited (Department of Health, 2012), at the centre of attention. Furthermore, the use of qualitative methods alongside trials including people living with dementia has been less frequent. As the main actors in their lives, and the ones who will be experiencing the harms and benefits of the interventions have the right to have a say. This thesis highlights the differences of individuals living with the same condition, but more importantly, demonstrates their ability to participate, to the extent that they are able and wish, in research seeking their views (Murphy, Jordan, Hunter, Cooney, & Casey, 2014). Furthermore, the use of qualitative methods and semi-structured approaches is useful to allow people living with dementia to express themselves in their own words. This means putting the person living with dementia in the centre of research and research methods to their service, instead of imposing more rigid (quantitative) methods to the person living with dementia's experiences.

The second strength identified in the TACIT Trial's design and this thesis was that there was a continuation in relationship with the author, since recruitment, all over dyad's involvement in the study, and during data collection points (i.e., weekly through phone calls). This helped to develop a rapport with participants over their participation in the study and facilitate face-to-face interactions and data collection processes. Such rapport facilitated the provision of honest feedback and comments, as they trusted the author and felt comfortable to give non-socially desirable responses (i.e., such as that they found Tai Chi "boring"). This, in turn, allowed to create a trustworthy picture of participants' experiences. Furthermore, collecting data from members of the dyads, instructors, and the author helped to enrich and complement such picture's description. The fact that participants were able to provide data both immediately after the classes (through feedback) and towards the end of the classes (through interviews) equally helped to adapt data collection to participants' needs and abilities (i.e., should they have a difficulty remembering about their participation, collecting data soon after the class might have been critical).

The third strength is that this thesis reflects the reactions of different types of dyad (i.e., spousal, child-parent and sisters) and living conditions (i.e., living together or not) that can impact on participants' experiences of class- and home-based practice. This has highlighted how different dyadic relationships and demographic characteristics will potentially have different needs (i.e., those who live separate might find dyadic home-practice more difficult) which are likely to have an impact on dyads (and individuals') adherence to exercise intervention. In this line, the fourth strength identified, is that

dyads who discontinued their participation in the classes were also invited for interview in the RCT Phase. Hence, the scope of participants' experiences included dyads who no longer kept attending classes and so benefited from their feedback.

8.6.2. Limitations

This thesis had several limitations, some have been addressed in Chapter 4 (Pilot Intervention Phase) which remained unchanged in the RCT Phase. This includes the lack of video recordings from the classes which would have facilitated more accurate and detailed information, the lack of inclusion of participants from different ethnical backgrounds, and the lack of exploration of DVD's impact on participants' adherence. Some additional limitations are that only 1:4 participants who showed interest in the study actually enrolled in the trial. This might point to a highly selective inclusion criteria and might have caused bias in the data. For example, those with severe dementia might have different experiences when engaging in Tai Chi. In addition, the data obtained in this thesis might be limited to the sample recruited. As indicated previously, there is a self-selection in those individuals prepared to take part in an exercise intervention. For example, those who do not have the necessary transport might not consider enrolling. As such transport to the venue was not rated as an issue by many of the participants.

Another limitation was that participants' dyadic relationships was not explored prior to the commencement of the classes. This would have allowed a comparison of changes in relationships over the duration of the trial. An exploration of their dyadic dynamics and relationship satisfaction (Sher et al., 2014) before the classes might be important to predict their adherence to the intervention.

This thesis did not specifically and systematically explore if participants would be willing to attend more classes instead of engaging in home-practice to obtain the recommended dosage. This could have helped to elucidate efforts to facilitate their adherence to the recommended dosage in future interventions. Additionally, this study did not objectively monitor class engagement. The use of heart rate monitors or activity monitors might provide objective information on the work-rate during classes and provide a measure of in-class adherence. The in-class adherence also has the potential to influence future or home-based adherence. At home, their adherence might not have been accurately reported as this is one of the risks of relying in self-reporting measures (Gardner, de Bruijn, & Lally, 2011). However, their actual adherence might have had an impact on their experiences of both class and home-practice (Hawley-Hague et al., 2016b; Miller et al., 2014).

In addition, it was not possible to incorporate the views of participants who totally withdrew from the study as they did not wish to carry on providing data. Apart from their reason to withdraw it might have been relevant to know about their experiences taking part in the classes, in case there were further (amendable) reasons behind their willingness to withdraw.

8.6.3. Future recommendations

Future exercise research targeting people living with dementia should keep exploring the experiences of participants in a formal way (not merely as anecdotal comments but including them in data collection) to ensure the appropriateness of interventions and the ways of adapting these to people living with dementia's needs. Additionally, further studies should examine the benefits of using a dyadic approach, as well as providing participants with the final decision to opt for individual approaches instead. Overall, flexible approaches, could also be translated and assessed in the context of the intervention delivery where participants can take part alone or in dyads, provided they are found eligible to take part on their own in the study. This would mean implementing more Person-Centred Approaches not only to practice, but also to research itself.

In terms of the characteristics of the intervention, research might benefit from the study of the different teaching styles (i.e., involving more or less correction) on people living with dementia's adherence. Using a crossover design, could help exploring the experiences of people living with dementia being led by instructors with different styles, together with their reactions to and preferences of different methods. This could be key in research or practice looking to replicate findings in different sites or explore interventions' impact more widely (multisite national or international interventions). In that context, different instructors will require specific implementation training but also have their own teaching styles and different backgrounds which might have an impact on participants' adherence to the interventions.

Given the large numbers of people living with dementia living on their own, it is also required to understand the impact of other type of dyadic relationships such as friends (Carr et al., 2018), neighbours, or volunteers on the person living with dementia's adherence. For instance, it might be that they have a higher availability (or willingness to take part) than other family carers with competing responsibilities to practise together with the person living with dementia; and might facilitate the main carer's respite in the meantime (McCurry et al., 2011). Future research could explore whether volunteers could successfully support home-practice for those living alone, or whether it would be more suitable to offer them more weekly classes.

The use of video to guide home-practice (or alternative ways of facilitating practice at home) would need to be studied in the context of dementia. There is some evidence pointing to videos being more useful than written materials to facilitate an accurate performance and adherence to home-based practice in the general adult population (Schoo & Morris, 2003). However, in an intervention combining class- and home-based practice, there is a need to determine its usefulness in the short- and long-term. Similarly, there is a need to explore whether narratives or visual methods such as photo- or video- diaries in the exercise and physical activity domain would be acceptable as means of understanding people living with dementia's practice, particularly as people become more familiar with new technologies (Phoenix, 2010). Nevertheless, some participants involved in this study who expressed a video would be helpful to guide their practice at home, or that this might be helpful to others in their group, also admitted not being familiar with new technologies such as DVD players. Accordingly, it is key to seek a balance between the need for efficient (and novel) data collection methods and its usability among its target population to avoid missing relevant data.

8.6.4. Novel contributions

This thesis has made a series of novel contribution by: a) Exploring the acceptability of a Tai Chi exercise intervention for people living with dementia and their carers (in Chapter 4); b) Contributing to a process evaluation of a Tai Chi exercise intervention in the context of dementia, to understand how to make adherence easier (Chapters 4-7); c) Included the views of both members of the dyad (formed by a person living with dementia and an informal carer) and involved them together in the qualitative data collection process, using a dyadic approach (Chapters 4-7); and d) Linked findings of an exercise study for people living with dementia to Self-Determination Theory. Overall, the novel contribution of this thesis has been gathering the views of people living with dementia and their carers taking part together in a Tai Chi exercise intervention to prevent falls. These types of interventions are as necessary as scarce, hence the importance of understanding people living with dementia's experiences to make their adherence easier. Similarly, this thesis findings might be relevant in the sport domain where there is a lack of exploration of participants' experiences during their involvement in practice (Coalter, 2008). Understanding the experiences of people living with dementia and their carers is key to be able to facilitate their access and sustained participation into exercise, sports and other physical activity interventions. Their increased and maintained practice, in turn, would allow a fairer assessment of the outcomes and effectiveness of interventions, which will constitute the literature based in evidence that is required to inform policy (Coalter, 2008; Oja et al., 2015).

8.6.5. Practical implications

This thesis' findings highlight the ability of people living with mild-to-moderate dementia to engage, enjoy, learn, and experience a benefit from their dyadic participation in a Tai Chi exercise intervention. Such finding should encourage researchers and practitioners to include them more in their exercise studies and programmes. Similarly, their successful involvement in the qualitative methods used, and their valuable contributions, support the claim for their active involvement in research, as principal actors. That is, their participation in research needs to go beyond their passive role of being assessed to establish interventions' effectiveness. This thesis provides evidence for the ability of people living with dementia to share their experiences and explain why or why not the intervention might be suitable for them and the ways to make it work better for them. Additionally, the positive reception of this dyadic approach, which has been valued for its mutual benefit for people living with dementia and their informal carers, provides evidence for the need to offer them opportunities to take part together in research and practice.

8.7. Conclusions

People living with dementia had been rarely included in studies where the effectiveness of Tai Chi to prevent falls has been tested. However, when they have been included, acceptability and adherence have scarcely been explored under qualitative methods. In fact, the use of qualitative methods in exercise research conducted amongst people living with dementia has been limited; as these have focused on its efficacy instead. This study, conducted alongside the two phases of the TACIT Trial, has been the first to explore people living with dementia and their carers' experiences of taking part in a Tai Chi exercise intervention. It has put the experiences of those living with dementia and their carers at the centre to explore the strengths, weaknesses and areas of improvement of the intervention. Lessons learnt from the Pilot Intervention Phase (i.e., in terms of amount of content and booklet format) have informed the refinement of the RCT Phase and had an impact on participants' experiences. Similarly, lessons learnt from the RCT Phase (i.e., the need for a DVD or alternative strategies to facilitate home-practice) will inform future exercise research and practice involving people living with dementia; including a further study on Tai Chi's effectiveness to prevent falls amongst people living with dementia to be conducted at a national level. Hence, this thesis' findings and derived publications will contribute to facilitate people living with dementia's involvement in exercise interventions with the potential to improve their quality of life and well-being. Such improvements, in turn, will have a positive impact on

relatives and friends who are currently supporting them; but also in the wider society, reducing associated social and healthcare costs.

References

- Aalten, P., van Valen, E., de Vugt, M. E., Lousberg, R., Jolles, J., & Verhey, F. R. J. (2006). Awareness and behavioral problems in dementia patients: A prospective study. *International Psychogeriatrics*, *18*(1), 3-17.
<https://doi.org/10.1017/S1041610205002772>
- Aartolahti, E., Hartikainen, S., Lonroos, E., & Hakkinen, A. (2014). Health and physical function predicting strength and balance training adoption: A community-based study among individuals aged 75 and older. *Journal of Aging and Physical Activity*, *22*(4), 543-549. <https://doi.org/10.1123/japa.2013-0113>
- Aizen, E. (2015). Falls in patients with dementia [Abstract]. *Harefuah*, *154*(5), 323-326. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/26168645>
- Algar, K., Woods, R. T., & Windle, G. (2014). Measuring the quality of life and well-being of people with dementia: A review of observational measures. *Dementia: The International Journal of Social Research and Practice*, *15*(4), 832-857.
<https://doi.org/10.1177/1471301214540163>
- Allan, L. M., Ballard, C. G., Rowan, E. N., & Kenny, R. A. (2009). Incidence and prediction of falls in dementia: A prospective study in older people. *PLoS One*, *4*(5), e5521. <https://doi.org/10.1371/journal.pone.0005521>
- Allan, L. M., Wheatley, A., Flynn, E., Smith, A., Fox, C., Howel, D., . . . Bamford, C. (2018). Is it feasible to deliver a complex intervention to improve the outcome of falls in people with dementia? A protocol for the DIFRID feasibility study. *Pilot and Feasibility Studies*, *4*(1), 170. <https://doi.org/10.1186/s40814-018-0364-7>
- Althubaiti, A. (2016). Information bias in health research: Definition, pitfalls, and adjustment methods. *Journal of Multidisciplinary Healthcare*, *9*, 211-217.
<https://doi.org/10.2147/JMDH.S104807>
- Alzheimer's Disease International. (2015). Dementia statistics. Retrieved from <http://www.alz.co.uk/research/statistics>

Alzheimer's Society. (2013). Factsheet 509LP: Dementia and aggressive behaviour.

Retrieved from

https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1797

Alzheimer's Society. (2014a). Dementia 2014 report statistics. Retrieved from

<https://www.alzheimers.org.uk/statistics>

Alzheimer's Society. (2014b). Dementia UK: Second edition – Overview. Retrieved

from [http://eprints.lse.ac.uk/59437/1/Dementia_UK_Second_edition -](http://eprints.lse.ac.uk/59437/1/Dementia_UK_Second_edition_-_Overview.pdf)

[_Overview.pdf](http://eprints.lse.ac.uk/59437/1/Dementia_UK_Second_edition_-_Overview.pdf)

Alzheimer's Society. (2014c). Demographics. Retrieved from

https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=412

Alzheimer's Society. (2015). Factsheet 525LP: Changes in behaviour. Retrieved from

https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2631

Alzheimer's Society. (2017). Factsheet 400LP: What is dementia? Retrieved from

[https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/what_is_de
mentia.pdf](https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/what_is_dementia.pdf)

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental*

Disorders (DSM-5®) (5th ed.). Arlington, VA, USA: American Psychiatric

Publishing.

American Psychological Association. (2010). Ethical principles of psychologists and

code of conduct. Retrieved from <http://www.apa.org/ethics/code/principles.pdf>

Andrade, L. P., Gobbi, L. T. B., Coelho, F. G. M., Christofolletti, G., Riani Costa, J. L., &

Stella, F. (2013). Benefits of multimodal exercise intervention for postural

control and frontal cognitive functions in individuals with Alzheimer's disease: A

controlled trial. *Journal of the American Geriatrics Society*, 61(11), 1919-1926.

<https://doi.org/10.1111/jgs.12531>

- Annesi, J. J., Unruh, J. L., Marti, C. N., Gorjala, S., & Tennant, G. (2011). Effects of the coach approach intervention on adherence to exercise in obese women: Assessing mediation of social cognitive theory factors. *Research Quarterly for Exercise and Sport*, 82(1), 99-108.
<https://doi.org/10.1080/02701367.2011.10599726>
- Arkin, S. M. (1999). Elder rehab: A student-supervised exercise program for Alzheimer's patients. *Gerontologist*, 39(6), 729-735.
<https://doi.org/10.1093/geront/39.6.729>
- Arkin, S. M. (2003). Student-led exercise sessions yield significant fitness gains for Alzheimer's patients. *American Journal of Alzheimer's Disease and Other Dementias*, 18(3), 159-170. <https://doi.org/10.1177/153331750301800302>
- Arksey, H. (1996). Collecting data through joint interviews. *Social Research Update*, Winter(15), 1-2. Retrieved from
<http://search.ebscohost.com/login.aspx?direct=true&db=sih&AN=13926769&site=eds-live&scope=site>
- Aslam, S., & Emmanuel, P. (2010). Formulating a researchable question: A critical step for facilitating good clinical research. *Indian Journal of Sexually Transmitted Diseases*, 31(1), 47-50. <https://doi.org/10.4103/0253-7184.69003>
- Atieno, O. P. (2009). An analysis of the strengths and limitation of qualitative and quantitative research paradigms. *Problems of Education in the 21st Century*, 13, 13-18. Retrieved from
http://www.scientiasocialis.lt/pec/files/pdf/Atieno_Vol.13.pdf
- Austin, Z., & Sutton, J. (2014). Qualitative research: Getting started. *The Canadian Journal of Hospital Pharmacy*, 67(6), 436-440.
<https://doi.org/10.4212/cjhp.v67i6.1406>

- Awick, E. A., Ehlers, D., Fanning, J., Phillips, S. M., Wójcicki, T., Mackenzie, M. J., . . . McAuley, E. (2017). Effects of a home-based DVD-delivered physical activity program on self-esteem in older adults: Results from a randomized controlled trial. *Psychosomatic Medicine, 79*(1), 71-80.
<https://doi.org/10.1097/PSY.0000000000000358>
- Ayala, G. X., & Elder, J. P. (2011). Qualitative methods to ensure acceptability of behavioral and social interventions to the target population. *Journal of Public Health Dentistry, 71 Suppl 1*, S69-S79.
<https://doi.org/10.1111/j.17527325.2011.00241.x>
- Ball, J. W., Bice, M. R., & Maljak, K. A. (2017). Exploring the relationship between self-determination theory, adults' barriers to exercise, and physical activity. *Health Educator, 49*(1), 19. Retrieved from
<https://files.eric.ed.gov/fulltext/EJ1156136.pdf>
- Ballesteros, S., Kraft, E., Santana, S., & Tziraki, C. (2015). Maintaining older brain functionality: A targeted review. *Neuroscience and Biobehavioral Reviews, 55*, 453-477. <https://doi.org/10.1016/j.neubiorev.2015.06.008>
- Ballinger, C., Yardley, L., & Payne, S. (2004). Observation and action research. In D. Marks & L. Yardley (Eds.), *Research methods for clinical and health psychology*. Thousand Oaks, California: SAGE Publications Ltd.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191-215.
<https://doi.org/10.1037/0033295X.84.2.191>
- Bandura, A. (2002). Social cognitive theory: An agentic perspective. *Asian Journal of Social Psychology, 2*(1), 21-41. <https://doi.org/10.1111/1467-839X.00024>
- Barnes, D. E., Mehling, W., Wu, E., Beristianos, M., Yaffe, K., Skultety, K., & Chesney, M. A. (2015). Preventing loss of independence through exercise (PLIÉ): A pilot clinical trial in older adults with dementia. *Plos One, 10*(2), e0113367-e0113367. <https://doi.org/10.1371/journal.pone.0113367>

- Barrado-Martín, Y., Heward, M., Polman, R., & Nyman, S. R. (2018). acceptability of a dyadic tai chi intervention for older people living with dementia and their informal carers. *Journal of Aging and Physical Activity*, 1-60.
<https://doi.org/10.1123/japa.2017-0267>
- Bartholomew, K. J., Ntoumanis, N., Ryan, R. M., & Thogersen-Ntoumani, C. (2011). Psychological need thwarting in the sport context: Assessing the darker side of athletic experience, *Journal of Sport and Exercise Psychology*, 33(1), 75-102.
Retrieved from
[http://selfdeterminationtheory.org/SDT/documents/06_Bartholomew_jsep_10_0049\[1\].pdf](http://selfdeterminationtheory.org/SDT/documents/06_Bartholomew_jsep_10_0049[1].pdf)
- Baumeister, R. F., Vohs, K. D., & Tice, D. M. (2007). The strength model of self-control. *Current Directions in Psychological Science*, 16(6), 351-355.
<https://doi.org/10.1111/j.1467-8721.2007.00534.x>
- Bekhet, A. K., & Zauszniewski, J. A. (2012). Methodological triangulation: An approach to understanding data. *Nurse Researcher*, 20(2), 40-43.
<https://doi.org/10.7748/nr2012.11.20.2.40.c9442>
- Berg, K. O., Wood-Dauphinee, S. L., Williams, J. I., & Maki, B. (1992). Measuring balance in the elderly: Validation of an instrument. *Canadian Journal of Public Health*, 83 Suppl 2, S7-S11. Retrieved from
<http://search.ebscohost.com/login.aspx?direct=true&db=mdc&AN=1468055&site=eds-live&scope=site>
- Bergold, J. T., S. (2012). Participatory research methods: A methodological approach in motion. *Forum: Qualitative Social Research*, 13(1).
<https://doi.org/10.17169/fqs-13.1.1801>
- Booth, V., Harwood, R. H., Hood-Moore, V., Bramley, T., Hancox, J. E., Robertson, K., . . . Logan, P. A. (2018). Promoting activity, independence and stability in early dementia and mild cognitive impairment (PrAISED): Development of an intervention for people with mild cognitive impairment and dementia. *Clinical Rehabilitation*, 32(7), 855-864. <https://doi.org/10.1177/0269215518758149>

- Bowling, A., Rowe, G., Adams, S., Sands, P., Samsi, K., Crane, M., . . . Manthorpe, J. (2015). Quality of life in dementia: A systematically conducted narrative review of dementia-specific measurement scales. *Aging and Mental Health, 19*(1), 13-31. <https://doi.org/10.1080/13607863.2014.915923>
- Bradley, E. H., Curry, L. A., & Devers, K. J. (2007). Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Services Research, 42*(4), 1758-1772. <https://doi.org/10.1111/j.1475-6773.2006.00684.x>
- Brady, D., Clifton, A., Burr, V., & Curran, S. (2014). The infantilisation of older people: Is it a problem? *Mental Health Nursing, 34*(5), 22-24. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=110906569&site=eds-live&scope=site>
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: SAGE Publications Ltd.
- Brodaty, H., & Burns, K. (2012). Nonpharmacological management of apathy in dementia: A systematic review. *The American Journal of Geriatric Psychiatry, 20*(7), 549-564. <https://doi.org/10.1097/JGP.0b013e31822be242>
- Brown, D., Spanjers, K., Atherton, N., Lowe, J., Stonehewer, L., Bridle, C., . . . Lamb, S. E. (2015). Development of an exercise intervention to improve cognition in people with mild to moderate dementia: Dementia And Physical Activity (DAPA) Trial. *Physiotherapy, 101*(2), 126-134. <https://doi.org/10.1016/j.physio.2015.01.002>
- Buckey, J. P., & Hughes, A. R. (2008). Introduction. In J. P. Buckley (Ed.), *Exercise physiology in special populations* (pp. 1-19). Edinburgh: Churchill Livingstone Elsevier.
- Bundy, R., & Minihane, A. M. (2018). Diet, exercise and dementia: The potential impact of a Mediterranean diet pattern and physical activity on cognitive health in a UK population. *Nutrition Bulletin, 43*(3), 284-289. <https://doi.org/10.1111/nbu.12339>

- Burgener, S. C., APRN-BC, FAAN, Yang, Y., Gilbert, R., & Marsh-Yant, S. (2008). The effects of a multimodal intervention on outcomes of persons with early-stage dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 23(4), 382-394. <https://doi.org/10.1177/1533317508317527>
- Burton, E., Cavalheri, V., Adams, R., Browne, C. O., Boverly-Spencer, P., Fenton, A. M., . . . Hill, K. D. (2015). Effectiveness of exercise programs to reduce falls in older people with dementia living in the community: A systematic review and meta-analysis. *Clinical Interventions in Aging*, 10, 421-434. <https://doi.org/10.2147/CIA.S71691>
- Burton, L. C., Shapiro, S., & German, P. S. (1999). Determinants of physical activity initiation and maintenance among community-dwelling older persons. *Preventive Medicine*, 29(5), 422-430. <https://doi.org/10.1006/pmed.1999.0561>
- Caldwell, K. (2014). Dyadic interviewing: A technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research*, 14(4), 488-507. <https://doi.org/10.1177/1468794113490718>
- Caldwell, P. H. Y., Hamilton, S., Tan, A., & Craig, J. C. (2010). Strategies for increasing recruitment to randomised controlled trials: Systematic review. *PLoS Medicine*, 7(11), e1000368. <https://doi.org/10.1371/journal.pmed.1000368>
- Cameron, I. D., Dyer, S. M., Panagoda, C. E., Murray, G. R., Hill, K. D., Cumming, R. G., & Kerse, N. (2018). Interventions for preventing falls in older people in care facilities and hospitals. *Cochrane Database of Systematic Reviews* (9). <https://doi.org/10.1002/14651858.CD005465.pub4>
- Cameron, I. D., Gillespie, L. D., Robertson, M. C., Murray, G. R., Hill, K. D., Cumming, R. G., & Kerse, N. (2012). Interventions for preventing falls in older people in care facilities and hospitals. *Cochrane Database of Systematic Reviews* (12), <https://doi.org/10.1002/14651858.CD005465.pub3>

- Campbell, M., Fitzpatrick, R., Haines, A., Kinmonth, A. L., Sandercock, P., Spiegelhalter, D., & Tyrer, P. (2000). Framework for design and evaluation of complex interventions to improve health. *BMJ*, *321*(7262), 694-696.
<https://doi.org/10.1136/bmj.321.7262.694>
- Campbell, R., Evans, M., Tucker, M., Quilty, B., Dieppe, P., & Donovan, J. L. (2001). Why don't patients do their exercises? Understanding non-compliance with physiotherapy in patients with osteoarthritis of the knee. *Journal of Epidemiology and Community Health*, *55*(2), 132.
<https://doi.org/10.1136/jech.55.2.132>
- Canonici, A. P., Andrade, L. P., Gobbi, S., Santos-Galduroz, R. F., Gobbi, L. T., & Stella, F. (2012). Functional dependence and caregiver burden in Alzheimer's disease: A controlled trial on the benefits of motor intervention. *Psychogeriatrics*, *12*(3), 186-192.
<https://doi.org/10.1111/j.14798301.2012.00407.x>
- Care Inspectorate and NHS Scotland. (2016). Managing falls and fractures in care homes for older people - Good Practise Resource. Revised edition. Retrieved from <http://www.careinspectorate.com/images/documents/2737/2016/Falls-and-fractures-new-resource-low-res.pdf>
- Carmody, J., Traynor, V., & Marchetti, E. (2015). Barriers to qualitative dementia research: The elephant in the room. *Qualitative Health Research*, *25*(7), 1013-1019. <https://doi.org/10.1177/1049732314554099>
- Carr, R. M., Prestwich, A., Kwasnicka, D., Thøgersen-Ntoumani, C., Gucciardi, D. F., Quested, E., . . . Ntoumanis, N. (2018). Dyadic interventions to promote physical activity and reduce sedentary behaviour: Systematic review and meta-analysis. *Health Psychology Review*, 1-69.
<https://doi.org/10.1080/17437199.2018.1532312>

- Caspersen, C. J., Powell, K. E., & Christenson, G. M. (1985). Physical activity, exercise, and physical fitness: Definitions and distinctions for health-related research. *Public Health Reports*, *100*(2), 126-31. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1424733/>
- Centers for Disease Control and Prevention. (n.d.). Risk Factors for Falls. Retrieved from https://www.cdc.gov/steady/pdf/risk_factors_for_falls-a.pdf
- Chan, W. C., Lautenschlager, N., Dow, B., Ma, S. L., Wong, C. S. M., & Lam, L. C. W. (2016). A home-based exercise intervention for caregivers of persons with dementia: Study protocol for a randomised controlled trial. *Trials*, *17*(1), 460-460. <https://doi.org/10.1186/s13063-016-1582-z>
- Chan, W. C., Yeung, J. W. F., Wong, C. S. M., Lam, L. C. W., Chung, K. F., Luk, J. K. H., . . . Law, A. C. K. (2015). Efficacy of physical exercise in preventing falls in older adults with cognitive impairment: A systematic review and meta-analysis. *Journal of the American Medical Directors Association*, *16*(2), 149-154. <https://doi.org/10.1016/j.jamda.2014.08.007>
- Chen, K. M., Lin, J. N., Lin, H. S., Wu, H. C., Chen, W. T., Li, C. H., & Kai Lo, S. (2008). The effects of a Simplified Tai-Chi Exercise Program (STEP) on the physical health of older adults living in long-term care facilities: A single group design with multiple time points. *International Journal of Nursing Studies*, *45*(4), 501-507. <https://doi.org/10.1016/j.ijnurstu.2006.11.008>
- Cheng, S.-T., Chow, P. K., Song, Y.-Q., Yu, E. C. S., Chan, A. C. M., Lee, T. M. C., & Lam, J. H. M. (2014). Mental and physical activities delay cognitive decline in older persons with dementia. *The American Journal of Geriatric Psychiatry*, *22*(1), 63-74. <https://doi.org/10.1016/j.jagp.2013.01.060>
- Choi, J. H., Moon, J. S., & Song, R. (2005). Effects of Sun-style Tai Chi exercise on physical fitness and fall prevention in fall-prone older adults. *Journal of Advanced Nursing*, *51*(2), 150-157. <https://doi.org/10.1111/j.1365-2648.2005.03480.x>

- Chong, T. W. H., Doyle, C. J., Cyarto, E. V., Cox, K. L., Ellis, K. A., Ames, D., & Lautenschlager, N. T. (2014). Physical activity program preferences and perspectives of older adults with and without cognitive impairment. *Asia-Pacific Psychiatry: Official Journal of The Pacific Rim College of Psychiatrists*, 6(2), 179-190. <https://doi.org/10.1111/appy.12015>
- Clarkson, P., Hughes, J., Xie, C., Larbey, M., Roe, B., Giebel, C. M., . . . Challis, D. (2017). Overview of systematic reviews: Effective home support in dementia care, components and impacts-Stage 1, psychosocial interventions for dementia. *Journal of Advanced Nursing*, 73(12), 2845-2863. <https://doi.org/10.1111/jan.13362>
- Clegg, A., Young, J., Iliffe, S., Rikkert, M. O., & Rockwood, K. (2013). Frailty in elderly people. *Lancet*, 381(9868), 752-762. [https://doi.org/10.1016/S0140-6736\(12\)62167-9](https://doi.org/10.1016/S0140-6736(12)62167-9)
- Close, J. C. T., Wesson, J., Sherrington, C., Hill, K. D., Kurrle, S., Lord, S. R., . . . Clemson, L. (2014). Can a tailored exercise and home hazard reduction program reduce the rate of falls in community dwelling older people with cognitive impairment: Protocol paper for the i-FOCIS randomised controlled trial. *BMC Geriatrics*, 14, 89. <https://doi.org/10.1186/1471-2318-14-89>
- Coalter, F. (2008). *A wider social role for sport?: Who's keeping the score?* Abingdon; New York: Routledge.
- Coelho, F. G. d. M., Andrade, L. P., Pedroso, R. V., Santos-Galduroz, R. F., Gobbi, S., Costa, J. L. R., & Gobbi, L. T. B. (2013). Multimodal exercise intervention improves frontal cognitive functions and gait in Alzheimer's disease: A controlled trial. *Geriatrics and Gerontology International*, 13(1), 198-203. <https://doi.org/10.1111/j.1447-0594.2012.00887.x>
- Collins, L. M., Murphy, S. A., Nair, V. N., & Strecher, V. J. (2005). A strategy for optimizing and evaluating behavioral interventions. *Annals of Behavioral*

Medicine: A Publication of The Society of Behavioral Medicine, 30(1), 65-73.

https://doi.org/10.1207/s15324796abm3001_8

Connell, C. M., & Janevic, M. R. (2009). Effects of a telephone-based exercise intervention for dementia caregiving wives: A randomized controlled trial.

Journal of Applied Gerontology, 28(2), 171-194.

<https://doi.org/10.1177/0733464808326951>

Couture, A. L., Zaidi, A. U., & Maticka-Tyndale, E. (2012). Reflexive accounts: An intersectional approach to exploring the fluidity of insider/outsider status and the researcher's impact on culturally sensitive post-positivist qualitative research.

Qualitative Sociology Review, 8(1), 86-105. Retrieved from

<http://search.ebscohost.com/login.aspx?direct=true&db=sih&AN=110874106&site=eds-live&scope=site>

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008).

Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*, 337, a1655. <https://doi.org/10.1136/bmj.a1655>

Cridland, E. K., Phillipson, L., Brennan-Horley, C., & Swaffer, K. (2016). Reflections and recommendations for conducting in-depth interviews with people with dementia. *Qualitative Health Research*, 26(13), 1774–1786.

<https://doi.org/10.1177/1049732316637065>

Crowley-Henry, M. (2009). Ethnography: Visions & Versions. In J. Hogan, P. Dolan, & P. Donnelly (Eds.), *Approaches to Qualitative Research: Theory & Its Practical Application. A Guide for Dissertation Students*. (pp. 37-63). Ireland: Oak Tree Press.

Cummings, J. L. (1997). The neuropsychiatric inventory: Assessing psychopathology in dementia patients. *Neurology*, 48(5 Suppl 6), S10-S16.

https://doi.org/10.1212/WNL.48.5_Suppl_6.10S

- Dal Bello-Haas, V. P. M., O'Connell, M. E., Morgan, D. G., & Crossley, M. (2014). Lessons learned: Feasibility and acceptability of a telehealth-delivered exercise intervention for rural- dwelling individuals with dementia and their caregivers. *Rural and Remote Health, 14*(3), 2715. Retrieved from http://www.rrh.org.au/publishedarticles/article_print_2715.pdf
- Daniel, B. K. (2018). Empirical verification of the "TACT" framework for teaching rigour in qualitative research methodology. *Qualitative Research Journal (Emerald Group Publishing Limited), 18*(3), 262-275. <https://doi.org/10.1108/QRJ-D-17-00012>
- Dawson, N., & Menne, H. (2017). Can interpreting nonsignificant findings inform the lessons learned from an intervention? *American Journal of Lifestyle Medicine, 11*(4), 354. <https://doi.org/10.1177/1559827615614571>
- Day, L., Hill, K. D., Jolley, D., Cicuttini, F., Flicker, L., & Segal, L. (2012). Impact of Tai Chi on impairment, functional limitation, and disability among preclinically disabled older people: A randomized controlled trial. *Archives of Physical Medicine and Rehabilitation, 93*(8), 1400-1407. <https://doi.org/10.1016/j.apmr.2012.03.018>
- Day, L., Hill, K. D., Stathakis, V. Z., Flicker, L., Segal, L., Cicuttini, F., & Jolley, D. (2015). Impact of Tai-Chi on falls among preclinically disabled older people. A randomized controlled trial. *Journal of The American Medical Directors Association, 16*(5), 420-426. <https://doi.org/10.1016/j.jamda.2015.01.089>
- Day, L., Trotter, M. J., Donaldson, A., Hill, K. D., & Finch, C. F. (2016). Key factors influencing implementation of falls prevention exercise programs in the community. *Journal of Aging and Physical Activity, 24*(1), 45-52. <https://doi.org/10.1123/japa.2014-0143>
- Deci, E. L., & Ryan, R. M. (2000). The "what" and "why" of goal pursuits: Human needs and the self-determination of behavior. *Psychological Inquiry, 11*(4), 227-268. https://doi.org/10.1207/S15327965PLI1104_01

- Deci, E. L., & Ryan, R. M. (2008). Facilitating optimal motivation and psychological well-being across life's domains. *Canadian Psychology/Psychologie canadienne*, 49(1), 14-23. <https://doi.org/10.1037/0708-5591.49.1.14>
- Department of Health. (2005). *Mental Capacity Act*. London: HMSO
- Department of Health. (2012). *The Prime Minister's Challenge on Dementia. Delivering major improvements in dementia care and research by 2015: A report on progress*. Retrieved from <http://media.dh.gov.uk/network/353/files/2012/11/The-Prime-Ministers-Challenge-on-Dementia-Delivering-major-improvements-in-dementia-care-and-research-by-2015-A-report-of-progress.pdf>
- Department of Health. (2015). *Prime Minister's Challenge on Dementia 2020*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf
- Dewing, J. (2002). From ritual to relationship: A person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia*, 1(2), 157-171. <https://doi.org/10.1177/147130120200100204>
- Dewing, J. (2008). Process consent and research with older persons living with dementia. *Research Ethics Review*, 4(2), 59-64. <https://doi.org/10.1177/174701610800400205>
- DiLauro, M., Pereira, A., Carr, J., Chiu, M., & Wesson, V. (2015). Spousal caregivers and persons with dementia: Increasing participation in shared leisure activities among hospital-based dementia support program participants. *Dementia*, 16(1), 9-28. <https://doi.org/10.1177/1471301215570680>
- Drabble, S. J., O'Cathain, A., Thomas, K. J., Rudolph, A., & Hewison, J. (2014). Describing qualitative research undertaken with randomised controlled trials in grant proposals: A documentary analysis. *BMC Medical Research Methodology*, 14, 24-24. <https://doi.org/10.1186/1471-2288-14-24>

- Drewelies, J., Chopik, W. J., Hoppmann, C. A., Smith, J., & Gerstorf, D. (2018). Linked lives: Dyadic associations of mastery beliefs with health (behavior) and health (behavior) change among older partners. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 73(5), 787-798.
<https://doi.org/10.1093/geronb/gbw058>
- Dugmore, O., Orrell, M., & Spector, A. (2015). Qualitative studies of psychosocial interventions for dementia: a systematic review. *Aging and Mental Health*, 19(11), 955-967. <https://doi.org/10.1080/13607863.2015.1011079>
- Edmunds, J., Ntoumanis, N., & Duda, J. L. (2006). A Test of self-determination theory in the exercise domain. *Journal of Applied Social Psychology*, 36(9), 2240-2265. <https://doi.org/10.1111/j.0021-9029.2006.00102.x>
- Edmunds, J., Ntoumanis, N., & Duda, J. L. (2007). Adherence and well-being in overweight and obese patients referred to an exercise on prescription scheme: A self-determination theory perspective. *Psychology of Sport and Exercise*, 8(5), 722-740. <https://doi.org/10.1016/j.psychsport.2006.07.006>
- Edmunds, J., Ntoumanis, N., & Duda, J. L. (2008). Testing a self-determination theory-based teaching style intervention in the exercise domain. *European Journal of Social Psychology*, 38(2), 375-388. <https://doi.org/10.1002/ejsp.463>
- Ednie, A., & Stibor, M. (2017). Influence and interpretation of intrinsic and extrinsic exercise motives. *Journal of Human Sport and Exercise*, 12(2), 414-425.
<https://doi.org/10.14198/jhse.2017.122.18>
- Eisikovits, Z., & Koren, C. (2010). Approaches to and outcomes of dyadic interview analysis. *Qualitative Health Research*, 20(12), 1642-55.
<https://doi.org/10.1177/1049732310376520>
- Escolar-Reina, P., Medina-Mirapeix, F., Gascón-Cánovas, J. J., Montilla-Herrador, J., Jimeno-Serrano, F. J., de Oliveira Sousa, S. L., . . . Lomas-Vega, R. (2010). How do care-provider and home exercise program characteristics affect patient adherence in chronic neck and back pain: A qualitative study. *BMC Health Services Research*, 10, 60. <https://doi.org/10.1186/1472-6963-10-60>

- Essery, R., Geraghty, A. W. A., Kirby, S., & Yardley, L. (2017). Predictors of adherence to home-based physical therapies: A systematic review. *Disability and Rehabilitation*, 39(6), 519-534. <https://doi.org/10.3109/09638288.2016.1153160>
- Eynon, M. J., O'Donnell, C., & Williams, L. (2018). Gaining qualitative insight into the subjective experiences of adherers to an exercise referral scheme: A thematic analysis. *Journal of Health Psychology*, 23(11), 1476-1487. <https://doi.org/10.1177/1359105316656233>
- Eys, M. A., Jewitt, E., Evans, M. B., Wolf, S., Bruner, M. W., & Loughead, T. M. (2013). Coach-initiated motivational climate and cohesion in youth sport. *Research Quarterly for Exercise and Sport*, 84(3), 373-383. <https://doi.org/10.1080/02701367.2013.814909>
- Farran, C. J., Staffileno, B. A., Gilley, D. W., McCann, J. J., Li, Y., Castro, C. M., & King, A. C. (2008). A lifestyle physical activity intervention for caregivers of persons with Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*, 23(2), 132-142. <https://doi.org/10.1177/1533317507312556>
- Farrance, C., Tsofliou, F., & Clark, C. (2016). Adherence to community based group exercise interventions for older people: A mixed-methods systematic review. *Preventive Medicine*, 87, 155-166. <https://doi.org/10.1016/j.ypmed.2016.02.037>
- Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *The Gerontologist*, 58(suppl_1), S10-S19. <https://doi.org/10.1093/geront/gnx122>
- Fenney, A., & Lee, T. D. (2010). Exploring spared capacity in persons with dementia: What WiiTM can learn. *Activities, Adaptation and Aging*, 34(4), 303-313. <https://doi.org/10.1080/01924788.2010.525736>
- Fernando, E., Fraser, M., Hendriksen, J., Kim, C. H., & Muir-Hunter, S. W. (2017). Risk factors associated with falls in older adults with dementia: A systematic review. *Physiotherapy Canada*, 69(2), 161-170. <https://doi.org/10.3138/ptc.2016-14>

- Phoenix, C. (2010). Seeing the world of physical culture: The potential of visual methods for qualitative research in sport and exercise. *Qualitative Research in Sport and Exercise*, 2(2), 93-08. <https://doi.org/10.1080/19398441.2010.488017>
- Phoenix, C., & Orr, N. (2014). Pleasure: A forgotten dimension of physical activity in older age. *Social Science & Medicine*, 115, 94-102. <https://doi.org/10.1016/j.socscimed.2014.06.013>
- Fogarty, J. N., Murphy, K. J., McFarlane, B., Montero-Odasso, M., Wells, J., Troyer, A. K., . . . Hansen, K. T. (2015). Taoist Tai Chi(R) and memory intervention for individuals with mild cognitive impairment. *Journal of Aging Physical Activity*, 24(2), 169-180. <https://doi.org/10.1123/japa.2014-0062>
- Forbes, D., Forbes, S. C., Blake, C. M., Thiessen, E. J., & Forbes, S. (2015). Exercise programs for people with dementia. *The Cochrane Database of Systematic Reviews*, 4. <https://doi.org/10.1002/14651858.CD006489.pub4>
- Fortier, M. S., Duda, J. L., Guerin, E., & Teixeira, P. J. (2012). Promoting physical activity: Development and testing of self-determination theory-based interventions. *International Journal of Behavioral Nutrition and Physical Activity*, 9(1), 20. <https://doi.org/10.1186/1479-5868-9-20>
- Frederiksen, K. S., Sobol, N., Beyer, N., Hasselbalch, S., & Waldemar, G. (2014). Moderate-to-high intensity aerobic exercise in patients with mild to moderate Alzheimer's disease: A pilot study. *International Journal of Geriatric Psychiatry*, 29(12), 1242-1248. <https://doi.org/10.1002/gps.4096>
- Fried, L. P., Ferrucci, L., Darer, J., Williamson, J. D., & Anderson, G. (2004). Untangling the concepts of disability, frailty, and comorbidity: Implications for improved targeting and care. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 59(3), 255-263. <https://doi.org/10.1093/gerona/59.3.M255>

- Fried, L. P., Young, Y., Rubin, G., & Bandeen-Roche, K. (2001). Self-reported preclinical disability identifies older women with early declines in performance and early disease. *Journal of Clinical Epidemiology*, *54*(9), 889-901.
[https://doi.org/10.1016/S0895-4356\(01\)00357-2](https://doi.org/10.1016/S0895-4356(01)00357-2)
- Friedrich, M., Cermak, T., & Maderbacher, P. (1996). The effect of brochure use versus therapist teaching on patients performing therapeutic exercise and on changes in impairment status. *Physical Therapy*, *76*(10), 1082-1088. Retrieved from
<https://search.ebscohost.com/login.aspx?direct=true&db=edsbl&AN=RN015788811&site=eds-live&scope=site>
- Gardner, B., de Bruijn, G.-J., & Lally, P. (2011). A systematic review and meta-analysis of applications of the self-report habit index to nutrition and physical activity behaviours. *Annals of Behavioral Medicine*, *42*(2), 174-187.
<https://doi.org/10.1007/s12160-011-9282-0>
- Gibson, G., Timlin, A., Curran, S., & Wattis, J. (2004). The scope for qualitative methods in research and clinical trials in dementia. *Age and Ageing*, *33*(4), 422-426. <https://doi.org/10.1093/ageing/afh136>
- Gillespie, L. D., Robertson, M. C., Gillespie, W. J., Sherrington, C., Gates, S., Clemson, L. M., & Lamb, S. E. (2012). Interventions for preventing falls in older people living in the community. *Cochrane Database of Systematic Reviews*, (9).
<https://doi.org/10.1002/14651858.CD007146.pub3>
- Gillison, F. B., Rouse, P., Standage, M., Sebire, S. J., & Ryan, R. M. (2018). A meta-analysis of techniques to promote motivation for health behaviour change from a self-determination theory perspective [Abstract]. *Health Psychology Review*, 1-40. <https://doi.org/10.1080/17437199.2018.1534071>
- Glasgow, R. E., Vogt, T. M., & Boles, S. M. (1999). Evaluating the public health impact of health promotion interventions: The RE-AIM framework. *American Journal of Public Health*, *89*(9), 1322-1327. <https://doi.org/10.2105/AJPH.89.9.1322>

- Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report*, 8(4), 597-607. Retrieved from <http://www.nova.edu/ssss/QR/QR8-4/golafshani.pdf>
- Gold, C. A., & Budson, A. E. (2008). Memory loss in Alzheimer's disease: Implications for development of therapeutics. *Expert Review of Neurotherapeutics*, 8(12), 1879-1891. <https://doi.org/10.1586/14737175.8.12.1879>
- Gonçalves, A.-C., Cruz, J., Marques, A., Demain, S., & Samuel, D. (2017). Evaluating physical activity in dementia: A systematic review of outcomes to inform the development of a core outcome set. *Age and Ageing*, 47(1), 34-41. <https://doi.org/10.1093/ageing/afx135>
- Greenwood, N. (2009). Reflections of a researcher interviewing older people. *Nursing Older People*, 21(7), 30-31. <https://doi.org/10.7748/nop2009.09.21.7.30.c7279>
- Groot, C., Hooghiemstra, A. M., Raijmakers, P. G., van Berckel, B. N., Scheltens, P., Scherder, E. J., . . . Ossenkoppele, R. (2016). The effect of physical activity on cognitive function in patients with dementia: A meta-analysis of randomized control trials. *Aging Research Reviews*, 25, 13-23. <https://doi.org/10.1016/j.arr.2015.11.005>
- Government, H.M. (2015). Sporting Future: A New Strategy for an Active Nation. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/486622/Sporting_Future_ACCESSIBLE.pdf
- Guadagnoli, M. A., & Lee, T. D. (2004). Challenge point: A framework for conceptualizing the effects of various practice conditions in motor learning. *Journal of Motor Behavior*, 36(2), 212. <https://doi.org/10.3200/JMBR.36.2.212-224>
- Guss, R., Middleton, J., Beanland, T., Moniz-Cook, E., Watts, S., & Bone, A. (2014). A guide to psychosocial interventions in early stages of dementia. Retrieved from <https://www.bps.org.uk/system/files/user->

[files/DCP%20Faculty%20for%20the%20Psychology%20of%20Older%20People%20\(FPoP\)/public/a_guide_to_psychosocial_interventions_in_dementia.pdf](https://doi.org/10.1080/08980101.2013.800000)

- Haas, R., Mason, W., & Haines, T. P. (2014). Difficulties experienced in setting and achieving goals by participants of a falls prevention programme: A mixed-methods evaluation. *Physiotherapy Canada*, 66(4), 413-422. <https://doi.org/10.3138/ptc.2013-30BC>
- Hagger, M., & Chatzisarantis, N. (2008). Self-determination theory and the psychology of exercise. *International Review of Sport and Exercise Psychology*, 1(1), 79-103. <https://doi.org/10.1080/17509840701827437>
- Haines, T. P., Day, L., Hill, K. D., Clemson, L., & Finch, C. (2014). "Better for others than for me": A belief that should shape our efforts to promote participation in falls prevention strategies. *Archives of Gerontology and Geriatrics*, 59(1), 136-144. <https://doi.org/10.1016/j.archger.2014.03.003>
- Hannes, K. (2011). Critical appraisal of qualitative research. In J. Noyes, A. Booth, K. Hannes, A. Harden, J. Harris, S. Lewin, & C. Lockwood (Eds.), *Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions*. Retrieved from <http://cqrmg.cochrane.org/supplemental-handbook-guidance>
- Harwood, R. H., van der Wardt, V., Goldberg, S. E., Kearney, F., Logan, P., Hood-Moore, V., . . . Orrell, M. (2018). A development study and randomised feasibility trial of a tailored intervention to improve activity and reduce falls in older adults with mild cognitive impairment and mild dementia. *Pilot and Feasibility Studies*, 4(49), 1-12. <https://doi.org/10.1186/s40814-018-0239-y>
- Hasselmann, V., Oesch, P., Fernandez-Luque, L., & Bachmann, S. (2015). Are exergames promoting mobility an attractive alternative to conventional self-regulated exercises for elderly people in a rehabilitation setting? Study protocol of a randomized controlled trial. *BMC Geriatrics*, 15, 108. <https://doi.org/10.1186/s12877-015-0106-0>

- Hauer, K., Schwenk, M., Zieschang, T., Essig, M., Becker, C., & Oster, P. (2012). Physical training improves motor performance in people with dementia: A randomized controlled trial. *Journal of The American Geriatrics Society*, 60(1), 8-15. <https://doi.org/10.1111/j.1532-5415.2011.03778.x>
- Hauer, K., Ullrich, P., Dutzi, I., Beurskens, R., Kern, S., Bauer, J., & Schwenk, M. (2017). Effects of standardized home training in patients with cognitive impairment following geriatric rehabilitation: A randomized controlled pilot study. *Gerontology*, 63(6), 495-506. <https://doi.org/10.1159/000478263>
- Hawley-Hague, H., Horne, M., Campbell, M., Demack, S., Skelton, D. A., & Todd, C. (2014). Multiple levels of influence on older adults' attendance and adherence to community exercise classes. *The Gerontologist*, 54(4), 599-610. <https://doi.org/10.1093/geront/gnt075>
- Hawley-Hague, H., Horne, M., Skelton, D. A., & Todd, C. (2016a). Older adults' uptake and adherence to exercise classes: Instructors' perspectives. *Journal of Aging and Physical Activity*, 24(1), 119-128. <https://doi.org/10.1123/japa.2014-0108>
- Hawley-Hague, H., Horne, M., Skelton, D. A., & Todd, C. (2016b). Review of how we should define (and measure) adherence in studies examining older adults' participation in exercise classes. *BMJ Open*, 6(6), e011560-e011560. <https://doi.org/10.1136/bmjopen-2016-011560>
- Hellström, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14(5), 608-619. <https://doi.org/10.1177/0969733007080206>
- Hennink, M. M., Hutter, I., & Bailey, A. (2011). *Qualitative research methods*. London: SAGE Publications Ltd.
- Heyn, P., Abreu, B. C., & Ottenbacher, K. J. (2004). The effects of exercise training on elderly persons with cognitive impairment and dementia: A meta-analysis. *Archives of Physical Medicine and Rehabilitation*, 85(10), 1694-1704. <https://doi.org/10.1016/j.apmr.2004.03.019>

- Hill, K. D., Hunter, S. W., Batchelor, F. A., Cavalheri, V., & Burton, E. (2015). Individualized home-based exercise programs for older people to reduce falls and improve physical performance: A systematic review and meta-analysis. *Maturitas*, 82(1), 72-84. <https://doi.org/10.1016/j.maturitas.2015.04.005>
- Hoogerheide, V., van Wermeskerken, M., van Nassau, H., & van Gog, T. (2018). Model-observer similarity and task-appropriateness in learning from video modeling examples: Do model and student gender affect test performance, self-efficacy, and perceived competence? *Computers in Human Behavior*, 89, 457-464. <https://doi.org/10.1016/j.chb.2017.11.012>
- Horner, S., Rew, L., & Torres, R. (2006). Enhancing intervention fidelity: A means of strengthening study impact. *Journal for Specialists in Pediatric Nursing: JSPN*, 11(2), 80-89. <https://doi.org/10.1111/j.1744-6155.2006.00050.x>
- Howe, T. E., Rochester, L., Neil, F., Skelton, D. A., & Ballinger, C. (2011). Exercise for improving balance in older people. *Cochrane Database of Systematic Reviews*, (11). <https://doi.org/10.1002/14651858.CD004963.pub3>
- Hu, Y.-N., Chung, Y.-J., Yu, H.-K., Chen, Y.-C., Tsai, C.-T., & Hu, G.-C. (2016). Effect of Tai Chi exercise on fall prevention in older adults: Systematic review and meta-analysis of randomized controlled trials. *International Journal of Gerontology*, 10(3), 131-136. <https://doi.org/10.1016/j.ijge.2016.06.002>
- Hubbard, G., Downs, M. G., & Tester, S. (2003). Including older people with dementia in research: Challenges and strategies. *Aging and Mental Health*, 7(5), 351-362. <https://doi.org/10.1080/1360786031000150685>
- Hurvitz, E. A., Richardson, J. K., Werner, R. A., Ruhl, A. M., & Dixon, M. R. (2000). Unipedal stance testing as an indicator of fall risk among older outpatients. *Archives of Physical Medicine and Rehabilitation*, 81(5), 587-591. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=mdc&AN=10807096&site=eds-live&scope=site>

- Ingledeu, D. K., & Markland, D. (2008). The role of motives in exercise participation. *Psychology and Health, 23*(7), 807-828.
<https://doi.org/10.1080/08870440701405704>
- Ingledeu, D. K., Markland, D., & Medley, A. R. (1998). Exercise motives and stages of change. *Journal of Health Psychology, 3*(4), 477-489.
<https://doi.org/10.1177/135910539800300403>
- Jansons, P. S., Robins, L., Haines, T. P., & O'Brien, L. (2018). Barriers and enablers to ongoing exercise for people with chronic health conditions: Participants' perspectives following a randomized controlled trial of two interventions. *Archives of Gerontology and Geriatrics, 76*, 92-99.
<https://doi.org/10.1016/j.archger.2018.02.010>
- Jennings, L. A., Palimaru, A., Corona, M. G., Cagigas, X. E., Ramirez, K. D., Zhao, T., . . . Reuben, D. B. (2017). Patient and caregiver goals for dementia care. *Quality of Life Research, 26*(3), 685-693. <https://doi.org/10.1007/s11136-016-1471-7>
- Joling, K. J., Schöpe, J., van Hout, H. P. J., van Marwijk, H. W. J., van der Horst, H. E., & Bosmans, J. E. (2015). Predictors of societal costs in dementia patients and their informal caregivers: A two-year prospective cohort study. *The American Journal of Geriatric Psychiatry, 23*(11), 1193-1203.
<https://doi.org/10.1016/j.jagp.2015.06.008>
- Judson, M. A. (2015). The clinical features of sarcoidosis: A comprehensive review. *Clinical Reviews in Allergy and Immunology, 49*(1), 63-78.
<https://doi.org/10.1007/s12016-014-8450-y>
- Kallio, H., Pietilä, A.-M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: Developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing, 72*(12), 2954-2965.
<https://doi.org/10.1111/jan.13031>

- Kelly, M. E., Loughrey, D., Lawlor, B. A., Robertson, I. H., Walsh, C., & Brennan, S. (2014). The impact of exercise on the cognitive functioning of healthy older adults: A systematic review and meta-analysis [Abstract]. *Ageing Research Reviews*, 16, 12-31. <https://doi.org/10.1016/j.arr.2014.05.002>
- Kemoun, G., Thibaud, M., Roumagne, N., Carette, P., Albinet, C., Toussaint, L., . . . Dugué, B. (2010). Effects of a physical training programme on cognitive function and walking efficiency in elderly persons with dementia. *Dementia and Geriatric Cognitive Disorders*, 29(2), 109-114. <https://doi.org/10.1159/000272435>
- Kendrick, D., Kumar, A., Carpenter, H., Zijlstra, G. A. R., Skelton, D. A., Cook, J. R., . . . Delbaere, K. (2014). Exercise for reducing fear of falling in older people living in the community. *Cochrane Database of Systematic Reviews*, (11). <https://doi.org/10.1002/14651858.CD009848.pub2>
- Kinney, J. M., & Rentz, C. A. (2005). Observed well-being among individuals with dementia: Memories in the Making, an art program, versus other structured activity. *American Journal of Alzheimer's Disease and Other Dementias*, 20(4), 220-227. <https://doi.org/10.1177/153331750502000406>
- Kitwood, T. M. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.
- Kitwood, T. M., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing and Society*, 12(03), 269-287. <https://doi.org/10.1017/S0144686X0000502X>
- Kok, G., Schaalma, H., Ruiter, R. A. C., Van Empelen, P., & Brug, J. (2004). Intervention mapping: A protocol for applying health psychology theory to prevention programmes. *Journal of Health Psychology*, 9(1), 85-98. <https://doi.org/10.1177/1359105304038379>
- Kulmala, J., Nykanen, I., Manty, M., & Hartikainen, S. (2014). Association between frailty and dementia: A population-based study [Abstract]. *Gerontology*, 60(1), 16-21. <https://doi.org/10.1159/000353859>

- Kwasnicka, D., Dombrowski, S. U., White, M., & Sniehotta, F. (2016). Theoretical explanations for maintenance of behaviour change: A systematic review of behaviour theories. *Health Psychology Review, 10*(3), 277-296.
<https://doi.org/10.1080/17437199.2016.1151372>
- Lam, L. C. W., Chau, R. C. M., Wong, B. M. L., Fung, A. W. T., Tam, C. W. C., Leung, G. T. Y., . . . Chan, W. M. (2012). A 1-year randomized controlled trial comparing mind body exercise (Tai Chi) with stretching and toning exercise on cognitive function in older chinese adults at risk of cognitive decline. *Journal of the American Medical Directors Association, 13*(6), 515-520.
<https://doi.org/10.1016/j.jamda.2012.03.008>
- Lam, L. C. W., & Cheng, S. T. (2013). Maintaining long-term adherence to lifestyle interventions for cognitive health in late life. *International Psychogeriatrics, 25*(2), 171-173. <https://doi.org/10.1017/S1041610212001603>
- Lam, P. (2007). History of Tai Chi. Retrieved from
<http://taichiforhealthinstitute.org/history-of-tai-chi-2/>
- Lamb, S. E., Jørstad-Stein, E. C., Hauer, K., Becker, C., & on behalf of the Prevention of Falls Network Europe and Outcomes Consensus, G. (2005). Development of a common outcome data set for fall injury prevention trials: The prevention of falls network Europe consensus. *Journal of the American Geriatrics Society, 53*(9), 1618-1622. <https://doi.org/10.1111/j.1532-5415.2005.53455.x>
- Lamb, S. E., Mistry, D., Alleyne, S., Atherton, N., Brown, D., Copsey, B., . . . Sheehan, B. (2018). Aerobic and strength training exercise programme for cognitive impairment in people with mild to moderate dementia: the DAPA RCT. *Health Technology Assessment, 22*(28), 1-202. <https://doi.org/10.3310/hta22280>
- Lamb, S. E., Sheehan, B., Atherton, N., Nichols, V., Collins, H., Mistry, D., . . . Lall, R. (2018). Dementia And Physical Activity (DAPA) trial of moderate to high intensity exercise training for people with dementia: Randomised controlled trial. *BMJ, 361*. <https://doi.org/10.1136/bmj.k1675>

- Lamotte, G., Shah, R. C., Lazarov, O., & Corcos, D. M. (2016). Exercise training for persons with Alzheimer's disease and caregivers: A review of dyadic exercise interventions. *Journal of Motor Behavior*, *49*(4), 365-377.
<https://doi.org/10.1080/00222895.2016.1241739>
- Laver, K., Dyer, S., Whitehead, C., Clemson, L., & Crotty, M. (2016). Interventions to delay functional decline in people with dementia: a systematic review of systematic reviews. *BMJ Open*, *6*(4), e010767.
<https://doi.org/10.1136/bmjopen-2015-010767>
- Lawton, M. P. (1994). Quality of life in Alzheimer disease. *Alzheimer Disease and Associated Disorders*, *8*(Suppl.6). <https://doi.org/10.1097/00002093-199404000-00015>
- Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*, *9*(3), 179-186.
https://doi.org/10.1093/geront/9.3_Part_1.179
- Lee, L.-L., Arthur, A., & Avis, M. (2008). Using self-efficacy theory to develop interventions that help older people overcome psychological barriers to physical activity: A discussion paper. *International Journal of Nursing Studies*, *45*(11), 1690-1699. <https://doi.org/10.1016/j.ijnurstu.2008.02.012>
- Lee, L.-L., Avis, M., & Arthur, A. (2007). The role of self-efficacy in older people's decisions to initiate and maintain regular walking as exercise: Findings from a qualitative study. *Preventive Medicine*, *45*(1), 62-65.
<https://doi.org/10.1016/j.ypped.2007.04.011>
- Leung, F.-H., & Savithiri, R. (2009). Spotlight on focus groups. *Canadian Family Physician*, *55*(2), 218-219. Retrieved from
<http://www.cfp.ca/content/55/2/218.short>
- Leung, L. (2015). Validity, reliability, and generalizability in qualitative research. *Journal of Family Medicine and Primary Care*, *4*(3), 324-327.
<https://doi.org/10.4103/2249-4863.161306>

- Leung, P., Orrell, M., & Orgeta, V. (2015). Social support group interventions in people with dementia and mild cognitive impairment: A systematic review of the literature. *International Journal of Geriatric Psychiatry, 30*(1), 1-9.
<https://doi.org/10.1002/gps.4166>
- Lewin, S., Glenton, C., & Oxman, A. (2009). Use of qualitative methods alongside randomised controlled trials of complex healthcare interventions: Methodological study. *BMJ, 339*. <https://doi.org/10.1136/bmj.b3496>
- Leyton, M., Batista, M., Lobato, S., Aspano, M. I., & Jiménez, R. (2017). Application of two intervention programs in order to optimize motivation and to improve eating habits in adult and elderly women. *Journal of Human Kinetics, 59*(1), 131-142.
<https://doi.org/10.1515/hukin-2017-0153>
- Lietz, C. A., & Zayas, L. E. (2010). Evaluating Qualitative Research for Social Work Practitioners. *Advances in Social Work, 11*(2), 188. Retrieved from
<http://search.ebscohost.com/login.aspx?direct=true&db=edo&AN=70459161&site=eds-live&scope=site>
- Littbrand, H., Carlsson, M., Lundin-Olsson, L., Lindelöf, N., Håglin, L., Gustafson, Y., & Rosendahl, E. (2011). Effect of a high-intensity functional exercise program on functional balance: Preplanned subgroup analyses of a randomized controlled trial in residential care facilities. *Journal of the American Geriatrics Society, 59*(7), 1274-1282. <https://doi.org/10.1111/j.1532-5415.2011.03484.x>
- Littbrand, H., Stenvall, M., & Rosendahl, E. (2011). Applicability and effects of physical exercise on physical and cognitive functions and activities of daily living among people with dementia: A systematic review. *American Journal of Physical Medicine and Rehabilitation, 90*(6), 495-518.
<https://doi.org/10.1097/PHM.0b013e318214de26>
- Lo, O.-Y., Conboy, L. A., Rukhadze, A., Georgetti, C., Gagnon, M. M., Manor, B., . . . Wayne, P. M. (2018). In the eyes of those who were randomized: Perceptions of disadvantaged older adults in a Tai Chi trial [Abstract]. *The Gerontologist, gny165*. <https://doi.org/10.1093/geront/gny165>

- Logghe, I. H. J., Verhagen, A. P., Rademaker, A. C. H. J., Zeeuwe, P. E. M., Bierma-Zeinstrá, S. M. A., Van Rossum, E., . . . Koes, B. W. (2011). Explaining the ineffectiveness of a Tai Chi fall prevention training for community-living older people: A process evaluation alongside a randomized clinical trial (RCT). *Archives of Gerontology and Geriatrics*, 52(3), 357-362.
<https://doi.org/10.1016/j.archger.2010.05.013>
- Logsdon, R. G., McCurry, S. M., Pike, K. C., & Teri, L. (2009). Making physical activity accessible to older adults with memory loss: A feasibility study. *The Gerontologist*, 49(Suppl 1), S94–S99. <https://doi.org/10.1093/geront/gnp082>
- Logsdon, R. G., McCurry, S. M., & Teri, L. (2005). A home health care approach to exercise for persons with Alzheimer's disease. *Care Management Journals*, 6(2), 90-97. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/16544870>
- Logsdon, R. G., McCurry, S. M., & Teri, L. (2007). Evidence-based interventions to improve quality of life for individuals with dementia. *Alzheimer's Care Today*, 8(4), 309-318. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=105493062&site=eds-live&scope=site>
- Lomas-Vega, R., Obrero-Gaitán, E., Molina-Ortega, F. J., & Del-Pino-Casado, R. (2017). Tai Chi for risk of falls. A meta-analysis. *Journal of the American Geriatrics Society*, 65(9), 2037-2043. <https://doi.org/10.1111/jgs.15008>
- Lowery, D., Cerga-Pashoja, A., Iliffe, S., Thuné-Boyle, I., Griffin, M., Lee, J., . . . Warner, J. (2014). The effect of exercise on behavioural and psychological symptoms of dementia: The EVIDEM-E randomised controlled clinical trial. *International Journal of Geriatric Psychiatry*, 29(8), 819-827.
<https://doi.org/10.1002/gps.4062>
- Lox, C., Martin Ginis, K. A., & Petruzzello, S. J. (2010). *The psychology of exercise: Integrating theory and practice* (3rd ed.). Scottsdale, Arizona: Holcomb Hathaway.

- Luborsky, M. R., & Rubinstein, R. L. (1995). Sampling in Qualitative Research: Rationale, Issues, and Methods. *Research in Aging, 17*(1), 89-113.
<https://doi.org/10.1177/0164027595171005>
- MacNeil Vroomen, J., Van Mierlo, L. D., van de Ven, P. M., Bosmans, J. E., van den Dungen, P., Meiland, F. J. M., . . . van Hout, H. P. J. (2012). Comparing Dutch case management care models for people with dementia and their caregivers: The design of the COMPAS study. *BMC Health Services Research, 12*, 132.
<https://doi.org/10.1186/1472-6963-12-132>
- MacPhail, C., Khoza, N., Abler, L., & Ranganathan, M. (2016). Process guidelines for establishing intercoder reliability in qualitative studies. *Qualitative Research, 16*(2), 198-212. <https://doi.org/10.1177/1468794115577012>
- Mahoney, F. I., & Barthel, D. (1965). Functional evaluation: The Barthel Index. *Maryland State Medical Journal, 14*, 56-61. Retrieved from
https://www.wcpt.org/sites/wcpt.org/files/files/resources/barthel_reprint.pdf
- Maki, Y., Amari, M., Yamaguchi, T., Nakaaki, S., & Yamaguchi, H. (2012). Anosognosia: Patients' distress and self-awareness of deficits in Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias, 27*(5), 339-345. <https://doi.org/10.1177/1533317512452039>
- Marlatt, G. A., & George, W. H. (1984). Relapse prevention: Introduction and overview of the model. *British Journal of Addiction, 79*(3), 261.
<https://doi.org/10.1111/j.1360-0443.1984.tb00274.x>
- Marson, S. M., & Powell, R. M. (2014). Goffman and the infantilization of elderly persons: A theory in development [article]. *Journal of Sociology and Social Welfare, 41*(4), 143-158. Retrieved from
<http://search.ebscohost.com/login.aspx?direct=true&db=edshol&AN=hein.journals.jrlsasw41.62&site=eds-live&scope=site>

- Matthews, F. E., Stephan, B. C. M., Robinson, L., Jagger, C., Barnes, L. E., Arthur, A., . . . Cognitive Function and Ageing Studies, C. (2016). A two decade dementia incidence comparison from the cognitive function and ageing studies I and II. *Nature Communications*, 7. <https://doi.org/10.1038/ncomms11398>
- McCurry, S. M., Pike, K. C., Logsdon, R. G., Vitiello, M. V., Larson, E. B., & Teri, L. (2010). Predictors of short- and long-term adherence to a daily walking program in persons with alzheimer's disease. *American Journal of Alzheimers Disease and Other Dementias*, 25(6), 505-512. <https://doi.org/10.1177/1533317510376173>
- McCurry, S. M., Pike, K. C., Vitiello, M. V., Logsdon, R. G., Larson, E. B., & Teri, L. (2011). Increasing Walking and Bright Light Exposure to Improve Sleep in Community-Dwelling Persons with Alzheimer's Disease: Results of a Randomized, Controlled Trial. *Journal of The American Geriatrics Society*, 59(8), 1393-1402. <https://doi.org/10.1111/j.1532-5415.2011.03519.x>
- McGovern, J. (2016). When actions speak louder than words: Extending the reach of qualitative data collecting. *Global Qualitative Nursing Research*, 3, 1-7. <https://doi.org/10.1177/2333393616660260>
- McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, 19(13), 1935-1943. <https://doi.org/10.1111/j.1365-2702.2009.03136.x>
- McKillop, J. (2002). Did research alter anything? In H. Wilkinson (Ed.), *The perspectives of people with dementia: Research methods and motivations* (pp. 109-116). London: Jessica Kingsley.
- McKillop, J., & Wilkinson, H. (2004). Make it easy on yourself! Advice to researchers from someone with dementia on being interviewed. *Dementia*, 3(2), 117-125. <https://doi.org/10.1177/1471301204042332>

- McNaughton Nicholls, C., Mills, L., & Kotecha, M. (2013). Observation. In J. Ritchie, J. Lewis, C. McNaughton Nicholls & R. Ormston (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 243-268). London: SAGE Publications Ltd.
- McPhate, L., Simek, E. M., & Haines, T. P. (2013). Program-related factors are associated with adherence to group exercise interventions for the prevention of falls: A systematic review. *Journal of Physiotherapy, 59*(2), 81-92.
[https://doi.org/10.1016/S1836-9553\(13\)70160-7](https://doi.org/10.1016/S1836-9553(13)70160-7)
- McPhate, L., Simek, E. M., Haines, T. P., Hill, K. D., Finch, C. F., & Day, L. (2016). "Are your clients having fun?" The implications of respondents' preferences for the delivery of group exercise programs for falls prevention. *Journal of Aging and Physical Activity, 24*(1), 129-138. <https://doi.org/10.1123/japa.2014-0168>
- Mehra, S., Dadema, T., Kröse, B. J. A., Visser, B., Engelbert, R. H. H., Van Den Helder, J., & Weijs, P. J. M. (2016). Attitudes of older adults in a group-based exercise program toward a blended intervention: A focus-group study. *Frontiers in Psychology, 7*, 1827. <https://doi.org/10.3389/fpsyg.2016.01827>
- Melunsky, N., Crellin, N., Dudzinski, E., Orrell, M., Wenborn, J., Poland, F., . . . Charlesworth, G. (2015). The experience of family carers attending a joint reminiscence group with people with dementia: A thematic analysis. *Dementia, 14*(6), 842-859. <https://doi.org/10.1177/1471301213516332>
- Meyer, C., Hill, S., Dow, B., Synnot, A., & Hill, K. (2015). Translating falls prevention knowledge to community-dwelling older plwd: A mixed-method systematic review. *The Gerontologist, 55*(4), 560-574.
<https://doi.org/10.1093/geront/gnt127>
- Meyer, C., Williams, S., Batchelor, F., & Hill, K. (2016). Enhancing adoption of a home-based exercise program for mild balance dysfunction: A qualitative study. *Journal of Aging and Physical Activity, 24*(1), 53-60.
<https://doi.org/10.1123/japa.2014-0035>

- Miller, F. L., O'Connor, D. P., Herring, M. P., Sailors, M. H., Jackson, A. S., Dishman, R. K., & Bray, M. S. (2014). Exercise dose, exercise adherence, and associated health outcomes in the TIGER study. *Medicine and Science in Sports and Exercise*, 46(1), 69-75. <https://doi.org/10.1249/MSS.0b013e3182a038b9>
- Moon, H., & Adams, K. B. (2013). The effectiveness of dyadic interventions for people with dementia and their caregivers. *Dementia*, 12(6), 821-839. <https://doi.org/10.1177/1471301212447026>
- Moore, G. F., Audrey, S., Barker, M., Bond, L., Bonell, C., Hardeman, W., . . . Baird, J. (2015). Process evaluation of complex interventions: Medical Research Council guidance. *BMJ*, 350, h1258. <https://doi.org/10.1136/bmj.h1258>
- Morgan, D. L. (1997). *Focus groups as qualitative research* (2nd ed.). London: SAGE Publications Ltd.
- Morgan, D. L. (2016). *Essentials of dyadic interviewing*. New York: Routledge.
- Morgan, D. L., Ataie, J., Carder, P., & Hoffman, K. (2013). Introducing dyadic interviews as a method for collecting qualitative data. *Qualitative Health Research*, 23(9), 1276-1284. <https://doi.org/10.1177/1049732313501889>
- Morgan, D. L., Eliot, S., Lowe, R. A., & Gorman, P. (2015). Dyadic interviews as a tool for qualitative evaluation. *American Journal of Evaluation*, 37(1), 109–117. <https://doi.org/10.1177/1098214015611244>
- Morris, R. L., Brand, C. A., Hill, K. D., Ayton, D. R., Redfern, J., Nyman, S. R., . . . Barker, A. L. (2014). RESPOND: A patient-centred programme to prevent secondary falls in older people presenting to the emergency department with a fall-protocol for a mixed methods programme evaluation. *Injury Prevention*, 22(2), 153-160. <https://doi.org/10.1136/injuryprev-2014-041453>
- Mulhall, A. (2003). In the field: Notes on observation in qualitative research. *Journal of Advanced Nursing*, 41(3), 306-313. <https://doi.org/10.1046/j.1365-2648.2003.02514.x>

- Mullan, E., & Markland, D. (1997). Variations in self-determination across the stages of change for exercise in adults. *Motivation and Emotion*, 21(4), 349-362.
<https://doi.org/10.1023/A:1024436423492>
- Murphy, K., Jordan, F., Hunter, A., Cooney, A., & Casey, D. (2014). Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies. *Dementia*, 14(6), 800-824.
<https://doi.org/10.1177/1471301213512489>
- Nascimento, C. M., Ingles, M., Salvador-Pascual, A., Cominetti, M. R., Gomez-Cabrera, M. C., & Viña, J. (2018). Sarcopenia, frailty and their prevention by exercise. *Free Radical Biology and Medicine*, S0891-5849(18), 31499.
<https://doi.org/10.1016/j.freeradbiomed.2018.08.035>
- Nascimento, C. M. C., Teixeira, C. V. L., Gobbi, L. T. B., Gobbi, S., & Stella, F. (2012). A controlled clinical trial on the effects of exercise on neuropsychiatric disorders and instrumental activities in women with Alzheimer's disease. *Revista Brasileira De Fisioterapia*, 16(3), 197-204. Retrieved from
<http://search.ebscohost.com/login.aspx?direct=true&db=mdc&AN=22499405&site=eds-live&scope=site>
- National Institute for Health and Care Excellence. (2013). *Falls in older people: Assessing risk and prevention*. Retrieved from
<https://www.nice.org.uk/guidance/cg161/resources/falls-in-older-people-assessing-risk-and-prevention-35109686728645>
- National Institute for Health and Clinical Excellence. (2007). Behaviour change at population, community and individual levels. Retrieved from
<http://www.ncsct.co.uk/usr/pub/guidance-on-behaviour-change-at-population.pdf>
- National Institute for Health Research. (2016). Public involvement in your research. Retrieved from <http://www.nihr.ac.uk/funding/public-involvement-in-your-research.htm>

- Neupert, S. D., Lachman, M. E., & Whitbourne, S. B. (2009). Exercise self-efficacy and control beliefs: Effects on exercise behavior after an exercise intervention for older adults. *Journal of Aging and Physical Activity, 17*(1), 1-16. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3740728/>
- NHS. (2014). Diverticular disease and diverticulitis. Retrieved from <http://www.nhs.uk/conditions/Diverticular-disease-and-diverticulitis/Pages/Introduction.aspx>
- NHS. (2016). Fibromyalgia. Retrieved from <http://www.nhs.uk/Conditions/Fibromyalgia/Pages/Introduction.aspx>
- Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence Based Nursing, 18*(2), 34-35. <https://doi.org/10.1136/eb-2015-102054>
- Noreña, A. L., Alcaraz-Moreno, N., Rojas, J. G., & Rebolledo-Malpica, D. (2012). Applicability of the Criteria of Rigor and Ethics in Qualitative Research. *Aquichán* (3), 263. Retrieved from <https://search.ebscohost.com/login.aspx?direct=true&db=edssci&AN=edssci.S1657.59972012000300006&site=eds-live&scope=site>
- Nowalk, M. P., Prendergast, J. M., Bayles, C. M., D'Amico, F. J., & Colvin, G. C. (2001). A randomized trial of exercise programs among older individuals living in two long-term care facilities: The FallsFREE program. *Journal of the American Geriatrics Society, 49*(7), 859-865. <https://doi.org/10.1046/j.1532-5415.2001.49174.x>
- Nygård, L. (2006). How can we get access to the experiences of people with dementia? Suggestions and reflections. *Scandinavian Journal of Occupational Therapy, 13*(2), 101-112. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=mdc&AN=16856467&site=eds-live&scope=site>.
- Nyman, S. R. (2011). Psychosocial issues in engaging older people with physical activity interventions for the prevention of falls. *Canadian Journal on Aging, 30*(1), 45-55. <https://doi.org/10.1017/S0714980810000759>

- Nyman, S. R., Adamczewska, N., & Howlett, N. (2017). Systematic review of behaviour change techniques to promote participation in physical activity among people with dementia. *British Journal of Health Psychology*, *23*(1), 148-170.
<https://doi.org/10.1111/bjhp.12279>
- Nyman, S. R., Hayward, C., Ingram, W., Thomas, P., Thomas, S., Vassallo, M., . . . Barrado-Martín, Y. (2018). A randomised controlled trial comparing the effectiveness of Tai Chi alongside usual care with usual care alone on the postural balance of community-dwelling people with dementia: Protocol for The TACIT Trial (TAi Chi for people with dementia). *BMC Geriatrics*, *18*(1), 263.
<https://doi.org/10.1186/s12877-018-0935-8>
- Nyman, S. R., Innes, A., & Heward, M. (2016). Social care and support needs of community-dwelling people with dementia and concurrent visual impairment. *Ageing and Mental Health*, *21*(9), 961-967.
<https://doi.org/10.1080/13607863.2016.1186151>
- Nyman, S. R., & Skelton, D. (2017). The case for Tai Chi in the repertoire of strategies to prevent falls among older people. *Perspectives in Public Health*, *132*(2), 85-86. <https://doi.org/10.1177/1757913916685642>
- Nyman, S. R., & Victor, C. R. (2011). Older people's recruitment, sustained participation, and adherence to falls prevention interventions in institutional settings: A supplement to the Cochrane systematic review. *Age and Ageing*, *40*(4), 430-436. <https://doi.org/10.1093/ageing/afr016>
- Nyman, S. R., & Victor, C. R. (2012). Older people's participation in and engagement with falls prevention interventions in community settings: An augment to the cochrane systematic review. *Age and Ageing*, *41*(1), 16-23.
<https://doi.org/10.1093/ageing/afr103>
- Nyman, S. R., & Victor, C. R. (2014). Older people's participation and engagement in falls prevention interventions: Comparing rates and settings. *European Geriatric Medicine*, *5*, 18-20. <https://doi.org/10.1016/j.eurger.2013.09.008>

- Oakley, A., Strange, V., Bonell, C., Allen, E., Stephenson, J., & Team, R. S. (2006). Process evaluation in randomised controlled trials of complex interventions. *BMJ*, 332. <https://doi.org/10.1136/bmj.332.7538.413>
- O’Cathain, A., Goode, J., Drabble, S. J., Thomas, K. J., Rudolph, A., & Hewison, J. (2014). Getting added value from using qualitative research with randomized controlled trials: A qualitative interview study. *Trials*, 15, 215. <https://doi.org/10.1186/1745-6215-15-215>
- O’Cathain, A., Hoddinott, P., Lewin, S., Thomas, K. J., Young, B., Adamson, J., . . . Donovan, J. L. (2015). Maximising the impact of qualitative research in feasibility studies for randomised controlled trials: Guidance for researchers. *Pilot and Feasibility Studies*, 1(1), 1-13. <https://doi.org/10.1186/s40814-015-0026-y>
- O’Cathain, A., Thomas, K. J., Drabble, S. J., Rudolph, A., & Hewison, J. (2013). What can qualitative research do for randomised controlled trials? A systematic mapping review. *BMJ Open*, 3, e002889. <https://doi.org/10.1136/bmjopen-2013-002889>
- Öhman, H., Savikko, N., Strandberg, T. E., & Pitkälä, K. H. (2014). Effect of physical exercise on cognitive performance in older adults with mild cognitive impairment or dementia: A systematic review. *Dementia and Geriatric Cognitive Disorders*, 38(5), 347-365. <https://doi.org/10.1159/000365388>
- Oja, P., Titze, S., Kokko, S., Kujala, U. M., Heinonen, A., Kelly, P., . . . Foster, C. (2015). Health benefits of different sport disciplines for adults: Systematic review of observational and intervention studies with meta-analysis. *British Journal of Sports Medicine*, 49(7), 434. <https://doi.org/10.1136/bjsports-2014-093885>
- Ormston, R., Spencer, L., Barnard, M., & Snape, D. (2013). The foundations of qualitative research. In J. Ritchie, J. Lewis, C. McNaughton Nicholls, & R. Ormston (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 1-26). London: SAGE Publications Ltd.

- Osho, O., Owoeye, O., & Armijo-Olivo, S. (2018). Adherence and attrition in fall prevention exercise programs for community-dwelling older adults: A systematic review and meta-analysis. *Journal of Aging and Physical Activity*, 26(2), 304-326. <https://doi.org/10.1123/japa.2016-0326>
- Ozbay, F., Johnson, D. C., Dimoulas, E., Morgan, C. A., Charney, D., & Southwick, S. (2007). Social support and resilience to stress: From neurobiology to clinical practice. *Psychiatry*, 4(5), 35-40. <https://doi.org/10.1007/s11920-008-0049-7>
- Patton, M. Q. (2013). *Qualitative research and evaluation methods* (4th ed.). Los Angeles: SAGE Publications Ltd.
- Peek, K., Bryant, J., Carey, M., Dodd, N., Freund, M., Lawson, S., & Meyer, C. (2018). Reducing falls among people living with dementia: A systematic review. *Dementia*. <https://doi.org/10.1177/1471301218803201>
- Petersen, R. C. (2000). Mild cognitive impairment or questionable dementia? *Archives of Neurology*, 57(5), 643-644. <https://doi.org/10.1001/archneur.57.5.643>
- Pitkälä, K. H., Pöysti, M. M., Laakkonen, M.-L., Tilvis, R. S., Savikko, N., Kautiainen, H., & Strandberg, T. E. (2013). Effects of the Finnish Alzheimer disease exercise trial (FINALEX): A randomized controlled trial. *JAMA Internal Medicine*, 173(10), 894-901. <https://doi.org/10.1001/jamainternmed.2013.359>
- Pitkälä, K. H., Savikko, N., Poysti, M., Strandberg, T., & Laakkonen, M.-L. (2013). Efficacy of physical exercise intervention on mobility and physical functioning in older people with dementia: a systematic review. *Experimental Gerontology*, 48(1), 85-93. <https://doi.org/10.1016/j.exger.2012.08.008>
- Podlog, L., & Dionigi, R. A. (2009). Psychological need fulfillment among workers in an exercise intervention: A qualitative investigation. *Research Quarterly for Exercise and Sport*, 80(4), 774-787. <https://doi.org/10.1080/02701367.2009.10599619>
- Podsiadlo, D., & Richardson, S. (1991). The timed "Up & Go": A test of basic functional mobility for frail elderly persons. *Journal of The American Geriatrics Society*, 39(2), 142-148. <https://doi.org/10.1111/j.1532-5415.1991.tb01616.x>

- Pozehl, B., Duncan, K., Hertzog, M., & Norman, J. F. (2010). Heart failure exercise and training camp: effects of a multicomponent exercise training intervention in patients with heart failure. *Heart and Lung: The Journal of Critical Care*, 39(6 Suppl), S1-S13. <https://doi.org/10.1016/j.hrtlng.2010.04.008>
- Prick, A. E., de Lange, J., Scherder, E., Twisk, J., & Pot, A. M. (2017). The effects of a multicomponent dyadic intervention with physical exercise on the cognitive functioning of people with dementia: A randomized controlled trial. *Journal of Aging and Physical Activity*, 25(4), 539-552. <https://doi.org/10.1123/japa.2016-0038>
- Prick, A. E., de Lange, J., Scherder, E., & Pot, A. M. (2011). Home-based exercise and support programme for people with dementia and their caregivers: Study protocol of a randomised controlled trial. *BMC Public Health*, 11, 894-894. <https://doi.org/10.1186/1471-2458-11-894>
- Prick, A. E., de Lange, J., Scherder, E., Twisk, J., & Pot, A. M. (2016). The effects of a multicomponent dyadic intervention on the mood, behavior, and physical health of people with dementia: a randomized controlled trial. *Clinical Interventions in Aging*, 11, 383-395. <https://doi.org/10.2147/CIA.S95789>
- Prick, A. E., de Lange, J., van 't Leven, N., & Pot, A. M. (2014). Process evaluation of a multicomponent dyadic intervention study with exercise and support for people with dementia and their family caregivers. *Trials*, 15(1), 401. <https://doi.org/10.1186/1745-6215-15-401>
- Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., . . . Salimkumar, D. (2014). *Dementia UK: Update*. Retrieved from https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2323
- Prochaska, J. O., & DiClemente, C. C. (1982). Transtheoretical therapy: Toward a more integrative model of change. *Psychotherapy: Theory, Research and Practice*, 19(3), 276-288. <https://doi.org/10.1037/h0088437>

- Radcliffe, E., Lowton, K., & Morgan, M. (2013). Co-construction of chronic illness narratives by older stroke survivors and their spouses. *Sociology of Health and Illness*, 35(7), 993-1007. <https://doi.org/10.1111/1467-9566.12012>
- Rahman, R. J., Hudson, J., Thøgersen-Ntoumani, C., & Doust, J. H. (2015). Motivational processes and well-being in cardiac rehabilitation: A self-determination theory perspective. *Psychology, Health and Medicine*, 20(5), 518-529. <https://doi.org/10.1080/13548506.2015.1017509>
- Rajati, F., Sadeghi, M., Feizi, A., Sharifirad, G., Hasandokht, T., & Mostafavi, F. (2014). Self-efficacy strategies to improve exercise in patients with heart failure: A systematic review. *ARYA atherosclerosis*, 10(6), 319-333. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/25815022>
- Ranby, K. W., & Aiken, L. S. (2016). Incorporating husband influences into a model of physical activity among older women. *British Journal of Health Psychology*, 21(3), 677-693. <https://doi.org/10.1111/bjhp.12195>
- Rankin, K. P., Baldwin, E., Pace-Savitsky, C., Kramer, J. H., & Miller, B. L. (2005). Self awareness and personality change in dementia. *Journal of Neurology, Neurosurgery, and Psychiatry*, 76(5), 632-639. <https://doi.org/10.1136/jnnp.2004.042879>
- Rapport, F., Storey, M., Porter, A., Snooks, H., Jones, K., Peconi, J., . . . Russell, I. (2013). Qualitative research within trials: Developing a standard operating procedure for a clinical trials unit. *Trials*, 14(1), 54. <https://doi.org/10.1186/1745-6215-14-54>
- Rausch, A., Caljouw, M. A. A., & van der Ploeg, E. S. (2017). Keeping the person with dementia and the informal caregiver together: A systematic review of psychosocial interventions. *International Psychogeriatrics*, 29(4), 583-593. <https://doi.org/10.1017/S1041610216002106>

- Ravelin, T., Isola, A., & Kylmä, J. (2013). Dance performance as a method of intervention as experienced by older persons with dementia. *International Journal of Older People Nursing*, 8(1), 10-18. <https://doi.org/10.1111/j.1748-3743.2011.00284.x>
- Reczek, C. (2014). Conducting a multi family member interview study. *Family Process*, 53(2), 318-335. <https://doi.org/10.1111/famp.12060>
- Reed, P., Carson, J., & Gibb, Z. (2017). Transcending the tragedy discourse of dementia: an ethical imperative for promoting selfhood, meaningful relationships, and well-being. *AMA Journal of Ethics*, 19(7), 693-703. <https://doi.org/10.1001/journalofethics.2017.19.7.msoc1-1707>
- Robbins, N. M., & Bernat, J. L. (2017). Should dementia be accepted as a disability to help restore hope during cognitive decline? *AMA Journal of Ethics*, 19(7), 649-655. <https://doi.org/10.1001/journalofethics.2017.19.7.ecas2-1707>
- Robinson, L., Tang, E., & Taylor, J.-P. (2015). Dementia: Timely diagnosis and early intervention. *BMJ : British Medical Journal*, 350, h3029. <https://doi.org/10.1136/bmj.h3029>
- Roethlisberger, F. J., Dickson, W. J., Wright, H. A., Pforzheimer, C. H., & Western Electric, C. (1939). *Management and the worker: An account of a research program conducted by the Western Electric Company, Hawthorne Works, Chicago*. Cambridge, Massachusetts: Harvard University Press.
- Rogers, R. W. (1975). A protection motivation theory of fear appeals and attitude change. *The Journal of Psychology: Interdisciplinary and Applied*, 91(1), 93-114. <https://doi.org/10.1080/00223980.1975.9915803>
- Rollin-Sillaire, A., Breuilh, L., Salleron, J., Bombois, S., Cassagnaud, P., Deramecourt, V., . . . Pasquier, F. (2013). Reasons that prevent the inclusion of Alzheimer's disease patients in clinical trials. *British Journal of Clinical Pharmacology*, 75(4), 1089-1097. <https://doi.org/10.1111/j.1365-2125.2012.04423.x>

- Room, J., Hannink, E., Dawes, H., & Barker, K. (2017). What interventions are used to improve exercise adherence in older people and what behavioural techniques are they based on? A systematic review. *BMJ Open*, 7(12), e019221. <https://doi.org/10.1136/bmjopen-2017-019221>
- Rubenstein, L. Z., Powers, C. M., & MacLean, C. H. (2001). Quality indicators for the management and prevention of falls and mobility problems in vulnerable elders. *Annals of Internal Medicine*, 135(8), 686-693. https://doi.org/10.7326/0003-4819-135-8_Part_2-200110161-00007
- Russell, K. L., & Bray, S. R. (2009). Self-determined motivation predicts independent, home-based exercise following cardiac rehabilitation. *Rehabilitation Psychology*, 54(2), 150-156. <https://doi.org/10.1037/a0015595>
- Ryan, R. M., & Connell, J. P. (1989). Perceived locus of causality and internalization: examining reasons for acting in two domains. *Journal of Personality and Social Psychology*, 57(5), 749-761. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=sih&AN=16690998&site=eds-live&scope=site>
- Ryan, R. M., & Deci, E. L. (2000). Intrinsic and extrinsic motivations: Classic definitions and new directions. *Contemporary Educational Psychology*, 25(1), 54-67. <https://doi.org/10.1006/ceps.1999.1020>
- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55(1), 68-78. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/11392867>
- Saldaña, J. (2016). *The coding manual for qualitative researchers* (3rd ed.). London: SAGE Publications Ltd.
- Samaras, N., Chevalley, T., Samaras, D., & Gold, G. (2010). Older patients in the emergency department: A review. *Annals of Emergency Medicine*, 56(3), 261-269. <https://doi.org/10.1016/j.annemergmed.2010.04.015>

- Saravanakumar, P., Higgins, I. J., Van Der Riet, P. J., Marquez, J., & Sibbritt, D. (2014). The influence of Tai Chi and yoga on balance and falls in a residential care setting: A randomised controlled trial. *Contemporary Nurse*, 48(1), 76-87. <https://doi.org/10.5172/conu.2014.48.1.76>
- Sauer, P. E., Fopma-Loy, J., Kinney, J. M., & Lokon, E. (2014). "It makes me feel like myself": Person-centered versus traditional visual arts activities for people with dementia. *Dementia*, 15(5), 895-912. <https://doi.org/10.1177/1471301214543958>
- Schardt, C., Adams, M. B., Owens, T., Keitz, S., & Fontelo, P. (2007). Utilization of the PICO framework to improve searching PubMed for clinical questions. *BMC Medical Informatics and Decision Making*, 7(1), 16. <https://doi.org/10.1186/1472-6947-7-16>
- Schoo, A., & Morris, M. E. (2003). The effects of mode of exercise instruction on correctness of home exercise performance and adherence. *Physiotherapy Singapore*, 6(2), 36-43. Retrieved from <https://search.ebscohost.com/login.aspx?direct=true&db=edsbl&AN=RN147551070&site=eds-live&scope=site>
- Schwarzer, R. (2008). Modeling health behavior change: How to predict and modify the adoption and maintenance of health behaviors. *Applied Psychology*, 57(1), 1-29. <https://doi.org/10.1111/j.1464-0597.2007.00325.x>
- Schwarzer, R. (2016). Health Action Process Approach (HAPA) as a theoretical framework to understand behavior change. *Actualidades en Psicología*, 30(121), 119-130. <https://doi.org/10.15517/ap.v30i121.23458>
- Schwenk, M., Zieschang, T., Englert, S., Grewal, G., Najafi, B., & Hauer, K. (2014). Improvements in gait characteristics after intensive resistance and functional training in people with dementia: A randomised controlled trial. *BMC Geriatrics*, 14, 73. <https://doi.org/10.1186/1471-2318-14-73>

- Sebire, S. J., Toumpakari, Z., Turner, K. M., Cooper, A. R., Page, A. S., Malpass, A., & Andrews, R. C. (2018). "I've made this my lifestyle now": A prospective qualitative study of motivation for lifestyle change among people with newly diagnosed type two diabetes mellitus. *BMC Public Health*, *18*(1), 204-204. <https://doi.org/10.1186/s12889-018-5114-5>
- Sekhon, M., Cartwright, M., & Francis, J. J. (2017). Acceptability of healthcare interventions: An overview of reviews and development of a theoretical framework. *BMC Health Services Research*, *17*, 88. <https://doi.org/10.1186/s12913-017-2031-8>
- Selzler, A.-M., Rodgers, W. M., Berry, T. R., McFadden, K., Husband, C., & Hall, C. (2018). Reciprocal relationships between self-efficacy, outcome satisfaction, and attendance at an exercise programme. *British Journal of Health Psychology*, *24*(1), 123-140. <https://doi.org/10.1111/bjhp.12343>
- Shaw, F. E. (2003). Falls in older people with dementia. *Geriatrics and Aging*, *6*(7), 37-40. Retrieved from <https://www.healthplexus.net/files/content/2003/August/0607dementiafall.pdf>
- Shelat, A. M. (2016). Neuralgia. Retrieved from <https://medlineplus.gov/ency/article/001407.htm>
- Sher, T., Braun, L., Domas, A., Bellg, A., Baucom, D. H., & Houle, T. T. (2014). The partners for life program: A couples approach to cardiac risk reduction. *Family Process*, *53*(1), 131-149. <https://doi.org/10.1111/famp.12061>
- Sherrington, C., Tiedemann, A., Fairhall, N., Close, J. C. T., & Lord, S. R. (2011). Exercise to prevent falls in older adults: An updated meta-analysis and best practice recommendations. *New South Wales Public Health Bulletin*, *22*(3-4), 78-83. <https://doi.org/10.1071/NB10056>
- Sherrington, C., Whitney, J. C., Lord, S. R., Herbert, R. D., Cumming, R. G., & Close, J. C. (2008). Effective exercise for the prevention of falls: A systematic review and meta-analysis. *Journal of the American Geriatrics Society*, *56*(12), 2234-2243. <https://doi.org/10.1111/j.1532-5415.2008.02014.x>

- Silva, M. N., Vieira, P. N., Coutinho, S. I., Minderico, C. u., Matos, M. G., Sardinha, L. s., & Teixeira, P. J. (2010). Using self-determination theory to promote physical activity and weight control: A randomized controlled trial in women. *Journal of behavioral medicine*, 33(2), 110-122. <https://doi.org/10.1007/s10865-009-9239-y>
- Simek, E. M., McPhate, L., & Haines, T. P. (2012). Adherence to and efficacy of home exercise programs to prevent falls: A systematic review and meta-analysis of the impact of exercise program characteristics. *Preventive Medicine*, 55(4), 262-275. <https://doi.org/10.1016/j.ypmed.2012.07.007>
- Slovinec D'Angelo, M. E., Pelletier, L. G., Reid, R. D., & Huta, V. (2014). The roles of self-efficacy and motivation in the prediction of short- and long-term adherence to exercise among patients with coronary heart disease. *Health Psychology*, 33(11), 1344-1353. <https://doi.org/10.1037/hea0000094>
- Smith, B., & McGannon, K. R. (2018). Developing rigor in qualitative research: problems and opportunities within sport and exercise psychology. *International Review of Sport and Exercise Psychology*, 11(1), 101-121. <https://doi.org/10.1080/1750984X.2017.1317357>
- Smith, R. E., Smoll, F. L., & Cumming, S. P. (2007). Effects of a motivational climate intervention for coaches on young athletes' sport performance anxiety. *Journal of Sport and Exercise Psychology*, 29(1), 39-59. Retrived from <https://www.ncbi.nlm.nih.gov/pubmed/17556775>
- Sniehotta, F. F., Presseau, J., & Araújo-Soares, V. (2014). Time to retire the theory of planned behaviour. *Health Psychology Review*, 8(1), 1-7. <https://doi.org/10.1080/17437199.2013.869710>
- Sousa, L. M. M., Marques-Vieira, C. M. A., Caldevilla, M. N. G. N. d., Henriques, C. M. A. D., Severino, S. S. P., & Caldeira, S. M. A. (2017). Risk for falls among community-dwelling older people: Aystematic literature review. *Revista Gaucha De Enfermagem*, 37(4), e55030. <https://doi.org/10.1590/1983-1447.2016.04.55030>

- Spradley, J. P. (1980). *Participant observation*. Fort Worth, London: Harcourt Brace Jovanovich.
- Steinberg, M., Leoutsakos, J., Podewils, L. J., & Lyketsos, C. G. (2009). Evaluation of a home-based exercise program in the treatment of Alzheimer's disease: the Maximizing Independence in Dementia (MIND) study. *International Journal of Geriatric Psychiatry, 24*(7), 680-685 686p. <https://doi.org/10.1002/gps.2175>
- Stella, F., Canonici, A. P., Gobbi, S., Ferreira Santos-Galduroz, R., de Castilho Cação, J., & Bucken Gobbi, L. T. (2011). Attenuation of neuropsychiatric symptoms and caregiver burden in Alzheimer's disease by motor intervention: A controlled trial. *Clinics, 66*(8), 1353-1360. <https://doi.org/10.1590/S1807-59322011000800008>
- Stevens, Z., Carpenter, H., Gawler, S., Belcher, C., Haworth, D., Kendrick, D., . . . Iliffe, S. (2013). Lessons learnt during a complex, multicentre cluster randomised controlled trial: the ProAct65+ trial. *Trials, 14*(1), 192-192. <https://doi.org/10.1186/1745-6215-14-192>
- Stewart, D. W., Shamdasani, P. N., & Rook, D. W. (2006). *Focus groups: Theory and practice* (2nd ed.). Thousand Oaks, California: SAGE Publications Ltd.
- Stopford, C. L., Thompson, J. C., Neary, D., Richardson, A. M. T., & Snowden, J. S. (2012). Working memory, attention, and executive function in Alzheimer's disease and frontotemporal dementia [Abstract]. *Cortex, 48*(4), 429-446. <https://doi.org/10.1016/j.cortex.2010.12.002>
- Strookappe, B., Swigris, J., De Vries, J., Elfferich, M., Knevel, T., & Drent, M. (2015). Benefits of physical training in sarcoidosis. *Lung, 193*(5), 701-708. <https://doi.org/10.1007/s00408-015-9784-9>
- Ströhle, A., Schmidt, D. K., Schultz, F., Fricke, N., Staden, T., Hellweg, R., . . . Rieckmann, N. (2015). Drug and exercise treatment of Alzheimer disease and mild cognitive impairment: A systematic review and meta-analysis of effects on cognition in randomized controlled trials. *American Journal of Geriatric Psychiatry, 23*(12), 1234-1249. <https://doi.org/10.1016/j.jagp.2015.07.007>

- Su, Y.L., & Reeve, J. (2011). A meta-analysis of the effectiveness of intervention programs designed to support autonomy. *Educational Psychology Review*, 23(1), 159-188. <https://doi.org/10.1007/s10648-010-9142-7>
- Sun, J., Kanagawa, K., Sasaki, J., Ooki, S., Xu, H. L., & Wang, L. (2015). Tai chi improves cognitive and physical function in the elderly: A randomized controlled trial. *Journal of Physical Therapy Science*, 27(5), 1467-1471. <https://doi.org/10.1589/jpts.27.1467>
- Suttanon, P., Hill, K. D., Said, C. M., Byrne, K. N., & Dodd, K. J. (2012). Factors influencing commencement and adherence to a home-based balance exercise program for reducing risk of falls: Perceptions of people with Alzheimer's disease and their caregivers. *International Psychogeriatrics*, 24(7), 1172-1182. <https://doi.org/10.1017/S1041610211002729>
- Suttanon, P., Hill, K. D., Said, C. M., Williams, S. B., Byrne, K. N., LoGiudice, D., . . . Dodd, K. J. (2013). Feasibility, safety and preliminary evidence of the effectiveness of a home-based exercise programme for older people with Alzheimer's disease: a pilot randomized controlled trial. *Clinical Rehabilitation*, 27(5), 427-438. <https://doi.org/10.1177/0269215512460877>
- Tang, K. C., & Davis, A. (1995). Critical factors in the determination of focus group size. *Family Practice*, 12(4), 474-475. <https://doi.org/10.1093/fampra/12.4.474>
- Taylor, M. E., Lord, S. R., Brodaty, H., Kurrle, S. E., Hamilton, S., Ramsay, E., . . . Close, J. C. T. (2017). A home-based, carer-enhanced exercise program improves balance and falls efficacy in community-dwelling older people with dementia. *International Psychogeriatrics*, 29(1), 81-91. <https://doi.org/10.1017/S1041610216001629>
- Teixeira, P. J., Carraça, E. V., Markland, D., Silva, M. N., & Ryan, R. M. (2012). Exercise, physical activity, and self-determination theory: A systematic review. *International Journal of Behavioral Nutrition and Physical Activity*, 9(1), 78. <https://doi.org/10.1186/1479-5868-9-78>

- Teri, L., Gibbons, L. E., McCurry, S. M., Logsdon, R. G., Buchner, D. M., Barlow, W. E., . . . Larson, E. B. (2003). Exercise plus behavioral management in patients with Alzheimer disease: A randomized controlled trial. *Journal of the American Medical Association*, 290(15), 2015-2022.
<https://doi.org/10.1001/jama.290.15.2015>
- Teri, L., Logsdon, R. G., & McCurry, S. M. (2008). Exercise interventions for dementia and cognitive impairment: the Seattle Protocols. *The Journal of Nutrition, Health and Aging*, 12(6), 391-394. Retrieved from
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2518041/>
- Teri, L., McCurry, S. M., Buchner, D. M., Logsdon, R. G., LaCroix, A. Z., Kukull, W. A., . . . Larson, E. B. (1998). Exercise and activity level in Alzheimer's disease: A potential treatment focus. *Journal of Rehabilitation Research and Development*, 35(4), 411-419. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/10220219>
- The Scottish Government. (2018). Falls and dementia. Retrieved from
<https://www.nhsinform.scot/healthy-living/preventing-falls/falls-and-dementia>
- Tinetti, M. E., & Williams, C. S. (1997). Falls, injuries due to falls, and the risk of admission to a nursing home. *The New England Journal of Medicine*, 337(18), 1279-1284. <https://doi.org/10.1056/nejm199710303371806>
- Torgé, C. J. (2013). Using conjoint interviews with couples that have been living with disabilities and illnesses for a long time: Implications and insights. *Qualitative Studies*, 4(2). <https://doi.org/10.7146/qs.v4i2.8860>
- Treweek, S., Lockhart, P., Pitkethly, M., Cook, J. A., Kjeldstrøm, M., Johansen, M., . . . Mitchell, E. D. (2013). Methods to improve recruitment to randomised controlled trials: Cochrane systematic review and meta-analysis. *BMJ Open*, 3(2), e002360. <https://doi.org/10.1136/bmjopen-2012-002360>

- Tsai, P.-F., Chang, J. Y., Beck, C., Kuo, Y.-F., Keefe, F. J., & Rosengren, K. (2015). A supplemental report to a randomized cluster trial of a 20-week Sun-style Tai Chi for osteoarthritic knee pain in elders with cognitive impairment. *Complementary Therapies in Medicine, 23*(4), 570-576.
<https://doi.org/10.1016/j.ctim.2015.06.001>
- UK Data Archive. (N. D.). Anonymisation. Retrieved from
<https://www.ukdataservice.ac.uk/manage-data/legal-ethical/anonymisation/qualitative.aspx>
- UK Parliament. (2015). Political challenges relating to an aging population: Key issues for the 2015 Parliament. Retrieved from
<https://www.parliament.uk/business/publications/research/key-issues-parliament-2015/social-change/ageing-population/>
- Ullén, F., de Manzano, Ö., Almeida, R., Magnusson, P. K. E., Pedersen, N. L., Nakamura, J., . . . Madison, G. (2012). Proneness for psychological flow in everyday life: Associations with personality and intelligence. *Personality and Individual Differences, 52*(2), 167-172.
<https://doi.org/10.1016/j.paid.2011.10.003>
- United Nations. (2017). *World population prospects: The 2017 revision, key findings and advancetables*. Retrieved from
https://esa.un.org/unpd/wpp/Publications/Files/WPP2017_KeyFindings.pdf
- van der Wardt, V., Hancox, J., Gondek, D., Logan, P., Nair, R. d., Pollock, K., & Harwood, R. (2017). Adherence support strategies for exercise interventions in people with mild cognitive impairment and dementia: A systematic review. *Preventive Medicine Reports, 7*, 38-45.
<https://doi.org/10.1016/j.pmedr.2017.05.007>
- van Gog, T., & Rummel, N. (2010). Example-based learning: Integrating cognitive and social-cognitive research perspectives. *Educational Psychology Review, 22*(2), 155-174. <https://doi.org/10.1007/s10648-010-9134-7>

- van Halteren-van Tilborg, I. A. D. A., Scherder, E. J. A., & Hulstijn, W. (2007). Motor-skill learning in alzheimer's disease: A review with an eye to the clinical practice. *Neuropsychology Review*, *17*(3), 203-212.
<https://doi.org/10.1007/s11065-007-9030-1>
- Van Mierlo, L. D., Meiland, F. J. M., Van Hout, H. P. J., & Dröes, R.-M. (2014). Towards personalized integrated dementia care: A qualitative study into the implementation of different models of case management. *BMC geriatrics*, *14*, 84-84. <https://doi.org/10.1186/1471-2318-14-84>
- van Stralen, M. M., De Vries, H., Mudde, A. N., Bolman, C., & Lechner, L. (2009). Determinants of initiation and maintenance of physical activity among older adults: A literature review. *Health Psychology Review*, *3*(2), 147-207.
<https://doi.org/10.1080/17437190903229462>
- Van't Leven, N., de Lange, J., Prick, A. E., & Pot, A. M. (2016). How do activating interventions fit the personal needs, characteristics and preferences of people with dementia living in the community and their informal caregivers? *Dementia* *18*(1), 157–177. <https://doi.org/10.1177/1471301216662378>
- Van't Leven, N., Prick, A. E., Groenewoud, J. G., Roelofs, P. D., de Lange, J., & Pot, A. M. (2013). Dyadic interventions for community-dwelling people with dementia and their family caregivers: A systematic review. *International Psychogeriatrics*, *25*(10), 1581-1603. <https://doi.org/10.1017/s1041610213000860>
- Vansteenkiste, M., Niemiec, C. P., & Soenens, B. (2010). The development of the five mini-theories of self-determination theory: An historical overview, emerging trends, and future directions. In T. C. Urdan & S. A. Karabenick (Eds.), *The decade ahead: Theoretical perspectives on motivation and achievement advances in motivation and achievement* (pp. 105-165). Bingley: Emerald Group Publishing Ltd.

- Verplanken, B., & Aarts, H. (1999). Habit, attitude, and planned behaviour: Is habit an empty construct or an interesting case of goal-directed automaticity? *European Review of Social Psychology*, 10(1), 101-134.
<https://doi.org/10.1080/14792779943000035>
- Vieira, E. R., Palmer, R. C., & Chaves, P. H. M. (2016). Prevention of falls in older people living in the community. *BMJ*, 353, i1419.
<https://doi.org/10.1136/bmj.i1419>
- Voigt-Radloff, S., Graff, M., Leonhart, R., Hull, M., Rikkert, M. O., & Vernooij-Dassen, M. (2011). Why did an effective Dutch complex psycho-social intervention for people with dementia not work in the German healthcare context? Lessons learnt from a process evaluation alongside a multicentre RCT. *BMJ Open*, 1(1), e000094. <https://doi.org/10.1136/bmjopen-2011-000094>
- Voukelatos, A., Cumming, R. G., Lord, S. R., & Rissel, C. (2007). A randomized, controlled trial of Tai Chi for the prevention of falls: The central Sydney Tai Chi Trial. *Journal of the American Geriatrics Society*, 55(8), 1185-1191.
<https://doi.org/10.1111/j.1532-5415.2007.01244.x>
- Walsh, J. N., Manor, B., Hausdorff, J., Novak, V., Lipsitz, L., Gow, B., . . . Wayne, P. M. (2015). Impact of short- and long-term tai chi mind-body exercise training on cognitive function in healthy adults: Results from a hybrid observational study and randomized trial. *Global Advances in Health and Medicine*, 4(4), 38-48.
<https://doi.org/10.7453/gahmj.2015.058>
- Warner, L. M., Wolff, J. K., Ziegelmann, J. P., Schwarzer, R., & Wurm, S. (2016). Revisiting self-regulatory techniques to promote physical activity in older adults: Null-findings from a randomised controlled trial. *Psychology and Health*, 31(10), 1145-1165. <https://doi.org/10.1080/08870446.2016.1185523>
- Watson, D., Clark, L. A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: the PANAS scales. *Journal of Personality and Social Psychology*, 54(6), 1063-1070. Retrieved from

<http://search.ebscohost.com/login.aspx?direct=true&db=mdc&AN=3397865&site=eds-live&scope=site>

- Wayne, P. M., Hausdorff, J. M., Lough, M., Gow, B. J., Lipsitz, L., Novak, V., . . . Manor, B. (2015). Tai Chi training may reduce dual task gait variability, a potential mediator of fall risk, in healthy older adults: Cross-sectional and randomized trial studies. *Frontiers in Human Neuroscience*, 9. <https://doi.org/10.3389/fnhum.2015.00332>
- Wayne, P. M., Walsh, J. N., Taylor-Piliae, R. E., Wells, R. E., Papp, K. V., Donovan, N. J., & Yeh, G. Y. (2014). Effect of Tai Chi on cognitive performance in older adults: Systematic review and meta-analysis. *Journal of the American Geriatrics Society*, 62(1), 25-39. <https://doi.org/10.1111/jgs.12611>
- Welsh, E. (2002). Dealing with Data: Using NVivo in the Qualitative Data Analysis Process. *Forum: Qualitative Social Research*, 3(2). Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/865/1880>
- Weman-Josefsson, K., Lindwall, M., & Ivarsson, A. (2015). Need satisfaction, motivational regulations and exercise: Moderation and mediation effects. *International Journal of Behavioral Nutrition and Physical Activity*, 12(1), 67. <https://doi.org/10.1186/s12966-015-0226-0>
- Wesson, J., Clemson, L., Brodaty, H., Lord, S., Taylor, M., Gitlin, L., & Close, J. (2013). A feasibility study and pilot randomised trial of a tailored prevention program to reduce falls in older people with mild dementia. *BMC Geriatrics*, 13, 89. <https://doi.org/10.1186/1471-2318-13-89>
- West, R., Walia, A., Hyder, N., Shahab, L., & Michie, S. (2010). Behavior change techniques used by the English stop smoking services and their associations with short-term quit outcomes. *Nicotine & Tobacco Research*, 12(7), 742-747. <https://doi.org/10.1093/ntr/ntq074>
- WHO. (2003). *Adherence to long-term therapies: Evidence for action*. Retrieved from http://www.who.int/chp/knowledge/publications/adherence_full_report.pdf

- WHO. (2004). *Ageing and health technical report volume 5: A glossary of terms for community health care and services for older persons*. Retrieved from http://www.who.int/kobe_centre/publications/Ageing_Tech_Report_5/en/
- WHO. (2007). *WHO global report on falls prevention in older age*. Retrieved from http://www.who.int/ageing/publications/Falls_prevention7March.pdf?ua=1
- WHO. (2015). *World report on ageing and health*. Retrieved from http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811_eng.pdf
- WHO. (2018). *Towards a dementia plan: A WHO guide*. Retrieved from <http://apps.who.int/iris/bitstream/handle/10665/272642/9789241514132-eng.pdf?ua=1>
- Wilkinson, H. (2002). Including people with dementia in research: methods and motivations. In H. Wilkinson (Ed.), *The perspectives of people with dementia: research methods and motivations*. London: Jessica Kingsley.
- Willson, J. (2007). Using the PICO model to formulate a search question. Retrieved from https://as.exeter.ac.uk/media/level1/academicsserviceswebsite/library/document/s/presentations/Using_the_PICO_model_to_formulate_a_Search_Question.pdf
- Wilson, P. M., Longley, K., Muon, S., Rodgers, W. M., & Murray, T. C. (2007). Examining the contributions of perceived psychological need satisfaction to well-being in exercise 1. *Journal of Applied Biobehavioral Research*, 11(3), 243-264. <https://doi.org/10.1111/j.1751-9861.2007.00008.x>
- Windle, G., Newman, A., Burholt, V., Woods, B., O'Brien, D., Baber, M., . . . Tischler, V. (2016). Dementia and Imagination: a mixed-methods protocol for arts and science research. *BMJ Open*, 6, e011634. <https://doi.org/10.1136/bmjopen-2016-011634>
- Windle, G., Woods, R. T., & Markland, D. A. (2010). Living with ill-health in older age: The role of a resilient personality. *Journal of Happiness Studies*, 11(6), 763-777. <https://doi.org/10.1007/s10902-009-9172-3>

- Wolf, E. M. (2015). Paired integrative home exercise for seniors with dementia and their caregivers (PairedPLIE). Retrieved from <https://clinicaltrials.gov/show/NCT02403752>
- Wolf, S. L., Barnhart, H. X., Kutner, N. G., McNeely, E., Coogler, C., & Xu, T. (1996). Reducing frailty and falls in older persons: An investigation of Tai Chi and computerized balance training. Atlanta FICSIT Group. Frailty and injuries: Cooperative studies of intervention techniques. *Journal of the American Geriatrics Society*, 44(5), 489-497. <https://doi.org/10.1111/j.1532-5415.1996.tb01432.x>
- Wolverson, E. L., Clarke, C., & Moniz-Cook, E. (2010). Remaining hopeful in early-stage dementia: A qualitative study. *Aging and Mental Health*, 14(4), 450-460. <https://doi.org/10.1080/13607860903483110>
- Woods, M., Paulus, T., Atkins, D. P., & Macklin, R. (2016). Advancing qualitative research using qualitative data analysis software (QDAS)? Reviewing potential versus practice in published studies using ATLAS.ti and NVivo, 1994–2013 [Abstract]. *Social Science Computer Review*, 34(5), 597-617. <https://doi.org/10.1177/0894439315596311>
- Woods, R. T., Orrell, M., Bruce, E., Edwards, R. T., Hoare, Z., Hounsome, B., . . . Russell, I. (2016). REMCARE: Pragmatic multi-centre randomised trial of reminiscence groups for people with dementia and their family carers: Effectiveness and economic analysis. *PLoS One*, 11(4), 1-19. <https://doi.org/10.1371/journal.pone.0152843>
- World Medical Association. (2013). World Medical Association Declaration of Helsinki. Ethical Principles for Medical Research Involving Human Subjects. 310(20), 2191-2194. <https://doi.org/10.1001/jama.2013.281053>
- Wu, E., Barnes, D. E., Ackerman, S. L., Lee, J., Chesney, M., & Mehling, W. E. (2015). Preventing loss of independence through exercise (PLIE): Qualitative analysis of a clinical trial in older adults with dementia. *Aging and Mental Health*, 19(4), 353-362. <https://doi.org/10.1080/13607863.2014.935290>

- Wu, G., Keyes, L., Callas, P., Ren, X., & Bookchin, B. (2010). Comparison of telecommunication, community, and home-based Tai Chi exercise programs on compliance and effectiveness in elders at risk for falls. *Archives of Physical Medicine and Rehabilitation, 91*(6), 849-856.
<https://doi.org/10.1016/j.apmr.2010.01.024>
- Wu, Y., MacDonald, H. V., & Pescatello, L. S. (2016). Evaluating exercise prescription and instructional methods used in Tai Chi studies aimed at improving balance in older adults: A systematic review. *Journal of the American Geriatrics Society. https://doi.org/10.1111/jgs.14242*
- Yao, L., Giordani, B., & Alexander, N. B. (2008). Developing a positive emotion-motivated Tai Chi (PEM-TC) exercise program for older adults with dementia. *Research and Theory for Nursing Practice, 22*(4), 241-255. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5672945/>
- Yao, L., Giordani, B. J., Algase, D. L., You, M., & Alexander, N. B. (2012). Fall risk-relevant functional mobility outcomes in dementia following dyadic Tai Chi exercise. *Western Journal of Nursing Research, 35*(3), 281-296.
<https://doi.org/10.1177/0193945912443319>
- Yardley, L., Bishop, F. L., Beyer, N., Hauer, K., Kempen, G. I. J. M., Piot-Ziegler, C., . . . Holt, A. R. (2006). Older people's views of falls-prevention interventions in six european countries. *Gerontologist, 46*(5), 650-660. Retrieved from <https://www.research.manchester.ac.uk/portal/files/29912088/POST-PEER-REVIEW-PUBLISHERS.PDF>
- Yardley, L., & Smith, H. (2002). A prospective study of the relationship between feared consequences of falling and avoidance of activity in community-living older people. *Gerontologist, 42*(1), 17-23. <https://doi.org/10.1093/geront/42.1.17>
- Yu, F., & Swartwood, R. M. (2012). Feasibility and perception of the impact from aerobic exercise in older adults with Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias, 27*(6), 397-405.
<https://doi.org/10.1177/1533317512453492>

- Yu, F., Thomas, W., Nelson, N. W., Bronas, U. G., Dysken, M., & Wyman, J. F. (2015). Impact of 6-month aerobic exercise on Alzheimer's symptoms. *Journal of Applied Gerontology, 34*(4), 484-500.
<https://doi.org/10.1177/0733464813512895>
- Zamawe, F. C. (2015). The implication of using NVivo software in qualitative data analysis: Evidence-based reflections. *Malawi Medical Journal, 27*(1), 13-15.
Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4478399/>
- Zheng, G., Liu, F., Li, S., Huang, M., Tao, J., & Chen, L. (2015). Tai Chi and the protection of cognitive ability: A systematic review of prospective studies in healthy adults. *American Journal of Preventive Medicine, 49*(1), 89-97.
<https://doi.org/10.1016/j.amepre.2015.01.002>

Appendices

Appendix A

Detailed Author’s Contribution to This Thesis and the TACIT trial

Table A 1. *Author’s Contributions to the TACIT Trial and This Thesis*

Pilot Intervention Phase	
Contributions to The TACIT Trial	Contributions to this thesis
<ul style="list-style-type: none"> • Publicity (PhD 1 & PhD 2). • Telephone screening (PhD 1 & PhD 2). • Baseline home-visit - demographic and baseline measurements collection (PhD 2). • Weekly and monthly falls calls monitoring (PhD 1). • Provision of refreshments during the classes (PhD 1). • Fidelity checks of the implementation process (PhD 1). • Analysis and write-up of a report for the Trial Management Team with lessons learnt in the Pilot Intervention Phase (PhD 1). 	<ul style="list-style-type: none"> • Literature review to identify gaps in previous research, including approach to literature review. • Research design, including approach to analysis. • Liaison with Patient and Public Involvement (PPI) group to check appropriateness of qualitative methods and questions (to be used in the Pilot Intervention and in the RCT Phase). • Attendance and observation of each of the 7 classes (with one PhD supervisor making observations to compare observational tool). • 2 Focus groups (with 1 PhD supervisor per group providing support). • Demographic data collected at baseline home-visits by PhD 2 was entered and used by PhD 1 to enrich description of the participants. • Research diary entries after each face-to-face contact with participants. • Checks and anonymisation of focus groups content (as focus groups were sent for professional transcription verbatim). • Analysis (with 1 PhD supervisor double-coding 10% of the data) and write up.
RCT Phase	
Contributions to The TACIT Trial	Contributions to this thesis
<ul style="list-style-type: none"> • Publicity actions (PhD 1 21/32 face-to-face actions to raise awareness of the TACIT Trial & PhD 2 11/32) and contacts with different organisations. • Telephone screening (PhD 1 282/359 dyads referred & PhD 2 74/359). • Join Dementia Research Website screening of potential participants (PhD 1). • Weekly recruitment progress updates to Trial Managers & CI (PhD 1). • Monthly recruitment updates to 3 NHS research sites (PhD 2). • Baseline home-visits - Demographic and baseline measurements collection (PhD 2 – 95 home-visits - > 85 randomised dyads). • Weekly & monthly monitoring falls calls with 	<ul style="list-style-type: none"> • Literature review to identify gaps in previous research. • Research design, including choice of Self-Determination Theory and analytical approach. • Collection of data regarding reasons for not being able to attend classes, during weekly monitoring calls. • Demographic data collected at baseline home-visits by PhD 2 relative to the participants included in this thesis was entered and used by PhD 1 to enrich description of the participants. • Attendance and observation of 23 classes. • 15 joint dyadic home-interviews. • Research diary entries after each face-to-face

<p>participants living with dementia and 3-monthly calls with carers (PhD 1, >2,200 processed forms, with 3 attempts per participant per week– except during a total of 6 weeks when the author left this task with a member of the supervisory team or a Research Assistant).</p> <ul style="list-style-type: none"> • Attendance reminders for dyads non-attending more than 2 classes in a row (PhD 1). • Revealing dyads allocation over the phone, due to randomisation taking place close to the start date of the classes (PhD 1). • Classes’ registers, home-exercises, falls calendars and Instructors’ home-visits’ forms scan and storage before sending hard-copies to Trial Managers (PhD 1). • Monitoring and processing of class and home data to i.e., to remind instructors to post class registers or participants to fill in their exercise logs (PhD 1). • Assisting participants with doubts regarding claiming travel expenses (PhD 1). • Fidelity checks of the implementation process (PhD 1: 20; Research Assistants:19). • Half-way through questionnaires (PhD 1: 30 dyadic questionnaires, Research Assistants: 10), and feedback on this questionnaire (PhD 1). • Adverse Events, Serious Adverse Events, Safety Monitoring and Withdrawal reports (PhD1). • Data queries (PhD 1 & PhD 2). • Follow-up home-visits (PhD 2). 	<p>contact with participants.</p> <ul style="list-style-type: none"> • Processing and incorporating data from implementation fidelity checks, class registers, home-exercise registers and instructor’s home-visits documents including coping and action plans. • Checks and anonymization of dyadic interview’s content (as interviews were sent for professional transcription verbatim). • Analysis (with 1 PhD supervisor double-coding 10% of the data) and write up.
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Appendix B

This Thesis' Research Questions and Sub-questions

Table B 1. *Research Questions and Sub-Questions*

Research Questions	Research Sub-Questions	When this will be assessed	Method
1. What is influencing participants' acceptability of a Tai Chi exercise intervention?	How are intervention (dosage, instructional methods, socialising component, instructor's rapport, enjoyable, engaging) and participant's characteristics (attitudes, mood, needs) impacting on participant's acceptability of the class-based Tai Chi practice?	Pilot Intervention Phase – During sessions.	Observation - Field notes (Greater Cincinnati elements)
	How is the implementation fidelity impacting on participants' acceptability of the intervention?	Pilot Intervention Phase – After the sessions (using video recordings).	Fidelity Checklist
	How do participant's enjoyment level of the classes and perceptions about Tai Chi impact on their acceptability of the intervention?	Pilot Intervention Phase – At the end of each class.	Feedback – Field notes
	What are the perceived benefits/harms of taking part in Tai Chi influencing their acceptability of the intervention?	Pilot Intervention Phase – At the end of each class.	Feedback – Field notes
	What is influencing participants' adherence to the home-based Tai Chi practice? (What are the barriers/facilitators they are encountering?)	Pilot Intervention Phase – At the end of each class.	Feedback – Field notes
	What are the strengths/weaknesses of the dyadic Tai Chi (group/home-based) intervention influencing participant's acceptability? How could weaknesses be overcome?	Pilot Intervention Phase – End of last session.	Focus group
	How is the research process impacting on participants' acceptability of the intervention?	Pilot Intervention Phase – End of last session.	Focus group

Research Questions	Research Sub-Questions		When this will be assessed	Method	
2. What is prompting or mitigating participants' adherence to a Tai Chi exercise?	How are intervention (dosage, instructional methods, socialising component, instructor's rapport, enjoyable, engaging) and participant's characteristics (attitudes, mood, needs) impacting on sustaining participant's adherence to the class-based Tai Chi?	Are there any changes between the two time-points observations?	RCT Phase – observation sessions.	During	Observation - Field notes (Greater Cincinnati elements)
	How do participant's enjoyment level of the classes and perceptions about Tai Chi impact on maintaining their adherence to the Tai Chi intervention?	Are there any changes compared with those reported in the Pilot Intervention Phase?	RCT Phase – the end of the observed classes.	At	Feedback – Field notes
	What are the perceived benefits/harms of taking part in Tai Chi influencing their adherence to the intervention?		RCT Phase – the end of the observed classes.	At	Feedback – Field notes
	How is participants' adherence to the home-based Tai Chi practice? (What are the barriers/facilitators?)		RCT Phase – the end of the observed classes.	At	Feedback – Field notes
	How is the implementation fidelity impacting on participants' adherence to the intervention?		RCT Phase – the session observed sessions (using video recordings).	After	Fidelity Checklist
	What characteristics of the class-based or home-based intervention help participants to adhere more to the Tai Chi intervention? (Do they express any preference for any formats?)		RCT Phase – the end of the observed classes.	At	Feedback – Field notes
			And Towards the end of the Tai Chi intervention.		And Dyadic Semi-Structured Interviews

Research Questions	Research Sub-Questions	When this will be assessed	Method
	What factors act as a barrier for participants' continued participation in Tai Chi classes and/or at home? How could this be overcome?	RCT Phase – At the end of the observed classes. And Towards the end of the Tai Chi intervention.	Feedback – Field notes And Dyadic Semi- Structured Interviews
	What is the perceived impact of Tai Chi in dyads' life?	RCT Phase – Towards the end of the Tai Chi intervention	Dyadic Semi- Structured Interviews
3. How do people living with dementia and their informal carers experience their joint participation in a Tai Chi exercise intervention?	How does the dyadic relationship impact on their experience of taking part together in Tai Chi? How the quality of their communication impacts on their joint experience?	RCT Phase – Towards the end of the Tai Chi intervention	Dyadic Semi- Structured Interviews
	How can any changes in their dyadic relationship (during their joint participation in the Trial) be explained?	RCT Phase – Towards the end of the Tai Chi intervention	Dyadic Semi- Structured Interviews
	How does the motivation of each member of the dyad impact on their adherence and experience of taking part in Tai Chi?	RCT Phase – At the end of the observed classes. And Towards the end of the Tai Chi intervention.	Feedback – Field notes And Dyadic Semi- Structured Interviews

Appendix C

PICO Components

Table C 1. *Description of PICO Components in This Thesis*

Element	Description
P	Population, patient or problem targeted by the intervention. For this thesis older people living with dementia and their informal carers were both considered participants as a dyad. Systematic reviews and individual studies around dyadic interventions were included.
I	Intervention or the condition which effects are under study. In the first instance, papers assessing Tai Chi intervention's impact on dyads were included. The preliminary search regarding Tai Chi interventions conducted in the target population were found to be limited. Parallel searches were also conducted including other exercise interventions. In this case, searches were also focused on exercise interventions conducted in dyads, as this approach was the one chosen for the TACIT trial and had an impact on the methodology chosen in this study. Similarly, neighbouring literature (i.e., exercise interventions involving people living with dementia or their carers, papers reporting opinions from their instructors) evaluating trials was searched and reported in this review. Those studying acceptability, adherence or reporting process evaluations of exercise interventions were examined.
C	Comparison or control, as another intervention or usual care. This element does not always apply, as is the case in the present study, where only participants in the intervention arm were included. It is important to acknowledge, however, that in trials included in this review participants allocated to control groups generally received usual care or another psychosocial intervention. In most of the cases this comparison of non-pharmacological interventions was another type of exercise (i.e., stretching).
O	Outcome or the measurable impact of the intervention. Studies designed to improve balance and/or reduce the number of falls amongst people living with dementia through exercise interventions were included. A general overview of cognitive and physical improvements observed in people living with dementia after exercise interventions it is also provided. Finally, the impact of fidelity on research outcomes is also examined.

Appendix D

Search Strategy Example

Different searches were conducted from February to July 2016 using Bournemouth University e-resources system to run searches across databases (including MEDLINE, CINAHL, PsycINFO, Science Direct, Scopus and ClinicalTrials.gov) keywords included “dement*”, “cognitive impair*”, “alzheimer*”, exercise, “physical activity”, “tai chi”, dyad*, acceptability, adherence, qualitative, barrier*, facilitator*, “process evaluation”, balance and fall*.

Table D 1. *Examples of Specific Search Strategies*

Section were this search is reported	Search Date	Booleans used	Hits (Searching in Bournemouth University e-resources)
2.3.1.2. Process evaluations in exercise interventions	22/07/2016	1) "process evaluation" AND dyad* AND (dementia OR "cognitive impair*" OR alzheimer*);	14 hits: CINAHL complete (n= 5), MEDLINE Complete (n=6), PsycINFO (n=2) and ScienceDirect (n=1).
		2) (barrier* OR facilitator* OR adherence OR acceptability OR qualitative) AND dyad* AND (dementia OR "cognitive impair*" OR alzheimer*) AND intervention.	
2.3.2.1. Tai Chi	16/06/2016	1 st) dyad* AND “tai chi” AND (dement* OR "cognitive impair*" OR alzheimer*)	18 hits: PsycINFO (n=4), Science Citation Index (n=4), Social Sciences Citation Index (n=4), MEDLINE Complete (n=2), ScienceDirect (n=1) and Scopus (n=3).
		2 nd) ("tai chi" OR "taichi") AND dyad*	
	28/06/2016	3 rd) "process evaluation" AND "tai chi" AND (dement* OR "cognitive impair*" OR Alzheimer*)	
		4 th) "process evaluation" AND ("tai chi" OR taichi OR tai-chi)	

At a later stage, all searches were updated (on 20/11/2018) and total numbers are provided in next page’s flow diagram.

Literature Review Flow Chart

Selection criteria:

- **Exclusion:**
 - Excluding or not involving people living with dementia or cognitive impairment (i.e., based on healthy ageing, prevention studies and Mild Cognitive Impairment).
 - Non-primary research studies or studies not involving an exercise intervention.
 - Studies conducted in hospitals or long-term care settings (except for Tai Chi studies meeting all previous criteria).
- **Inclusion:**
 - Studies including people living with dementia.
 - Studies reporting primary research on exercise interventions.
 - Studies conducted with community-dwelling people living with dementia.

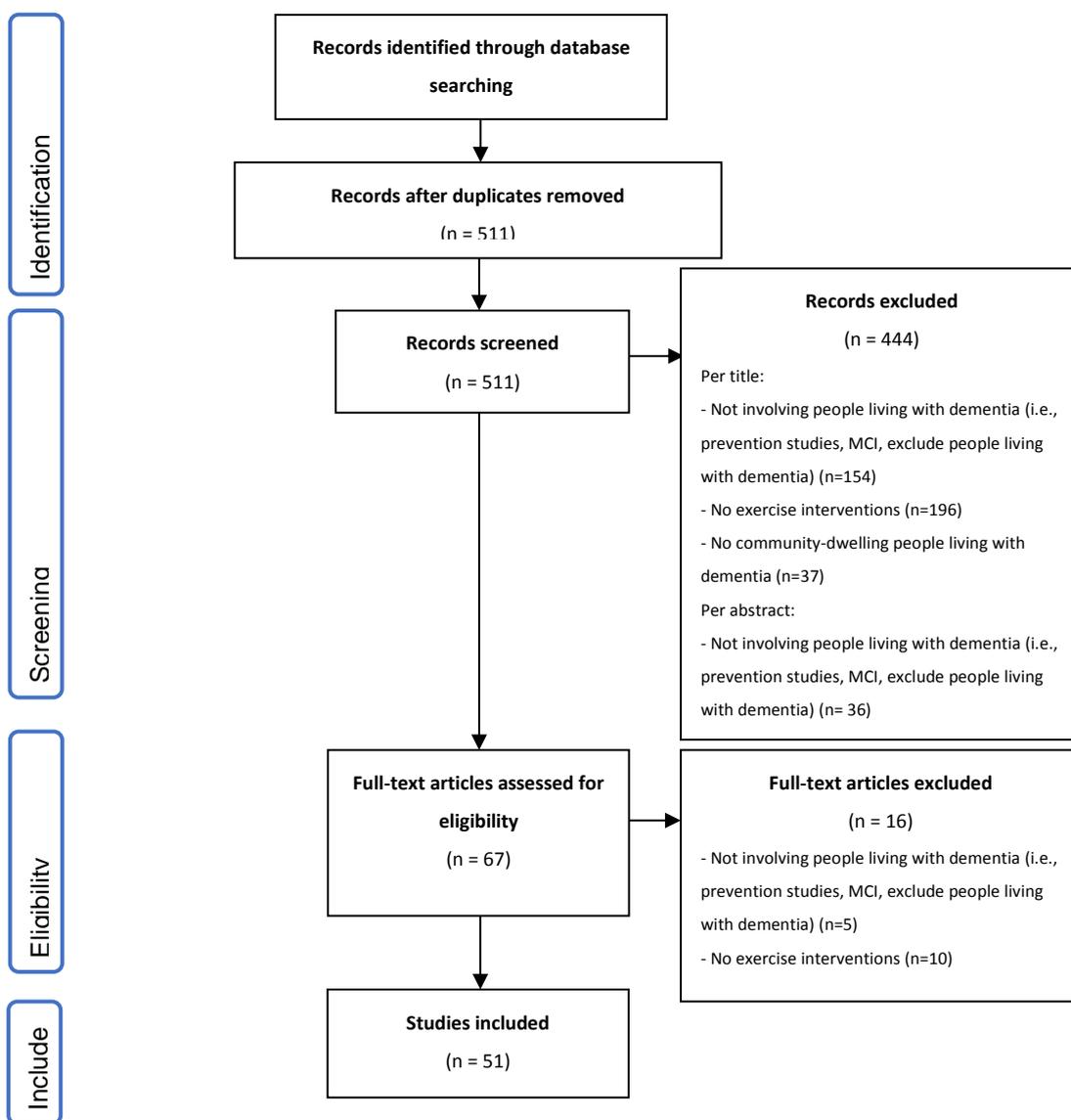


Figure D 1. Flow diagram of papers identified and finally included in the main body of the literature review. Adapted from The PRISMA Statement²¹.

²¹ Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097.

Appendix E

Process Evaluation Elements Included in a Tai Chi Exercise Intervention for Older People (Logghe et al., 2011).

a) Fidelity to the protocol. Instructors were asked to complete a questionnaire after the last class conducted with each group to record deviations from the protocol. Deviations were only reported in four out of eleven groups organized. Those were considered as minor deviations to adapt the intervention to participants needs. In one of the groups participants were not able to stand for an hour, so a 10-minute break was provided. In the other 3 groups, additional exercises were incorporated to the warm-up and cool-down movements. However, the fact that these checks were conducted by the instructors and at the end of the intervention could have hindered the assessment of the fidelity to the protocol in the daily conduct of the intervention. For this thesis fidelity checks will be conducted by the researcher during all the sessions in the Intervention Pilot Intervention Phase and in 10% of the sessions in the RCT Phase. This will facilitate an ongoing assessment, based on direct observation of the sessions, and will allow possible deviations to be timely addressed.

b) Older adults' attendance and adherence to the sessions. Instructors registered participants' attendance to the classes and an independent researcher called participants who withdraw before or during the session to record their reasons. Adherence was measured at the end of the intervention using a self-report questionnaire for participants (regarding their home-based practice) and an additional questionnaire for instructors (were participants' effort during the classes was recorded). After registering 36% attrition, 64% of participants completed the course. Half of the attrition was recorded before the first session, and those who withdrew during the intervention did it due to poor health, low motivation, problems with transportation, or death. Only 47% of recruited participants attended 80% of the sessions (the cut-off point used by the authors for adherence). Self-reported adherence to the home-based component was 59%, however, only 28% followed the recommended dose of a minimum of 10 minutes twice a week. However, authors did not use qualitative methods to explore the reasons for this low adherence to the recommended dosage.

c) Views from intervention's deliverers and recipients about the program. Their opinions, together with the identifications of benefits from taking part in the intervention and the improvement suggestions were collected through a self-administered questionnaire or by telephone. Most of the participants were positive about the intervention, although close to half of them thought it was too difficult for them to remember the movement forms. In terms of perceived benefits most of them commented on their improved well-being, physical fitness (i.e., balance), and on an increase in PA. Instructors' views were quite similar, though slightly less positive about the intervention but more positive about its benefits than the participants'. An important limitation of this study was that participants views were obtained through questionnaires rather than interview as such limiting response opportunities. To avoid this, in this thesis, a qualitative approach will be used to gather participants and instructors' views instead of imposing possible responses anticipated by the author, which could not represent the realities of our participants.

Appendix F

Data Extracted from Papers Around Exercise Interventions Conducted Amongst Community-Dwelling People Living with Dementia

Table F 1. *Studies Around Exercise Interventions Using Qualitative Methodology in the Community*

Study	Intervention/Study characteristics	Barriers and facilitators reported/Feedback from participants
<p>(Suttanon, Hill, Said, Byrne, & Dodd, 2012).</p> <p>*Paper related to Suttanon et al. (2013) reported amongst quantitative papers</p> <p>Australia</p>	<p>Intervention type: Balance exercise intervention to prevent falls amongst people living with dementia living in the community. Home-based for 6-months. A dyadic approach was used.</p> <p>Participants: Participants with mild to moderate AD (n=10) and their carers (n=9).</p> <p>Methods: Semi-structured interviews (after completing the intervention and post- measures) with participants with AD and their carers. Audio-recordings (interviews) were verbatim transcribed. Interviews took place an average of 47 days after the intervention had finished. People living with dementia and their carers were asked about the level of difficulty of the exercise; the person living with dementia’s motivations to get involved and maintain their participation along for the duration of the intervention; (if they had dropped out) their reasons for doing this; suggestions about improvements in the intervention; and attitudes about exercise.</p> <p>Background theory: Phenomenological theoretical framework.</p> <p>Type of qualitative analysis: Thematic analysis.</p>	<p>Facilitators to commence the exercise intervention: “possible benefits of the program, recommendations from health professionals, value of research, positive attitude towards exercise, and minimizing caregivers’ burden” (p. 1172).</p> <p>Facilitators for adherence: “program characteristics, physiotherapist [regular support], exercise recording sheet, caregivers’ support, sense of commitment, and perceived benefit” (p. 1172).</p> <p>Barriers for adherence: “pre-existing conditions, dislike of structured exercise, absence from home, caregiver’s health or commitment, and bad weather” (p. 1172).</p>
<p>(Yu & Swartwood, 2012)</p> <p>USA</p>	<p>Intervention type: Aerobic exercise (cycling) intervention. 6h/exercise a week x 6-months. There seems to be a group-based intervention, but details on the original group(s) number of participants are not provided. A dyadic approach was used.</p> <p>Participants: People living with AD (n=10) and carers (n=10).</p> <p>Methods: 4 Focus groups (2 with people living with AD and 2 with their family carers). Transcriptions of the focus groups and notes from researcher were qualitatively analysed. People living with AD were asked about their experiences of taking part in the exercise interventions; the aspects they liked and disliked about the intervention; the perceived changes in their live, memory and relationships with other; and their intentions (and reasons) to keep practising or not exercise. Family carers were asked about changes perceived in their relationship with the person living with AD; the impact of the intervention in carer’s social life and well-being; the impact of the intervention on the person living with AD; and the strengths and weaknesses of the program.</p> <p>Background theory: Not reported.</p> <p>Type of qualitative analysis: Content analysis</p>	<p>Authors conclude cycling was feasible and acceptable for the participants.</p> <p>Participants did not appreciate any impact on cognition, but on physical strength and valued the socialising component (with other participants in a similar situation and with the instructors) and found their participation positive. Carers reported more positive attitudes in people living with AD and felt less stressed by the end of the intervention.</p>

Study	Intervention/Study characteristics	Barriers and facilitators reported/Feedback from participants
<p>(Hawley-Hague, Horne, Skelton, & Todd, 2016a)</p> <p>UK</p>	<p>Intervention type: No intervention is reported in this study, but instructors’ opinions on multicomponent, group-based, exercise interventions to prevent falls amongst general older people are reported.</p> <p>Participants: This paper includes the opinions of 19 instructors delivering these interventions. 3 of the interviews took place in dyads, following instructors’ request.</p> <p>Methods: Semi-structured (30-90 min) interviews were around how instructors structured and delivered the classes; how they encourage their participants to engage in the intervention; what they think are the motivators for participants attending their classes; what makes participants maintaining their adherence in the long-term; how the classes impact on participants; what relevance have the classes for participants; to what extent other people influence on their attendance; and which are the barriers their participants face to attend the classes.</p> <p>Background theory: Theory of planned behaviour.</p> <p>Type of qualitative analysis: Content analysis using qualitative description (to remain close to the data).</p>	<p>Barriers for uptake: negative attitudes towards exercise, participants’ lack of identification with exercise making it a non-relevant activity for them, fear towards a new activity, the discouragement of people of their environment not helping them to feel confident to take part, the wording used to publicise the interventions (i.e., falls class), the lack of choice for participant’s when pushed to attend by someone else, and the lack of own motivations to attend; the cost of the exercise activity; venues and the exercise type expected in each venue (i.e., gym – intense exercise).</p> <p>Barriers for adherence: negative attitudes, unmet needs and expectations; and negative social influences.</p> <p>Facilitators for uptake: Use a more positive wording when publicising the interventions; help participants feeling they have the control and that they decide to take part in the intervention to achieve a relevant goal for themselves; providing free taster sessions; emphasising health benefits; support from family environment; and referral from health professionals.</p> <p>Facilitators for adherence: social cohesion of the group; keeping in touch if participants do not attend to a session; and helping participants to realise about achieved outcomes.</p>
<p>(Day, Trotter, Donaldson, Hill, & Finch, 2016)</p> <p>Australia</p>	<p>Intervention type: Various exercise interventions to prevent falls amongst community-dwelling general older people. Home and group-based interventions were included.</p> <p>Participants: Staff (n= 12) and coordinators (n=5).</p> <p>Methods: 9 interviews around 60 min each. Semi-structured interviews (19 open-ended questions) with exercise programs leaders (interviewed in group) and coordinators (individually).</p> <p>Background theory: Diffusion of Innovations theory.</p> <p>Type of qualitative analysis: Deductive content analysis.</p> <p>Authors used the Diffusion of Innovations theory, to report the extent to which instructors were able to implement a series of (new) home-based and group-based exercise interventions.</p>	<p>Professionals delivering exercise intervention in a home-based format pointed it was useful to adapt this intervention to each individual’s environment making it, in turn, safer for participants.</p> <p>Instructors found hard to adapt the intervention to be challenging enough to their participants, so they had to use their previous expertise to make necessary adaptations. Otherwise, participants dropped out.</p> <p>Challenging characteristics of the venues were identified as flooring and lack of storage space. Big intervention groups were also challenging.</p> <p>Cognitive impairment was perceived by instructors as an implementation difficulty. Instructors were able to provide anecdotal comments coming from participants about perceived improvements on physical functioning (i.e. balance, strength); however, they stated they were not able to objectively report such improvements.</p>

Study	Intervention/Study characteristics	Barriers and facilitators reported/Feedback from participants
<p>(McPhate et al., 2016)</p> <p>Australia</p>	<p>Intervention type: Group exercise interventions for the prevention of falls.</p> <p>Participants: 245 Community-dwelling general older adults who were involved or had been involved in group-based exercise interventions. Participants interviewed were asked about their preferences around exercise type, duration and frequency.</p> <p>Methods: Telephone interview – open-ended questions.</p> <p>Background theory: framework approach.</p> <p>Type of qualitative analysis: Thematic analysis.</p>	<p>Participants might value more the short-term benefits of taking part in a falls prevention intervention such as practising the exercises and engaging in social interaction, over more long-term benefits like the prevention of falls.</p> <p>Social interaction, enjoyment of the activity and instructor’s qualities seem to be the most frequently mentioned facilitators. Whereas, a lack of adaptation of the intervention to individual’s needs, individual impairments and accessibility issues were the most outstanding barriers.</p>
<p>(Haines, Day, Hill, Clemson, & Finch, 2014)</p> <p>Australia</p>	<p>Intervention type: No intervention, but study to find out older adults’ perceptions about home and group-based exercise interventions.</p> <p>Participants: 394 older adults living in the community without significant cognitive impairment.</p> <p>Methods: Telephone Survey – Likert scale and open-ended questions (relative to 4 interventions to prevent falls, one of them exercise intervention including tai chi)</p> <p>Background theory: Health Belief Model and Protection Motivation Theory.</p> <p>Type of qualitative analysis: Thematic analysis. And statistical analysis for Likert responses.</p>	<p>Amongst participants included in the survey, most of them accepted interventions (to prevent falls) described would be effective.</p> <p>However, amongst them, between 25 and 26% thought that this would work better for others in home-based and group-based exercise interventions respectively. Only 3% of participants in this survey thought that these interventions would work better for them than for their peers. Amongst those thinking that exercise interventions would be better for others, it was common to identify women.</p> <p>When asked to provide reasons why this intervention would better for others, it was frequent to identify older people asked saying their physical condition was good or that they did no identified themselves being at risk of falling: 29% said this when asked about group exercise, 38% when asked about home-based exercise interventions and up to 51% or 68% , respectively, in the case of home assessments and multifactorial interventions, as those were perceived as suitable for frailer people.</p> <p>The other common response was that they were already involved in other activities with similar expected outcomes on balance.</p>

Table F 2. *Studies Around Exercise Interventions Using Quantitative Methodology in the Community*

Study	Intervention characteristics	Adherence/ Attrition Rates	Barriers and facilitators reported	Outcome measures	Conclusions
<p>(Yu et al., 2015)</p> <p>USA</p> <p>Context: Pilot study (no control group).</p>	<p>Exercise type: Moderate Cycling (aerobic standardized exercise). Group-based (?).</p> <p>Exercise dosage: 15 to 45 minutes sessions (plus 10 minutes warm-up and 10 minutes cool-down) x 3 times/week x 6 months.</p> <p>Participants: 26 Community-dwelling people with mild-to-moderate AD (n=26) and their family carers.</p> <p>Methods: "single-group repeated-measures design" (p. 486). Measures were taken at baseline, 3 months and 6 months.</p>	<p>Measurement of acceptability/adherence: Individual log</p> <p>"Adherence to the exercise program was high. Participants attended 83% of their prescribed sessions." (p. 492)</p> <p>Except for one outlier who achieved the cycling prescription only in 4% of the sessions, the remaining 25 participants (96%) achieved the session cycling prescription on an average 90% of their sessions" (p. 492)</p> <p>"22 (79% [retention rate]) completed the 6-month data collection." (p. 492)</p>	<p>In place measures to increase adherence to the protocol: "staff was re-trained during regular weekly staff meetings and if deviations from the protocol were observed. The first author randomly checked 10% of the exercise sessions" (p. 489).</p> <p>In place measures to increase participants' adherence to the exercise: establishment of rapport, use of an individual log (were the progress of the person living with dementia was recorded and it was use as a communication strategy with families), regular phone calls, provision of support with transport (provided by the research team) and gym memberships costs.</p> <p>Carers valued positively the intervention, as the intervention provided them amongst 8-10h respite. Apart from this, in a focus group conducted they reported "improved attitudes, physical function, and confidence" in their loved ones which made the caring role easier.</p>	<p>Cognition tests.</p> <p>ADLs.</p> <p>Behavioural and Psychological Symptoms of Dementia (BPSD).</p> <p>Carer distress.</p>	<p>There was a significant reduction in primary family carer's distress.</p> <p>"Community-dwelling older adults with mild-moderate AD maintained their cognition over the 6-month period" (p. 493) Similarly no increase was registered in their ADLs.</p> <p>There was a clinically meaningful reduction in a Neuropsychiatric Inventory (NPI-Q) Questionnaire.</p>
<p>(Pitkälä, Pöysti, Laakkonen, & et al., 2013)</p> <p>Related paper identified (Öhman et al., 2016)</p> <p>Finland</p> <p>Context: RCT</p>	<p>Exercise type: Balance and strengthening exercises.</p> <p>Exercise dosage: Intervention length was 12 months. Home-based (tailored) exercise: 1h x 2times/week. Group-based exercise (10 AD participants in day care centres): 1h x 2times/week.</p> <p>Participants: 140 Community-dwelling</p>	<p>Measurement of acceptability/adherence: Attendance to exercise (home or group-based).</p> <p>Total attrition rate: 23.3% (mainly due to deaths and entering in care homes).</p> <p>Adherence to the home-based exercise was higher than to the group-based.</p>	<p>Not reported.</p>	<p>Physical functioning and mobility.</p> <p>Use/cost of social healthcare services (number of falls and hospitalization)</p>	<p>Home –based exercise was related with a lower progression of the physical function deterioration.</p> <p>Home and group-based exercise was related with a reduction in the number of falls and, particularly group exercise decreased the social/healthcare costs occurred by both members of the dyads. No significant effect was found on mobility.</p>

Study	Intervention characteristics	Adherence/ Attrition Rates	Barriers and facilitators reported	Outcome measures	Conclusions
	<p>people with AD living with their spouses were allocated to intervention groups: 70 to home-based exercise / 70 to group-based exercise.</p> <p>Methods: Repeated measures at baselines, 3, 6 and 12 months.</p>				
<p>(Suttanon et al., 2013)</p> <p>Australia</p> <p>Context: Pilot RCT</p>	<p>Exercise type: Otago, including balance and strengthening exercises. Home-based (tailored) exercise.</p> <p>Exercise dosage: 19 Participants were allocated to the exercise intervention and asked to practise it 5 times/week. Duration of the intervention: 6 months.</p> <p>Participants: 19 community-dwelling participants with mild-to-moderate AD were allocated in the exercise intervention group. Carers were involved as supporters, to encourage participants to practise and to ensure safety.</p> <p>Methods: Pre- and post-measures.</p>	<p>Attrition rate in the exercise arm: 42.12%</p> <p>Adherence to the exercise arm was in average: 82.96%</p> <p>Monthly adherence logs were completed by participant (with carer’s assistance).</p> <p>“Full compliance (100%) was defined as a participant doing the exercises five days a week (information derived from monthly exercise recording sheets)” (p. 431).</p>	<p>In place measures to increase adherence: 6 home-visits and 5 phone calls. Participants were provided with a booklet with pictures and explanations. Physiotherapist details were provided to solve questions.</p> <p>Physiotherapist recorded barriers detected along home visits.</p> <p>Barriers for adherence, according to participants who adhered less to the intervention were: previous health conditions or unwillingness to get involved in the exercise intervention.</p>	<p>Cognition: MMSE.</p> <p>Balance and mobility (Functional Reach test; Step Test; Timed Chair Stands; Timed Up and Go Test (single task) plus Timed Up and Go Test with a secondary cognitive task and Timed Up and Go Test with a secondary motor task (carrying a full cup of water while performing the task); and the Human Activity Profile).</p> <p>Falls and falls risk.</p> <p>Carer’s QoL and burden were also measured.</p>	<p>This intervention might improve balance, mobility and decrease the risk of falling amongst participants.</p>

Study	Intervention characteristics	Adherence/ Attrition Rates	Barriers and facilitators reported	Outcome measures	Conclusions
<p>(Schwenk et al., 2014)</p> <p>USA</p> <p>Context: double-blinded RCT (intervention group versus placebo control group).</p>	<p>Exercise type: Specific (specifically developed for people living with dementia) standardized training (progressive resistance and functional group training) to improve gait parameters in people living with dementia.</p> <p>Group-based.</p> <p>Exercise dosage: 2x2h/week. For 3 months.</p> <p>Participants: Outpatient (in hospital or nursing care) participants with mild to moderate dementia (n=61). 4-6 participants per group.</p> <p>Methods: Pre- and post-measures.</p>	<p>“Training adherence was documented as percentage of training sessions successfully performed by each participant” (p.5).</p> <p>“Adherence to the intervention was excellent, averaging 91.9%” (p. 2).</p> <p>Attrition rate: Only one participant dropped out from the intervention group.</p>	<p>In place measures to facilitate adherence: instructors used a slowly and clear speaking, simple and direct requests, and tactile and rhythmic cues to facilitate teaching.</p> <p>Before starting the exercise intervention, participants were asked to fill activity logs to establish their baseline physical activity. And to define a long-term exercise goal, providing details on its dosage. However, “Participants were encouraged to set a goal that consisted of a minimum of 30 minutes of low-to-moderate intensity aerobic exercise at least three times a week, supplemented by stretching and strength training.” (p. 176)</p> <p>In place measures to increase adherence: Participants received a variety of materials: such as a video “to model desired behaviour”, “ a choice of exercise videos”, a booklet with “information on flexibility, strength, and balance exercises for older adults”, a “workbook that explains each step of the program and includes forms for participants to keep track of their weekly goals and</p>	<p>Clinical characteristics were assessed by using tests and standardised interviews).</p> <p>Gait performance.</p>	<p>Participants with “higher multimorbidity, higher depression, and lower functional performance at baseline” improved their gait speed (p. 9. “These findings may suggest that the most functionally impaired participants reaped the most benefit.” P11</p> <p>“The intensive, dementia-adjusted training was feasible and improved clinically meaningful gait variables [“speed, cadence, stride length, stride time and double support” p7] in people with dementia.” (P.2). Cognitive performance and “adherence did not predict training response [in gait]” p.9</p> <p>“Based on the patient-centred approach, training adherence was excellent suggesting high feasibility of intensive exercise training specifically designed for individuals with dementia.” P.11</p>
<p>(Connell & Janevic, 2009)</p> <p>USA</p> <p>Context: RCT</p>	<p>Exercise type: Telephone exercise intervention for carer spouses or people living with dementia.</p> <p>Exercise dosage: Tailored to their availability, participants were asked to set their exercise goals (although were provided with a dosage recommendation). The intervention lasted 6 months.</p> <p>Participants: Wives</p>	<p>This seems to be measured merely in terms of withdrawals: 15.9% during the study period (n=26).</p> <p>Fidelity to the program design was promoted by training offered to the counsellors involved in the project as well as by monitoring calls.</p>	<p>Before starting the exercise intervention, participants were asked to fill activity logs to establish their baseline physical activity. And to define a long-term exercise goal, providing details on its dosage. However, “Participants were encouraged to set a goal that consisted of a minimum of 30 minutes of low-to-moderate intensity aerobic exercise at least three times a week, supplemented by stretching and strength training.” (p. 176)</p> <p>In place measures to increase adherence: Participants received a variety of materials: such as a video “to model desired behaviour”, “ a choice of exercise videos”, a booklet with “information on flexibility, strength, and balance exercises for older adults”, a “workbook that explains each step of the program and includes forms for participants to keep track of their weekly goals and</p>	<p>Using different measurements for sociodemographic details, physical health, carer burden, exercise behaviour, self-efficacy and depressive symptomatology.</p> <p>Underpinning theory: Social cognitive theory and “motivational interviewing” (p.174).</p>	<p>“At 6 months, participants had greater reductions in perceived stress relative to controls. Participants also reported significantly greater increases in exercise self-efficacy than carers in the control group at both follow-up points.” (p. 171).</p> <p>Carers in the intervention arm significantly increased their PA by taking part in the study.</p>

Study	Intervention characteristics	Adherence/ Attrition Rates	Barriers and facilitators reported	Outcome measures	Conclusions
	<p>caregiving of people living with dementia, approximately half of the recruited were allocated to the intervention arm (n=86)</p> <p>Methods: Repeated measures at the end of the 6 months intervention and 6 months post intervention.</p>		<p>progress toward their long-term goals; and two “motivational” newsletters” (p.175). Additionally, “participants received 14 telephone calls from trained behaviour change counsellors over a 6-month period” (p. 175-176). And “a problem-solving process was used to address any barriers to goal attainment.” (p. 176).</p>		
<p>(Farran et al., 2008)</p> <p>USA</p> <p>Context: Pilot study.</p>	<p>Exercise type: Telephone –based lifestyle physical activity intervention for carers of people living with AD. Multicomponent intervention (EPA – Enhancing Physical Activity) to promote carer’s health.</p> <p>Exercise dosage target: Practise exercise for 30 minutes a day (with a minimum of 150 minutes a week). Duration of the intervention was 6 months.</p> <p>Participants: 15 carers of people living with AD.</p> <p>Methods: Repeated measures.</p>	<p>Instructor log kept data regarding “frequency, intensity, time, and type of activity” (p.135) of the activities conducted by the carers.</p> <p>Most of the carers used “pedometers (93%) and completed physical activity logs with no difficulty (80%).”</p>	<p>In place measures to increase adherence: 14 contacts for 6 months, 1 face-to-face and 13 via telephone. Calls were used to provide support, gather data about physical activity and to assist with identified barriers (with were recorded in the instructor’s log).</p> <p>Materials included: information about EPA project, resources and information kit. Log to record physical activity. Pedometer. Problem-solving methods.</p> <p>Barriers for adherence reported by carers: “Caregiving roles and responsibilities (i.e. heavy non-caregiving responsibilities, heavy caregiving responsibilities), caregiver’s concerns (i.e. feeling anxious/ down/tired; physical health not good; no support from family/ friends) and environmental (hot summer weather and unsafe neighbourhood). These barriers are reported as reasons for the significant decline observed in carer’s physical activity according to the data provided by the activity instructor.</p> <p>Facilitators for adherence reported by carers: “combining activities (i.e., walking to work, doing yard work), scheduling physical activity first thing in the morning, involving their CR in physical activity, and joining a formal exercise program” (p. 137).</p> <p>Barriers identified by interventionist during the intervention period were: changes in health, in carer’s</p>	<p>PA questionnaire.</p> <p>Activity monitor.</p> <p>Blood pressure.</p> <p>Underpinning theory: “self-efficacy theory, based on Bandura’s social learning theory.” (p.134).</p>	<p>“Nearly half of the CGs selected walking as their physical activity of choice. [However,] Only 25% of CGs were involved in moderate-intensity physical activity” (p. 137)</p> <p>Carers evaluated the intervention positively. And was found to be feasible.</p>

Study	Intervention characteristics	Adherence/ Attrition Rates	Barriers and facilitators reported	Outcome measures	Conclusions
			<p>life, carer’s “apprehension concerning increasing physical activity” as well as challenges of using technology. “A challenge for the interventionist was that it often took multiple attempts to reach CGs for telephone calls even when they were prescheduled.” (p. 139).</p>		
<p>(Lamb, Mistry, et al., 2018)</p> <p>Protocol paper: (Lamb, Sheehan, et al., 2018)</p> <p>UK</p> <p>Context: RCT</p>	<p>Exercise type: Mixed aerobic and strength exercises initially class and home based (4 months) and later at home only (8months).</p> <p>Exercise dosage target: 150 minutes per week for 12 months.</p> <p>Participants: 494 People living with dementia (2/3 allocated to intervention arm: n=329). Carers encouraged to attend the sessions but staying in a separate area chatting with other carers.</p> <p>Methods: Repeated measures at baseline, 6 months and 12 months.</p>	<p>2/3 were considered non-adherent (as they did not comply with 75% or more of the recommended dosage).</p> <p>Intervention arm retention until follow-up: 80%.</p>	<p>Qualitative methods were used, and some participants living with dementia were interviewed as well as some carers and physiotherapists. However, but no analysis was made on the barriers / facilitators of participants’ adherence specifically. Overall, participants reported their enjoyment of the classes and the exercise itself.</p>	<p>ADAS-Cog</p> <p>Activities of Daily Living Scale</p> <p>QoL</p> <p>NPI</p>	<p>Authors reported no meaningful changes in participants’ function, health related QoL, or carer’s burden. However, there was an enjoyment of the classes reported by participants.</p>

Study	Intervention characteristics	Adherence/ Attrition Rates	Barriers and facilitators reported	Outcome measures	Conclusions
<p>(Hauer et al., 2017)</p> <p>Germany</p> <p>Context: RCT</p>	<p>Exercise type: Postural control and strength exercise.</p> <p>Exercise dosage: Daily practice was encouraged (through 2 series of 7-10 repetitions each) during the 6 weeks long intervention.</p> <p>Participants: 34 participants living with dementia (17 in the intervention group) and their carers supporting them.</p> <p>Methods: Repeated measures.</p>	<p>Adherence was monitored weekly over the phone, and adaptations were made to the intervention dosage an intensity according to the reactions of the participants.</p> <p>“Patients in the immediate group completed 40.9 ±25.9 training sessions” (p.502).</p> <p>14 participants continued to follow-up assessment (18% withdrawal rate).</p>	<p>None.</p>	<p>Demographic questionnaire.</p> <p>PA questionnaire.</p> <p>Short Physical Performance Battery.</p>	<p>Results showed a better functional performance and an increased physical activity in those in the intervention group.</p>
Additional papers					
<p>(Andrade et al., 2013)</p> <p>Brazil</p> <p>Context: Non-randomised controlled trial</p>	<p>Exercise type: Multimodal exercise consisting of dual-task intervention (exercise plus cognitive task).</p> <p>Exercise dosage: 60 minutes x 3 times/week x 16 weeks.</p> <p>Participants: 30 older adults living with AD.</p> <p>Methods: Quantitative methods, standardised measurements.</p>	<p>Not reported.</p> <p>Participants were required to attend to minimum 70% of the sessions.</p>	<p>The use of a qualitative approach is not reported, but researchers asked carers about their feelings about the intervention and they reported people living with dementia seemed to have enjoyed it.</p> <p>A barrier to participant’ adherence reported by authors’ was that carers were not always available to provide transportation to participants to the venue.</p>	<p>Assessment of the frontal cognitive function, physical activity and postural control.</p> <p>Functionality was assessed by “Timed Up and Go Test, the 30-second sit-to-stand test, the sit-and-reach test, and the Berg Functional Balance Scale.” (p. 1919.)</p>	<p>Participants in the intervention arm had “had less body sway than controls, which indicates better balance, and fewer falls” (p. 1923)</p> <p>However, another study from the same authors, testing the same intervention, found only an impact on the frontal cognitive functioning (Coelho et al., 2013)</p>

Study	Intervention characteristics	Adherence/ Attrition Rates	Barriers and facilitators reported	Outcome measures	Conclusions
<p>(Taylor et al., 2017)</p> <p>Australia</p> <p>Context: Pilot Trial</p>	<p>Exercise type: Individually tailored home-based exercise.</p> <p>Exercise dosage: varied over the participation in the study in terms of number of exercises and repetitions prescribed.</p> <p>Participants: 42 dyads.</p> <p>Methods: pre- and post-measurements.</p>	<p>“The average adherence to the prescribed exercise sessions was 45% (...) Those who adhered to ≥70% of prescribed sessions had significantly better balance at reassessment compared with those who adhered to <70% of sessions.” (p.81).</p> <p>Adherence to the prescribed dosages declined over time: started with 63%, at three months was 47%, and at 6 months was (34%).</p> <p>78.6% completion rate.</p>	<p>None.</p>	<p>Demographic</p> <p>History of falls</p> <p>Falls concerns</p> <p>PA</p> <p>QoL</p> <p>Hand reaction time</p> <p>Knee extension strength</p> <p>Fall risk score</p> <p>Geriatric Depression Scale</p>	<p>Authors found a significant improvement in postural sway and a reduction in concerns about falls. They found no impact on depression levels.</p> <p>Authors finished with an advice to explore ways to facilitate uptake and adherence to interventions in this population.</p>
<p>(Canonici et al., 2012)</p> <p>Brazil</p> <p>Context: Controlled trial.</p>	<p>Exercise type: Various types of motor exercises (including flexibility, strength, agility and balance).</p> <p>Exercise dosage targeted: 60 minutes x 3 days a week. Duration of the intervention group 6 months.</p> <p>Participants: 32 people living with AD and 32 carers (split in two groups: intervention and control, non-randomised but similar groups in activity levels ((Modified Baecke Questionnaire for the Elderly)) and NPI scores. Methods: Repeated measures.</p>	<p>It is assumed that participants in the intervention group attended 70% of the sessions, as this was the cut-off point used to include their data in the analysis.</p>	<p>Not reported.</p>	<p>Pfeiffer Questionnaire</p> <p>NPI carer distress</p> <p>Functional Balance (Berg Scale)</p> <p>Zarit Scale</p>	<p>After six months, significant differences were found between participants in the intervention and the control group. Participants in the intervention group had: preserved their functional abilities (particularly in terms of mobility and communication), better functional balance, lower carer burden and stress. A significant decrease in NPI scores was also identified.</p>

Study	Intervention characteristics	Adherence/ Attrition Rates	Barriers and facilitators reported	Outcome measures	Conclusions
<p>(Hauer et al., 2012)</p> <p>Germany</p> <p>Context: RCT</p>	<p>Exercise type: Strength and functional group-based training.</p> <p>Exercise dosage: 2h x 2 times/week x 12 weeks.</p> <p>Participants: 62 people living with mild to moderate dementia.</p> <p>Methods: Repeated measures (baseline, at the end of the 3 months intervention, and at 3 months follow-up).</p>	<p>Adherence rate not reported, authors only comment it was excellent.</p> <p>Attrition in the intervention arm was: 22.6%. Of them, 6 had serious health issues, 5 died, 3 dropped out due to a lack of motivation.</p>	<p>Not reported.</p>	<p>Maximal strength and functional performance.</p> <p>Physical function and level of physical activity.</p>	<p>Authors found a significant improvement in “postural control and dynamic balance, transfer ability (sit to stand, stair rise), and walking” (p.14).</p> <p>Participants with poorest performances at baselines were the ones who benefited more from the intervention.</p>
<p>(Kemoun et al., 2010)</p> <p>France</p> <p>Context: RCT</p>	<p>Exercise type: A combination including walking, endurance and equilibrium exercises.</p> <p>Exercise dosage: 60 minutes x 3 times/week x 15 weeks.</p> <p>Participants: 16 people living with dementia (MMSE <23) were allocated in the intervention arm.</p> <p>Methods: Repeated measures pre- and post-intervention.</p>	<p>Adherence rate not reported.</p> <p>Attrition rate was: 25%. 3 participants dropped out due to a lack of motivation and 1 due to health reasons.</p>	<p>Not reported.</p>	<p>Walking assessment.</p> <p>Cognitive assessment.</p>	<p>This intervention had an impact in slowing the progression of the cognitive impairment and in improving walking performance.</p> <p>Authors found a significant correlation amongst the cognitive scores and gait or walking performance.</p>

Study	Intervention characteristics	Adherence/ Attrition Rates	Barriers and facilitators reported	Outcome measures	Conclusions
<p>(Nascimento et al., 2012)</p> <p>Brazil</p> <p>Context: Non-randomized controlled trial.</p>	<p>Exercise type: A combination of diverse exercises (i.e., aerobic, stretching, balance...) of low to moderate intensity. Also used a second task based on cognitive stimulation (i.e., of memory, attention)</p> <p>Exercise dosage: 60 minutes x 3 times/week x 24 weeks.</p> <p>Participants: 15 people living with mild to moderate dementia were allocated to the intervention arm.</p> <p>Methods: Repeated measures pre- and post-intervention.</p>	<p>Adherence to minimum 75% of the sessions was a requirement to analyse participants' data. 10 participants in the intervention group attended at least this amount of sessions, whereas 3 did not.</p> <p>Attrition: 2 participants dropped out from the intervention arm (13.3%), and an additional 20% (3 participants) were not included in data analyses due to not having attended 75% of the sessions.</p>	<p>Not reported.</p>	<p>Cognitive assessment: MMSE.</p> <p>Neuropsychiatric Inventory (NPI).</p> <p>IADLs</p>	<p>Results showed a significant reduction in the scores related to the NPI questionnaire, a stabilization of the functionality in IADLs.</p>
<p>(Dawson & Menne, 2017)</p> <p>USA</p> <p>Context: Study replication in the community (RDAD)</p>	<p>Exercise type: Home-exercise (consisting of balance, strength and flexibility) for people living with dementia (or memory issues) and educational training for their carers (to learn managing challenging behaviours).</p> <p>Exercise dosage: 12 sessions x 60min each. Initially 2 sessions per week progressing towards one session every two weeks towards the end. Dyads were encouraged to do</p>	<p>Adherence levels are not reported.</p> <p>It is only mentioned that 73% of the sample completed the post-intervention assessment.</p>	<p>Not reported.</p>	<p>Cognitive assessment: Short Blessed Memory-Orientation-Concentration Test (SBT).</p> <p>Physical performance measures of gait, balance and functional reach.</p>	<p>This paper concludes with a discussion of the possible reasons behind the lack of differences in the physical performance measures used (pre- and post- intervention). These potential reasons included the lack of intensity or exposure of the exercise, the lack of an implementation fidelity assessment and the outcome measures chosen.</p>

Study	Intervention characteristics	Adherence/ Attrition Rates	Barriers and facilitators reported	Outcome measures	Conclusions
	<p>10-15min of exercise practice 3 days a week. Total duration of the intervention: 3 months.</p> <p>Participants: 508 dyads (formed by participants living with dementia/memory issues and an informal carer).</p> <p>Methods: Repeated measures pre- and post-intervention.</p>				

Table F 3. *Studies Included About the Acceptability of Community Exercise Interventions*

Study	Intervention characteristics	Acceptability recordings	Barriers and facilitators reported	Conclusions
<p>(Dal Bello-Haas, O’Connell, Morgan, & Crossley, 2014)</p> <p>Canada</p> <p>Context: feasibility study.</p>	<p>Exercise type: tele-health aerobic exercise intervention designed for rural-dwelling people living with dementia and their carers. Authors divided their study in two phases: In the first phase they conducted 16 semi-structured interviews to assist with a survey development. This survey included questions regarding exercise habits, partners and peer influences on those habits, attitudes towards exercise, perceived barriers and facilitators for exercise and group exercise practice, as well as accessibility to tele-health interventions. In the second phase, they run the tele-health exercise program. Various standardised measures were taken at the recruitment stage.</p> <p>Exercise dosage in the second phase: 40-45 min exercise x 4 weeks.</p> <p>Participants: First phase: 16 dyads of people living with dementia and their carers to inform the survey development. And 42 people living with dementia</p>	<p>Second phase: Authors report a high rate of attendance (100%) and engagement to the sessions by participants and that carers provided adequate support during the intervention.</p> <p>Researchers recorded participants’ attendance and by the end of the intervention participating dyads were interviewed and responded to satisfaction questionnaires.</p>	<p>Authors also interviewed professionals working in the tele-health centre and reported some of the challenges faced along the process.</p> <p>According to highly rated participants’ responses to the questionnaires, diverse aspects of the intervention could have had a role on their experience such as: accessibility of the venue, respect of their privacy, level of sustained attention, group-based intervention and engagement with the facilitator.</p>	<p>First phase: Authors reported a link between wanting to take part in a group-based exercise and participants’ willingness to engage in a tele-health intervention, instead of attitudes towards exercise being the best predictor.</p>

Study	Intervention characteristics	Acceptability recordings	Barriers and facilitators reported	Conclusions
	<p>and 35 carers to assess the demand and feasibility of the intervention designed or the second phase. Second phase: 2 dyads (formed by a person living with dementia and a carer)</p> <p>Methods: Mixed methods exploratory approach.</p>			
<p>(Frederiksen, Sobol, Beyer, Hasselbalch, & Waldemar, 2014)</p> <p>Denmark.</p> <p>Context: pilot study.</p>	<p>Exercise type: Aerobic exercise intervention.</p> <p>Exercise dosage: 1h x 3times/week x 14 weeks</p> <p>Participants: 8 community-dwelling patients living with mild to moderate Alzheimer’s Disease (AD) recruited from memory clinics.</p> <p>Methods: Quantitative (pre- and post- intervention clinical outcomes were measured) and qualitative.</p>	<p>Attendance rate was high (90%), though carers or the research team had to remind most of the participants to attend the following session.</p> <p>Authors assessed the acceptability of this moderate-to-high intensity exercise mainly quantitatively (i.e., attendance rate, level of exercise intensity and occurrence of adverse events) and using self-reports. However, focus group interviews were conducted amongst people living with dementia and their carers separately, which helped the authors to identify barriers to take part in the intervention, further participants’ needs and participants’ perceptions of the intervention.</p>	<p>Whereas participants living with dementia would have appreciated more information about the intervention (prior to their involvement on it), both carers and people living with dementia claimed a more progressive introduction to the exercise. Also, both reported people living with dementia felt more tired and, probably for this reason, decreased their involvement in other activities. However, this intervention was perceived as time consuming, which could also affect their involvement in previous activities. On the other hand, motivations for carry on attending the sessions included expectations for slowing down dementia progression, being helping future patients, and the socialising component. A perceived benefit of practising exercise was “that physical fitness but not memory had improved” (p.1245).</p>	<p>Focus groups allowed the authors to know that participants and their carers had had a positive overall experience, but also to identify areas of improvement.</p> <p>Even when this was not the aim of the feasibility study, authors found a positive impact on the physical function of the participants.</p>
<p>(Wesson et al., 2013)</p> <p>Australia</p> <p>Context: Pilot randomised trial.</p>	<p>Exercise type: Falls prevention programme for people living with mild dementia. Intervention comprised two components (home hazard reduction and tailored strength and balance exercises). Participants received 11 visits from professionals and 3 calls during the 12 weeks period.</p> <p>Participants: Amongst the 11 dyads allocated in the intervention group only 7 were supervised by their carers (the rest were considered independent to practise the exercises or they were not accompanied while exercising according to participant or carer’s preferences).</p>	<p>Participants or carers (depending if participants were able to practise exercises alone) were asked to record their adherence to the intervention in their booklets. The research team supervised those recordings during their visits. Telephone calls.</p> <p>Adherence to the intervention was rated as very good (72.7% were still adhering to the intervention)</p>	<p>The authors found adherence to the intervention was influenced by health issues, holiday periods or carers’ availability to supervise. All the participants reported satisfaction and enjoyment while taking part in the program.</p>	<p>No differences in clinical outcome measures were identified between the control and intervention group. However, there was a trend in carer burden that was almost double in the intervention group compared to the control group.</p> <p>A potential benefit of the intervention was identified through a trend for reduction in falls rates.</p>

Study	Intervention characteristics	Acceptability recordings	Barriers and facilitators reported	Conclusions
	<p>Methods: Quantitative. Feasibility of the intervention process was recorded by using field notes.</p> <p>Outcome Measures: Clinical outcome measurements included functional and physical performance as well as mood, behaviour, fear of falling and physical activity levels. Carer measurements included burden and the ability to simplify tasks. Falls were recorded also in a calendar.</p>			

Table F 4. *Studies Included About Adherence to Community Exercise Interventions*

Study	Intervention characteristics	Adherence recordings	Barriers and facilitators reported	Conclusions
<p>(Teri et al., 1998)</p> <p>USA</p>	<p>Exercise type: Exercise (strength, endurance, balance and flexibility components) and psychoeducational. The aim was to promote exercise adherence amongst people living with dementia with and without the habit (to maintain and increase, or create it, accordingly) of practising exercise, and ask them to practise an exercise of their choice for 30 minutes most days.</p> <p>Exercise dosage: 2 sessions/week x 3 weeks, and 1 session/week x 4 weeks. Intervention's length was 3 months.</p> <p>Participants: 30 people living with AD.</p> <p>Family carers were also involved in the 12-week intervention as proxy informants, facilitators and supervisors of their family members, after receiving psychoeducational and psychosocial training.</p> <p>Measurements of physical performance, function and health status were taken at baselines.</p>	<p>100% of the participants adhered to some of the exercises suggested; whilst only around 38% completed all of them as requested. In terms of exercise logs completion 96% completed some and 29% all of them.</p> <p>50% of participants reported that they were taking part in aerobic activities as homework, in 3 or more occasions whilst the intervention was taking place.</p> <p>Carers were in charge of reporting falls, functionality of the person living with dementia and exercise participation (i.e., duration and number of repetitions of prescribed exercises). Adherence to the intervention was also assessed by professionals leading the exercise interventions, who completed adherence forms and progress notes at the end of each class. Professionals checked exercise logs filled by carers in order to respond to any difficulties encountered and observed various</p>	<p>Not reported.</p> <p>In place measures to increase adherence: Homework exercises were tailored to participants needs.</p>	<p>Adherence to endurance, followed by strengthening, was better than to stretching exercises.</p>

Study	Intervention characteristics	Adherence recordings	Barriers and facilitators reported	Conclusions
<p>(McCurry et al., 2011)</p> <p>USA</p> <p>Context: RCT</p>	<p>Exercise type: Walking.</p> <p>Exercise dosage: 30min x 7 days/week x 8 weeks.</p> <p>Participants: 66 community-dwelling people diagnosed with AD were allocated to the walking intervention arm.</p> <p>Methods: A standardised semi structured interview was conducted with carers (proxy reports) before starting the intervention to explore frequency, severity and carer's distress to the person living with dementia's sleep problems. A complementary objective measure was also taken from people diagnosed with AD.</p>	<p>sessions to make sure (strength, balance and flexibility and endurance) exercises were being practised correctly.</p> <p>Adherence to the intervention was recorded through daily logs to be completed filled by carers. Adherence to the protocol along the intervention was checked along the research process. At the end of the intervention, participants were asked to rate the study burden and their perceived effectiveness of the treatment.</p> <p>At the beginning of the intervention 65.7% of participants allocated to the intervention arms adhered to the treatment at least 4 days per week, whilst at post-test 64.6% participants fell under this category. At 6-month follow-up participants' adherence was 48.5%.</p>	<p>A complementary paper based on this RCT was published analysing predictors for adherence only to the walking intervention arm (McCurry et al., 2010). Factors identified as barriers for initial adherence to the intervention were: the presence of more memory and behavioural problems and depression. Whereas the fact that the carer was a spouse made carers more likely to perceive less stress and facilitated the person living with dementia's adherence to the 30 minutes' walk per day as prescribed. Authors commented possible alternatives to reduce carers stress such as providing the person with dementia with somebody else, which could be more motivated towards exercise and facilitate adherence.</p>	<p>Authors found that at post-test participants allocated to intervention arms were awake for less time than controls (between 31 and 39.8 minutes less per night); however, this was not subjectively reported by carers. In terms of adherence, frequency and duration of adherence to prescribed treatment diminished.</p> <p>Significant differences were observed in sleep percentage and wake time amongst more and less adherent participants at post-test, but not at follow-up measurements.</p>
<p>(Aartolahti, Hartikainen, Lonnroos, & Hakkinen, 2014)</p> <p>Finland</p> <p>Context: Population-based study (random recruitment).</p>	<p>Exercise type: Strength and balance exercises in a gym context.</p> <p>Exercise dosage: An exercise dosage was not provided. The purpose of the study was to quantify how many of the people invited to engage in exercise actually did it during the study period.</p> <p>Participants: 339 community dwelling people living with dementia.</p> <p>Methods: Measures taken from de sample included a geriatric, health and physical functioning assessment. Afterwards an exercise plan was tailored to individuals needs by a physiotherapist.</p>	<p>Not reported.</p>	<p>Not reported.</p> <p>Results of the study pointed out that older people who did not attend the gym during the study period were older, less educated, experienced more comorbidities, had poor balance and mobility and had a lower cognitive performance. In terms of self-reported functioning they had more difficulties in daily life activities and tend to engage less in physical activities.</p>	<p>Authors recognised that probably people who could have benefited more from taking part in the intervention, as were those with poorest physical performance in their sample did not attend the gym.</p>

Study	Intervention characteristics	Adherence recordings	Barriers and facilitators reported	Conclusions
<p>(Steinberg, Leoutsakos, Podewils, & Lyketsos, 2009)</p> <p>USA</p> <p>Context: RCT</p>	<p>Exercise type: included aerobic fitness, strength and balance and flexibility training.</p> <p>Exercise dosage: Duration: 12 weeks.</p> <p>Participants: 27 participants with AD diagnosis living in the community were recruited and randomised to control or home-based exercise intervention delivered by their carers.</p> <p>Methods: Functional and cognitive measures were taken from participants in the intervention arm, together with a neuropsychiatric symptoms and QoL assessment at baselines. Carer burden was also assessed at this stage. Repeated measures were taken at 6 and 12 weeks.</p>	<p>Carers were asked to complete weekly diaries on participants' activities during the intervention.</p> <p>Diaries completed represented the 57-59% in the control and the exercise group respectively. From information contained in diaries, received participants achieved 72 – 79% of their goals.</p>	<p>Not reported.</p>	<p>Adherence rates to the intervention delivered by carers were acceptable.</p> <p>A “significantly improved performance was found on a hand function task predictive of ADL performance, with a trend for improved performance on a test of lower extremity strength.” (p.683).</p>
<p>(Brown et al., 2015)</p> <p>UK</p> <p>Context: Protocol paper.</p>	<p>Exercise type: Aerobic and resistance exercise (aiming to improve cognition). Group and home-based.</p> <p>Exercise dosage: The intervention will last 12 months.</p> <p>In the first part: 1h supervised exercise classes x 2times/week and 50 minutes of unsupervised exercise</p> <p>In the second part: 150 minutes of unsupervised exercise.</p> <p>Participants living with mild to moderate dementia.</p>	<p>Not applicable.</p>	<p>Not applicable.</p> <p>In place measures to increase adherence: An action plan will be designed, calendars to register adherence to the intervention will be provided, telephone calls will be made to encourage participants to follow the intervention and a face-to-face meeting with carers will take place.</p>	<p>Not applicable.</p>
<p>(Close et al., 2014)</p> <p>Australia</p> <p>Context: Protocol paper.</p>	<p>Intervention: Combined home-based exercise and home-hazard reduction intervention to reduce falls in cognitively impaired older people. The exercise program will be tailored to participants needs.</p> <p>Exercise dosage: Participants will be asked to practise balance and strengthening exercises for 30 minutes 6 times per week.</p>	<p>Not applicable.</p>	<p>Not applicable.</p> <p>In place measures to increase adherence: A log book will be provided to record exercises practised and any adverse event experienced. 11 home visits will take place.</p>	<p>Not applicable.</p>

Study	Intervention characteristics	Adherence recordings	Barriers and facilitators reported	Conclusions
Methods: The carer will report falls.				

And papers included in other tables:

Table G 1. Tai Chi Interventions Conducted Amongst People Living with Dementia: Yao et al. (2012).

Table F 1. Studies Around Exercise Interventions Using Qualitative Methodology in the Community: Suttanon et al. (2012).

Table F 2. Studies Around Exercise Interventions Using Quantitative Methodology in *the Community*: Connell & Janevic (2009), Farran et al. (2008), Schwenk et al. (2014) and Yu et al. (2015).

Appendix G

Previous Tai Chi Studies Including People Living with Dementia

Table G 1. *Tai Chi Interventions Conducted Amongst People Living with Dementia*

Study	Intervention characteristics	Adherence and attrition Rates	Barriers and facilitators reported	Outcome measures (and balance measures used)	Conclusions	Setting
<p>(Yao et al., 2012)</p> <p>Protocol paper identified: (Yao et al., 2008)</p> <p>USA</p>	<p>Tai Chi type: Adapted/Simplified Yang Style.</p> <p>Group based (maximum 5 dyads per group).</p> <p>Participants: 22 dyads formed by people with AD living in the community and their carers. Dose provided: 16-week program consisting of group-based (60 min/session x 2 session/week x 4 weeks) and home-based (20 min Tai Chi practice at home x 3 times/week x 12 weeks) Intervention.</p> <p>There is a dyadic intervention, carers support the person with Alzheimer’s during the class-based sessions and practising Tai Chi at home.</p>	<p>Attendance to the group-based component was 100%.</p> <p>84% of the dyads adhered to the home-based component, those who practised Tai Chi for minimum 20 minutes, 3 times/week for 12 weeks, that is 720 minutes of Tai Chi in total.</p> <p>Attrition rate was 13.6%. “All three dropouts occurred at the home-practice stage. One participant stopped participation due to changes in a medical condition unrelated to the study, one carer withdrew due to change of mind, and the 3rd dyad did not return calls for final follow-up”</p> <p>Adherence to the intervention protocol was assessed by researcher.</p>	<p>Although no qualitative methods are reported, 3 carers suggested the appropriateness of more group-based sessions.</p> <p>Authors comment that “A dyadic program can facilitate Tai Chi participation and adherence and result in functionally relevant improvement but needs further study, particularly under more rigorous randomized controlled conditions.” (p.294)</p> <p>Similarly, “Goal setting, self-monitoring, problem solving, and the provision of feedback and positive reinforcement were provided to make exercise more accessible to patients with mild cognitive impairment.” (p.292).</p>	<p>Measurement of dementia severity: MMSE.</p> <p>Fall-risk-relevant functional mobility performance: Timed Up and Go test (TUG) (used to measure fall risk), Unipedal Stance time (UST) (used to measure the risk to experience an injurious fall).</p>	<p>There was an improvement in mobility outcomes frequently associated to falls.</p> <p>TUG performances improved 16% from baselines. “Effects size on TUG and UST were small (~0.2-0.4).” (p.289).</p>	<p>Community</p>
<p>(Choi et al., 2005)</p> <p>No protocol paper identified.</p> <p>South Korea</p>	<p>Group-based.</p> <p>Tai Chi type: Sun style.</p> <p>Participants allocated to the Tai Chi group: 29 older adults living in long-term care settings with MMSE >20. They report MMSE <20 as exclusion criteria but do not provide information on the cognitive functioning characteristics of the included participants.</p> <p>Tai Chi dose provided: 35min sessions x 3 times/week x 12 weeks.</p> <p>No dyadic approach is described.</p>	<p>Mean attendance rate: 80.3%</p> <p>Attrition rate in the Tai Chi group: 14.7%</p> <p>Drop out reasons were: 1 hospitalization, 2 transfer to another facility, and 2 less than 70% attendance at the 36 exercise sessions.</p>	<p>Not reported.</p>	<p>Measurement of dementia severity: MMSE.</p> <p>Physical fitness (knee and ankle muscle strength, balance, flexibility, and mobility), fall avoidance efficacy, and fall episodes.</p> <p>Standardized instruments to measure balance were not reported. “Balance was assessed by how long (in seconds) the person could stand on one foot either with eyes closed or eyes opened.” (p.152).</p>	<p>“The physical fitness of the exercise group was significantly improved after a 12-week programme, in terms of improved knee and ankle muscle strengths, mobility, flexibility, and balance with eyes open” (p.154)</p> <p>Authors comment “the effects of Tai Chi exercise on fall prevention may be clinically relevant” (p. 155) as 9 people in the Tai Chi group fell whereas in the control group there were 15 falls; however, there was no statistical difference.</p>	<p>Long-term care settings</p>

Study	Intervention characteristics	Adherence and attrition Rates	Barriers and facilitators reported	Outcome measures (and balance measures used)	Conclusions	Setting
<p>(Saravanakumar et al., 2014)</p> <p>No protocol paper identified.</p> <p>Australia</p>	<p>Pilot RCT Group- based. Tai Chi type: Modified Tai Chi (style not described). Participants in the Tai Chi arm: 11 long-term care settings residents (mean MMSE= 25.7). Tai Chi dose provided: 30 min sessions x 2 times/week x 14 weeks. It is stated that volunteers and staff assisted to make the intervention safe for participants. However, is not possible to decide if this was used as a dyadic approach, because the amount of support (or the ratio) is not described.</p>	<p>Average attendance rate to the Tai Chi arm: 78.2% Attrition rate to the Tai Chi arm: 27.27%. 1 participant lost at follow-up. The other two are reported together with the drop outs reasons for the Yoga arm (1 failing vision, 1 feeling unwell, 1 loss of interest, 1 no reason, 1 exclusion for safety reasons and 3 deaths). It is not possible to determine which ones correspond to the drop outs in the Tai Chi arm.</p>	<p>Not reported.</p> <p>Authors comment on the barriers “such as care routines, and perceptions about physical ability, frailty and the limitations of cognition.” (p.85). They also point the need for spaces in these facilities, as well as workers open to facilitate the attendance of older people to these interventions.</p>	<p>Measurement of dementia severity: MMSE.</p> <p>Balance was the primary outcome (was measured using the Berg Balance Scale).</p> <p>Fall incidence</p> <p>Pain</p> <p>QoL</p>	<p>Participants in the Tai Chi arm showed a decline in balance (as those in the control group) and no reduction in the incidence of falls. Authors suggest the level of frailty and dependency of participants as possible explanations for these results, as well as the lower amount of time practising Tai Chi in a standing position (compared with participants in the yoga arm).</p>	<p>Long-term care settings</p>
<p>(Nowalk et al., 2001)</p> <p>No protocol paper identified.</p> <p>USA</p>	<p>Tai Chi and behaviour/psychotherapy (to reduce fear of falling) were delivered together. Group- based. Tai Chi type: not specified. Participants: 38 residents in care facilities (with an average MMSE=25.7) Tai Chi dose provided: length not stated x 3 times/week x 24 months. No dyadic approach is described.</p>	<p>Adherence is reported as percentage of sessions attended in 4 ranges of months from month 0 to month 24 (comprising 6 months each). For tai chi, the corresponding averages were: 36.5%, 24.1%, 19.1% and 21.2%, respectively. “Adherence was defined as attending 67% of all possible exercise sessions” (p.863). (Accordingly, average adherence rate to Tai Chi for the whole 24 months period should be 25.23 %). Overall attrition rate: 27% (including control group and another exercise intervention arm). 21% participants died and 6% left the care setting.</p>	<p>Not reported.</p> <p>To facilitate access to the participants and reduce attrition all the intervention and assessments were developed in the facility environment, and they were free of charge.</p> <p>Authors report that “participants provided positive responses about the exercise programs. They found that the programs provided a pleasant means of socialization and improved their sense of well-being and their ability to prevent falls, and they would recommend the class to a friend.” (p.862).</p>	<p>Measurement of dementia severity: MMSE.</p> <p>Physical assessments included muscle strength and mobility. Stand time, walk time, grip strength and quadriceps and hip flexor strength.</p> <p>Functional ability.</p> <p>The Nutrition Screening Initiative. Other measures were: depression, health habits, stress and health perception, self-perceived fall risk, fear of falling, and other measures of health status.</p>	<p>Results showed no reduction in number of falls or fall risk factors. However, as suggested by the authors, such a long –term intervention could require a more individualised approach in order to meet changing participants’ needs.</p>	<p>Long-term care settings</p>

Study	Intervention characteristics	Adherence and attrition Rates	Barriers and facilitators reported	Outcome measures (and balance measures used)	Conclusions	Setting
<p>(Burgener et al., 2008)</p> <p>No protocol paper identified.</p> <p>USA</p>	<p>Intervention comprised Tai Chi, Cognitive-behavioural intervention and support group.</p> <p>Group-based.</p> <p>Tai Chi type: Not specified.</p> <p>Traditional Tai Chi.</p> <p>Participants in the intervention arm: 24 people diagnosed with dementia, at an early stage.</p> <p>Dose provided of Tai Chi: 60min sessions x 3times/week x 40 weeks.</p> <p>It does not seem to be a dyadic intervention, where possible family carers provided help with transport.</p>	<p>Attendance rate to the Tai Chi component: 75% attended all the sessions and 90% attended most of the sessions (66%).</p> <p>Attrition rate in the intervention arm was 20.83%. Reasons for dropping out were: 1 change of residence, 1 illness, 3 not needing the intervention.</p>	<p>Although no qualitative methods are reported, authors comment on anecdotal comments from participants were the intervention was positively valued. Participants felt they were actively doing something to improve their situation, they noticed an improvement after practising and enjoyed the social interaction.</p>	<p>Measurement of dementia severity: MMSE.</p> <p>Physical functioning: the SLS (measures both lower leg strength and balance), BBS (functional balance assessment), and a measure of physical illness: CIRS (measures degree of impairment in major body systems).</p> <p>Behavioural outcomes.</p>	<p>The cognitive performance of participants improved during the first 20 weeks of intervention, whilst no further improvement was found at 40 weeks. The physical function stayed stable during the intervention. Participants enjoyed the intervention.</p>	<p>Community</p>
<p>(Barnes et al., 2015)</p> <p>No protocol paper identified.</p> <p>USA</p>	<p>Intervention comprised Tai Chi and other types of exercise (physical therapy, occupational therapy, yoga Feldenkrais Method, Rosen Method and Dance Movement Therapy). Cross-over pilot clinical trial (Intervention and Usual care)</p> <p>Tai Chi type: Not specified (possibly Chuan, according to instructor's expertise).</p> <p>Group-based.</p> <p>Participants: 12 People living with any type of (mild-to-moderate) dementia. Dose of exercise provided: 45min sessions x 3 times/week (although participants were asked to take part in at least 2 of them) x 18 weeks (then participants in group 1 started receiving usual care until week 36, opposite to those in group 2) + 4 home-visits.</p> <p>Authors' comment participants are recruited in dyads, however, paid or family carers seem to be only providing help at home and at data</p>	<p>"The mean ± SD (range) number of PLIÉ classes attended was 39 ± 4 (34–46) in Group 1 and 39 ± 9 (30–47) in Group 2." (p.10). According to this and taking into account that participants could take part in a maximum of 54 sessions, average attendance to the sessions was 72.22%. Attrition rate was 16.7%. That is two people dropped out, 1 because was not satisfied with the program, and 1 because entered a long-term care setting.</p> <p>Adherence to the protocol was assessed by principal investigator.</p>	<p>No barriers or facilitators were reported from participants.</p> <p>Authors only comment on the approach taken by instructors delivering the sessions. They tried to increase participant's motivation by linking movements to their personal interests. Also commented on the characteristics of the programme, which was developed to create a comfortable and friendly environment to the participants, where some of them developed social relationships.</p>	<p>Measurement of dementia severity: ADAS-Cog, Modified MMSE (3MS).</p> <p>Physical performance.</p> <p>Cognitive function.</p> <p>Person living with dementia's QoL.</p> <p>Dementia related behaviours.</p> <p>QoL and carer burden.</p>	<p>Authors highlight the potential clinical significance of improvements in cognitive function, QoL and carer burden observed in participants involved in their program.</p> <p>"Results were similar when within-group comparisons were made before and after cross-over." (p.2)</p>	<p>Community</p>

Study	Intervention characteristics	Adherence and attrition Rates	Barriers and facilitators reported	Outcome measures (and balance measures used)	Conclusions	Setting
	collection points. Carer’s role is not described.					
(Cheng et al., 2014) No protocol paper identified. China	Cluster-randomized open-label controlled design. Group-based. Tai Chi type: Yang style. Seated Tai Chi. Participants allocated in the Tai Chi intervention group: 42 residents with mild-to-moderate dementia (MMSE=10-24). Dose provided of Tai Chi: 60 min sessions x 3 times/week x 12 weeks. No dyadic approach is described. Apart from an expert facilitator, there was a student per each 3 participants assisting to facilitate the intervention.	Attendance rate: Not reported. Attrition rate in the Tai Chi group: 7.14%. Drop out reasons: 1 passed away, 1 hospitalization, 1 not reported.	Not reported.	Measurement of dementia severity: MMSE and CDR. Cognitive assessments, together with the 15-item Geriatric Depression Scale (GDS). Data from health-related tests (i.e., APOE, cholesterol).	Tai Chi showed potential to maintain global cognitive function.	Long-term care settings
(Tsai et al., 2015) No protocol paper identified. USA	Group-based. Tai Chi type: Sun-style Tai Chi. Participants: 55 people living in retirement apartments or senior centres scoring 18–28 in the MMSE. Dose provided: 40min sessions x 3times/week x 20 weeks This intervention had been modified after conducting a previous pilot study. It does not seem to be a dyadic intervention.	Not reported. Authors admit there were drop outs when said that they compared baseline data with participants who dropped out, however, do not provide data on the amount of people or their reasons to drop out.	Not reported.	Measurement of dementia severity: MMSE. Verbal descriptive scale Observation of pain behaviour. Analgesic intake.	Authors conclude this style of Tai Chi could be used together with medication to help reducing pain related to this condition independently of their cognitive performance.	Long-term care settings

Appendix H

Acceptability and Adherence Barriers and Facilitators

Table H 1. *Acceptability Barriers and Facilitators Identified Along Exercise Interventions Conducted Amongst Community-Dwelling People Living with Dementia*

Factor	People living with dementia's	Carers	Instructors	Additional sources
Source of advice and publicising the intervention	Recommended through advertising and supported by health professionals (Chong et al., 2014; Suttanon et al., 2012).		On the other hand, trust in doctors' advice to take part in these interventions could have a controversial effect according to situations reported by exercise instructors (Hawley-Hague et al., 2016a, p. 121) where "the doctor had told the participant not to exercise, saying things such as: "...well you're 80, what do you expect? ...you should be doing your knitting"". However, instructors also value the positive effect on older adults' confidence towards the intervention once exercise has been recommended by their doctor.	This seems to be consistent with the positive social control (side-) effect commented by Ranby and Aiken(2016) regarding husbands' influences on their wife's exercise habits. This research suggested that husband's positive social control has not the expected positive effect on wife's engagement to exercise when she does not have the intention to practise it.
	Although, it was not clear if their family members advise would be equally welcome (Chong et al., 2014).		This argument has also been supported by instructors' opinions who think participants' motivation is required to reduce resistance and facilitate uptake and adherence (Hawley-Hague et al., 2016a).	Family could potentially help older adult participant's engagement to exercise by attending together (Hawley-Hague et al., 2016a; Ranby & Aiken, 2016) and supporting self-efficacy.
	More information about the intervention (Frederiksen et al., 2014).		Using a more positive vocabulary and closer to older adult's identities (i.e. "improving function" versus "falls class") (Hawley-Hague et al., 2016a).	Knowledge about exercise's impact on the prevention of falls is required amongst older adults to facilitate their engagement to these interventions (Nyman, 2011).
Intervention's characteristics	Conducted in a group-based format, as for some participants –particularly woman-this was a motivating factor (Chong et al., 2014).		Actually, this format allows social interactions and can help to develop a sense of competence practising exercise (Hawley-Hague et al., 2016a).	When delivered in group-based formats, a low ratio of participants per instructor has been used to facilitate close support during the exercises (Logsdon et al., 2009).
	Authors reported a link between wanting to take part in a group-based exercise and participants' willingness to engage in a tele-health intervention, instead of attitudes towards exercise being the best predictor (Dal Bello-Haas et al., 2014).			
	Adapted to participant's needs (Chong et al., 2014).			The timing of the intervention (i.e., at early stages of dementia), the need for activity, dyad's lifestyles, the need to do activities together or separate and the meaning of activity have been identified as factors that could determine the suitability of the exercise intervention for those living with dementia and their carers (Van't Leven et al., 2016).

Factor	People living with dementia's	Carers	Instructors	Additional sources
				Cultural appropriateness has been highlighted as an important element for its acceptability (Lam & Cheng, 2013).
	Affordable in case of having to pay for them (Chong et al., 2014).		This is consistent with instructors' perspective, as they identified having to pay as a barrier to uptake their interventions (Hawley-Hague et al., 2016a).	
Perceived benefits	Value of research (Suttanon et al., 2012).			
	Minimising carer burden (Suttanon et al., 2012).			
	Perceived benefits (Suttanon et al., 2012): Positive impact on cognition (Chong et al., 2014).			
Participants' characteristics				Older people who did not start practising exercise were older, less educated, had more comorbidities, had poor balance and mobility and had a lower cognitive performance. In terms of self-reported functioning they had more difficulties in daily life activities and tend to engage less in physical activities (Aartolahti, Hartikainen, Lonnroos, & Hakkinen, 2014).
	Positive attitude towards exercise (Chong et al., 2014; Suttanon et al., 2012).		However, attitude towards classes was, in turn, perceived as a barrier by exercise instructors (Hawley-Hague et al., 2016a).	Older adults attitudes towards exercise interventions after having experienced a fall can be very different. Whilst some would understand a fall as an isolated event, others would perceive it as a sign of an age related decline or as a threat to be aware of or avoid. Their perceptions of these events, together with their beliefs about their ability to modify their risk, will impact on their adherence to these interventions (Nyman, 2011).
Instructors contributions to acceptability			Helping older adults to find their own motivation towards exercise (i.e. to work towards the maintenance of their independence) (Hawley-Hague et al., 2016a).	
			Establishing a bond with them (Hawley-Hague et al., 2016a).	

Table H 2. Adherence Facilitators Identified Along Exercise Interventions Conducted Amongst Community-Dwelling People Living with Dementia

Factor	Views as reported by...			
	People living with dementia	Informal carers	Instructors	Additional sources
Program characteristics	Program characteristics (Suttanon et al., 2012).		Providing monthly refresher sessions was also used in the maintenance phase of a Tai Chi intervention to promote adherence amongst older adults living in the community or in care centres (Lam et al., 2012). These authors also suggested alternative strategies to facilitate adherence as implementing techniques to increase self-efficacy and allow participants to self-assess their functional improvements.	
	Group-based setting (Dal Bello-Haas et al., 2014).			
	Socialising component (Frederiksen et al., 2014).	Enrolling in group-based interventions helped carers to engage in exercise (Farran et al., 2008).	Promoting social support and cohesion amongst participants was also identified as a key factor by instructors (Hawley-Hague et al., 2016a).	Social support obtained from group-based interventions could facilitate adherence and self-efficacy as a motivational factor which will also influence maintenance (Lam & Cheng, 2013).
	Exercise tailored to participants' needs and environment, when home-based (Day et al., 2016; Pitkälä, Pöysti, et al., 2013).	In exercise interventions for carers, the possibility of combining activities, have a flexible schedule, involving the person living with dementia in the exercise (Farran et al., 2008).	Meeting participants' needs, establishing achievable goals and highlighting progress made (Hawley-Hague et al., 2016a).	Yao et al. (2008) conclude, after revising previous literature and before designing their intervention, that one-to-one support and positive reinforcement can facilitate people living with dementia's adherence to physical interventions.
	Carer's support (Suttanon et al., 2012).			Close supervision, which could be provided by carers in home-based interventions (Lam & Cheng, 2013).
	Respect of participant's privacy in the context of a tele-health intervention (Dal Bello-Haas et al., 2014).			
			Calling participants when they missed a class (Hawley-Hague et al., 2016a; Lam et al., 2012).	
	Positive experience or enjoyment (Frederiksen et al., 2014; McPhate et al., 2016; Wesson et al., 2013; Yu & Swartwood, 2012).			
Environment Characteristics	Accessibility to the venue (Dal Bello-Haas et al., 2014).			

Factor	Views as reported by...			
	People living with dementia	Informal carers	Instructors	Additional sources
Instructor's Characteristics	Qualities (i.e., kindness, charisma, expertise) of the professional leading the intervention (McPhate et al., 2016; Suttanon et al., 2012).		Previous experience was also identified as a facilitator by instructors, as they need it to adapt sessions to participants' needs and avoid drop outs (Day et al., 2016).	
	Engagement with the facilitator (Dal Bello-Haas et al., 2014).			The presence of the instructor helped participants to be willing to get involved in all the exercises (Prick et al., 2014).
Participant's Characteristics	Ability to sustain attention (Dal Bello-Haas et al., 2014).			
	Sense of commitment (Suttanon et al., 2012).			
	Participants expected outcomes of the intervention – slow dementia progression (Frederiksen et al., 2014).			
				Prick et al. (2014) pointed that motivation of the dyads, or the participation of sportive dyads and/or healthy dyads, has been identified as a facilitator to the delivery of class-based exercise interventions.
				The fact that the carer was a spouse made carers more likely to perceive less stress and facilitated the person living with dementia's adherence to the prescribed intervention (McCurry et al., 2011).
Memory Aids	Attendance reminders (Frederiksen et al., 2014).			
	Logsdon et al. (2009) have suggested the use of written materials and memory aids for interventions with home-based components.			A manual with pictures of exercises helped participants to know how to perform the activities when the instructor was not present (Prick et al., 2014).
	Repeating exercises in small portions each time to facilitate recall (Logsdon et al., 2009).			
Motivational Techniques	Sheet to record exercise practised (Suttanon et al., 2012).			
Altruism	Feeling their participation could help future patients (Frederiksen et al., 2014).			
Perceived Benefits	Participant's perceived benefits (Suttanon et al., 2012):	Carers identified an improvement in attitude in their family members (Yu &		

Factor	Views as reported by...			
	People living with dementia	Informal carers	Instructors	Additional sources
	<p>As a socially rewarding intervention for AD participants and their carers (McPhate et al., 2016; Yu & Swartwood, 2012).</p> <p>In strength (Yu & Swartwood, 2012) and balance (Day et al., 2016).</p> <p>Physical fitness (Frederiksen et al., 2014).</p>	<p>Swartwood, 2012).</p> <p>Reduction of carer’s stress (Yu & Swartwood, 2012).</p>		

Table H 3. Adherence Barriers Identified Along Exercise Interventions Conducted Amongst Community-Dwelling People Living with Dementia

Factor	Views as reported by...			
	People living with dementia	Informal carers	Instructors	Additional sources
Participants Characteristics	<p>Frailty of dyads’ members (Connell & Janevic, 2009; McCurry et al., 2011).</p> <p>Their pre-existing conditions (Chong et al., 2014; Suttanon et al., 2012).</p>		<p>Changes in health were also reported by instructors as a barrier for carer’s engagement in exercise interventions (Farran et al., 2008; Wesson et al., 2013).</p>	<p>Frailty and age were defined as possible barriers for sustaining activity levels (Lam & Cheng, 2013).</p> <p>Health issues were also pointed by Burton et al. (2015)’s systematic review as one of the reasons for lower adherence rates to exercise.</p> <p>Prick et al. (2014) suggested physical complaints as a barrier for adherence to class-based exercise interventions.</p>
	<p>Behavioural challenges and cognitive decline of the person living with dementia or carer’s way of interacting with the person with dementia (Teri et al., 1998).</p> <p>Their memory challenges (Day et al., 2016) and motivation (Chong et al., 2014; McPhate et al., 2016).</p>			<p>Particularly, cognitive impairment could have a significant impact on motivation to take part in physical activities, due to mood disturbances associated (Lam & Cheng, 2013).</p> <p>The presence of more memory and behavioural problems and depression has been pointed as a barrier for continued adherence to exercise interventions (McCurry et al., 2011).</p>
		<p>Carers concerns materialised through anxious feelings or the lack of support providing care was also identified as a barrier (Farran et al., 2008).</p>		<p>Prick et al. (2014) carer burden as a barrier for adherence to class-based exercise interventions.</p>

Factor	Views as reported by...			
	People living with dementia	Informal carers	Instructors	Additional sources
				A systematic review conducted recently (Burton et al., 2015) mainly based in randomised controlled trials reported that studies which provided reasons for lower adherence rates to exercise programmes (not including Tai Chi) was frequently due to lack of previous experience practising exercise.
				Barriers to home-based interventions included physical impairments of the person with dementia, time constraints, burden of the carer, fatigue of the person with dementia and difficulties in motivating the person with dementia by the carer (Prick et al., 2014).
Intervention's Characteristics	A more progressive introduction of the exercises –was claimed by people living with dementia and their carers- (Frederiksen et al., 2014).			
			Big intervention groups were pointed as barriers by instructors (Day et al., 2016), probably for their difficulty to provide adequate support to the participants. Probably to overcome this barrier, some authors (Suttanon et al., 2012) have recommended home-based interventions with professional and carers support Instead.	
			Instructors leading exercise interventions for carers also identified challenges in using technology appliances (Farran et al., 2008).	
	Lack of adaptation to participants' needs (McPhate et al., 2016).		Adherence to the intervention was challenged when the intervention did not match participant's needs or previous expectations about the exercise (Hawley-Hague et al., 2016a).	
	Perceiving the intervention as time-consuming by people living with dementia and their carers (Frederiksen et al., 2014).			
	The complexity, intensity and safety of these activities. In terms of length of the session, most of the participants suggested interventions between 30 minutes and 1 hour long. However, compared to general older adults, they suggested a higher frequency for these sessions (Chong et al., 2014).			

Factor	Views as reported by...			
	People living with dementia	Informal carers	Instructors	Additional sources
Intervention's Adverse Effects	Dizziness or muscle strain (Teri et al., 1998).			
	The person living with dementia feeling more tired could have prevented them to engage in previous activities (Frederiksen et al., 2014).			
Built Environment	Difficulty to find appropriate areas to walk in the surroundings of their homes (McCurry et al., 2011).			
	Weather conditions (Farran et al., 2008; McCurry et al., 2011; Suttanon et al., 2012).			
	Commitments away from home (Suttanon et al., 2012).			
	Holiday periods (Wesson et al., 2013).			Holiday periods was also pointed by Burton et al. (2015)'s systematic review as one of the reasons for lower adherence rates to exercise.
	The venue and time availability (Chong et al., 2014; McPhate et al., 2016).		The venue was also mentioned by exercise instructors as an external barrier, however, more linked with older people's attitudes and identities (i.e. feeling that more vigorous exercise is practised in certain environments, such as a gym). Also, in another study instructors mentioned poorly maintained or non-appropriate flooring and a lack of storage as barriers (Day et al., 2016).	
Social Environment	The lack of somebody to practise exercise with (Chong et al., 2014) due to carer's health or lack of commitment (Suttanon et al., 2012; Wesson et al., 2013).	In exercise interventions designed for carers, however, their caring roles and other responsibilities made difficult to some of them to engage in the intervention (Farran et al., 2008). Caring roles (Connell & Janevic, 2009).		

Factor	Views as reported by...			
	People living with dementia	Informal carers	Instructors	Additional sources
			<p>Social influences: when the participant has a main bond with another participant who drops out or when there is a change of instructor. However, personal or a family member's illness was also pointed as a common reason for dropping out (Hawley-Hague et al., 2016a).</p>	

Appendix I

PPI Advisory Group Meeting on 15/03/2016

Focus group and interviews schedules were presented to the PPI Group

A PPI advisory group meeting for this project was held on the 15/03/2016 at Bournemouth University. The advisory group was formed of four people living with dementia, and six carers (four of them spouses of the four people living with dementia). Of the four people living with dementia there were two males and two females. The two carers who were not accompanied by their relatives living with dementia were both females. Apart from the PhD researcher, the Chief Investigator (CI) and supervisor for this PhD research, a member of the Bournemouth University Clinical Research Unit, as well as Bournemouth University Dementia Institute (BUDI) Administrator were present. A three-page document was handed out to each of the individuals in the room. A 14-font size was selected, as well as doubles line spacing and bold letters as this was regarded as the most appropriate for people living with dementia. The PhD researcher explained briefly the context where the questions would be formulated (as previous information had been provided by the PI of the project, as well as by one of the Tai Chi instructors involved in this project). The time available to discuss these questions was 15-30 minutes, as previous issues in this meeting took more time than expected. Participants where asked about the appropriateness of the questions, as well as if they would feel comfortable responding these questions in front of their family members (person living with dementia or carer). Participants of this group did not provide any negative comment on the questions. Two of them asked if those questions would be handed out to the participants or asked verbally instead, they found more appropriate to formulate the questions to participants. One of the participants reported it was not a problem for him (carer) to talk openly in positive or less positive terms in front of his wife (person living with dementia). The rest of the group agreed. He also advised to ask first the dyad if they are happy to take part in a joint interview.

Appendix J

Evaluation Frameworks

Different evaluation frameworks have been reported in the literature such as Reach Effectiveness Adoption Implementation Maintenance (RE-AIM) (Glasgow, Vogt, & Boles, 1999), Intervention Mapping (Kok, Schaalma, Ruiters, Van Empelen, & Brug, 2004), Multiphase Optimization Strategy (MOST) (Collins, Murphy, Nair, & Strecher, 2005) or guidelines around the evaluation of behavioural change interventions in community settings (National Institute for Health and Clinical Excellence, 2007). These evaluations are explained in Table J 1, together with the context where these have been used.

Table J 1. *Description of Evaluation Frameworks Used in Previous Research*

Evaluation Framework	Characteristics
RE-AIM (Glasgow et al., 1999)	It was developed to assess “public health and community-based interventions” (p. 1322) in five different areas: reach, efficacy, adoption, implementation, and maintenance. Its purpose was to counteract evaluations performed in an artificial RCT environment, by assessing the impact of additional factors which are relevant in natural, community-based interventions. This evaluation aims to increase the ecological validity of the research outcomes, being more representative of the general population.
Intervention Mapping (Kok et al., 2004)	It is a protocol designed to help developing health interventions informed by evidence and theory (p.85). This tool was created to guide this development by grounding objectives, methods, programme plan, implementation plan and evaluation plan on previous evidence and theory (p.88).
MOST (Collins et al., 2005)	It was developed to assess and optimise behavioural programs. MOST consists of three phases: screening, refining and confirming. This evaluation starts with the assessment of the program as initially designed, then the improvements to be made and, finally, about an assessment of the optimization process.
Guidelines around the evaluation of behavioural change interventions in community settings (National Institute for Health and Clinical Excellence, 2007)	These are a compilation of recommendations for planning, delivery and assessment of behaviour change interventions targeting people living in the community.

In the TACIT Trial, the RE-AIM evaluation was found more appropriate for the subsequent definitive trial, as this assessment focuses not only on the implementation but also on the maintenance of the behavioural change.

Appendix K

Study Phases

a) Pilot Intervention Phase

The Pilot Intervention Phase of the TACIT Trial was used to identify and address problems which might undermine the acceptability of the intervention and the research processes (i.e., baseline measurements or phone calls). This was similar to the purpose of the pilot study reported by O’Cathain et al. (2015), and had similar research questions to inform the intervention’s enhancement before conducting the main trial the main trial:

- Intervention development and adaptation: What needed to be adapted in the RCT Phase to make it more acceptable to participants? Were participants happy or unhappy with any aspect of the content or delivery of the intervention?
- Perceived impact: Which were the perceived values, benefits and harms or unintended consequences of the intervention identified by participants?

b) RCT Phase

The aim of this RCT Phase was to analyse the adherence and involvement of participants to the intervention. This will inform future research on barriers and facilitators of participant’s adherence to Tai Chi interventions. At this stage dyads were asked to participate in Tai Chi practice for 50hrs over 20 weeks.

The process evaluation of this RCT phase was used to learn more about:

- The delivery process: What worked and how was the Tai Chi intervention implemented?
- Impact of the intervention: How did the intervention influence participants? How did the intervention context affect the results of the intervention?
- Scope of the intervention: Did the participants adhere to the planned intervention? If not, what were the reasons for this? (Moore et al., 2015)

But also:

Dyadic participation: Did participants benefit from dyadic interventions? Did it benefit their adherence to the intervention? If yes, in which ways?

Appendix L

Semi-Structured Observation Schedules

An adapted version of the Greater Cincinnati Chapter Well-Being Observation Tool (Kinney & Rentz, 2005; Sauer, Fopma-Loy, Kinney, & Lokon, 2014) based on the domains of QoL described by Lawton (1994) was used. This tool has been successfully used in other psychosocial (arts) interventions for people living with dementia and found more appropriate in an intervention context (Algar, Woods, & Windle, 2014) than other popular observational tools such as Dementia Care Mapping™ (DCM). For this thesis, however, the original tool was not used for pragmatic reasons. This tool requires various researchers observing the research situation, or using video recording, as each researcher can only observe three participants during each session (Kinney & Rentz, 2005). In this thesis, qualitative observations were based on the observation of all participants attending on the day (and including both people living with dementia and their carers).

L 1. Observations' codebook

Research stage: Pilot Intervention Phase / RCT Phase

Date: XX/XX/XXXX

Session number: XX

Starts at – time when the class starts

Ends at – time when the class finishes

Instructor – Instructor's name

Research Site: Bournemouth/Southampton

Venue – Name of the venue

Number of participants attending the session: XX

Participants' names – Name & ID for each member of the dyad (and a note on the colours of the clothes they wear to make notes and later identification easier).

1. Notes on the Intervention setting

Venue description – Description of the physical environment: accessibility to the building, Tai Chi room's flooring conditions, windows, natural/artificial lighting, size of the room (big/small), temperature of the room (warm/cool), other objects in the room.

Interaction amongst (and affect) participants before the intervention starts – Affect (signs of positive/ negative affect as described in table below) shown by

participants at their arrival to the session, dyads interactions, interaction with members of other dyads when they arrive in the venue.

Participants' / Space distribution in the room – Map of participants distribution in the room (using their ID number and colour of their clothes, to match this with other notes during the observation).

Session structure – Parts of the session, as introduced by the instructor.

2. Notes on participants'...:

Quotes from participants will be recorded using inverted commas, to differentiate those from behaviour observed by the researcher.

Aspects to observe	Take notes on...
Interactions	
With the other member of the dyad	General assessment of the interactions between members of the dyads: Positive – Negative – Neutral
Kind of responses provided by people living with dementia to the carers	Verbal/ non-verbal expressions of support acceptance/rejection and positive/negative responses to the carer.
Kind of support provided by carers	Verbal communication speed and tone used to talk to provide support to the person living with dementia. Physical support provided (i.e., area of physical contact, soft/brusque movements). Examples of disempowerment (i.e., do something for the person living with dementia when he/she can do it) and/or infantilization (use of childlike vocabulary, while speaking slowly and loudly (Marson & Powell, 2014, p. 144), expressions as “good [boy/] girl” (Brady, Clifton, Burr, & Curran, 2014, p. 22)).
With other participants Interest	General assessment of the interaction amongst participants: Positive – Negative – Neutral
Camaraderie between peers	Interest shown towards other participants and verbal or non-verbal interactions established with them (i.e., “making eye contact, smiling or acknowledging” support from peers (Kinney & Rentz, 2005, p. 224)).
With the instructor	General assessment of the interactions with the instructor: Positive – Negative – Neutral
Initiated by participants	Verbal (direct questions) or non-verbal (i.e., raising a hand, pointing somebody) interactions with the instructor started by the person living with dementia or the carer. Purpose of these interactions will be recorded (i.e., to ask for help, clarification, express a comment related or unrelated to the exercise).
Instructor's rapport	

Aspects to observe	Take notes on...
Interaction started by the instructor	<p>Purpose of the interactions started by the instructor (i.e., to correct exercise, gather their attention, check they are ok) and speed and tone used by the instructor in these interactions.</p> <p>Examples of situations where the instructor points that an exercise is being correctly performed and/or encourages participants to carry on performing a movement.</p>
Tailored comments for people living with dementia or carers	<p>Presence or absence of tailored comments for (a) specific dyad(s). If present, purpose/content of those.</p> <p>Instructor's response to participant's comments (i.e., examples of verbal/ non-verbal acknowledgement, appreciation), establishment of eye contact with participants when they are talking to the instructor.</p>
<p>Engagement</p> <p>Interest and sustained attention (Kinney & Rentz, 2005)</p>	
Participants' engagement	<p>Examples of verbal/non-verbal signs of active/passive engagement/non-involvement (i.e., they are able to sustain attention for 10 minutes/ need prompting to sustain their attention in the activity/ interact with peers or instructor and are able to return to the activity and refocus).</p>
<p>Attitudes towards Tai Chi</p>	
Verbal/non-verbal positive / negative / neutral attitudes	<p>Verbalizations on expected benefits/harms from practising Tai Chi, or positive/negative feelings while performing the movements (i.e., comments or non-verbal reactions when performing Tai Chi movements).</p>
<p>Affect (before/during/after Tai Chi) (Watson, Clark, & Tellegen, 1988)</p>	
Examples of positive and negative affect	<p><u>Positive</u> – interested, excited, strong, enthusiastic, proud, alert, inspired, determined, attentive, active (Watson et al., 1988).</p> <p><u>Negative</u> – Distressed, upset, guilty, scared, hostile, irritable, ashamed, nervous, jittery, afraid (Watson et al., 1988).</p> <p>Agitation, angry, verbalizes feeling anxious (“I feel nervous,” “I am jumpy,” “I feel funny today”)) (Kinney & Rentz, 2005, p. 224).</p> <p>Confusion: Participant shrugs his/her shoulders and does not know what to do or how to perform the movements; verbalizes feeling lost and asks what is happening (Sauer et al., 2014).</p>
<p>Communication</p> <p>Expressions of pleasure / sadness/self-esteem (Kinney & Rentz, 2005), feelings about being in a group setting –normalcy (Kinney & Rentz, 2005).</p>	

Aspects to observe	Take notes on...
<p>Verbal expressions of pleasure/displeasure, sadness, self-esteem and normalcy.</p>	<p><u>Pleasure</u>: Participants verbalize a sense of pleasure with phrases such as: “this feels good,” “this is relaxing,” or in the verbal expression of unintelligible phrases such as oooh, aah, accompanied with smiles, crinkling of eyes, or relaxed facial expression (Kinney & Rentz, 2005, p. 224).</p> <p><u>Displeasure</u>: Participants verbalise they do not like the movement/Tai Chi, they feel in pain, they want to stop performing the exercise or leave the class, they find an exercise embarrassing, they do not like performing the activity in front of other dyads.</p> <p><u>Sadness</u>: Participants verbalize feeling sad at some point in the activity (Kinney & Rentz, 2005, p. 224).</p> <p><u>Self-esteem</u>: Participants verbally express satisfaction after completing a successful pattern/movement. Participants verbally express pride through expressions of reminiscence (Kinney & Rentz, 2005, p. 224).</p> <p><u>Normalcy</u>: Participants verbally express feeling good about being in a group activity, which may be expressed as “I feel normal again,” “I don't feel so alone,” or other positive statements (Kinney & Rentz, 2005, p. 224).</p>
<p>Non-verbal expressions of pleasure/displeasure, sadness, self-esteem, normalcy.</p>	<p><u>Pleasure</u>: Participants have relaxed body language, smiles, and laughs during the activity (Kinney & Rentz, 2005, p. 224).</p> <p><u>Displeasure</u>: Participants have a tense body language, do not establish eye contact with other participants and/or the instructor, and/or shake their heads saying no.</p> <p><u>Sadness</u>: Participants show “flat affect or weeping quietly (...) eyes drooping; sighing, head in hand, eyes/head turned downward and face expressionless” (Kinney & Rentz, 2005, p. 123).</p> <p><u>Self-esteem</u>: “Participants nonverbally express pride in participating and completing a pattern by smiling, nodding happily, tearfulness, clapping” (Kinney & Rentz, 2005, p. 224).</p> <p><u>Normalcy</u>: Participants “nonverbally express social normalcy evidenced by one or all of the following: interest in others, sustained attention to task, relaxed body language; if there is an affective reaction that reaction does not escalate or perseverate”. Participants, when joining or leaving the activity, chat openly with another, shakes hands, pats back, says or nods good-bye” (Kinney & Rentz, 2005, p. 224).</p>
<p>Psychological needs (Ryan & Deci, 2000)</p>	
<p>Competence</p>	<p>Participants are able /unable to perform the exercises.</p> <p>Participants' comments on the level of difficulty of the exercises, on their ability to replicate these exercises at a later stage and/or at home.</p>
<p>Relatedness</p>	<p>Participants' comments about their experience taking part in Tai Chi with the other member of their dyad or with other dyads (closeness with the other member of the dyad and sense of belonging to the group).</p>
<p>Autonomy (freedom of act)</p>	<p>Participants' freedom to choose if they want to perform a movement with/without additional support (i.e., chair), stop performing a movement if they do not want to do it or if they feel tired. Describe if any member of the dyad is not allowing this freedom of act to the other member.</p>

L 2. Template used in the Pilot Intervention Phase

Research stage: Pilot Intervention Phase / RCT Phase

Date:

Session number:

Starts at:

Ends at:

Instructor:

Research Site:

Venue:

Number of participants attending the session:

Participants' names:

Dyad ID	People living with dementia	Carers

3. Notes on the Intervention setting

Venue description [Physical environment: accessibility to the building, Tai Chi room's flooring conditions, windows, type of lighting, size of the room, temperature of the room, other objects in the room].

Interaction amongst (and affect) participants before the intervention starts [Affect shown by participants at their arrival to the session, dyads interactions, interaction with members of other dyads when they arrive in the venue].

Participants' / Space distribution in the room [Map of participants distribution in the room]

Session structure as introduced by the instructor

1. Notes on participants'...:

Interactions	
With the other member of the dyad	Positive – Negative – Neutral
<p>Kind of responses provided by people living with dementia to the carers</p> <p>Verbal/ non-verbal expressions of support acceptance/rejection and positive/negative responses to the carer.</p> <p>Kind of support provided by carers</p> <p>Verbal communication speed and tone, physical support provided (i.e., area of physical contact, soft/brusque movements), Examples of disempowerment and/or infantilization.</p>	
With other participants Interest	Positive – Negative – Neutral
<p>Comaraderie between peers</p> <p>Interest shown towards other participants and verbal or non-verbal interactions established with them (i.e., "making eye contact, smiling or acknowledging" support from peers.</p>	
With the instructor	Positive – Negative – Neutral
<p>Initiated by participants</p> <p>Verbal or non-verbal interactions and their purpose.</p>	
Instructor's rapport	
<p>Interaction started by the instructor</p> <p>Purpose of these interactions and speed and tone used. Examples of positive feedback.</p>	

<p>Tailored comments for people living with dementia or carers</p> <p>Presence or absence of tailored comments for (a) specific dyad(s). If present, purpose/content of those.</p> <p>Instructor's response to participant's comments (i.e., examples of verbal/ non-verbal acknowledgement, appreciation), establishment of eye contact with participants when they are talking to the instructor</p>	
<p>Engagement</p>	
<p>Participants' engagement</p> <p>Examples of verbal/non-verbal signs of active/passive engagement/non-involvement (i.e., they are able to sustain attention for 10 minutes/ need prompting to sustain their attention in the activity/ interact with peers or instructor and are able to return to the activity and refocus).</p>	
<p>Attitudes towards Tai Chi</p>	
<p>Verbal/non-verbal positive / negative / neutral attitudes</p> <p>Verbalizations on expected benefits/harms from practising Tai Chi, or positive/negative feelings while performing the movements.</p>	
<p>Affect (during/after Tai Chi)</p>	
<p>Positive – interested, excited, strong, enthusiastic, proud, alert, inspired, determined, attentive, active.</p> <p>Negative – Distressed, upset, guilty, scared, hostile, irritable, ashamed, nervous, jittery, afraid. Agitation, angry, feeling anxious. Confusion.</p>	

Communication	
<p>Verbal</p> <p><u>Pleasure</u></p> <p><u>Displeasure</u></p> <p><u>Sadness</u></p> <p><u>Self-esteem</u> – satisfaction, pride.</p> <p><u>Normalcy</u> - feeling good about being in a group activity.</p>	
<p>Non-verbal</p> <p><u>Pleasure</u> – relaxed body language</p> <p><u>Displeasure</u> – tense body language</p> <p><u>Sadness</u></p> <p><u>Self-esteem</u> – satisfaction, pride.</p> <p><u>Normalcy</u> - feeling good about being in a group activity.</p>	
Psychological needs	
<p>Competence</p> <p>Ability to perform the exercises.</p>	
<p>Relatedness</p> <p>Closeness with the other member of the dyad and sense of belonging to the group.</p>	
<p>Autonomy</p> <p>Freedom of act to choose if they want to perform a movement with/without additional support (i.e., chair), stop performing a movement if they do not want to do it or if they feel tired. Describe if any member of the dyad is not allowing this freedom of act to the other member.</p>	

Other notes:

L 3. Template used in the RCT Phase

Research stage: RCT Phase

Date:

Session number:

Starts at:

Ends at:

Instructor:

Research Site:

Venue:

Number of participants attending the session:

Participants' names:

Dyad ID	People living with dementia	Carers

1. Notes on the Intervention setting

Venue description [Physical environment: accessibility to the building, Tai Chi room's flooring conditions, windows, type of lighting, size of the room, temperature of the room, other objects in the room].

Interaction amongst (and affect) participants before the intervention starts [Affect shown by participants at their arrival to the session, dyads interactions, interaction with members of other dyads when they arrive in the venue].

Participants' / Space distribution in the room [Map of participants distribution in the room]

Session structure as introduced by the instructor

2. Notes on participants'...:

Verbal and non-verbal interactions (between members of the dyad, amongst participants and with or initiated by the instructor)

Participants' reactions to the intervention (engagement, enjoyment, level of attention, attitudes and affect)

Participant's psychological needs (competence, relatedness and autonomy)

Other notes:

Appendix M

Feedback Collected at the End of the Classes

M 1. Participant's feedback template

Session 1

Venue:

Date:

PERCEPTIONS AND MOTIVATION TO TAKE PART IN TAI CHI (if possible, to ask before class starts)

1. What do you think about Tai Chi?

2. Why did you decide to take part in Tai Chi?

- Were any of you [dyad] more willing to take part in Tai Chi classes?
 - IF yes: How did you convince him/her to join as well?

3. Had you ever practised exercise before?

- IF yes: Which exercise? For how long?

EXPERIENCE OF TAKING PART IN THE TAI CHI CLASS

4. How have you found the class?

- Enjoyment:
 - What have you liked the most about the Tai Chi class?
 - What have you liked the less about the Tai Chi class?

- Instructor:
 - What do you think about the instructor?
 - How do you find his instructions (too fast/too slow)?

5. How have you felt taking part in the class?

- Competence (ability to perform the exercises):
 - How would you describe the level of difficulty of the class?
 - How did you find taking part in Tai Chi for 45 minutes?

- Relatedness (closeness with the other member of the dyad and sense of belonging to the group):
 - How have you felt taking part in Tai Chi in a group?
 - How have you felt taking part in Tai Chi in pairs?

6. Further comments:

Session 2**Venue:****Date:*****PERCEIVED IMPACT OF TAI CHI*****1. Have you noticed any changes since you started practising Tai Chi?**

- Benefits:
 - Have you noticed any benefit from taking part in Tai Chi?

- Harms:
 - Have you noticed any harm from taking part in the Tai Chi classes, or has anything not worked so well since you started practising Tai Chi?

EXPERIENCE OF TAKING PART IN THE TAI CHI CLASS**2. How have you found the class?**

- Enjoyment:
 - What have you liked the most about the Tai Chi class?
 - What have you liked the less about the Tai Chi class?

- Instructor:
 - What do you think about the instructor?
 - How do you find his instructions (too fast/too slow)?

3. How have you felt taking part in the class?

- Competence (ability to perform the exercises):
 - How would you describe the level of difficulty of the class?
 - How did you find taking part in Tai Chi for 45 minutes?

- Relatedness (closeness with the other member of the dyad and sense of belonging to the group):
 - How have you felt taking part in Tai Chi in a group?
 - How have you felt taking part in Tai Chi in pairs?

PERCEPTIONS AND MOTIVATION TO TAKE PART IN TAI CHI AT HOME**4. What is it like practising Tai Chi at home?**

- Barriers and facilitators:
 - What is helping you to practise Tai Chi at home?
 - What is making taking part in Tai Chi at home more difficult?

- Tai Chi instructor's visit:
 - How would you describe the Tai Chi instructor's visit to show you how to safely practise Tai Chi at home?

- Practising in pairs:
 - How do you find planning a time to practise Tai Chi together?
 - How do you find practising Tai Chi at home with him/her?

- Materials:
 - How would you describe your use of the clock alarm and the Tai Chi booklet?

5. Further comments:

Session 3**Venue:****Date:*****PERCEPTIONS AND PERCEIVED IMPACT OF TAI CHI*****1. What do you think about Tai Chi?****2. Have you noticed any changes since you started practising Tai Chi?**

- Benefits:
 - Have you noticed any benefit from taking part in Tai Chi?

- Harms:
 - Have you noticed any harm from taking part in the Tai Chi classes, or has anything not worked so well since you started practising Tai Chi?

EXPERIENCE OF TAKING PART IN THE TAI CHI CLASS**3. How have you found the class?**

- Enjoyment:
 - What have you liked the most about the Tai Chi class?
 - What have you liked the less about the Tai Chi class?

- Instructor:
 - What do you think about the instructor?
 - How do you find his instructions (too fast/too slow)?

4. How have you felt taking part in the class?

- Competence (ability to perform the exercises):
 - How would you describe the level of difficulty of the class?
 - How did you find taking part in Tai Chi for 45 minutes?

- Relatedness (closeness with the other member of the dyad and sense of belonging to the group):
 - How have you felt taking part in Tai Chi in a group?

- How have you felt taking part in Tai Chi in pairs?

PERCEPTIONS AND MOTIVATION TO TAKE PART IN TAI CHI AT HOME

5. What is it like practising Tai Chi at home?

- Barriers and facilitators:
 - What is helping you to practise Tai Chi at home?
 - What is making taking part in Tai Chi at home more difficult?

- Tai Chi instructor's visit:
 - How would you describe the Tai Chi instructor's visit to show you how to safely practise Tai Chi at home?

- Practising in pairs:
 - How do you find planning a time to practise Tai Chi together?
 - How do you find practising Tai Chi at home with him/her?

- Materials:
 - How would you describe your use of the clock alarm and the Tai Chi booklet?

6. Further comments:

M 2. Instructors' feedback

Research stage: Pilot Intervention Phase / RCT Phase

Date:

Starts at:

Ends at:

Instructor:

Research Site:

Venue:

Group number:

1. Notes on Instructor's:

1.1. Overall feeling about the Tai Chi group:

1.2. Level of engagement appreciated in Tai Chi:

1.3. Social interaction amongst participants:

1.4. Barriers perceived:

1.5. Facilitators identified:

1.6. Home-visits experiences:

1.7. Suggested improvements:

1.8. Further comments:

Appendix N

Research Diary

N 1. Research diary – At the end of the classes

Research stage: Pilot Intervention Phase / RCT Phase

Date:

Session number:

Research Site:

Venue:

Group number:

1. Notes on researcher's perceptions on:

1.1. Participants' understanding of instructor's explanations:

1.2. (Second session onwards) Participants' familiarity with session structure:

1.3. Exercises' level of difficulty for participants:

1.4. Level of enjoyment along the session:

1.5. Participants' behavioural changes along the session:

1.6. Group cohesion:

1.7. Emergent group leaders (If it is the case, how do the rest of participants react to this?)

1.8. Impact of participants' being observed by a researcher:

1.9. Likelihood for participants to turn up in the next session:

1.10. Further comments:

N 2. Research diary– After the focus group (Pilot Intervention Phase)

Research stage: Pilot Intervention Phase

Date:

Starts at:

Ends at:

Research Site:

Venue:

Group number:

1. Notes on Participants'

1.1. Enjoyment of the focus group:

1.2. Comfort along the focus group:

1.3. Contribution to the focus group (Did all the participants engage? Was there any leader?):

1.4. Comments after the focus group has finished:

1.5. Chance to talk individually to the Researcher (did carers and people living with dementia provide any individual comment about their experience of taking part together in the intervention)?

2. Notes on Researcher's:

1.1. Feelings before focus group:

1.2. Along focus group:

1.3. Experience as moderator - easiness of difficulty of moderation:

1.4. Level of directedness applied (Low – medium – high) and reasons:

1.5. Impression on level of honesty of participants' answers:

1.6. Further observations / reflections:

Appendix O

Focus Group

This technique had been widely used previously in qualitative research to gain participants' perspectives in a more efficient way than interviews, providing the amount of data that can be gathered during a focus group (Morgan, 1997). In this thesis obtaining participants' views after engaging in the intervention for 4 weeks, allowed to understand their experiences and assess the adequacy of the Tai Chi intervention for this population. Participants' experiences, in turn, were used to assess the need for improvements to be made in the intervention before running a 5-months trial.

Despite the limitations of using focus groups at this phase, because they tend towards consensus and can mask dissenting views (Morgan, 1997; O'Cathain et al., 2015); the "give and take process" suggested by Morgan (1997) allowed participants to express and complement their opinions. By using this method, participants had the opportunity to compare their perspectives and show agreement or disagreement towards other participants' views. Most of the current methods used either in quantitative and qualitative research can influence participants responses, because they might wish to adapt to socially accepted responses or produce a positive impression on the researcher. In this specific case, it must be accepted that social pressure could have had an effect on participants' responses. Having considered the limitations of alternative methods, focus group was still a valid method to respond to the research questions.

It must be noted that participants living with dementia were not alone in the focus groups but accompanied with an informal carer who had been involved in the intervention as well. The presence of a familiar face accompanying the person living with dementia during the research process had been previously used in research to create a comfortable environment (Chong et al., 2014). In the context of a focus group, the presence of the carer could help the person feel more confident when sharing their opinions with the rest of the group; although there was also the risk for them to take over the conversation. In parallel to reassure participants a series of ground rules were established before starting the focus groups: a) Its purpose; b) That there were no right or wrong answers, just different opinions equally respectable which would help to improve the intervention for other participants in a similar situation; c) That they would be encouraged to share their views but as their participation it is totally voluntarily, they did not have to feel pressured to respond; d) That even if they had agreed to take part in the focus group, they could withdraw at any time, without having to provide an

explanation. Similarly, and to avoid silencing any opposite voices, participants were given the opportunity to share any unexpressed opinion directly to the researcher at the end of the focus group.

At the Pilot Intervention Phase, the social component of this technique facilitated social interaction and cohesion which could help participants to sustain their relationships after the 4 weeks intervention. This outcome was not monitored in the current thesis. However, it is known that social engagement and the availability of a social support network in the community has a positive impact on people living with dementia and their carers, who can rely on peer support and might help to live better with dementia (Leung, Orrell, & Orgeta, 2015; Ozbay et al., 2007).

The researcher, acted as a moderator (Leung & Savithiri, 2009) in the discussion and attempted to elicit participation from all members, ensuring that appropriate direction was maintained. Although focus group is reported as the method employed, it must be noted that it was presented to participants as an informal group discussion. This decision was made mainly to facilitate participants understanding. However, the approach used during the discussion was slightly different from focus groups. Whilst focus groups tend to analyse the group dynamics of participants (Stewart, Shamdasani, & Rook, 2006) and for this reason the facilitator is not supposed to ask directly a participant's opinion, in this study a more directive approach was preferred. The main reason to choose this approach was participants' living with dementia characteristics (i.e., they could forget the questions (Chong et al., 2014) or lose their attention during the conversation) and check their willingness to carry on contributing to the discussion. However, this approach would also contribute to the response of the research question itself which required from the perspectives of both members of the dyad. A more directive role of the researcher was needed to ensure participants living with dementia's opinions were taken, apart from the one of their carers. The use of this approach together with the establishment of a ground rule, inviting people living with dementia to provide their views before their carers, was used to balance a potential initial inequality amongst participants. This approach also allowed the researcher to provide more time to those participants with communication challenges, or simply those who needed more time before sharing their opinions. One of the limitations of the focus groups is that some people tend to lead the conversation, whereas shyer participants rest in silence (Chong et al., 2014). In this case, as the researcher took a more active role, the voices of all participants were targeted and prompted, and the contributions from more talkative participants were regulated by asking the views of other participants as well.

Pilot Intervention Phase - Focus group schedule

Before starting the focus group

- ✓ Set up the room: place chairs in circle, confirm drinks are provided.
- ✓ Test video and audio recording equipment.
- ✓ Check preliminary questions and ball pens are ready.
- ✓ Provide name badges to participants.
- ✓ Check every participant knows what will happen and accept to be recorded.

Introduction

Housekeeping – fire, loos, stretching legs.

I would like to thank you all for coming today. My name is _____ and my assistant_____. We are both researchers at Bournemouth University. Today _____ will be taking notes and helping me if I forget anything.

Over the last few weeks you have been taking part in Tai Chi classes and practising Tai Chi at home as part of our research project. We feel that the best way to improve the sessions and the Tai Chi practice at home is talking with you about your opinions and experiences of taking part in it. It is particularly important for us to gather the views of those of you who have dementia, and also those of your family member or friend. Even if you have not been able to attend all the classes or do the exercises at home, your views and opinions are still very valuable to us.

To learn from your experiences, we are going to conduct a group discussion. Your participation in this group is voluntary, so if you prefer not to participate you are completely free to leave. However, we value all your opinions and would like to hear them. Whatever you say in this group will be confidential and used only for this research project. We will audio record this discussion in order to help us produce an accurate written record of this meeting and make sure that the record is an accurate version of your views. Any information that might disclose your identity will be anonymised in the written record. If we use any quotes from your contributions in research conferences, publications or events, we won't include any information that could identify you personally. We will also video record this conversation, just to make easier for us to identify who is talking at each time. Is it OK with everyone to audio and video record this discussion? (Check consent)

During this discussion I will ask you a few questions. There are no right or wrong answers, just different opinions that we would like to hear. Please feel free to state what you really think, even if you disagree with others but please respect their views. I would appreciate if <name of participants living with dementia> could give their opinions first, and then family members or friends. It is important that only one person

talks at a time as this makes it easier for the discussion to be clearly recorded and for <researcher's name> to take notes. Can I ask you to say your names in order, so we will be able to recognise your voices in the recording? (Check every participant says his/her name). Thank you.

This discussion will last around an hour or an hour and a half. If you want to have some refreshments, please feel free to help yourselves during the conversation. Half way through the conversation I will ask if you would like to have a short break. So, we will be able to have a pause and the restart the conversation if you need so.

Are there any questions before we start?

Before starting the group discussion, we would like you to consider the three topics that we will be discussing:

1. What has helped you to take part in Tai Chi in the classes and at home?
2. How could the Tai Chi have worked better for you in class and at home?
3. How would you describe your experience of taking part in Tai Chi together with your family member, friend or neighbour?

These 3 questions are written on this paper (hand out). You do not need to write your name on this page, so your thoughts will be anonymous. However, I would like to ask <carers names> to write a C on the right corner of your paper, please. Just to be able to differentiate which member of the dyads' responses come from. We would like you to note down your answers. This might help in our conversation as people can forget what they want to say in the group conversation. Should you need any support in writing, just let <focus group facilitator name> or <focus group assistant> know. You don't have to share everything you write down, but we will collect these anonymous papers at the end of the group discussion.

EXPERIENCE OF TAKING PART IN TAI CHI

1. Tell me about your experience of taking part in the Tai Chi classes.

[Prompt: Some images of people doing Tai Chi classes]

- Enjoyment:
 - What did you like about the Tai Chi classes?
 - What did you not like about the Tai Chi classes?
- Participation:
 - What helped you to take part in the Tai Chi classes?
 - What if anything, made taking part in the Tai Chi classes more difficult?
 - How did you feel about taking part in a group activity? E.g. keen, anxious, uncertain?

- Improvements:
 - How could the classes be improved to make it easier for you to participate?
 - Length of the session?
 - Frequency?
 - Intensity?
 - Timing and venue?
 - Explanations, support and guidance (by the Tai Chi instructor)?

2. Tell me about your experience of doing the Tai Chi exercise at home.

[Prompt: Hold up the Booklet that was provided for people to take home and follow]

- Participation:
 - How did you do the Tai Chi exercises at home?
 - How often did you practise the Tai Chi exercises at home?
 - How many minutes did you practise the Tai Chi exercises at home?
 - What helped you do the Tai Chi exercises at home?
 - Did anything stop you doing the Tai Chi exercises at home?
- Enjoyment:
 - What did you like most about the Tai Chi exercises at home?
 - What did you not like about the Tai Chi exercises at home?
- Home visit by Tai Chi instructor:
 - How did you feel about the home-visit by the Tai Chi instructor?
- Booklet:
 - How did you find the booklet for guiding you while doing the Tai Chi exercises at home?
 - Was it easy to follow?
 - How could the booklet have worked better for you?
- DVD:
 - How did you find the DVD for guiding you while doing the Tai Chi exercises at home?
 - Was it easy to follow?
 - How could the DVD have worked better for you?

WILLINGNESS TO CONTINUE

3. Do you feel there have been any changes to your health or well-being since taking part in the Tai Chi exercise?

- Benefits and harms:
 - Do you think there has been any benefit to you from taking part in the Tai Chi classes?
 - Do you think there has been any harm to you from taking part in the Tai Chi classes, or has anything not worked so well?

4. **How did you feel about carrying out Tai Chi with your family/friend member?**
5. **Would you be willing to carry on practising Tai Chi?**
 - Why/ why not?

EXPERIENCE OF TAKING PART IN RESEARCH

6. **Tell me about your experience of taking part in this research.**
 - How did you find the first interviews and tests (at baseline)?
 - How did you find filling in the weekly log of your Tai Chi exercise?
 - How did you find filling in the falls calendar?
 - How did you feel about being observed while doing the Tai Chi Classes?
 - How did you feel about the weekly telephone calls with the researcher?
 - How could this research be improved for you to make it easier to take part in?

DOUBTS AND COMMENTS

7. **Is there anything else you would like to let us know?**
8. **Are there any questions you would like to ask us?**

Conclusion

I would like to thank you all again for coming today and sharing your opinions with us. Your views will help us improve Tai Chi classes for others to take part.

If you have further questions or you want to share any information personally regarding the Tai Chi sessions or the research, please contact me (provide Researcher's University e-mail and contact number).

At the end of the focus group

- ✓ Seek verbal process consent.
- ✓ Collect preliminary questions sheets.
- ✓ Check and secure video and audio recording equipment.
- ✓ Tidy up the room.

Thank you for attending this group discussion. Your opinion is very important for us.

Before starting, **we would like you to consider the three topics** that we will be talking about today.

Please note:

- You do not need to write your name in this page. What you say will be anonymous.
- Should you need any help in writing, just let <focus group facilitator name> or < focus group assistant> know.
- You don't have to share what you have written down later with the group if you do not want to.
- These notes are to help you think about what you would like to say. We would also like to collect this paper at the end of the group discussion if you agree.

Please, turn the page when you are ready to start answering.

1. What has helped you to participate in Tai Chi in the classes and at home?

2. How could the Tai Chi have worked better for you in class and at home?

3. How would you describe your experience of taking part in Tai Chi together with your family member, friend or neighbour?

Thank you for noting your thoughts down.

Appendix P

RCT Phase – Qualitative Dyadic Interview

A dyadic approach was chosen again in the interview context to provide people living with dementia with a supportive familiar face, so they could feel more confident when sharing their opinions with the researcher. Informal carers could also provide help in rephrasing questions, inviting the person living with dementia to contribute to the conversation and inform the researcher of any non-verbal signs of the person living with dementia expression discomfort or unwillingness to carry on.

Some limitations from this method were also expected. In the case of reassuring carers, these could encourage the person living with dementia to express their opinions and take active part in the conversation. However, when interviewing dyads, it was expected that some of the carers could take over the conversation as had happened in previous family research (Reczek, 2014). To overcome this barrier, as part of the ground rules it was established that the person living with dementia would respond first to the questions, and then the carer. Another expected difficulty was that people living with dementia or their carers were reluctant to express a weakness of the intervention involving the other member of the dyad. To avoid this to happen, participants were encouraged to provide any confidential comment directly to the researcher (either in the same home-visit or contacting the researcher later, as they were provided with her details). Similarly, the fact that the researcher had been in contact with them during their participation in the study and encouraging them to inform of what was working well and not so well, should have facilitated the expression of intervention's weaknesses.

In terms of the role of the researcher in the dyadic interview, it was anticipated that she would need to moderate the conversation in order to ensure data collection from both participants. In this respect, a further description of the role taken by the researcher during the dyadic interviews is provided in Data Collection section of Chapter 3.

Qualitative Interview Schedule

Before starting the interview

- ✓ Allow time for informal conversation.
- ✓ Test the recording equipment.
- ✓ Ensure consent form is signed by each member of the dyad:
 - To take part in the interview.
 - To be recorded.

Introduction

I would like to thank you for allowing me to come to your home to interview you. Just as a reminder, my name is _____ and I am a researcher at Bournemouth University.

Over the last months you have been taking part in the Tai Chi research project. We feel now that the best way to improve the classes and the Tai Chi practice at home is talking with you about your opinions and experiences. It is particularly important for us to understand what helped you to take part, but also what could be improved to make it easier. We also would like to know about your experiences of taking part together (name the dyad members). Even if you have not been able to attend all the classes or do the exercises at home, your views and opinions are still very valuable to us.

To learn from your experiences, I would like to interview you together. Is it OK with you? (Check consent). Your participation in this interview is voluntary, so if at any point you prefer not to carry on please feel free to stop the interview. We can also have a break during the interview if you wish.

The TACIT research team values your opinions and would like to hear them. Whatever you say in this interview it will be confidential and used only for this research project. I will record this interview, and have it transcribed later to keep an accurate record of your views. If anything is recorded that could reveal your identity it will not be included in the written transcription which will be anonymised. If we use any quotes from your contributions in research conferences, publications or events, nothing that could identify you will be included. Is it OK with you to record this interview? (Check consent)

During this interview I will ask you a few questions. There are no right or wrong answers, just different opinions that we would like to hear, so please feel free to state what you really think, even if you disagree with each other. If you do disagree, please be respectful of the other's view.

This interview will last around an hour.

Are there any questions before we start?

EXPERIENCE OF TAKING PART IN TAI CHI**1. Tell me about your experience of taking part in the Tai Chi classes.**

[Prompt: Tai Chi classes pictures]

- Enjoyment:
 - What was good about the Tai Chi classes?
 - What did not work so well about the Tai Chi classes?
 - How did you feel just before attending every Tai Chi class?
 - Was there anything in particular that made you willing to attend the Tai Chi classes?
 - Was there anything in particular that made you reluctant to attend the Tai Chi classes?
- Participation:
 - What helped you to take part in the Tai Chi classes?
 - Did anything stop you from taking part in the Tai Chi classes?
 - How did you feel about taking part in a group activity?
- Improvements:
 - How could the classes be improved to make it easier for you to participate?
 - Length of the session?
 - Frequency?
 - Intensity?
 - Timing and venue?
 - Explanations, support and guidance (by the Tai Chi instructor)?

2. Tell me about your experience of doing the Tai Chi exercise at home.

[Prompt: Booklet]

- Participation:
 - What helped you to take part in the Tai Chi exercises at home?
 - Did anything stop you from taking part in the Tai Chi exercises at home?
- Enjoyment:
 - What did you like about the Tai Chi exercises at home?
 - What did you not like about the Tai Chi exercises at home?
- Home visit by Tai Chi instructor:
 - How did you feel about the home-visit by the Tai Chi instructor?
 - What made it particularly useful?
 - What could be done to make it more useful?
- Booklet:
 - How did you find the booklet as a guide to doing the Tai Chi exercises at home?
 - Was it easy to follow?
 - How could we improve it?
- DVD:
 - How did you find the DVD as a guide to doing Tai Chi exercises at home?

- Was it easy to follow?
 - How could we improve it?
 - Improvements:
 - How could the home exercises be improved to make it easier for you to participate?
- 3. How has your experience been of taking part in the Tai Chi exercise with your family/friend member?**
- (Person living with dementia) How did you feel being supported by your family member at home?
 - (Carer) How did you feel supporting your family member at home?
 - Have you noticed any change in your relationship since you started taking part in Tai Chi? Can you give examples?

EXPECTATIONS AND MOTIVATIONS

- 4. Many people find it difficult to carry on doing Tai Chi every week for several weeks. How would you describe the time you have invested in the Tai Chi exercise?**

[Prompt: class attendance]

- Have you been able to attend as many sessions as you wanted to?
- What, if anything, made it difficult for you to attend sometimes?
- What helped you keep going every week?

[Prompt: log of Tai Chi practice at home]

- Have you been able to practise Tai Chi at home as frequently as you planned?
- What, if anything, made it difficult to practise Tai Chi at home sometimes?
- What helped you keep doing Tai Chi at home every week?
- What was it like completing the weekly exercise log (Tai Chi exercise at home)?
 - i. What was it about the weekly logs that made them useful?
 - ii. How could we improve the weekly logs?

[Prompt: Action and coping plans]

- How do you feel about the action plan that you did for practising Tai Chi at home?
- What things helped you keep to your plan?
- What things made keeping to your plan difficult?
- Person with dementia – Tell me about how you used your coping plan
- Carer – Tell me about how you used your coping plan
- Has your perception about Tai Chi changed since you started practising it? In what way?

- 5. If you had the chance to continue with the Tai Chi classes would you be willing to carry on with it?**
- Why? / Why not?

IMPACT**6. Have you experienced any change to your health and well-being since taking part in the Tai Chi exercise?**

- Have you appreciated any benefit from taking part in the Tai Chi exercise?
 - If yes, please explain. When did you notice it?
- Have you appreciated any consequences from taking part in the Tai Chi exercise?
 - If yes, please explain. When did you notice it?
- Has getting involved in this Tai Chi exercise stopped you from engaging in other activities you wanted to take part in?
 - If yes, Why? Which ones?
- Has getting involved in this Tai Chi exercise helped you to engage in other new activities?
 - If yes, Why? Which ones?

7. In the Tai Chi classes, you met with the Tai Chi instructor and other people. How would you describe your relationship with them?

- Are you willing to maintain this (those) relationship (s) after the research finishes?
- What things did the instructor do that was helpful?
- How could the instructor improve the classes?
- What things did other people in the class do that was helpful?
- How could we improve the classes so that people can better encourage each other in their home-practice of Tai Chi?

EXPERIENCE OF TAKING PART IN RESEARCH**8. Is there anything else you would like to let us know about your participation in the Tai Chi exercise?****9. Is there anything else you would like to let us know about your participation in the research project?****10. Do you have any questions you would like to ask me?**Conclusion

I would like to thank you again for letting me come into your house and for sharing your opinions with me. Your views will help us to understand your needs better and make the Tai Chi exercise appealing to more people.

If you have further questions or you want to share any information individually regarding the Tai Chi sessions or the research, please let me know now or by contacting me later if you have any other questions (provide Researcher's University e-mail and contact number).

At the end of the interview

- ✓ Seek verbal process consent.
- ✓ Check and secure recording equipment.

Engage in informal conversation if they wish to do so.

Appendix Q

Fidelity Checklist



The TACIT Trial



Tai Chi Class Fidelity Checklist

Tai Chi instructor name:

Week no. of the course:

Date and time of visit:	Observer:
Location of visit:	No. of attendees:

+ Please tick each box if evident during the 60min class:

7 core principles	
1. Safety: Those unsteady on their feet were encouraged to stand near support, particularly during dynamic movements	<input type="checkbox"/>
2. Tailoring: Instruction was tailored to each individual	<input type="checkbox"/>
3. Don't sit down: All were encouraged to stand for the class	<input type="checkbox"/>
4. Progression: All were encouraged to do more than last week	<input type="checkbox"/>
5. It's the taking part: People were invited into a friendly environment, to enjoy Tai Chi, and to do the form correctly	<input type="checkbox"/>
6. Home practise is key: All were encouraged to do Tai Chi at home 20mins daily, and the importance of this was emphasised	<input type="checkbox"/>
7. Socialising: All were asked to talk to each other at the end	<input type="checkbox"/>
Content	
The warm-ups corresponded with the week number	<input type="checkbox"/>
The Tai Chi forms corresponded with the week number	<input type="checkbox"/>
The winding-down corresponded with the week number	<input type="checkbox"/>
Record keeping	
The instructor kept a register	<input type="checkbox"/>
The participants handed in their exercise logs at the end	<input type="checkbox"/>

Notes

On completion, please securely forward to Samuel Nyman.



The TACIT Trial



Prompts for completing the notes section: Did the instructor...? (Stevens et al, 2013)

- Welcome participants?
- Engage participants to motivate and promote confidence?
- Explain the purpose of the exercises, relating them to postural stability and daily life?
- Demonstrate the use of observation and effective correction?
- Encourage interactive communication, to check or clarify understanding, with group and one to one?
- Give effective visual and verbal instructions?
- Change teaching position to improve observation and enhance communication?
- Speak clearly, audibly and at an appropriate pace?
- Reinforce the specific relevant teaching points at regular intervals?

Stevens, Z., Carpenter, H., Gawler, S., Belcher, C., Haworth, D., Kendrick, D., et al. (2013). Lessons learnt during a complex, multicentre cluster randomised controlled trial: The ProAct65+ trial. *Trials*, 14, e192. DOI: | <http://www.trialsjournal.com/content/14/1/192>.

Appendix R

Ethical Issues Considered for this Thesis

Before gaining ethical approval, the researcher had applied for her NHS passport, conducted several ethics trainings (i.e., Good Clinical Practice in Primary and Secondary Care, Ethics 1 & 2 modules from Bournemouth University) and created risk assessments forms for each of the research situations she was going to face along the study. Further ethical issues considered for this study included: a) Safe storage of research data, physical documents and materials (as multimedia and electronic devices) were stored in a locked cabinet at Bournemouth University premises. Electronic data were kept on password protected Bournemouth University devices. Data was only shared securely within the Research Team; b) Confidentiality and anonymising data to avoid personal data disclosure. Participants' names were replaced by a code and transcriptions were anonymised for further use in this thesis, conferences and publications. Audio recordings were sent for transcription via company's website using their secure password protected systems.

Additional ethical measures were in place during this study, learning from the experiences of researchers working with older people (Greenwood, 2009):

- a) Observation to the non-verbal communication of all participants to ensure they are willing to continue taking part in the study. Some might find it difficult to withdraw even when they are told they can do this at any point of the research process. In the focus groups and interviews, for instance, participants showing distress would have been asked for their willingness to continue or a pause would be considered (Braun & Clarke, 2013).
- b) Avoidance of certain terminology such as "carer" or "dementia", when possible participant's names will be used instead of their role or condition. Some participants can feel unrepresented by these terminologies, and it is important to preserve person's identity.
- c) Ending the research relationship in a progressive manner, allowing enough time after focus groups and interviews for informal conversation. For the home-based interviews in particular, time before the interview will allow to establish a good rapport, but also at the end of the interview time will be allocated to close this rapport. Should participants wish to contact the researcher after the focus groups and interviews, they will be encouraged to do so.

Appendix S

Ethical Approvals

S 1. REC approval letter

WoSRES
West of Scotland Research Ethics Service



Dr Samuel Nyman
Principal Academic
Bournemouth University
Dept. of Psychology & Bournemouth
University Dementia Institute
P515 Talbot Campus
Poole
BH12 5BB

West of Scotland REC 4
West Ambulatory Care Hospital
Dalnair Street
Yorkhill
Glasgow
www.nhsqgc.org.uk

Date 02 August 2016
Direct line 0141-232-1806
e-mail Wosrec4@ggc.scot.nhs.uk

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

Version 2: reissued as original letter was addressed to student rather than CI

Dear Dr Nyman

Study title: A randomised controlled trial comparing the effectiveness of Tai Chi alongside usual care with usual care alone on the postural balance of community-dwelling people with dementia

REC reference: 16/WS/0139
Protocol number: TACIT01
IRAS project ID: 209193

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Assistant Coordinator, Miss Sophie Bagnall, wosrec4@ggc.scot.nhs.uk.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Contract/Study Agreement [209193_Contract with NIHR 17.12.2015]	N/A	17 December 2015
Contract/Study Agreement [209193_TACIT draft Collaboration Agreement v1_15.06.16]	1.0	15 June 2016
Copies of advertisement materials for research participants [209193_PILOT TACIT flyer v1_15.06.16]	1	15 June 2016
Copies of advertisement materials for research participants [209193_RCT TACIT flyer v1_15.06.16]	1	15 June 2016
Covering letter on headed paper [209193_CI Cover Letter_15.06.16]	N/A	16 June 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [209193_Bournemouth insurance_clinical trials liability]	N/A	20 July 2015
GP/consultant information sheets or letters [209193_GP notification letter v1_15.06.16]	1.0	15 June 2016
Interview schedules or topic guides for participants [209193_Falls telephone interview with PWD v1_15.06.2016]	1.0	15 June 2016
Interview schedules or topic guides for participants [209193_Falls telephone interview with Carer v1_15.06.2016]	1.0	15 June 2016
Interview schedules or topic guides for participants [209193_Health service use telephone interview schedule (Fall) v1_15.06.2016]	1.0	15 June 2016
Interview schedules or topic guides for participants [209193_Safety monitoring telephone interview schedule v1_15.06.2016]	1.0	15 June 2016
Interview schedules or topic guides for participants [209193_Health	1.0	15 June 2016

Document	Version	Date
service use telephone interview schedule (Tai Chi injury) v1_15.06.2016]		
Interview schedules or topic guides for participants [209193_PILOT Focus Group interview schedule v1_15.06.2016]	1.0	15 June 2016
Interview schedules or topic guides for participants [209193_Qualitative interview schedule v1_15.06.2016]	1.0	15 June 2016
Interview schedules or topic guides for participants [209193_M-ACE Administration (UK Version B_25.05.2014)]	UK Version B	25 May 2014
Interview schedules or topic guides for participants [209193_M-ACE Administration (UK Version C_25.05.2014)]	UK version C	25 May 2014
Interview schedules or topic guides for participants [209193_RCT Exit interview v1_15.06.2016]	1.0	15 June 2016
IRAS Application Form [IRAS_Form_17062016]		17 June 2016
Letter from funder [209193_Award letter 21.08.2015]	N/A	21 August 2015
Letter from sponsor [209193 Confirmation of sponsorship 20.01.2015]	N/A	20 January 2015
Letters of invitation to participant [209193_PILOT Cover letter for PIS v1_15.06.2016]	1.0	15 June 2016
Letters of invitation to participant [209193_RCT Cover letter for PIS v1_15.06.2016]	1.0	15 June 2016
Non-validated questionnaire [209193_Demographic interview v1_15.06.2016]	1.0	15 June 2016
Other [209193_RCT_Control welcome letter_vl_15.06.16]	1.0	15 June 2016
Other [209193_RCT_Intervention welcome letter_vl_15.06.16]	1.0	15 June 2016
Other [209193_Joint action plan_v1_15.06.2016]	1.0	15 June 2016
Other [209193_Joint coping plan_v1_15.06.2016]	1.0	15 June 2016
Other [209193_Bournemouth insurance_employer liability]	N/A	20 July 2015
Other [209193_Bournemouth insurance-professionals indemnity]	N/A	20 July 2015
Other [Response to REC]	N/A	15 July 2016
Other [209193 Study Protocol_tracked changes]	2.0	13 July 2016
Other [209193 Study Protocol]	2.0	13 July 2016
Participant consent form [209193_PILOT Participant Informed Consent Form v1_15.06.2016]	1.0	15 June 2016
Participant consent form [209193_RCT Informed Consent Form v1_15.06.2016]	1.0	15 June 2016
Participant consent form [209193_Qualitative Informed Consent Form for interview v1_15.06.2016]	1.0	15 June 2016
Participant consent form [209193 Consent to contact form_v1_15.06.16]	1.0	15 June 2016
Participant consent form [209193 Consent to access MAS records_v1_15.06.2016]	1.0	15 June 2016
Participant information sheet (PIS) [209193_Qualitative Participant Information Sheet for interview v1_15.06.2016]	1.0	15 June 2016
Participant information sheet (PIS) [209193 Pilot PIS]	2.0	13 July 2016
Participant information sheet (PIS) [209193 Pilot PIS_tracked changes]	2.0	13 July 2016
Participant information sheet (PIS) [209193 PILOT Key Facts Sheet]	2.0	14 July 2016

Document	Version	Date
Participant information sheet (PIS) [209193 RCT PIS]	2.0	13 July 2016
Participant information sheet (PIS) [209193 RCT PIS_tracked changes]	2.0	13 July 2016
Participant information sheet (PIS) [209193 RCT Key Facts Sheet]	2.0	13 July 2016
Participant information sheet (PIS) [209193_PILOT Key Facts Sheet v2_14.07.2016_tracked changes marked]	2.0	14 July 2016
Participant information sheet (PIS) [209193_RCT Key Facts Sheet v2_14.07.2016_tracked changes marked]	2.0	14 July 2016
Referee's report or other scientific critique report [209193_Scientific Statistical Review 10.01.2015]	N/A	20 January 2015
Referee's report or other scientific critique report [209193_Scientific review 15.06.2016]	N/A	15 June 2016
Sample diary card/patient card [209193_Home Tai Chi Exercise Diary_v1_15.06.2016]	1.0	15 June 2016
Sample diary card/patient card [209193_Serious injury alert v1_15.06.2016]	1.0	15 June 2016
Sample diary card/patient card [209193 Falls Diary]	2.0	13 July 2016
Sample diary card/patient card [209193 Falls Diary_tracked changes]	2.0	13 July 2016
Summary CV for Chief Investigator (CI) [209193_CI_CV_Samuel Nyman]	N/A	01 May 2016
Summary CV for student [209193_Student_CV_Yolanda Barrado-Martín]	N/A	12 April 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [209193_Summary flowchart v1_15.06.16]	1.0	15 June 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [209193_PILOT Schedule of participant tasks_v1_15.06.2016]	1.0	15 June 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [209193 RCT Schedule of participant tasks_v1_15.06.2016]	1.0	15 June 2016
Validated questionnaire [209193_Ioon-FES (short)]		
Validated questionnaire [209193_ICECAP-O scale]		
Validated questionnaire [209193_Zarit Burden short form]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments

- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/WS/0139

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



On behalf of
Dr Brian Neilly
Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers"

Copy to: Dr Peter Phiri

West of Scotland REC 4**Attendance at Sub-Committee of the REC meeting in correspondence****Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mrs Laura Kenicer	Medicines Information Pharmacist	Yes	
Dr Brian Neilly	Consultant Physician	Yes	
Mr Iain Wright	Retired - Technical Manager	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Sophie Bagnall	Assistant Coordinator

S 2. HRA approval letter



Health Research Authority

Dr Samuel Nyman
Principal Academic
Bournemouth University
Department of Psychology and Bournemouth University
Dementia Institute
Faculty of Science and Technology
Talbot Campus
Poole
BH12 5BB
snyman@bournemouth.ac.uk

Email: hra.approval@nhs.net

14 September 2016 [Re-issued 21 September 2016]

Dear Dr Nyman

Letter of HRA Approval

Study title:	A randomised controlled trial comparing the effectiveness of Tai Chi alongside usual care with usual care alone on the postural balance of community-dwelling people with dementia
IRAS project ID:	209193
Protocol number:	TACIT01
REC reference:	16/WS/0139
Sponsor	Southern Health NHS Foundation Trust

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.

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- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

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If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is 209193. Please quote this on all correspondence.

Yours sincerely

Gemma Oakes
Assessor

Email: hra.approval@nhs.net

Copy to: *Dr Peter Phiri, Southern Health NHS Foundation Trust [Sponsor Contact & Lead NHS R&D Contact]*
peter.phiri@southernhealth.nhs.uk
Miss Yolanda Barrado-Martín, Bournemouth University [Student]
ybarradomartin@bournemouth.ac.uk
NIHR CRN Portfolio Applications Team
portfolio.applications@nihr.ac.uk

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Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	Version	Date
Contract/Study Agreement [209193_Contract with NIHR 17.12.2015]	N/A	17 December 2015
Contract/Study Agreement [209193_TACIT draft Collaboration Agreement v1_15.06.16]	1.0	15 June 2016
Contract/Study Agreement [Statement of Activities]	1	15 June 2016
Contract/Study Agreement [Schedule of Events]	1	15 June 2016
Copies of advertisement materials for research participants [209193_PILOT TACIT flyer v1_15.06.16]	1	15 June 2016
Copies of advertisement materials for research participants [209193_RCT TACIT flyer v1_15.06.16]	1	15 June 2016
Covering letter on headed paper [209193_CI Cover Letter_15.06.16]	N/A	16 June 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [209193_Bournemouth insurance_clinical trials liability]	N/A	20 July 2015
GP/consultant information sheets or letters [209193_GP notification letter v1_15.06.16]	1.0	15 June 2016
Interview schedules or topic guides for participants [209193_Falls telephone interview with PWD v1_15.06.2016]	1.0	15 June 2016
Interview schedules or topic guides for participants [209193_Falls telephone interview with Carer v1_15.06.2016]	1.0	15 June 2016
Interview schedules or topic guides for participants [209193_Health service use telephone interview schedule (Fall) v1_15.06.2016]	1.0	15 June 2016
Interview schedules or topic guides for participants [209193_Safety monitoring telephone interview schedule v1_15.06.2016]	1.0	15 June 2016
Interview schedules or topic guides for participants [209193_Health service use telephone interview schedule (Tai Chi injury) v1_15.06.2016]	1.0	15 June 2016
Interview schedules or topic guides for participants [209193_PILOT Focus Group interview schedule v1_15.06.2016]	1.0	15 June 2016
Interview schedules or topic guides for participants [209193_Qualitative interview schedule v1_15.06.2016]	1.0	15 June 2016
Interview schedules or topic guides for participants [209193_M-ACE Administration (UK Version B_25.05.2014)]	UK Version B	25 May 2014
Interview schedules or topic guides for participants [209193_M-ACE Administration (UK Version C_25.05.2014)]	UK version C	25 May 2014
Interview schedules or topic guides for participants [209193_RCT Exit interview v1_15.06.2016]	1.0	15 June 2016
IRAS Application Form [IRAS_Form_17062016]		17 June 2016
IRAS Application Form XML file [IRAS_Form_17062016]		17 June 2016
Letter from funder [209193_Award letter 21.08.2015]	N/A	21 August 2015
Letter from sponsor [209193 Confirmation of sponsorship 20.01.2015]	N/A	20 January 2015
Letters of invitation to participant [209193_PILOT Cover letter for PIS v1_15.06.2016]	1.0	15 June 2016
Letters of invitation to participant [209193_RCT Cover letter for PIS v1_15.06.2016]	1.0	15 June 2016
Non-validated questionnaire [209193_Demographic interview v1_15.06.2016]	1.0	15 June 2016
Other [Sponsor approval of Non-Substantial Amendment]		12 September 2016

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Other [209193_RCT_Control welcome letter_v1_15.06.16]	1.0	15 June 2016
Other [209193_RCT_Intervention welcome letter_v1_15.06.16]	1.0	15 June 2016
Other [209193_Joint action plan_v1_15.06.2016]	1.0	15 June 2016
Other [209193_Joint coping plan_v1_15.06.2016]	1.0	15 June 2016
Other [209193_Bournemouth insurance_employer liability]	N/A	20 July 2015
Other [209193_Bournemouth insurance-professions indemnity]	N/A	20 July 2015
Other [Response to REC]	N/A	15 July 2016
Participant consent form [209193_Qualitative Informed Consent Form for interview v1_15.06.2016]	1.0	15 June 2016
Participant consent form [209193 Consent to contact form_v1_15.06.16]	1.0	15 June 2016
Participant consent form [209193 Consent to access MAS records_v1_15.06.2016]	1.0	15 June 2016
Participant consent form [Pilot (Tracked Copy)]	1	15 June 2016
Participant consent form [Pilot (Clean Copy)]	1	15 June 2016
Participant consent form [RCT (Tracked Copy)]	1	15 June 2016
Participant consent form [RCT (Clean Copy)]	1	15 June 2016
Participant information sheet (PIS) [Pilot (Tracked Copy)]	2	13 July 2016
Participant information sheet (PIS) [Pilot (Clean Copy)]	2	13 July 2016
Participant information sheet (PIS) [209193_Qualitative Participant Information Sheet for interview v1_15.06.2016]	1.0	15 June 2016
Participant information sheet (PIS) [209193 RCT Key Facts Sheet]	2.0	14 July 2016
Participant information sheet (PIS) [209193_RCT Key Facts Sheet v2_14 07 2016_tracked changes marked]	2.0	13 July 2016
Participant information sheet (PIS) [209193 PILOT Key Facts Sheet]	2.0	14 July 2016
Participant information sheet (PIS) [209193 RCT PIS]	2.0	13 July 2016
Participant information sheet (PIS) [209193 RCT PIS_tracked changes]	2.0	13 July 2016
Participant information sheet (PIS) [209193_PILOT Key Facts Sheet v2_14 07 2016_tracked changes marked]	2.0	14 July 2016
Referee's report or other scientific critique report [209193_Scientific Statistical Review 10 01 2015]	N/A	20 January 2015
Referee's report or other scientific critique report [209193_Scientific review 15.06.2016]	N/A	15 June 2016
Research protocol or project proposal [(Tracked Copy)]	2	13 July 2016
Research protocol or project proposal [(Clean Copy)]	2	13 July 2016
Sample diary card/patient card [209193_Home Tai Chi Exercise Diary_v1_15.06.2016]	1.0	15 June 2016
Sample diary card/patient card [209193_Serious injury alert v1_15.06.2016]	1.0	15 June 2016
Sample diary card/patient card [209193 Falls Diary]	2.0	13 July 2016
Sample diary card/patient card [209193 Falls Diary_tracked changes]	2.0	13 July 2016
Summary CV for Chief Investigator (CI) [209193_CI_CV_Samuel Nyman]	N/A	15 June 2016
Summary CV for student [209193_Student_CV_Yolanda Barrado-Martín]	N/A	12 April 2016
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [209193_Summary flowchart v1_15.06.16]	1.0	15 June 2016
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [209193 PILOT Schedule of participant tasks_v1_15.06.2016]	1.0	15 June 2016

IRAS project ID	209193
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Summary, synopsis or diagram (flowchart) of protocol in non-technical language [209193 RCT Schedule of participant tasks_v1_15.06.2016]	1.0	15 June 2016
Validated questionnaire [209193_Icon-FES (short)]		
Validated questionnaire [209193_ICECAP-O scale]		
Validated questionnaire [209193_Zarit Burden short form]		
Names of Participating NHS Organisations		13 September 2016

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Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.*

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Dr Peter Phiri (Tel: 02380 475 112, peter.phiri@southernhealth.nhs.uk)

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	IRAS [A2-1] does not include the details of PHD Student 2. Once the student has been named, submission of an amendment is required. IRAS [Part C] does not include the details of the participating NHS organisations. An email dated 12 September 2016 detailing the sites has been supplied.
2.1	Participant information/consent documents and consent process	Yes	No Comments.
3.1	Protocol assessment	Yes	No Comments.
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A Statement of Activities and Schedule of Events has been provided, however the Sponsor has indicated that a modified Collaboration Agreement will be used as the agreement between the sponsor and participating NHS

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Section	HRA Assessment Criteria	Compliant with Standards	Comments
			<p>organisations in England.</p> <p><u>Rationale for not using mNCA</u> Bournemouth University has engaged all parties including the Sponsor in a collaboration agreement in association with the NIHR contract that has funded this project (awarded to Bournemouth University). Bournemouth University has also engaged the Sponsor and the Clinical Trials Unit in a task allocation matrix that clarifies the roles and responsibilities of each organisation.</p> <p>A copy of the collaboration agreement has been provided.</p>
4.2	Insurance/indemnity arrangements assessed	Yes	<p>University of Bournemouth Insurance Certificate dated 20 July 2015 expired on 31 July 2016.</p> <p>Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study.</p>
4.3	Financial arrangements assessed	Yes	<p>The study is funded by the NIHR (NIHR Carer Development Fellowship).</p> <p>The sponsor has confirmed that funding will be provided to participating NHS organisations, as detailed in the Collaboration Agreement.</p>
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No Comments.
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No Comments.
5.3	Compliance with any	Yes	No Comments.

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Section	HRA Assessment Criteria	Compliant with Standards	Comments
	applicable laws or regulations		
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	Following REC review a non-substantial amendment was submitted and the updated documentation has been listed in Appendix A (above).
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No Comments.
6.3	Devices – MHRA notice of no objection received	Not Applicable	No Comments.
6.4	Other regulatory approvals and authorisations received	Not Applicable	No Comments.

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is one site type participating in this study. Study activity is the same at all participating NHS organisations as detailed in the **modified** Collaboration Agreement (provided).

Please note that the remit of HRA Approval is limited to the NHS involvement in the study. Research activity undertaken at non-NHS sites is therefore not covered and the research team should make appropriate alternative arrangements with relevant management at these organisations to conduct the research there.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England that are will be expected to formally confirm their capacity and capability to host this research.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The [Assessing, Arranging, and Confirming](#) document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

The sponsor has confirmed that a Local Principal Investigator would be required at each participating NHS organisation and these have already been identified.

The sponsor has confirmed that the Local Principal Investigator and his/her team will receive training from the Chief Investigator in how to facilitate recruitment into the study. This will be an information session held at the local site along with the provision of standard operating procedures for the study.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

It is not expected that local staff carrying out research activities will require access arrangements.

Research staff carrying out research activities (delivering tai chi intervention) on NHS premises that do not have contractual arrangements in place with the site, are expected to have an Honorary Research Contract. DBS/Occupational Health checks are required where an Honorary Research Contract is expected.

Research staff carrying out research activities (accessing identifiable data) that do not have contractual arrangements in place with the site, are expected to have an Honorary Research Contract in place. No DBS/Occupational Health Checks are required where an Honorary Research Contract is expected.

Research staff carrying out research activities (accessing anonymised data) that do not have

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contractual arrangements in place with the site, are expected to have a Letter of Access in place. No DBS/Occupational Health Checks are required where a Letter of Access is expected.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

- The applicant has indicated that they intend to apply for inclusion on the NIHR CRN Portfolio.
- The applicant has confirmed that the Tai Chi DVDs will be provided by the Tai Chi instructions directly to the participants.

S 3. BU ethics checklist



Research Ethics Checklist

Reference Id	12811
Status	Approved
Date Approved	15/09/2016

Researcher Details

Name	Samuel Nyman
School	Faculty of Science & Technology
Status	Staff
Course	Staff
Have you received external funding to support this research project?	Yes
RED ID	8535
Funding Body	NIHR
Please list any persons or institutions that you will be conducting joint research with, both internal to BU as well as external collaborators.	Institutions: Southern Health NHS Foundation Trust, Dorset HealthCare University NHS Foundation Trust, Elemental Tai Chi, Alzheimer's Society, University of Southampton, Royal Bournemouth & Christchurch Hospitals NHS Foundation Trust, University of Plymouth; BU staff: Peter Thomas, Sarah Thomas, Helen Allen; BU PhD students: Yolanda Barrado-Martin and Iram Bibi

Project Details

Title	The TACIT Trial: TAI CHI for people with demenTia
Proposed Start Date of Data Collection	03/10/2016

Proposed End Date of Project	01/06/2018
Original Supervisor	
Approver	Research Ethics Panel

Summary - no more than 500 words (including detail on background methodology, sample, outcomes, etc.)
Please see attached

External Ethics Review

Does your research require external review through the NHS National Research Ethics Service (NRES) or through another external Ethics Committee?	Yes
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Please ensure that the researcher obtains external ethical approval before commencing research.

Researcher Statement

JOURNALISM / BROADCAST RESEARCHERS: I confirm that I have consulted and understand the Research Ethics Supplementary Guide: For Reference by Researchers Undertaking Journalism and Media Production Projects (available on the Research Ethics page)	Yes
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Appendix T

Qualitative Interviews Participant Information Sheet and Consent Form

T 1. Participant information sheet



The TACIT Trial: TAI CHI for people with demenTia



PARTICIPANT INFORMATION SHEET FOR HOME INTERVIEWS

Thank you for taking some time to read this information sheet. I am a postgraduate researcher supervised by Dr Samuel Nyman at Bournemouth University. As part of the TACIT Trial's research team, I am interested in understanding what it is like for people taking part in this project.

If you have any questions about this study please contact:



Researcher: Yolanda Barrado-Martín

E-mail: ybarradomartin@bournemouth.ac.uk

Tel: 01202 962213

What is it like for people with dementia and their carers to do Tai Chi?

We want to know what it is like for people with dementia and their carers to do Tai Chi. To do this we are interviewing a number of participant pairs (a person with dementia and their carer) who have been through the TACIT Tai Chi programme to see how they got on. Your feedback will help us to understand how we might improve the Tai Chi program for other people in a similar situation. If you think that both you and your informal carer might be interested in giving us some detailed feedback in an interview with the researcher, then please read on....

SOME KEY POINTS...

- It is entirely up to you whether or not to take part in this interview. If you decide to take part but change your mind later on, that's fine - you can withdraw at any time along the interview and up to the point where the data are transcribed and made anonymous, so your identity cannot be determined. Your usual medical care will continue unaffected whether you take part or not and you will be able to keep taking part in the TACIT Trial.
- If you choose to take part the researcher will visit you at home or another suitable location on one occasion for a joint interview (you and your informal carer). Should you not wish to answer any particular question, you are free to decline. This interview will be audio-recorded to help remember what you say.

Who can take part in the interview?

This interview, as with the main TACIT Trial, relies on recruiting participants in pairs. Each pair will have a person with dementia and their informal carer. Due to time and resources restrictions, we are not able to interview all the participants taking part in the trial. For this reason, we will offer 10 - 15 pairs of participants the opportunity to take part in an interview, trying to reflect as many different points of view as possible.

Why do you want to hear my opinion?

We know many people find it difficult to carry on doing Tai Chi every week for several weeks, so we would like to explore why and how we could make this easier. Similarly, some other people find this easier than others, and their views will help us to promote those aspects that they find important.

Do we have to take part?

No - participation is entirely voluntary, and it is completely up to you to decide. If you choose not to take part in this research project, your on-going treatment will not be affected in any way and you will be able to keep taking part in the TACIT Trial whether or not you decide to do this additional home interview.

Even if you do decide to take part, you can choose to withdraw from the interview at any time and from this research project up to the point where the data are processed and made anonymous, so your identity cannot be determined. If you want to withdraw from this research project the researcher will ask for a reason, because this helps us improve the way we do studies. However, you do not have to give a reason if you do not want to.

What happens if we decide to take part?

The researcher from the TACIT team will arrange to visit you at home or at another suitable location for an interview. It is important that both the person with dementia and the carer are present for this interview. Initially we would like to interview you together, however, you will be asked if you agree with this or prefer to be interviewed individually before starting the interview.

The researcher will explain the research project and answer any questions you have. Provided you are willing to continue, the researcher will ask you both to sign a consent form. After you have signed the consent form, the researcher will ask you some questions about your experience of participating in the TACIT Trial. They will ask questions about participating in the Tai Chi classes, practising Tai Chi at home, and your experience of taking part in the TACIT Trial. Should you not wish to answer any particular question, you are free to decline. The interview will take around an hour to complete and will be audio-recorded. This audio-recording will be typed up into written form, anonymised (so your identity cannot be determined) and then analysed. Please note that, if you smoke, you will be asked not to do so in presence of the researcher. Also, if you have pets at home, you will be asked to keep them in a separate room during the visit.

What are the benefits of taking part?

We cannot say that you will benefit from taking part. You will be helping us to understand the needs of people living with dementia, and their carers, when doing Tai Chi. You might find sharing your opinions beneficial in itself.

What are the risks and disadvantages of taking part?

We do not foresee any major risks in taking part in the interview. You could find it difficult to talk about your experience of taking part in Tai Chi with your Tai Chi partner when you will be together in the interview. If this were the case, you will be able to add any comments individually if you wanted to at the end of the interview or contact the researcher at a later stage to add any other comments.

The small print

Research studies are strictly regulated, and it is important to understand all the implications of your participation. The following sections may be a little tedious, but please read through and contact us if you have any questions.

Will our taking part in the study be kept confidential?

If you decide to take part, all information collected about you will be kept strictly confidential. Data will be stored and analysed by Bournemouth University, and paper copies kept in locked filing cabinets and electronic records held on secure university computers.

Will the study information be used to help with other research?

It is important that good quality research data can be shared with others to advance clinical research and to benefit patients in the future. After the end of the study, de-identified information collected during the study will be made available to other researchers under an appropriate data sharing agreement. It will not be possible to identify you personally from any information shared.

What happens when the research study stops? Will I find out the results?

Once your participation in the study has ended, your usual care will continue as before. When every participant has completed the TACIT Trial, we will prepare the study results (this normally takes several months) and send you a summary of the findings.

This summary will contain the main TACIT Trial results and what we have learnt from conducting these interviews. Results from this research project may be presented at national and international conferences and published in medical journals but you will not be identified in any information included in any presentation or publication.

What if there is a problem?

Complaints:

If you have a concern about any aspect of this study, please speak to researcher in the first instance (see box on page 1). If you remain unhappy and wish to complain formally, you can do this by making a complaint with the

Chief Investigator for the TACIT Trial, who is also the PhD supervisor, Dr Samuel Nyman.

E-mail: snyman@bournemouth.ac.uk

Telephone (via Michelle O'Brien, administrator): 01202 962771

Address: Department of Psychology, Bournemouth University, Poole House, Talbot Campus, Fern Barrow, Poole, Dorset, BH12 5BB.

Harm:

We don't expect any harm to come to you as a result of participating in this interview. If you are harmed and this is due to someone's negligence, then you may have grounds for a legal action for compensation against Bournemouth University, but you may have to pay your legal costs. There are no special compensation arrangements in place.

Who is organising and funding this research?

These interviews are being conducted as part of a PhD studentship, which is funded by a National Institute for Health Research (NIHR) Career Development Fellowship awarded to the PhD supervisor, Dr Samuel Nyman.

Who has reviewed this study?

All NHS research is looked at by an independent panel of experts and lay members (a Research Ethics Committee). The study has been reviewed and given a favourable opinion by the *West of Scotland REC 4 - 16/WS/0139*. The study has also been reviewed and approved by the NHS Health Research Authority whose primary role is to protect and promote the interests of patients and the public in health research.

Thank you for considering taking part in the study and taking the time to read this information leaflet

T 2. Consent form



The TACIT Trial



Participant Pair Informed Consent Form

Study Title: The TACIT Trial: TAI ChI for people with demenTia.

Researcher: Yolanda Barrado-Martín.

Supervisor: Dr Samuel Nyman.

Please **initial** each box

	Participant	
	1	2
I have read the information sheet version 1.0 dated 15.06.2016 for this study. I have had time to consider the information and have had any questions answered satisfactorily.		
I understand that my participation in this interview is voluntary and that I am free to withdraw at any time. I also understand that my usual medical care and participation in the main TACIT trial will continue unaffected whether I decide to take part or not in this interview. I understand that if after the interview I decide I do not want my information to be used, I can only request this before the data is transcribed and made anonymous.		
During the interview, which may take place in my home, I am free to withdraw without giving any reason.		
I am free to decline to answer any particular question.		
I give permission for members of the research team to have access to my anonymised responses. I understand I will not be identifiable in any results that are published.		
I understand that the information collected in the interview will be used to support other research in the future and may be shared anonymously with other researchers.		
I agree to be audio-recorded during the interview.		
I agree to take part in the above study.		



The TACIT Trial

ADRC
Ageing & Dementia
Research Centre
Bournemouth University

Participant Pair Informed Consent Form

_____	_____	_____
Name of participant 1 (person with dementia)	Date	Signature
_____	_____	_____
Name of participant 2 (carer)	Date	Signature
_____	_____	_____
Yolanda Barrado-Martín	Date	Signature

Appendix U

Author's Background

Academically, I did a BSc (Hons) in Psychology followed by some post-graduate training in prevention of cognitive impairment and an MSc in Geropsychology. I did all my training in Barcelona, Spain, where I acquired most of my clinical experience working with older people with and without dementia in a large senior citizen, day care and care home centre. Before my MSc, however, I did gain some caring experience in a UK care home over a summer break. After finishing my MSc, I also delivered memory training courses amongst older adults in Barcelona with the Red Cross and worked as Research Assistant both at the University of Barcelona and at Bangor University (UK). In Bangor, I worked on the “Dementia and Imagination” project, where the impact of art in people living with dementia’s QoL was studied.

Personally, I have always felt close to older people, perhaps due to the fact of being the youngest of the family for long and part of my family’s origins coming from a rural (and ageing) locality in Spain, where I used to spend most of my summer holidays as a child. Being the younger of the family for long, I have also experienced my grandparents’ ageing process and, regrettably, their loss; with two of them having received a diagnosis of dementia. One of them was diagnosed Alzheimer’s type and, the other one with the wrongly called “senile”, which I was quite sure it was, considering its progression and symptomatology, Vascular type. Even when my granddad was only diagnosed Alzheimer’s when I was 10, I very well remember the start and progression was radically different, from my grandmother’s. Similarly, I remember how I felt when he was told not to keep attending the day care centre as he was breaking his peer’s paintings. At that time something felt wrong, as a kid who does not behave at school and it is punished to stay home. I remember feeling surprised of day care centre professionals could not being able to handle this situation, when at home was mostly quiet and “disconnected” from reality. Considering my current experience, the situation would have probably benefited from a person-centred approach to try and suggest activities more relevant to his life story than “painting for all”. My grandmother’s dementia progressed very differently, with her “self” preserved by herself for longer, and more “connected” throughout with us, at least verbally. However, the family acceptance of the diagnosis was harder, as the caring needs, and caring time was also longer. Hence, apart from my professional experience, I also have the personal experience of dealing with two very different journeys of dementia. Hence, the motivation to do research in dementia and working with people living with dementia,

comes from this inner need to contribute more than I could at my grandparents' time to help others going throughout this journey with as much dignity and QoL as possible. My personal approach to work then is to treat people living with dementia as I would have liked my grandparents to be treated by professionals at their time, and how I would like to be treated if one day I am also diagnosed and there is no cure yet.

In terms of Tai Chi, I must admit I started my PhD knowing very little about it and its benefits, apart from its origins and assuming a positive effect on health as exercise in general does. Similarly, I must admit that despite my awareness and defence of the Latin phrase "*mente sana in corpore sano*", I have not generally been involved in regular exercise practice, not even when I have been living opposite to a gym (and being registered) for many years. Instead, I have tried to preserve my health paying more attention to follow a Mediterranean diet and avoiding risk behaviours (i.e., smoking). However, I very much admire people with the perseverance to sustain exercise practice and would like to find an exercise that motivates enough. Hence, I started this research assuming some people would find it easier than others to adhere to the Tai Chi, and that any barriers identified would help the TACIT Trial and future exercise interventions to meet better the needs of those who struggle more.

Appendix V

Coding Differences

Researcher 3 (supervisor) coded an interview using the Analysis Framework designed after the Pilot Intervention Phase (see Table V 1) and its corresponding codebook. After coding one interview, the level of agreement in coding was low (see Table V 2 for an example of the coding mismatch), this basically due to initial codes were too broad, and author having coded mostly against only one code, instead of several possible, which made more sense. Hence, author decided to re-start data coding, using an inductive approach and coding more narrowly. This would make the list of initial codes longer (as in the Pilot Intervention Phase), but also facilitate the identification of quotes that would need to be coded in more than one occasion (according to a more explicit way of coding). Later it would still be feasible to see the similarities between codes and see higher relationships. This thesis' author realised the need for coding this way might be related to her way of thinking, which might be different from Researcher 3's. However, this way of coding from the narrower to the broader worked for both researchers during the Pilot Intervention Phase, even if it was harder to remember to code a quote to several codes.

Table V 1. *Analysis Framework*

Dyads' experiences in the RCT Phase	Overarching Themes	Themes
	Motivation & SDT	1. Motivations to take part 2. Motivations to carry on
	Taking part in the Tai Chi exercise intervention	3. Intervention's characteristics 4. Participants' reactions to the classes 5. Participants' reactions to home-practice 6. Impact & fidelity
	Getting involved in research	7. Research Process
	Miscellaneous	8. Miscellaneous

Table V 2. *Example of Mismatch Between Coders When Using the Analytical Framework*

Example quote	Author's notes to Researcher 3's double coding
<p>Researcher 1 you have mentioned that it was good to, to, to join with other people, how do you feel about the, the size of the...of the group? 03005P Well our group was lovely but, I mean, they could have taken up to five sets. Researcher 1 Five dyads maybe or...? 03005P Five clients, yeah, but no more. Because, um, the help that <Instructor 1> gave us individually that would have lessened wouldn't it?</p>	<p>I understand that checking the codebook I should have coded this as intervention's characteristics as they are talking about the size of the group. However, I would also leave my initial code (Participants' reactions to the classes) as they not only mention the size of the group but how "lovely" their group was. So, after revision, I will add this code to intervention's characteristics.</p>

Appendix W

RCT Phase’s Codebook

Table W 1. RCT Phase: Codebook

Name	Description	Example Quotes	Resources	References
1. Motivation and Impact	INCLUDE a) Any reasons provided by participants to decide to take part in Tai Chi and continue practising Tai Chi during their involvement in the study; b) Any comments/notes regarding who made the decision to take part or carry on with the practice (i.e., was the participant who made this decision or there was somebody else pushing them to do so?) and; c) any references to the impact of the intervention on participants.		36	454
1.1. Previous Exercise Experience	INCLUDE references to previous exercise experience such as going to the gym, playing any sport, but also references to physical activity. EXCLUDE and code in child node references to no previous exercise experience.	<i>He (03003P) was a footballer and a bowler, and he was always sport, I've never done it. (03003C-1).</i>	21	36
1.1.1. No Exercise Experience	INCLUDE references to not having previous experience of practising exercise.		7	8
1.2. Motivations to Take Part	INCLUDE any reasons that moved the participants to be willing to take part in the Tai Chi intervention. Include their previous exercise experience. EXCLUDE any references to their motivations to carry on practising Tai Chi over the course of their participation in the classes/home-practice.	03005C and 03005P comment “We were very interested in Tai Chi” and that they were interested before knowing about this study. When they knew about the project through the NHS, they thought it would be good for both. They think it can be of help and they had anyway always been interested in doing Tai Chi. (03005-FB).	25	55
1.3. Motivations to Carry On	INCLUDE any reasons that moved the participants to carry on practising Tai Chi over the course of their participation in the classes/home-practice; the reasons that made them willing to attend the next class, feelings before going to the session and participants' feelings about the time they have invested or are investing in practising Tai Chi in class and/or at home. EXCLUDE reasons regarding their initial motives to take part when they had not started practising.	<i>Really impressive last lesson. Both <01021C> and <01021P> intend to carry on with Tai Chi practice. (Instructor 1 -FB).</i>	28	186
1.4. Interventions' Impact	INCLUDE references to the impact appreciated (in terms of harms/benefits) since participating in Tai Chi, the impact of Tai Chi experience's hindering/facilitating participants' involvement in further activities, and participants' willingness to keep relationships developed during Tai Chi classes.		28	177

Name	Description	Example Quotes	Resources	References
1.4.1. Dyadic participation	INCLUDE here general references to their dyadic participation in the study, including if they felt any impact in their dyadic relationship since their involvement in Tai Chi together. EXCLUDE references to one participant practising better than the other.	01012P-I <i>Well, <01012C>, <01012C> picks me up because I don't drive. And we tootle over there, and get on with the game, and come back. And we, we usually go for lunch somewhere.</i>	16	46
Competition and Comparisons Between members	INCLUDE references to carer or people living with dementia comparing their performance with the other member of the dyad or with other participants.	01012C-I <i>I don't think it's changed [or relationship], had an, an effect on our relationship. But it, it is nice to have something we do together, you know, apart from just go out for lunch, or shopping.</i> 01012P-I <i>And also, to be competitive, and who's getting on the fastest [laughter].</i>	5	10
1.4.2. Tai Chi Benefits	INCLUDE references to benefits experienced or attributed to practising Tai Chi. EXCLUDE but include in child node other activities participants might have joined in after joining the Tai Chi class.	<i>...I...I should have felt better, but I'm...I'm always well anyway. I'm one of those lucky people. (03006C-I).</i>	20	88
Facilitated Activities	INCLUDE further activities participants joined due to taking part in Tai Chi.	<i>Yeah, we were gonna try that Friday thing, I think <01045C> and <01045P> have been once. And we're gonna try to go there together. (01036C-I).</i>	14	15
1.4.3. Tai Chi Harms	INCLUDE references to harms experienced and potentially attributable to Tai Chi practice. EXCLUDE, but include in child node any hindered activity due to participants' engagement in the Tai Chi classes.	<i>No. No harm at all. Just get on with it and do it. If it hurts don't do it. But so far touch wood and whistle [whistles] been all right. (01002P-I).</i>	15	35
Hindered Activities	INCLUDE references to other activities participants had to stop practising or where affected in a way due to their participation in Tai Chi (both in their home and class-practice).	<i>[laugh] it's stopped us...er, er, it may...may have reduced the amount of time we sit around watching TV, in my case, which is jolly good and I'm sure that <01008P> ...<01008P> will have been busy doing something, gardening, pottering around with plants or whatever. But yes, I'm sure it's done us good overall. (01008C-I).</i>	15	18
2. Taking part in the Tai Chi exercise intervention	INCLUDE any references to participants' experiences practising Tai Chi in the classes or at home, as well as to any reactions to the design or delivery of the intervention in both settings. EXCLUDE any references related with their participation in research, but not strictly with their involvement in the intervention (i.e., experiences undergoing baseline home-visits or weekly falls calls).		174	1394
2.1. Experiences of the Classes	INCLUDE references to participants involvement in the classes, such as observed responses to the interventions (i.e., verbal and non-verbal communication amongst participants or with the instructor, enjoyment, (dis) engagement, affect); as well as participants' feelings towards the classes and their relationships with others in the class. EXCLUDE references to their dyadic participation.		174	1070
2.1.1. Practicalities of the	INCLUDE here references describing the characteristics of the venue, timing, length, size of the groups, instructors (' home-visits), or		77	346

Name	Description	Example Quotes	Resources	References
Classes	participants' reactions to the design (i.e., to the session structure) or characteristics of this intervention that go beyond the home or class-based practice (i.e., dyadic participation). EXCLUDE references regarding to participants' reactions specifically related to their class or home-practice and to the intervention's impact in term of harms/benefits experienced.			
Frequency	INCLUDE here references to the frequency of the classes or the number of classes in the course. Include also if participants express any preference for more or less frequent sessions.	<i>But, you know, one...one a week, I don't know, maybe it's enough for some people, maybe two. You could have an option to go to more maybe or something like that. (03008C-I).</i>	14	19
Intensity - Difficulty	INCLUDE here references to the intensity or difficulty of the classes, including if participants felt it was or was not enough for them.	<i>Well, I...I thought they were very good [intensity wise] but my capabilities in...in those Tai Chi classes was very limited. (02002P-I).</i>	19	29
Length	INCLUDE references to the length of the classes, and also if participants would have preferred longer or shorter classes. Include here as well, the impact of the sessions being 45 minutes long.	<i>Oh, the...the time didn't really bother me, it didn't seem that long. Er, we were quite surprised you said that because I would have said it probably was about half an hour. But looking back...but it was probably...it was longer, as <03008C> says, so it didn't...it wasn't, um, what's the word, boring or anything... (03008P-I).</i>	14	18
Session structure	INCLUDE references to the structure of the session. EXCLUDE references to the teaching style of the instructors.	<i>Er, and I... I mean, <Instructor 1> does move on the chatty bit at the beginning so she's anxious that people aren't sitting round chatting at the beginning, the time is devoted to the lesson which I'm happy with. (01002C-I).</i>	27	28
Group Size	INCLUDE references to the size of the groups, including the advantages and disadvantages of small and large groups, the ideal size of the group or the varying numbers in participants' classes. Add here as well, references to the concern of the small numbers in certain groups and participants' feelings.	03006C comments with the instructor that 03006P was saying to her this morning that he was worried that "if people don't turn up to the classes, these will be stopped before 20 weeks". Instructor 1 reassures both of them and ensures that there will be 20 weeks of classes. (03006C-FB).	12	32
Social Side of the Classes	INCLUDE references to the socialising component of the intervention, to the presence or lack of this component and improvements suggested; to the (dis) enjoyment of this component, and any reference to participants' relationships with others in the class.	<i>It's nice, you know, to chat with other people. (01045P-FB).</i>	51	118
Relationships Maintenance	INCLUDE references to participants willingness or unwillingness to maintain their relationships with others in their group after their involvement in the study.	<i>I would like to think so, yes [to maintain the relationships]. Certainly, with one couple but <03003C> and <03003P> who are in <03003's local area>, I can't imagine that we would, but <03006C> and <03006P> who are here I hope we will. (03005P-I).</i>	15	16

Name	Description	Example Quotes	Resources	References
Timing	INCLUDE references related to the time the class took part, including positive and critical comments regarding this. Include comments regarding the day of the week when the classes took place.	<i>But for, er, old fogeys like us, we like to get home a bit earlier before half past six in the evening. Am I right?</i> (01008P-I).	13	19
Venue	INCLUDE positive, neutral and negative comments regarding venues' characteristics (i.e., flooring, car park, etc.). Include also any suggestions of improvement.	<i><01009P> and <01022P> sat out some of the class due to the previous class leaving heating too high. This will be rectified for the next class.</i> (Instructor 2 -FB).	65	83
2.1.2. Instructors' Characteristics	INCLUDE any references to the characteristics of the instructors. EXCLUDE references related to instructors' communications with participants during the classes.		92	360
I1 Communication with Participants	INCLUDE references to Instructor 1's communication with the participants and any observed reaction/response of the participants to this way of communicating. Add here references to feedback provided to the participants, corrections made to the participants and instructions provided to the participants.	"Bring your pelvis back a little bit <03006P>"- "you're doing it less I see you've been practising this at home"-instructor 1 approaches participant to correct pelvis posture after two verbal corrections. (Observations).	45	154
I1 Teaching Style and Personality	INCLUDE here comments regarding Instructor 1's teaching style and characteristics. Including strengths, weaknesses and areas of improvement. Include participants' feelings regarding her corrections.	<i>She...she knows that his health's ...not great, and very often as soon as we walk in the door, she'll say, oh, I've put a chair there in case you want to sit there, and she is brilliant. She really is brilliant.</i> (03006C-I).	12	38
I2 Communication with Participants	INCLUDE references to Instructor 2's communication with the participants and any observed reaction/response of the participants to this way of communicating. Add here references to feedback provided to the participants, corrections made to the participants and instructions provided to the participants.	Instructor 2 keeps providing positive feedback after pattern one: "wonderful, good", "good start, lovely form", and reinforcing home-practice: "it's so good when you practise at home, because you do my work much easier". (Observations).	30	136
I2 Teaching Style and Personality	INCLUDE here references to Instructor 2's (leading Instructor) instructional methods and characteristics. Including strengths, weaknesses and areas of improvement. Include participants' feelings regarding his corrections.	<i>He'll gently tell you if you've got your, something not quite right, he'll gently tell you, no, you just do it this way. Or, erm, and he's, he's very good, actually, at making sure that people don't fall. And if, you know, he has the chairs for people... to be able to hang onto, if they're beginning to feel...he, he's very caring.</i> (01009P-I).	10	32
2.1.3. Participants' Reactions	INCLUDE verbal and non-verbal expressions of (dis) enjoyment, (dis) engagement or affect shown during the classes, experienced before going to the classes, or when reporting about the classes. Include also Instructors' feedback around participants' engagement in the classes.		84	143
Participants' Distribution	INCLUDE references to participants positions at the beginning and during the classes.	Instructor 1: "Can you move back a little bit, so we avoid colliding <01021P>" (Observation). Instructor is as usual in front of the participants (leaving the	50	61

Name	Description	Example Quotes	Resources	References
		mirrors at her back), in each end of the first row 02004P (on the right-hand side of the instructor) and 01002P (on the left-hand side of the instructor). In the second row, more centred are 02002C (centred and towards the right-hand side of the instructor) and 01002C (centred and towards the left-hand side of the instructor – behind 01002P). (Observations).		
Participants' Interaction	INCLUDE references to participants' verbal or non-verbal communications during the classes, including looking at other participants.	01036P "Oh, I did it wrong!" (in the opposite direction) - Instructor 2 responds "No worries" and looking to the rest of participants adds "at least she recognises this". (Observations).	59	193
Participants' Performance	INCLUDE references regarding participants' way of performing the movements during the classes.	03005C Finishes one of the movements before the instructor and then instructor 1 adds "One more". Laughs whilst instructor 1 demonstrates warm up number 4 (is it because he thinks it's complicated?). Coughs, but carries on practising. (Observations). 01023P and 01025P seem not to be doing the lifting up the heel as instructed. Instructor 2 makes a general correction and 01023P and 01025P lift their heels - Instructor 2 reinforces "that's it 01025P!" (Observations).	69	217
2.1.4. Class Barriers	INCLUDE references to barriers, weaknesses or difficulties faced by participants or observed by researcher/instructor that could be impacting on participants' attendance or engagement during the classes.	<03008C> again I felt was slightly overbearing with her mum <03008P> and I feel that can be distracting for her as she is trying to watch me as <03008C> is stood right in front of her. (Instructor 1-FB).	35	86
2.1.5. Class Facilitators	INCLUDE references to facilitators or strengths of the intervention that could have facilitated dyad's attendance to the classes or their engagement during the classes. Include participant, researcher and instructors' views.	Instructor 2 mentions it was great to see that only after one class 01006P changed his mind as before the first class was a bit sceptical. After this class he expressed he could feel all the work. (Instructor 2-FB).	29	98
2.1.6. Classes' Suggested Improvements	INCLUDE improvements suggested for the classes i.e., to better encourage participant's home-practice.	Well you could...if you added on the...this fifteen minutes where you sat down with a cup of coffee and had a general chat, then that would...you could find out if they do their home exercises and...and encourage them to do it or whatever. Um, and I think it...it does boil down to this...this extra social contact... because while we're doing our exercises, there's no social contact at all. So, it's just the few minutes before and the few minutes after. (01022C-I).	15	37
2.2. Experiences of the Home-Practice	INCLUDE references to participants' experiences during their home-practice, the results of home-practice, the way they practise at home and any barriers/facilitators to their continued practice at home. EXCLUDE references to their dyadic participation (unless they explicitly		35	324

Name	Description	Example Quotes	Resources	References
	link this to their home-based experience).			
2.2.1. Booklet	INCLUDE any references to the booklet, positive and negative.		17	52
- Booklet	INCLUDE negative reactions to the booklet and ways of improving it to facilitate home-practice.	<i>Instead of having to keep looking down to see when you should be breathing, and when you should be, erm, what's the next step. Because I find the footwork hard to remember without keeping looking. (01009C-I).</i>	16	35
DVD or video	INCLUDE references to participants requesting a DVD to facilitate their practice, the way this DVD should be designed and limitations of DVD use (i.e., some people not being able to use DVDs or reduced portability).	01021C mentions that a DVD would make it a lot easier the home-practice than the book. (01021C-FB).	13	31
+ Booklet	INCLUDE positive and neutral reactions to the booklet.	<i>I must admit, I'm fascinated by the images that are included in the book. (01012P-I).</i>	8	17
2.2.2. Behaviour Change Elements	INCLUDE references to elements of the home-practice that were in place to facilitate participants' adherence to the Tai Chi practice at home.		22	79
Alarm Clock	INCLUDE here any references to the use or not use of the alarm clock provided to remind participants of their practice at home.	<i>No, no, just...just to time us for the...doing the, you know, I find half an hour is...is right. (03006C-I).</i>	5	5
Coping and Action Plans	INCLUDE references to participants' (not) remembering about these forms, about their (not) use and the way participants used or felt about these forms.	<i>Something I've filed and... [laughs]. I didn't file it under 'b' for bin I filed it in 'bag' [laughs]. (01012C-I).</i>	13	19
Crib Sheets	INCLUDE references to participants' use or not use of the crib sheets provided.	<i>That's right, yes. Yeah, I followed those [crib sheets], yes. Yeah, very good. That...that was...that was good. Yes, 'cause we've practically done all the stages now. (03006C-I).</i>	4	4
Home-Exercise Logs	INCLUDE references to filling the exercise logs.	<i>Yeah. So, I lied. I lied on the [exercise log] paper. (01036P-I).</i>	17	23
Instructor's Home-Visit	INCLUDE references to the instructor's home-visit i.e., if they find it was useful or not and if it could be improved in any way to make it more useful to the participants. EXCLUDE mentions to the baseline home-visit.	<i>Yes, it was useful that she came and checked where we were going to do it and wh...and confirmed what we...were going to do. (03005C-I).</i>	18	28
2.2.3. Ways of Practising	INCLUDE references to descriptions of the way participants got involved in home-practice such as the time, place and way they practised.	<i>And, erm, it got to a stage, a couple of times <Instructor 2> told us, don't face one another, go alongside one another, so we...but we wanted to face one another, didn't we, for some reason. (01025C-I).</i>	20	64

Name	Description	Example Quotes	Resources	References
2.2.4. Home Barriers	INCLUDE references to difficulties or weaknesses attributed to practice at home, and any way to compensate practice that has been used.	<i>Um, neither of us felt like doing it February, I suppose. It was the worst month. We had this cold which was almost a flu bug... and, um, it really did put us back. So, we...we missed out quite a bit. Um, [sigh] nothing else...no, we'll...we'll...we'll...we'll...well we did...we didn't do it while we were away this weekend...(01022C-1).</i>	25	70
2.2.5. Home Facilitators	INCLUDE references to facilitators or strengths of home-practice.	<i>Well again before the <Serious Adverse Event 1> we were doing it every day and thoroughly enjoying it. (03005P-1).</i>	19	55
2.2.6. Home-Practice's Suggested Improvements	INCLUDE any suggestions to improve the practice at home.	<i>The, the only thing that I could think of, and I think it would be too expensive, anyway, is to have a little video... (01009C-1).</i>	4	4
3. Getting Involved in Research	INCLUDE references to participants' experiences of getting involved in research, such as their reactions to the forms and procedures of the RCT phase, including harms/benefits identified and ways their participation in the study has facilitated/hindered their involvement in other activities. EXCLUDE requests for further support to join community groups of Tai Chi for people living with dementia.		16	34
3.1. Research Process	INCLUDE references to participants' experiences of taking part in research and undergo research forms and procedures of the TACIT trial in general or this qualitative study. EXCLUDE references to participants' experiences of participating in Tai Chi.	<i>Well, um, you...everything can be a burden if you want to say, oh, blimey, I've got to do that. But if you say, okay, I'm taking part, they're very kindly offering <01008P> the chance to practise Tai Chi, the least I can do is make sure that we keep the records. No...no big deal. (01008C-1).</i>	16	34
Forms	INCLUDE references to participants' experiences filling and sending back the research forms throughout their participation in the TACIT Trial.	<i>Um, but I didn't find anything wrong. It was a bit of a bind filling in the, um, forms, but it was for research anyway, so that didn't really matter. (02002C-1).</i>	9	16
Miscellaneous	INCLUDE any other relevant quotes/comments not fitting into the previous codes (i.e., exploring possibility to expanding participants' involvement in the study or participants' willingness to have support to find similar Tai Chi groups in their community to carry on once the study is finished).	<i>So, on ours, there's, erm, only one that has dropped out and it's because he's not well. (01009C-1).</i>	10	15

Appendix X

Pilot Intervention Phase Participants' Demographic Data

Table X 1. *Pilot Intervention Phase: Participants' Demographic Data*

Participant	Item	Site 1 (n = 4) Frequencies or means (and Standard Deviations (SD))	Site 2 (n = 6) Frequencies or means (and Standard Deviations (SD))	Total	
People Living with Dementia	Gender	Male	2	3	5
		Female	2	3	5
	Mean age (SD)		73.75 (0.96)	81.17 (5.04)	78.20 (5.39)
	Relationship status	Married / Civil partnership	3	5	8
		With partner	1	0	1
		Widowed	0	1	1
	Current living situation	Living with family/friends	4	6	10
	Level of education	Primary	0	2	2
		Secondary	2	2	4
		Higher education college / university	1	0	1
		Further education / professional qualification	1	2	3
	Ethnicity	White	4	6	10
	Dementia type	Alzheimer's	3	6	9
		Mixed Alzheimer's & Vascular	1	0	1
	Mean number of months diagnosed with dementia (SD)		21 (22.23)	25.67 (28.56)	23.80 (24.97)
	Other chronic conditions	Yes	3 (Glaucoma, high pressure, headache/hypertension/sarcoidosis ²²)	4 (fibromyalgia ²³ and stroke/ prostate cancer and diverticulitis ²⁴ /neuralgia ²⁵ /hypertension)	7
		No	1	2	3

²² Sarcoidosis is a disease “characterized by the formation of immune granulomas” in any organ affected (Strookappe et al., 2015, p. 701). If present, symptomatology generally disappears spontaneously or with adequate treatment without further consequences for the patient (Judson, 2015).

²³ Fibromyalgia is a syndrome characterised by chronic “widespread pain” and possibly other physical (i.e., “muscle stiffness”) and psychological (“memory and concentration” difficulties) manifestations (NHS, 2016).

²⁴ Diverticulitis is an infection caused by bacterial accumulation in “small bulges that stick out of the side of the large intestine” which is generally cured after dietary, pharmacological or (rarely) surgical intervention (NHS, 2014).

²⁵ Neuralgia is the pain caused by nerve irritation or damage (Shelat, 2016).

Participant	Item	Site 1 (n = 4) Frequencies or means (and Standard Deviations (SD))	Site 2 (n = 6) Frequencies or means (and Standard Deviations (SD))	Total	
	Existing injuries or health injuries to be	No	4	6	10
	Uses a walking aid?	No	4	6	10
	Mean prescribed daily medications (SD)	3.5 (1.29)	5.5 (4.32)	4.7 (3.47)	
	Falls in the last year?	Yes	0	1 (minor injury)	1
		No	4	5	9
	Falls in the last month?	Yes	0	1 (minor injury)	1
		No	4	5	9
	Frequency of moderate PA practice	Everyday	1	2	3
		3 times per week	1	0	1
		2 times per week	2	1	3
		Weekly	0	1	1
		Rarely/never	0	2	2
	Frequency of vigorous PA practice	Monthly	1	0	1
		Rarely/never	3	6	9
	Previous experience practising Tai Chi?	No	4	6	10
	Mean confidence about being able to practise Tai Chi for at least 20 minutes per day (SD)	1.75 (0.96) ²⁶	2.67 (1.21) ⁷	2.3 (1.16) ⁷	
	Mean intention to practise Tai Chi for at least 20 minutes per day (SD)	2.25 (0.96) ²⁷	2.17 (0.75) ⁸	2.2 (0.79) ⁸	
Carers'	Gender	Male	2	2	4
		Female	2	4	6
	Mean age (SD)	69.25 (1.5)	74.5 (5.96)	72.40 (5.28)	
	Relationship with the person living with dementia	Spouse/partner	4	5	9
		Other	0	1 (niece)	1
	Live with the person living with dementia	Yes	4	6	10
	Relationship status	Married / Civil partnership	3	6	9
		With partner	1	0	1
	Current living situation	Living with family/friends	4	6	10

²⁶ Participants were asked to rate their confidence using a Likert scale from 1 (true) to 7 (false), where 1 was the best score –showing participants' confidence about being able to practise for 20 minutes per day.

²⁷ Participants were asked to rate their intention using a Likert scale from 1 (likely) to 7 (unlikely), where 1 was the best score –showing participants' intention to practise for at least 20 minutes per day.

Participant	Item	Site 1 (n = 4) Frequencies or means (and Standard Deviations (SD))	Site 2 (n = 6) Frequencies or means (and Standard Deviations (SD))	Total
Level of education	Primary	0	1	1
	Secondary	1	2	3
	Higher education college/university	2	1	3
	Further education/professional	1	2	3
Ethnicity	White	4	6	10
Previous experience practising Tai Chi?	No	4	6	10
Mean confidence about being able to practise Tai Chi for at least 20 minutes per day (SD)		1.33 (0.58) ⁷	1.17 (1.17) ⁷	1.89 (1.05) ⁷
Mean intention to practise Tai Chi for at least 20 minutes per day (SD)		1.33 (0.58) ⁸	2 (1.1) ⁸	1.78 (0.97) ⁸

Appendix Y

Acceptability Barriers, Facilitators and Improvements Suggested

Table Y 1. *Barriers, Facilitators and Improvements Suggested to Increasing Participant’s Acceptability of the Tai Chi Intervention*

Theme / Subtheme	Facilitators	Barriers	Improvements suggested (by...)
Interventions characteristics			
<i>Instructional methods</i>	<ul style="list-style-type: none"> • Instructor’s qualities (i.e., use of clear speech, adequate tone, nice manner; made the classes interesting; had a calming personality and professional competency). • Provision of regular positive feedback. • Creation of a reassuring, failure free and warm class environment. • Use of everyday life examples to facilitate copying the movements and create rapport with participants. • Adaptation of the classes to participants’ needs or requests. 	<ul style="list-style-type: none"> • Amount of content delivered during the classes. • Lack of tailored support to individuals who kept performing the movements wrong after correction. 	<ul style="list-style-type: none"> • Reduce the amount of content to be delivered during the classes to adapt the intervention to participants with more difficulties copying the movements (instructor and participants). • Approach participants individually if required copying the movements closer and in front of them to support their individual and safe practice (research team).
<i>Class-based Tai Chi</i>	<ul style="list-style-type: none"> • Movements’ repetition - most of the movements were practised twice. • Participants’ ability to sustain attention for 45 minutes. • Participants’ ability to stand for 45 minutes. • Chosen venues. • Timings. • Length of the classes. • Group sizes. • Allocation of socialising time at the end. 	<ul style="list-style-type: none"> • Unexpected or unavoidable difficulties to attend the classes: traffic accident, ill-health, planned holiday period. • During classes: coughing, stopping practice because of fear of falling or feeling stiff. 	<ul style="list-style-type: none"> - • Instructor’s closer relationship with participants to know the reasons they must stop their practice during classes and provide any support required to facilitate their continued engagement (author).
<i>Home-based Tai Chi</i>	<ul style="list-style-type: none"> • Carers supporting practice. • Role of routine. • Importance of repetition to improve practice and get the benefits of the intervention. • Participants’ determination to achieve perceived benefits. • Participants’ pointing to unexpected events as barriers to practice and being positive providing ways to overcome these difficulties and do the practice. • (When conducted) Instructor’s home-visits were useful to clarify and make home-practice easier. 	<ul style="list-style-type: none"> • Booklet (overwhelming and unclear). <ul style="list-style-type: none"> ○ Negative feelings raised by the home-exercises booklet. • Carers’ lack of confidence guiding the person living with dementia. • Difficulty remembering (how to start) the movements/practice. • Early start of home-practice. • Carers’ discontinued engagement in practice due to their lack of confidence. 	<ul style="list-style-type: none"> • Provide the booklet in smaller volumes (participants). • Delay home-practice at least two weeks after starting the class-based practice, so participants are more familiar with the movements and carers feel more confident to guide the person living with dementia (participants and research team). • Create a DVD as requested by participants or provide a crib sheet to guide their practice (participants and instructor).
		<ul style="list-style-type: none"> • Instructor’s time constraints to arrange home-visits. • Carers’ difficulties to motivate the person living with dementia to do things or to carry on practising for 20 minutes. • Participants’ not filling their action and coping plans. 	<ul style="list-style-type: none"> • Allow at least two weeks between intervention groups lead by the same instructor to facilitate home-visits scheduling (instructor). • Prompt participants to fill in their action

Theme / Subtheme	Facilitators	Barriers	Improvements suggested (by...)
		<ul style="list-style-type: none"> Finding time to practise. No use of the alarm clock provided as a memory aid. 	<ul style="list-style-type: none"> and copying plans or use a duplicate system to reduce instructor’s work load during home-visits (instructor). Ask carers about ways of going over people living with dementia’s lack of motivation (author).
Participant’s reactions to the intervention			
<i>Feelings towards the intervention and their dyadic participation</i>	<ul style="list-style-type: none"> Chance to take part together in the intervention as a facilitator for people living with dementia’s involvement in Tai Chi practice. People living with dementia’s value of their carers’ role supporting their practice. Participants’ positive or neutral feelings towards Tai Chi before and after the first class. Carers not feeling burden in taking part together with the person living with dementia and providing support at home. Rewarding for both members of the dyad. Willingness to carry on practising Tai Chi or reengage in previously practised exercises (i.e. Pilates). Discovery of a new pleasurable activity to practise together. 	<ul style="list-style-type: none"> Feeling sceptical about the intervention. Perception of Tai Chi as an “awkward activity”. Carers feeling hard to take part in the intervention (although the socialising component would compensate this effort). Perception of Tai Chi as not appropriate for people living with dementia at more advanced stages, or as being less beneficial for them. 	<ul style="list-style-type: none"> Reassure participants who express this and explain them the potential benefits of practising Tai Chi (author). Reinforce the idea that practice is more important than the number of patterns performed, to avoid participants feeling that they are not practising enough (i.e., if they are only practising the warm-ups at home and they feel this is beneficial to them, there is no need to feel like they should be doing all the patterns) (author).
<i>(Dis) engagement with Tai Chi</i>	<ul style="list-style-type: none"> Participants’ autonomy to engage in class-based practice. Attribution of a beneficial effect to their Tai Chi practice. Joint participation and enjoyment. Participants’ familiarity with the Tai Chi movements over session, allowing them to anticipate the movements. Participants’ perceived progression in practice, getting more into Tai Chi and feeling the “flow”. Benefiting from home and class-based practice’s advantages. 	<ul style="list-style-type: none"> Previous health issues. Adverse events (i.e., feeling dizzy). Participants’ difficulties to engage in the intervention in a non-familiar (class-based) environment without supports nearby. 	<ul style="list-style-type: none"> Instructors should be aware of participants’ health conditions and provide them a tailored advice on how to practise depending on these conditions or adverse events experienced during their practice. Similarly, more contact at the end of the session with participants will allow instructors to identify possible difficulties linked to home or class-based settings and provide tailored recommendations to facilitate participants’ adherence to the intervention (author).

Theme / Subtheme	Facilitators	Barriers	Improvements suggested (by...)
<i>Interaction with others</i>	<ul style="list-style-type: none"> • Creation of a semi-circle of chairs before starting the first class to encourage participants' conversations whilst waiting for the rest of participants. • Allowing time at the end of the sessions for participants' socialisation was perceived as something positive particularly for carers. • Involving participants in their coffee/tea preparation. 	-	-
Research Process			
<i>Participants' involvement in research</i>	<ul style="list-style-type: none"> • Taking their participation as an opportunity to contribute to research and try to get the benefits from a different activity they would not have tried outside the research context. • Participants' willingness to provide research data, even after withdrawal. • Participants did not perceive the amount of data collected during their participation in the study as excessive. • Participants' did not feel observed during the classes when the researcher was taking notes. 	<ul style="list-style-type: none"> • Difficulties with recruitment (participants declining to take part – some due to not having balance or falls issues). • Lengthy baseline home-visits. • Difficulties to fill in exercise logs correctly. • Asking people living with dementia to fill the exercise logs when some of them have difficulties in writing. • Some people living with dementia's difficulties to report data over the phone. • Some carers' willingness to be present or asked always the questions that are formulated to the person living with dementia. 	<ul style="list-style-type: none"> • Include additional research sites, bring recruitment earlier and start with publicity once the green light is received (researcher team). • Modify participant facing documents to stress the aim of the study on analysing the impact of Tai Chi on general well-being (researcher team). • Reorder the tests to be administered to save time (PhD 2). • Explain the purpose of the clock and how to fill in exercise logs accurately (author). • Ask participants to fill their exercise logs as a dyad (author). • In some cases, it might be necessary to obtain weekly falls-data from carers or to speak with both members of the dyad to get this information. It could be necessary to break falls questions into smaller questions for some participants (author). • Explain the purpose of getting their views separately (author).
<i>Participants' expectations</i>	<ul style="list-style-type: none"> • Willingness to carry on practising Tai Chi and taking part in research. 	<ul style="list-style-type: none"> • Misinformation. 	<ul style="list-style-type: none"> • To avoid confusion the role of randomisation should be clearly explained and participants' understanding of their implications should be double-checked (author).

Appendix Z

RCT Phase Participants' Demographic Characteristics

Table Z 1. RCT Phase: Participants' Living with Dementia Demographic Characteristics

Dyad number	Gender	PLVD's Age at recruitment	Relationship status	Living situation	Highest level of education	Dementia type	Months since diagnosis at baseline	Any long-term health conditions?	if yes, specific conditions	Conditions to be considered for Tai Chi?	if yes, specific conditions	Walking aid use	Number of medications per day	Falls in the past year	if yes, injury level	Falls in the past month	if yes, injury level	Frequency of moderate PA	Frequency of vigorous PA	Previous TC experience	Confidence to do Tai Chi (1-7) ²⁸	Intention to do Tai Chi (1-7) ²⁹	M-ACE Score
03003	Male	83	Married	Living with family	None	Alzheimer's	3	Yes	COPD + stint in the heart	No		No	2	Yes	Minor injury	No		3 times per week	Rarely/ never	No	4	1	15
03005	Female	70	Married	Living with family	Further education/ professional qualification	Mixed Alzheimer's and Vascular	2	Yes	Arthritis	No		Yes	7	Yes	Minor injury	Yes	Minor injury	Every day	Rarely/ never	No	1	1	27
03006	Male	81	Married	Living with family	Secondary school	Alzheimer's	67	Yes	Diabetes + irregular heart beat + sleep apnoea + urology issues (has urine bag attached)	No		No	11	No		No		Rarely/ never	Rarely/ never	Yes	4	1	11
01002	Male	84	Married	Living with family	Secondary school	Alzheimer's	12	Yes	Arrhythmia	Yes	N/D	No	4	No		Yes	Minor injury	Every day	Weekly	No	2	1	13
01008	Female	79	Married	Living with family	Further education/ professional qualification	Mixed Alzheimer's and Vascular	9	Yes	Coeliac, can't eat gluten + Hem hyperplagic + Bowl operation	No		No	2	Yes	Moderate injury	No		Every day	Rarely/ never	No	1	1	12
02002	Male	86	Married	Living with family	Higher education college/ university	Alzheimer's	5	Yes	Had had prostate cancer and years ago radiotherapy	Yes	Pain in the lower back and goes down to the left leg. It is narrowing of the vertebrae.	No	3	Yes	Minor injury	No		Rarely/ never	Rarely/ never	No	4	4	17
02004	Male	82	Married	Living with family	Primary school	Alzheimer's	5	Yes	Angina, COPD + Hernia	Yes	Left hip replaced 3 times, left knee replaced 1 time	Yes	13	Yes	Moderate injury	Yes	Minor injury	Rarely/ never	Rarely/ never	No	3	1	16
01015	Female	66	Married	Living with family	Secondary school	Alzheimer's	Approx. 84	Yes	Chronic asthma + Diverticula + Knee replacement in 2011	No		Yes	9	No		No		Rarely/ never	Rarely/ never	No	2	2	12
03008	Female	87	Widowed	Living with family	Secondary school	Alzheimer's	35	Yes	High blood pressure + hypothyroidism + flat foot	Yes	Knee replacement	No	6	No		Yes	Minor injury	Rarely/ never	Rarely/ never	No	3	3	13

²⁸ Participants were asked to rate their confidence using a Likert scale from 1 (true) to 7 (false), where 1 was the best score –showing participants' confidence about being able to practise for 20 minutes per day.

²⁹ Participants were asked to rate their intention using a Likert scale from 1 (likely) to 7 (unlikely), where 1 was the best score –showing participants' intention to practise for at least 20 minutes per day.

Dyad number	Gender	PLWD's Age at recruitment	Relationship status	Living situation	Highest level of education	Dementia type	Months since diagnosis at baseline	Any/long-term health conditions?	If yes, specific conditions	Conditions to be considered for Tai Chi?	If yes, specific conditions	Walking aid use	Number of medications per day	Falls in the past year	If yes, injury level	Falls in the past month	If yes, injury level	Frequency of moderate PA	Frequency of vigorous PA	Previous TC experience	Confidence to do Tai Chi (1-7) ²⁸	Intention to do Tai Chi (1-7) ²⁹	M-ACE Score
03007	Male	75	Married	Living with family	Secondary school	Alzheimer's	30	Yes	Heart attack and bypass, breathing related problems (related with heart); stents	No	No	No	8	Yes	No injury	No	No	Every day	Rarely/ never	No	2	2	11
01021	Male	81	Married	Living with family	Secondary school	Mixed Alzheimer's and Vascular	24	Yes	Narrowing of arteries of heart but no pains + hypothyroidism.	No	Yes	Yes	5	No	No	No	No	3 times per week	Rarely/ never	No	4	1	11
01006	Male	76	Married	Living with family	Secondary school	Alzheimer's	6	No		No	No	No	3	No	No	No	No	Every day	Weekly	Yes	1	1	15
01009	Female	84	Single	Living alone	Higher education college/ university	Alzheimer's	3	Yes	High blood pressure	No	No	No	4	No	No	No	No	3 times per week	Rarely/ never	No	1	1	16
01012	Female	87	Divorced	Living with family	Secondary school	Alzheimer's	7	No		No	Yes	Yes	1	Yes	No injury	No	No	2 times per week	Rarely/ never	No	1	1	11
01022	Female	81	Married	Living with family	Secondary school	Mixed Alzheimer's and Vascular	4	Yes	Arthritis, right foot painful since last 7 years has been through 3 operations due to arthritis.	No	Yes	Yes	5	Yes	Minor injury	No	No	Every day	Rarely/ never	No	1	1	24
01023	Male	78	Married	Living with family	Secondary school	Alzheimer's	Approx. 48	Yes	Blood pressure issues (chronic high blood pressure) uses medication for it.	No	No	No	3	No	No	No	No	Every day	Rarely/ never	No	1	1	13
01025	Male	76	Married	Living with family	Secondary school	Alzheimer's	23	No		No	No	No	2	No	No	No	No	Monthly	Rarely/ never	No	1	1	11
01031	Female	73	Married	Living with family	Higher education college/ university	Mixed Alzheimer's and Vascular	15	No		No	No	No	7	No	No	No	No	Every day	Every day	No	1	1	21
01034	Female	75	Married	Living with family	Secondary school	Alzheimer's	35	Yes	High blood pressure	No	No	No	5	Yes	No injury	No	No	Rarely/ never	Rarely/ never	No	2	2	16
01035	Female	68	Married	Living with family	Secondary school	Frontal Lobe	21	No		No	No	No	3	No	No	No	No	Every day	Rarely/ never	Yes	1	1	15
01036	Female	79	Married	Living with family	Secondary school	Alzheimer's	8	Yes	Osteoarthritis+ Cholesterol + High blood pressure	No	No	No	8	No	No	No	No	Every day	Rarely/ never	No	3	1	19
01039	Male	62	Married	Living with family	Higher education college/ university	Alzheimer's	5	Yes	Type 2 diabetes	No	No	No	5	No	No	No	No	Every day	Rarely/ never	No	1	1	17
01043	Female	59	Single	Living alone	Higher education college/ university	Alzheimer's	6	No		No	No	No	1	No	No	No	No	Every day	Rarely/ never	No	3	4	10
01045	Male	84	Married	Living with family	Secondary school	Mixed Alzheimer's and Vascular	17	Yes	Blood pressure + stiff wrist and elbow.	No	No	No	6	No	No	No	No	Every day	Rarely/ never	No	1	1	21
01055	Male	84	Married	Living with family	Higher education college/ university	Alzheimer's	50	Yes	Heart issues - two heart attack, 3 stents, 1 pacemaker.	Yes	Spinal injury of the vertebrae	Yes	15	Yes	Minor injury	No	No	Rarely/ never	Rarely/ never	Yes	1	1	27

Table Z 2. RCT Phase: Carers' Demographic Characteristics

Dyad number	Gender	Carer's Age at recruitment	Relationship with PLWD	Live with PLWD?	Relationship status	Living situation	Highest level of education	Previous Tai Chi experience	Confidence to do Tai Chi (1-7)	Intention to do Tai Chi (1-7)
03003	Female	80	Spouse	Yes	Married	Living with family	Primary school	No	1	1
03005	Male	69	Spouse	Yes	Married	Living with family	Higher education college/ university	No	1	1
03006	Female	79	Spouse	Yes	Married	Living with family	Primary school	No	5	5
01002	Female	67	Spouse	Yes	Married	Living with family	Higher education college/ university	No	1	1
01008	Male	82	Spouse	Yes	Married	Living with family	Higher education college/ university	No	1	1
02002	Female	81	Spouse	Yes	Married	Living with family	Higher education college/ university	No	3	3
02004	Female	80	Spouse	Yes	Married	Living with family	Secondary school	No	2	1
01015	Male	68	Spouse	Yes	Married	Living with family	Secondary school	No	1	1
03008	Female	51	Daughter	Yes	With partner	Living with family	Secondary school	No	3	3
03007	Female	70	Spouse	Yes	Married	Living with family	Secondary school	No	2	2
01021	Female	67	Spouse	Yes	Married	Living with family	Secondary school	Yes	1	4
01006	Female	56	Spouse	Yes	Married	Living with family	Secondary school	No	1	1
01009	Female	83	Sister	No	Single	Living with family	Secondary school	No	1	1
01012	Female	58	Daughter	No	Married	Living with family	Secondary school	No	1	1
01022	Male	82	Spouse	Yes	Married	Living with family	Further education / professional qualification	Yes	1	1
01023	Female	81	Spouse	Yes	Married	Living with family	Secondary school	No	1	1
01025	Female	70	Spouse	Yes	Married	Living with family	N/D	No	1	1
01031	Male	73	Spouse	Yes	Married	Living with family	Higher education college/ university	No	1	1
01034	Male	76	Spouse	Yes	Married	Living with family	Secondary school	No	1	1
01035	Male	67	Spouse	Yes	Married	Living with family	Secondary school	No	4	4
01036	Female	78	Sister	No	Married	Living with family	Secondary school	No	3	1
01039	Female	60	Spouse	Yes	Married	Living with family	Further education / professional qualification	No	1	1
01043	Female	60	Sister	No	Single	Living alone	Higher education college/ university	Yes	2	2
01045	Female	79	Spouse	Yes	Married	Living with family	Secondary school	No	1	1
01055	Female	74	Spouse	Yes	Married	Living with family	Further education / professional qualification	No	3	3

Appendix AA

Class Attendance in Groups 1 to 6

Table AA 1. RCT Phase: Class Attendance to Group 1

Participant Number	Instructor	Site	Venue	Session Number																			Classes attended per participant	Average attendance per participant	Dyads interviewed?		
				1	2	3	4	5	6	7	8	9	10	11	12	13 ³⁰	14	15	16	17	18	19				20	21
03003P ³¹	1	3	1	1	1	1	1	0	1	0	0	1	0	0	0		0	0	0	0	0	0	6	30%	Yes		
03003C	1	3	1	1	1	1	1	0	1	0	0	1	0	0	0		0	0	0	0	0	6	30%	Yes			
03005P	1	3	1	1	1	1	1	1	1	1	0	0	0	0	0		0	0	1	0	1	9	45%	Yes			
03005C	1	3	1	1	1	1	1	1	1	1	0	0	0	0	0		0	0	1	0	1	9	45%	Yes			
03006P	1	3	1	1	0	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	19	95%	Yes			
03006C	1	3	1	1	0	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	19	95%	Yes			
Total participants attending each class				6	4	6	6	4	6	4	2	4	2	2	2		2	2	4	2	4		2	2	2		
Average attendance per session				100%	67%	100%	100%	67%	100%	67%	33%	67%	33%	33%	33%		33%	33%	67%	33%	67%		33%	33%	33%		57%

* Marked in green (/shaded) are participants observed during any of the observation's sessions, those not observed are participants who did not attend the classes observed. Session numbers over 20 indicate that the class had been postponed due to a previous cancellation. This was done to facilitate participants' uptake of the 20 sessions planned.

³⁰ Empty boxes shadowed (red) indicate the session was cancelled. Session numbers over 20 correspond to the sessions postponed.

³¹ Participant numbers shadowed (green) are those who were observed during any of the classes.

Table AA 2. RCT Phase: Class Attendance to Group 2

Participant Number	Instructor	Site	Venue	Session Number																						Classes attended per participant	Average attendance per participant	Number of weeks involved in the study (Excluding WI & WT) ³²	Average attendance to the classes during involvement in the study	Dyads interviewed?
				1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22					
02002P	1	2	2	1	1	1	0	0	0	0	0	0	0	0	1	WI	WI	4	20%	11	36%	Yes								
02002C	1	2	2	1	1	1	0	0	1	0	1	1	0	0	1	0	WI	WI	7	35%	11	64%	Yes							
02004P	1	2	2	1	1	1	1	0	0	0	0	0	0	0	1	1	0	WT	WT	WT	WT	WT	WT	WT	6	30%	10	60%	No	
02004C	1	2	2	1	1	1	1	0	0	0	0	0	0	0	1	0	0	WT	WT	WT	WT	WT	WT	WT	5	25%	10	50%	No	
01002P	1	2	2	0	1	1	1	1	0	0	1	0	0	1	1	1	1	1	1	1	1	1	1	1	17	85%	20	85%	Yes	
01002C	1	2	2	0	1	1	1	1	0	0	1	0	0	1	1	1	1	1	1	1	1	1	1	1	17	85%	20	85%	Yes	
01008P	1	2	2	1	1	1	1	1	1	0	0	0	0	0	0	1	1	1	1	1	1	1	1	0	16	80%	20	80%	Yes	
01008C	1	2	2	1	1	1	1	1	1	0	0	0	0	0	0	1	1	1	1	1	1	1	1	0	16	80%	20	80%	Yes	
Total participants attending each class				6	8	8	6	4	3	3	1	4	5	6	4	4	4	4	4	4	4	4	4	2	4					
Average attendance per session				75%	100%	100%	75%	50%	38%	38%	13%	50%	63%	75%	50%	50%	50%	50%	50%	50%	50%	50%	50%	25%	50%	55%		68%		
Total participants in the intervention group per session				8	8	8	8	8	8	8	8	8	8	8	6	4	4	4	4	4	4	4	4	4	4					
Average session attendance per participants in the intervention (excluding withdrawn/not recruited)				75%	100%	100%	75%	50%	38%	38%	13%	50%	63%	75%	67%	100%	100%	100%	100%	100%	100%	100%	100%	50%	100%			75%		

³² WI= Withdrew from intervention. / WT= Withdrew totally from the study. / Empty boxes shadowed (red) indicate the session was cancelled. Session numbers over 20 correspond to the sessions postponed. / Participant numbers shadowed (green) are those who were observed during any of the classes.

Table AA 4. RCT Phase: Class Attendance to Group 4

Participant Number	Instructor	Site	Venue	Session Number																						Classes attended per participant	Average attendance per participant	Number of weeks involved in the study (Excluding NR, WI & WT)	Average attendance to the classes during involvement in the study	Dyads interviewed
				1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22					
01006P	2	2	4	1	1	1	0	1	1	1	0	0	0	0	WT	WT	WT	6	30%	12	50%	No								
01006C	2	2	4	1	1	1	0	1	1	1	0	0	0	0	WT	WT	WT	6	30%	12	50%	No								
01009P	2	2	4	1	1	1	0	1	1	1	1	1	1	1	1	1	0	1	1	1	1	1	18	90%	20	90%	Yes			
01009C	2	2	4	1	1	1	0	1	1	1	1	1	1	1	1	1	0	1	1	1	1	1	18	90%	20	90%	Yes			
01012P	2	2	4	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	20	100%	20	100%	Yes			
01012C	2	2	4	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	20	100%	20	100%	Yes			
01022P	2	2	4	NR ³⁴	NR	1	1	1	1	1	1	0	0	1	1	0	1	0	0	1	1	1	13	65%	18	72%	Yes			
01022C	2	2	4	NR	NR	1	1	1	1	1	1	0	0	1	1	0	1	0	0	1	1	1	13	65%	18	72%	Yes			
Total participants attending each class				6	6	8	4	8	8	8	6	4	4	6	6	4	4	4	4	4	4	6	6	6						
Average attendance per session				75%	75%	100%	50%	100%	100%	100%	75%	50%	50%	75%	75%	50%	50%	50%	50%	50%	50%	75%	75%	75%	71%		78%			
Total participants in the intervention group per session				6	6	8	8	8	8	8	8	8	8	8	8	6	6	6	6	6	6	6	6	6						
Average attendance per session per participants in the intervention (excluding withdrawn/not recruited)				100%	100%	100%	50%	100%	100%	100%	75%	50%	50%	75%	75%	67%	67%	67%	67%	67%	100%	100%	100%	100%			82%			

³⁴ NR= Not Recruited. / WT= Withdrew totally from the study. / Empty boxes shadowed (red) indicate the session was cancelled. Session numbers over 20 correspond to the sessions postponed. / Participant numbers shadowed (green) are those who were observed during any of the classes.

Table AA 5. RCT Phase: Class Attendance to Group 5

Participant Number	Instructor	Site	Venue	Session Number																									Total number of classes attended per participant	Average attendance per participant	Dyads interviewed?
				1	2	3	4 ³⁵	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25			
01023P ³⁶	2	1	5	1	1	1		1	1	1	1	1	1	1	1	1		1		1	1		0	1	1	1	19	95%	No		
01023C	2	1	5	1	1	1		1	1	1	1	1	1	1	1												19	95%	No		
01025P	2	1	5	1	1	1		1	1	1	1	1	1	1	1			0		0	0		0	0	0	0	13	65%	Yes		
01025C	2	1	5	1	1	1		1	1	1	1	1	1	1	1			0		0	0		0	0	0	0	13	65%	Yes		
Total participants attending each class				4	4	4	0	4	4	4	4	4	4	4	4	4	4	0	0	2	0	2	2	0	0	2	2	2			
Average attendance per session				100%	100%	100%		100%	100%	100%	100%	100%	100%	100%	100%	100%	100%			50%		50%	50%		0%	50%	50%	50%	80%		

³⁵ Empty boxes shadowed (red) indicate the session was cancelled. Session numbers over 20 correspond to the sessions postponed. / Participant numbers shadowed (green) are those who were observed during any of the classes.

³⁶ Participant numbers shadowed (green) are those who were observed during any of the classes.

Table AA 6. RCT Phase: Class Attendance to Group 6

Participant Number	Instructor	Site	Venue	Session Number																				Total number of classes attended per participant	Average attendance per participant	Number of weeks involved in the study (Excluding NR, WI & WT)	Average attendance to the classes during involvement in the study	Dyads interviewed?
				1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20					
01031P ³⁷	2	2	6	1	1	1	1	1	1	1	1	1	1	1	1	WI	12	60%	12	100%	No							
01031C	2	2	6	1	1	1	1	1	1	1	1	1	1	1	1	WI	12	60%	12	100%	No							
01034P	2	2	6	1	0	0	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	4	20%	20	20%	No	
01034C	2	2	6	1	0	0	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	4	20%	20	20%	No	
01035P	2	2	6	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	20	100%	20	100%	No	
01035C	2	2	6	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	20	100%	20	100%	No	
01036P	2	2	6	0	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	0	1	17	85%	20	85%	Yes	
01036C	2	2	6	0	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	19	95%	20	95%	Yes	
01039P	2	2	6	1	0	1	1	1	1	1	1	1	1	0	0	1	1	1	1	1	0	1	16	80%	20	80%	Yes	
01039C	2	2	6	1	0	1	1	1	1	1	1	1	1	0	0	1	1	1	1	1	0	1	16	80%	20	80%	Yes	
01043P	2	2	6	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	0	0%	0	N/A	N/A	
01043C	2	2	6	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	WT	0	0%	0	N/A	N/A	
01045P	2	2	6	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	20	100%	20	100%	No	
01045C	2	2	6	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	20	100%	20	100%	No	
01055P	2	2	6	NR	0	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	4	20%	19	21%	Yes	
01055C	2	2	6	NR	0	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	4	20%	19	21%	Yes	
Total participants attending each class				10	8	12	14	14	14	10	10	10	10	8	8	8	8	8	8	8	7	5	8	8				
Average attendance per session				63%	50%	75%	88%	88%	88%	63%	63%	63%	63%	50%	50%	50%	50%	50%	50%	50%	44%	31%	50%	50%	59%			
Total participants in the intervention group per session				12	14	14	14	14	14	14	14	14	14	14	14	14	12	12	12	12	12	12	12	12				
Average attendance per session per participants in the intervention (excluding withdrawn/not recruited)				83%	57%	86%	100%	100%	100%	71%	71%	71%	71%	57%	57%	67%	67%	67%	67%	67%	58%	42%	67%	67%				71%

³⁷ NR= Not Recruited. / WI= Withdrew from intervention. / WT= Withdrew totally from the study. / Participant numbers shadowed (green) are those who were observed during any of the classes.

Appendix BB

Further Representations of Participants Home-Practice and Overall Class Plus Home Practice Minutes

Table BB 1. RCT Phase: Participants' Adherence to Class and Home Practice (Minutes and Averages per Participant)

Dyad number	Withdraw?	Week when they were offered to join the classes	Instructor's home visit was conducted after session number...	if withdrawn - number of their last session	Interviewed?	Person Living with Dementia										Carer									
						Number of classes attended	Number of classes unattended	Number of classes offered since recruitment	Average classe attended since recruitment	Minutes of class practice	Total minutes of home practice	Average home practice since instructor's home-visit (weekly dosage=120min)	PLWD's average home-practice (out of 35hrs recommended)	PLWD's overall hours of TC (until FU home-visit)	Average dosage received by the person living with dementia (out of 50hrs)	Number of classes attended	Number of classes unattended	Number of classes since recruitment	Average classe attended since recruitment	Minutes of class practice (Carer)	Minutes of home practice (Carer)	Average home practice since instructor's home-visit (weekly dosage = 120min)	Carers' average home-practice (out of 35hrs recommended)	Carers' overall hours of TC (until FU home-visit)	Average dosage received by carer (out of 50hrs recommended)
03003	No	1	3		Yes	6	14	20	30%	270	220	11%	10%	8	16%	6	14	20	30%	270	220	11%	10%	8	16%
03005	No	1	2		Yes	9	11	20	45%	405	445	21%	21%	14	28%	9	11	20	45%	405	445	21%	21%	14	28%
03006	No	1	3		Yes	19	1	20	95%	855	3650	179%	174%	75	150%	19	1	20	95%	855	3650	179%	174%	75	150%
01002	No	1	3		Yes	17	2	20	85%	765	2360	116%	112%	52	104%	17	2	20	85%	765	2250	110%	107%	50	101%
01008	No	1	3		Yes	16	3	20	80%	720	1570	77%	75%	38	76%	16	3	20	80%	720	1655	81%	79%	40	79%
02002	Yes - From classes only	1	2	12	Yes	4	16	20	20%	180	70	3%	3%	4	8%	7	12	20	35%	315	610	28%	29%	15	31%
02004	Yes	1	2	13	No	6	13	20	30%	270	192	9%	9%	8	15%	5	14	20	25%	225	150	7%	7%	6	13%
01015	Yes	2	N/R	3	No	1	0	19	5%	45	0	N/A	0%	1	2%	1	0	11	9%	45	0	N/A	0%	1	2%
03008	Yes - From classes only	1	3	12	Yes	9	11	20	45%	405	147	7%	7%	9	18%	9	11	20	45%	405	137	7%	7%	9	18%
03007	No - did not attend any of the classes	1	Not received		No	0	20	20	0%	0	0	N/A	0%	0	0%	0	11	11	0%	0	0	N/A	0%	0	0%
01021	No	6	6		Yes	16	0	16	100%	720	1410	84%	67%	36	71%	16	0	16	100%	720	1413	84%	67%	36	71%
01006	Yes	1	3	13	No	6	14	20	30%	270	0	0	0%	5	9%	6	14	20	30%	270	0	0%	0%	5	9%
01009	No	1	3		Yes	18	2	20	90%	810	1650	81%	79%	41	82%	18	2	20	90%	810	1440	71%	69%	38	75%
01012	No	1	3		Yes	20	0	20	100%	900	395	19%	19%	22	43%	20	0	20	100%	900	500	25%	24%	23	47%
01022	No	3	5		Yes	13	5	18	72%	585	1240	69%	59%	30	61%	13	5	18	72%	585	1240	69%	59%	30	61%
01023	No	1	2		No	19	1	20	95%	855	1440	67%	69%	38	77%	19	1	20	95%	855	2880	133%	137%	62	125%
01025	No	1	2		Yes	13	7	20	65%	585	1359	63%	65%	32	65%	13	7	20	65%	585	1371	63%	65%	33	65%

Dyad number	Withdraw?	Week when they were offered to join the classes	Instructor's home visit was conducted after session number...	If withdrawn - number of their last session	Interviewed?	Person Living with Dementia										Carer										
						Number of classes attended	Number of classes unattended	Number of classes offered since recruitment	Average classes attended since recruitment	Minutes of class practice	Total minutes of home practice	Average home practice since instructor's home-visit (weekly dosage=120min)	PLWD's average home-practice (out of 35hrs recommended)	PLWD's overall hours of TC (until FU home-visit)	Average dosage received by the person living with dementia (out of 50hrs)	Number of classes attended	Number of classes unattended	Number of classes since recruitment	Average classes attended since recruitment	Minutes of class practice (Carer)	Minutes of home practice (Carer)	Average home practice since instructor's home-visit (weekly dosage = 120min)	Carers' average home-practice (out of 35hrs recommended)	Carers' overall hours of TC (until FU home-visit)	Average dosage received by carer (out of 50hrs recommended)	
01031	Yes - From classes only	1	2	13	No	12	8	20	60%	540	903	42%	43%	24	48%	12	8	20	60%	540	908	42%	43%	24	48%	
01034	No	1	4		No	4	16	20	20%	180	295	15%	14%	8	16%	4	16	20	20%	180	295	15%	14%	8	16%	
01035	No	1	2		No	20	0	20	100%	900	890	41%	42%	30	60%	20	0	20	100%	900	1200	56%	57%	35	70%	
01036	No	1	2		Yes	17	3	20	85%	765	1837	85%	87%	43	87%	19	1	20	95%	855	2421	112%	115%	55	109%	
01039	No	1	3		Yes	16	4	20	80%	720	1255	62%	60%	33	66%	16	4	20	80%	720	1255	62%	60%	33	66%	
01043	Yes	1	Not received	1	No	0	20	20	0%	0	0	N/A	0%	0	0%	0	20	20	0%	0	0	N/A	0%	0	0%	
01045	No	1	4		No	20	0	20	100%	900	2625	137%	125%	59	118%	20	0	20	100%	900	2625	137%	125%	59	118%	
01055	No	3	3		Yes	4	15	19	21%	180	180	9%	9%	6	12%	4	15	19	21%	180	180	9%	9%	6	12%	
Totals						285	186	492		12825	24133			616		289	172	475		13005	26845			664		
Total averages						11,4	7,4	19,7	58,1%	513,0	965,3	54%	46,0%	24,6	49,3%	11,6	6,9	19,0	59,1%	520,2	10738	60%	51,1%	26,6	53,1%	
Range						Max	20	20	20	100%	900	3650	179%	174%	75	150%	20	20	20	100%	900	3650	179%	174%	75	150%
						Min	0	0	16	0%	0	0	0%	0	0%	0	0%	0	0%	0	0	11	0%	0	0	0%

Dyad number	Weeks in the study	Weeks that could have been doing home practice	Person living with dementia		Carer	
			Average classes attended whilst in the study	Average home-practice done whilst in the study	Average classes attended whilst in the study	Average home-practice done whilst in the study
03003	20	17	30%	11%	30%	11%
03005	20	18	45%	21%	45%	21%
03006	20	17	95%	179%	95%	179%
01002	20	17	85%	116%	85%	110%
01008	20	17	80%	77%	80%	81%
02002	12	10	33%	6%	58%	51%
02004	13	11	46%	15%	38%	11%
01015	2	N/A	50%	N/A	50%	N/A
03008	12	9	75%	14%	75%	13%
03007	20	N/A	0%	N/A	0%	N/A
01021	14	14	100%	84%	100%	84%
01006	13	10	46%	0%	46%	0%
01009	20	17	90%	81%	90%	71%
01012	20	17	100%	19%	100%	25%
01022	17	15	76%	69%	76%	69%
01023	20	18	95%	67%	95%	133%
01025	20	18	65%	63%	65%	63%
01031	13	11	92%	68%	92%	69%
01034	20	16	20%	15%	20%	15%
01035	20	18	100%	41%	100%	56%
01036	20	18	85%	85%	95%	112%
01039	20	17	80%	62%	80%	62%
01043	0	N/A	N/A	N/A	N/A	N/A
01045	20	16	100%	137%	100%	137%
01055	17	17	24%	9%	24%	9%
Totals	413	338				
Total averages	16,5	15,4	68%	56%	69%	63%
Range Max	20	18	114%	179%	114%	179%
Range Min	0	9	0	0	0	0

Figure BB 1. RCT participants' adherence to class and home-based components (adjusted per time involved in the study).

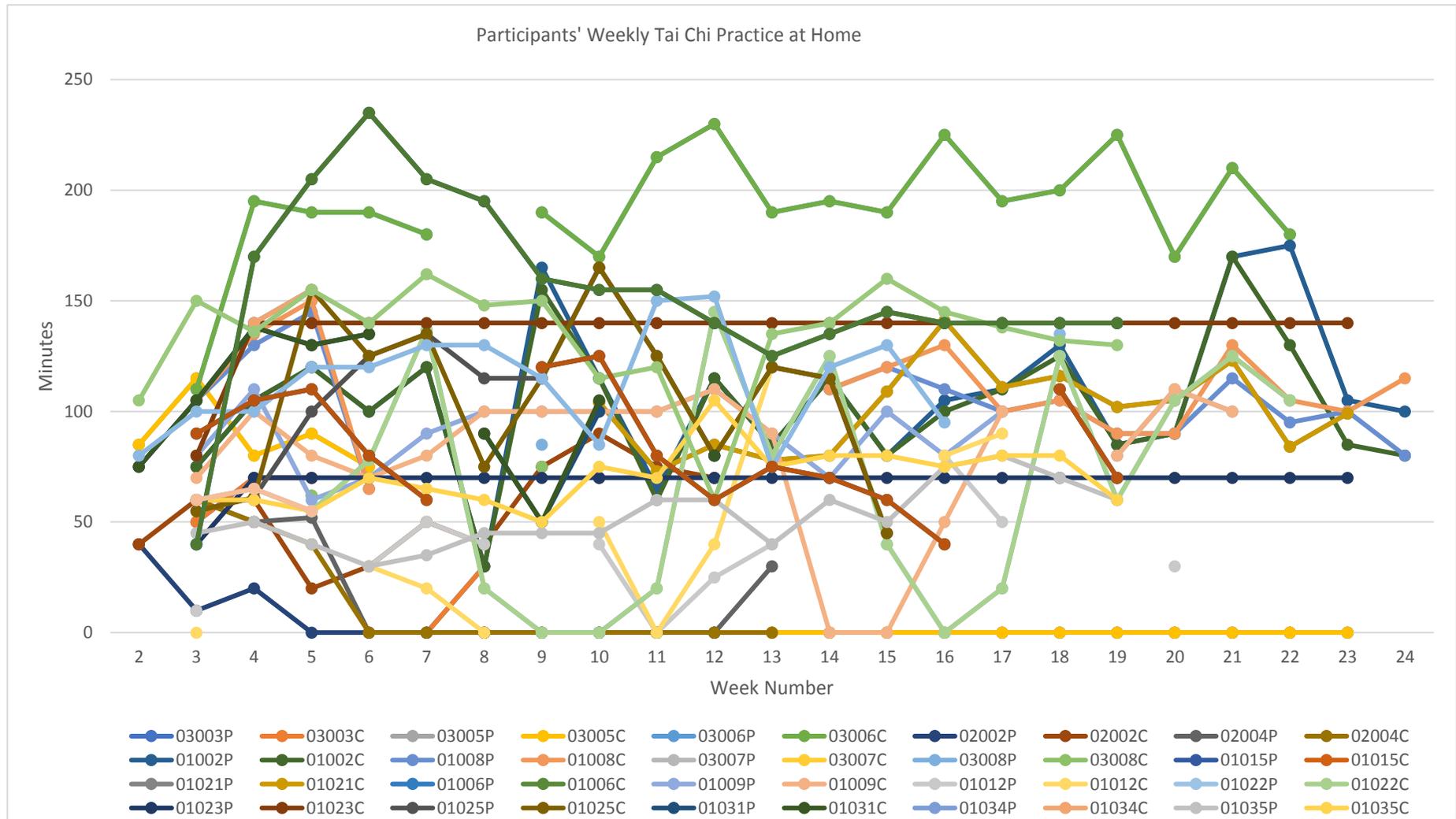


Figure BB 2. Participants in groups 1 to 6's weekly adherence to Tai Chi practice at home.

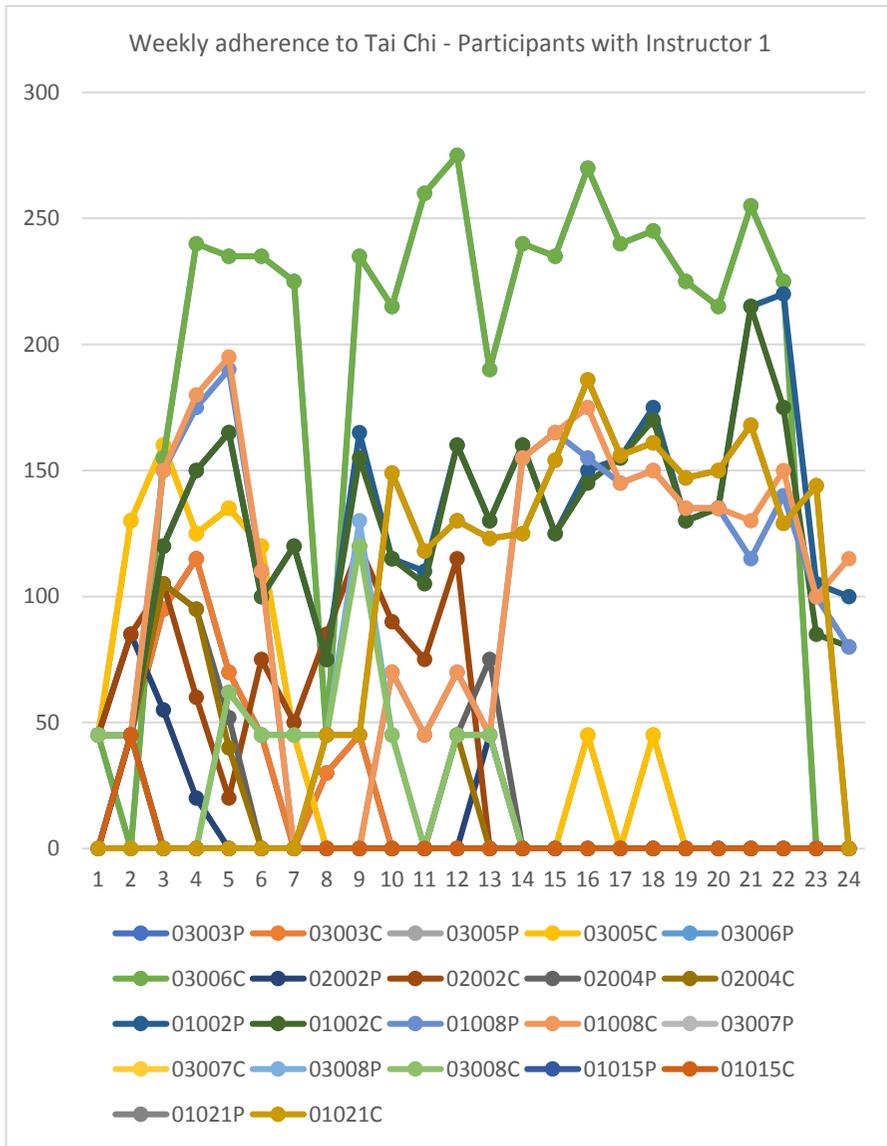


Figure BB 3. Participants with instructor 1 overall's weekly adherence to Tai Chi.

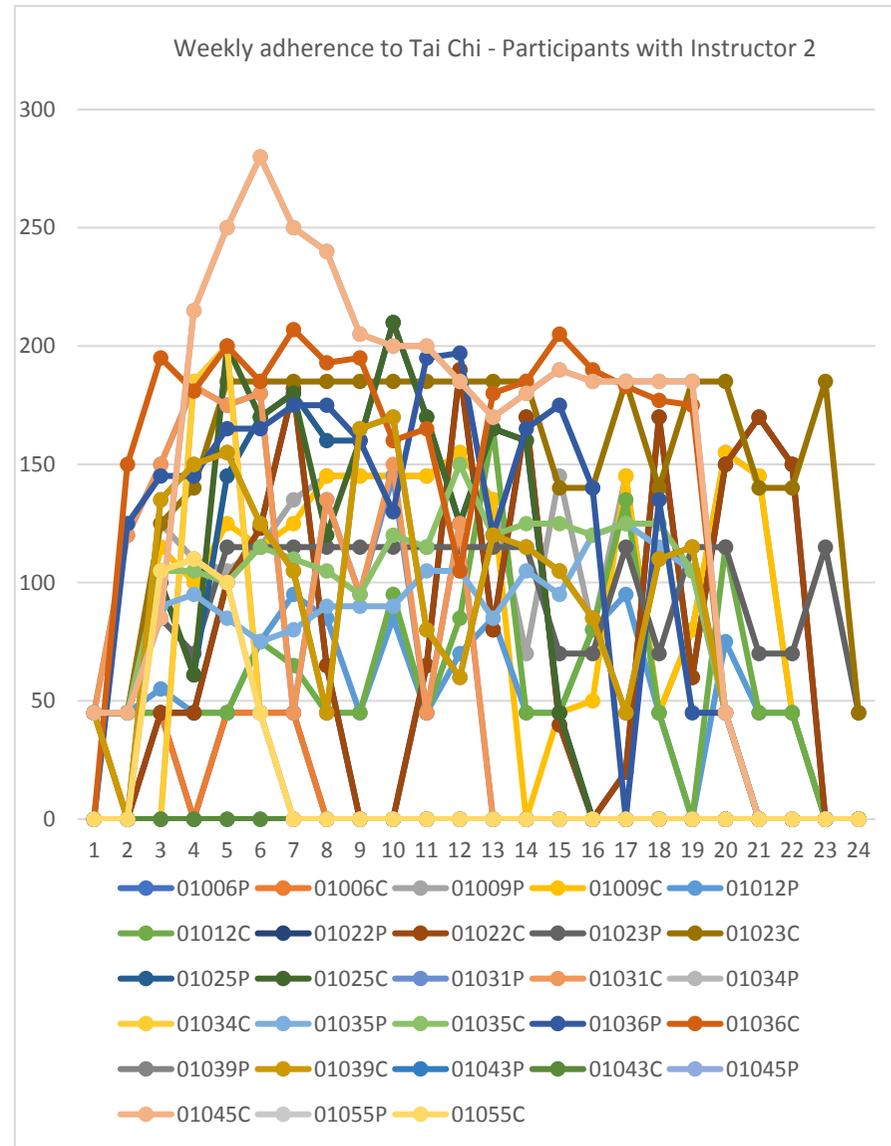


Figure BB 4. Participants with instructor 2 overall's weekly adherence to Tai Chi.

Appendix CC

RCT Venues' Characteristics

Table CC 1. RCT Phase: Characteristics of Venues 1-6

Venue number	Venue type	Natural lighting	Artificial lighting	Ground floor (number of steps if no ramp available)	Flooring type and conditions	Room temperature	Room location and quietness	Kitchen / space to socialise and have refreshments available	Attended reception	Surrounding areas	Car park available within the venue
1	Community centre.	Yes.	Yes.	Yes.	Wooden -in good condition, but slightly sticky.	Comfortable.	Located by the door and in front of the café, but generally quiet.	Only sink available, but refreshments were prepared and enjoyed in the same Tai Chi Room (instructor 1 brought the kettle).	Yes.	Seems a quiet neighbourhood, and the entrance seems to be hidden or separated from main room, however, there seems to be always people attending the café or other activities in the centre.	Yes.
2	Leisure centre.	No.	Yes.	Yes, ramp available at the entrance.	Wooden -in very good condition.	Tends to be cold. Instructor 1 requested heating on but made no difference.	Located at the end of the corridor, next to the fitness room, generally quiet.	No and room booked afterwards, so refreshments need to take place in another room, in another floor.	Yes.	This seems to be a live area, as many people from different ages attend the centre.	Yes.
3	Sports Centre.	Yes (in one of the rooms, not in the second one given).	Yes.	Yes, no steps to the entrance.	Carpet - in very good condition.	Temperature varies, but air-conditioned works very well. Second room can get quite warm if door is closed.	First room was in the middle of the corridor, in quite a large area. Then a small class was offered, much quieter.	Refreshments are provided by the venue.	Yes.	It does not seem to be a busy area, but an area with large supermarkets and factories.	No.

Venue number	Venue type	Natural lighting	Artificial lighting	Ground floor (number of steps if no ramp available)	Flooring type and conditions	Room temperature	Room location and quietness	Kitchen / space to socialise and have refreshments available	Attended reception	Surrounding areas	Car park available within the venue
4	Community Hall.	Yes.	Yes.	Yes – no steps to access the venue.	Wooden -in very good condition.	It can get cold or warm, difficulty is managing the heating during cold weather to find the right temperature for everyone.	The room is in an independent building. It is quiet, as there is no one else around when the Tai Chi class is taking part.	Yes.	No.	It is located very close to the main road of the locality, so there are plenty of shops and good public transport available.	No.
5	Community Hall.	Yes.	Yes.	Yes – no steps to access the venue.	Wooden -in very good condition.	Comfortable.	The room is a huge hall, it is located in front of the main door of the building, but at the time of the classes is generally quiet.	Yes.	No.	It is close to the centre of the locality and well connected by public transport.	Yes.
6	Community Hall.	Yes.	Yes.	Yes, but there are 3 steps at the entrance.	Wooden – in good condition.	Generally good.	The room is in an independent building. It is quiet, as there is no one else is around during the class.	Yes.	No.	It is in a quiet neighbourhood, with Primary School nearby.	No.

Appendix DD

RCT Phase: Contributions per Dyad's Member

