Evaluation of the Effect of Adherence to a Tai Chi exercise intervention on the Quality of Life of older People with Dementia.

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

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Copyright Statement

Abstract

Evaluation of the Effect of Adherence to a Tai Chi exercise intervention on the Quality of Life of older People with Dementia.

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The present PhD aimed to assess effect of adherence to a Tai Chi exercise intervention on the Quality of Life (QoL) of community-dwelling older People with Dementia (PWD) and their carers. It was part of an assessor blind, parallel group, randomized controlled trial conducted in the south of England with 83 dyads (person with dementia and informal carer). The intervention group (N = 42) received 20 weeks of Tai Chi classes and home practice along with treatment as usual, and the control group (N = 41) received treatment as usual only. The present PhD partially derived its data from the main trial. It consisted of three sub-studies. Study-I validated a generic QoL scale, The Investigating Choice Experiments for the Preferences of Older People — CAPability index (ICECAP-O), for PWD. It was found to be a valid and reliable QoL measure for PWD (i.e., face validity, feasibility of administration, internal and external reliability, construct validity and confirmatory factor analysis). Study-II evaluated patterns, predictors and factors affecting adherence and causes of non-adherence to Tai Chi intervention among PWD. Dyad's acute health conditions were found to be the most dominating factor to reduce PWD's attendance to Tai Chi classes. Study-III analyzed predictors of dyad's QoL, effect of their QoL on their adherence to the Tai Chi intervention, and the effect of adherence to the Tai Chi intervention on dyad's QoL. Carer burden was found to be a negative predictor of carers' QoL. However, adherence to Tai Chi intervention improved the QoL of dyads. The present PhD added valuable knowledge in the realms of psychometric evaluation of PWD's QoL, predictors of dyads' QoL and exercise adherence, along with the effects of adherence to an exercise programme on dyad's QoL. The findings will be useful in future policy formation and intervention designs to improve QoL of PWD and their carers.

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Last but not the least I am deeply indebted to the unwavering support of my family and friends, who never let me doubt my potentials, believed in me, and prayed for my success, which enabled me to achieve my goal.

Author's Declaration

This dissertation is submitted in partial fulfilment of the requirements of Bournemouth University for the degree of Doctor of Philosophy. The research described here was conducted under the supervision of Dr Samuel Nyman, and Professor Remco Polman, between September 2016 and January 2022. This is original work except where acknowledgements and references are made to the previous work. This work was a part of the TACIT trial, however the detailed description of my individual contribution which differentiates it from the TACIT trial is provided in chapter 1 (section 1.5). Findings of study-I have been presented in a national conference through a poster presentation. One paper is also expected to be published from study-I.

Dedication

Dedicated to my parents for their endless love and being a constant source of light, power, and meaning in my life.

1 Introduction

The global population is ageing, which has led to a transformation of major health threats (Li et al., 2019; United Nations, Department of Economic and Social Affairs, Population Division, 2019). According to Han et al. (2019) in the early twentieth century the major health threats were communicable diseases, including infections and parasitic diseases, which claimed the lives of infants and children. However, at present there is a rise in non-communicable diseases including, heart diseases, arthritis, and dementia (Han et al., 2019). The risk of developing dementia increases exponentially with ageing (Fratinglioni et al., 2020). With increase in ageing population worldwide, there is risk of sharp rise in the number of PWD in the decades to come (Livingston et al., 2020). According to the World Health Organization (2021) there are more than 55 million PWD worldwide with an annual increase of 10 million new cases. Currently, among all diseases, dementia is the seventh leading cause of death and a major cause of disability and dependence globally for older adults (World Health Organization, 2022). Dementia is a complex disease (Fisher et al., 2016) and has physical, emotional, psychological, and economic impacts for PWD and their carers as well (World Health Organization, 2022; Lindeza et al., 2020).

1.1.1 Dementia as a Long-term Condition

Dementia has been described as “a clinical syndrome that encompasses difficulties in memory, language, and behaviour that leads to impairments in activities of daily living” (Robinson et al., 2015 p.1). It is an umbrella term characterized by two groups of symptoms: cognitive symptoms that include difficulties with memory, communication, and executive functioning; and non-cognitive symptoms that include behavioural disturbances, mood disorders, and psychotic symptoms (Sandilyan & Dening, 2015). Early dementia is marked by cognitive and functional impairments (Giebel et al., 2015). These impairments are reflected in behavioural disturbances (Kosel et al., 2020), which have been divided into four categories: 1) mood disturbances including depression and apathy, 2) sleep disturbance such as reduced Rapid Eye Movement (REM) sleep, 3) agitation, and 4) psychotic symptoms (e.g., delusion and hallucinations) (Desai et al., 2012). Comorbidity of neuropsychiatric disorders such as depression, anxiety, and apathy has also been reported among PWD (Steinberg et al., 2008).

WHO in its Global Action Plan on Dementia (2017, p. 6) illustrates the idea of "a world in which dementia is prevented and people with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy, and equality." WHO's Global Action Plan on Dementia (2017) was devised to ensure better QoL of PWD and their carers/family members, therefore it focused on broader aspects of the lives of both PWD and their carers. Likewise, living well with dementia: a national dementia strategy (2009) was UK's national strategy on dementia, which envisioned creating awareness about dementia, its early diagnosis, improving treatment and care services for PWD and their carers. Its objectives and outcomes involved improvement in QoL of PWD and their carers on each stage of dementia. These strategies highlight the importance of overall well-being and QoL of PWD and their carers. In addition, Public Health England (2019) indicated that for productive healthy ageing the contributing factors include: falls prevention, dementia awareness, physical activity, social connectedness, improving mental health, and balanced diet. Productive healthy ageing is defined as improved health and well-being, social engagement, increased independence and resilience to adversity, financial security, enhanced friendship and support, and enjoying life in good health (UK Health Security Agency, 2017). These aspects of productive healthy ageing were similar to the attributes measured in the QoL scale the ICECAP-O (Coast, Peters, et al., 2008) which was aimed to be validated for community dwelling PWD in the present PhD. Falls prevention among older adults was reported to be one of the contributing factors towards the outcome of productive healthy ageing (Public Health England, 2019), therefore the present PhD attempted to explore effect of adherence to Tai Chi exercise intervention on QoL of PWD and their carers which is a broader and more encompassing construct as compared to falls prevention which was secondary outcome in the TACIT trial. This differentiates the present PhD from the main TACIT trial.

1.1.2 QoL of PWD

Complexity of dementia's signs and symptoms and irreversible neurological damage it causes makes it challenging to maintain QoL of PWD (The National Dementia Strategy for England, 2009). To maintain or improve QoL the basic requirement is to have a clear definition of QoL. There is no universally acceptable definition of QoL in general (Selai & Trimble 1999; Ready et al., 2004; Walker & Lowenstein 2009). In addition, QoL becomes more complex in case of PWD as the population is challenging due to complexity of the condition. Absence of a uniformed definition of QoL of PWD also reflects in QoL assessment approaches for PWD.

PWD's QoL measures are either health-related (e.g., EuroQol 5Dimensions (EQ 5D) (EuroQol Group, 1990*)* or for specific types of dementia (e.g., Quality of Life for Alzheimer's disease (QoL-AD) (Logsdon et al., 1999, 2002)). Health is a means to attain QoL, it is not representative of QoL (Grewal et al., 2006). Therefore, health-related QoL (HrQoL) scales do not provide actual QoL measure for PWD. Likewise, dementia type specific QoL measures are not comparable with cognitively intact older adults. Furthermore, there is reliance on proxy reporting for QoL of PWD, for example Dementia Quality of Life Proxy Version (DEMQOL-Proxy) (Mulhern et al., 2013) and proxy-related Quality of Life in Alzheimer Disease scale (QOL-AD) (Logsdon et al., 1999, 2002), which is often misleading, reflecting carers' bias due to their own emotional or psychological state (Karttunen et al., 2011; Conde-Sala et al., 2009) or level of carer burden (Sands et al., 2004). It is also observed that carers' better rating of PWD's QoL is frequently influenced by PWD's low dependency (Hoe et al., 2006). In addition, proxies are also found to have conflict with self-reported QoL scores of PWD (Hoe et al., 2006; Ready et al., 2004; Thorgrimsen et al., 2003). Therefore, proxy scoring of QoL may only be accepted in unavoidable circumstances, where PWD is completely unable to provide their own opinion about their QoL.

1.1.3 Carers of PWD

Dementia not only affects PWD but carers of PWD as well. The forecasted rise in people with dementia from 57·4 million cases globally in 2019 to 152·8 million cases in 2050 (Kisa et al., 2022) will result in increased number of informal carers. Informal care is usually provided by family members, and it has a vital role in dementia care (Alzheimer's Disease International, 2013). According to The Alzheimer's Association (2012) in the USA 80% of the home care is provided by family. According to Alzheimer's Association (2017) more than 15 million people provide care to PWD in America. The National Dementia Strategy for England: Living well with dementia (2009) regarded carers of PWD as the most valuable resource as 600,000 informal carers of PWD provide £8 billion per annum of unpaid care in the United Kingdom. However, Lewis and colleagues reported in 2014 that currently estimated 700,000 carers of PWD will increase to around 1.7 million by 2050.

Family carers of PWD are a vital source of positive outcomes related to PWD, such as the coresident carers of PWD reduce the risk of PWD's institutionalization many folds (Banerjee et al., 2003). Informal carers of the PWD need support and guidance in their role of care giving (Thompson & Roger, 2013). Increases in the number of dementia cases have raised the need to formally design support programs for informal carer of PWD (Afram et al., 2015).

There are vital concerns about the capacity of existing care providers to cope with the increased demands of care in the future (Macdonald & Cooper, 2007). Even during the initial onset of dementia with only mild cognitive impairments in PWD the carers experience distress (Blieszner & Roberto, 2010). Early intervention is proposed to be effective in reducing carer’s strain and delaying institutionalization of PWD (Kjallman et al., 2013). In the initial onset of dementia carer burden and strain is relatively low which gives an opportunity to the professionals to support the carers in preparing to cope with the future demands of their care role (Verhey & de Vugt, 2013). Boots et al. (2015) reported that while providing care to the PWD the informal carer’s role changes from the previous one. The new care giving role requires certain level of confidence which can be increased by positive experiences including time alone, spending time with PWD or with people from carer’s social network.

1.1.4 QoL of Carers of PWD

Due to the vital role of carers of PWD in providing care to PWD maintenance of their QoL becomes of utmost importance. However, QoL of carers of PWD has similar issues related to its definition and measurement as that of PWD’s. There is lack of consensus regarding cares’ QoL and its measurement (Daley et al., 2019). It is viewed in the context of PWD, which cannot be a true reflection of their actual QoL, because carers’ QoL must be based on their own views about what they consider as their QoL. Therefore, in the present PhD it seemed pertinent to assess carers QoL on the same generic measure of QoL the ICECAP-O, which measures the actual attributes of QoL. It was also found useful to have a comparable QoL measure of PWD and their cares. In addition, it was aimed to investigate factors associated with QoL of carers of PWD to subsequently use this knowledge to improve their QoL.

Exercise has shown to have positive effect on QoL of cognitively intact older adults (Campbell et al., 2021). Likewise, there is some evidence of positive effect of exercise on QoL of PWD (Ojagbemi & Akin-Ojagbemi, 2019). In addition, mind-body interventions involving meditative movements have been shown to have positive effect on improvement in QoL, depressive symptoms, and sleep quality in older adults without mental health conditions, which indicates preventive potential of such interventions (Weber et al., 2020). Therefore, mind-body exercise interventions may also improve QoL of carers of PWD. However, there is requirement to design such exercise interventions which may improve QoL of PWD and their carers simultaneously. WHO (2010) has recommended 150-300 minutes of moderate intensity exercise per week for both cognitively intact older adults and older adults with neurodegenerative disease. Therefore, it is vital to engage PWD and their carers in exercise.

National Institute of Health and Clinical Excellence [NICE]/Social Care Institute for Excellence (2011) has recommended the use of nonpharmacological approaches to benefit PWD. Non-pharmacological approaches focus more on the person than on the disease (Edvardsson et al., 2010). Exercise interventions are such non-pharmacological approaches which have shown to have relative success in management of cognitive and non-cognitive symptoms of PWD (Forbes et al., 2013), maintaining their physical functioning (Pitkälä et al., 2013) and improving their QoL, for example health related QoL (Teri et al., 2003) and Alzheimer’s Disease related QoL (Steinberg et al., 2009). Non-pharmacological approaches including exercise have also been reported to have positive effect on QoL of family carers of PWD (Olazarán et al., 2010).

1.1.5 *Tai Chi and its Impact on QoL of PWD and Carers*

Based on the existing evidence regarding positive contribution of exercise on QoL of PWD and their carers it was pertinent to select such exercise for PWD which is easy for them to follow and perform, and useful for their carers as well. Its slow and gentle movement, repetitive in nature, and involvement of mind and body simultaneously makes Tai Chi particularly suitable for PWD (Huang & Liu, 2015; Tadros et al., 2013). It is also safe for older adults to perform. Tai Chi has been recommended by Public Health England (Foster et al., 2018) and the National Health Services (NHS Choice Framework, 2020) for older adults. Tai Chi Chuan was initially practiced as a form of fighting by older Chinese individuals emphasizing strength, flexibility, speed, and balance. Tai Chi Chuan is a form of martial arts, which is translated as "grand ultimate fist" (Nyman, 2021). It involves Chinese philosophy of Tai Chi (Chang et al., 2010), however, Tai Chi gradually evolved from it into a slow, soft, and gentle form of exercise suitable for all age groups (Tsao, 1995). Qualitative reports about effectiveness of Tai Chi started being published in China in the mid-1970s (Zhuo et al., 1984) and in the western literature in the 1980s (Van Deusen, & Harlowe, 1987). In the present PhD Tai Chi was selected due to its suitability for PWD (Huang & Liu, 2015; Tadros et al., 2013) and usefulness for their carers (Foster et al., 2018).

Tai Chi is a Chinese mind-body exercise, which has shown to have numerous benefits including improvement in cognition, memory, and executive functioning among people with Mild Cognitive Impairment (Whitty et al., 2020), preserving cognitive performance and delaying cognitive decline in PWD (Cheng et al., 2014), improving QoL (Wang et al., 2020; Tajik et al., 2018), and balance (Rogers, 2016) among cognitively intact older adults. Due to its widespread benefits, it was deemed necessary to explore its usefulness for PWD and their carers. There is a gap in the previous research regarding the effect of Tai Chi on QoL of PWD and their carers. Also, it was vital to assess PWD's and their carers' QoL in a broader perspective. Therefore, it was considered in terms of their scores on ICECAP-O instead of restricting it to health related, or specific type of dementia for PWD and viewing it in the context of PWD for the carers.

1.2 Brief Overview of the TAi ChI for People with DemenTia (TACIT) Trial

This PhD project was a part of a Randomized Control Trial (RCT), “Comparing the effectiveness of Tai Chi alongside usual care with usual care alone on postural balance of community-dwelling People with Dementia: The TACIT Trial.” It is pertinent to highlight here the aim of the TACIT trial and rationale for deriving a separate PhD project from it. Subsequently, a detailed account of the present PhD will be provided.

The aim of the TACIT trial was to investigate the effect of a Tai Chi exercise intervention on postural balance of community dwelling People with Dementia (PWD) and their carers. Tai Chi is an ancient mind-body exercise, involving slow, smooth, fluid, and repetitive movements (Huang & Liu, 2015) that makes it suitable for PWD to perform. The trial was a randomized, assessor blind, parallel group (i.e., intervention and control) study. The control group received usual care, while the intervention group received usual care plus the TACIT Tai Chi exercise intervention.

1.2.1 *Role of Present Researcher in the TACIT Trial*

The present researcher was a team member of the TACIT trial, who was responsible for all baseline and post-intervention quantitative data collection for the trial. The trial investigated the effect of Tai Chi exercise on the primary outcome of dynamic postural balance of community dwelling PWD, however it included extensive data collection involving several secondary outcomes.

1.2.2 *Blinding of the Researcher*

In the trial the researcher was blind to the treatment of the participants. To maintain blindness of the researcher a few steps were taken including informing the participants in advance on call to keep their allocation hidden from the researcher during the post intervention visit. They were also reminded at the beginning of the post intervention data collection session to keep it hidden. However, there were still instances in which due to rapport with the researcher, or by chance participants revealed their allocation leading to unblinding the researcher. In such cases it was recorded in the data forms to ensure accuracy of data collected. The researcher collected baseline and post intervention data, therefore, the researcher was also blind to the data pertaining to Tai Chi exercise intervention i.e., allocation of participants to treatment and control groups, Tai Chi class attendance, causes of absence from Tai Chi class(es), Tai Chi home practice, mid-way data (i.e., after 10 sessions of Tai Chi) related to enjoyment, confidence, and intention to come to remaining Tai Chi classes, and data pertaining to withdrawal of participants from the TACIT trial. Data pertaining to Tai Chi exercise intervention was collected by another unblind researcher who was also a PhD student.

1.2.3 Distinction between the TACIT trial and the Present PhD

Data for the present PhD was derived from the TACIT trial, however, it was different in its aims, objectives, outcomes, data collection (some of the data for the present PhD was derived from outside the trial (see Study-I, sections 5.4 and 5.5 for detail). Moreover, only data relevant to the present PhD was taken from the trial), data analysis, and results. See Table 1 (appendix M) for detailed description of differences between present PhD and the TACIT trial and contribution of the present researcher in both.

Table 1:

Distinctions between present thesis and the TACIT trial and contribution of present researcher in both (appendix M).

1.3 Brief Overview of the PhD

Although the present PhD was a part of the TACIT trial, its aims and objectives were different from the main trial. Its aims included validation of a generic QoL scale - the ICECAP-O - for PWD (study-I), investigation of adherence to Tai Chi exercise intervention among PWD (study-II), and effect of adherence to Tai Chi exercise intervention on QoL of community dwelling PWD and their carers (study-III). The present PhD mainly focused on class-based Tai Chi exercise adherence. Home-based Tai Chi exercise adherence among PWD was not explored in depth as it was assessed by another researcher in terms of influence of action plan and coping plan on home-based adherence among PWD. Therefore, the present study focused on PWD’s class adherence only, however, association between home-based practice and class adherence among PWD was assessed in the present study (see study-II for rational of the comparison). Moreover, the effects of both class and home-based Tai Chi exercise on QoL of PWD and only class-based Tai Chi exercise on QoL of their carers was investigated (as data for carers’ home-based practice was not available) (see study-III for detail). Objectives of the present PhD were as follows:

1.3.1 Primary Objectives

1. To determine construct validity, face validity (in terms of readability and comprehension), feasibility of administration, test retest (external) and Cronbach alpha (internal) reliability, and factorial structure (in terms of confirmatory factor analysis) of a generic QoL measure the ICECAP-O for community dwelling PWD.
2. To assess patterns, baseline predictors, factors associated with adherence during intervention phase, causes of nonadherence to class-based Tai Chi exercise intervention and comparison of adherence to home and class-based Tai Chi practice among community dwelling PWD.

3. To assess factors associated with QoL of PWD, association of baseline QoL with their adherence to home and class-based Tai Chi practice, and effect of adherence to home and class-based Tai Chi exercise on their QoL.

1.3.2 Secondary Objectives

1. To assess factors associated with QoL of carers of PWD.
2. To investigate association between carers' baseline QoL and their adherence to class-based Tai Chi intervention.
3. To assess effect of adherence to class-based Tai Chi exercise intervention on QoL of carers of PWD.

1.3.3 Primary Outcomes

Primary outcomes of the present PhD were:

1. Psychometric validation of generic QoL measure the ICECAP-O for community dwelling PWD.
2. QoL of community dwelling PWD measured with a generic QoL measure ICECAP-O, which was earlier validated for them.
3. Adherence to Tai Chi exercise intervention among PWD.

1.3.4 Secondary Outcome

QoL of carers of PWD was the secondary outcome of the present study, which was also measured using ICECAP-O.

1.3.5 Rationale of the Present PhD

As mentioned above the TACIT trial aimed to evaluate the effect of Tai Chi exercise intervention on postural balance of community dwelling PWD and their carers. However, the PhD mainly focused on the effect of Tai Chi exercise intervention on QoL of community dwelling PWD. Tai Chi has shown to have a positive effect on QoL of cognitively intact older adults (Wang et al., 2020; Tajik et al., 2018) and individuals with neurological conditions other than dementia (Taylor-Piliae et al., 2014; Hakney & Earhart, 2009), however, its effect on QoL of PWD has not been investigated previously. Therefore, considering the usefulness of Tai Chi for QoL of cognitively intact older adults and a gap in the existing knowledge regarding PWD, it was pertinent to explore the potential benefit of Tai Chi for QoL of PWD. It was aimed to evaluate adherence to Tai Chi exercise intervention among PWD to assess its ease and feasibility of administration for PWD. Moreover, to measure the actual attributes of QoL of PWD ICECAP-O (a capability based generic QoL scale (Coast, Peter et al. (2007)) was selected in the TACIT trial, however the scale was validated for older adults in general and required psychometric validation for community dwelling PWD. The aim of the present study was to validate ICECAP-O for community dwelling PWD.

1.3.5.1 Validation of ICECAP-O for PWD

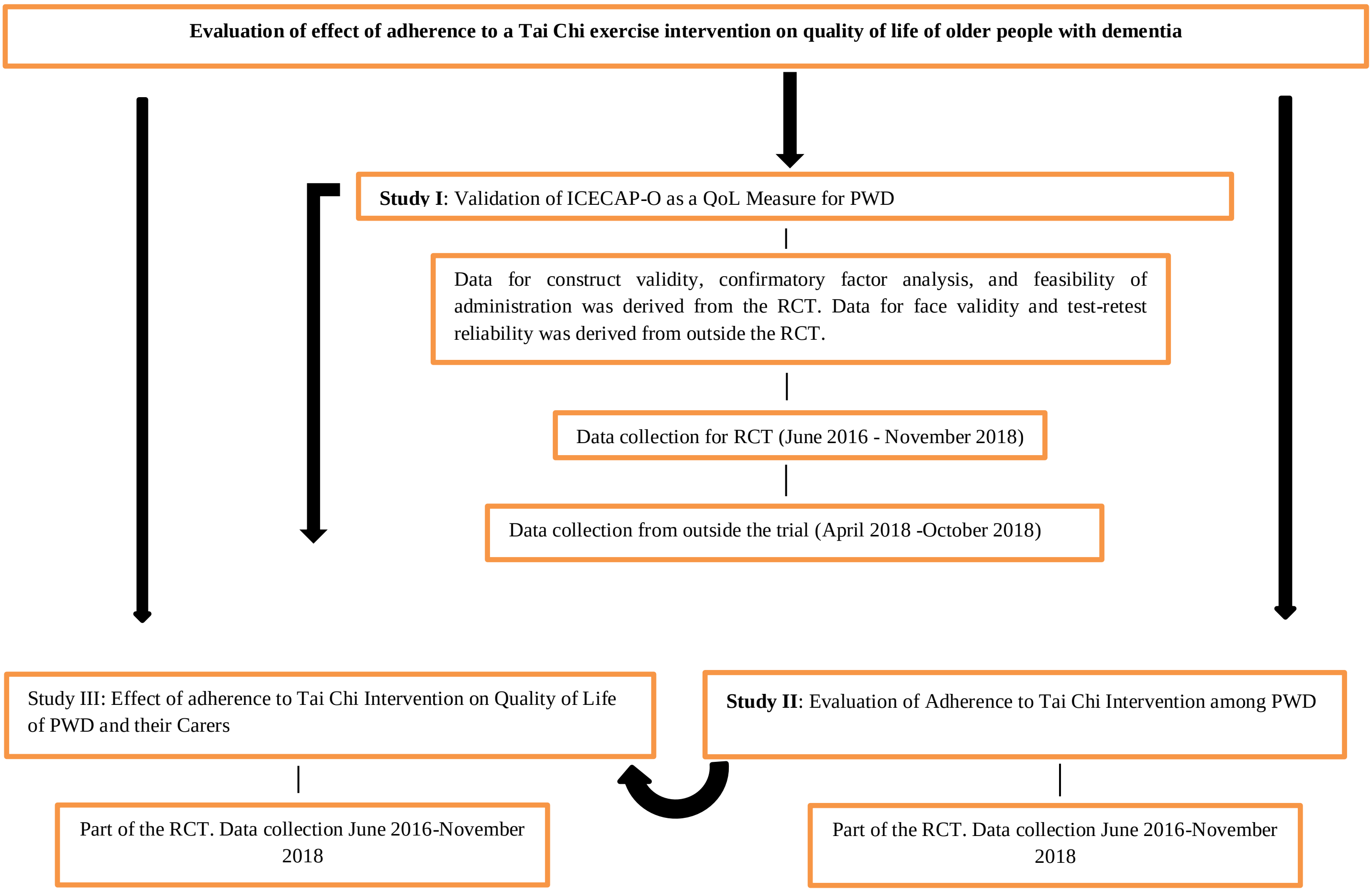
In the present PhD the WHOQOL Group’s (1995, p. 1405) definition of QoL, “individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” was considered as representative for PWD. Coast, Peter et al. (2007) generic QoL scale the ICECAP-O resonates with the WHO definition of QoL. It is already validated for cognitively intact older adults. It is based on Grewal et al. (2006) concept of QoL that attributes of QoL are not restricted to health but are more encompassing and broader. There was no such measure of QoL available for PWD. Therefore, it was aimed to fill this gap and validate a generic QoL measure for community dwelling PWD, which measures actual attributes of QoL and is comparable with cognitively intact older adults.

1.4 Study Design:

The PhD consisted of three interrelated studies. They contributed towards evaluation of the effect of adherence to Tai Chi intervention on QoL of PWD and their carers. To measure QoL a scale i.e., ICECAP-O was validated for PWD (Study-I). It was also used to measure QoL of carers. To understand adherence to Tai Chi intervention among PWD, predictors, and associated factors of adherence along with causes of non-adherence of PWD to class-based Tai Chi exercise were explored (Study-II). Moreover, the effect of adherence to home and class-based Tai Chi exercise intervention on QoL of PWD and effect of adherence to class-based Tai Chi exercise on QoL of carers of PWD was evaluated. In addition, factors associated with QoL of PWD and their carers, and association of PWD and their carers' QoL with their adherence to Tai Chi exercise intervention were also explored (Study-III). Study-II and III were part of the TACIT trial, while Study-I was partially conducted outside the trial (i.e., data for test-retest reliability and face validity was collected outside the main trial). See figure 1 for an overview of study design. Detailed description of study design is given in Chapter 4 "Methodological underpinnings."

Figure 1:

Illustration of overall PhD study design



1.5 Overview of Thesis

The present thesis has been structured around the following chapters:

1. Chapter 1. Introduction: explains different terms and concepts involved in this thesis (i.e., dementia, PWD, carers of PWD, QoL of PWD and their carers, Tai Chi and its impact on QoL of PWD and carers) also overviews the TACIT trial, distinctions between TACIT trial and the present PhD, and highlights aims, objectives, outcomes and rationale for the PhD.
2. Chapter 2. Literature review: provides an in-depth review of the research conducted around the QoL of PWD and their carers, Tai Chi, adherence to Tai Chi exercise

intervention, effect of exercise interventions including Tai Chi on QoL of older adults, PWD, and carers of PWD to strengthen the rationale and unique contribution of the PhD.

3. Chapter 3. Systematic Literature Review of Existing Studies related to Evaluation of Psychometric Properties of ICECAP-O: comprises a systematic literature review involving any attempts previously made to determine the psychometric properties of the ICECAP-O for older populations to inform the methodology of study-I of the PhD i.e., validation of ICECAP-O as a QoL measure for PWD.
4. Chapter 4. Methodological underpinnings: explains and justifies this thesis' methodology, the methods chosen, as well as the ethical consideration. It also elaborates the research design, including its time frame.
5. Chapter 5. Study- I: Validation of ICECAP-O as QoL Measure for PWD: demonstrates the psychometric validation of a QoL scale ICECAP-O for community dwelling PWD.
6. Chapter 6. Study- II: Evaluation of Adherence to Tai Chi Intervention among PWD: illustrates patterns of Tai Chi class attendance, causes of lack of adherence to Tai Chi exercise classes, predictors, and factors of adherence among PWD, and association between their home-based practice and class adherence.
7. Chapter 7: Study- III: Effect of Adherence to Tai Chi on QoL of PWD: provides detailed assessment of QoL of PWD and their carers, and effect of Tai Chi adherence on their QoL.
8. Chapter 8: Discussion: discusses the overall findings of the study in detail.
9. Chapter 9: Conclusion: provides a summary of the main findings of the thesis, recommendations for future research, and practical implications.

1.6 Summary

The present PhD was a part of a RCT the TACIT trial, which aimed to explore the effect of Tai Chi exercise intervention on postural balance of community dwelling PWD to ultimately prevent falls in them. Falls including injurious falls among PWD are likely to be twice as higher than their cognitively intact counter parts, which may result in adverse health consequences for PWD. Therefore, it was vital to design an intervention to facilitate prevention of falls among PWD by improving their dynamic balance. Tai Chi has proven benefits for postural balance and falls prevention among older adults therefore, it was selected as the intervention exercise in the TACIT trial. Tai Chi due to its gentle, protective, and repetitive nature of movements was also considered suitable for PWD. Sample for the TACIT trial was recruited as dyads (PWD + their carers). Effect of Tai Chi exercise intervention on postural balance of carers of PWD was also explored. The present PhD, however, evaluated the effect of adherence to Tai Chi exercise intervention on QoL of PWD and their carers which was different than the main trial. Dementia affects QoL of PWD and their carers (The National Dementia Strategy for England, 2009; Daley et al., 2019). Tai Chi improves QoL of cognitively intact older adults (Wang et al., 2020; Tajik et al., 2018) therefore, it was aimed to explore its usefulness to improve QoL of PWD and their carers. In addition, validation of a generic QoL scale the ICECAP-O was considered necessary to fill the gap in the existing measures of QoL of PWD, which are either for HrQoL or for specific type of dementia. The present PhD was conducted in the form of three inter-related studies. Detailed review of existing literature on all aspects of the present PhD and the three studies will be reported in the next chapters.

2 Literature Review

This chapter consists of review of QoL of PWD and their carers, and adherence to Tai Chi exercise intervention and its effect on QoL of PWD and their carers. Due to limited research regarding effect of adherence to Tai Chi exercise intervention on QoL of PWD and their carers the review extended to include effect of exercise intervention including Tai Chi exercise on QoL of older adults in general, PWD, and carers of PWD. This chapter is divided into four sections: 1) aim, 2) method and search strategy, 3) results (reviewed literature), 4) summary.

2.1 Aim

The literature review critically analysed the concept of QoL of PWD and their carers and how it can be improved. It aimed to address the following questions:

1. How is QoL of PWD and their carers defined?
2. What factors influence QoL of PWD and their carers?
3. How is QoL of PWD and their carers measured?
4. Which interventions including exercise interventions influence QoL of PWD and their carers?
5. How adherence to exercise intervention among older adults including PWD is defined and measured?
6. How adherence to exercise interventions contribute to QoL of PWD and their carers?
7. What factors affect adherence to exercise interventions among older adults including PWD?

2.2 Method and Search Strategy

Systematic search and review type (Grant & Booth, 2009) literature review was conducted, which combines critical review with comprehensive search process. This style of review was followed due to its broad scope as it incorporates multiple study types unlike systematic review focusing on a single study design. The review style complemented the aim of the literature as it addressed broader questions and focused on bringing about best evidence synthesis. Inclusion of multiple types of studies provides a complete picture of the research available in a particular domain therefore, it was suitable for the present literature review. The resultant literature was subsequently reviewed critically by the researcher as in such review type a standardized tool or checklist is not required. The following inclusion/exclusion criteria was followed for the systematic searches.

2.2.1 Inclusion Criteria:

Included studies involving:

1. Older adults both cognitively intact and with neurological conditions including dementia.
2. PWD and their carers.
3. QoL of older adults including PWD and their carers.
4. Assessment of QoL of older adults including PWD and their carers.
5. Interventions for QoL of older adults including PWD and their carers.
6. Adherence to interventions including exercise intervention among older adults with or without dementia.
7. Tai Chi.

2.2.2 Exclusion Criteria:

Included studies involving:

1. Younger adults > 60 years.
2. Pharmacological interventions.

Systematic searches were conducted between October 2016 to September 2017, which was later updated in January 2022. Bournemouth University e-resources were used to search across the databases (MEDLINE, Web of Science, Science Direct, Sage, PsycInfo, PubMed, PsycBooks, google scholars). Keywords included, dementia, people AND dementia, quality of life AND dementia, carers AND dementia, carers AND people AND dementia, carers AND quality of life AND dementia, ICECAP-O AND quality of life, exercise AND intervention AND older, Tai Chi AND older, Tai Chi and quality of life, quality of life AND assessment AND older, quality of life AND measures AND dementia, adherence AND exercise AND older, adherence AND exercise AND intervention, factors AND adherence AND exercise AND older. There was no time restriction in the search strategy.

2.3 Result (Reviewed Literature)

The literature review included characteristics of dementia and carers of PWD, QoL of PWD and their carers, factors associated with their QoL, measures of existing QoL of PWD and their limitations, measures of QoL of carers of PWD, ICECAP-O as measure of quality of life, which measure actual attributes of QoL, characteristics of Tai Chi, factors affecting adherence to exercise interventions among older adults including PWD, and the effects of Tai Chi intervention on QoL of PWD and their carers. This literature review highlights the gaps in the existing knowledge and forms the basis on which the PhD hypotheses were formulated.

2.3.1 Quality of life (QoL) of People with Dementia (PWD)

To understand QoL among PWD and how it is affected by various contributing factors it is important to develop insight in the concept of QoL. Such understanding will facilitate attempts to improve and sustain the QoL of PWD. QoL is a complex term and there has been disagreement on its definition and its constituents. No universally acceptable definition for it has emerged as yet (Selai & Trimble 1999; Ready et al., 2004; Walker &

Lowenstein 2009). However, there is general agreement that it is a multidimensional construct that includes psychological, emotional, physical, and social components of wellbeing (Birren & Dieckermann, 1991). Brown et al., (2004) proposed specific factors affecting QoL among older people. In their systematic review they included 45 studies on the QoL of older people and suggested nine significant contributing factors. These factors included relationship with family, relationships with others, personal health and health of close ones, independence, emotional and psychological health, religion or spirituality, standard of living or finances, and leisure activities. Their systematic review advanced understanding of the difference between factors affecting QoL and the actual attributes of QoL among older people (Coast, Peters, et al., 2008; Grewal et al., 2006).

However, understanding of QoL among PWD was facilitated by Lawton (1983, 1991, 1997) who extensively explored this concept. He proposed that it has both objective and subjective dimensions which are based on four components including the PWD's behaviour, objective environment, perceived quality of life, and psychological wellbeing. This concept of PWD's QoL is comparable with World Health Organization's definition of older adults' QoL in general, which states "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHOQOL Group, 1995, p. 1405). It includes both objective and subjective dimensions of QoL. It also aligns with the actual attributes of QoL including attachment, role, enjoyment, security, and control as proposed by Coast and colleagues (2008). Therefore, the World Health Organization's definition of QoL will be followed in the present thesis as it is broad and more encompassing. Moreover, the demarcation established between factors affecting QoL and actual attributes of QoL among older adults (Coast, Peters, et al., 2008; Grewal et al., 2006) along with dimensions of QoL among PWD as proposed by Lawton (1983, 1991, 1997) warrant the requirement of developing a comprehensive and representative measure of QoL for PWD. Various attempts have been made to develop different measures for QoL among PWD, however, these measures have their own limitations. A brief overview of some of them is provided below.

2.3.2 *Measurement of QoL of PWD*

Currently there are several QoL measurement scales available for use with PWD. These are either designed for HrQoL (e.g., EuroQol 5Dimensions (EQ 5D) (EuroQol Group, 1990)) and Dementia Quality of Life (DemQoL) (Mulhern et al., 2013)) or for specific sub-types of dementia (e.g., Quality of Life for Alzheimer's disease (QoL-AD) (Logsdon et al., 1999, 2002)). The misconception that QoL of PWD is mainly concerned with HrQoL needs to be addressed. Grewal et al. (2006) refuted this pre-conception by highlighting that health is a means to attain QoL among older adults. Hence, it cannot be attributed as QoL itself. QoL may be rated by older adults in the context of their current health. However, health is not the only representative measure of QoL among older adults. This demarcation led the way towards measurement of capabilities of older adults to ascertain their QoL.

Proxy measures for QoL of PWD are also available such as the Dementia Quality of Life Proxy Version (DEMQOL-Proxy) (Mulhern et al., 2013) and proxy-related Quality of Life in Alzheimer Disease scale (QOL-AD) (Logsdon et al., 1999, 2002). However, Karttunen et al. (2011) reported that the proxy measure QOL-AD can be misleading as in their study the carer's rating of QoL of the PWD was affected by prevalence of depression among carers. Likewise, Arons et al. (2013) reported that proxy ratings of HrQoL of Alzheimer's patients was affected by carers' own HrQoL; carers with higher self-reported HrQoL tended to also rate the PWD they care for as having high HrQoL. Furthermore, Sheehan et al. (2012) compared results of self-reported and proxy measures of HrQoL among people hospitalised with moderate to severe dementia and found discrepancies in reports. Self-rated and proxy measures of Quality-of-Life Alzheimer's Disease (QoL-AD) (Logsdon et al., 1999, 2002) and European Quality of Life 5 Dimension (EQ-5D) (Mulhern et al., 2013) scales were used. PWD rated their QoL higher than their carer’s proxy ratings. EQ-5D proxy ratings were found to be associated with impaired Instrumental Activities of Daily Living (ADL) and more severe dementia, whereas QoL-AD proxy ratings were found to be associated with severity of dementia only. Keeping these associations into account they suggested that proxy measures of QoL are the only practical option for people with moderate to severe dementia. They also reported that lower patient scores on EQ-5D were associated with carer’s stress, whereas lower QoL-AD patient scores were associated with patient’s impaired ADL, their depression and proxy psychiatric symptoms. These associations of patients’ rating of their QoL with various factors of QoL are equally important as those of proxy QoL associations, therefore, it seems less plausible to attribute proxy ratings as the only viable method of measuring patients’ QoL.

It is pertinent to highlight that feasibility of administration of proxy measures does not guarantee that these measures can be used as an alternative form of measurement in all cases. Discrepancies in the patient and proxy ratings of QoL of PWD put further emphasis on requirement of validation of self-reported QoL scales. Proxy rating can be biased due to personal judgement factors which requires cautious consideration. In addition, due to its conflict with self-reported scores, proxy measures of PWD’s QoL are not well-aligned with the concept of person-centred care, which is a holistic approach of care provision to PWD including their psychosocial, emotional, and physical well-being (Heuer & Willer, 2020). It keeps PWD at the centre of decision making regarding all aspects of their lives including care decisions (Douglas et al., 2018). It is also related to the World Health Organization’s broader definition (WHOQOL Group, 1995, p. 1405) and Coast et al. (2008) concept of actual attributes of QoL, which is the focus of the present PhD. Therefore, it is advisable that proxy measures may be used only in unavoidable circumstances where the patient is considered to be completely unable to self-report. In this context requirement of validation of self-report QoL scales for PWD to measure broader dimensions of QoL becomes more crucial.

2.3.3 ICECAP-O as a Measure of QoL of PWD

There is one existing scale, the ICECAP-O, which has been developed by Coast et al. (2008) for general QoL of cognitively intact older adults. It is based on the attributes of QoL introduced by Grewal et al. (2006). It measures actual attributes of QoL instead of factors responsible for QoL or being specific to any one dimension of QoL.

The concept of attributes of QoL and the distinction between attributes of and factors contributing to QoL was introduced by Grewal et al. (2006). They conducted in-depth interviews with 40 older participants concerning what older adults regarded as contributing to their joy and pleasure towards their QoL. It also involved information about the factors which if missing would reduce QoL of older people. They divided the factors regarded by older adults as contributing to QoL into six broad categories: 1) activities or doing something, 2) home or surroundings, 3) family and other relationships, 4) standard of health, 5) standard of living or wealth and 6) religion, faith or spirituality. They also documented the factors which contributed to a reduction in QoL of older people. These included: 1) bereavement, 2) requirement to provide informal care, 3) poor health and 4) financial concerns. Finally, they proposed the attributes of QoL identified by older adults as being affected by these positive and negative factors. These attributes of QoL were: 1) Attachment, 2) role, 3) enjoyment, 4) security, and 5) control. Each of the attributes can be affected by several factors reported. Likewise, one factor can contribute to more than one attribute.

Using the attributes of QoL identified by Grewal et al. (2006), Coast and colleagues (2008) developed the ICECAP-O scale to measure QoL based on capability wellbeing among general older adult population. The capability theory of Sen (1993) underlines the development of the ICECAP-O. In his theory, Sen differentiated between capabilities and functions. He suggested that despite being capable of functioning in certain ways some people may not choose to do so. Therefore, their choice to not function in certain ways doesn't undermine their capabilities to function. As such a distinction between capabilities and functioning is required. The scale (ICECAP-O) measures the five attributes of QoL based on capabilities of older adults (i.e., attachment, security, role, enjoyment, and control). Coast and colleagues (2007) found that the QoL of older people decreased in line with a decline in their ability to attain different attributes of QoL. Later, psychometric validation of the ICECAP-O (Coast et al., 2008) measure was carried out and this will be briefly discussed in the next chapter. Although the scale is developed for general older population it would be worthwhile endeavour to extend the scope of this scale to assess QoL of PWD. If found applicable to PWD the measure can clarify general QoL of PWD and efforts can be made to improve it overall.

2.3.4 *Factors associated with PWD's QoL*

There is a complex array of factors affecting QoL of PWD including demographic, physical, psychological, social, and religious. Jing et al. (2016) noted that these factors vary across different living arrangements of PWD, their severity of dementia, and perspective through which they are reported e.g., PWD, their carers, or care staff. Martyr et al. (2018) highlighted positive factors associated with QoL of PWD including greater social engagement of PWD, better quality of relationship with carers, better QoL of carers, and better health related QoL of PWD, spousal carers, and living in the community. Moreover, PWD's demographic characteristics including higher education, male gender, white ethnicity, extroversion, and being widowed were reported to be positive factors associated with their QoL (Jing et al., 2016). Likewise, living in own home (Nikmat et al., 2015), social connectedness, and less isolation (Nikmat et al., 2015), active participation in daily physical activity and leisure activities (Jing et al., 2016), having more autonomy (O'Rourke et al., 2015), and better quality of relationship with carers and family members (Clare et al., 2014) were also found to be positive factors affecting PWD’s QoL. However, a number of factors negatively affecting QoL of PWD have also been highlighted including increase in age (Banerjee et al., 2006), more severe dementia (Marventano, 2015; Mjørud et al., 2014), and increasing number of chronic health issues (Jing et al., 2016). Holopainene et al. (2019) in their scoping review categorized factors associated with PWD’s QoL as sociodemographic, related to dementia, and related to social and care environment. Sociodemographic factors were not found to be related to PWD’s QoL. Dementia related factors which were negatively associated with PWD’s QoL included: Lewy body dementia, early onset, depression in early or middle stage dementia, anxiety, agitation, pain, and dependence on assistance in activities of daily living. Factors related to social environment which promoted QoL among PWD included: contact with family members or other residents of care facility, feeling of being heard, understood, and received required help when needed. While negative factors related to social environment included: lack of opportunity to interact and communicate, feeling of not belonging, and loneliness. Whereas factors related to care environment which positively affected PWD’s QoL included: home-like environment, sufficient caring staff with relevant training to support PWD.

In the above sections, QoL of PWD, factors associated with it, the existing scales to measure it along with their limitations have been discussed. It has been argued that the ICECAP-O has the potential to be a valid measure for the QoL of PWD. However, there is another relevant dimension of QoL that requires attention, i.e., the QoL of informal carers of PWD. As it has been highlighted above that better quality of relationship with carers and family members (Clare et al., 2014), spousal carers (Jing et al., 2016), living at own home with family and friends, connectedness with family and friends, and being less isolated (Nikmat et al., 2015) affect PWD’s QoL positively. Therefore, QoL of carers seem to have a great impact on the QoL of PWD, hence, there is requirement to pay attention to this aspect as well to ultimately improve QoL of PWD.

2.3.5 QoL of Carers of PWD

Caring for PWD is a challenging responsibility. Many valued aspects of carers of PWD's lives are affected by their caring responsibilities including relationships, leisure activities, work, plans, and future expectations (Daley et al., 2019). Caring PWD can have detrimental physical, psychological, and financial effect on carers (Lakey et al., 2012). Carers of PWD have more anxiety, stress, and depression as compared to carers of other disorders, which suggests that caring for PWD is more impactful (Moise et al., 2004). It suggests that major factors associated with QoL as indicated by World Health Organization (1997) including physical and psychological health, independence, and relationships are affected while caring for PWD. As carers of PWD are a vital source of support for the economy (Chari et al., 2015) and PWD's well-being (Knapp et al., 2016; Banerjee et al., 2003), therefore, there is crucial requirement to focus on improvement in their QoL. To improve their QoL it is vital to understand factors associated with it and its assessment in broader perspective to include their own independent point of view about their overall QoL. Therefore, the following sections will review measures of QoL of carers of PWD and factors associated with their QoL.

2.3.6 Measurement of QoL of Carers of PWD

QoL of PWD is measured with self-rated and proxy measures of QoL scales, whereas QoL of carers is measured indirectly in context of the level of needs met related to their care role (Black et al., 2012). The more of the carers' needs are met, the better QoL of carer is regarded. However, this approach towards measurement of QoL of carers of PWD is reflective of a dearth of assessment tools for actual QoL of carers of PWD. QoL is a distinct construct which can be measured irrespective of the context of needs met related to the care role. It also signifies the fact that identification and use of appropriate measures for QoL of carers of PWD is vital to derive logical conclusion related to improvement in their QoL. There is requirement to measure QoL of carers of PWD using validated scales of QoL for general population which encompass general dimension or actual attributes of QoL.

In addition to factors associated with QoL of carers of PWD such as care burden and unmet needs of PWD, previous studies have also focused on the interventions related to outcome measure of QoL among carers of PWD. These interventions are also indicative of a lack of accuracy of QoL measurement for dementia carers. Van Mierlo et al. (2012) reported in their systematic review article that five studies were identified involving psychosocial intervention related to QoL of carers of PWD. These interventions included: a home-environment skill building programme (Gitlin et al., 2003), an individualised intervention focusing on coping and information (Moniz-Cook et al., 2008), attending memory clinic (LoGiudice et al., 1999), an education and support programme (Millan-Calenti et al., 2000), and telecare (Strawn et al., 1998).

The interventions reported to have positive effect on QoL of carers of PWD, however, each intervention study defined QoL differently. Gitlin et al. (2003) attributed QoL of carers as care burden and carer well-being in specified domains of care e.g., less upset with memory related and disruptive behaviour of the PWD, better affect, over all well-being and mastery. QoL of carers is not reported as subjective perception of an individual’s own QoL, rather it is viewed in the context of being less upset at PWD’s upsetting behaviours and feeling better in the context of skills learned during the intervention. Carer’s QoL has to be addressed as a separate construct which may or may not be affected by providing care for PWD, instead of being linked to the behaviour of PWD. Behaviour of PWD can be a contributing factor in compromised QoL of carers of PWD, it is not logical to regard its impact as QoL of carer. Moniz-Cook et al. (2008) categorized QoL of carers of PWD into two categories HrQoL and carer disease specific QoL. Grewal et al. (2006) and Coat and colleagues (2008) have refuted the idea of health being representative measure of QoL of a person, therefore, this study has limited scope as regards QoL of carers of PWD. LoGiudice et al. (1999) in their pilot RCT measured QoL in terms of psychosocial health e.g., functional limitations including social interaction and alertness behaviour, these concepts are also not a true representative of QoL. These attributes can be reflective of a specific dimension of QoL of carers, however, they cannot be regarded as representative measure of QoL of carers. Millan-Calenti et al. (2000) measured QoL of carers in terms of their anxiety. Likewise, Strawn et al. (1998) regarded stress, anxiety, mood, general health, and care burden as QoL.

All these studies are indicative of the fact that QoL of carer of PWD is not a well-defined concept and no consensus has been achieved so far regarding a representative definition of QoL of carer of PWD. In addition, none of these studies have used a specific scale developed for measuring QoL of carers of PWD, carers in general, PWD or general population. This fact highlights the scarcity of accuracy with regards to investigation of QoL of carers of PWD. It also signifies the requirement of more research in this domain to add to existing knowledge and to improve QoL of carers of PWD.

In the backdrop of the above it is plausible to consider QoL of carers as a distinct property, which may have its own measurement tools. It is also important to consider how carers of PWD view their own QoL. In a qualitative study conducted by Vellone et al. (2008) carers of PWD regarded good QoL as serenity, tranquillity, freedom, financial stability, psychological well-being, good health, and general well-being. They highlighted factors which they considered to have improved their QoL including good health of PWD, independence from the PWD, and more support in care giving responsibilities. They also reported the factors which worsened their QoL including: worries about the future, progression of illness of PWD, and stress.

The characteristics of QoL highlighted by carers in Vellone et al. (2008) study were similar to the concept of QoL provided by Grewal et al. (2006) as they reported that there were five attributes of QoL i.e., 1) Attachment, 2) role, 3) enjoyment, 4) security, and 5) control. On the basis of these attributes Coast et al. (2006) developed the ICECAP-O which has five items i.e., 1) Love and friendship (attachment) 2) Thinking about the future (security) 3) Doing things that make me feel valued (role) 4) Enjoyment and pleasure (Enjoyment) 5) Independence (control). The attributes of QoL i.e., serenity and tranquillity are somewhat similar with the factors of QoL i.e., religion, faith or spirituality, presented by Grewal et al. (2006). Likewise, the attribute of freedom resonates similarity with independence and control. Independence has also been highlighted as one of the factors contributing in QoL by participants in Vellone and colleague’s (2008) study. Financial stability has been attributed as either factor or attribute of QoL in both the studies. In addition, worries and concerns about future and general health have been accentuated in the context of QoL in both studies.

In the wake of these similarities related to QoL in both the studies, ICECAP-O seems a suitable measure for QoL of carers of PWD. As one of the studies have investigated the concept of QoL as perceived by carers of PWD in their given circumstances (Vellone et al., 2008), whereas the other has focused on QoL as a general concept among older adults (Grewal et al., 2006). Both have reported similar findings. ICECAP-O appears to be a representative tool for the attributes presented in both studies. Furthermore, Jones et al. (2014) in their qualitative study, suggested ICECAP-O as a suitable measure for QoL of carers of PWD as it is more encompassing and measures broader aspects of carers’ QoL. Hence, gives more accurate information about QoL of carers of PWD. Therefore, it seems plausible here to utilize ICECAP-O as a QoL measure for carers of PWD. Its utilization for carers of PWD along with PWD themselves will provide an added benefit to make comparison of QoL of both on the same scale. ICECAP-O has been used with different clinical populations and general older adults (see chapter 3 for details), however, it has not been used extensively as a QoL measurement tool for carers of PWD. Hence, it will be a valuable addition in existing knowledge. In addition to measures of QoL of carers it is also imperative to evaluate factors associated with their QoL for its better understanding and attempts to improve it.

2.3.7 Factors associated with QoL of Carers of PWD

Although QoL of PWD's carers have been reported to be low (Karg et al., 2018), there is a dearth of research related to factors associated with QoL of carers of PWD. However, carer burden is one of the factors, which has been explored in relation to carers' QoL. Carer burden has been reported to be higher among carers of PWD as compared to carers of patients without dementia (Brodaty & Donkin, 2009). Bleijlevens et al. (2015) attempted to assess the relationship between HrQoL and carer burden among carers of PWD living at home or those who recently moved to a long-term care facility. No differences were reported related to HrQoL between both groups of carers. Although, they found that carers of recently institutionalised PWD reported significantly less care burden and psychological distress to those whose PWD were still living with them. However, numerous factors associated with PWD which increase carers burden have been reported to ultimately affect carer's QoL negatively (Santos et al., 2014). For example, Etters et al. (2008) reported that the care burden negatively affects health of the informal carers or family members involved in the care provision to the PWD. In an Alzheimer's Association Report (2021), carers of people with Alzheimer's disease or any other type of dementia indicated experiencing higher levels of emotional and physical stress while providing care or even if the care recipient is institutionalised. The report revealed that the carers are at risk of becoming secondary patients themselves experiencing high physical and emotional stress. Chronic stress and difficulty in maintaining good health behaviours may result in poor health and illnesses among informal carers of dementia (Alzheimer’s Association Report, 2021).

Likewise, research in the past few decades have also associated caregiving to PWD with physical and psychosocial problems among their carers (Eagles et al., 1987; Pot et al., 1997; Schoenmakers et al., 2009; Van Mierlo et al., 2012). Daley et al. (2019) in their qualitative study highlighted 12 themes under three categories of factors associated with QoL of family carers of PWD. Category one comprised factors related to PWD including quality of relationship with PWD which carers considered a significant contributing factor in their QoL. Furthermore, changes in PWD’s personality as a consequence of dementia onset, and certain dementia characteristics such as loss of short-term memory, repetitiveness, anger, poor motivation, and hallucinations were considered upsetting and challenging affecting carers’ QoL negatively. Likewise, demands of caring was considered significantly challenging for QoL of carers. Category two comprised factors related to carers of PWD. It included: personal freedom to participate in activities of interest other than caring of the PWD, acceptance of the caring role, considering caring role meaningful, and carers better health as positive factors, while uncertainty about future as a negative factor associated with their QoL. The third category comprised external environmental factors, which included satisfaction with external support, be it from family or statutory services, and contact with family and social network as positive influence on carers QoL, while overwhelming weight of caring responsibilities as a negative factor associated with carers’ QoL.

Farina et al. (2017) in their systematic review covered factors associated with QoL of carers of PWD extensively. They reported spouse carers having worse QoL as compared to off springs. Health and unmet medical needs of PWD were reported to be vital determinants of carers’ QoL. The majority of studies in their review found no association between severity of cognitive impairment of PWD and carers’ QoL. Whereas younger onset and longer duration of disease was reported to have positive association with carers' QoL. PWD's and carers' QoL was found to be interlinked. In addition, carers' mental and physical health, their health in general, and their sleep quality all were found to be negatively associated with carers' QoL. Carers' burnout, burden, time spent caring, length of caring time, worrying about future in terms of PWD's disease progression and stress were found to be negatively, while carers' meaning in caring responsibilities, independence to participate in activities other than caring, self-efficacy, and sense of coherence positively associated with carers' QoL. Carers were reported to believe additional caring and financial support will impact their QoL positively. Likewise, the majority of evidence in their systematic review suggested positive effect of increase income on carers' QoL.

Despite widespread effect of caring responsibility of PWD on lives of carers there is a dearth of evidence regarding direct association of PWD's and carers' QoL. Similarly, there is a scarcity of research regarding demographic factors, quality and type of relationship and living arrangements of carers on their QoL. In the backdrop of the above mentioned findings it is evident that QoL of carers of PWD needs to be further explored including factors contributing negatively to their QoL. There is urgent requirement of measurement of actual attributes of QoL of PWD's carers and investigation of the factors which affect the actual QoL of carers of PWD. Utilization of ICECAP-O, to measure QoL of carers of PWD and exploration of the factors associated with their QoL will be a novel contribution in the existing knowledge regarding.

2.3.8 Interventions to Improve QoL of PWD and their Carers

In addition to the factors associated with QoL of carers previous studies have investigated different interventions to improve QoL of carers of PWD. Camic et al. (2013) introduced singing together in a group in their qualitative study for PWD and their carers to investigate effects of a combined activity on QoL of both PWD and their carers. The rationale of the study was exploration of the impact of social inclusion activities on QoL of PWD and their carers. They argued that reducing care burden may not be equivalent to improving carers' QoL. They advocated "sense of selfhood" to promote QoL among PWD and their carers. The concept of selfhood has been developed by Snyder (2006) and it is based on earlier concept of personhood (Kitwood, 1997) in relation to PWD. This highlights that despite the potential changes to the personality of PWD at the core there still exists the person. A supportive environment can nourish and a malignant environment can deteriorate that personhood (Kitwood, 1997). Camic et al. (2013) have extended the concept of selfhood and included carers of PWD in this as well. They argued that due to communication difficulties PWD become socially excluded from the activities once they enjoyed and the carers of PWD also become isolated due to their care giving responsibilities. Hence, activities which promote social inclusion for the dyad may help improving their QoL. Their findings were supportive of their hypothesis as carers and PWD enjoyed participation in a social activity together, they reported enjoying the singing and the peers' and instructor's company as well. Seeing glimpses of PWD's older self while singing was reported to be a pleasant feeling for the carers. In the light of these findings further exploration of such activities which encourage social inclusion for PWD and their carer may appear to be a source of improvement in the QoL of both.

The social activities which involve the dyad (i.e., PWD along with their carer) may have a positive impact on carers' QoL in an indirect way. In Vellone et al. (2008) qualitative study carers of PWD attributed mental freedom from the care giving responsibilities as a contributing factor in their QoL. They reported that even respite or independence for a few hours from their care giving responsibilities cannot give them that sense of mental freedom as they still remain mentally occupied about the PWD. They even reported feeling guilty for leaving PWD alone with another carer or in respite. The social activities which promote social inclusion for both the PWD and their cares together may lead towards such mental freedom for carers of PWD. They can enjoy mental freedom to some extent during such social activities as PWD is also with them in the group activity but independently enjoying themselves requiring less attention of their carers. Carers on the other hand can enjoy social inclusion, group participation, and mental freedom simultaneously which may have better impact than respite or reduced care giving hours. Kim et al. (2011) reported that increased care giving hours are a predictor of increased care burden among carers of PWD. However, reduced care giving hours may not necessarily lead to reduced carers' stress or their improved QoL (Vellone et al., 2008; Camic et al., 2013), hence interventions aimed to improve QoL of carers of PWD may require addressing multiple psychological and socio-demographic aspect of both PWD and their carers.

Review of previous literature indicates scarcity of exercise interventions for QoL of carers of PWD, however, a mind-body intervention for family care givers of PWD has shown some promising results regarding improvement in depressive symptoms and cognitive and mental functions (Lavretsk et al., 2013). A yogic meditation activity was selected as an eight-week intervention for carers of PWD in a pilot RCT study. The findings suggested improvement in the cognitive and mental functioning along with a reduction in depressive symptoms among the carers of PWD in the intervention arm as compared to those in the control arm (Lavretsk et al., 2013). The findings that a mind body intervention reduced mental health symptomology are of particular interest to QoL of carers. The activities if combined with the PWD can elevate positive impact on QoL of both. Mind-body interventions need to be explored for PWD's and their carer's QoL.

With regards to outcomes of interventions, characteristics of carers of PWD have also been explored in previous studies. Van Mierlo et al. (2012) conducted a systematic review to explore association of effectiveness of psychosocial interventions for carers of PWD with their personal characteristics. Characteristics of carers' of PWD which were reported to have positive association with outcome measure of QoL of these interventions included: female gender, no use of care at baseline of intervention, caring PWD with dementia not otherwise specified type and Alzheimer's disease, and PWD with mild to moderate dementia.

In the backdrop of the interventions reported to have positive effects on QoL of carers of PWD, it can be summarised that interventions involving social inclusion for PWD and their carers can be useful to improve QoL of both. Interventions which encourage active participation of the PWD may help in mental freedom for carers of PWD while still being part of the same activity. Camic et al. (2013) introduced singing for brain activity to promote social inclusion for PWD and their carers, enhance a sense of selfhood of PWD, increase mental freedom of carers of PWD, and to improve their QoL subsequently. They reported its positive effects on QoL of carers of PWD. As there is dearth of findings related to effects of physical exercise on QoL of carers of PWD. However, the mind-body exercise (yogic meditation) has previously shown to reduce depressive symptoms and improve the cognitive functioning among carers of PWD (Lavretsk et al., 2013). Therefore, if the mind-body element is combined with the social inclusion of both (PWD and their carers), it may lead towards a novel intervention suitable for PWD and their carers in improving their QoL. The effect of Tai Chi (a mind-body exercise) as a dyadic activity on QoL of PWD and their carers has not been studied previously therefore, this investigation will be a valuable addition in existing knowledge. Furthermore, the effect of Tai Chi on broader dimensions of QoL of carers of PWD and not HrQoL or QoL in PWD's context, will be another novel aspect of this project. In addition, a few more elements previously reported to be positive for QoL among carers of PWD can also be integrated in the same intervention to make it more effective e.g., using home environment for skill building and designing a personalised intervention.

Keeping these characteristics of an appropriate intervention to improve QoL of PWD and their carers in view Tai Chi (a gentle mind-body exercise) appears to be relevant, meeting nearly all factors discussed previously required to be useful for QoL of PWD and their carers. Tai Chi can be practiced in a group. It is a specialised exercise which requires a qualified instructor to deliver. If delivered in a group format those participating in Tai Chi activity will have an opportunity to interact with the instructor and the peers, which will encourage social inclusion. PWD and their carers can join the activity together, despite being together they can still have an opportunity to be able to enjoy the activity independently in their own space. It may encourage more independence among PWD and give carers of PWD an opportunity to liberate themselves mentally from caregiving and engage in the same activity within the same group along with the PWD they are caring. It may also enhance enjoyment and pleasure among the PWD and their carers leading towards improvement in their general QoL. A more detailed account of Tai Chi in terms of its characteristics, effects and previous research on its various dimensions and its relevance with PWD and their carers is discussed below.

2.3.9 Tai Chi: Background, Characteristics, and Effects

Tai Chi Chuan was initially practiced as a form of fighting by older Chinese individuals emphasizing strength, flexibility, speed, and balance. Tai Chi Chuan is a form of martial arts, which is translated as “grand ultimate fist” (Nyman, 2021). It involves Chinese philosophy of Tai Chi (Chang et al., 2010), however, Tai Chi gradually evolved from it into a slow, soft, and gentle form of exercise suitable for all age groups (Tsao, 1995).

Tai Chi has been shown to be effective for healthy older adults in terms of improved physical function (Wooton, 2010), better HrQoL (Ho et al., 2007), and fewer falls (Low et al., 2009). Tai Chi is reported to be safe for individuals with chronic diseases including Parkinson’s and survivors of stroke (Li et al., 2012). A systematic review revealed that Tai Chi may have association with improved psychological well-being, and reduced stress, anxiety, depression, and mood disturbances (Wang et al., 2010). The RCT of Yeh et al. (2016) revealed that patients with chronic heart failure who participated in 12 weeks Tai Chi intervention reported increased self-efficacy, social support, overall empowerment, and additional gains (e.g., internal locus of control, stress management, and self-awareness) as compared to their counterparts in the educational group. These findings are indicative of widespread benefits and positive effects of Tai Chi. However, to understand underlying mechanism of its functioning there is a requirement to have knowledge about the defining characteristics of Tai Chi.

2.3.10 Characteristics of Tai Chi Intervention

One of the main characteristics of Tai Chi is its mind body interaction. It is also described as moving meditation (Jin, 1992). Researchers have investigated two approaches, using a life-span perspective, to examine its effectiveness on cognitive functioning i.e., intellectual stimulation and physical exercise (Daffner, 2010; Hanna-Pladdy & MacKay, 2011). A mind-body exercise combines both (Wu, 2012). Mind-body exercise is a form of physical activity, however, it involves conscious control of each body movement in a relaxed state of mind. Moreover, the body movements involve slow motion and require attention of the participant to each movement sequence (Chan et al., 2005). Researchers have identified four potential inter-linked beneficial elements of mind-body exercise: focus on mind, movement, and breathing while being in a deeply relaxed state (Larkey et al., 2009). More cognitive functioning is involved in the practice of mind-body exercise compared to general physical activities or exercise. This is because it includes meditation, active attention on movement, and memorizing sequences of movements (Wu, 2012). Bialystok et al. (2007) argued that voluntary and constant attention management have cognitive benefits especially for executive functioning and memory. They reported that bilingualism involves voluntary management of attention throughout the life among bilingual individuals. They attributed such constant attention management, involved in switching from one language to the other, to delaying the symptoms of dementia among PWD in their study. Using a similar analogy of Bialystok and colleagues (2007) constant management of attention while performing slow movements of mind-body exercise may lead towards positive cognitive outcomes for PWD. However, evaluation of the effect of a mind-body exercise on QoL of PWD and their carers requires further exploration as there is scarcity of evidence in this regard.

The physical characteristic of Tai Chi involves dynamic postural control through weight shifting, whereas practicing this control through maximal movement engages participants cognitively (Hackney et al., 2007). Petzinger et al. (2013) argued that goal based physical activity which involves cognitive engagement and feedback to enhance motivation of the participants may incorporate neuroplasticity resulting in neuro-restoration and neuro-preservation in people with different neurological disorders including Parkinson’s and Alzheimer’s diseases. They elaborated that goal-based physical activities should involve practice and repetition to improve performance. There is some evidence that Tai Chi improves cognitive functioning. For example, Cheng et al. (2014) reported Tai Chi to have preserved cognitive performance on the MMSE over a nine-month period among PWD. They concluded that Tai Chi preserves cognitive functioning and delays decline in certain cognitive domains. A number of other studies have also reported benefits of intellectual stimulation and physical activity in delaying age-related cognitive decline which may be helpful in preventing onset of dementia (National Collaborating Centre for Mental Health, (UK), 2007; Orrell et al., 2005; Knapp et al., 2006). Whitty et al. (2020) highlighted in their systematic review that aerobic exercise programmes, combined cognitive and motor challenges, Tai Chi, and resistance training tend to have positive effect on cognition, memory, and executive functioning of participants with Mild Cognitive Impairment, which illustrates the protective effect of exercise including Tai Chi on global cognition. Therefore, exercise can be a vital factor in delaying cognitive decline or dementia. Previous studies provided evidence of association between cognitive functioning and QoL among PWD (Marventano, 2015; Mjørud et al., 2014), which suggests Tai Chi may have an indirect positive effect on PWD's QoL by improving cognitive functions and subsequently improving their QoL. However, direct effect of Tai Chi exercise on QoL of PWD needs further exploration.

Another defining characteristic of Tai Chi is its slow and gentle movements which make it safe to practice for older adults with or without dementia who may have compromised body balance or strength (Tsao, 1995). Tai Chi is also reported to be appropriate to practice for PWD in their early stages of dementia (Lyu et al., 2018). Researchers suggest that Tai Chi can be used as an alternative form of physical activity e.g., aerobic and strength training for older adults. It will reduce the risk of sport-related injuries and cardiac hazard among older adults (Chan et al., 2005). Li et al. (2001) recommended Tai Chi for older adults because of its low impact and slow movements which could easily maintain interest of the participants. Tai Chi involves different types of movements and different levels of intensity it can be simplified and tailored to make it more suitable for older adults so that they can reap maximum benefits from it (Kwok et al., 2010). To highlight how characteristics of Tai Chi discussed in this section affect different functional domains, deemed to decline among PWD over the course of their condition, effects of Tai Chi intervention are discussed separately in the next sections.

2.3.11 Effect of Tai Chi on QoL

Tai Chi has been reported in a meta-analysis to have a significant positive effect on overall QoL of cognitively intact older adults (SMD = 1.23; 95% CI: 0.56-1.98; P < 0.0001) (Wang et al., 2020). Similarly, in an eight-week intervention it was found to have improved QoL of older male adults (Tajik et al., 2018). Furthermore, Tai Chi has been reported to be useful in improving QoL in terms of self-perceived physical health, and mental health i.e., depression, and quality of sleep among stroke survivors (Taylor-Piliae et al., 2014). In another study Tai Chi was shown to have no significant impact on HrQoL among people with Parkinson's disease, whereas Tango dancing was reported to have positive effect on HrQoL (Hakney & Earhart, 2009). However, it was unclear whether to attribute the positive effects to participation in Tango with a partner/carer, or to its physical activity component. Tai Chi was performed without a partner, relative or carer. This was a pilot study which highlighted the areas to be explored in future. There is requirement of RCT studies for further investigation of contribution of physical activity and social interaction elements of an intervention in QoL among PWD. There is also requirement to view QoL in broader perspective among PWD, which should be irrespective of their HrQoL. Effect of Tai Chi on these broader and more encompassing constructs of QoL of PWD need exploration as there is dearth of research in this domain. Although, the TACIT trial (Nyman, 2019) reported significant improvement in QoL of PWD in the intervention arm as compared to their counterparts in the control arm, whereas no significant difference was found in QoL of carers in the intervention. However, effect of adherence to Tai Chi intervention on QoL of PWD and their carers was not investigated in the TACIT trial. Therefore, it is imperative to explore the effect of adherence to Tai Chi exercise intervention on QoL of PWD and their carers, which will be explored in the present PhD. It will be a novel investigation in the present PhD as it has neither been explored in the TACIT trial nor in any previous studies.

Having discussed characteristic, suitability, and effects of Tai Chi for older adults and PWD it is pertinent here to investigate the strategies to utilize fundamental components of Tai Chi to make it a useful and effective intervention for PWD.

2.3.12 Tai Chi as an Intervention

For an overall view of previous research involving Tai Chi as an intervention and its outcome measures, systematic reviews of previous systematic reviews are a substantial contribution (Lee & Ernst, 2012; Solloway et al., 2016). Lee and Ernst (2012) reported 35 systematic reviews from 2010 indicating effectiveness of Tai Chi in falls prevention, improving psychological health, and general health benefits among older adults. Solloway et al. (2016) conducted another systematic review of previous systematic reviews focusing on primary studies involving Tai Chi and the health-related outcomes. They draw an evidence map reporting 107 systematic reviews. The largest number of RCTs i.e., 57 among those included in their systematic review involved general health benefits associated with Tai Chi. 37 RCTs involved outcome measure as psychological well-being, 31 included interventions for older adults, 27 explored balance, 18 reported hypertension, 15 reported falls prevention, whereas 11 revealed cognitive performance as an outcome measure of Tai Chi. Their evidence map also reflects the clinical areas which lack research including dementia, QoL, metabolic syndrome, post-traumatic stress disorder, and multiple sclerosis.

Although the systematic reviews have highlighted dearth of research with regards to effectiveness of Tai Chi for dementia, however, effectiveness of Tai Chi to preserve cognitive functions for older adults with cognitive impairment in general in terms of scores on MMSE and Digit Symbol-Coding cognitive tests has been reported (Chang et al., 2011). Some evidence reported in the RCT study of Mortimera et al. (2012) indicated that Tai Chi resulted in increased brain volume in older adults without dementia and improved their cognitive performance. Wu et al. (2013) reported in their meta-analysis that Tai Chi affects cognitive functions positively including global cognitive function and memory, especially verbal working memory. However, improvement in executive functions were not reported with consistency in combined studies. These findings are suggestive of further investigation of the effects of Tai Chi on cognitive function of PWD. Studies have also reported that severity of dementia tends to decrease QoL among PWD (Marventano, 2015; Mjørud et al., 2014). Therefore, preserving or improving cognitive functioning among PWD may facilitate maintenance or improvement in their QoL. However, evaluation of direct effect of Tai Chi on QoL of PWD will be a novel and valuable addition in knowledge.

Previous studies have also indicated effectiveness of social interaction and subsequent intellectual stimulation in reducing the risk of incident dementia (Saczynski et al., 2006; Bennett et al., 2006). Social interaction is also reported to increase volume of brain tissues in the RCT of Mortimera et al. (2012). Likewise, meditation has shown to be effective for attention and executive functions by allocation of attentional resources to these cognitive processes among older as well as younger adults (Chiesa et al., 2011; Prakash et al., 2012). Studies have also attempted to combine different interventions involving physical activity, meditation, and social activity components. These multimodal interventions are reported for the probability of positive influence on the neurobiological mechanisms involved in age-related cognitive decline (Burgener et al., 2008; Tai et al., 2018). Characteristics of Tai Chi make it a multimodal exercise as it incorporates diverse activities including: physical, meditative, and cognitive, which can be combined with the social interaction element if it is performed as a group activity (Wayne & Fuerst, 2013). These promising characteristics of Tai Chi make it potentially useful intervention for PWD. Its physical and meditative components combined with the social interaction to introduce it as a mind-body social activity may lead towards positive cognitive and QoL outcomes for PWD.

Previous literature highlighted in this section is indicative of the fact that Tai Chi has been reported for its health-related and psychological benefits for participants, whereas little or no adverse effects have been associated with it. It has widespread benefits including improvement in cognition, memory, and executive functioning of people with Mild Cognitive Impairment (Whitty et al., 2020) and QoL of PWD (Nyman, 2019). It has the ability to preserve PWD’s cognitive performance on MMSE (Cheng et al., 2014). Its slow gentle movements (Li et al., 2001) are suitable for PWD with less severe dementia (Lyu et al., 2018). Additionally, the different types of movements and varying levels of intensity (Kwok et al., 2010) can be utilized to tailor personalized Tai Chi exercise intervention for PWD according to their requirements and capabilities. Furthermore, it can be delivered in group format to allow inclusiveness of PWD and their carers, which can have positive effect on cognition and QoL of PWD and their carers. All these characteristics make it safe, much better and more suitable exercise for PWD as compared to other general exercise e.g., aerobic and strength training (Chan et al., 2005). Due to its unique characteristics mentioned above it becomes a promising exercise to be explored for improvement in QoL of PWD and their carers who are evidently less studied for Tai Chi effectiveness. Therefore, evaluation of the effect of Tai Chi on QoL of PWD and their carers will be a valued addition in the existing knowledge. Moreover, it is also important to investigate the factors contributing in adherence to Tai Chi exercise intervention among PWD, their carers, and older adults in general to improve their adherence to Tai Chi intervention to reap its benefits.

2.3.13 Factors affecting Adherence to Exercise Interventions among Older Adults with and without Dementia

Documented benefits of Tai Chi or any other exercise for older adults in general and for PWD cannot be attained if the individual does not regularly adhere to it. Before identifying factors affecting adherence to physical activity or exercise among older adults with or without dementia it is vital to understand the concepts of physical activity, exercise, and adherence to an exercise intervention or physical activity.

The terms exercise and physical activity are often used interchangeably, however, there are subtle differences which reflect in the definitions of these terms. “Physical activity refers to body movement that is produced by the contraction of skeletal muscles and that increases energy expenditure” (Chodzko-Zajko et al., 2009, p. 1511). In contrast, “exercise refers to planned, structured, and repetitive movement to improve or maintain one or more components of physical fitness” (Chodzko-Zajko et al., 2009, p. 1511), while physical fitness is defined as a set of measurable health- or skill-related attributes (Caspersen et al., 1985). Furthermore, exercise class is defined as “a group of people gathered together to follow a leader or instructor to carry out planned, structured and repetitive bodily movement done to improve more than one component of physical fitness” (Hawley-Hague et al. 2016, p. 2). The present thesis is primarily focused on Tai Chi as an exercise as in the TACIT trial Tai Chi was offered in a group format that corresponds to the exercise class definition described above. Furthermore, adherence to and effects of exercise are highlighted extensively in the present thesis as factors affecting adherence to physical activity and exercise also differ e.g., BCT such as goal setting, and feedback and monitoring are useful for exercise adherence (Rivera-Torres et al., 2019; Room et al., 2017) while counter effective for physical activity (French et al., 2014).

Adherence is a key component of intervention studies aiming to attain health outcomes for older adults, however, there is little consensus on its definition and its reporting also varies considerably between studies (Hawley-Hague et al., 2016). In their systematic review Hawley-Hague and colleagues (2016) identified a broad range of definitions used for adherence in the literature including; completion of two third of the prescribed exercise routine (King et al., 1997), self-reporting of minutes and hours of exercise completed (Fielding et al., 2007), exercise class adherence i.e., still attending class at the follow up of the study, and class attendance (though it is considered a subset of adherence) (Hawley-Hague et al., 2014). Furthermore, if adherence to exercise classes is considered separately from individual or alone physical activity there seems to be no agreed definition of adherence to exercise classes. Self-reporting data also becomes less reliant which further intricates defining adherence in relation to exercise classes (Hawley-Hague et al., 2016). Finally, physical activity participation and adherence have been used synonymously in some studies

(Allen & Morey, 2010). Assessment of adherence to exercise is equally complex as there is no standardized assessment procedure for it.

Visek et al. (2011) identified four measures used for adherence to exercise in trials including; completion (i.e., of the intervention study), attendance in classes (i.e., number of exercise classes attended over the programmed period), duration adherence (i.e., duration of exercise carried out in each exercise sessions), and intensity adherence (i.e., exercising at a level of intention as intended). Hawley-Hague and colleagues (2016), reported in their systematic review that the majority of studies used percentage of class attendance as measure of adherence and few focused on exercise intensity. This reflects lack of consensus regarding the assessment of adherence, however, it is also logical to define adherence in terms of the purpose of the intervention or exercise program and to measure it accordingly. To assess feasibility of an exercise program class attendance may be considered as a measure of adherence, likewise, if purpose of the intervention is assessment of health outcomes and gains adherence may be defined by a number of measures including; class attendance, completion or retention, duration and intensity (Gillespie et al., 2012).

There is another discrepancy regarding cut off point for adherence measures which may determine higher or lower levels of adherence to physical activity or exercise. Hawley-Hague and colleagues (2016) recommended cut off points for different adherence measures based on previous studies. For example, attendance may be measured in terms of percentage of attendance to the exercise classes offered. Completion or retention may be considered as still attending classes on the follow up and non-completion may be considered as withdrawal from exercise classes or non-attendance in the follow up. Likewise, intensity may depend on type of program being offered, it may vary across studies. Duration adherence may be measured in terms of adherence to predefined minutes or hours of physical activity.

There are two concepts similar to adherence associated with physical activity including initiation and maintenance of physical activity. It is vital to draw distinction between these concepts for better understanding of the factors affecting them with regard to physical activity among older adults. Adherence was defined in the earlier part of this section, however, it is pertinent to define initiation and maintenance of physical activity as well. Initiation is referred to as adoption of initial physical activity, while physical activity maintenance is regarded as sustained participation in physical activity (van Stralen et al., 2009). In the light of definition highlighted above of the concepts i.e., adherence, initiation and maintenance, a fine distinctive line can be drawn between these concepts. Adherence has different aspects including retention, class attendance, intensity, and duration adherence (Visek et al., 2011). All these aspects are calculated in a particular time frame involving initiation and completion. Therefore, it can be inferred that initiation is part of the adherence process. Whereas maintenance to physical activity involves habit formation that is beyond a certain time frame. Therefore, maintenance may be attributed as a more sustained form of adherence to physical activity (Tak et al., 2012). As these concepts are interlinked the factors which influence them may also be overlapping. However, it is important to note here that identification and understanding of factors influencing adherence is more crucial and vital as sustained adherence will ultimately result in habit formation and maintenance of physical activity. Incorporation of these factors in physical activity interventions for older adults will make these interventions more effective and useful for long term behaviour change among the participants.

Physical activity initiation and maintenance are regarded as two different phases of physical activity behaviour change. It has also been reported that both phases are influenced by different factors (van Stralen et al., 2009). Physical activity initiation phase is influenced by pre-motivational, motivational, and post-motivational factors. Pre-motivational factors may include awareness, knowledge, and risk factors of indulging in physical activity. Motivational factors influence thinking and decision making to become active, which involve peoples’ attitude to physical activity, self-efficacy believes, and social influence. Post-motivational factors involve translation of intention into behaviour e.g., goal setting and planning (De Vries et al., 2006). Physical activity maintenance phase is primarily influenced by post motivational factors including skills and strategies to facilitate sustained participation in physical activity to prevent relapse into inactivity (De Vries et al., 2006; Schwarzer, 2001). Utilization of these factors in an exercise intervention for older adults with or without dementia can be useful for their sustained participation in it.

In the context of established benefits of exercise for older adults (Langhammer et al., 2018) attempts have been made previously to better understand exercise adherence among cognitively intact older adults. Good health, low body mass index, fewer depressive symptoms, better physical and cognitive abilities (Picorelli et al., 2014), participation with spouse (Osuka et al., 2017), higher socioeconomic and educational level (Forechi et al., 2018), extrinsic motivation e.g., cash incentives and smartphone applications (Finkelstein et al., 2008; Helbostad et al., 2017), and supervised exercise programs (Lacroix et al., 2016; Picorelli et al., 2014) have been found to be positively associated with adherence to exercise in cognitively intact older adults. Supervised exercise programs also demonstrated some additional benefits such as low rate or absence of exercise related injuries, low withdrawal rate, and higher effectiveness. The subjective factors e.g., health, physical and cognitive abilities, fewer depressive symptoms, and body mass index need careful consideration while devising exercise interventions for old adults as they may not be modifiable, hence require personalized adjustments in exercise interventions. For example, provision of additional exercise sessions to the participants with poor health may compensate for their absence from exercise sessions. Likewise, assistance for psychotherapeutic sessions for depression or any other psychological issues may facilitate adherence to exercise intervention in older adults. Additionally, such components may be incorporated in the exercise interventions which have proven efficacy to reduce depressive symptoms e.g., exercise self-efficacy, and social support (Miller et al., 2019). Moreover, supervised exercise programs may be arranged for better adherence in older adults. The notion that enhanced adherence is associated with higher maintenance/adaptation (Lacroix et al., 2016) is important and would require further examination with regards to more complex cognitive conditions including dementia, to help benefit PWD from physical activity or exercise.

A number of factors positively associated with adherence to exercise interventions specifically among PWD and people with MCI have also been identified in a systematic review and meta-analysis (Di Lorito et al., 2020) including endurance/ resistance training, short duration (in weeks), less frequent (in weekly), use of incentives, group format, offered in community. Interestingly, the review reported that adherence to exercise intervention among PWD and people with MCI was found to be highest when delivered by non-professionals (e.g., students or research assistants) and lowest when delivered by professional trainers, however, the underlying mechanism was not reported. It may be an outcome of difference in personal interaction styles between supervisors and the participants. During exercise/training sessions for cognitively intact older adults, personal interaction between supervisors and participants has been regarded as a positive factor for social interaction, social, mental, and emotional health, and well-being (Picorelli et al., 2014). It may also have affected adherence to exercise program. However, this hypothesis needs further exploration and supportive evidence.

Factors contributing to non-adherence to exercise in people with MCI was reported to be poor health, time constraints and ease of access to location of exercise program (Tak et al., 2012), except health other factors are practical constraints. Health has been shown to be a vital factor among cognitively intact older adults and those with MCI for adherence to exercise. Therefore, exercise interventions for older adults with or without cognitive conditions including MCI and dementia must carefully consider participants' health and make adjustments/provisions for participants in the interventions accordingly. In addition, supervised exercise programs may be offered to PWD as they have positive effect on adherence to exercise among cognitively intact older adults (Lacroix et al., 2016; Picorelli et al., 2014). However, supervision must involve good communication (Sjösten et al., 2007) and interaction (Picorelli et al., 2014) between supervisors and participants. It has been suggested that instructions for participants (older adults) in exercise programs must be simple, and less demanding (Flegal et al., 2007) this also highlights importance of good communication in exercise interventions for older people and PWD. Some other suggested strategies to promote adherence to exercise intervention for older adults in general may also be useful for PWD such as offering social support, reinforcement, reminders (Flegal et al., 2007), activities carefully planned according to the needs of older adults (Rivera-Torres et al., 2019), and continuous motivation (Sjösten et al., 2007). Social and environmental contexts should also be considered (Stineman et al., 2011; Sullivan-Marx et al., 2011) as social and environmental factors have been reported to have negative effect on adherence to physical activity among older adults (Allen & Morey, 2012; Garmendia et al., 2013).

2.4 Summary

In this chapter previous literature regarding QoL of PWD and their carers was extensively reviewed. Factors associated with QoL of PWD and their carers, along with available measures of QoL of both, and their limitations were highlighted. It was established that there is requirement of a more encompassing QoL measure for both. In this regard suitability of ICECAP-O for both was ascertained. Moreover, widespread positive effects of

Tai Chi on lives of older adults in general and on cognition, memory, executive functioning, and QoL of PWD were reported. It was also highlighted that without adherence documented benefits of Tai Chi cannot be attained. Therefore, factors associated with adherence, initiation, and maintenance of exercise were also highlighted. Additionally, factors associated with adherence to exercise interventions in older adults and PWD were reported. It was established that there is requirement to explore the effect of adherence to Tai Chi exercise intervention on QoL of PWD and their carers. Furthermore, it was found valuable to explore utility of ICECAP-O for measurement of QoL of PWD and their carers. Therefore, three sub-studies of the present PhD were designed, which attempted to validate ICECAP-O as a QoL measure for PWD, explored adherence to Tai Chi intervention among PWD, and investigated effects of adherence to Tai Chi intervention on QoL of PWD and their carers, while ICECAP-O was used as a QoL measure for both i.e., PWD and their carers. The next chapter extensively reviewed literature regarding psychometric evaluation of ICECAP-O for various older populations to identify gaps in knowledge and to design study-I (psychometric evaluation of ICECAP-O for community dwelling PWD) to fill these gaps.

3 Systematic Literature Review of Existing Studies related to Evaluation of Psychometric Properties of ICECAP-O

This chapter is comprised of a systematic literature review designed to identify the evidence base for conducting a psychometric evaluation of the ICECAP-O directly with older PWD. The review considers any attempts previously made to determine the psychometric properties of the ICECAP-O for older populations. The evidence base is then used to inform the methodology of study-I of the present PhD i.e., validation of ICECAP-O as a QoL measure for PWD. To examine the properties of a questionnaire a number of concepts are of importance. These include different forms of validity and reliability as well as the properties of the scale (e.g., factorial structure). Validity assesses the extent to which an instrument measures what it purports to measure (Anastasi & Urbina, 1997). There are different types of validity including: construct validity, face validity, criterion validity, and content validity (Streiner et al., 2015). Convergent and discriminant validity are two ways to assess construct validity of a measurement, instrument, or scale. Convergent validity represents the concept that different measures of the same construct will correlate with each other. If the correlation is of significant magnitude, it reflects that measures of that construct converge with each other. The strength of correlation is yet undefined to be regarded as standard for convergent validity (Carlson & Herdman, 2012). However, moderate or at least some correlation between the two measures will reflect level of convergence between the measures. Discriminant or divergent validity is the concept that measures of unrelated constructs will have weak or zero correlation (Hair et al., 2017). Face validity concerns that an instrument “looks valid” to the respondents, administrative personnel, and to technically untrained observers (Krabbe, 2017). It means that the instrument looks representative of the concepts which it purports to measure.

It is essential for any scale or measurement tool to be valid that it should measure what it purports to measure. However, it is equally important for the scales/questionnaires to be reliable (Anastasi & Urbina, 1997). In order to be reliable a scale must be able to measure certain trait(s) which it purports to measure with consistency over time. Correlation coefficient can be used to assess degree of reliability of any measurement tool or scale. High positive correlation is indicative of reliability of a scale. There are two types of reliability: internal and external. Internal reliability refers to the extent to which a scale or test is consistent within itself. This can be calculated using the split half and Cronbach alpha procedures (Anastasi & Urbina, 1997). Split half reliability is the assessment of the extent to which parts of a scale or test are contributing towards the overall measurement of the attribute for which the scale is designed (Frey, 2018), whereas Cronbach alpha refers to the extent to which each item of a scale measures the same construct. It assesses interrelatedness of all items of the scale. It is expressed as a number between 0 to 1 (Tavakol & Dennick, 2011). External reliability has three categories i.e., test-retest reliability, interrater or inter observer reliability, and parallel reliability. Test-retest reliability is consistency of score on a test item over time. In order to determine test-retest reliability a test is given on two separate occasions (McLeod, 2007).

The present systematic literature review aimed to assess the psychometric properties of ICECAP-O which have already been determined, methods used for this, strength of the findings, the population for which psychometric validation attempts were made, and the gap in existing knowledge. This review included discussion of previous studies involving attempts to establish any psychometric property of ICECAP-O i.e., validity (e.g., content, construct, convergent, divergent, or face validity), reliability (e.g., internal, external), factorial structure, feasibility of completion/ administration, or sensitivity to change. In the end the findings of the present systematic literature review (conducted in January 2018) were compared with another systematic review regarding psychometric validation of ICECAP-O from its development till October 2018 (Proud et al., 2019).

3.1 Aim

The present systematic literature review assessed previous literature for evaluation of psychometric properties of ICECAP-O. The review aimed to address the following questions.

1. What methods have previously been used for psychometric validation of ICECAP-O for older populations?
2. In which populations and settings these methods were used?
3. Are these methods suitable for psychometric validation of ICECAP-O for community dwelling PWD?

3.2 Method and Search Strategy

Systematic literature reviews tend to address a specific and fused research question (Dewey & Drahota, 2016). Therefore, it was an appropriate choice to assess the psychometric properties of ICECAP-O for older population, as evaluation of psychometric properties is an exclusive domain of research in psychology. The following inclusion/exclusion criteria were followed.

3.2.1 Inclusion Criteria

Studies involving:

1. Evaluation of psychometric properties of ICECAP-O including construct validity, convergent validity, discriminant validity, test-retest reliability, Cronbach alpha reliability, factorial structure, feasibility of administration).
2. Older/geriatric population (aged > 65 years).

3.2.2 Exclusion Criteria:

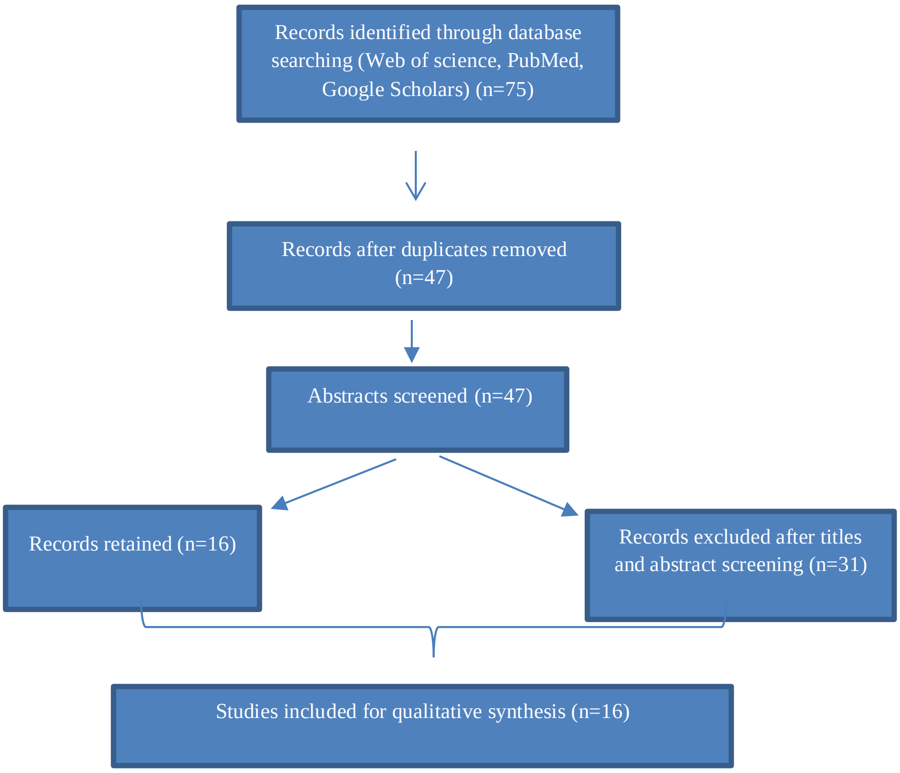
Studies involving:

1. Younger populations (aged < 65 years).
2. Utilization of ICECAP-O to assess QoL of older adults in various contexts.

Systematic searches were conducted in January 2018 using Bournemouth University e-resources to search across the databases PubMed, Web of Science, and Google scholar (google scholar searches provided studies from the databases of Science Direct, Sage, MEDLINE, and PsychInfo). Keywords included, psychometric AND validation AND ICECAP-O, older AND people AND ICECAP-O, ICECAP-O AND construct validity, ICECAP-O AND convergent validity, ICECAP-O AND divergent validity, ICECAP-O AND face validity, ICECAP-O AND reliability AND test-retest reliability, ICECAP-O AND psychometric AND properties from 2006-2008. Figure 2 provides an overview of the selection process of relevant studies (see Figure 2).

Figure 2:

Flowchart illustrating search process.



The full texts of 16 studies were screened, which were selected for qualitative synthesis. Table 2 illustrates the populations which have been studied till January 2018 with regards to evaluation of psychometric properties and validation of ICEAP-O.

3.3 Results

In this systematic literature review studies exploring validity, reliability, and other psychometric properties (e.g., sensitivity to change, responsiveness, feasibility of administration, and agreement between self-reported and proxy measures) of the ICECAP-O for various older populations were assessed.

Table 2: *Illustration of ICECAP-O validation attempts for various older adult populations.*

Papers	**Population**	**ICECAP-O versions**	**Findings**
Construct validity results			
Coast et al. (2008)	(N = 315) Cognitively intact older adults (≥ 65 years)	Self-reported	Most of the associations between the ICECAP-O's attributes and other study variables appeared to be in the anticipated direction.
Franklin et al. (2013)	(N = 601) Frail Older adults. three samples of older adults (≥ 65 years) i.e., discharged from an acute medical unit, admitted to hospital with physical and mental health problems, and residing in care homes.	Self-reported	ICECAP-O's significant strong correlation with psychological wellbeing and self-reported dementia quality of life measures.
van Leeuwen et al. (2015)	(N = 191) Frail older adults living in homes (Mean age = 82 years)	Self-reported	ICECAP-O strongly correlated to the Health Global Rating Scale and the Quality-of-Life Global Rating Scale.
Keeley et al. (2016)	(Average age 71.2) Post stroke blood pressure management group of older adults	Self-reported	Moderate correlations were found between ICECAP-O and EQ-5D index scores, SF-36 (36 items Short Form Survey) subscales of general health, social functioning and vitality, and an inverse relation with disability level. Provides positive evidence for the validity.
Discriminant/convergent validity results			
Makai et al. (2012)	(N = 96) Nursing professionals, (N = 68) family carers for psycho-geriatric restrained and unrestrained care home residents.	Dutch proxy version	As predicted the ICECAP-O demonstrated convergence with most of the QOL measures and discriminated with anxiety and depression scale. It was able to discriminate between restrained and unrestrained patients.
Makai et al. (2013)	(N = 275) Post hospitalized older adults (65-75 years)	Self-reported	ICECAP-O demonstrated good convergent validity with wellbeing and health measures and discriminates between various groups of post-hospitalized older people
Xin et al. (2016)	Early stage (N = 1010) and late stage (N = 227) older people with Parkinson's Disease	Self-reported	The ICECAP-O discriminated between early and later stage of Parkinson's, and it was highly correlated with validated measures of QoL.
Hackert et al. (2017)	(N = 205) Older adults (≥ 70 years) using social care services at their own homes/ day care centres/ residential facilities	Self-reported	ICECAP-O correlated highly with general health, mental health, and wellbeing measures, and moderately with physical health measures. It discriminated between higher income and lower income individuals.
Sarabia-Cobo et al. (2017)	(N = 217) PWD (> 65 years) in residential care	Spanish proxy version	ICECAP-O showed moderate to good convergent validity with other QoL measures and discriminated between various age groups, level of dementia, and activities of daily living.

Face validity results			
Horwood et al. (2014)	(N = 20) Knee hip arthroplasty patients (Mean age = 70 years)	Self-reported	Generally good understanding of all the concepts of ICECAP-O except a few issues related to completion of the questionnaire in the context of the health conditions participants were experiencing.
Test-retest validity results			
Van Leeuwen et al. (2015)	(N = 191) Frail older adults living in homes (Mean age = 82 years)	Self-reported	Good test-retest reliability with Intra Class Correlation (ICC) to be higher than 0.70.
Hörder et al. (2016)	(N = 40) Older adults in general (70 years)	Swedish self-reported version	Good test-retest reliability with ICC to be 0.80.
Responsiveness/feasibility of administration results			
Davis et al. (2013)	(N = 215) Cognitively intact older adults (Mean age = 79.3 years)	Self-reported	92.1% ICECAP-O completion rate.
van Leeuwen et al. (2015)	(N = 149) Frail older adults living in homes (Mean age = 82 years)	Self-reported	Change score between ICECAP-O and other measures at follow up was weak. Hence there was weak evidence regarding ICECAP-O's responsiveness to change.
Keeley et al. (2016)	(N = 592) Post stroke blood pressure management group of older adults (Mean age = 71.2 years)	Self-reported	Change in health, vitality, social functioning, and levels of disability, over time was related to change in ICECAP-O tariff scores in the same direction. This provides evidence of ICECAP-O's responsiveness to change.
Davis et al. (2017)	(N = 341) Older adults (≥70 years) with mobility impairment as consequence of falls	Self-reported	ICECAP-O was responsive to falls through 12 months follow-up ($p > .05$).
Self-reported and proxy agreement results			
Davis et al. (2016)	(N =71) People with mild Vascular cognitive impairment (Mean age = 74 years) and their informal carers.	Self-reported and Proxy versions	Weak evidence of agreement between patient and carers' reporting of QoL (ICECAP-O score).
Suitability for PWD carers results			
Jones et al. (2014)	(N = 8) Family carers of PWD (Mean age = 69.4 years)	Self-reported	Suitable to use with carers of PWD.
Summary: Construct validity (4 studies), convergent and discriminant validity (5 studies), face validity (1 study), test-retest reliability (2 studies), responsiveness and feasibility of administration (4 studies), sensitivity to change (1 study), self-reported and proxy agreement (1 study), predicting capability index (1 study), suitability for PWD carers (1 study)			

Synthesis of the studies examined in this systematic literature review along with description of the psychometric concepts against which ICECAP-O has been tested and gaps in knowledge regarding psychometric evaluation of ICECAP-O for community dwelling PWD will be discussed in the following sections in detail.

The review of previous studies related to validation of ICECAP-O suggested that validity (i.e., construct validity, convergent and discriminant validity, and face validity) of ICECAP-O has been determined in different settings. The types of validity against which ICECAP-O has been tested are highlighted below.

3.3.1 Construct Validity of ICECAP-O

As an initial step to validate the ICECAP-O, Coast et al. (2008) attempted to determine the construct validity of ICECAP-O as an alternative to criterion validity, given that there was no gold standard measurement for capability based QoL available at that time (not even until now). To determine construct validity of the ICECAP-O, Coast et al. (2008) conducted an interview survey with (N = 315) older participants aged 65 or above from across the UK. The study compared responses to the ICECAP-O with demographic information and those on some established questionnaires with which associations would be expected.

As Coast and colleagues (2008) expected, an association was found between age and role, control, and enjoyment factors of the ICECAP-O but not with attachment or security. Increased age resulted in lower levels of self-reported capabilities. There were no associations between sex, social class, and the capabilities. However, associations between social contact and capabilities were found to be in the expected direction, with strong association between social contact and capability, the more frequent social contact the greater the capability. General well-being was found to be directly associated with capability level. Those who reported lower levels of well-being reported lower levels of their capabilities (for all 5 factors). This was similar for general health (except for the security factor). Physical disabilities were found to be inversely associated with capabilities. Scores on the EQ-5D (instrument for measuring generic health status) were strongly related with enjoyment and control, however, there was no association with the attachment factor. Overall, poorer health was related with lower capabilities as assessed by the ICECAP-O. No associations were observed between capabilities and locality or environment (e.g., neighbourliness, vandalism, local transport, leisure facilities). Finally, participation in an organisation was found to be related with enjoyment in the expected direction, whereas participation in informal care was not found to be associated with any of the capabilities. Most of the associations between the factors of the ICECAP-O and other variables appeared to be in the anticipated direction. This provides some initial evidence for its construct validity.

The study by Coast et al. (2008) was not without limitations. First, several anticipated associations were not confirmed. A potential explanation for this was that participants rated themselves higher on the attachment capability. However, they reported lower effort to contact friends or relatives. This reflects their choice of not performing in certain ways whilst having the capabilities to do so. As such, the relationship between capabilities and function is influenced by participants' choice to engage or not to engage in certain activities. However, Coast and colleagues (2008) justified this comparison of capability index with function by advocating that those functions are dependent on capabilities ultimately and given that there was no empirical work available related to capabilities they were bound to make comparison within the existing body of knowledge.

Moreover, construct validity of ICECAP-O has also been examined for people with Parkinson's disorder with early (who have just initiated treatment) and later stage (who were on adjuvant therapy to levodopa) (Xin et al., 2016). ICECAP-O (index score) was found to be correlated with EQ-5D ($r = 0.65$) and with PDQ-39 (Parkinson's Disease Questionnaire-39) (r = 0.73). ICECAP-O also discriminated between early and later stages of Parkinson's (Xin et al., 2016). This is the only study available with regards to validation of ICECAP-O for a specific neurological condition i.e., Parkinson's disease. However, its findings cannot be generalized to types of dementia because Parkinson's disease may not necessarily progress into Parkinson's disease dementia (PDD). Initially Parkinson's disease is comprised of motor deterioration which progresses into cognitive decline even dementia. However, its progression and nature of neuropsychiatric symptoms differ from dementia (Aasrland et al., 2001; Urso et al., 2022). Therefore, findings related to Parkinson's cannot be generalized to PWD.

Likewise, Construct validity of ICECAP-O has also been studied for frail older adults (Franklin et al., 2013). ICECAP-O was found to have significant strong correlation with psychological wellbeing and self-reported dementia quality of life measures which was taken as evidence for the construct validity of ICECAP-O among frail older adults. Keeley et al. (2016) have also provided evidence for construct validity of ICECAP-O in their RCT. They reported moderate correlations between ICECAP-O tariff and EQ-5D index scores (r = 0.51) as well as SF-36 (36 items Short Form Survey) subscales of general health (r = 0.60), social functioning (r = 0.52) and vitality (r = 0.59) and an inverse relation with disability level among post stroke blood pressure management group of older adults. Moreover, Van Leeuwen et al. (2015) reported ICECAP-O's association with other study variables to be in the expected direction such as strong association with Adult Social Care Outcomes Toolkit, mastery, client centeredness, and emotional influences, and less strongly associated with activities of daily living, physical limitations, and Health Global Rating Scale. Whereas contrary to expectation association of ICECAP-O with QoL Global Rating Scale was not strong. However, based on most of the study hypotheses accepted ICECAP-O showed evidence of construct validity for frail older adults living in homes.

However, there is requirement of further exploration of ICECAP-O validation for PWD. There is no study available for validation of ICECAP-O for PWD which could encompass most of the types of dementia. ICECAP-O for PWD with no restriction of specific category of dementia will be a valuable addition into existing knowledge regarding validation of ICECAP-O. There is no existing criterion measure available to compare capability well-being based QoL of PWD, therefore, in order to determine construct validity of ICECAP-O for PWD focus may be laid on comparison of ICECAP-O measure with different dimensions of functioning and demographic variables by keeping the same rationale as that of Coast et al. (2008) in account. As cognitive functioning deteriorates in PWD, therefore inclusion of cognitive functioning of PWD as one of the comparison measures will be vital.

3.3.2 *Convergent and Discriminant Validity*

Attempts have been made previously to determine convergent and discriminant validity of ICECAP-O. Makai et al. (2012) determined the convergent and discriminant validity of the Dutch proxy versions of the ICECAP-O among psycho-geriatric restrained and unrestrained residents of a Dutch nursing home. They used two proxy versions: the nursing professional version and family version. To determine convergent validity of the ICECAP-O proxies they used different QoL scales including the EQ-5D (EuroQol, 1990), EuroQol Visual Analogue Scale (EQ-VAS), Cantril’s ladder (Cantril, 1966) and an overall life satisfaction scale (Veenhoven, 2010). They also tried to determine the association of the ICECAP-O with anxiety and depression (Hospital Anxiety and Depression Scale (HADS); Bjelland et al., 2002), and care dependency (Care Dependency Scale (CDS); Dijkstra et al., 1996). As predicted the ICECAP-O demonstrated convergence with most of the QOL measures including Cantril’s ladder (r = .60 and r = .33 for the nursing and family scale respectively), EQ5D (r = .48 and r = .57), EQ-VAS (r = .55 and r = .43). ICECAP-O was not significantly correlated with Hospital Anxiety and Depression Scale (r = -.18 and r = -.01) but was significantly correlated with the Care Dependency Scale (r = .56 and r = .32). These findings suggest that ICECAP-O is correlated with other QoL measures but not with anxiety and depression measures, which provides indication of an adequate convergent and discriminant validity of ICECAP-O with these measures.

For discriminant validity of ICECAP-O proxies, Makai et al. (2012) also compared the restrained and unrestrained participants. As expected, the restrained participants scored lower on most scales including most of the ICECAP-O factors. However, some differences were found between the nursing and family proxy scores. This may be attributed to difference of perception of nursing professionals and that of the relatives as family members perceive their relative in comparison to their previous independent life whereas the nursing professionals perceive them in the context of the specific care facility setting (different frame of reference). Further research is required to explore the underlying factors contributing to the differences of professional and family proxy versions of ICECAP-O. Makai et al. (2012) study attempted to validate the ICECAP-O proxy for psycho-geriatric adults. However, there is no evidence of ICECAP-O self-report version validation for psycho-geriatric population. Furthermore, they also reported that some of the participants of this study might have had cognitive limitation or even dementia which they did not control for.

Discriminant and convergent validity of ICECAP-O has also been determined among general older adults (> 70 years) who used social care services at their own homes, day care centre, or residential facility. It was reported that ICECAP-O was highly correlated with general health, mental health, and wellbeing measures, whereas moderately correlated with physical health measures. It was also reported that ICECAP-O can discriminate among higher income and lower income individuals, those who can meet ends easily scored higher on ICECAP-O as compared to those who have lower economic resources (Hackert et al., 2017). There is a requirement of extending the scope of ICECAP-O from care facilities to general life setting and from general older people to people with specific health condition (e.g., dementia). There is no study available in the existing literature in which ICECAP-O has been validated or studied in the context of community dwelling PWD. Although discriminant and convergent validity of Spanish proxy version of ICECAP-O has been determined in the care setting for PWD (Sarabia-Cobo et al., 2017). However, there is still requirement of its validation for PWD living in their own home in the community directly rather than via a proxy. In Sarabia-Cobo et al. (2017) study nursing professionals served as proxy for care resident PWD. ICECAP-O was reported to have moderate to good convergent validity with the EQ-5D+C, Alzheimer's Disease Related Quality of Life, and Barthel Index Scores for activities of daily living (with correlation being r = 0.62, r = 0.61, and r = 0.68, respectively). ICECAP-O was found to be able to discriminate between different levels of dementia severity. There is need for further research for validation of self-reported ICECAP-O for community dwelling PWD.

Convergent and discriminant validity of ICECAP-O has also been assessed in the hospital setting (Makai et al., 2013). In this study convergent validity of ICECAP-O was determined with health and wellbeing measures of post hospitalized older adults in the Netherlands. Discriminant validity of ICECAP-O was determined among various subgroups of post hospitalized individuals. It was reported that ICECAP-O had good convergent validity with wellbeing and health related measures, and it can discriminated among different subgroups of post hospitalised individuals (Makai et al., 2013).

The studies described above highlight the fact that attempts to validate ICECAP-O have been restricted to institutional settings e.g., care homes, care facilities, and hospitals. There is requirement to broaden validity of ICECAP-O to other general life settings. There is a need to investigate convergent and discriminant validity of ICECAP-O for different and well-defined geriatric populations. There is also a need to determine validity of self-reported version of the instrument among community dwelling PWD.

3.3.3 Face Validity of ICECAP-O

Although ICECAP-O was developed and its construct validity and valuation system determined through a two-stage in-depth quantitative interview process (Coast, Peter et al., 2008; Coast, Flynn et al., 2008), it was still not known whether the ICECAP-O was understandable for use with the general older population. The concept is generally known as face validity. Therefore, to determine face validity of ICECAP-O and to identify any issues related to understanding and interpretation of the ICECAP-O interviews were conducted by Horwood et al. (2014) with twenty knee and hip arthroplasty patients. The “think aloud” interviewing technique was used. This involves asking participant to verbalise their thoughts about different questions, concepts, or items of a scale. Participants are not required to explain or justify their thoughts or to mention their strategies they are using for interpretation of any concept. They are only required to reveal what comes in their mind by reading any particular concept or question (Ericsson & Simon, 1993).

Generally, problems identified in responding to a questionnaire are related to comprehension and interpretation of questions, and the comfortable level of disclosure for the participant in responding to various questions (Drennan, 2003). Horwood and colleagues (2014) tried to identify the extent and nature of problems older people encountered while completing ICECAP-O. The research in particular examined participants’ comprehension (e.g., misunderstanding on part of the participant regarding any word, phrase, or response option), retrieval (e.g., difficulty in recalling relevant information), judgement (e.g., experience or irrelevant information recalled), and response (e.g., there is inconsistency between response given and its explanation or the experience which participant has revealed). This classification scheme was based on the “question and answer” model of cognitive psychology which highlights that participants adopt four actions while responding to a question (Tourangeau, 1984; Willis, 2006). Difficulty with a question was regarded as re-reading several times or questioning the rationale of the question or arriving at the relevant response or explanation eventually.

Horwood et at. (2014) reported that from among all the 100 question segments only 7% judgement related problems occurred. The majority of these problems were related to comprehension or understanding. No retrieval problems emerged. However, participants mostly struggled with the capability “control” related question. Nature of problems was also derived from participants’ responses. Two types of problems were identified related to attachment capability (i.e., love and friendship); one was that that the participants interpreted the question in the context of their knee or hip replacement surgery which caused confusion among a minority of respondents. The second issue was related to participants who perceived love and friendship in the context of intimate relationship and linked their physical restriction due to arthritis with this capability. Although they restricted the scope of the question their interpretation of the concept was accurate which was reflected in their think aloud verbalization process. Security capability (i.e., thinking about future) was misunderstood as if it is about an individual’s future or future in general or global future. Some tried to link it solely to their physical condition. On role (i.e., doing things that make you feel valued) some struggled to figure out if the question was about personal ability or more general in nature. Minimum difficulty was faced while answering questions related to the attributes of enjoyment and control.

Overall, the findings by Horwood et al. (2014) indicated that there was generally good understanding of all the concepts presented in this questionnaire; there were few issues related to completion of the questionnaire in the context of the health conditions participants were experiencing and the measure performed well. However, the study was restricted to participants having knee and hip replacement issues, which restricts its generalization to other populations and importantly one of the exclusion criteria was PWD. As such it would be essential to explore how this measure is perceived among PWD. A separate study for PWD would be a useful and novel contribution to the existing knowledge about ICECAP-O as such this is a major gap in the knowledge as no capability-based QoL measure available for PWD. One of the problems reported in the above study in comprehension was confusion about the nature of the questions being individual or global (Horwood et al., 2014). In the future validation studies of ICECAP-O, it will be useful to highlight at the start of the interview that this measure concerns personal perception of an individual's capabilities. Following the same process to determine face validity of ICECAP-O among PWD may help in furthering understanding about the positive or negative influences on the general attributes of QoL from perspective of PWD.

3.3.4 Test- Retest Reliability of ICECAP-O

Despite the importance of reliability for a scale reliability of ICECAP-O has not been investigated extensively. Only two studies in the previous literature have been found which examined test-retest reliability of the ICECAP-O (Hörder et al., 2016; van Leeuwen et al., 2015). Van Leeuwen et al. (2015) attempted to determine test-retest reliability of ICECAP-O along with two other scales (i.e., EQ-5D and Adult Social Care Toolkit (ASCOT)) among care in transition frail older adults. They reported good test-retest reliability with Intra Class Correlation (ICC) to be higher than 0.70 for all the scales. On the basis of 95% Confidence Interval of ICC estimate, Koo and Li (2016) regarded values less than 0.5 as poor, between 0.5 to 0.75 as moderate, between 0.75 and 0.9 as good and greater than 0.9 as excellent. This study (Van Leeuwen et al., 2015) was limited in that on both occasions of test administration there was no research team member present. On both occasions participants completed the tests independently at their homes in a computer assisted personal interview. The environmental conditions or the variables required to be kept constant on both occasions of administration have not been reported which is a limitation of the study.

Hörder et al. (2016) also attempted to determine test-retest reliability of ICECAP-O among 70 years old cognitively intact older adults. In the first administration of ICECAP-O the scale was given in addition to those scales already been administered on the participants as a part of another population based broader health study. For the second administration the scale was posted to the participants to complete and return by mail. Similar to the previous study test administration conditions varied greatly. Whereas the first completion occurred during a hospital visit the second happened in the home environment.

In context of structural and design limitations of existing studies which attempted to determine reliability of ICECAP-O (e.g., not keeping conditions on both administration constant, absence of relevant researcher to monitor effects of any environmental or individual factors on test completion or to clarify to participants if they faced any difficulty in completing the questionnaire) a well-designed study to investigate reliability of ICECAP-O is needed. Furthermore, in both the studies the study population was homogenous consisting of frail adults aged 70 years and above. This limitation restricts generalization of the findings to the broader population. Test-retest reliability of ICECAP-O has been examined in only two above mentioned studies which had a few limitations as well. Therefore, there is a need to conduct more work to determine test-retest reliability of ICECAP-O for various older populations e.g., older adults without frailty, or with neurological conditions including dementia.

3.3.5 ICECAP-O's Feasibility of Administration, Responsiveness, and Sensitivity to Change

It is vital for a psychometrically valid and reliable measure to be feasible for the participants to complete (Anastasi & Urbina, 1997). There is only one study available by

Davis et al. (2013) to investigate feasibility of administration and completion of ICECAP-O among older adults. They investigated feasibility of ICECAP-O completion among 215 cognitively intact community dwelling older adults (Mean age = 79.3). They administered three scales (i.e., ICECAP-O, EQ-5D, and EQ-VAS) to determine feasibility of administration of each of the scales. All the scales were administered on the participant's first visit to a falls clinic for their initial assessment and at twelve months follow-up. Feasibility of completion of scales in terms of item completion rate was found to be 99.1% for EQ-5D, 97.7% for EQ-VAS, and 92.1% for ICECAP-O. According to findings of this study (Davis et al., 2013) feasibility of completion of ICECAP-O is lower as compared to the other two measures. One of the factors contributing towards this difference may have been the primary characteristic of the sample population as they were recruited from falls clinic, they were likely to have balance issues restricting their mobility and independence. Individuals in this population due to their physical limitation might not have found certain items of ICECAP-O relevant and omitted responses to them. However, it remains unclear as to which items were mostly not responded to by the participants, therefore, no conclusion could be drawn about differences in the feasibility of completion. Furthermore, no information has been reported with regards to sequence of the questionnaire administration, therefore, no concrete conclusion can be drawn as to which factor might have contributed towards lower rate of ICECAP-O completion as compared to the other two measures.

There is no study other than Davis et at. (2013) available regarding feasibility of administration or completion of ICECAP-O. Although this scale was developed and validated through quantitative interviews with older adults there is still requirement that feasibility of administration of this tool may be explored among different types and segments of older population including PWD.

ICECAP-O's responsiveness and sensitivity to change has been studied in various contexts such as mobility impairment as a consequence of falls among general older people (Davis et al., 2017), frail older adults living in homes (van Leeuwen et al., 2015), and post stroke blood pressure management group of older adults (Keeley et al., 2016). It was found to be significantly (*p* > .05) sensitive and responsive to falls over the 12 months follow up (Davis et al., 2017). Keeley et al. (2016) in their RCT reported that change in EQ-5D-3L (health), SF-36 subscales (general health, vitality, and social functioning), and Modified Rankin Scale (level of disability) over time was found to be related to change in ICECAP-O tariff scores in the same direction. They concluded that their RCT provided positive evidence for responsiveness of ICECAP-O to change in the post stroke blood pressure management in a group of older adults. This study also provides evidence for the efficacy of the ICECAP-O to be used in intervention studies. However, van Leeuwen et al. (2015) reported weak correlations between change scores of ICECAP-O, EuroQol five-dimensional questionnaire, Adult Social Care Outcomes Toolkit, Client-Centred Care Questionnaire, Mental health Component Summary, and Quality of Life Global Rating Scale. Hence, there was mix evidence regarding ICECAP-O's responsiveness to change depending on the context in which it was evaluated as two studies (Davis et al., 2017; Keeley et al., 2016) reported significant while one (van Leeuwan et al., 2015) reported weak responsiveness of ICECAP-O to change. However, ICECAP-O's responsiveness for community dwelling PWD has not been determined yet which is a novel context. This suggests a need to extend research towards PWD in this regard.

3.3.6 *ICECAP-O's Miscellaneous Psychometric Properties*

ICECAP-O has been tested for its suitability for carers' of PWD, and agreement of its self-reported and proxy versions. Suitability of ICECAP-O to measure QoL of family carers of PWD has also been studied qualitatively. Findings suggested ICECAP-O as suitable for carers of PWD to measure their QoL (Jones et al., 2014). However, further research is required to determine its suitability for PWD as well. In addition, Davis et al. (2016) examined the agreement between self-reported and the proxy versions of ICECAP-O among people with mild Vascular cognitive impairment and their carers. They reported that two (i.e., attachment and control) among five domains of ICECAP-O demonstrated slight agreement, whereas ICC agreement was poor between self-reported and proxy versions of ICECAP-O. However, further research is required to determine the utility of ICECAP-O for other cognitive disorders including dementia.

3.4 Comparison with a recent Systematic Review

The present systematic literature review was conducted in January 2018, it included only those studies that involved psychometric assessment of ICECAP-O. The systematic literature review was conducted as a part of the present PhD. However, recently a systematic review (Proud et al., 2019) was published, which included the studies involving psychometric assessment of ICECAP-O from its development (i.e., 2006) till October 2018. It was different from the present systematic literature review in a way that it also included studies involving utilization of ICECAP-O within economic evaluation. As indicated above the present systematic literature review shortlisted 16 studies involving psychometric assessment of ICECAP-O, whereas Proud and colleagues’ (2019) systematic review included 24 studies involving psychometric assessment of ICECAP-O. There are eight studies which are in addition to those included in the present systematic review. The reason due to which the present systematic literature review fell short of these seven studies was differences in the search strategy of both the reviews. Search strategy in the present systematic literature review involved studies having used the keywords mentioned in the start of this chapter in the abstracts. However, Proud and colleagues (2019) initially conducted a scoping search, which highlighted that many studies which used ICECAP-O did not make reference to it in the title or the abstract. Therefore, they expanded their search to include full texts. They also included published conference full text papers.

The additional ICECAP-O validation studies included in Proud and colleagues' (2019) systematic review assessed content validity (Milne et al., 2014; Haywood et al., 2014), construct validity (Ratcliffe et al., 2011), responsiveness (Parsons et al., 2014), discriminant and convergent validity of ICECAP-O German proxy version for the nursing home residents PWD (Makai et al., 2014). Their systematic review provided evidence for good construct validity, test-retest reliability, and responsiveness to change. However, it showed some issues in its content validity regarding relevance and interpretation of its items among older adults (Horwood et al., 2014). However, their results were not mainly different from the present systematic literature review as regards evaluation of psychometric properties of ICECAP-O among older adults. Both have found it to be a valid and reliable measure of capability based QoL for older adults. None among these studies involved community dwelling PWD, hence there remains the requirement of evaluation of psychometric properties of ICECAP-O for community dwelling PWD.

3.5 Summary

Overall, it is clear that there is limited evidence for the psychometric properties of the ICECAP-O for PWD. As such psychometric properties of ICECAP-O have been examined for various cognitively intact older populations. Its construct validity has been determined with community dwelling older adults (Coast et al., 2008), frail older adults (Franklin et al., 2013; van Leeuwen et al., 2015), and post stroke blood pressure management group (Keeley et al., 2016). Additionally, its convergent and discriminant validity has been tested with care home residents (Dutch proxy version) (Makai et al., 2012), post hospitalized older adults (Makai et al., 2013), people with Parkinson's (Xin et al., 2016), older adults availing social care services (Hackert et al., 2017), and institutionalized PWD (Spanish proxy version) (Sarabia-Cobo et al., 2017). This was the only study to examine proxy version's discriminant and convergent validity with institutionalized PWD (Sarabia-Cobo et al., 2017). Moreover, one study has examined its face validity with cognitively intact older adults (Horwood et al., 2014), while only two studies evaluated its test-retest reliability with older adults in general (van Leeuwen et al., 2015; Hörder et al., 2016), while one examined its feasibility of administration (Davis et al., 2013). There are three studies which tested its responsiveness to change (van Leeuwen et al., 2015; Keeley et al., 2016; Davis et al., 2017) and one to evaluate agreement between self-reported and proxy versions in people with mild vascular cognitive impairment and their carers (Davis et al., 2016). There was only one study which evaluated its suitability for carers of PWD (Jones et al., 2014). The review of existing research suggested that self-reported version of ICECAP-O has not been validated for community dwelling PWD. Therefore, evaluation of its psychometric properties for community dwelling PWD would be a novel contribution in knowledge and fill a major gap in research regarding QoL assessment in community dwelling PWD. To fill the gap in knowledge identified in the systematic literature review regarding validation of self-reported version of ICECAP-O for community dwelling PWD, study-I in the present PhD was conducted (detail is provided in Chapter 4: Methods and Chapter 5: Study I: Validation of ICECAP-O as QoL Measure for PWD).

4 Methodological Underpinnings

This chapter highlights the research design followed in this thesis. It explains the present thesis in the six layers of Saunders et al. (2007) research onion. All aspects of research design along with main research questions (informed by research gaps highlighted in Chapters 2 and 3) are described in this chapter. The present chapter is divided into the following six sections (see Table 3 for an overview of the present chapter).

1. Research Philosophy
2. Research Approach
3. Research Strategy
4. Research Choices
5. Time Frame
6. Techniques and Procedures

Table 3:
An overview of research methodology.

S.No	**Saunders et al. (2007) research onion**	**Research methodology of present thesis**
1	Research Philosophy / theoretical framework	Epistemology Post-Positivism
2	Methodology	Quantitative/deductive
3	Research Strategy	Intervention/Experimental
4	Research Choices	Quantitative methods i.e., primarily quantitative, only a small segment involved “think aloud” interviews regarding readability and comprehension of a QoL scale (ICECAP-O) among PWD.
5	Time Frame and Study Design	Study-I: Cross sectional
		Study-II: Longitudinal
		Study-III: Experimental
6	Techniques and Procedures	Statistical and descriptive analyses including percentages, bivariate correlation, t-test, multiple linear regression, non-parametric Kruskal-Wallis tests

4.1 Research Philosophy

The present research has considered epistemology post-positivism as research philosophy. Epistemology is concerned with knowledge about the world/reality, nature of knowledge, its possibility (whether it is possible to attain or not), scope and legitimacy (Crotty, 1998). It is defined as “an issue concerns the question of what is (or should be) regarded as acceptable knowledge in a discipline” (Bryman, 2008, p.13). It is concerned with the basis of knowledge, its nature and acquisition, and how it is communicated with others (Manion & Morrison, 2007). The researcher’s view of knowledge (i.e., tangible and objective or subjective and unique) determines their research approach and method to uncover reality (Manion & Morrison, 2007). The present PhD aims to add to existing knowledge pertaining to QoL of community dwelling PWD and their carers. The present researcher views knowledge as objective, tangible, and quantifiable. Therefore, the theoretical framework complementing the researcher’s view of knowledge is post-positivism (Petter & Gallivan, 2004; Deluca et al., 2008) which elucidate that knowledge is produced by testing propositions, and hypotheses must be derived from theories and then empirically examined. Therefore, the underlying research philosophy for the present thesis is epistemology post-positivism.

4.2 Research Approach

The present thesis adopted a quantitative/deductive logic approach which is in line with the post-positivist philosophical approach on which the thesis was based. As a deductive approach the research started with a research problem/question (Creswell & Clark, 2007) of does adherence to a Tai Chi exercise intervention improve QoL of community dwelling PWD? The research question was based on the TACIT trial logic model (see Table 4) which illustrates the theoretical underpinning and connectedness of Tai Chi with QoL of PWD and their carers. It highlights that, as a direct outcome of the trial there will be reduction in the risk of falls among PWD and their carers via increased dynamic, functional, and static balance (in both PWD and their carers), and delayed deterioration of cognitive and visuospatial functions, and reduced fear of falls (in PWD), which will indirectly affect their QoL positively (Nyman et al., 2018).

Table 4: *Logic model of the TACIT Tai Chi intervention*

Inputs	Activities	Outputs	Impacts	Outcomes
Human resources: • Tai Chi instructors to deliver the intervention • Research team to make telephone calls to remind dyads to attend classes Products: • Booklet to support practice of home-based Tai Chi • Homework sheets to support practice of home-based Tai Chi • Alarm clocks to help remind dyads to practice Tai Chi at home Estates: • Venues in the NHS / community accessible by public transport and that have free car parking for hire of the Tai Chi classes	Intervention contact: • • Weekly 90 min Tai Chi class for 20 weeks (45mins Tai Chi, 45mins socializing/Q&A with instructor). • A home visit by Tai Chi instructor in weeks 3–4 to support Tai Chi practice at home through behaviour change techniques (joint action & coping planning with carer). • Telephone contact by research team in weeks 2–18 to remind to attend classes if consecutively fail to attend 2 classes for unknown reason Intervention led by carer: • PWD to practice Tai Chi 20 mins per day. • Daily self-monitoring & weekly instructor feedback: PWD to complete a daily diary of Tai Chi practiced at home and hand to instructor at Tai Chi class weekly	• Joint action plan for practicing Tai Chi at home. • Joint coping plan for practicing Tai Chi at home. • Diaries of Tai Chi practiced at home	• Increased participation in Tai Chi; physical activity designed to improve balance and prevent falls. • Increased support to do Tai Chi via weekly instructor-led classes. • Increased social support to practice Tai Chi through weekly contact with instructor and peers at the classes, and telephone reminders. • Increased support to do Tai Chi at home via home booklet, homework sheets, action and coping planning, self-monitoring, instructor feedback, and alarm clock reminder.	Direct: • Reduction in risk of falls via increased dynamic balance (postural stability). • Further reduction in risk of falls via: (a) increased functional balance (postural stability) (b) increased static balance (postural stability) (c) reduced fear of falls (d) delayed deterioration in global cognitive functioning (e) delayed deterioration in visual-spatial cognitive functioning. • Reduction in risk of falls in the carer via: (a) increased dynamic balance (postural stability) (b) increased static balance (postural stability). Indirect (via the above): • Reduction in rate of falls. • Increased quality of life • Increased quality of life in the carer • Reduced carer burden

Note. From" 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)." By Nyman, S., Hayward, C., Ingram, W., Thomas, P., Thomas, S., Vassallo, M., Raftery, J., Allen, H., & Barrado-Martín, Y. (2018). *BMC Geriatrics* 18 (263), p 4. https://doi.org/10.1186/s12877-018-0935-8.

Previously, in a RCT (Bjerk et al., 2018) increased fear of falls was reported to be associated with reduced QoL, while better physical balance, lower number of falls, and higher level of cognition with better QoL among older adults. Moreover, Schoene et al. (2019) in their systematic review also highlighted an inverse association between fear of falls and QoL among older adults. Similarly, in the systematic review by Vaapio (2009) a positive effect of falls prevention interventions on QoL of older adults was reported. Also, cognitive domains of attention and visuospatial abilities were reported to be significantly associated with QoL of post-stroke patients (Cumming, 2014). Visuospatial abilities are also reported to be associated with independent living and better QoL in older adults (Widagdo et al., 2021). Hence, the previous evidence is supportive of association of these variables with QoL in older adults.

Tai Chi has shown to have reduced fear of falls and risk of falls among older adults in a RCT (Mortazavi et al., 2017). Moreover, a systematic review and meta-analysis of RCTs (Lin et al., 2021) showed Tai Chi can significantly improve cognitive functioning in terms of overall cognition, executive function, learning and memory, and visuospatial function. Hence, the existing evidence suggests effectiveness of Tai Chi in reduction of risk of falls and fear of falls along with improvement in cognition, which have established association with QoL of older adults (Vaapio, 2009; Cumming, 2014; Widagdo et al., 2021). Based on existing evidence the logic model of the TACIT trial indicated an indirect positive effect of falls reduction, reduced fear of falls, and improved cognition as an outcome of Tai Chi on QoL of PWD and their carers. However, the present PhD aimed to explore further the association between Tai Chi exercise intervention and QoL of PWD by investigating the direct effect of adherence to a Tai Chi exercise intervention on QoL of PWD. This is novel contribution of present study in knowledge. This has not been explored earlier in any study including the TACIT trial.

To address the research question based on TACIT trial logic model existing literature was reviewed to identify the available evidence and the gaps in knowledge (see chapter 2 and 3 for literature review). Based on these identified gaps in existing research specific research sub-questions were formulated (see Table 5).

Table 5: *Summary of research gaps and research sub-questions.*

S.No.	Research gaps	Research sub-questions
1	There is no QoL scale available for community dwelling PWD to assess actual attributes of their QoL.	Is ICECAP-O (a capability based QoL scale for cognitively intact older adults), psychometrically valid for community dwelling PWD?
2	There is lack of studies investigating adherence to an exercise intervention among community PWD.	What factors affect adherence to a Tai Chi exercise intervention among community dwelling PWD?
3	There is scarcity of studies examining factors associated with QoL of community dwelling PWD and their carers.	What factors affect QoL of community dwelling PWD and their carers?

The study hypotheses were based on these research questions (see sections 5.3,6.3, and 7.3 for rationale and hypotheses). Data was collected and analysed accordingly to determine whether empirical evidence is supportive of the study hypotheses while ethical measures were in place (see section 4.5.2. ethical consideration) to conduct the research.

4.3 Research Strategy

As mentioned above the main research question was, does adherence to a Tai Chi exercise intervention improve QoL of community dwelling PWD? To address this question intervention study design suited the present study. The present PhD as a part of a larger RCT, the TACIT trial, attempted to investigate the effect of adherence to a Tai Chi exercise intervention on QoL of community dwelling PWD (see appendix-M for distinction between the present study and the TACIT trial and role of the present researcher in both).

4.4 Research Choices

The quantitative method approach adopted in the present PhD was primarily comprised of quantitative methods, however, a small segment of the study involved cognitive interviews based on “think aloud” technique (Ericsson & Simon, 1993). These were conducted to examine readability and comprehension of ICECAP-O among PWD (see below section 4.6.1 Thesis structure for details).

4.5 Time Frame & Study Design

It was a mix of cross sectional (study-I), longitudinal (study -II), and experimental (study-III) study design and time frame, which involved measurement and assessment of study variables at different time points i.e., from start till 6 months after start of the intervention.

4.6 Techniques and Procedures

4.6.1 Thesis Structure

The main research question of the present thesis was does adherence to a Tai Chi exercise intervention improve QoL of community dwelling PWD? To answer the research question, it was vital to address components of adherence and QoL. Therefore, a thorough literature review was conducted, in which certain gaps in knowledge were identified. Informed by the research gaps three sub-questions were formulated (see Table 5 for the gaps in research and research sub-questions).

Based on these research questions the present thesis was divided into three sub-studies i.e., 1) Validation of ICECAP-O as QoL measure for PWD, 2) Evaluation of adherence to Tai Chi intervention among PWD, 3) Effect of adherence to Tai Chi intervention on QoL of PWD and their carers.

Study-I: It was vital to understand QoL of PWD before assessing how it was affected by an exercise intervention. The literature review identified that currently PWD’s QoL is measured by either health-related QoL tools (e.g., EuroQol 5Dimensions (EQ 5D) (*EuroQol Group, 1990)* or dementia-specific tools (e.g., Dementia Quality of Life (DemQoL, Mulhern et al., 2013)) or designed for specific sub-types of dementia (e.g., Quality of Life for Alzheimer's disease (QoL-AD) (Logsdon et al., 1999, 2002)). There is no QoL scale available for community dwelling PWD which measures actual attributes of QoL directly. ICECAP-O (Coast, Peter et al., 2008) is the only measure available for cognitively intact older adults which measure actual attributes of their QoL based on their capabilities. These attributes were identified by older adults during the development process of ICECAP-O (Coast, Peter et al, 2008). It was, therefore, aimed to examine its psychometric properties for PWD. It was considered that if found psychometrically valid and reliable this would be a major contribution in the assessment of QoL of PWD as it would be the first capability based QoL measure for PWD which assesses actual attributes of their QoL. Therefore, its validity (construct validity in terms of convergent and discriminant validity, face validity), reliability (test-retest reliability, Cronbach alpha reliability), and factorial structure (confirmatory factor analysis) were assessed (see chapter 5 for details).

Study-II: It was essential to understand adherence to an exercise intervention among PWD to answer the main research question. It was identified in the literature review that there is lack of consensus regarding definition of adherence to exercise intervention among older adults with or without dementia (Di Lorito et al., 2020; Hawley-Hague et al., 2016). Therefore, adherence to a Tai Chi exercise intervention among PWD in the present study was defined cautiously. Adherence to the Tai Chi exercise intervention was defined in terms of percentage of class attendance among the participants. Despite lack of consensus regarding definition of adherence to exercise interventions among older adults, the majority of the previous studies have defined adherence to exercise interventions among older adults with or without dementia in terms of percentage of classes attended (Di Lorito et al., 2020). This approach suited the purpose of the present study as Gillespie et al., (2012) suggested that it is better to define adherence according to its relevance and suitability to the purpose of the research. There is lack of research regarding adherence to exercise intervention among community dwelling PWD and no study available examining adherence to Tai Chi exercise intervention among this population. Therefore, it would be a major contribution in research related to adherence to an exercise intervention among PWD. It was attempted to explore patterns of adherence, factors associated with adherence to Tai Chi exercise intervention, and causes of non-adherence among community dwelling PWD (see chapter 6 for details). The findings would contribute to strategies for improvement in adherence to exercise interventions among PWD to benefit them.

Study-III: Third study aimed to investigate the main outcome of the study i.e., effect of adherence to Tai Chi exercise intervention on QoL of community dwelling PWD. Adherence was primarily taken in terms of percentage of class attendance and QoL was assessed in terms of ICECAP-O scores. A few additional analyses were also considered e.g., association between percentage of minutes of Tai Chi home practice and QoL among PWD, and association between percentage of class attendance and QoL of carers of PWD. The TACIT trial included participants as dyads (PWD and their informal carer), however, the primary focus of the present thesis was only on PWD. QoL of carers of PWD was assessed as a secondary outcome of the study. In addition, factors associated with QoL of PWD and their carers were also examined. The present study is the first to explore effect of adherence to an exercise intervention (Tai Chi) on actual attributes of QoL of community dwelling PWD. Therefore, it is a major contribution in research pertaining to the effect of exercise adherence on QoL of PWD.

4.6.2 Reference Guide to Determine Effect Size of Statistical Tests

To determine the effect size of statistical tests to be used in the present study a reference guide was made (see Table 6).

Table 6:

Effect sizes of correlation, and independent sample t-test, level of Cronbach alpha, and test-retest reliability used in the present PhD.

Tests			
		Effect Size	
Pearson Correlation (r)	Small	Medium	Large
	.10-.29	.30-.49	.50-1.0
		Effect Size	
Independent Sample t-test	Small	Moderate	Large
	.01	.06	.14
		Levels of α	
Cronbach Alpha (α)	Moderate	High	Excellent
	.70-.79	.80-.89	.90-1.0
		Levels of Test-retest Reliability	
Test-retest Reliability	Fair	Good	Excellent
	.40-.59	.60-.74	≥ .75

Note. Effect size of r and independent sample t-test is adapted from Cohen (1992), and level of α and test-retest reliability from Nunnally (1978) and Cicchetti (1994) respectively. Nunnally (1978) recommended level of reliability does not represent a cut-off point rather a value near to his criteria would be considered as his criteria is met e.g., .78 for .80 (Cho, 2020).

4.6.3 Sample Selection/ Methodology

Convenient sampling method was used in the present study because the sample of community dwelling PWD was difficult to recruit. Due to limited budget and practical constraints such as availability of participants as dyads (PWD and carer), and willingness of PWD or their carers to participate probability sampling was not possible to recruit a nationally representative sample. Therefore, convenience sampling was a suitable choice. However, detailed inclusion/exclusion criteria and recruitment strategies were devised to be inclusive to accommodate a broad sample.

4.7 Ethical considerations

The present study employed the following ethical principles (Pannbacker et al., 1996; Declaration of Helsinki, 1964):

1. **Autonomy:** commitment to respect the participants' independent choices and actions.
2. **Beneficence:** responsibility to convey benefits and help others to further legitimate interests.
3. **Confidentiality:** understanding that the participants' personal data will be kept safe and not revealed to others.
4. **Nonmaleficence:** obligation to not cause any harm or risk of harm to participants.
5. **Professional responsibility:** obligation to observe the rules of professional conduct with research participants and colleagues.

The study was judged to have potential benefits for PWD and their carers. The researcher was mindful of the participants' privacy and psychological well-being.

4.7.1 Participant Information:

All relevant and necessary information was provided to the participants of the study in a balanced manner. Excessive information was avoided, and complicated information was simplified for participants' understanding and to avoid their stress (British Society of Gerontology, 2008). Participant information sheets, key fact sheets were prepared following the best practice for design detailed by the National Research Ethics Service (Appendices F, G).

4.7.2 Informed Consent*:*

Participants' consent to participate involved assessment of capacity to consent and informed consent. Participants had no pressure to participate in the study. The participants gave informed consent to the researcher by demonstrating full understanding of the research they were agreeing to involve (Alzheimer’s Association, 1997). Participants were free to discuss with another person to decide whether to participate (Alzheimer’s Association, 1997). They were also encouraged to ask questions (Alzheimer’s Association, 1997). Specifically for participants from TACIT trial consent was checked and confirmed from PWD along the research process, considering the progressive nature of dementia and through their verbal and non-verbal cues (Wilkinson, 2002). It was in accordance with Good Clinical Practice guidelines instructed by the National Institute for Health Research (NIHR), which defines consent as an “ongoing process”. Objective was to obtain maximally informed consent from PWD (Hellström, 2007). Data outside the trial was cross sectional hence this did not apply to it and consent was taken only once at the start of the study.

The researcher acted in the best interests of the PWD. In accordance with Mental Capacity Act (UK Government, 2005) PWD’s capacity to participate was assumed unless established otherwise. Compliance did not indicate capacity (UK Department of Health, 2009). Capacity for PWD was assessed specifically in relation to understanding, retention, using or weighing information and communicating (Medical Research Council, 2007). Initial consideration of PWD’s capacity to participate was based on informal assessment by researcher during first data collection visit/session. Only PWD with capacity to consent in line with the Mental Capacity Act (UK Department of Health, 2005) having mild/moderate dementia were recruited for the TACIT Trial and therefore into this present PhD and to the study segment outside the trial.

Participants were free to withdraw from the study at any time. In addition, it was also ensured that the participation would be cancelled or delayed if PWD did not appear to assent, actively expressed discomfort or distress, or indicated in any other way that they did not wish for the data collection session to continue (UK Department of Health, 2009).

4.7.3 Ethical and Legislative Approval:

The trial was registered at ClinicalTrials.Gov with registration number: NCT02864056 (Nyman et al., 2018). The trial was scrutinised at the highest level (nationally) by experts in this area and was approved for ethics and governance arrangements. The Ethical approval for the trial was obtained from the NHS Research Ethics Committee (REC) and the Health Research Authority (HRA). Ethical approval for one component of the present PhD which was outside the TACIT trial was obtained from Bournemouth University's Research Ethics Panel (see appendix B).

4.7.4 Assessment and Management of Emotional Distress:

For management of researcher's distress in the TACIT trial and the study component outside the trial there was a provision in lone worker protocol p.272 Appendix E, which states:

1. "**Researcher's distress:**
   i. A PGR's supervisor will be available for debriefing after activities conducted under lone working, in case this is needed.
   ii. Counselling advise will be sought at the University if persistent distress is manifested by the Postgraduate Researcher."

Although, there were no specific provisions regarding participant's distress management in the TACIT trial protocol, however, there was a provision in the lone worker protocol p.272, appendix E, regarding participants living with dementia's behavioural changes which states:

2. **"Participants living with dementia's behavioural challenges:**
   i. If during a home visit: Participants will be offered the possibility to stop for a while, arrange an alternative moment to carry out the interview/visit/measurements or withdraw with no negative consequences for their

participation in the TACIT Trial.

ii. Home-interviews/data collection: will be conducted in the presence of an informal carer."

The above provision was in line with Declaration of Helsinki 1964 (III. 4b p. 2) *"At any time during the course of clinical research the subject or his guardian should be free to withdraw permission for research to be continued. The investigator or the investigating team should discontinue the research if in his or their judgement, it may, if continued, be harmful to the individual."*

Furthermore, the researcher was given training by the TACIT trial management team and the principal investigator regarding communication with PWD (including assessing capacity to give consent), data collection (including how to conduct the balance tests safely, and how to administer the questionnaires / structured interviews), and data protection/management. The researcher also completed GCP online training, and ethics e-Modules as per trial's basic requirements before conducting research (see appendices Q and R). Therefore, the researcher was well trained and aware of the ethical standards to ensure the wellbeing of the participants of the research. Therefore, the researcher remained vigilant to the verbal and non-verbal signs and signals in PWD that might be interpreted as symptoms of distress resulting from participation in the research project. There was no incidence of participant(s)' distress to the extent, during pre/post intervention data collection sessions, which warranted discontinuation of the data collection session or withdrawal from participation. Participants' comfort was of paramount importance to the researcher and the TACIT trial team. Participants' comfort was ensured throughout the data collection sessions. Informal carers were part of the TACIT trial sample. Data collection sessions were arranged at the place of participants' convenience (which in all the cases was their homes). Therefore, all PWD completed data collection sessions in their comfort zones under conducive environment. However, future research may explore PWD's distress management to enhance knowledge in this regard.

4.7.5 General Data Protection Regulation (Data Protection Act, 1998) and Confidentiality:

The TACIT trial participant information sheet (see Appendix F) included a section titled "*What will happen if we don't want to carry on with the study?* p. 280, which stated "All information collected about you during the course of your participation will be kept strictly confidential and in accordance with the Data Protection Act 1998. Your medical records will remain within the establishments which usually maintain them (your GP or local hospital for example) but may be reviewed by members of the research team to confirm your eligibility to take part and to gather information regarding any hospital admissions during the study period if needed. The Peninsula Clinical Trials Unit (PenCTU, part of the University of Plymouth) and members of the research team at Bournemouth University will prepare the study data collected about you for analysis.

Your name and other identifying information will be removed from any study data before being transferred to either party so that you cannot be identified from the data. Your contact details (name, address, telephone number) will be provided to PenCTU to enable collection of some information by post. These details will be stored separately from the de-identified study information on secure computers accessible only to authorized members of PenCTU.

Paper-based information will be stored in locked offices, in locked filing cabinets and information kept on computers will be stored securely on a system maintained by either the University of Plymouth or Bournemouth University.

Authorized people from Southern Health NHS Foundation Trust, Dorset HealthCare University Foundation Trust, Bournemouth University or PenCTU may need to review your medical records to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research team."

Confidentiality and data protection of the participants outside the TACIT trial (for study-I) was also ensured in accordance with the Data Protection Act (1998). Participants were informed that no personally identifiable information will be associated with the data collected from them. The following clauses were made part of the consent form for study-I (Appendix-D):

i. I understand that I am free to withdraw up to the point where the data are processed and become anonymous, so my identity cannot be determined.
ii. I give permission that de-identified information collected in this study may be shared with other researchers to support other research in the future. I understand that I cannot be identified from this information.
iii. I give permission for members of the research team to have access to my anonymized responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the outputs that result from the research.

The present researcher was an official member of the TACIT trial, therefore allowed to use trial data relevant to her study. Approval to use the trial data for all TACIT members was sought collectively. However, the present researcher's contracts to be part of this trial are added in (appendices O, P).

4.8 Summary

The present research was designed to add into practical knowledge regarding QoL assessment, and adherence to Tai Chi exercise intervention among community dwelling PWD, and effect of adherence to Tai Chi exercise intervention of QoL of PWD and their carers. The research was divided into three sub-studies to evaluate psychometric properties of a capability based QoL scale (ICECAP-O) for community dwelling PWD (study-I, cross sectional), to assess adherence to Tai Chi exercise intervention among community dwelling PWD (study-II, longitudinal), and to examine effect of adherence to Tai Chi exercise intervention on QoL of PWD and their carers (experimental). Detail of each sub-study and overall discussion of all the findings is given in the next chapters.

5 Study I: Validation of ICECAP-O as QoL Measure for PWD

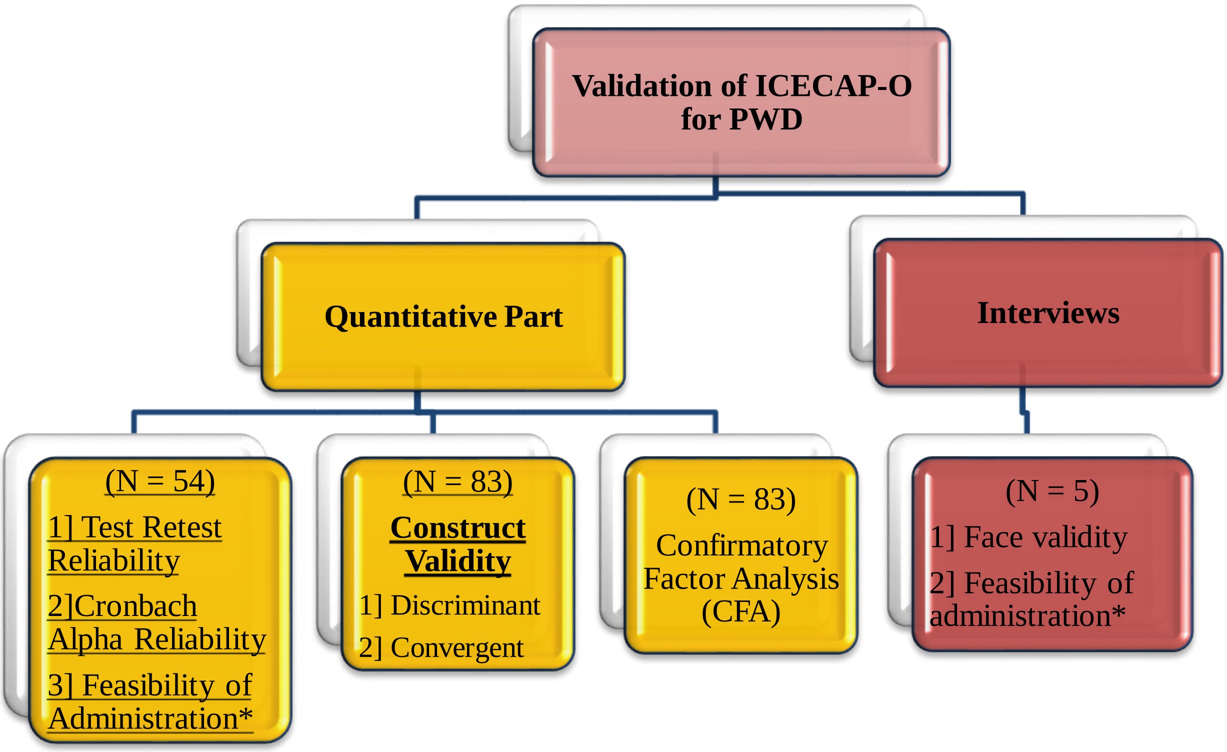
5.1 Aim of the Study

Aim of the study was to validate a QoL measure (ICECAP-O) for PWD to enable the measurement of actual attributes of QoL among PWD and to contribute to the improvement of their QoL.

Study I consisted of interviews for face validity and quantitative component to assess the validity, reliability, and feasibility of administration of the ICECAP-O among PWD. In particular, the interviews of Study I examined the face validity of the ICECAP-O in terms of readability and comprehension as well as the feasibility of administration of the ICECAP-O among PWD. The construct validity and reliability of the ICECAP-O were examined quantitatively.

Figure 3:

Illustration of study-I design.



* Data for assessment of feasibility of administration of ICECAP-O among PWD was derived from reliability and face validity sample.

5.2 Objectives

The study has following objectives:

1. To assess face validity in terms of readability and comprehension of ICECAP-O among community dwelling PWD.
2. To assess feasibility of administration of ICECAP-O among community dwelling PWD.
3. To assess internal and external reliability of ICECAP-O among community dwelling PWD.

4. To assess construct validity of ICECAP-O in terms of discriminant and convergent validity among community dwelling PWD.
5. To assess the factorial structure through Confirmatory Factor Analysis (CFA) of ICECAP-O among community dwelling PWD.

5.3 Rationale and Hypotheses

5.3.1 *Face Validity*

A test not only has to be a valid measure of the construct it intends to measure, but it also must be understandable for the population it is designed for (Anastasi & Urbina, 1997). This concept is known as face validity. To determine face validity of ICECA-O among PWD, the procedure devised by Horwood et al. (2014) has been followed in the present study. They conducted 20 qualitative interviews with knee and hip arthroplasty patients. They used the "think aloud" technique of cognitive interviewing. They aimed to identify any issues related to understanding and interpretation of the ICECAP-O. Findings indicated that there was generally good understanding of all the concepts presented in the questionnaire. The same procedure has been followed in the present study, as that used for general older adults, assuming it is equally applicable to PWD as long as their reading ability is intact. The following hypothesis has been made regarding face validity of ICECECP-O:

1. ICECAP-O is a readable and comprehensible measure for PWD.

5.3.2 *Feasibility of Administration*

Alongside validity and reliability feasibility of administration of a scale is also essential. Feasibility of completion of ICECAP-O has previously been investigated among cognitively intact older adults aged 70 years and above. Feasibility of completion of ICECAP-O in terms of completion of all items of the scales was reported to be 92.1% of the participants (Davis et al., 2014). Feasibility of administration of ICECAP-O for PWD has to be established for its psychometric accuracy. Therefore, it has been attempted in the present study to establish feasibility of administration of ICECAP-O for PWD in terms of item completion rate. The following hypothesis has been made, on the basis of existing evidence regarding its feasibility of completion (i.e., 92.1%) among general older adult population (Davis et al., 2014):

2. ICECAP-O is a feasible measure to administer among community dwelling PWD in terms of completion of the scale.

5.3.3 Reliability

It is essential for a test to be valid as well as reliable. Reliability refers to consistency of scores on the same test over time (Anastasi & Urbina, 1997). Hence, assessment of reliability of ICECAP-O for PWD is also vital. There are two broad categories of reliability: internal and external. Internal reliability of the scale refers to consistency of scores within itself, whereas external reliability refers to consistency of scores on different occasions, by different raters and on parallel forms (McLeod, 2007).

Internal reliability is further divided into two types: split half (McLeod, 2007) and Cronbach alpha (Goforth, 2015). In split half reliability the test is divided into two equal halves. It is the assessment of the extent to which two halves of a scale or test are contributing towards the overall measurement of the attribute for which the scale is designed (McLeod, 2007). Cronbach alpha reliability is computed by correlating the scores of each item of the scale with total scores of each participant on the scale, subsequently comparing the variance of all individual item scores (Goforth, 2015). Ideally Cronbach alpha coefficient should be above 0.70, however, with short scales such as scales with less than ten items it is common to find lower Cronbach alpha (e.g., 0.5). This is due to the fact that Cronbach alpha values are sensitive to the number of items in the scale. In case of low Cronbach alpha, it is appropriate to report mean inter-item correlations (Pallant, 2001). Optimal range of inter-item correlation is recommended to be 0.2-0.4 (Briggs & Cheek, 1986).

External reliability is classified as test-retest reliability, interrater or inter observer reliability and parallel forms reliability. Test-retest reliability refers to consistency of score on the same scale on two different occasions. Inter rater reliability is consistency of scores when a scale is rated by different observers or raters. Parallel forms reliability refers to consistency of scores on different forms of the same scale (McLeod, 2007). The latter two forms of reliability are not relevant to the present study.

Reliability of ICECAP-O has not been investigated extensively. Only two studies investigating test-retest reliability are available (Hörder et al., 2016; van Leeuwen et al., 2015), whereas no study has investigated its internal reliability. Van Leeuwen et al. (2015) reported good test-retest reliability with Intra Class Correlation (ICC) to be higher than 0.70. Hörder et al. (2016) also reported good test-retest reliability for the index scores with ICC to be 0.80. On the basis of 95% Confidence Interval of ICC estimate, Terry and Mae (2016) regarded values less than 0.5 as poor, between 0.5 to 0.75 as moderate, between 0.75 and 0.9 as good and greater than 0.90 as excellent. In both the studies population of the studies was homogenous consisting of frail cognitively intact adults aged 70 years and above. This limitation restricts generalization of the findings to the broader population or populations with chronic conditions. Therefore, assessment of reliability (both internal and external) of ICECAP-O for PWD is important. The present study will determine internal reliability by means of Cronbach alpha. Considering the relatively small scale size, it was not deemed appropriate to also use the split half methodology.

In order to determine external reliability of the scale test-retest procedure has been adopted as inter-rater and parallel forms procedures are not applicable in this case. The following hypotheses have been made:

3. ICECAP-O has good (> .70) (Cicchetti, 1994; Nunnaly & Bernstein, 1994) Cronbach alpha reliability among community dwelling PWD.
4. ICECAP-O has good (> .75) (Cicchetti, 1994) test-retest reliability among community dwelling PWD.

5.3.4 Construct Validity

ICECAP-O has been validated for general older adult population (Coast, Peters et al., 2008). Coast, Peters et al. (2008) determined the construct validity of ICECAP-O instead of criterion validity as there is currently no gold standard measure available for capability based QoL to be compared. They compared ICECAP-O scores of 315 participants aged 65 and above with their demographic information (i.e., age, sex, social class, social contact, general wellbeing, physical disabilities, general health, membership of an organization, participation in informal care, and locality or environment), and few of already established questionnaires such as EQ-5D (instrument for measuring QoL based on generic health).

Coast, Peters et al. (2008) reported associations between age and social contact with self-reported capabilities. Increased age was associated with lower capabilities level. Likewise, the more frequent the social contact the greater their capabilities. General well-being and general health were found to be positively associated and physical disabilities inversely associated with capabilities. EQ-5D scores were found to be strongly associated with enjoyment and control but not attachment capability. Likewise, membership of an organization was reported to be associated with enjoyment, whereas participation in informal care was not associated with capabilities. Similarly, sex, social class, locality, or environment were not found to be associated with capabilities. The study found most of the associations in the expected direction. To investigate the construct validity of ICECAP-O for community dwelling PWD the present PhD aimed to follow the methodology of Coast, Peter et al., (2008) as a standard approach to examine construct validity of ICECAP-O.

Makai et al. (2012) demonstrated convergence of proxy ICECAP-O with other QoL measures, but no association with depression and anxiety measure as measured with the Hospital Anxiety and Depression Scale (HADS) (Bjelland et al., 2002). Makai et al. (2012) also found, as expected, that restrained individuals scored lower on the ICECAP-O proxy measure compared to unrestrained individuals. These findings demonstrate evidence for construct validity of ICECAP-O for older adults as it converged well with other QoL measures and discriminated between two different populations. Therefore, it was expected in the present study that ICECAP-O would converge with similar and discriminate with unrelated variables among community dwelling PWD.

To determine construct validity of ICECAP-O for PWD long term health conditions other than dementia have been included in the present study as Coast, Peter et al. (2008) found a positive association between health and ICECAP-O capabilities among cognitively intact older adults. The following hypothesis has been made regarding association of long-term health conditions other than dementia with ICECAP-O among PWD:

5. PWD with long term health condition other than dementia will have lower capability scores on ICECAP-O as compared to those with no long-term health conditions other than dementia.

Currently there is no other capability based QoL instrument available, therefore, it is not possible to determine convergent validity by comparing scores to similar measures. Hence, in the present study Coast, Peter et al. (2008) approach has been followed to compare other abilities/functions of PWD with ICECAP-O capabilities to determine convergent validity of the scale. PWD's ICECAP-O scores have been compared with their cognitive and physical abilities, measured through already established measurement instruments i.e., Berg Balance Scale (a measure of body balance, which is a physical ability) and Statue Test (a measure of visuo-spatial ability, which is a cognitive ability).

The BBS measures individual's physical ability i.e., body balance which is required for most human activities. Gouveia et al. (2018) reported beneficial effects of Pro Balance program on HRQoL, comprised of both physical and mental components, among community dwelling older adults. Similarly, Dunsky (2019) in their mini review suggested positive effects of balance and coordination exercises on QoL among older adults. Keeping into consideration the positive relationship between body balance and QoL among older adults in general it is pertinent to extend the scope of investigation to PWD as well. Therefore, the following hypothesis has been made:

6. There will be positive low to moderate association between PWD's ICECAP-O and Berg Balance Scale (BBS) scores.

The Statue Test is designed to investigate visuo-spatial abilities of individuals. Pal et al. (2016) reported significant impairment of visuospatial functions among PWD particularly in Alzheimer's, Lewy Body, and Vascular dementia types. They also indicated increased visuospatial dysfunction with increased severity of dementia. Salimi et al. (2019) reported impairment on almost all visuospatial tasks among Alzheimer's and behavioural variant of Frontotemporal dementia participants as compared to their controlled counterparts. Severity of impairment was reported to be greater among Alzheimer's patients than that of behavioural variant of Frontotemporal dementia. Visuospatial functions are reported to be impaired even in the early stages of Alzheimer's (Quental et al., 2018). Attention and visuospatial abilities are found to be strongly associated with QoL among post stroke patients (Cumming et al., 2014). Visuospatial abilities are also reported to be associated with independent living and better QoL in older adults (Widagdo et al., 2021). As these studies indicated prevalence of impairment of visuospatial abilities among PWD and a strong association between visuospatial abilities and QoL among stroke patients, therefore, it is assumed in the present study that visuospatial dysfunction may affect QoL among PWD as well. On the basis of this assumption, it has been attempted to compare visuospatial abilities (in terms of scores on Statue Test) with capabilities of QoL (in terms of ICECAP-O scores) among PWD. Poor performance on Statue Test (in terms of more errors) indicates poor visuospatial abilities, hence, it was assumed that greater errors on Statue Test will be associated with lower ICECAP-O scores among PWD. Therefore, the following hypothesis has been made:

7. There will be an inverse association between PWD’s ICECAP-O and Statue Test scores.

Contrary to convergent validity, *discriminant validity* is the concept that two measures of unrelated constructs will have weak or zero correlation (Hair et al., 2017). As Makai and colleagues (2012) reported convergence of proxy ICECAP-O with other QoL measures but no correlation with HADS i.e., a depression and anxiety scale (Bjelland et al., 2002) deemed to be unrelated with ICECAP-O. Furthermore, for discriminant validity of ICECAP-O they also compared proxy ICECAP-O measure for psycho-geriatrics restrained and unrestrained participants and found their scores to be different which indicates that two different groups of participants will score differently on ICECAP-O. Hence, to determine the discriminant validity of ICECAP-O among PWD, the present study compared ICECAP-O with a cognitive test (i.e., M-ACE) as small or negligible associations of QoL have been found with cognitive test scores among PWD (Martyr et al., 2018). M-ACE is a global cognitive test involving four cognitive domains i.e., orientation of time, memory, language, and visuospatial abilities. Each domain of M-ACE may have varied relation with capability based QoL scale ICECAP-O, which collectively may not reveal a direct association. Therefore, it was assumed that M-ACE was a measure unrelated to ICECAP-O, hence used as a measure for discriminant validity of ICECAP-O. It is expected that ICEAP-O may have small or negligible association with M-ACE among PWD. Hence, the following hypothesis has been made:

8. There will be a low, non-significant association between PWD’s scores on ICECAP-O and M-ACE.

5.4 Sample for Face Validity

The sample for face validity and feasibility of administration of ICECAP-O included five community dwelling participants diagnosed with dementia (recruitment for face validity stopped as saturation point was achieved, however for feasibility of administration of ICECAP-O reliability sample (N = 54) was also included). Both male and female participants were included.

The sample for the face validity of ICECAP-O was determined based on data saturation i.e., no new information emerged, and further data collection became redundant (Hennink & Kaiser, 2022).

5.5 Sample for Quantitative Component

5.5.1 Sample for Reliability

The sample for test-retest and Cronbach alpha reliability included 54 community dwelling participants diagnosed with dementia. Both male and female participants were included.

Test-retest reliability analysis involves correlation coefficient analysis. Based on study assumption that ICECAP-O has good (> .75) (Cicchetti, 1994) test-retest reliability among community dwelling PWD, a minimum sample size of n = 15 was required (Hull et al., 1925). For the present study 54 participants were recruited for the test-retest reliability as such meeting the sample size criteria. A larger sample was purposefully recruited considering the heterogeneity among PWD in terms of both physical and cognitive abilities (due to high likelihood of comorbidities), and therefore a larger sample was prudent to accommodate a larger expected amount of variance in the data. Hence, the proposed minimum sample size is based on cognitively intact participants.

Similarly, to obtain a Cronbach alpha reliability of >.70, with 5 items and a significance level of 0.05 a minimum sample size of 16 participants was required. Again, the 54 participants in the present study exceeded this requirement. This was done to consider the potential neurological and/or cognitive complications associated with the sample under consideration.

5.5.2 *Recruitment Strategy for Participants of Face Validity and Reliability*

Participants for the face validity along with reliability of the scale were recruited from outside the main (TACIT) trial. As such, Bournemouth University ethical approval was acquired for this part of the validation (see appendix B). Participants for the face validity and reliability were initially approached through different resources including: Ageing and Dementia Research Centre (ADRC) contact list, Department of Psychology, Bournemouth University pool of participants, Public and Patient Involvement (PPI) Groups, Alzheimer’s Society, charity/community groups for people with dementia, day care centres (gatekeepers’ approval was sought for this) and publicity of the study in the community/local and national media. The study was conducted in the Wessex region.

Participants who had provided their contact details and consent to be contacted for participation in research, to Bournemouth University, were contacted through telephone calls. If they were willing to know about the study, they were given a brief overview of the study. If they were available and interested to take part in the study, they were asked a few questions pertaining to eligibility to take part in the study (except M-ACE scores which was obtained during initial data collection session). Once their eligibility was ascertained they were requested to provide their mailing details to post or email them the Participant Information Sheet (PIS) and Key Fact Sheet detailing the study information in written form. Participants were also assured on the telephone calls that they will be free to not participate after reading the study information sheets and that they will be contacted in a few days to confirm if they have received and read the study information sheet and they were still willing to proceed with their participation. Data collection sessions were arranged with only those participants who were finally agreed to take part in the study.

Participants who were recruited through public relation activities such as delivering a talk or distribution of leaflets about the study at charity/ community groups for people with dementia, dementia café, support groups, day care centres, social and local media, PPI groups, and Alzheimer’s society to increase awareness about the study, contacted the researcher either in person after the talk or contacted through telephone calls. During telephone calls the same procedure was adopted as mentioned above to confirm their willingness and eligibility to take part in the study. Those who approached the researcher in person and expressed interest in taking part in the study were provided with the participant information sheet and key fact sheet to take with them to read. They were requested for their contact details; telephone number/email to contact them to confirm their final decision about participation in the study. They were contacted in a couple of days to confirm their willingness to participate in the study. Afterwards, they were asked initial screening questions to ascertain their availability to take part in the study. M-ACE was administered in the first test-retest reliability session in a structured interview format. For face validity single session was conducted for each participant, in which M-ACE was administered in a structured interview format."

5.5.3 Inclusion Criteria for Face Validity and Reliability

1. Diagnosis of dementia.
    - i. This was self-reported by the PWD or by their informal carer (N = 11 from test-retest reliability sample of 54, and N = 5 from face validity sample) during the first interaction with them. To verify the self-reported diagnosis and type of dementia, participants were requested to provide a copy of GP letter which indicated a diagnosis of dementia, date of diagnosis and type of dementia. If they did not have a copy of a GP letter, they were requested to allow the researcher to contact the GP of PWD or the memory assessment clinic, which made the diagnosis so that it may be confirmed for the research purpose. Self-reported diagnosis of dementia of three out of 11 participants of test-retest reliability was confirmed from their GPs with their prior permission.
    - ii. The diagnosis of the participants, recruited through the day care centres (N = 43 out of N = 54 participants of test-retest reliability), was confirmed through the gatekeepers by checking the on-site record of the participant.
2. Aged 18 years and above.
3. Living at home in the community (participants attending day care centres have also been included in test-retest reliability and face validity part. However, participants for construct validity were included from the main trial, therefore, they were not recruited from day care centres as it was one of the exclusion criteria of the main trial).

5.5.4 Exclusion criteria for Face Validity and Reliability

1. Living in a care home.

2. In receipt of palliative care.
3. Scores of nine or less on the Mini-Addenbrooke’s Cognitive Examination (M-ACE), as this was regarded as severe dementia.
4. Severe sensory impairment.
5. Lack of mental capacity to consent.

If any of the inclusion criteria was not met the participants were not included in the study. Likewise, if any of the exclusion criteria was met the participants were not included in the study.

5.5.5 Sample for Construct Validity

The construct validity sample (N = 83) was taken from the main RCT. Ethical approval for the main trial was sought from the NHS Research Ethics Committee (REC) and the Health Research Authority (HRA). People with mild to moderate dementia were the target population for the main trial. Both male and females were included. Detailed strategy was devised in the main trial for the recruitment of the participants (Heward et al., 2022). People with confirmed diagnosis of dementia were included.

5.5.6 Inclusion Criteria for Construct Validity

Inclusion criteria (relevant to the present study) for participants to be included in the trial was as follows:

1. Aged 18 years or above.
2. Living at home.
3. Diagnosis of dementia is confirmed.

5.5.7 Exclusion Criteria for Construct Validity

Exclusion criteria (relevant to the present study) for participants of the trial was as follows:

1. Living in care home.
2. In receipt of palliative care.
3. Have severe dementia (scores of 9 or less on M-ACE was regarded as severe dementia).
4. A Lewy body dementia or dementia with Parkinson's disease.
5. Severe sensory impairment.
6. Lack mental capacity to provide informed consent.

5.6 Instruments

5.6.1 Mini-Addenbrooke's Cognitive Examination (M-ACE)

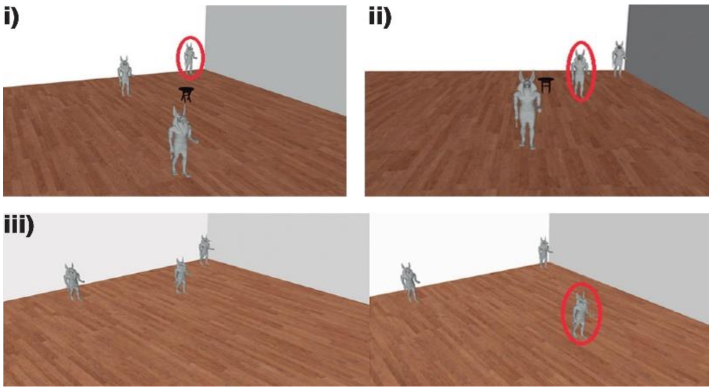
M-ACE was developed by Hsieh et al. (2015) for cognitive screening for individuals with dementia. It is a brief tool, which consists of five items with a maximum score of 30. It has four cognitive domains: orientation, memory, language, and visuospatial functioning. Higher scores indicate better cognitive function. It takes approximately five minutes to complete. It has two cut off scores; 25 and 21. Score of 25 or lower indicates five times higher likelihood of having dementia, whereas a score of 21 or less indicates certainty of dementia prevalence. It has been regarded as a more sensitive measure, among PWD, than Mini Mental State Examination (MMSE) that is another global cognitive assessment measure (Hsieh et al., 2015). In addition, MMSE is a paid test, therefore it was not cost effective to use. Moreover, M-ACE in comparison to original ACE version is a shorter test battery, therefore, it was less demanding and easier to administer with PWD. Hence, it has been used in the present study for general assessment of cognitive function.

5.6.2 Statue Test

The Statue test is a brief visuo-spatial measure requiring participants to make spatial judgement, using a tablet, for a room with three statues and a stool (Reed, & Spiers, Unpublished thesis). Compared to global cognitive functioning tests such as the M-ACE it has cognitive involvement of the hippocampus (Nyman et al., 2018). It involves three visuo-spatial tasks. In the first task, participants are required to indicate which statue is closest to one of the walls, which represent a landmark. In the second task, participants are required to identify the statue closest to the stool, which is a transient landmark. In the last task, participants are asked to indicate the statue which moved from its previous location among the three after a small delay. Participants indicate the correct statue in each task by tapping on it with their finger. All the three tasks involve easy, medium, and hard conditions (Coughlan et al., 2018). It is a brief cognitive measure of visuo-spatial functioning (Nyman et al., 2018), It is a performance based cognitive test which was included in addition to a paper based cognitive test M-ACE to keep the interest of the participants in completing the task. It was assumed that it would be interesting and not laborious for PWD to complete. There is no other performance-based scale for assessment of visuospatial functioning is available. Hence, Statue test was an appropriate choice.

Figure 4:

Screenshots of (i) wall, (ii) stool, and (iii) memory tasks from statue test



Note: The encircled statues in the screenshot are for illustrative purposes for correct choices in each task. The correct choices were not shown to the participants. “From Diagnostic Relevance of Spatial Orientation for Vascular Dementia A Case Study,” by G. Coughlan, E. Flanagan, S. Jeff, M. Bertoux, H. Spiers, E. Mioshi, M. Hornberger, 2018, *Dement*

Neuropsychol, *12*(1), Procedure section, Figure 2, 88 (DOI: 10.1590/1980-57642018dn12-010013).

5.6.3 Berg Balance Scale (BSS)

The BBS is a 14-item scale, for the objective assessment of 14 common movements in everyday life. Each item is rated on a five-point ordinal scale ranging from 0 to 4, 0 indicating the lowest level of functioning whereas 4 indicates the highest level of functioning. It takes approximately 20 minutes to complete. The material and setting required to complete all tasks involve; a ruler, footstool, or step, 15 feet walkway, stop or wristwatch, two standard chairs (one with arm rests the other without it).

The BBS was developed to measure balance among older adults. Inter- and intra-rater reliability of the scale as whole were .98 and .99 respectively. Cronbach alpha reliability of the scale was .96 and inter-item correlation ranged from .71 to .99 (Berg et al., 1989). Its test-retest reliability is reported to be high among people with hemiparesis (i.e., .98) (Berg, 1995). Criterion validity was supported by its moderate correlation with caregiver and self-ratings of balance along with laboratory measures of sway, and strong correlation with functional and motor performance among older stroke patients (Berg, Wood-Dauphine, Williams, & Gayton, 1992). Core Outcome Measures in Effectiveness Trials database (www.comet-initiative.org) and Sibley et al. (2015) reported a consensus regarding two scales to measure standing balance among adults i.e., BBS and Mini Balance Evaluation System Test (MBEST). It has been selected for PWD in the main trial for its ease of administration among older adults (Berg, et al., 1989) and suitability for use with PWD (van Iersel et al., 2007; Telenius et al., 2015). Moreover, in TACIT trial MBEST was considered as risky to administer by the TACIT team as it may require professionals such as physiotherapists to administer without causing any distress in PWD. Therefore, BBS was selected in the best interest of the participants of the study.

5.6.4 *ICECAP-O*

ICECAP-O is the only existing scale to measure actual attributes of QoL of cognitively intact older adults, which has been developed by Coast et al. (2008). These attributes of QoL are (with lay terms in brackets):

1. Attachment (love and friendship).
2. Security (thinking about the future without concern).
3. Role (doing things that make you feel valued).
4. Enjoyment (enjoyment and pleasure).
5. Control (independence).

Items of the scale are based on the lay terms. Each item has four choices given against it. These choices range from “I can have all of the certain attributes,” having maximum score of four to “I cannot have any of the certain attributes,” having minimum score of one on an item. It is a self-reported measure. The participants’ self-reported scores are called raw scores which range from a minimum score of five to a maximum score of 20. The raw scores are converted into weighted scores called ICECAP-O tariffs, using the scoring system for ICECAP-O (Coast, Flynn et al., 2008). Although ICECAP-O tariffs are based on the best-worst scaling, ranging from 0 to 1, however, the minimum ICECAP-O tariff is never absolute zero, it is always 0.12, whereas the maximum is always 1, as all the levels of attributes have been assigned specific values. These values are used to calculate ICECAP-O tariffs. The best and the worst levels of scores indicate presence or absence of an attribute, whereas the scores in between indicate mild to moderate levels of an attribute. There is no existing measure for actual attributes of QoL among PWD, therefore, ICECAP-O which is the only existing measure for actual attributes of QoL among cognitively intact older adults has been selected for validation among PWD.

5.6.4.1 *Scoring of ICECAP-O*

Valuing the ICECAP capability index for older people is comprehensive and elaborate (Coast, Flynn et al., 2008). It is a system of the best-worst scaling, which clearly indicates presence or absence of a particular capability. The scoring ranges from 0-1, which are called weighted or tariff scores. Although, all the five attributes being measured through ICECAP-O have four levels of options. For example, first capability in the scale i.e., attachment (love and friendship in layman term) can be rated on one of the four levels i.e., "I can have all of the love and friendship that I want," "I can have a lot of the love and friendship that I want," "I can have a little of the love and friendship that I want," and "I cannot have any of the love and friendship that I want." All the remaining items are rated on similar four levels. The highest level of any capability is scored as 4 and the lowest of any capability is regarded as 1. These are called raw scores which are subsequently converted into tariff scores. However, anyone scoring a one on each question would indicate zero score or absence of the capabilities. Although, choosing 1 as an option on all the capabilities will still not be considered as absolute zero because zero or complete absence of capabilities is regarded as death (Coast, Flynn et al., 2008). Therefore, 5x1 will have a value closest to zero due to tariffs assigned to level 1 of each capability. The score of 5x4 would be considered 1 indicating maximum of all the capabilities. Raw scores in between these levels will be converted into tariff scores a per pre-determined tariff values for each level of all capabilities. See table 7 (Coast, Flynn et al., 2008) for further clarification of the scoring of ICECAP-O capability index.

Table 7:

Terminology for attribute levels, and rescaled values, such that the absence of capability, state11111, is equal to zero, and full capability, state44444, is equal to one (n=255).

Attribute	**Value**
Attachment	
I can have all of the love and friendship that I want	0.2535
I can have a lot of the love and friendship that I want	0.2325
I can have a little of the love and friendship that I want	0.1340
I cannot have any of the love and friendship that I want	-0.0128
Security	
I can think about the future without any concern	0.1788
I can think about the future with only a little concern	0.1071
I can only think about the future with some concern	0.0661
I can only think about the future with a lot of concern	0.0321
Role	
I am able to do all of the things that make me feel valued	0.1923
I am able to do many of the things that make me feel valued	0.1793
I am able to do a few of the things that make me feel valued	0.1296
I am unable to do any of the things that make me feel valued	0.0151
Enjoyment	
I can have all of the enjoyment and pleasure that I want	0.1660
I can have a lot of the enjoyment and pleasure that I want	0.1643
I can have a little of the enjoyment and pleasure that I want	0.1185
I cannot have any of the enjoyment and pleasure that I want	0.0168
Control	
I am able to be completely independent	0.2094
I am able to be independent in many things	0.1848
I am able to be independent in a few things	0.1076
I am unable to be at all independent	-0.0512

Note. From “Valuing the ICECAP Capability Index for Older People,” by J. Coast, T. N. Flynn, L. Natarajan, K. Sproston, J. Lewis, J. J. Louviere, and T. J. Peters, 2008, *Social Science & Medicine*, *67*(5), Results section, Table 2879, (https://doi.org/10.1016/j.socscimed.2008.05.015).

Measures of QoL for PWD, their scope and limitations, along with the requirement of a QoL scale for PWD that measures actual attributes of QoL (i.e., ICECAP-O) and attempts to validate it for various population have been discussed in detail. It has been differentiated earlier that factors of QoL are different than actual attributes of QoL. Although, a distinction has been made between attributes of QoL and factors affecting QoL (Grewal et al, 2006), but QoL itself is a complex construct due to which there is generally lack of consensus over its definition (Selai & Trimble 1999; Ready et al., 2004; Walker & Lowenstein 2009), which makes it challenging to explore factors associated with it (Holopainen et al., 2019). Moreover, QoL of PWD becomes particularly more intricate due to their complex emotional, physical, and psychosocial needs. Therefore, it is pertinent to explore factors affecting QoL of PWD to advance understanding of the concept of QoL of PWD and to ultimately improve it. Review of existing evidence in this regard will highlight the complexity of factors associated with PWD's QoL, which will ultimately facilitate attempts on improving it.

5.7 Procedure

5.7.1 *Face Validity and Reliability*

Although informal carers did not participate in the actual validation process, their assistance was invited to accompany the participant during the recruitment and testing phases in order to make the PWD feel comfortable. Participant Information Sheet (PIS) was shared with the PWD or their informal carer, during first interaction with them, providing an overview of the study. The study process was explained verbally as well by the researcher to the potential participants. Those participants who consented to be contacted for confirmation of their willingness to take part in the study were asked to take the PIS home with them and take time to read all the study information. They were informed that they would be contacted in a couple of days to confirm if they are still interested to take part in the study after reading information about it.

Once diagnosis of PWD was confirmed and their willingness to participate in the study was ascertained a mutually convenient time for data collection was coordinated. The participants had the choice to either come to Bournemouth University to take part in the study in the psychology lab or allow the researcher to visit their home or any other place of their convenience. In cases where the researcher had to visit the home or any other venue of participant's convenience the lone worker protocol was followed (see appendix E). In cases where participants opted to visit Bournemouth University their travel costs were reimbursed.

The participants ***for face validity*** completed three forms: Informed consent form, demographic sheet, and M-ACE for screening of global cognitive functioning. Afterwards they were interviewed in which they were asked to describe what they understood from each item of the ICECAP-O (the QoL scale) and in their opinion what it enquired. They self-completed the ICECAP-O by reading each item and sharing their comprehension of each item. Interviews were audio recorded with participant's prior consent. The following instructions were provided to each participant before starting the interview:

"This questionnaire contains five questions each of which has four choices given against it. Your task is to read each question and the choices given against it aloud and then explain what you understand from it and what you think is asked in each question. You are appreciated to share what comes in your mind after reading each question. If you think you need an explanation for a question to understand it you can tell that as well. However, it may not be possible for the researcher to explain it to you during your interview as this interview is exclusively to record your thinking about this questionnaire. Your interview will be audio recorded, therefore, it is requested to you to be loud and clear while sharing your thoughts on each of the question."

The interview started after the instructions were provided to the participants. The participants completed the interview independently. However, if the participant stopped at any point during the interview, they were politely prompted to carry on. Apart from that no hints or explanations were provided. Interviews data was transcribed verbatim to help in understanding, readability, comprehension, and overall face validity of the ICECAP-O for PWD.

The ***quantitative part*** was split into two parts: test-retest reliability and construct validity. Data for both quantitative parts was collected through structured interviews. Test-retest reliability was used to assess the consistency of a measure from one time to another. A tool/scale is considered reliable if its measurement is stable over time. The time duration between the two administrations has to be long enough to prevent effects of learning or recall (Anastasi & Urbina, 1997). Therefore, two weeks' time duration for re-administration of the scale is considered appropriate for people with dementia as it will be enough to prevent learning and recall effects. For ***test-retest reliability*** PWD completed ICECAP-O with a difference of two weeks on average. Data collection from each participant took around 30 minutes for the first session of the test-retest reliability part of the study. Four forms were used in the first session of test-retest reliability part of the study including: informed consent form, demographic sheet, M-ACE, and ICECAP-O. It was made clear in the beginning of the study that if they were interested in taking part in test-retest part of the study they would have to be part of two sessions over the period of two weeks otherwise the contribution in the study would result in incomplete data. Only those participants who were willing to commit for two sessions were included in this part of the study. They were told at the end of their first session that they would be contacted soon through telephone for the confirmation of their availability for the second data collection session and suitable time for it. The second data collection session for the test-retest reliability took around 10 minutes in which the participants had to complete two questionnaires; the ICECAP-O for the second time after two weeks from their first session and the MMSE (for the assessment of their global cognitive functioning), while all other conditions of testing were kept constant. All participants for test-retest reliability completed the questionnaire on both occasions.

Data for ***construct validity*** of ICECAP-O was derived from the main trial. Construct validity, which encompasses both the discriminant and the convergent validity, is an important research methodology that refers to how well a test measures the behaviour or construct for which it is intended. The participants consented to take part in the main trial, the demographic information regarding their type of dementia, having any long-term health condition other than dementia, along with their M-ACE (for cognitive ability), Statue Test (for visuo-spatial ability) and Berg Balance Test (for body balance) scores were collected from the main trial.

The researcher had specific training on using and interpreting the scores of M-ACE and Statue test from an academic colleague Dr Shanti Shanker at Bournemouth University she is also Honorary Associate Psychologist, Acquired Brain Injury Rehabilitation Service and Adult Neuropsychology Service Dorset Health University Foundation Trust (DHUFR). She is trained and experienced in using the M-ACE with patients and in interpreting the scores. She is also experienced in using Statue test. She and Dr Samuel Nyman, the Principal Investigator TACIT trial who was also the first supervisor, independently observed the researcher in using the M-ACE and Statue tests along with all other tests of the TACIT trial with couple of participants and gave feedback. Therefore, the researcher was well trained to deliver and interpret the scores of cognitive tests competently.

The cognitive tests were selected considering ease of administration and minimum burden on PWD in completing assessment tests. From the researcher’s perspective they completed these tests comfortably without feeling any burden or distress. None of the situations resulted in participants not being able to continue or feeling uncomfortable. The participants completed both cognitive tests (i.e., M-ACE and statue test) successfully. Overall participants found the statue test interesting and enjoyed completing it. Not one participant complained about cognitive tests being hard to complete, or too complicated to carry on.

Table 8 in (appendix N) provides an overview of the distinction between new data (data derived from outside the trial), and data derived from the TACIT trial for the present study, along with difference in utilization and reporting of ICECAP-O in both, and role of researcher in data collection for the trial and present study.

5.8 Data Analysis Strategy

5.8.1 Face Validity

Face validity of ICECAP-O was determined in terms of readability and comprehension of the scale. Data collected in the interviews was analysed descriptively to determine readability and comprehension of the scale among PWDs. Theory suggests that problems with questionnaires involve difficulty with interpretation and comprehension of questions, retrieval of answers; response problems and level of disclosure with which respondent is comfortable (Drennan, 2003). Hence, it was attempted to find the problems PWD might face while completing the ICECAP-O. The problem PWD might face have been divided into three categories i.e., comprehension, interpretation, and discomfort during disclosure. In addition to that participants' ability to read correctly was also included in the assessment.

5.8.2 Feasibility of Administration

Feasibility of administration will be analysed descriptively regarding convenience, comfort, and understanding of the participants for each item of the scale and completion rate of the scale. In addition to that any difficulty faced during completion of the scale will also be analysed.

5.8.3 Cronbach Alpha Reliability

Cronbach alpha reliability analysis will be carried out to determine internal reliability of ICECAP-O using the data from both administrations of test-retest sessions with both raw and tariff scores of ICECAP-O.

5.8.4 Test-Retest Reliability

Data collected through test-retest sessions will be correlated to establish test-retest reliability (the consistency of scores of the same participants for the same measure on two different occasions, a stable measure reflects reliability of the scale) of ICECAP-O. Pearson Product Moment correlation coefficient of ICECAP-O scores between two administrations will be calculated to determine test-retest reliability of the scale. Coefficient of correlation or coefficient of stability between 0.9 and 0.8 is considered good reliability and between 0.8 to 0.7 is considered acceptable reliability (Hughes et al., 2000).

5.8.5 Construct Validity

For assessment of construct validity presence/absence of any long-term health condition will be compared with ICECAP-O scores. Pearson Product Moment Correlation will be conducted. Furthermore, discriminant and convergent validity with other variable will also be assessed.

5.8.6 Convergent Validity

To assess convergent validity of ICECAP-O procedure adopted by Coast et al. (2008) for the construct validity of original ICECAP-O scale, will be adhered to. PWD's cognitive abilities (in terms of visuo-spatial abilities score on the Statue Test) and physical abilities (in terms of body balance scores on Berg Balance Scale) will be compared with the attributes of QoL (in terms of ICECAP-O scores). Pearson Product Moment Correlation will be computed.

5.8.7 Discriminant Validity

To assess discriminant validity of ICECAP-O, ICECAP-O scores will be compared with M-ACE scores. Pearson Product Moment Correlation will be computed.

5.8.8 Confirmatory Factor Analysis

Data were first checked for univariate normality. The absolute values of skewness and kurtosis did not exceed 2 or 7 respectively (Finney et al., 2006). Following this confirmatory factor analysis (CFA) was conducted using the maximum likelihood method of estimation and a covariance matrix in AMOS 25 software for structural equation modelling (Arbuckle & Wothke, 1999). Lambda was set at 1 for the first observed indicator for the latent variable (Quality of Life). Error weights and all other parameters were allowed to be freely estimated. For model fit determination the following indices were used: Chi-square statistic (χ^2); Chi square/df (χ^2/df); standardized root mean square residual (SRMR: Bollen, 1989), root mean square of approximation (RMSEA: Browne & Cudeck, 1993), Tucker-Lewis index (TLI), Goodness-of Fit Index (GFI), Comparative Fit Index (CFI: Bentler, 1990) and P of close fit (Pclose; Hu & Bentler, 1999). The χ^2 and the χ^2/df statistics provide an indication of the fit of the data to the model. A non-significant P value for χ^2 and a value of ≤ 2 for χ^2/df indicates a good fit. In terms of the SRMR a value of $\leq .08$ indicates a good fit whereas for the RMSEA a value of $\leq .06$ indicates a good fit and a value $\leq .08$ as acceptable (Browne & Cudeck, 1993) when taken together with other indices (Kline, 2011). Although cut-off values of .08 for RMSEA and .10 for SRMR have been indicated as acceptable lower bounds of good model fit (Vandenberg & Lance, 2000). For the TLI, GFI and CFI a value $\geq .95$ indicates a good fit and $\geq .90$ an adequate fit (Hu & Bentler, 1999). Finally, the Pclose is required to be non-significant (Browne & Cudeck, 1992; Hooper et al., 2008).

5.9 Results Study-I

5.9.1 *Face Validity*

Face validity of ICECAP-O among community dwelling PWD was assessed descriptively by conducting interviews based on “think aloud” cognitive interviewing technique (Ericsson & Simon, 1993). Table 9 displays the demographic details of participants.

Table 9:

Demographic information of participants of think aloud ICECAP-O interviews (N = 5).

Variables	*F* (*N=5*)
Gender	
Male	2
Female	3
Education	
Secondary	3
Higher education College/University	2
Ethnicity	
White	5
Living Arrangement	
Living alone	1
Living with family and friends	4
Type of Dementia	
Alzheimer’s	2
Mixed (Alzheimer’s and Vascular)	3

The mean age of the face validity sample (N=5) was 77.2 years with standard deviation of 10.03 (minimum – maximum ages: 60 - 84 years). Their M-ACE scores ranged from 22-25. There were no identified problems in any of the assessed categories i.e., readability, comprehension, interpretation, and discomfort in completion of the scale among all the five participants. The result supports the prediction regarding face validity of

ICECAP-O among PWD i.e., ICECAP-O is a readable and comprehensible measure for PWD.

5.9.2 Feasibility of Administration

Feasibility of administration of ICECAP-O was assessed in terms of completion of all items and any problem faced during the completion of the scale. Data to assess completion of all items of ICECAP-O was derived from reliability (N = 54) and face validity (N = 5) samples. Demographic details of both samples are provided in table 9 and table 10 respectively. Completion rate was found to be 100%. No participant left the scale incomplete. Participants did not face any problem in terms of readability, comprehension, and interpretation of each item of the scale. They did not experience any discomfort during completion of the scale. These findings support the prediction that ICECAP-O is a feasible measure to administer among community dwelling PWD in terms of completion of scale and ease of administration i.e., having no problems in completion of scale.

Table 10:

Demographic information of ICECAP-O reliability sample (N =54).

Variables	*F* *(N=54)*
Gender	
Male	32
Female	22
Education	
None	2
Primary	2
Secondary	30
Higher education College/University	15
Further education/professional education	5
Ethnicity	
White	53
Others	1
Living Arrangement	
Living alone	3
Living with family and friends	51
Type of Dementia	
Alzheimer's	34
Vascular	5
Mixed (Alzheimer's and Vascular)	11
Others	4

The mean age of the sample (N=54) was 78.9 years with standard deviation of 7.5. The minimum age was 60 and the maximum was 90.03 years.

5.9.3 Reliability

Reliability analyses was conducted for external (test-retest) and internal (Cronbach alpha) reliability of ICECAP-O. ICECAP-O raw scores as well as weighted/tariff scores were analyzed for assessment of Cronbach alpha and test-retest reliability. Both categories of scores (i.e., raw and tariffs) were analyzed to investigate any differences in the respective reliability findings. Table 10 demonstrates distribution of ICECAP-O reliability sample based on their gender, ethnicity, education, living arrangement, and type of dementia.

5.9.4 *Cronbach Alpha*

Cronbach alpha reliability was separately analysed for raw and tariff scores of ICECAP-O. Data was derived from the test-retest reliability sample. Data from both administrations of ICECAP-O was analysed.

Cronbach Alpha for ICECAP-O raw and tariff scores from 1st administration:

Cronbach alpha for the ICECAP-O raw scores from the 1st administration was moderate with a value of .68 (Nunnaly & Bernstein, 1994). Inter-item correlations for 1st administration raw scores are presented in Table 11. Correlations were from low to high and there was an inverse correlation between items 1 and 5.

Table 11:

Inter item correlation of ICECAP-O raw scores of 1st administration (N=54).

S. No	Items of Scale	1	2	3	4	5
1	Love and Friendship	-	.06	.26	.24	-.06
2	Thinking about Future		-	.46	.43	.24
3	Doing Things that Make You Feel Valued			-	.54	.42
4	Enjoyment and Pleasure				-	.33
5	Independence					-

To examine if the reliability of the scale could be improved items were deleted in a systematic way (see Table 12). Only deletion of item 1 improved the Cronbach alpha value marginally (from .68 to .72). This was not deemed a meaningful change and as such the scale as a whole was used for further analysis.

Table 12:

Item total statistics for ICECAP-O raw scores of 1st administration (N = 54).

Scale Items	Scale Mean if Item Deleted	Corrected Item-Total Correlation	Cronbach's α if Item Deleted
Love and Friendship	12.66	.17	.72
Thinking about Future	13.37	.46	.64
Doing Things that Make You Feel Valued	13.16	.66	.53
Enjoyment and Pleasure	13.16	.59	.55
Independence	13.25	.35	.66

Finally, calculation of Cronbach alpha tariff scores resulted in a value of .53. This is low and close to chance. Systematic removal of items did not result in an improved alpha value (see Table 14). Table 13 provide the item-correlations for the tariff scores. Correlations were low to moderate in magnitude with an inverse correlation between item 1 and 5. Both the alpha and item-correlations cast doubt on the conversion of the scale items to a tariff.

Table 13:

Item total statistics for ICECAP-O raw scores of 1st administration (N = 54).

S. No	Items of Scale	1	2	3	4	5
1	Love and Friendship	-	.14	.34	.25	-.03
2	Thinking about Future		-	.36	.23	.20
3	Doing Things that Make You Feel Valued			-	.41	.35
4	Enjoyment and Pleasure				-	.23
5	Independence					-

Table 14:

Item total statistics for ICECAP-O tariffs of 1^{st} administration (N = 54).

Scale Items	Scale Mean if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Love and Friendship	.64	.21	.51
Thinking about Future	.76	.35	.55
Doing Things that Make You Feel Valued	.70	.56	.38
Enjoyment and Pleasure	.72	.39	.45
Independence	.70	.27	.48

Mean and standard deviation of ICECAP-O items for the raw and tariffs were also calculated. Table 15 illustrates descriptive scale statistics.

Table 15:

Descriptive Item statistics of ICECAP-O raw and tariff scores of 1st administration.

Items of Scale	(N=54)			
	M Raw scores	SD Raw scores	M Tariffs	SD Tariffs
Love and Friendship	3.74	.48	.24	.01
Thinking about Future	3.03	.91	.12	.04
Doing Things that Make You Feel Valued	3.24	.64	.17	.01
Enjoyment and Pleasure	3.24	.69	.15	.01
Independence	3.14	.56	.18	.02
Total	16.39	3.28	.86	.09

Cronbach Alpha for ICECAP-O raw and tariff scores from 2nd administration:

Cronbach alpha for the ICECAP-O raw scores from the 2nd administration was good with a value of .70 (Cicchetti, 1994; Nunnaly & Bernstein, 1994). Inter-item correlations for 2nd administration raw scores are presented in Table 16. Correlations were from low to medium.

Table 16:

Inter item correlation of ICECAP-O raw scores of 2nd administration (N=54).

S. No	Items of Scale	1	2	3	4	5
1	Love and Friendship	-	.01	.20	.39	.36
2	Thinking about Future		-	.32	.40	.35
3	Doing Things that Make You Feel Valued			-	.45	.41
4	Enjoyment and Pleasure				-	.31
5	Independence					-

To investigate if the reliability of the scale could be improved items were deleted in a systematic way. Deletion of any item did not improve the Cronbach alpha value (see Table 17).

Table 17:

Item total statistics for ICECAP-O raw scores of 2nd administration (N = 54).

Scale Items	Scale Mean if Item Deleted	Corrected Item-Total Correlation	Cronbach's α if Item Deleted
Love and Friendship	12.51	.29	.69
Thinking about Future	13.16	.42	.66
Doing Things that Make You Feel Valued	13.00	.60	.56
Enjoyment and Pleasure	12.99	.59	.57
Independence	13.11	.34	.67

Calculation of Cronbach alpha for tariff scores of the 2nd administration resulted in a high value of .70. Interitem correlation were from low to medium with one exception of a high correlation between item 1 and 4. All correlations were in positive direction except an inverse correlation between item 1 and 2. There is not much difference in the scale Cronbach alpha and inter-item correlations with raw scores and converted tariff scores in the second administration.

Table 18:

Inter item correlation of ICECAP-O tariffs of 2nd administration (N = 54)

S. No	Items of Scale	1	2	3	4	5
1	Love and Friendship	-	-.01	.33	.53	.45
2	Thinking about Future		-	.24	.26	.37
3	Doing Things that Make You Feel Valued			-	.73	.41
4	Enjoyment and Pleasure				-	.42
5	Independence					-

Systematic deletion of items did not result in improved Cronbach alpha, except marginal improvement (i.e., from .72 to .76) with deletion of item 2. This was not deemed a meaningful change in the scale, therefore, the scale as a whole was used for further analysis.

Table 19:

Item total statistics for ICECAP-O tariffs of 2nd administration (N = 54).

Scale Items	Scale Mean if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Love and Friendship	.60	.38	.68
Thinking about Future	.74	.30	.76
Doing Things that Make You Feel Valued	.68	.55	.62
Enjoyment and Pleasure	.69	.66	.61
Independence	.68	.58	.59

Mean and standard deviation of ICECAP-O 2nd administration raw and tariff scores were also calculated. Descriptive statistics are illustrated in table 15.

Table 20:

Descriptive Item statistics of ICECAP-O raw and tariff scores of 2nd administration.

Items of Scale	(N=54)			
	M Raw scores	SD Raw scores	M Tariffs	SD Tariffs
Love and Friendship	3.79	.52	.24	.02
Thinking about Future	2.85	.95	.11	.04
Doing Things that Make You Feel Valued	3.14	.81	.17	.03
Enjoyment and Pleasure	3.24	.77	.15	.02
Independence	3.00	.77	.17	.04
Total	16.02	3.82	0.84	0.15

The Cronbach alpha findings did not fully support the prediction that ICECAP-O has a good (> .70) (Cicchetti, 1994; Nunnaly & Bernstein, 1994) Cronbach alpha reliability among community dwelling PWD. Although Cronbach alpha was .68 (moderate) for raw score of 1st administration and .70 for the raw and tariff scores of the 2nd administration, however, it was not found to be > .70 in all of the analyses. One of the findings also indicated low and close to chance Cronbach alpha (i.e., with ICECAP-O tariff scores for 1st administration), due to these varied findings it can be concluded that there is some evidence that ICECAP-O has moderate to good Cronbach alpha reliability among community dwelling PWD, although the prediction is not fully supported.

5.9.5 *Test-Retest Reliability*

Test-retest analysis was conducted for ICECAP-O raw and tariff scores separately. There was a strong correlation between the 1st and 2nd administration of the ICECAP-O based on its raw scores ($r = .68$; $n = 54$; $P < .01$). Similarly, there was strong relationship between

1st and 2nd administration of ICECAP-O based on its tariff scores ($r = .56$; $n = 54$; $P < .01$). Although, the correlations between 1st and 2nd administration were strong with both raw and tariff score, however, the findings did not support the strength of relationship predicted in this study i.e., ICECAP-O has good (> .75) (Cicchetti, 1994) test-retest reliability among community dwelling PWD. The strength of relationship was not found to be > .75, still there is evidence that ICECAP-O has acceptable test-retest reliability among community dwelling PWD.

5.9.6 Construct Validity

For assessment of construct validity of ICECAP-O, PWDs ICECAP-O raw and tariff scores were compared with PWD’s long term health condition, Statue test error scores, and M-ACE scores. Sample ($N = 83$) for this analysis was derived from the main trial. Demographic information is given in the table 21.

Table 21:

Demographic information of participants from the main trial at baseline for ICECAP-O construct validity sample (N = 83).

Variables	*F*	%
Gender		
Male	51	61.4
Female	33	39.7
Education		
None	3	3.6
Primary	2	2.4
Secondary	45	54.2
Higher education College/University	24	28.9
Further education/professional education	9	10.8
Ethnicity		
White	81	97.5
Asian	1	1.2
Black	1	1.2
Living Arrangement		
Living alone	7	8.4
Living with family and friends	76	91.5
Type of Dementia		
Alzheimer’s	56	67.4
Vascular	6	7.2
Mixed (Alzheimer’s and Vascular)	15	18.07
Others	6	7.2

Table 21 represents distribution of total sample based on their gender, ethnicity, education, living arrangement, and type of dementia. Mean age of the sample was 78.04 years, with standard deviation 7.89. The age ranged from 59.03 to 97.43.

5.9.7 Convergent Validity

In order to determine convergent validity, it was expected that better QoL will be associated with higher scores on BBS, lower error scores on statue test and no long-term health problems other than dementia. The correlation between ICECAP-O raw scores and BBS total scores was found to be small and non-significant in the positive direction (r = .14; n = 83), whereas the correlation between the ICECAP-O raw scores and Statue test error scores was inverse, medium, non-significant (r = -.33; n = 21). The correlation between ICECAP-O raw scores and long-term health condition other than dementia was inverse, very small, and non-significant (r = -.005; n = 83).

There was also a small, non-significant correlation (Cohen, 1988) between the ICECAP-O tariff score and BSS total (r = .15; n = 83) and a small, non-significant, inverse correlation between ICECAP-O and the Statue test error score (r = -.19; n = 21) and long-term health problems other than dementia (r = -.04; n = 83).

The findings based on raw and tariff scores support the predictions of the study. Low to moderate correlation in positive direction was predicted between ICECAP-O and BBS. There was a small positive correlation between ICECAP-O and BBS. Likewise, an inverse correlation was predicted between ICECAP-O and Statue test error score. There was a low (based on ICECAP-O tariff scores) to moderate (based on ICECAP-O raw scores) inverse correlation between ICECAP-O and Statue test error scores. An inverse correlation between ICECAP-O and long-term health conditions other than dementia was predicted. There was an inverse correlation between the two, however, it was very small.

5.9.8 Discriminant Validity

There was only a small, non-significant correlation between the ICECAP-O tariffs score and the M-ACE total score (r = .12; n = 83). Similarly, the correlation between the ICECAP-O raw score and the M-ACE total score was low (r = .17; n = 83). The correlation between ICECAP-O and M-ACE is supportive of the study prediction as low non-significant correlation was predicted between the two variables.

5.9.9 Factorial Structure

The CFA showed an adequate fit for the model (χ^2 df 5 = 7.82; P = .17; χ^2/df = 1.56; SRMR = .03; RMSEA = .08; TLI = .91; CFI = .96; GFI = .97 and Pclose = .26). All fit indices were acceptable with only the RMSEA at the upper boundary and the TLI acceptable rather than a good fit.

5.10 Discussion

The study aimed to validate a QoL measure ICECAP-O for PWD to enable measurement of actual attributes of QoL among PWD instead of relying on factors (Grewal et al., 2006) contributing in their QoL. There is only one existing scale for measurement of attributes based QoL for cognitively intact older adults, developed by Coast et al. (2008) i.e., ICECA-O. Therefore, in the present study ICECAP-O was selected for validation for PWD, assuming that the concept of QoL is similar among PWD and their cognitively intact counterparts.

Overall, the ICECAP-O was found to have good face validity and it was feasible to administer among community dwelling PWDs. It also had acceptable test-retest reliability and acceptable level of Cronbach alpha among PWDs. There was some evidence of construct validity of the scale in terms of convergent and discriminant validity among PWD. The CFA also showed a good fit. In their systematic review Proud et al. (2019) reported psychometric properties of ICECAP-O among general older adult population. ICECAP-O was shown to have good construct validity, responsiveness, and test-retest reliability, whereas some issues pertaining to content validity were reported e.g., questioning the relevance of the scale or its certain domains with the study population. No study was reported to have PWD population, therefore, the present study is a valuable addition in the knowledge pertaining to psychometric properties of ICECAP-O.

Face validity of the ICECAP-O was found to be good. Participants were able to complete the instrument and the think aloud procedure showed that there were no issues with regard to readability, comprehension, interpretation or discomfort of the scale for PWD (Drennan, 2003; Greenhalgh et al., 2004). This provides evidence, that in its current format, the ICECAP-O is a valid instrument to be used in community dwelling, educated people with mild to moderate dementia to examine QoL. However, future studies should also include participants with severe dementia, lower education level, and those who reside in care homes.

The ICECAP-O was also found to be a feasible instrument in that all participants across the different assessment points (N = 59) were able to complete the scale. Hence, there was a 100% completion rate and at no point participants appeared to have difficulty completing the instrument. The sample who completed the ICECAP-O was more diverse compared to those used for assessing face validity. This was reflected in more diverse educational background and M-ACE scores. This provides good evidence for the feasibility of using the ICECAP-O among a diverse range of individual with dementia living in the community. Similar to face validity, feasibility needs to be assessed to PWD living in care homes in future studies.

The ICECAP-O was found to have acceptable internal consistency, in particular considering the relatively few items for the scale (Pallant, 2001) and the modest sample size. Cronbach alpha values were moderate in nature (> .70) except for the tariff scores for baseline assessment of the test-retest. This showed a low and unacceptable Cronbach alpha (.53). The conversion of the raw scores into tariff scores is based on previous studies with older individuals without cognitive impairment. The present study provides some doubt whether the conversion of raw scores is suitable for PWD.

Similarly, test-retest reliability of the ICECAP-O was found to be acceptable. Although, scores felt short of the .75 level and were better for the raw scores (.68) compared to the tariff scores (.56). Of course, the .75 level is based on studies with individuals without cognitive impairment. The nature of dementia is more likely to result in participants providing different answers over time. Having adopted the 14 days period for test-retest assessment as suggested in the literature might be too long for PWD. Hence, PWD are prone to illness and mood variations (Desai et al., 2012). It would be important for future studies to explore optimal time periods for test-retest reliability for PWD.

There was some evidence indicating that PWD with better QoL in terms of score on ICECAP-O had better body balance (BBS scores), visuo-spatial abilities (statue test scores) and cognitive function (M-ACE scores). It was also found that PWD having any long-term health problem other than dementia had lower QoL as compared to their counterparts having no long-term health problems. Although the evidence is not very strong, however, it is still suggestive of the construct validity of ICECA-O among community dwelling PWD.

The CFA provided evidence that the factorial structure of the ICECAP-O was maintained for the PWD. Like all questionnaires it is imperative to examine the factorial structure with other samples to provide more evidence for its use across different older populations with varied chronic conditions.

It was first study which attempted to validate a general QoL measure for PWD, which had already been validated for general older adult population, therefore, the study had a few limitations. Future studies may overcome these limitations and strengthen the evidence with regard to validity and reliability of ICECAP-O for PWD. The limitations of the present study included:

1. Locale of the study was restricted to Wessex region of United Kingdom and the population was difficult to recruit due to their health, age, and challenging life circumstances.
2. The study was restricted to community dwelling PWD, therefore, the findings cannot be generalized to residents of care homes, those with compromised movement e.g., wheelchair bound or having any severe sensory impairment e.g., visual or hearing impairment.

3. Sample for face validity was not diverse as it only included well educated, English speaking PWD, due to which the findings cannot be generalized to PWD with lower educational background or not having English as their primary language.
4. Although there is no other general QoL measure available for comparing ICECAP-O scores with, to determine convergent validity, however, it may have been worth endeavouring to compare scores of ICECAP-O with any of the existing QoL measures for PWD pertaining to any specific aspects of their QoL. It may have led to stronger evidence of convergent validity of ICECAP-O among PWD.
5. To determine construct validity data was derived from the main trial, in which participants had to complete numerous tests as requirement of the trial, due to which it was not feasible to add more than one QoL measures and increase test completion burden for the participants. It would have been better to have exclusive sample for construct validity outside the main trial to allow inclusion of more QoL measures for comparison purposes.
6. In the present study convenience sampling method was used. Due to time and resource constraints using probability sampling method was not possible. Therefore, the sample may not be representative of older PWD across the UK.

Future studies may have broader locale and larger sample for robustness of findings. More diverse sample may lead to generalization of the findings. Therefore, PWD with other physical challenges such as restricted movement e.g., being wheelchair bound or having severe sensory impairments e.g., visual or hearing impairments, and more severe form of dementia or residents of care homes may be included. Similarly, inclusion of PWD with diverse educational and ethnic background may reveal more generalizable evidence for face validity. Comparison of ICECAP-O with any existing QoL measure(s) for PWD irrespective of its specificity may reveal more meaningful and stronger conclusion regarding convergent validity of ICECAP-O. Likewise, comparison of two different population e.g., community dwelling PWD and those residing in the care homes may augment knowledge regarding discriminant validity of ICECAP-O.

5.11 Summary

The present study has advanced the knowledge and evidence regarding validation of the ICECAP-O among community dwelling PWD. ICECAP-O is found to be a comprehensible and easy to administer measure among PWD. It is also found to be an internally and externally reliable measure of QoL among PWD and some evidence of its construct validity has also been found. Finally, CFA provided evidence for its adequate factorial structure. Therefore, it may be used in future research to assess QoL in general, among community dwelling PWD. It may be used to investigate factors and predictors responsible for sustaining or enhancing QoL among PWD. Similarly, it may be used in formulation of appropriate policies regarding QoL among community dwelling PWD. ICECAP-O has been utilized in the remaining two studies of the present PhD. The second study has investigated QoL of PWD in terms of their ICECAP-O scores as a predictor of PWD’s adherence to Tai Chi intervention, whereas the third study has explored contribution of adherence to Tai Chi intervention in improving QoL among PWD.

6 Study-II: Evaluation of Adherence to Tai Chi Intervention among PWD

6.1 Aim of the Study

The aims of this study were:

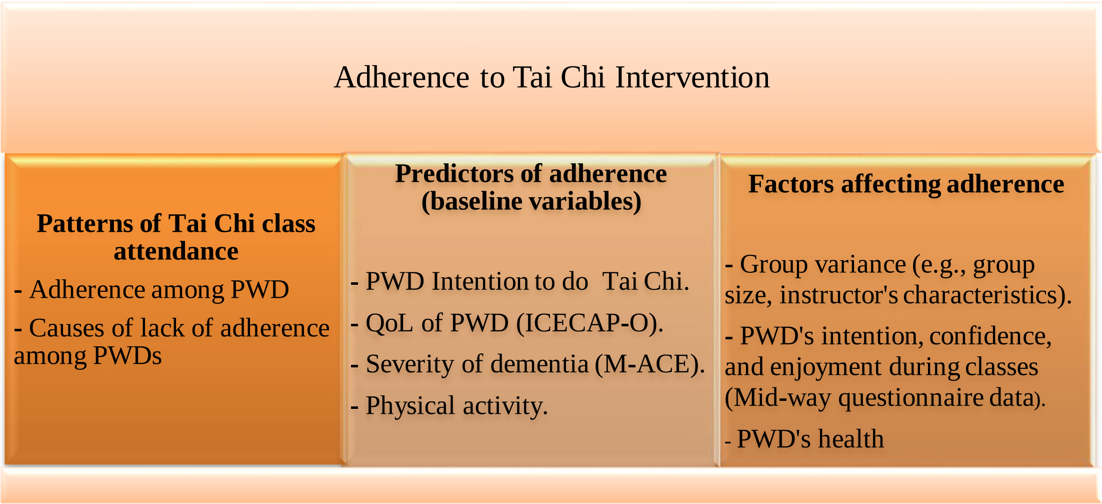
1. To assess PWD’s adherence to the intervention in terms of Tai Chi class attendance.
2. Investigation of patterns of adherence in terms of percentages of attendance during Tai Chi classes among PWD.
3. Exploration of causes of lack of adherence to Tai Chi intervention among PWD.
4. Exploration of the effect of instructors’ gender difference on adherence to Tai Chi intervention among PWD.

Study II consisted of assessment of patterns of Tai Chi class attendance, causes of lack of adherence, predictors, and factors of adherence among PWD. In the present study exercise adherence has been defined as “Attendance adherence: percentage of classes attended out of the actual number of sessions offered. Duration adherence: adherence to predefined minutes” (Hawley-Hague et al., 2016 p.4).

Note, adherence to home-based Tai Chi practice was assessed by another researcher in terms of influence of action plan and coping plan on home-based adherence among PWD, therefore, the present study focused on PWD’s class adherence only, however, association between home-based practice and class adherence was assessed in the present study.

Figure 5:

Illustration of study-II design.



6.2 Objectives

The study had the following objectives:

1. To compare adherence to home-based and class-based Tai Chi among PWD.
2. To investigate predictors of adherence to Tai Chi intervention among PWD, based on data collected during baseline interviews, such as intention of PWD to do Tai Chi for next 20 weeks, QoL of PWD in terms of their ICECAP-O scores, severity of dementia in terms of their M-ACE scores, and their level of physical activity.
3. To investigate factors affecting adherence to Tai Chi intervention among PWD including: Tai Chi class/group size, instructor’s gender, PWD’s intention to come to classes and their confidence and enjoyment to do Tai Chi during classes (based on data collected in mid-way interviews during RCT phase), and the health problems faced during the intervention phase.

6.3 Rationale and Hypotheses

Higher exercise adherence among older adults affects treatment outcomes related to pain, physical function, physical performance (Room et al., 2017) and QoL (Jordan et al., 2010). Therefore, low adherence may restrict the benefit of exercise. Despite the established benefits of exercise adherence, overall, there is lack of consensus on its definition (Hawley-Hague et al., 2016). Therefore, there is lack of clarity on defining exercise adherence in interventions among people with dementia. In a systematic review and meta-analysis Di Lorito et al. (2020) reported that less than half exercise interventions for people with mild cognitive impairment and dementia operationally defined adherence. It was also noted that adherence was not the primary outcome in interventions (Di Lorito et al., 2020). Therefore, there is a requirement to clearly define adherence in exercise interventions and explore it as a primary outcome. This will increase understanding of patterns, rate, factors, facilitators, and strategies to improve adherence among PWD to subsequently extend exercise benefits to them. Hence, the present study aimed to address this gap as adherence to Tai Chi exercise intervention among PWD was primary outcome in Study-II. Moreover, adherence to Tai Chi exercise intervention was defined clearly in terms of percentage of Tai Chi classes attended against the total number of classes offered and percentage of minutes Tai Chi practiced at home against minutes of Tai Chi expected to be practiced. In addition, in the present study robust measurement of adherence was devised as monitoring of exercise adherence among PWD lacks robustness e.g., more frequently self-reported (Di Lorito et al., 2020) which make the data less reliable or increases the chances of bias. Therefore, in the present study class attendance was recorded by the Tai Chi instructors and for home practice participants were required to complete a daily log of Tai Chi practice and submit the weekly report/diary to the Tai Chi instructor in the Tai Chi class. Carers of PWD were requested to assist them in reporting and to remove any inaccuracies. It has been found previously that exercise interventions delivered in a group format has higher adherence rates among older adults. Therefore, In the present study Tai Chi exercise was arranged in class format, offered to 10 different groups of PWD. However, it was also vital to understand which factors may have influenced participation in Tai Chi exercise classes among PWD. Previously factors affecting adherence to exercise interventions among cognitively intact older adults have been reported e.g., low levels of baseline physical activity, poor treatment adherence, low self-efficacy, depression, anxiety, helplessness, inadequate social support, more perceived barriers to exercise, and higher pain thresholds during exercise (Jack et al., 2010) health status, (Picorelli et al., 2014) low self-efficacy, lack of interest, low expectations, depression, low motivation, health and socioeconomic status, characteristics of exercise program, fear of falling, and physical ability (Picorelli et al., 2014; Hill et al., 2011). However, factors affecting adherence to exercise intervention among PWD have sparsely been reported in the previous literature. Therefore, it was timely requirement to explore such factors. Hence, associations between variables at baseline, and mid-way (intervention) with PWD's adherence to Tai Chi exercise intervention were explored (see detail in sections 6.3.2 and 6.3.3). Furthermore, adherence has been found to be higher in supervised exercise programs than in individualized unsupervised home-based exercise among cognitively intact older adults (Gardner et al., 2011). Therefore, it was also attempted to explore the association between class-based (supervised exercise) and home-based Tai Chi exercise (unsupervised exercise) among PWD in the present study.

Strategies to support exercise adherence among PWD is a well-researched area. A number of exercise adherence support strategies among PWD have been noted for example, the use of behaviour change theories to underpin exercise programs, individual tailoring, worksheets or exercise booklets, goal setting, phone calls and reminders, newsletter, support to overcome exercise barriers, information, adaptation period, individual supervision, support for clinicians, group setting, music, accelerometer/pedometer, and emphasis on enjoyable activities (van der Wardt et al., 2017). Some of these strategies were utilized in the TACIT trial to support home and class based Tai Chi adherence among PWD and their carers, however detailed work in this regard has been reported by two other researchers in their PhD and Masters' theses. Therefore, the present study could not include adherence support strategies in its scope.

6.3.1 Adherence to Tai Chi Intervention among PWDs

Exercise has been reported to improve physical function and QoL among older adults in general (Baker et al., 2007). Physical exercise has also been reported to have positive effects on physical and cognitive functions of PWD (Lamb et al., 2018; Karssemeijer et al., 2017; Prick et al., 2017). Therefore, to reap the benefits of exercise it is vital for older adults with or without dementia to adhere to exercise interventions. Exercise interventions involve structured exercise classes (Barreto et al., 2015) and home-based exercise programmes (Hancox et al., 2019). Hawley-Hague et al. (2016) defined exercise classes as "a group of people gathered together to follow a leader or instructor to carry out planned, structured and repetitive bodily movement done to improve more than one component of physical fitness." Tai Chi exercise classes conducted in the main TACIT trial fulfilled the criteria of this definition. However, to ascertain the definition of adherence relevant to the present study cautious consideration is required as there is lack of consensus in the existing literature regarding definition of adherence to exercise interventions among older adults with or without dementia (Di Lorito et al., 2020; Hawley-Hague et al., 2016).

Hawley-Hague et al. (2016) identified four different types of adherence to exercise interventions among cognitively intact older adults based on completion (retention) of all exercise classes, attendance during classes, duration and intensity of exercise within or outside the classes. Adherence defined by completion (retention) involved being part of the exercise intervention until its last exercise class, despite being absent from classes for even 10 weeks and ultimately returning to the classes was also considered completion (retention). In completion reasons for the absence are taken into consideration. Completion adherence was defined in terms of attendance involved actual attendance records or percentage of attendance of participants. Duration base adherence is referred to adherence to predefined time duration and intensity-based adherence represented adherence to prescribed moderate intensity exercise within or outside the exercise classes. Similarly, Di Lorito et al. (2020), in their systematic review regarding adherence to exercise intervention among PWD, reported that only 20 out of 41 reviewed studies operationally defined adherence as percentage of participants' attendance, with one study defining adherence as percentage of personal goals attained by participants, and remaining 20 studies did not define adherence.

Despite the lack of consensus regarding a definition of adherence among older adults with or without dementia percentage of attendance has widely been considered as adherence to exercise intervention (Di Lorito et al., 2020). Therefore, in the present study it was decided to use percentage of class attendance as adherence to Tai Chi intervention. As exercise adherence is not a well-defined phenomenon therefore, evidence regarding exercise adherence rates among older adults with or without dementia vary. A systematic review reported exercise adherence rates among cognitively intact older adults based on completion ranged from 56-86%, and percentage of attendance ranged from 58-77%. Furthermore, adherence rates were higher in supervised exercise programs as compared to non-supervised exercise (Picorelli et al., 2014). In another systematic review and meta-analysis (Di Lorito et al., 2020) exercise adherence rate among people with Mild Cognitive Impairment and dementia were reported. Among 41 studies included in this review 21 did not operationally define adherence while remaining 20 studies defined adherence as percentage of attendance. Overall adherence rates were reported to range from 16-100% with mean adherence 70% (SD

= 21). Likewise, adherence to Tai Chi intervention among community dwelling older adults have been reported to be high, ranging from 71-81% (Nyman, 2020). In the backdrop of existing evidence, PWD’s high adherence to supervised TACIT trial Tai Chi classes was expected. However, it is also evident that there are a number of factors which adversely affect exercise adherence among older people with dementia including: physical and mental health issues, severity of dementia, fear of injury, frailty, low level of previous activity and slow walking speed, lack of cohesion within exercise groups, unwillingness to continue, family expectations and low socioeconomic status (Di Lorito et al., 2020). Similarly, for cognitively intact older adults, older age, female gender, low socioeconomic status, lack of enjoyment and group cohesion, low self-efficacy, and motivation to do exercise, low social support, poor fitness and low level of previous physical activity, and lack of access to facility have been reported to be the adversely associated with adherence to Physical activity (Rivera-Torres et al., 2019). Keeping these factors in view it was aimed to also explore causes of non-adherence to Tai Chi classes among PWD to add to exiting knowledge and for better understanding of exercise adherence among PWD.

In addition to Tai Chi classes participants in the TACIT trial were engaged in home-based Tai Chi practice as well. Home-based exercise has been described as a parallel form of class-based exercise among PWD (Middleton et al., 2018). Therefore, the present study also attempted to explore association between home-based Tai Chi practice and class-based Tai Chi exercise among PWD.

The following hypothesis was made:

1. There is a positive association between PWD’s home-based and class-based Tai Chi exercise.

6.3.2 Predictors of Adherence to Tai Chi intervention among PWDs

Findorff et al. (2009) reported health in general, and cognitive functioning as predictors of adherence to walking for long-term and QoL and cognitive functioning as predictors of adherence to balance exercises among cognitively intact but sedentary older women. Likewise, McCurry et al. (2010) revealed severity of dementia among community dwelling PWD (in terms of their MMSE scores) and their carers being their spouses as strong predictors of adherence to a walking program. They also reported more behavioural disturbances among non-walkers during the walking program as compared to their walker counterparts. The theory of planned behaviour (Ajzen, 1991) provides support for the role of previous physical active behaviour and intention as predictors of adherence to physical exercise (Bozionelos & Bennett, 1999). Intention to become physically active, and having high physical activity level at the baseline, was found to have positive association with physical activity initiation and maintenance among older adults (van Stralena et al., 2009). To further enhance and augment the knowledge regarding predictors of adherence to exercise intervention among PWD, it would be important to explore the predictive ability of PWDs' QoL (in terms of scores on ICECAP-O), cognitive functioning/severity of dementia (in terms of scores on M-ACE), strength of intention to do Tai Chi for next 20 weeks, and existing physical activity level at baseline, for adherence to Tai Chi exercise classes. Due to small sample size (N = 42) only four predictor variables could be included in the regression model (Pallant, 2001) i.e., PWD's QoL, cognitive functioning, intention to engage in physical activity in next 20 weeks and being physical active. These variables have been selected as they have been reported to be associated with adherence to physical activity among older adults with (Findorff et al., 2009; Ajzen, 1991) or without dementia (McCurry et al., 2010). The following hypothesis has been made in this regard:

2. PWD’s better QoL (in terms of ICECAP-O scores), better cognitive functioning (in terms of M-ACE scores), stronger intention, and being physically active at baseline predict higher adherence to a Tai Chi intervention.

6.3.3 Factors affecting Adherence to Tai Chi intervention during Intervention Phase among PWD

In addition to the factors at baseline, which may predict adherence to exercise intervention among older adults, it is also vital to investigate the factors associated with adherence to Tai Chi exercise during the intervention phase, which may also improve adherence to exercise intervention. In their systematic review Van der Wardt et al. (2017) reported a number of adherence support strategies to exercise intervention among PWD including use of behaviour change strategies, individual tailoring of exercise, worksheets, goal setting, telephone calls and reminder, support to overcome barriers, information, adaptation period, individual supervision, group setting, music, accelerometers/ pedometers, and emphasis on enjoyable activities. They found only individually tailored group setting (involving good relationship with personal trainer and other exercise group members), information about intervention and telephonic support as effective strategies for adherence to exercise interventions among PWD. They also found that music was only effective for those participants to adhere to exercise intervention who were interested in participation. Systematic review and meta-analysis by Di Lorito et al. (2020) also reported higher adherence in group setting exercise interventions as compared to delivery of exercise at individual level among PWD and people having mild cognitive impairment. Another systematic review by Vseteckova et al. (2018) also revealed individually tailored and adjusted physical activity and well-communicating, engaging and knowledgeable instructor as factors of improving adherence to exercise among institutionalized older adults with dementia. Factors to improve exercise adherence among PWD have often been studied posthoc and not part of primary or secondary study outcomes. Therefore, information about them is limited and lacks in-depth analysis (Van der Wardt et al., 2017). In this context, in the present study, variables were selected which have already been reported to be effective in improving adherence to exercise intervention among PWD to augment and add to exiting knowledge by investigating the aspects which have not been studied yet. However, in the present study adherence to Tai Chi classes among PWD is the primary outcome therefore, investigation of factors with it is novel contribution of the present study, which has not been explored earlier.

Lack of group cohesion has been reported to have negative effect on exercise adherence among older adults with or without dementia (Di Lorito et al., 2020). It has also been found to be a mediator in exercise adherence among cognitively intact older adults (Beauchamp et al., 2021). Group cohesion and exercise task perception has been reported to be greater in smaller groups (Carron & Spink, 1995). Therefore, in the present study it was expected that smaller group size will have a positive effect on adherence to Tai Chi intervention among PWD. The following hypothesis has been formulated:

3. Smaller group size will increase adherence to Tai Chi intervention among PWDs.

The role of instructor has also been highlighted as supportive in improving adherence to exercise intervention among PWDs (Van der Wardt et al., 2017; Vseteckova et al., 2018). Factors affecting instructor's attitude towards exercise delivery to older adults have been reported (Hawley et al., 2012), however, research regarding instructor's specific characteristics which contributes to improving adherence among older adults with or without dementia is lacking. Therefore, it has been aimed in the present study to explore the role of instructor's personal characteristic i.e., gender in facilitating adherence to Tai Chi intervention among PWD. It will partially add into knowledge regarding role of instructor's characteristics in exercise adherence among PWD and open a new research dimension for future studies to be explored.

In addition to characteristics of instructor which facilitate adherence to exercise interventions among PWD, it is also imperative to investigate participants' and intervention program's characteristics, supportive of adherence among PWD. Teri et al. (2008) showed that the exercise classes which are not enjoyable will not sustain. Hence, enjoyability increases adherence to exercise intervention among PWD. Van der Wardt et al. (2017) suggested music as a supportive strategy to improve adherence among PWD, but it was only enjoyed by those participants who were interested in taking part in the exercise intervention as compared to those who were not interested in taking part in the intervention. Likewise, intentions can predict involvement in exercise (Ajzen, 1991). However, there is not much research available regarding role of intention in adherence to exercise among older adults except Brenes et al. (1998) study which reported intention as non-significant predictor of exercise behaviour among older adults. There is major gap in research regarding the role of intention in adherence to exercise among PWD, therefore, evaluation of effect of intention to do Tai Chi on adherence would be a vital contribution of present study in knowledge. Similarly, a subset of social cognitive theory i.e., self-efficacy theory (Bandura, 1986) suggested self-efficacy (an individual's perception of their capabilities), as a key determinant of their success. Self-efficacy is a similar concept to self-confidence which was used to develop The Self-Efficacy for Exercise Questionnaire (Garcia & King, 1991). The questionnaire measured participant's confidence on a scale of 0-100 to do exercise despite different barriers. Brassington et al. (2002) used the questionnaire to measure older adults' confidence to do exercise despite various potential barriers. They reported self-confidence to be significantly associated with exercise adherence among healthy older adults, however, there is dearth of knowledge in this domain regarding PWD. Therefore, investigation of association between PWD’s confidence to do Tai Chi and Tai Chi class adherence would be a novel contribution in knowledge as this aspect has not been studied before for PWD. Hence, in the present study it has been attempted to explore the relationship of PWD’s intention to come to Tai Chi classes, confidence, and enjoyment to do Tai Chi in the classes with their adherence to Tai Chi intervention. The following hypothesis has been made:

3. PWDs’ stronger intention to come to Tai Chi classes, higher confidence to do Tai Chi, and more enjoyment during classes has positive relation with adherence to Tai Chi intervention among PWDs.

Good health, physical fitness and fewer depressive symptoms have been associated with adherence to exercise among cognitively intact older adults (Rivera-Torres et al., 2019; Picorelli et al., 2014; Findorff et al., 2009). However, there is lack of evidence regarding health as a factor associated with adherence to exercise among PWD. Therefore, it has been attempted to investigate effect of health on adherence to Tai Chi intervention among PWD which is a novel contribution of the present study in knowledge. Health has been considered in terms of acute health problems which emerged during the intervention phase i.e., back pain, shoulder pain, headache, and dizziness, breathing problem, flue, cold, infection, chest pain, not feeling well and needed rest, and mini stroke. All these issues were not related to or outcome of any serious adverse event. These were the health conditions in general which PWD experienced during the intervention phase of the trial. The following hypothesis has been made:

4. PWDs’ Poor health has inverse association with adherence to Tai Chi intervention.

6.4 Procedure

6.4.1 *Sample*

The sample (N = 83) was taken from the main RCT, the TACIT trial. The sample was randomized to intervention (N = 42) and control (N = 41) groups. Sample and its inclusion, exclusion criteria have been derived from the main trial (Nyman, 2018). Ethical approval for the main trial was obtained from the NHS Research Ethics Committee (REC) and the Health Research Authority (HRA). People with mild to moderate dementia were the target population for the main trial. Both male and females were included. There was no restriction on maximum age. Detailed strategy was devised in the main trial for the recruitment of the participants. People with confirmed diagnosis of dementia were included.

6.4.2 *Inclusion Criteria*

Inclusion criteria for participants to be included in the trial was as follows:

1. Aged 18 years or above.
2. Living at home.
3. Diagnosis of dementia is confirmed (Diagnosis of dementia was indicated on the patient records held by Memory Assessment Research Centre/ Memory Assessment Service/ Memory Support and Advisory Service (Alzheimer’s Society). Diagnosis of dementia was recognized as follows: A diagnosis made by a Consultant Physician of either probable Alzheimer’s disease according to the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer’s Disease and Related Disorders Association criteria (McKhann et al., 2011) or probable Vascular Dementia according to the Neuroepidemiology Branch of the National Institute of Neurological Disorders and Stroke and Association Internationale pour la Recherche et l'Enseignement en Neurosciences criteria (Román et al., 1993)).

4. Able to do standing Tai Chi (e.g., not be wheelchair bound).
5. Willing to attend weekly Tai Chi classes.

6.4.3 *Exclusion Criteria*

Exclusion criteria for participants of the trial was as follows:

1. Living in care home.
2. In receipt of palliative care.
3. Have severe dementia (scores of 9 or less on M-ACE was regarded as severe dementia).
4. A Lewy body dementia or dementia with Parkinson's disease.
5. Severe sensory impairment.
6. Are already currently practising (on average once a week or more) or have been practising within the past six months (on average once a week or more) Tai Chi or similar exercise (Qigong, yoga, or Pilates).
7. Are currently under the care of or have been referred to a falls clinic for assessment, or are currently attending a balance exercise programme (e.g. Otago classes).
8. Lack mental capacity to provide informed consent.

6.4.4 *Participant Recruitment*

Participants were recruited from the south of England through multiple resources including National Health Service (NHS) research/ clinical databases, memory assessment clinics, local charities, Joint Dementia Research Website, and self-referral in response to study promotion on various platforms including; dementia cafés, support groups, general practices, chemists, pharmacies, day-care centres, newspapers, radio, social media, informal newsletters, and leaflets/ posters.

As a basic requirement of the Trial focus was on dyads recruitment in which the carer was willing to support PWD throughout the trial duration. All potential participants (dyads) were provided with the Participant Information Sheet (PIS). Their permissions were taken to contact them at their provided contact numbers within 48 hours to ensure they had sufficient time to go through the study information provided in the PIS. The researcher then contacted the participants to ascertain their willingness to participate in the study after having gone through the study information in PIS. Once their willingness was ascertained they were requested to provide any time and place of their convenience for the baseline home visit for data collection. All participants agreed to have a home visit as it was convenient for them to stay at home to provide data.

6.4.5 Sample Size Calculation

Sample sizes for all correlation analyses of present PhD were based on David (1938) recommendations i.e., ≥ 25 participants. The number of participants in all these analyses was higher than the required number.

6.4.6 Data collection and Intervention Description

The present researcher collected baseline and post intervention data for the trial. As it was an ***assessor blind study***, the researcher was blind to randomization procedure and allocation of participants to either of the study groups until all data (i.e., baseline and post intervention) was transferred to the clinical trial unit, which was monitoring the whole trial. Data was collected from all the participants at their homes at a mutually agreed time of convenience. The researcher collected data alone, therefore, lone worker protocol was followed (see appendix- E) to ensure the researcher's safety.

At the ***baseline visit*** participants' (dyads) mental capacity to consent was ascertained during the informal conversation before proceeding to acquire their informed consent formally. Afterwards, PWD were required to complete Mini-Addenbrooke's Cognitive

Examination (M-ACE) for assessment of their global cognitive functioning. M-ACE was scored immediately after its completion as only those participants were eligible to participate in the study who scored above nine. Those who scored nine or below on the M-ACE were politely informed about the limitation of the study in this regard and data collection session was discontinued. Those participants who scored ten or above were proceeded with remaining data collection measures. Baseline data collection visits took almost two hours on average. In addition to the M-ACE, baseline data measures included dyads' demographic information, Iconographical Falls Efficacy Scale (Delbaere et al., 2011) for PWD's assessment of fear of falls, ICECAP-O for dyads' QoL, Zarit Burden Short Form (Bédard et al., 2001) for carer burden, Statute Test (Reed, & Spiers, Unpublished thesis) for PWD's visuo-spatial cognitive functioning, dyad's Postural Sway (Taylor et al., 2014) and Timed Up and Go tests (Podsiadlo & Richardson, 1991) for their balance assessment, and PWD's Berg Balance Scale (BBS) (Berg et al., 1989) for their additional balance assessment. All the data except the performance tests i.e., balance and visuo-spatial and carer self-completed scales (carer burden and QoL were completed using pen and paper in a place away from PWD), was collected in a structured interview format. After data collection all data was transferred to the Clinical Trials Unit and participants' basic information along with their data of baseline home visit was recorded in the Trial's local database at Bournemouth University. For the present study PWD's M-ACE, Statue test, BBS, dyads' relevant demographic, QoL (ICECAP-O) data along with carers' care burden score were utilized.

After sufficient number of participants were recruited into study and baseline data collected from them Tai Chi classes were arranged at three different sites i.e., Southampton, Dorset, and Portsmouth. There were seven different venues at these three sites. A total of 83 participants were recruited in the Trial, among them 42 were allocated to the intervention arm and the remaining 41 were allocated to the control arm. Participants allocated to the intervention arm were divided into 10 groups. Participants were assigned to different venues according to their convenience and ease of access to the venue. There were two Tai Chi instructors i.e., a male and a female. Each was assigned five groups of participants.

Tai Chi classes were offered for 20 weeks. Duration of each Tai Chi class/session was 90 minutes in which 45 minutes were for instructor-led Tai Chi exercise. The instructors provided individual support and guidance during the exercise sessions. The remaining 45 minutes were for socialization with peers and instructors. It also provided an opportunity to seek guidance from the instructor on the ongoing Tai Chi home practice. Attendance to Tai Chi classes was recorded by Tai Chi instructor (see appendix-M point 7 for further details). Adherence to Tai Chi classes was recorded in terms of percentage of class attendance. PWD's Adherence to Tai Chi exercise classes was evaluated in-depth in the present study.

Causes of non-adherence to Tai Chi intervention Tai Chi instructors were responsible to take attendance of all the participants in each session and provide it to the TACIT team. An unblind researcher was responsible to call the participants weekly to collect data on falls. However, the participants who were absent in the previous session volunteered to provide data regarding causes of their absence. In addition, if a participant missed two consecutive classes due to unknown reasons, the unblind researcher would remind them to attend the classes and enquire if they were able to attend the next class. During these calls data regarding causes of absence was collected. All the causes of their absence were recorded. Later, the data was provided to the researcher, as after completion of intervention phase the researcher became unblind to the data.

Tai Chi home practice started between second and fourth Tai Chi class following the Tai Chi instructor's home visit to guide them on how to do Tai Chi at home. Participants were provided with a colorful home exercise booklet and weekly homework sheets as a reminder of all that had been covered during the weekly classes. Carers were encouraged to support PWD in practicing Tai Chi at home for at least 20 minutes per day. Participants were required not to start Tai Chi practice at home before Tai Chi instructor's home visit. Adherence to Tai Chi home practice was assessed through the weekly Tai Chi home practice diaries (see appendix R). Participants were required to record the minutes of Tai Chi home practice in a diary each week and provide it to the instructor during the weekly Tai Chi session (see Table appendix-M point 7 for further details).

Mid-way data collection was arranged by another researcher to avoid unblinding of the present researcher. The participants (N = 32) provided data in a structure interview format. They were asked five questions regarding their intention and confidence to come to the remaining 10 Tai Chi classes, their enjoyment during the classes and their motivation based on their Tai Chi home practice to continue to come to the classes. Among this data only three variables in relation to PWD's Tai Chi class adherence were utilized in study-II of the present PhD i.e., intention and confidence to come to remaining Tai Chi classes and enjoyment during the classes. This data was used in relation to PWD's adherence to Tai Chi exercise classes.

To collect ***post intervention data*** home visits were arranged six months apart from the baseline home visit to allow participants to have practiced Tai Chi for 20 weeks in the classes. All post intervention visits were arranged at participants' home. All arrangements for post intervention home visits were the same as those for the baseline data collection visits. Exact same data was collected in the post intervention visits except that the demographic information was not re-collected. During telephone calls to the participants to arrange a post intervention data collection visit, participants were requested to keep their allocation to either of the groups hidden and not to reveal it to the researcher. At the start of the home visit, they were again reminded of it. Despite these reminders if the researcher was unblinded accidentally to the allocation of the participants, it was recorded.

After the completion of data collection and its transfer to the clinical trial unit, the researcher was provided access to the data relevant to her PhD.

6.5 Data Analysis Strategy

6.5.1 Adherence to Tai Chi Intervention among PWD

To investigate adherence to Tai chi intervention among PWD 2 aims and one hypothesis was formulated. The following data analysis strategy was devised for investigation of each:

1. *Aim 1:* Investigation of patterns of adherence in terms of percentages of attendance during Tai Chi classes among PWD. Patterns of adherence to Tai Chi intervention among PWD. Dyads (PWD + Carer) will be explored in terms of percentages of their attendance on a weekly basis (per session) and overall, as a whole in the entire intervention phase. Discrepancies in the patterns of each dyad's attendance will be noted. Descriptive analysis and line graphs will be used to illustrate the findings.
2. *Aim 2:* Exploration of causes of lack of adherence to Tai Chi intervention among PWD. Causes of non-adherence among PWD in terms of absence from sessions were recorded. All causes will subsequently be categorized. Descriptive analysis will be carried out to see which causes contributed the most towards non-adherence (i.e., absence from sessions).
3. *Hypothesis 1:* There is a positive association between PWD's home-based and class-based Tai Chi exercise. Percentages of minutes of home-base Tai Chi practice among PWD will be calculated in terms of number of minutes Tai Chi practiced at home during the entire period of intervention phase against number of total minutes required to be practiced at home. Likewise, Percentages of number of sessions attended against number of sessions offered to each PWD will be calculated. Subsequently Pearson

product moment correlation will be conducted to the see the association between home-based and class-based Tai Chi practice.

6.5.2 *Predictors of Adherence to Tai Chi Intervention among PWD*

1. *Hypothesis 2:* PWD’s better QoL (in terms of ICECAP-O scores), cognitive functioning (in terms of M-ACE scores), stronger intention, and being physically active at baseline predict higher adherence to a Tai Chi intervention. Multiple linear regression analysis will be conducted to find out the predictive value of each predictor variable.

6.5.3 *Factors affecting Adherence to Tai Chi Intervention during Intervention Phase among PWD*

To investigate the effect of various factors on adherence among PWD during the intervention phase the following data analyses strategy was formulated:

1. *Hypothesis 3:* Smaller group size will increase adherence to Tai Chi intervention among PWDs. Non-parametric Kruskal-Wallis test will be conducted to find out the effect of group size on adherence to Tai Chi intervention among PWD. The non-parametric test has been selected due to small sample size (i.e., number of groups to be compared).
2. *Aim 3:* Exploration of the effect of instructors’ gender difference on adherence to Tai Chi intervention among PWD. To find out the effect of instructor’s gender on adherence to Tai Chi intervention among PWD independent sample t-test will be conducted.
3. *Hypothesis 4:* PWDs’ stronger intention to come to Tai Chi classes, higher confidence to do Tai Chi, and more enjoyment during classes has positive relation with adherence to Tai Chi intervention among PWDs. Pearson product moment correlation analysis

will be conducted to see the effect and direction of relationship of these factors with adherence to Tai Chi intervention among PWD.

4. *Hypothesis 5:* PWDs’ Poor health has inverse association with adherence to Tai Chi intervention among PWDs. Association of health problems, reported during the intervention phase which resulted in non-adherence or absence from sessions, with adherence to Tai Chi intervention among PWD will be investigated by conducting Pearson product moment correlation.

6.6 Results

6.6.1 *Demographic information*

Data for the present study was derived from the TACIT trial intervention arm. While participants were recruited as dyads in the trial, the focus of this chapter is on PWD, who were the primary target of the intervention.

Table 22:

Participants' demographic information.

Characteristics of PWD (N = 42)	Values
Age in years mean (SD)	77.86
Gender	
Male	24
Female	18
Ethnicity n	
White	42
Number of participants withdrawn completely from 1st session	1
Number of participants did not attend any session without withdrawing	1
PWD relationship with carer n	
Spouse	34
Children	3
Sibling	4
Other	1
Living situation n	
Living alone	4
Living with family and friends	38
Dementia diagnosis n	
Alzheimer's	30
Vascular	1
Mixed Alzheimer's and Vascular	9
Other	2

6.6.2 *Participants' Patterns of Adherence to Tai Chi Intervention Classes*

Patterns of adherence to Tai Chi intervention among individual PWDs and the dyads collectively, in terms of their overall percentages of class attendance during the intervention phase were analysed. Table 25 provides the attendance for the dyads which had a different attendance record. Finally, the association between class adherence and home-based practice among PWD is reported.

Table 23:

PWDs' patterns of adherence to Tai Chi intervention classes in terms of their overall percentages of attendance (inclusive withdrawn participants) (N = 42). See appendix-I.

Average attendance of all participants: M (SD); min-max (%) = 69.19 (29.95); 0-20 (0-100%).

Figure 6:

Patterns of incremental progress of each participant's attendance over 20 sessions, inclusive withdrawn participants (N=42).

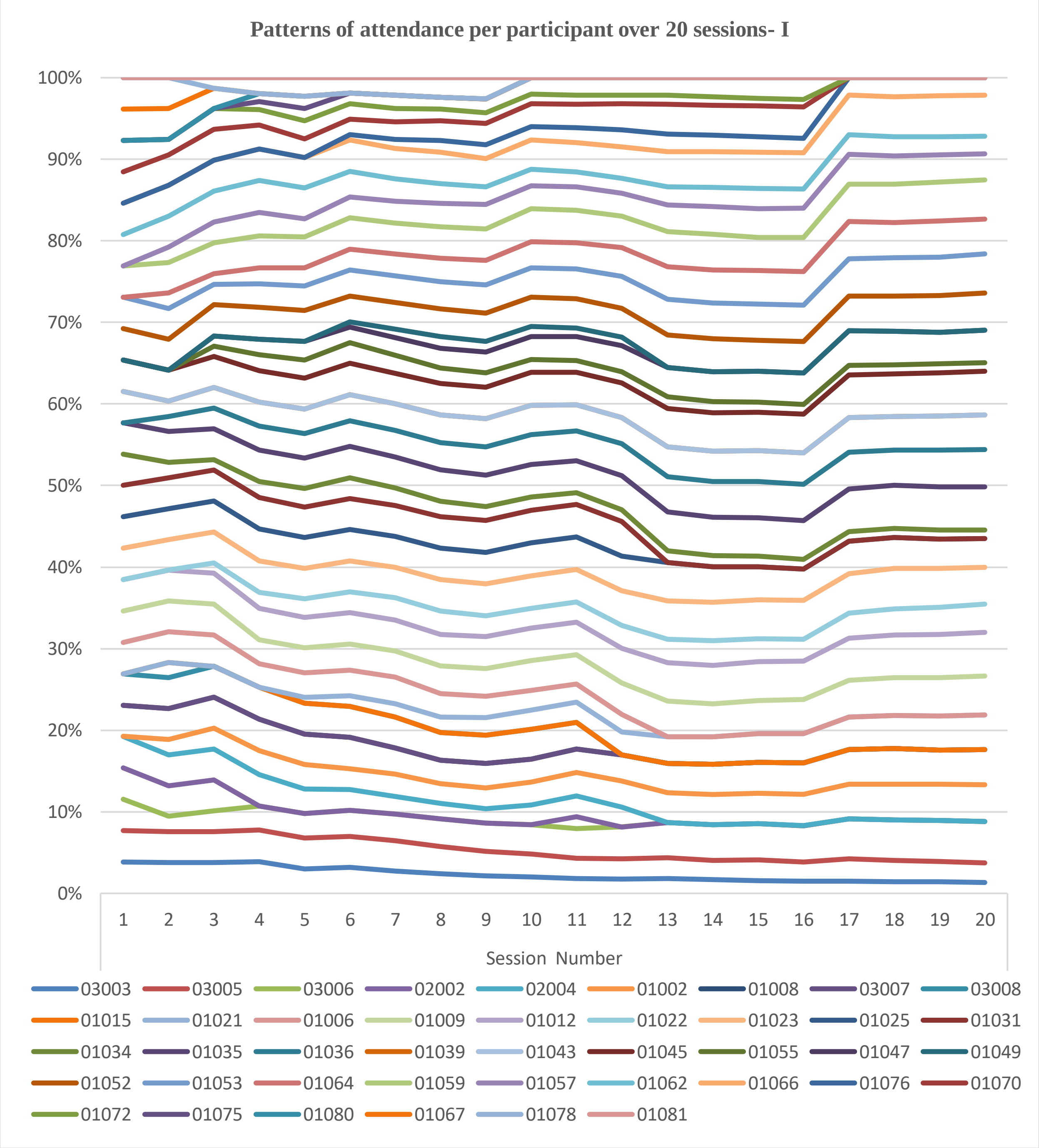


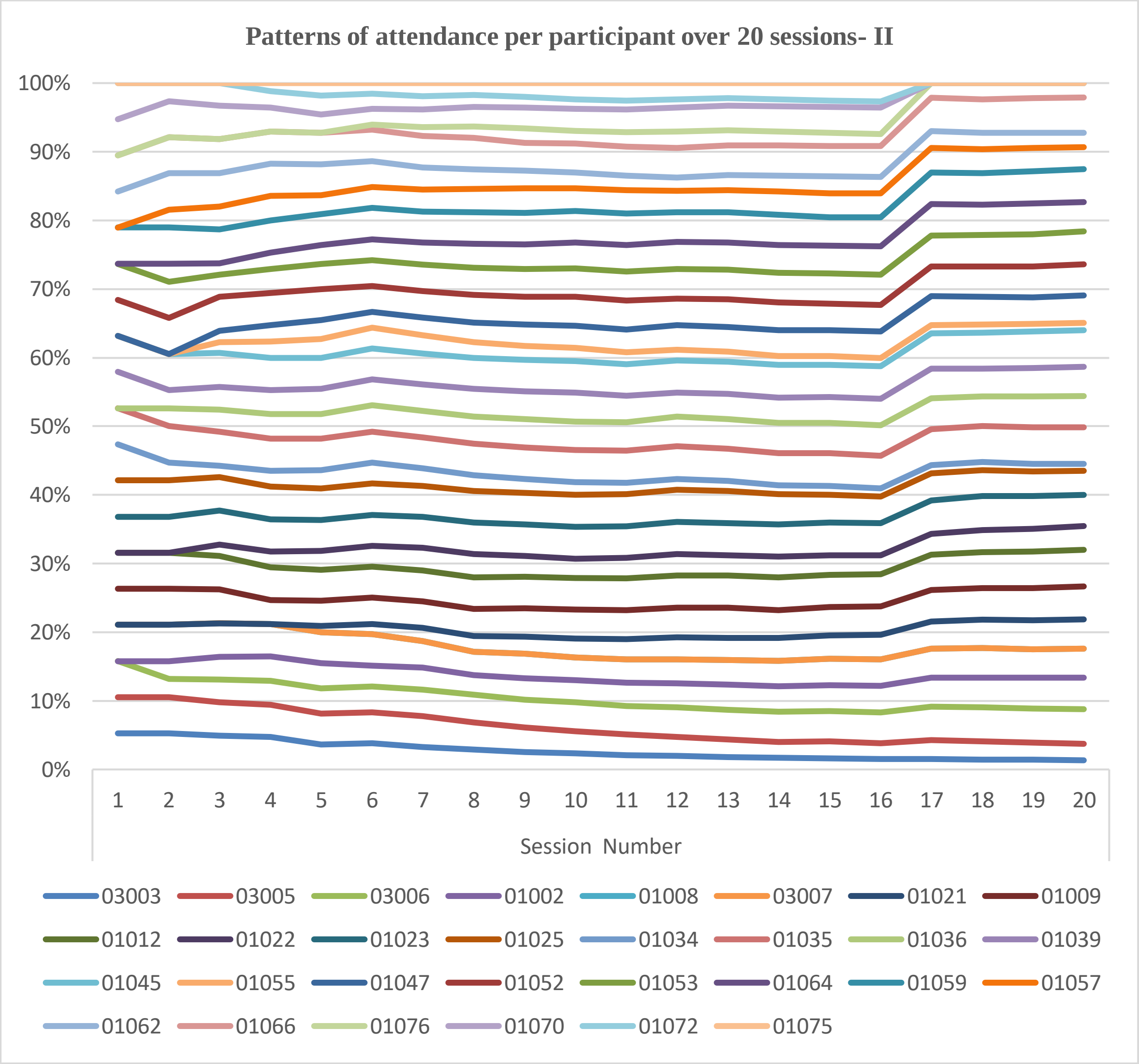
Table 24:

PWDs' patterns of adherence to Tai Chi intervention classes in terms of their overall percentages of attendance (withdrawn participants excluded) (N = 30). See appendix- J.

Average attendance of all participants: M (SD); min-max (%) = 70.33 (28.72); 0-20 (0-100%)

Figure 7:

Patterns of incremental progress of each participant's attendance over 20 sessions, excluding withdrawn participants (N=30).



6.6.3 *Patterns of Dyads' Attendance*

Patterns of attendance within the dyad were exactly the same as for the data provided for PWD except for seven dyads (i.e., 02002, and 02004 from group two, 01036 from group six, 01047, and 01052 from group seven, 01057, and 01062 from group eight). The discrepancies in the pattern of their attendance in terms of overall percentages ranged 5-45% and are provided in Table 25.

Table 25:

Discrepancies in the patterns of dyads' class attendance and their relationship with each other.

S #	Group	PWD	% of attendance	Carer	% of attendance	Carer's Relationship with PWD
1	2	02002P	36	02002C	64	Offspring
2	2	02004P	50	02004C	42	Spouse
3	6	01036P	85	01036C	95	Sibling
4	7	01047P	75	01047C	55	Spouse
5	7	01052P	85	01052C	95	Spouse
6	7	01053P	90	01053C	95	Sibling
7	8	01057P	60	01057C	15	Spouse
8	8	01062P	40	01062C	35	Spouse

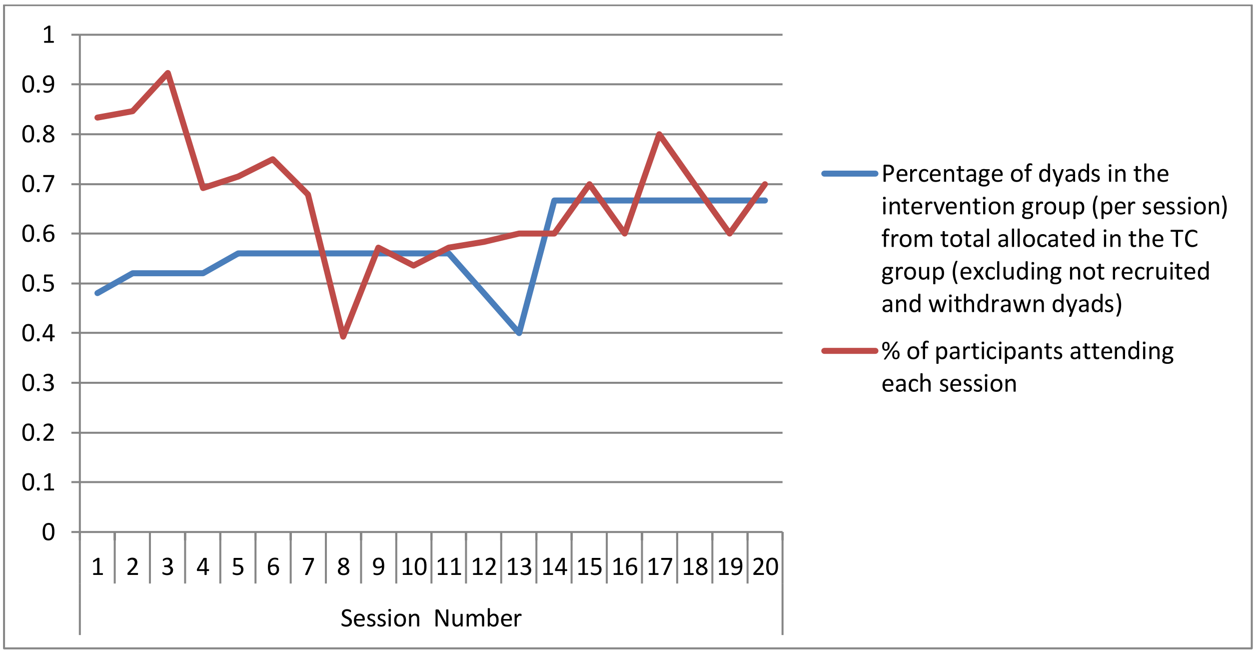
Attendance of carers in dyads; 02002, 01036, 01052, 01053 was higher. Among them dyad 02002 was offered 11 sessions (as they withdrew after 11th session). Carer was offspring of PWD. They attended only four sessions (36% overall attendance) together, while carer attended three additional sessions without PWD (65% carer's attendance). PWD had severe back pain issues and unable to join the carer in these three classes. Participants in dyad 01036 were siblings. They attended 17 out of 20 sessions together. Their overall attendance was 85% together. However, carer attended two additional sessions alone as PWD was away on holidays. Therefore, carer's attendance was 95%. Dyad 01052 were spouse. They attended 17 out of 20 sessions together (overall attendance was 85%), while carer attended two additional sessions without PWD. Therefore, their attendance was 95%. The reason for PWD's absence in these sessions was not specified. It was only mentioned that PWD was unable to attend. Dyad 01053 were siblings. They attended 17 out of 20 sessions together (overall attendance was 85%), while carer attended an additional session without PWD (carer attendance was 90%). PWD was absent because they were away on an away day.

Attendance of PWD in dyads; 02004, 01047, 01057, and 01062 was higher than the carers. Among them, 02004 were spouse. They were offered 12 sessions as they withdrew after the 12th session. PWD attended six out of 12 sessions (50%) and carer attended five out of 12 session (42%). Carer was absent in one session due to a fall in which they had a fractured arm and hip. Dyad 01047 were spouse. They were offered 20 sessions. PWD attended 15 sessions (75%) and carer attended 11 sessions (11%). Causes of carers absence were not recorded.

Dyad 01057 were spouse. PWD attend 12 out of 20 sessions (60%), while carer attended 3 out of 20 sessions (15%). Causes of carer's absence were not recorded/unknown. The causes of differences in dyads' attendance reflected various practical constraints, which does not indicate a uniformed pattern.

Figure 8:

Number of total participants (dyads) allocated to the intervention arm and percentage of participants attending each session against total allocated.



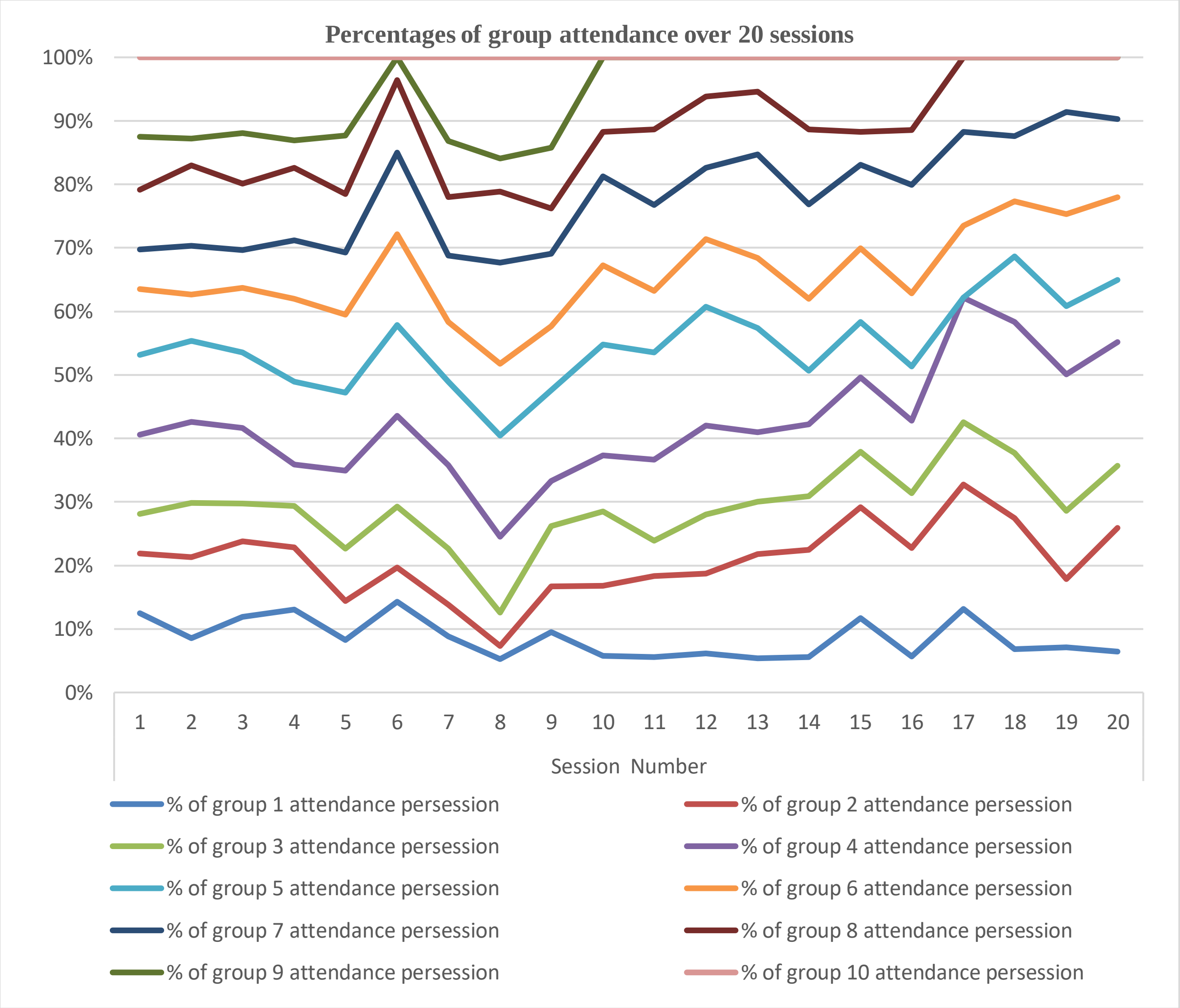
Note: Figure 8 illustrates percentage of participants (dyads) included in each session against total participants allocated to intervention arm (reflected by blue line, excluding those who were not yet recruited or withdrawn) and percentage of participants who actually attended each session against those who were recruited by that session (reflected by red line).

Table 26:

Patterns of each group's percentage of attendance over 20 sessions. See appendix- K.

Figure 9:

Percentages of each group's attendance over 20 session (N = 10).



6.6.4 Association between Tai Chi Class Adherence and Home-Based Practice

Association between class adherence (in terms of overall percentages of class attendance, M (SD) = 65.87% (29.34)) and home-based practice (i.e., percentage of actual minutes of home-based practice against total minutes required to be practiced, M (SD) = 31.71% (30.75)) among PWD (N = 42) was found to be strong, (r = .62, p < .001). Similarly, exclusion of those participants who withdrew from study (total number of participants (42) -

number of participants who withdrew (12) = N =30) association between class adherence (M (SD) = 66.29% (31.11)) and home practice (M (SD) = 40.05% (31.21)) further augment the findings as it was found to be very strong and highly significant (r = .73, *p* < .001). Therefore, the study hypothesis "there is a positive association between PWD's home-based and class-based Tai Chi exercise" was supported.

6.6.5 Causes of Non-adherence to Tai Chi Intervention

Initially, 52 causes of non-adherence of PWD in terms of absence from Tai Chi classes during the intervention phase were identified, then they were classified into seven broad categories to examine reasons of non-adherence (see Table 27, appendix L). PWD's health issues were found to be major cause of absence/ nonadherence to the classes.

Table 27: *Categories of causes of non-adherence to Tai Chi intervention among PWDs. See appendix- L.*

6.6.6 Predictors of Adherence to Tai Chi Intervention among PWDs

Four baseline variables i.e., PWDs' intention to do Tai Chi for next 20 weeks, their QoL (in terms of ICECAP-O tariff scores), level of moderate physical activity, and severity of dementia (in terms of M-ACE scores) were analysed to find out their predictive values for adherence to Tai Chi intervention classes among PWD. 42 Dyads were allocated to intervention arm in the TACIT trial. Pearson product moment correlation analysis of factors (i.e., group variance in terms of group sizes and different instructors (gender difference), PWD's intention and confidence to attend Tai Chi classes, and enjoyment during Tai Chi classes, PWD and their carers' health issues) affecting adherence to Tai Chi classes among PWD was conducted. Health issues of PWD and their carers were found to be strongly associated with adherence to Tai Chi classes, affecting adherence inversely (reported in detail later in this chapter). Therefore, considering dyads' health issues a major confounding variable affecting adherence, two multiple linear regression models were designed. In the first model adherence data of those participants was removed from this analysis who missed more than five sessions either due to carer's or PWD's health issues. It resulted in data of only 33 participants. The second model included all participants who were allocated to intervention arm irrespective of their health issues. Multiple linear regression was conducted. For the first model overall a significant regression equation was found, however, among individual factors only physical activity was found to have significant effect (see Table 26). For the second model (i.e., inclusive dyads with health issues (N = 41), only one participant was excluded from analysis who had withdrawn from the study from the first session i.e., 01043) an overall non-significant regression equation was found, however, the second model also indicated a significant effect of physical activity factor (see Table 29).

Table 28:

Multiple linear regression analysis to test the effect of PWD's intention, QoL, severity of dementia, and level of physical activity on their adherence to Tai Chi intervention classes (N = 33).

Variables	Adherence to Tai Chi Classes among PWDs			
	B	SE B	β	*p*
PWD intention to do Tai Chi for next 20 weeks	6.73	4.23	.30	.09
PWD QoL	-20.63	38.78	-.08	.45
Level of moderate Physical activity	- 6.39	2.0	-.61	.001
Severity of dementia	-.86	.83	-.17	.37
R^2	.28			
F	2.81			

p = .01

The first model was found to be significant however all factors except level of moderate physical activity were found to have a non-significant relationship with adherence to Tai Chi intervention among PWD. Therefore, the study hypothesis, "PWD's better QoL (in terms of ICECAP-O scores), cognitive functioning (in terms of M-ACE scores), stronger intention, and being physically active at baseline predict higher adherence to a Tai Chi intervention" was not supported.

Table 29:

Multiple linear regression analysis to test the effect of PWD's intention, QoL, severity of dementia, and level of physical activity on their adherence to Tai Chi intervention classes (N = 41).

Variables	Adherence to Tai Chi Classes among PWDs			
	B	SE B	β	*p*
PWD intention to do Tai Chi for next 20 weeks	3.67	4.74	.13	.44
PWD QoL	-15.44	49.93	-.04	.75
Level of moderate Physical activity	- 5.57	2.20	-.43	.01
Severity of dementia	-.95	.91	-.16	.30
R^2	.08			
F	1.97			

p = .11

The second model was found to be non-significant. In addition to that all factors except level of moderate physical activity were found to have a non-significant relationship with adherence to Tai Chi intervention among PWD. Therefore, the study hypothesis, "PWD's better QoL (in terms of ICECAP-O scores), cognitive functioning (in terms of M-ACE scores), stronger intention, and being physically active at baseline predict higher adherence to a Tai Chi intervention" was not supported.

6.6.7 *Factors affecting Adherence to Tai Chi Intervention among PWD*

The factors which may have affected adherence to intervention classes among PWDs during the intervention phase were analysed (i.e., group variance in terms of group size, and instructors (being male or female)), PWD's intention to come to classes, confidence to do Tai Chi, and enjoyment during Tai Chi classes (based on mid-way questionnaire data), and PWDs' and carers' health issues. Each factor's association with adherence among PWD are illustrated below.

6.6.8 *Group Variance*

6.6.9 *Instructors and Average Attendance of Group*

There were 10 groups and two instructors: a male and a female. Five groups were allocated to each instructor. Average attendance over the intervention period for both instructors' groups is illustrated in Table 30.

Table 30:

Average attendance of both instructors' groups over the intervention period.

	Instructors					
	M			F		
S. No.	Groups	No of Participants (PWDs+ Carers)	Average attendance per Group (%)	Groups	No of Participants (PWDs+ Carers)	Average attendance per Group (%)
1	5	4	80	1	6	57
2	4	8	78	10	6	95
3	7	10	71	2	8	64
4	8	10	65	3	8	70
5	6	16	74	9	8	60
M (SD); min-max =		73.60 (5.94); 65-80			69.20 (15.22); 57-95	

Size of the group and the instructors' gender did not seem to have contributed differently towards adherence to intervention classes. An independent sample t-test was conducted to compare adherence in terms of percentages of attendance of groups supervised by male and female instructors. There was no significant difference in adherence between the groups supervised by male (M (SD) = 73.60 (5.94) and female instructor (M (SD) = 69.20 (15.22); t (8) = .60, *p* = .56).

To investigate whether instructors' gender affects adherence to Tai Chi classes among male and female participants differently descriptive analyses was carried out as inferential testing was not possible with such small sample size (N= 16; n = 6 females, n = 10 males) participants with female instructor and (N = 25; n = 12 females, n = 13 males) participants with male instructors. Moreover, it was not planned analysis in the present PhD therefore findings may be considered tentative. However, another researcher has qualitatively analysed adherence to Tai Chi exercise intervention among male and female PWD in her PhD and reported no differences in comments among them.

16 participants (n = 6 females, n = 10 males) were allocated to the Tai Chi exercise groups which female instructor conducted. Percentage of attendance among female participants ranged from 15-100% with M(SD) = 61.97 (30.99). Whereas percentage of attendance among male participants ranged from 30-95% with M(SD) = 59.88 (31.10).

25 participants (n = 12 females, n = 13 males) were allocated to the Tai Chi exercise groups which male instructor conducted. Percentage of attendance among female participants ranged from 20-100% with M (SD) = 73.37 (24.84). Whereas percentage of attendance among male participants ranged from 21-100% with M (SD) = 66.75 (33.41).

The results did not indicate marked differences between male and female participants' adherence to Tai Chi classes in context of instructors' gender difference.

A non-parametric Kruskal-Wallis test was conducted to compare effect of different group size on adherence in terms of percentages of overall group attendance. All the ten groups were divided into three sub-groups based on number of participants (i.e., group 1 = 2-6, group 2 = 7-9, and group 3 = 10^+ participants). No significant difference in adherence across all the three sub-groups was found (χ^2 = .89, df = 2, p = .64). Therefore, the study hypothesis, “Smaller group size will increase adherence to Tai Chi intervention among PWDs” has not supported.

6.6.10 PWD’s Enjoyment, Confidence, and Intention during Tai Chi Classes

Pearson product moment correlation analysis was conducted to assess associations of PWD’s enjoyment during classes, their strength of intention and confidence to come to remaining Tai Chi classes with their adherence to Tai Chi intervention classes. Data for these variables was conducted half-way through the intervention from selected participants (N = 32). Strong inverse significant associations were found with intention (r = -.52; *p* = .002), and confidence (r = -.62; *p* < .001) and very small non-significant association with enjoyment (r = .03; *p* = .86) and adherence. The associations were not in the expected direction for intention and confidence. However, they were in the expected direction for enjoyment, but the association is very small. Therefore, the study hypothesis, “PWDs’ stronger intention to come to Tai Chi classes, higher confidence to do Tai Chi, and more enjoyment during classes has positive relation with adherence to Tai Chi intervention among PWDs” was not supported.

6.6.11 PWD’s and Carer’s Health Issues

PWD’s and carer’s health factors during the intervention phase was analysed to assess their effect on adherence to intervention among PWD. Health issues of PWD and carers included any reported health problems, serious adverse events, medical appointments, and hospitalization during intervention phase, which resulted in missing any Tai Chi classes for PWD. Initially 42 participants (dyads) were allocated to intervention arm, however, one dyad i.e., 01043 had withdrawn from study completely from the first session, therefore, they were removed from analysis, hence number of participants was 41. A strong inverse highly significant association of these factors with PWDs’ adherence to intervention was found (r = -.64; n = 41; p < .001 r = -.45; n = 41; p = .003 for PWD’s and carer’s health issue respectively.). It indicates that higher health issues of PWD and their carers were associated with lower adherence to intervention and more absents from the Tai Chi classes.

6.7 Discussion

This study aimed to explore class adherence to Tai Chi intervention, offered in the TACIT trial, among PWD. It focused on potential baseline predictors (i.e., PWD's intention to do Tai Chi over 20 weeks, QoL in terms of their ICECAP-O score, severity of dementia in terms of their M-ACE scores, and level of physical activity), contributing factors of adherence during the intervention phase (i.e., group size, instructor's gender, mid-way PWD's intention to do Tai Chi, confidence to do Tai Chi for remaining sessions and enjoyment during Tai Chi classes among PWD), and comparison of home-based and class-based exercise adherence among PWD.

Adherence to Tai Chi classes was considered in terms of percentages of class attendance (Di Lorito et al., 2020) session-wise as well as overall. Patterns of PWD's and dyad's adherence were explored. Contrary to earlier findings (McCurry et al., 2010) PWD's overall adherence and incremental progression session-wise did not indicate any specific patterns in which adherence rate increased or decreased. Variations in patterns of adherence were observed. PWD's and their carer's pattern of overall adherence was found to be similar except in case of eight dyads who had discrepancies in their adherence patterns. These dyads' relationship also varied i.e., five among them were spouse, two siblings, and one offspring of PWD. Previously, it was reported that the PWD who had their spouses as their carers had higher adherence to exercise intervention (McCurry et al., 2010) as compared to their counterparts who had non-spousal carers. The present findings, however, have added to the existing knowledge by indicating that adherence patterns may vary among spousal dyads. However, this needs to be further explored as to which factors may be responsible for such variation in adherence patterns of spouse dyads. In addition to adherence to classes, causes of lack of adherence in terms of absence from classes was explored. Adherence to exercise intervention among older adults with mild cognitive impairment and dementia (Di Lorito et al., 2020) and cognitively intact older adults (Rivera-Torres et al., 2019) have been reported to be affected by their physical health issues. Similarly, the present study found health issues of PWD and their carers as the major contributing factor to non-adherence among PWD. This a major contribution to knowledge in regard to community dwelling PWD as earlier findings were related to people with MCI or cognitively intact older adults. These health issues are likely to be the main factor for the fluctuations in adherence patterns. In the present study, these health issues were also found be strongly inversely associated with PWD adherence to the TACIT trial intervention program. Therefore, health issues of PWD and their carers must be taken into consideration in future exercise intervention studies for PWD and their cares.

Group adherence patterns were also examined session-wise over the 20 weeks. Session-wise group adherence did not seem to have any specific patterns. If anything, visual inspection of figures 9 showed that all groups tended to decrease and increase adherence from session 5 to 8 and 15 to 18. For example, all classes seem to have a decline in session 5 followed by an increase in adherence in session 6 followed by an additional decline in sessions 7 and 8. Similarly, in session 15 there was an increase in adherence, which declined in session 16 and then increased in session 17 among all groups. Underlying causes of such uniformity of adherence patterns across these sessions was unclear. Future studies may explore the patterns and underlying causes of adherence to exercise intervention among PWD to fill the gap in knowledge.

Class-based physical activity has been reported to have greater positive effect on physical activity and health gains as compared to home-based exercise programs (Hinman & Hazan, 2020; Fisher et al., 2017). Although, there is gap in research regarding direct association between home-based and class-based exercise, however, the existing studies have suggested an indirect effect of home-base exercise on physical activity behaviour (Hill et al., 2015) and potential benefit of community-based exercise program for home-based exercise

(Jack et al., 2010). Hill et al. (2015) reported in their systematic review and meta-analysis that home based exercise increased physical activity, mobility, balance, and muscular strength among older adults. In another systematic review Jack et al. (2010) reported low social activity, lack of social and family support as barriers to outpatient physical therapy and suggested designing such treatment programs which involves social support and contact such as group-based rehabilitation programs, community-based exercise classes and spousal/partner involvement to encourage participation in home based physical therapy. Therefore, it was expected in the present study that there would be a positive strong association between home-based and class-based adherence to Tai Chi among PWD, which was supported by the findings of the study.

To investigate predictive value of baseline variable i.e., PWD intention to do Tai Chi for next 20 weeks, QoL, severity of dementia and their level of physical activity, two multiple linear regression models were conducted. The first model excluded those participants who missed more than five sessions due to PWD's or carer's health issues (N = 33). The second model included all participants irrespective of their health issues (N = 41) excluding only one participant who withdrew from study from beginning and did not attend any session. Overall, the first model was found to be significant explaining 28% of the variance, with only physical activity levels at baseline as a significant predictor. The second model was not found to be significant. Further inspection did show that baseline physical activity was still the only significant predictor of adherence to Tai Chi exercise classes. This would indicate that irrespective of PWD's or carer's health issues, baseline physical activity level strongly contributed to adherence among PWD. Strong association of level of physical activity at baseline with adherence to Tai Chi exercise classes among PWD was in line with previous evidence regarding cognitively intact older adults (Ajzen, 1991; Bozionelos & Bennett, 1999) that baseline physical activity is associated with exercise adherence subsequently. However, PWD’s intention to do Tai Chi in the next 20 weeks, QoL, and severity of dementia at baseline were found to have no predictive value, which require further investigation to supplement or refute the findings of present study.

Factors during the intervention phase that influenced PWD’s adherence were also assessed. Health issues of PWD and their carers were found to be major negative contributing factors to adherence. As PWD are vulnerable with complex health needs (Desai et al., 2012), therefore, health issues may have overshadowed the remaining factors and predictors of adherence to intervention. Smaller class size was expected to have a positive effect on adherence to Tai Chi intervention, however, it was not found to have any effect. Likewise, gender difference of the instructor did not contribute to adherence among PWD. PWD’s mid-way intention to come to Tai Chi classes, confidence to do Tai Chi, and enjoyment during the classes appeared to have an inverse association with PWD’s adherence to Tai Chi classes. Intention ($r = -.52$; $p = .002$) and confidence ($r = -.62$; $p < .001$) had a strong inverse association while enjoyment ($r = -.03$; $p = .86$) had only small non-significant association. In a meta-analysis (Rhodes & de Bruijn, 2013), which investigated the intention-physical activity behaviour gap among older adults, it was reported that 32% of intenders were not successful in participating in physical activity subsequently. Further, only 42% of those who intended were successful in their participation to physical activity. The overall intention-behaviour gap was found to be 46%. This highlights that there might be additional constructs contributing in intention-behaviour gap that needs to be explored. PWD self-reported mid-way their level of confidence and intention to do Tai Chi in remaining 10 sessions, on a seven-point Likert scale in a structured interview. The data may have involved some degree of bias, which could have been validated either by cross opinion of their instructors and carers or by asking a few more supplementing questions. Furthermore, the association may have been affected by any unforeseen circumstances which participants could not foresee at the time of interview. Although PWD mid-way enjoyment during classes was found to have a positive association with adherence to intervention however, the association was not strong or significant.

The present study tested predictive values of several baseline (i.e., intention to Tai do Chi in next 20 weeks, QoL, severity of dementia, and level of physical activity at baseline) and mid-way variables (i.e., class size, instructor's gender, level of confidence and intention to do Tai Chi in the remaining 10 weeks, and enjoyment during the classes) and association of health issues of PWD and carer with adherence to the Tai Chi intervention. Among the baseline variables only, physical activity was found to have significant predictive value. Among the mid-way variables, health issues of PWD and their carers during the intervention phase were found to have greatest negative impact on PWD's adherence to Tai Chi intervention. The study sample (PWD) not only had complex health status involving physical and neurological conditions, they also were almost entirely dependent on their carers to participate in Tai Chi classes as the trial was designed for the dyads to attend and absence of one person for extended sessions would definitely affect adherence of the other. Therefore, carers health issues not only affected their own participation in the classes but also restricted PWD's participation in the classes. Additionally, PWD's mid-way confidence to do Tai Chi and intention to come to Tai Chi classes was also strongly associated with their adherence to intervention, however, the association was inverse which was not in the expected direction. Furthermore, class size, instructor's gender, and PWD's enjoyment during classes were found to have small non-significant association with PWD's adherence to intervention. The findings suggested that only PWD's and carers' health issues had a strong negative influence on PWD's adherence to the Tai Chi intervention. The present finding is in line with the previous finding regarding physical health and fitness as contributing factors in adherence to exercise among cognitively intact older adults (Rivera-Torres et al., 2019). There was gap in knowledge regarding effect of physical health of PWD on their adherence to exercise intervention, which has been filled in the present study, which a novel contribution of present study in knowledge.

TACIT trial design placed a few restrictions to the approach adopted in the present study. Participants in TACIT trial intervention arm (N = 42) restricted number of predictive variables to only four for adherence to Tai Chi class exercise among PWD. As a rule of thumb 10 participants per variable were required for regression analysis (VanVoorhis & Morgan, 2007). Had the sample been larger predictive value of more variables e.g., gender, long term health conditions other than dementia, living with family and friends or alone, and PWD's confidence (self-efficacy) may have been explored. Role of instructor in exercise adherence has been reported to be positive (Van der Wardt et al., 2017; Vseteckova et al., 2018), however in TACIT trial detailed data about instructor's characteristics was not collected due to which it could not be investigated in depth in the present study. In TACIT trial BCTs were used to encourage Tai Chi class participation and home practice. Effect of BCTs (i.e., joint action plan, joint coping plan, self-monitoring, feedback from Tai Chi instructor on home practice, and provision of alarm clock to set as a reminder) on home practice were evaluated (by another researcher in her Masters thesis). However, effect of BCTs (i.e., social support from Tai Chi instructor and other participants, feedback on class performance from Tai Chi instructor, and a reminder phone call if two consecutive classes were missed) on class-based adherence to Tai Chi intervention among PWD were not measured in the trial. Hence, TACIT trial restricted the scope of the present study.

The present study explored adherence to Tai Chi intervention in depth, however, it had a few limitations which may be overcome in the future studies. The study limitations are as follows:

1. In the TACIT trial the process of recruitment and randomization was ongoing as participants were being recruited during the trial, they were allocated to one of the ten Tai Chi exercise groups being run according to the closest proximity to the respective participants. However, classes could not start until at least two to three dyads were allocated to a group (i.e., minimum required number of participants). Moreover, participants were allowed to join an already running class in the first few weeks but no later than week 5, so they may not have attended all the 20 classes. Therefore, classes/sessions did not start for all the 10 groups simultaneously. They started as and when the minimum required number of participants for each group was recruited successfully. In addition, there were some participants who joined from the first session. They were offered 20 sessions, however, they due to different reasons could not attend all the sessions (see Table 21, appendix- L for causes of nonadherence/absence from Tai Chi class sessions). Hence, all participants could not attend 20 Tai Chi sessions/classes. They received lower than the planned dose of Tai Chi. The number of sessions participants attended varied, which may have affected outcomes of the study.
2. The study involved dyads (carer + PWD) carers health issues were an important factor which affected PWD adherence inversely. Having more than one carer to alternate the one having health or other restricting issues may have contributed in PWD's adherence to intervention positively.
3. PWD's health issues were another factor which negatively affected their adherence to intervention. Arrangement of additional sessions for PWD who had

missed Tai Chi sessions due to their health issues or any other unavoidable circumstances may have contributed positively in their adherence to intervention.

4. Although instructor’s characteristics are reported to have a positive effect on exercise adherence among PWD (Van der Wardt et al., 2017; Vseteckova et al., 2018), in the present study only the effect of instructor’s gender on adherence to intervention among PWD could be investigated. Exploration of other contributing characteristics of the instructors could have added to the existing knowledge. The study involved community dwelling PWD, therefore, the findings cannot be generalized to PWD residing in the care homes.
5. Behaviour Change Techniques (BCTs) are reported to support adherence to exercise intervention among PWD and older adults with Mild Cognitive Impairment (Van der Wardt et al., 2017). However, due to restriction of TACIT trial (i.e., BCTs were used to explore home-based and class-based Tai Chi practice among PWD) effect of BCTs on class-based adherence to Tai Chi intervention among PWD could not be explored.

Adherence to intervention is a complex and multifactorial phenomenon (Di Lorito et al., 2020; Hawley-Hague et al., 2016). The study population was also complex with numerous health issues and challenging life circumstances. Exploration of adherence to intervention among this population was a challenging task. Future studies may focus on such study designs which may address the health issues of PWD and their carers to avoid their adverse effect on adherence to exercise intervention among PWD. Likewise, broader locale of the study will facilitate recruitment of larger sample, which will enhance understanding of the predictors and facilitators of adherence to exercise intervention among PWD. Future studies may focus on exploration of techniques which may facilitate adherence to intervention among community dwelling as well as care home resident PWD. Effects of various BCTs on adherence to class-based exercise intervention among PWD may also be explored to enhance adherence to exercise intervention among PWD to reap effects of exercise. Indeed, future research is warranted, given a recent systematic review (Nyman et al., 2018) found inconclusive results regarding effectiveness of use of BCTs in promoting physical activity among PWD. However, it may be considered that BCTs which involve cognitive processes may not be as effective for PWD due to their impaired cognition. Therefore, non-cognitive BCTs such as implicit behaviour learning (which does not involve cognitive processes), behaviorist approach or choice architecture (which involves encouraging people to choose healthy behaviors) may be adopted along with partnership of carers to reap the benefits of BCTs to promote physical activity among PWD (Nyman, 2019). The role of the instructor in facilitating adherence to exercise intervention among PWD may also be explored in detail.

6.7.1 Summary

Although health benefits of exercise adherence among older adults with or without dementia are already documented, however, the present study highlighted the fact that PWD’s and their carer’s health does have a reverse effect on PWD’s adherence to intervention. Therefore, to enhance PWD’s exercise adherence their health issue may also be addressed. Findings of present study may be used in future research involving predictors and facilitators of exercise adherence, techniques of effective delivery of exercise intervention among PWD, and formulation of more encompassing exercise intervention for community dwelling and care home resident PWD to broadly benefit PWD. Third study of present PhD has focused on adding in the existing knowledge regarding benefits of Tai Chi exercise on QoL of PWD by investigating effect of adherence to Tai Chi intervention on QoL among community dwelling PWD.

7 Study-III: Effect of Adherence to Tai Chi on QoL of PWD

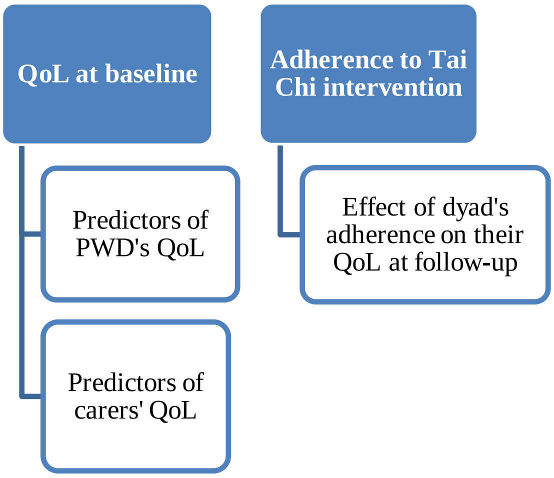
7.1 Aim of the Study

Aims of the study were to assess predictors of QoL of PWD and their carers and to investigate effects of adherence to Tai Chi intervention on QoL of the dyad (PWD + carer).

Study-III consisted of assessment of predictors of QoL of PWD and their carers at baseline, association of dyads' (PWD + Carer) QoL at baseline and follow-up with their adherence to Tai Chi intervention (i.e., home-based and class-based for PWD and only class-based for the carers), association between dyads' QoL at baseline and follow-up, and effect of Tai Chi adherence on their QoL (post intervention).

Figure 10:

Illustration of study-III design.



7.2 Objectives

The study had the following objectives:

1. To investigate baseline factors affecting QoL of PWD, including: age, gender, general health issues, severity of dementia, use of walking aid, living arrangement, relationship with carer, and carer's QoL.
2. To investigate baseline factors effecting QoL of carers, including age, gender, care burden, relationship with PWD, and PWD's QoL.
3. To investigate the association between PWD's baseline QoL and their adherence to home-based and class-based Tai Chi intervention.
4. To investigate effect of PWD's adherence to Tai Chi intervention (i.e., home-base and class-based) on their QoL at follow-up.
5. To investigate the association between carers' baseline QoL and their adherence to class-based Tai Chi intervention.
6. To investigate effect of carers' adherence to class-based Tai Chi intervention on their QoL at the follow-up.

7.3 Rationale and Hypotheses

7.3.1 Associations of PWD's QoL

To improve QoL of PWD it is imperative to understand the factors influencing QoL of PWD. A complex variety of factors influencing QoL of PWD encompassing, demographic, physical, psychological, social, and religious aspects have been highlighted. These factors have been found to vary across different living arrangements (e.g., living in community and care home), severity of dementia and perspectives (e.g., PWD, family, care staff) (Jing et al., 2016). Demographically, higher education (Marventano et al., 2015), male (Woods et al., 2014), white ethnicity (Black et al., 2012), extroverted (Li et al., 2012), and widowed (Samus et al., 2005) were reported to be positive factors, while increase in age negatively (Banerjee et al., 2006) associated with PWD's QoL. A recent systematic review (Martyr et at. 2018) indicated that positive factors of PWD's QoL were as follows: PWD's greater social engagement, better quality of relationship with carer, carer being spouse, better self-rated QoL of carers, better self-rated health of PWD, and living in the community. The present study attempted to explore effect of age and gender on PWD's QoL. It was expected for young male PWD to have better QoL as compared to PWD with older age. QoL has been reported to decline with ageing (Web et al., 2011; Brett et al., 2019) and strong inversely associated with age (Raggi et al., 2016) among cognitively intact older adults and PWD (Banerjee et al., 2006). Likewise, QoL and age has been found to have a U-shaped relationship across the life span suggesting a steep decline in QoL among older adults aged 75 and above and then increase in QoL in the oldest old cohort (Netuveli et al., 2006; Blanchflower & Oswald, 2008; Baired et al., 2010; Jivraj et al., 2014). However, the relationship may differ depending on the measure of QoL, for instance there is strong evidence suggesting stability in QoL even in oldest old in terms of life satisfaction (Eid & Diener, 2004; Kahneman & Krueger, 2006; Clark et al., 2008). Therefore, there is requirement to investigate association between age and a more encompassing or representative measure of QoL. Association between age and QoL is vital to explore to develop age-appropriate interventions to improve QoL among cognitively intact older adults and PWD. Hence, in the present study it was aimed to explore association between age and QoL in terms of ICECAP-O which is a broader and representative measure of QoL.

Female gender was also expected to have negative association with QoL among community dwelling PWD. Previous studies have shown that female gender has negative association with QoL among cognitively intact older adults (Gott et al., 2006; Lee et al., 2020) and institutionalized PWD (Barca et al., 2011). Older women with heart failure were reported to have lower health related QoL than their male counterparts (Friedman, 2003; Gott et al., 2006). Similarly, female gender was found to be a major negative predictor of QoL among older adults with heart failure (Cline et al., 1999). Another study involving community dwelling older adults (N= 33,019) from lower- and middle-income countries identified QoL to be lower among women as compared to men (Lee et al., 2020). Moreover, QoL was also found to be significantly lower in females institutionalized PWD as compared to the male participants (Barca et al., 2011). However, there is lack of evidence regarding association of gender with QoL among community dwelling PWD. Therefore, in the present study it was aimed to address this gap in the knowledge and examine association of gender with QoL among community dwelling PWD. It will help in designing individually tailored interventions for both genders to improve their QoL. Based on previous evidence it was assumed that female PWD will have a negative association with QoL.In terms of physical factors affecting PWD's QoL, better general health has been found to be positively correlated, while increasing number of chronic health issues has been found to be inversely correlated with PWD's QoL (Jing et al., 2016). Severity of dementia tended to decrease PWD's QoL (Marventano, 2015; Mjørud et al., 2014). Therefore, it was expected in the present study that PWD with better general health (i.e., fewer health issues), and less severe dementia (i.e., in terms of PWD's M-ACE scores) would have better QoL as compared to their counterparts with greater physical health issues and more severe dementia.

Additionally, active participation in daily physical activities including physical exercise (i.e., aerobic, balance and flexibility) and leisure activities (i.e., parlour games and excursion) was found to have positive effect on PWD's QoL (Jing et al., 2016). Autonomy was also found to be a strong predictor of PWD's QoL (O'Rourke et al., 2015). This suggests that PWD who lack autonomy or are unable to participate in daily physical activities may have lower QoL. Therefore, in the present study it was assumed that PWD who used a walking aid may have limitations in participating in daily physical activities and may have compromised autonomy as well, which in turn may affect their QoL negatively. In addition, one of the attributes of QoL measured in ICECAP-O is independence i.e., item 5 (see appendix-A). Therefore, a negative association between use of walking aid and PWD's QoL in terms of ICECAP-O scores was expected. Moreover, Logsdon et al. (2007) in their review identified four empirically driven components of good QoL in PWD including depression and pleasant events, activities of daily living, physical functioning and mobility, and cognitive functioning. They also reported evidence from randomized controlled trial (Teri et al. 2003), non-randomized trials (Arkin, 1999, 2003) and meta-analysis (Heyn, 2004) to support positive effect of physical exercise on physical functioning and positive association of physical functioning with QoL among PWD. Studies have also reported adverse impact of restricted life-space mobility on QoL of PWD (Saraiva et al., 2021; Rantakokko et al., 2015). Moreover, mild physical impairment has been identified to be significantly associated with QoL among PWD (Jayakody & Arambepola, 2022). Therefore, it was expected in the present study that PWD with restricted mobility (in terms of use of walking aid) may have lower quality of life.

Different living arrangements have been reported to have varied effect on PWD's QoL. PWD living in their own homes as compared to living in care homes tended to have higher QoL (Nikmat et al., 2015). Moreover, social connection and communication with family, friends and neighbours enhanced PWD's QoL (Jing et al., 2016). Hence, living at own home if considered together with connection with family, friends, and neighbours, it may be expected that PWD living in their own home with family or friends may have higher QoL as compared to those who live in their own home alone. This aspect has not been explored yet, therefore the present study will add to existing knowledge.

Quality of relationship with carers and family members as perceived by PWD has been reported to be a strong predictor of PWD's QoL (Clare et al., 2014). Nikmatet al. (2015) reported higher connectedness with family, less isolation, and better QoL among PWD living in their own homes as compared to those living in the care facility. Although effect of quality of relationship with carer has been investigated, effect of type of relationship with carer on QoL of PWD has not yet been explored. Therefore, in the present study it was attempted to investigate effect of type of relationship (i.e., spouse, offspring, siblings, neighbours, and friends) on QoL of PWD.

Another important aspect of carers' effect on PWD's QoL is the amount of time spent on caring the relative with dementia. 50% Of community dwelling PWD have reported to get 35+ hours per week of informal care at their own homes (Murray et al., 1999). This highlights that informal/family carers may have vital influence on QoL of their care recipients. Although numerous factors have been identified which affect QoL of family carers of PWD related to caring their relative (Farina et al., 2017) however, there is sparse evidence regarding direct effect of carers QoL on PWD's QoL. It is evident that QoL of carers is affected by caring responsibilities of their relative with dementia and interventions to improve QoL of carers helps in delaying PWD's admission to care facilities (Brodaty & Donkin, 2009). This indicates that carers' QoL affects PWD's QoL indirectly as PWD living in their own homes have been reported to have higher QoL as compared to those living in the care facility (Nikmat et al., 2015). However, there is scant literature highlighting direct effect of carers' QoL on PWD's QoL. Therefore, it was deemed worth exploring effect of carers' QoL on PWD's QoL. It was expected that carers better QoL has positive effect of PWD's QoL. In the backdrop of study expectations, the following hypothesis was formulated:

1. PWD’s age, female gender, general health issues, severity of dementia, use of walking aid, are strong negatively associated, while living with family and friends, spouses being carers, and carer’s QoL are strong positively associated with PWD’s QoL.

7.3.2 Associations of Carers’ QoL

Family carers, also called informal carers, are integral part of caring for PWD. QoL of PWD’s carers have been reported to be low (Karg et al., 2018). Largest proportion of dementia carers are spouses followed by children and children in law. Mostly are female of middle-old age range (Brodaty & Donkin, 2009). However, carers’ gender has not been found to be related to their own QoL (Schoenmakers et al., 2010). There is also dearth of knowledge regarding effect of type of relationship with PWD (i.e., spouse, sibling, offspring, friend, neighbour) on carers’ QoL. Therefore, the present study focused to investigate both; the effect of carers’ gender and type of their relation with the PWD on their own QoL to augment and add to existing knowledge.

Carers’ QoL have been found to be interlinked with PWD’s QoL (Farina et al., 2017). Care giving experience may be satisfactory for the relatives of PWD, however, it is documented that carers of PWD experience more care burden as compared to those caring for patients without dementia (Brodaty & Donkin, 2009). Numerous factors associated with PWD increase care burden which subsequently affect QoL of carers (Santos et al., 2014). Therefore, it was expected in the present study that there will be a negative association of care burden on carers’ QoL and positive association of PWD’s better QoL with their carers’ QoL. The following hypothesis has been formulated regarding carer’s QoL:

2. Carer’s age, female gender, care burden, and spousal relationship with PWD are negatively, while PWD’s QoL is positively associated with carer’s QoL.

7.3.3 Effect of PWD's QoL on their Adherence to Tai Chi Intervention

Health related QoL was reported to have greatest variance to exercise adherence in community-based older women (Findorff et al., 2009). Similarly, QoL, maximal balance range, and six minutes walk per day accounted for 33% variance to exercise adherence in community dwelling post stroke older adults (Tiedemann et al., 2012). There is a scarcity of literature regarding effect of PWD's QoL on their adherence to exercise interventions. Therefore, in the present study it was attempted to explore the effect of PWD's QoL on their adherence to Tai Chi intervention. It was expected that PWD's QoL would have positive effect on PWD's adherence to Tai Chi intervention similar to that of cognitively intact older adults on their exercise adherence. The following hypothesis has been made:

3. PWD's baseline QoL has a positive association with their adherence to home-based and class-based Tai Chi intervention.

7.3.4 Effect of PWD's Adherence on their QoL

There is mixed evidence regarding the effect of exercise on PWD's QoL. A quasi RCT (Tanaka et al., 2021) reported positive effect of a group exercise combined with cognitive stimulation on PWD's QoL, while a recent systematic review (Russ et al., 2021) found high intensity exercise training to have no effect on PWD's QoL, though it improved their balance performance and ability to perform activities of daily living independently. A double parallel RCT (Henskens et al., 2018), which offered three different types of physical activity trainings i.e., activities of daily living training, multicomponent aerobic and strength training, and a combination of both, also reported no benefit of exercise on QoL of PWD. However, PWD's activities of daily living were improved with physical exercise participation, and improvement in their activities of daily living impacted PWD's QoL positively. Hence, it may be inferred that exercise contributed in improvement to PWD's QoL indirectly. Such mixed evidence is likely due to the many factors associated with exercise interventions including mode, frequency, duration, and intensity. It also indicates the requirement of exploration of right type, frequency, duration, and intensity of exercise to improve PWD’s QoL. Additionally, it is evident that without adherence to exercise its benefits cannot be achieved. Therefore, the present study attempted to explore effect of adherence to Tai Chi intervention on PWD’s QoL. A systematic review and meta-analysis (Wang et al., 2020) reported Tai Chi to have positive effect on overall QoL of older adults. Similarly, eight weeks of Tai Chi practice was reported to have improved QoL among older male adults (Tajik et al., 2018). The TACIT trial reported significant improvement in PWD’s QoL in the intervention group (i.e., Tai Chi + treatment as usual) as compared to their counterparts in the control group (i.e., treatment as usual only) (Nyman, 2019), however, the direct effect of adherence to Tai Chi intervention on PWD’s QoL was not investigated, which was explored in the present study. Therefore, it was expected in the present study that Tai Chi, which has shown to have positive effect on QoL of cognitively intact older adults (Wang et al., 2020; Tajik et al., 2018) and that of PWD (Nyman, 2019), would improve PWD’s QoL. Furthermore, as a group exercise combined with cognitive stimulation has also shown to have positive effect on PWD’s QoL (Russ et al., 2021) further augmented the assumption of the present study that Tai Chi, which is known as a mind-body exercise (Wu et al., 2013) when arranged in groups for dyads (PWD + carers) would have positive effect on PWD’s QoL. Therefore, the following hypothesis was made in this regard:

4. PWD’s adherence to Tai Chi intervention (i.e., home-based and class-based) has a positive association with their QoL at follow-up.
5. High adherent PWD to Tai Chi intervention (i.e., home-based and class-based Tai Chi) has higher QoL as compared to that of PWD in the control arm at follow-up.

7.3.5 *Effect of Carer's QoL on their Adherence to Tai Chi Intervention*

Exercise has proven positive effects on physical and cognitive functions and QoL of older adults (Baker et al., 2007; Lamb et al., 2018; Karssemeijer et al., 2017). However, exercise adherence is the key to achieve these benefits. Carers of PWD have vital role in caring for PWD, therefore, exercise adherence must be promoted among them to benefit them and the people they care for. To promote exercise adherence, it is crucial to have knowledge of factors which facilitate exercise adherence. Therefore, the present study attempted to explore effect of carers' QoL on their adherence to Tai Chi intervention, as QoL has been shown to be a predictor of exercise adherence among older adults (Findorff et al., 2009; Tiedemann et al., 2012). There is dearth of evidence regarding effect of carers of PWD's QoL on their adherence to exercise interventions. It was expected in the present study that carers' QoL would have positive effect on their adherence to Tai Chi intervention, similar to that of general population's. The following hypothesis was formulated in this regard:

6. Baseline QoL of carers has a positive association with their adherence to class-based Tai Chi intervention.

7.3.6 *Effect of PWD Carers' Tai Chi Adherence on their QoL*

It was attempted in the present study to investigate relationship between carers' QoL and their adherence to Tai Chi intervention. Therefore, it was aimed to explore the reciprocal effect of adherence on carers' QoL. Several studies have demonstrated that health related QoL deteriorates among carers of PWD (Coen et al., 2002; Takai et al., 2009; Igarashi et al., 2020). It has also been observed that carers of PWD have lower physical, psychological, social, and environmental QoL (Srivastava et al., 2016). These findings highlight the fact that carers' compromised QoL may affect their ability to fulfil their caring responsibilities for PWD efficiently. It also necessitates investigation of contributing factors to maintain or improve dementia carers' QoL. Involvement in regular moderate-intensity exercise has been reported to improve QoL of PWD carers (Hirano et al., 2011). Moreover, dyadic exercise has been shown to have reduced care burden of carers of PWD (Lamotte et al., 2017). Care burden of dementia carers of PWD has been reported to be inversely associated with their QoL (Srivastava et al., 2016; Contreras et al., 2021). However, direct effect of dyadic exercise on carers' QoL has not been explored yet. Therefore, it was expected in the present study that, if explored, dyadic exercise would have positive effect on QoL of PWD's carers. Additionally, Tai Chi has varying levels of intensity, which may be adjusted according to the requirement of the participants (Kwok et al., 2010). It has been shown to affect general older adults' QoL positively (Wang et al., 2020), therefore, it was assumed in the present study that adherence to dyadic Tai Chi exercise will affect PWD carers' QoL positively. The following hypothesis was formulated to investigate the assumption of the present study:

7. Carers' adherence to class-based Tai Chi intervention has positive association with their QoL at follow-up.
8. High adherent carers to class-based Tai Chi intervention have higher QoL as compared to that of carers in the control arm at the follow-up.

7.4 Procedure

Procedure for study-II and III is same. It is illustrated in detail in study-II Method section.

7.4.1 Sample

The study sample consisted of dyads (PWD + carers). It was derived from the main trial (Nyman et al., 2018), as in study-II of the present PhD. Therefore, PWD and their inclusion/ exclusion criteria remained the same as that in study-II. However, study-III included carers as well, therefore, inclusion/exclusion criteria of carers is illustrated below.

7.4.2 Inclusion Criteria

Inclusion criteria for PWD's carers was as follows:

1. Commitment to support PWD throughout the trial period.
2. Able to participate in data collection.
3. Willingness to attend weekly Tai Chi classes, if allocated to intervention group.
4. Physically able to do standing Tai Chi.

7.4.3 Exclusions Criteria

Exclusion criteria for PWD's carers was as follows:

1. Have severe sensory impairment.
2. Lack mental capacity to consent to participate in the study.

7.5 Sample Size Calculation

Based on Cohen's (1992) criteria for independent group t-test sample size, these parameters were determined a priori; confidence interval = 95%, level of significance = .05, effect size (large) = .80. The required sample based on these parameters was N = 26 in each group a total of N = 52. We recruited a total of N = 83 participants in the main trial, among them N = 41 were allocated to control arm, while N = 42 to intervention arm. The large effect size was determined based on theoretical underpinning and previous evidence (see section 2.3.12) for positive effect of Tai Chi on QoL of older adults.

For all regression analyses in the present PhD as a rule of thumb 10 participants per variable were required (VanVoorhis & Morgan, 2007). The number of participants in all these analyses was higher than the required number. As regards rule of thumb, obviously it is not ideal to use as a criterion for sample size calculation, however, in case of having no consensus regarding required sample size, it is the only appropriate available choice.

7.6 Data Analysis Strategy

To investigate the hypotheses of the study the follow data analysis strategy has been devised:

1. *Hypothesis 1:* PWD's age, female gender, general health issues, severity of dementia, and use of walking aid, were strongly negatively associated with PWD's QoL, while living with family and friends, spouses being carers, and carer's QoL were strong positively associated with PWD's QoL.
2. *Hypothesis 2:* Carer's age, female gender, care burden, and spousal relationship with PWD were negatively associated with carer's QoL, while PWD's QoL was positively associated with carer's QoL.

To investigate the association of these variables in relation to PWD's and carer's QoL multiple linear regression was carried out for the first two hypotheses.

3. *Hypothesis 3:* PWD's baseline QoL had a positive association with their adherence to home-based and class-based Tai Chi intervention.
4. *Hypothesis 4:* PWD's adherence to Tai Chi intervention (i.e., home-based and class-based) was positively associated with their QoL at follow-up.
5. *Hypothesis 5:* PWD highly adherent to the Tai Chi intervention (i.e., home-based and class-based Tai Chi) had higher QoL as compared to that of PWD in the control arm at follow-up.
6. *Hypothesis 6:* Baseline QoL of carers had a positive association with their adherence to class-based Tai Chi intervention.
7. *Hypothesis 7:* Carers' adherence to class-based Tai Chi intervention had a positive association with their QoL at follow-up.

8. *Hypothesis 8:* Carers highly adherent to the class-based Tai Chi intervention had higher QoL as compared to that of carers in the control arm at the follow-up.

To investigate the association between the variables in hypothesis three, four, six and seven pearson product moment correlation analyses were carried out. Adherence to Tai Chi intervention was considered in terms of percentage of classes attended, and minutes Tai Chi practiced at home against the required number of classes and minutes of home practice time. To investigate effect of Tai Chi intervention on QoL of PWD and carers in intervention and control arms of TACIT trial as per hypotheses five and eight a median split of adherence to Tai Chi intervention was conducted for PWD (i.e., percentage of classes attended against the required number of classes to be attended and percentage of minutes Tai Chi practiced at home against the required number of minutes for Tai Chi home practice) and carers (i.e., only percentage of classes attended against the required number of classes to be attended) in the intervention arm. Subsequently, to compare follow-up QoL of participants in the higher median split with that of control arm participants independent sample t-tests were carried out.

7.7 Results

7.7.1 *Demographic Information*

The present study consisted of dyads. Demographic information for PWD is the same as that in study-I (i.e., information regarding all PWD included in the trial (N = 83)) and study-II (i.e., information regarding PWD included in the intervention arm (N = 42)). However, demographic information for PWD's carers as whole (N = 83) and from intervention arm (N = 42) is illustrated in Table 31.

Table 31:

Carers' demographic information from TACIT trial and intervention arm.

Characteristics of Carers	Main trial Values (N = 83)	Intervention Arm Values (N = 42)
Age in years mean (SD)	71.37(10.11)	71.97(9.91)
Gender		
Male	17	10
Female	66	32
Ethnicity (n)		
White	82	42
Asian	1	
PWD relationship with carer (n)		
Spouse	65	34
Children	8	3
Sibling	6	4
Friend	2	-
Other	2	1
Living situation (n)		
Living alone	3	2
Living with family and friends	80	40

7.7.2 *Associations of PWD's QoL*

Multiple linear regression was carried out to investigate the association of PWD's age, gender, general health issues, severity of dementia, use of walking aid, living arrangements, relationship with carer and carer's QoL for PWD's QoL. The regression model was not significant (*p* = .07) explaining 17% of the variance in PWD's QoL at baseline. All variables had small non-significant associations except relationship with carers (i.e., spouses or others) which had small but significant association ($p < .05$). PWD's gender, living arrangements (i.e., living with family and friends or living alone) use of walking aid, relationship with carer, PWD health issues and severity of dementia indicated inverse associations for PWD's QoL (see table 26).

Table 32:

Multiple linear regression analysis to test the effect of PWD's age, gender, general health issues, severity of dementia, use of walking aid, living arrangements, relationship with carer, and carer's QoL on PWD's QoL (N = 83).

Baseline variables	PWD's QoL			
	B	SE B	β	*p*
PWD Gender	-.02	.26	-.12	.31
PWD Age	.002	.001	.19	.09
Living arrangements	- .04	.04	-.12	.35
Use of walking aid	-.01	.02	-.06	.57
Relationship with Carer	-.08	.03	-.36	.02
Carer's QoL	.16	.09	.19	.09
PWD health issues	-.001	.01	-.008	.94
Severity of dementia	-.001	.002	-.06	.54
R^2	.17			
F	1.88			

p = .07

7.7.3 *Associations of carer's QoL*

Multiple linear regression was carried out to investigate the association of carer's age, gender, care burden, relationship with PWD, and PWD's QoL for carer's QoL. The regression model was found to be highly significant explaining 34% of the variance in carers' QoL at baseline. All variables had small non-significant associations except carer burden, which had a moderate and highly significant association ($p < .001$) with carers' QoL. Direction of all variables in the model was in expected direction (see table 33).

Table 33:

Multiple linear regression analysis to test the effect of carer's age, gender, care burden, relationship with PWD, and PWD's QoL on carer's QoL (N = 83).

Baseline variables	Carer's QoL			
	B	SE B	β	*p*
Carer's Age	-.002	.001	-.17	.12
Carer's Gender	-.02	.02	-.08	.41
Relationship with PWD	.03	.03	.13	.27
Carer burden	-.007	.001	-.52	.000
PWD's QoL	.18	.11	.16	.10
R^2	.34			
F	7.76			

$p < .001$

7.7.4 Association between PWD's Baseline QoL and their Adherence to Tai Chi Intervention

Pearson product moment correlation analysis was conducted to assess associations between PWD's baseline QoL and their adherence to Tai Chi intervention. PWD's QoL was measured in terms of their ICECAP-O total scores at baseline. PWD's adherence to Tai Chi intervention was measured in terms of minutes of attended Tai Chi classes, minutes of Tai Chi home-based practice, total minutes of Tai Chi practice (i.e., minutes of Tai Chi attended classes + minutes of Tai Chi home-based practice), percentage of attended Tai Chi classes against Tai Chi classes offered, and percentage of home-based Tai Chi practice against required time to practice.

PWD's baseline QoL was found to have small non-significant association with PWD's adherence to Tai Chi intervention. However, the associations were positive as expected. Moreover, PWD's adherence to Tai Chi class and home-based practice was found to have strong and highly significant association sharing 62% of the variance (see table 34).

Table 34:

Correlation of PWD's baseline QoL with their adherence to Tai Chi intervention and association of Tai Chi class and home-based practice (N = 42).

S. No	Variables	1	2	3	4	5	6
1	PWD's QoL	-	.10	.17	.16	.17	.21
2	Minutes of attended Tai Chi classes		-	.79**	.88**	.77**	.80**
3	Minutes of Tai Chi home practice			-	.98**	.59**	.98**
4	Total minutes of Tai Chi practice				-	.66**	.97**
5	% of attended Tai Chi classes					-	.62**
6	% of Tai Chi home practice						-

** Correlation is significant at .01 level.

7.7.5 Association between PWD's Adherence to Tai Chi Intervention and their Post Intervention QoL

Pearson product moment correlation analysis was conducted to assess associations between PWD's adherence to Tai Chi intervention and their QoL at follow-up. Association of PWD's (N = 42) Tai Chi adherence in terms of minutes of Tai Chi classes attended (r = .18; *p* = .29), minutes of home practice (r = .21; *p* = .19), percentage of attended Tai Chi classes (r = .27; *p* = .10), and home practice (r = .26; *p* = .12) with their QoL at follow-up in terms of their ICECAP-O was found to be small and non-significant. However, direction of associations was positive as it was expected in the study. Furthermore, PWD's baseline and post-intervention QoL was found to have moderate and highly significant association (r = .52; *p* < .001).

The TACIT trial has already found significant improvement in QoL of PWD in the intervention arm of the main trial (Nyman, 2019), however, no significant difference in carer's QoL in intervention arm was found. To evaluate specifically the effect of Tai Chi intervention on PWD's QoL a median split was carried out for adherence (home and class based) to Tai Chi intervention among PWD. Subsequently, post-intervention QoL of PWD in the intervention arm in the higher median split was compared with PWD's post-intervention QoL in the control arm. Independent sample t-tests were conducted. PWD's (n = 20) QoL was significantly higher in intervention arm home-based Tai Chi adherence (M = .89; SD = .08) as compared to that of PWD (n = 32) in the control arm (M = .80; SD = .13), t (50) = 2.67, *p* = .01 with large effect size *d* = .79 (Cohen, 1992). Likewise, PWD's (n = 21) QoL was significantly higher in intervention arm class-based Tai Chi adherence (M = .88; SD = .09) as compared to that of PWD (n = 32) in the control arm (M = .80; SD = .13), t (51) = 2.43, *p* = .01 with large effect size *d* = .68 (Cohen, 1992). The findings supported the study assumption that Tai Chi intervention improves PWD's QoL

7.7.6 Association between Carer's Baseline and Follow-up QoL and their Adherence to Tai Chi Intervention

Pearson product moment correlation was conducted to assess association between carer's (N = 42) baseline and follow-up QoL and their adherence to Tai Chi intervention in terms of percentage of Tai Chi classes they attended against the required number of classes to be attended. Carer's baseline (r = .14; *p* = .40) and follow-up QoL (r = .13; *p* = .41) had small non-significant association with their adherence to Tai Chi intervention. However, the associations were in the expected positive direction. Additionally, carers' baseline and follow-up QoL had strong and highly significant association (r = .77; *p* < .001).

To evaluate the effect of Tai Chi intervention on carers' QoL a median split was carried out for carers' adherence to class-based Tai Chi. Subsequently, to compare post-intervention QoL between groups independent sample t-test was conducted for high adherent carers' QoL in the intervention arm and that of carers in the control group. Carers' (n = 19) QoL in intervention arm was non-significantly higher (M = .80; SD = .12) than that of carers (n = 32) in the control arm (M = .78; SD = .11), t (49) = .59, *p* = .55 with small effect size (*d* = .17). The findings partially support the study assumption that Tai Chi intervention improves carers' QoL, as carers' post-intervention QoL was higher in intervention arm as compared to that of carers in the control arm, however, it was non-significant.

7.8 Discussion

The study aimed to explore baseline factors associated with PWD's and their carers' QoL. It also focused on the association between dyads' QoL and their adherence to Tai Chi intervention. It attempted to establish the effect of adherence to the Tai Chi intervention on QoL of dyads. PWD's relationship with carers (i.e., spouses or others) was found to be the most influential factor associated with their QoL, in that PWD' QoL was higher if supported by a spousal carer. Carers' QoL was mainly affected by carer burden. Moreover, PWD's and carers' baseline QoL was found to have a weak correlation with their home and class-based Tai Chi practice. Similarly, their home and class-based Tai Chi practice had a weak correlation with their post-intervention QoL . However, subsequent analysis indicated that dyads with a higher level of adherence to the Tai Chi intervention (as per median split) had higher reports of QoL among both PWD and their carer at post-intervention than those in the control arm.

It was expected in the present study that there would be a positive association between spouse carers and PWD's QoL which was supported by the study findings. The study findings are in agreement with previous results highlighting the positive association of spouse carers on PWD's QoL (Martyr et at., 2018). This may be because of spousal carers' better understanding of personalized factors of PWD's QoL due to being in a close relationship with them. Therefore, they may be contributing in PWD's QoL according to their personalized requirements and making them feel better about their QoL. As regards carers own QoL in context of their care giving experience, as expected carer burden was negatively associated with carers QoL. This support previous research which has found that higher carer burden is associated with compromised carer QoL (Srivastava et al., 2016; Contreras et al., 2021). This association is likely due to carers' feelings of helplessness (Santos et al., 2014) in controlling the clinical aspects of dementia progression as they cannot do anything about it despite all their input in care giving (Campbell et al., 2008). Carer burden keeps increasing with disease progression leading carers to feel helpless which in turn may affect their QoL. In the present study carer burden may have affected various aspects of carers' QoL which were measured e.g., love and friendship, thinking about the future without any concern, being able to do things that make one feels valued, enjoyment and pleasure, and independence. The caring responsibilities may have left very little time for carers themselves.

PWD's and carers' QoL at baseline had a positive but small and non-significant association with their Tai Chi practice. Although the direction of the association was in line with study expectations, the strength of the relationship was weak. Although no previous studies have examined the role of QoL in PWD's or their carers adherence to an exercise intervention, health related and general QoL has been reported to be an important contributing factor to exercise adherence among community dwelling older women and post stroke adults (Findorff et al., 2009; Tiedemann et al., 2012). Adherence to exercise programs is multifaceted. Previous work in the present thesis has found that health conditions of PWD and their carers are important factors to attendance adherence (see Study - II). The QoL measure used in the present study, however, was capability based, future research might explore different measurement instruments of QoL to explore their predictive validity to adherence to exercise programs. In addition, in the present study exercise was conducted in dyads. This means there was a dependency of the PWD on the carer to attend classes. Finally, the mode of exercise (tai chi in the present study), session duration, intensity and session frequency might all influence adherence to the program and need further exploration.

Tai Chi has been reported to have improved QoL among cognitively intact older adults (Wang et al., 2020). The TACIT trial has also reported significant improvement in QoL of PWD in the intervention arm of the main trial (Nyman, 2019), however, no significant difference in carer's QoL in intervention arm was found. Therefore, it was expected in the present study to have a positive association of PWD's and their carers' Tai Chi adherence with their post-intervention QoL. However, initial correlation analysis suggested Tai Chi practice to have a positive but small and non-significant correlation with their post-intervention QoL. Therefore, it was deemed necessary to further investigate the specific effect of adherence to Tai Chi intervention on QoL of PWD and their carers to fill the gap in the existing knowledge as specific effect of adherence to Tai Chi intervention on QoL of PWD and their carers had not been explored yet. Further exploration suggested positive effect of higher level of adherence to Tai Chi intervention on QoL of both PWD and their carers at follow-up. Findings of the present study are in line with the existing evidence indicating positive effect of Tai Chi on QoL of older adults (Tajik et al., 2018) and PWD (Nyman, 2019).

The present study explored various aspects of PWD's and their carers' QoL including factors associated with their QoL at baseline, its association with their adherence to Tai Chi intervention and effects of Tai Chi intervention on QoL of PWD and their carers. However, the present study had a number of limitations, which are as follows:

1. PWD's adherence to Tai Chi intervention was assessed in terms of their ratio of Tai Chi classes attended and that of Tai Chi practiced at home. However, Carers' adherence to Tai Chi intervention was considered only in terms of their ratio of attended Tai Chi classes due to unavailability of their home-practice data. Carers' adherence to Tai Chi intervention has shown to have a positive effect on carers' QoL in the intervention arm, however, the effect was non-significant. Their home practice data may have strengthened the findings. Therefore, future studies may focus on gathering more detailed exercise adherence data to augment the findings of the present study.

2. In addition to session adherence, it would also be important to examine the adherence to session objectives. Future studies could ask the instructors to rate participants engagement in each session. Such a measure has been shown to influence injury rehabilitation (Levy et al., 2008).
3. Multiple linear regression model that investigated association of PWD’s age, gender, general health issues, severity of dementia, use of walking aid, living arrangements, relationship with carer, and carer’s QoL on PWD’s QoL lacked power on a few variables e.g., there were only two out of 83 PWD who reported to be living alone, while only eight carers were offspring, six siblings, two friends and two others. This lack of power may have impacted the statistical analysis. Future studies might enhance the power for these variables.
4. Sample of the study involved mobile community dwelling PWD, who were able to do standing Tai Chi and were not wheelchair bound or had severe sensory disability. These limitations restrict generalization of study findings to those who do not meet these inclusion/exclusion criteria e.g., wheelchair bound or living in a care home or assisted residential facility.
5. There were 81 out of 83 dyads who had white ethnicity. a culturally more diverse sample may have contributed to uncover various cultural factors associated with adherence to Tai Chi intervention and QoL of the dyads (PWD + carers). Future studies may explore involvement of cultural aspects in adherence to exercise interventions and QoL among PWD and their carers.

Despite the limitations, the present study has provided findings that could be expanded on in future research. For example, future studies may arrange longer than 20 weeks Tai Chi intervention involving both home and class-class based practice components. Longer intervention may enhance adherence by facilitating participants to overcome the practical constraints, which may have hindered their participation. Higher level of adherence has been shown to have positive effect of PWD’s QoL in the present study which indicates a dose response effect, therefore, enhancing the dose i.e., adherence to Tai Chi intervention may result in enhanced QoL among PWD. Home-based Tai Chi practice along with Tai Chi classes has shown to have positive effect on PWD’s QoL, therefore, the same Tai Chi practice combination may be arranged for carers to benefit them. Factors contributing to Tai Chi adherence among PWD, and their carers may be explored to maximize their adherence and subsequently reap the benefits associated with Tai Chi practice. One of such factors was found in study-II of present PhD i.e., PWD’s and their carers’ health conditions, which largely affected their adherence to Tai Chi intervention negatively. Therefore, future intervention may be tailored as such to address the health issues of PWD and their carers to maximize their adherence to intervention. Carer burden has been found to have negative effect on QoL of carers, therefore, future policies and research may focus to reduce carer burden to improve their QoL and enable them to care for PWD more efficiently. An effective and well-organized system to provide respite to the carers to share their burden and to provide them some time for themselves may be of much value to enhance carers QoL.

Findings of present study may also be extended to future Tai Chi interventions to improve QoL of PWD in residential facilities and their carers who are trying to cope with the transitional phase of their loved ones may also use these findings. The findings may also benefit research attempting to investigate effect of carers’ relationship dynamics, carer burden, carer QoL, PWD’s living arrangements, their health and independence on their QoL and effect of caring experience on QoL of the PWD’s carers. Hence, present study has provided a pathway towards improvement in QoL of PWD and their carers.

7.9 Summary

It has been established in the present study that adherence to Tai Chi intervention has positive effect on general QoL of PWD and their carers. However, future studies may also explore effects of adherence to Tai Chi intervention on psychological and emotional well-being and health related QoL of PWD and their carers. Findings of present study may be used in research designs and policy formulation targeted at improving QoL of PWD and their carers.

8 Discussion

This chapter provides an overview of the main findings from each of the three studies conducted in this PhD thesis. It then discusses these findings collectively in relation to the main research question of does adherence to a Tai Chi exercise intervention improve QoL of community dwelling PWD and addresses the three research questions that underlie this: (1) Is the ICECAP-O (a capability based QoL scale for cognitively intact older adults), psychometrically valid for community dwelling PWD? (2) What factors affect adherence to a Tai Chi exercise intervention among community dwelling PWD? and (3) What factors affect QoL of community dwelling PWD and their carers? It highlights overall strengths, limitations, and implications of the present research, and then discusses recommendations for future research.

This novel research project attempted to validate a scale of actual attributes of QoL (ICECAP-O) for PWD, measure actual attributes of PWD's QoL, and assess how it is affected by adherence to an exercise intervention Tai Chi. In previously research, focus was not on studying QoL of PWD in context of its actual attributes or what PWD attribute as their QoL. Therefore, validating a QoL scale (ICECAP-O) for PWD, which measures actual attributes of QoL of older adults, and subsequently evaluating effect of adherence to a Tai Chi exercise intervention on QoL (measured by ICECAP-O) of PWD is a major contribution of the present study to the research field.

8.1 Study-I Findings: Validation of ICECAP-O as a QoL Measure for PWD

The main finding of study-I was that the ICECAP-O which was a capability based QoL scale for cognitively intact older adults, was found to be a valid and reliable measure of QoL of community dwelling PWD. It demonstrated good face validity and feasibility to administer, acceptable test-retest reliability, and Cronbach alpha level, and some evidence of construct validity among community dwelling PWD. The Confirmatory Factor Analysis (CFA) also showed a good fit. It has shown to be a valid and reliable measure to be directly used with community dwelling PWD as earlier only its proxy versions were validated with PWD (Sarabia-Cobo et al., 2017). These are the major contributions in research pertaining to measurement of QoL as there has been no capability based QoL scale available for community dwelling PWD which measures actual attribute of QoL (see section 8.4 for detail) directly with PWD. The existing QoL scales for PWD were either related to factors of QoL (e.g., Control, Autonomy, Self-realization, Pleasure Scale-19 (CASP-19) (Hyde et al., 2003), Older People Quality of Life scale (OPQOL) (Bowling, 2009)), health related QoL (European Quality of Life 5 Dimension (EQ-5D) (Mulhern et al., 2013)), or dementia specific QoL (Quality-of-Life Alzheimer's Disease (QoL-AD) (Logsdon et al., 1999, 2002)). Therefore, the present finding filled a significant gap in regard to measurement of QoL of community dwelling PWD.

8.2 Study-II Findings: Evaluation of adherence to Tai Chi exercise intervention among PWD

The main finding of study-II was that there was no uniformed pattern of Tai Chi exercise adherence among PWD. Adherence among them fluctuated in varied ways which was reflected in their absence from the classes. Among causes of absence, PWD and their carers' acute health issues were found to be strongly inversely associated with PWD's adherence to the Tai Chi exercise intervention. Examination of causes which affected completion rates gave a broader real-life picture of PWD's adherence to Tai Chi exercise intervention. PWD's and their carers' acute health issues which emerged during the intervention phase were also found to be the major cause of non-adherence/absence from Tai Chi exercise classes. Duration adherence (in terms of Tai Chi home practice pre-defined minutes/day for twenty weeks) was not evaluated in-depth in study-II, however, an association between percentage of class attendance and percentage of minutes of Tai Chi home practice was found to be strong positively associated. This may be because the causes of absence from the classes affected duration adherence in the same manner. However, this requires further exploration in future studies.

8.3 Study-III Findings: Effect of adherence to Tai Chi on QoL of PWD

In this study adherence to Tai Chi intervention among PWD was considered in terms of percentage of class attendance (attendance adherence) and percentage of minutes of Tai Chi home practice (duration adherence). However, for carers adherence was considered as percentage of class attendance only due to nonavailability of home practice data for carers. In this study association of baseline factors with QoL of PWD and their carers was also explored. QoL was measured in terms of actual attributes of QoL using ICECAP-O. The main findings of study-III included high rates of attendance adherence (69%) among PWD, a positive association of PWD and their spousal carers' QoL, and a negative association of carer burden with carer QoL. Moreover, PWD and carers with high adherence to the Tai Chi classes (in terms of median split) had significantly higher QoL at follow-up as compared to their counterparts in the control arm.

8.4 Overall Findings

In this section overall findings of the present research will be discussed in context of the main research question of does adherence to a Tai Chi exercise intervention improve QoL of community dwelling PWD?

QoL is a complex and multidimensional construct for which there is no universally acceptable definition (Selai & Trimble 1999; Ready et al., 2004; Walker & Lowenstein 2009). Hence, it has a wide range of assessment tools. Therefore, it has been recommended that a QoL scale must be selected according to the context in which it is being utilized as no

QoL scale may be considered unequivocally the best (Siette et at., 2021). Indeed, there is no QoL scale which can be considered suitable for all contexts. QoL measures for use with PWD are either health-related (e.g., EuroQol 5Dimensions (EQ 5D) (*EuroQol Group, 1990)* or for specific types of dementia (e.g., Quality of Life for Alzheimer's disease (QoL-AD) (Logsdon et al., 1999, 2002)). Health has been considered a means to attain QoL, not representative of QoL (Grewal et al., 2006). Therefore, Health related QoL (HrQoL) scales do not provide actual QoL measure for PWD. Likewise, dementia type specific QoL measures are not comparable with cognitively intact older adults. In the present PhD a person-centred approach towards PWD was adopted, which kept PWD at the centre of decision making regarding all aspects of their lives including care decisions (Douglas et al., 2018). Therefore, it was vital to select a QoL scale suitable for this approach.

Aguirre et al. (2016) investigated psychometric performance of HrQoL measure EQ-5D and dementia specific QoL measures QoL-AD and Dementia Quality of Life Scale (DEMQOL) (Smith et al., 2007) among PWD. They reported that all measures were found to be internally consistent and converged well with each other. However, EQ-5D was found to be reliable in its self-reported and proxy scores for mild to moderate level of dementia. Therefore, they suggested EQ-5D has advantage over dementia specific measures. However, in comparison to ICECAP-O, EQ-5D showed smaller variance for construct validity for older adults with mobility impairments (Davis et al., 2013). EQ-5D has earlier been used for PWD, however, ICECAP-O which has shown more psychometric strength for older adults in general has not been used for PWD. In addition, it is not a measure of HrQoL, due to which it has broader scope related to QoL. Therefore, its utilization for PWD has been considered more useful for them as it is more encompassing and representative measure. Siette et al. (2021) in their systematic review regarded ICECAP-O as more encompassing and person-centred focusing on emotional and subjective sentiment towards personal circumstances and levels of satisfaction regarding current physical health and higher-order needs such as love, independence, and control.

Furthermore, studies identified an increase in the development of dementia specific QoL scales after year 2000 (Siette et at., 2021; Garratt et al., 2002). However, later the trend shifted towards more encompassing but subjective and person-centred measures of QoL, as such after 2005 five out of nine developed scales of QoL were not dementia specific. This shift in the focus was due to consideration of QoL being a broader construct and not restricted to a specific disease (Siette et at., 2021).

In addition, there are generic QoL scales other than ICECAP-O available for older adults such as Control, Autonomy, Self-realization, Pleasure Scale-19 (CASP-19) (Hyde et al., 2003), Older People Quality of Life scale (OPQOL) (Bowling, 2009), and World Health Organization Quality of Life (WHOQOL) (WHOQOL Group, 2012). These generic QoL scales are mostly used with general older adult populations, however they all are relatively long and include factors rather than attributes of QoL, except ICECAP-O. For example, CASP has two versions CASP-19 (Hyde et al., 2003) and CASP-12 (Wiggins et al., 2008) having 19 and 12 items respectively. It has questions regarding health, shortage of money, and family responsibilities which restrict the individuals from the things they want to do. OPQOL has 32-35 items. Items are related to health, social relationships, home and neighbourhood, psychological and emotional well-being, financial circumstances, and leisure activities. The WHOQOL has 26 items, which relate to support from others, pain, medical treatment, physical environment, money to meet needs, activities of daily living, access to health services, transport, and negative feelings i.e., anxiety, depression, despair, blue mood. Longer questionnaires may become burdensome for PWD to complete. Moreover, factors of some of the QoL measures do not represent QoL (Grewal et al., 2006; Coast, Peters et al., 2008). Therefore, psychometric evaluation of ICECAP-O for community dwelling PWD is a major novel contribution of the present study in knowledge as it will allow assessment of actual attributes of QoL rather than factors associated with it. ICECAP-O has been validated as a self-reported measure for PWD in the present study rather than reliance on proxy reporting. Additionally, a brief and comprehensive measure of QoL for PWD has been validated which will be easy to administer and complete.

ICECAP-O as compared to the above-mentioned generic scales is brief and covers the capability-based dimension of QoL which are more intrinsic/personalized. It has a focus on those attributes of QoL which are regarded by older adults as the attributes of their QoL (Coast, Peters et al., 2008). Therefore, the attributes of QoL included in it have been based on the selection and subjective reporting of older adults. It also excludes factors affecting QoL assuming that factors may be responsible for QoL, but they do not constitute QoL (Grewal et al., 2006) (see section 2.3 for detail) It is informed by the preferences of older adults regarding constituents of their QoL. Hence, it is person-centred measurement, which implies more attention to the person than the external factors for their QoL. ICECAP-O is based on the capability theory of QoL by Sen (1993) which attributes individuals’ capabilities to function to their QoL (see section 2.3.1 for detail). Therefore, it along with its underpinning theory deemed suitable for the person-centred approach of the present PhD. Therefore, in the present research it was first psychometrically examined for PWD and afterwards utilized for assessment of QoL of PWD.

ICECAP-O was found to be a valid and reliable measure of QoL of community dwelling PWD. The findings support the study hypotheses. The present study has filled a major gap in the knowledge by validating a capability based QoL scale which measures actual attributes of QoL of older adults for community dwelling PWD. There was no QoL measure available for PWD which measures actual attributes of QoL prior to this PhD project. As such this PhD thesis makes a novel and unique contribution to the literature and provide researchers with opportunities to use ICECAP-O in future studies with community dwelling PWD.

The present research also aimed to examine the effect of adherence to Tai Chi exercise intervention on actual attributes of QoL of PWD (measured by using ICECAP-O). However, before assessment of effect of adherence to Tai Chi exercise intervention it was essential to explore whether PWD adhere to Tai Chi exercise intervention and what factors influence their adherence. There is lack of consensus on the definition of adherence to exercise intervention in older adults, neither is there uniformity in measurement of adherence to exercise interventions (Hawley-Hague et al., 2016).

Four different ways have been identified in which adherence to exercise interventions among older adults has been defined; i) completion (retention), ii) attendance, iii) duration, and iv) intensity adherence (Visek et al., 2011; Hawley-Hague et al., 2016). Completion (retention) adherence is defined as being part of the exercise intervention until the last class irrespective of number of classes missed. In completion adherence reasons for the absence are taken into consideration. Attendance adherence is defined in terms of actual attendance records or percentage of attendance of participants. Duration adherence is adherence to predefined time duration and intensity adherence is adherence to prescribed intensity exercise within or outside the exercise classes (Hawley-Hague et al., 2016). Each adherence concept is distinct from the others such as attending all exercise classes during an intervention may not equate with prescribed intensity or duration adherence (Visek et al., 2011). Moreover, characteristics of exercise programs or interventions relate to various aspects of adherence distinctly (Martin & Sinden, 2001; Hong et al., 2008). For example, Hong et al. (2008) in their meta-analysis reported that predictors of attendance differed from completion adherence among sedentary older adults.

Di Lorito et al. (2020) in their systematic review reported similar inconsistency in defining adherence to exercise intervention in PWD. They reported that only 20 out of 41 reviewed studies operationally defined adherence as percentage of participants' attendance, with one study defining adherence as percentage of personal goals attained by participants and remaining 20 studies did not define adherence. Hawley-Hague et al. (2016) also reported in their systematic review that most studies used percentage of class attendance as measure of adherence and few focused on exercise intensity in cognitively intact older adults. Despite the lack of consensus regarding a definition of adherence among older adults with or without dementia percentage of attendance has widely been considered as adherence to exercise intervention (Lorito et al., 2020; Hawley-Hague et al., 2016).

As each adherence definition represents a distinct concept (Visek et al., 2011) and relates differently to different exercise interventions (Martin & Sinden, 2001; Hong et al., 2008), therefore a viable option to define adherence is according to its relevance with the purpose/outcome of the research. Hawley-Hague et al. (2016) suggested to assess feasibility of an exercise program with attendance adherence, and health outcomes and gains with a combination of attendance, completion (retention), duration and intensity adherence. Therefore, in the present study adherence was defined in two different ways in accordance with the outcomes being measured. It was based on Frequency, Intensity, Type of exercise, and Time (duration) (FITT) principle for prescribing exercise (Burnet et al., 2019). In the study Tai Chi classes were offered in a uniformed manner in which Intensity (directed by instructor), Type of exercise (Tai Chi), and Time/ duration (45 minutes of active Tai Chi) (ITT) components of FITT were constant. Therefore, to examine PWD's adherence to Tai Chi exercise classes attendance adherence (percentage of class attendance/frequency) was used which was the best measure for Tai Chi exercise class adherence. However, an additional element of completion adherence, that of recording the causes of non-adherence/absence from classes was also included. Completion adherence was not followed completely as it was more relevant to the studies involving health outcomes (Hawley Hague et al., 2016). However, recording causes of absence from Tai Chi exercise classes along with percentage of attendance gave a clearer and more realistic picture of adherence to Tai Chi exercise intervention among community dwelling PWD. Therefore, the study not only informed about patterns of adherence among PWD but corresponding causes of non-adherence/absence. Among causes of non-adherence to Tai Chi exercise interventions PWD's and their carers' acute health conditions (which emerged during the intervention phase) were found to be the most recurrent and prominent cause. Findings of the present study are in line with the previous evidence regarding cognitively intact older adults and PWD in residential care. Picorelli et al. (2014) in their systematic review also identified that attendance to exercise interventions among older adults was affected by participants' health conditions. Participants with better health conditions in terms of fewer health issues, better self-reported health, and taking fewer medicines, had higher class attendance to exercise programs. Vseteckova et al. (2018) identified acute disease as one of the barriers to adhere to exercise programs among institutionalized PWD. Rivera-Torres et al. (2019) identified carers' health issues as a negative factor to PWD exercise adherence. The present research has added to knowledge by providing evidence regarding community dwelling PWD's and their carers' health issues as negative contributors in PWD's adherence to a Tai Chi exercise intervention. In previous research health issues of cognitively intact older adults (Rivera-Torres et al., 2019) and institutionalized PWD (Vseteckova et al., 2018) were found to be barriers in adherence to exercise intervention. However, there was a gap in knowledge because such evidence regarding community dwelling PWD was lacking, which has been provided in the present study. Hence, future exercise interventions should take PWD's and their carers' health issues into consideration and practical arrangements should be made to minimize the effect of such health constraints on adherence to the exercise intervention among PWD. Knowledge of determinants of adherence to exercise interventions will enhance implementation of future physical activity or exercise interventions.

Despite health constraints, overall attendance adherence rate among community dwelling PWD was found to be high with a mean attendance of 69% (SD = 29.95). Nyman, (2020) reported adherence to Tai Chi intervention among community dwelling older adults to be high, ranging from 71-81%. Considering adherence rate (71-81%) to Tai Chi intervention among cognitively intact older adults, a slightly lower adherence rate (69%) among PWD is expected. Moreover, Rolland et al. (2007) regarded attendance at more than two thirds of the sessions as high. Therefore, the attendance rate in the present study reflects that the Tai Chi exercise intervention was viable and engaging for PWD. The adherence rate in this study is in conformity with the previous research pertaining to exercise adherence among people with mild cognitive impairment and dementia (Lorito et al., 2020). Moreover, a strong positive association between PWD's exercise class attendance and Tai Chi home practice (duration adherence) was found. It indicates that PWD's class attendance corresponded to their Tai Chi home practice. It is contrary to previous research which reported higher adherence to supervised exercise programs than unsupervised exercise (Picorelli et al., 2014). It further strengthens the findings regarding viability of Tai Chi exercise intervention and PWD's interest in it as both adherence to supervised exercise classes and independent practice of Tai Chi at home was positively associated.

Moreover, to examine the effect of adherence to Tai Chi exercise intervention on QoL of PWD, adherence was measured as frequency ((F)component of FITT principle(Burnet et al., 2019)) in terms of percentage of Tai Chi class attendance and frequency and time/duration ((FT) components of FITT principle) for Tai Chi home practice (i.e., percentage of minutes practice against predefined minutes of Tai Chi home-practice). For class exercise as mentioned above the intensity, type of exercise and time (ITT) components were constant, therefore frequency or percentage of class attendance was most appropriate option. Whereas for Tai Chi home practice it was not possible to keep frequency, intensity, and time (duration) (FIT components of FITT) constant, only exercise type (Tai Chi) was constant because PWD practiced Tai Chi at home independently with accompanying carers. Therefore, frequency and time (duration) for Tai Chi home practice were measured and multiplied then its percentage calculated against predetermined required minutes of home practice. Hawley-Hague et al., (2016) recommended using a combination of adherence measurements made up of attendance, duration, completion, and intensity, for health outcome assessment. Although this outcome (QoL of PWD) of the present study was not health related, it does pertain to PWD’s overall well-being and whether Tai Chi exercise intervention affects it in some way. Therefore, inclusion of both attendance percentage/ frequency and duration adherence was relevant. Intensity adherence could not be included because the study design did not include adherence to a pre-defined intensity of exercise. In addition, the use of heart rate monitors would be invasive whereas the use of subjective rates of perceived exertion scales (RPE) is problematic in PWD (Bevan, Vidoni, & Watts, 2020). Completion adherence was not included because exclusion of data of the participants who withdrew from the study after attending considerable number of sessions would compromise valuable data from those participants. Moreover, excluding the withdrawn participants from analysis would result in smaller sample size which would compromise the power of the findings. As regards effect of adherence to Tai Chi exercise intervention on QoL of PWD’s carers only attendance adherence (percentage of Tai Chi classes attended) could be included due to non-availability of duration adherence (home practice) data for them. The present study found that highly adherent PWD and carers had higher QoL at follow-up than their control arm counterparts.

8.5 Novel Contribution

This thesis provides a number of novel contributions to the literature. First, it provides evidence for the use of a capability based QoL scale (ICECAP-O) for community dwelling PWD and their carers. In addition, it provides new information on correlates of adherence to exercise intervention for this population. Thirdly, it provides information on the association between exercise adherence and QoL.

Validation of ICECAP-O is a major contribution in QoL assessment among community dwelling PWD. It has filled a significant gap in knowledge. Moreover, the present research is first to examine the actual attributes of QoL among PWD by using ICECAP-O and first to evaluate the effect of adherence to Tai Chi exercise intervention on QoL of PWD and their carers. It has produced evidence of positive effect of Tai Chi exercise intervention on actual (representative) attributes of QoL of PWD and their carers. Identification of viability of Tai Chi exercise intervention among community dwelling PWD in terms of overall attendance rate (69%) is also a novel contribution of present research. The present research has rendered new information pertaining to a negative contribution of health issues for community dwelling PWD and their carers in adherence to an exercise intervention, Tai Chi, adding to existing knowledge.

8.6 Practical Implications

The present research has the following practical implications:

1. ICECAP-O a capability based QoL scale which is more representative of QoL may be used in evaluation of QoL of community dwelling PWD. It will provide a more encompassing and broader measurement of their QoL. It may also be useful in policy formulation pertaining to QoL of community dwelling PWD as it will provide

information about PWD’s perception of their actual QoL without restricting them to health related, dementia related, or contributing factors-based QoL.

2. Community based supervised Tai Chi exercise classes may be offered to community dwelling PWD and their carers as it has been shown to be viable for PWD and positive for QoL of PWD and their carers.
3. Health practitioners, and researchers may encourage PWD and their carers to practice Tai Chi to improve their QoL.
4. Health care providers and policy makers may make Tai Chi classes a part of the health care plan of PWD and their carers as it has shown to have affected QoL of PWD and their carers positively.

8.7 Strengths

The present PhD has a number of strengths such as:

1. Complete data for study-II, and III, while partial data for study-I was derived from the TACIT trial, which was a very robustly conducted RCT. Its data was collected in a systematic way by trained staff. The data was collected manually in structured interview format, then double data-entered in the TACIT database, to ensure rectification of any errors processing. Therefore, there was great confidence in the reliability and validity of the trial data.
2. All tools used to collect the data were standardized and data collection settings before and after the intervention phase were almost same, if there were any changes they were also recorded. All the measurement tools/scales were selected keeping the study population in consideration to make it easy for them to provide data and not to make it complicated or laborious for them. Therefore, the evidence based on the TACIT trial data was of the highest quality.

3. Additional data of study-I, other than that of the TACIT trial was derived from the local community. It had sufficient sample size to warrant reliability, validity, and CFA for ICECAP-O.
4. Recruitment of dyads was another strength, which increased credence of the findings as data of adherence to Tai Chi intervention and QoL was not collected from PWD in isolation, rather it was collected in real life setting together with their carers. As the centrality of carers in ensuring adherence to exercise intervention and reporting the actual adherence data has been highlighted (Di Lorito et al., 2020), and QoL of carers have been reported to be intertwined with the PWD (Farina et al., 2017), therefore, the present evidence was authentic and robust as it involved carers of PWD.
5. Adherence to Tai Chi exercise intervention was clearly defined, which makes it comparable for future exercise interventions aiming at adherence among PWD and their carers.
6. Tai Chi exercise was offered in group format by professional Tai Chi instructors which is a suggested method to design exercise intervention for PWD as it has been found to be associated with higher adherence among them (Di Lorito et al., 2020).

8.8 Limitations

Despite the strengths and positive contributions of the present PhD to existing knowledge. It had a number of limitations as well which are as follows:

1. The PhD was restricted to community dwelling PWD, therefore, the findings cannot be generalized to residents of care homes, those with compromised movement e.g., wheelchair bound or having any severe sensory impairment e.g., visual or hearing impairment.

2. There was a small fraction of sample who were non-English due to which it lacked cultural diversity therefore, study findings cannot be generalized to other cultures.
3. Locale of the PhD was restricted to Wessex region of United Kingdom and the population was difficult to recruit due to their health, age, and challenging life circumstances, which resulted in relatively small sample. Larger sample may have resulted in more robust findings.
4. Sample was recruited as dyads (i.e., PWD + carers) due to which PWD's adherence to intervention became dependent on carers continuous participation. Therefore, in some cases carers' health conditions also affected adherence of PWD. Recruiting more than one carers with each PWD to provide replacement for each other may have helped to overcome some practical constraints which prohibited PWD from adherence.
5. Tai Chi intervention offered 20 weeks of classes, therefore, PWD who missed Tai Chi classes either due to their or their carers' health conditions or any other unforeseen circumstances could not be offered compensatory additional classes. Due to such design restriction those participants who were even willing to attend maximum classes could not avail the opportunity, which also affected evaluation of effect of adherence to Tai Chi intervention on their QoL.
6. PWD's adherence to Tai Chi intervention was considered in terms of Tai Chi class and home-based practice. However, carers' adherence was considered in terms of Tai Chi class practice only, which may have restricted carers' from benefitting from Tai Chi intervention to the fullest.
7. BCTs are reported to support exercise adherence among PWD and cognitively intact older adults (Van der Wardt et al., 2017), however, due to TACIT trial design restrictions it was not possible to evaluate the effects of BCTs on adherence to class-based Tai Chi intervention.

8. Instructors are found to have positive effect on exercise adherence among PWD (Van der Wardt et al., 2017; Vseteckova et al., 2018), however, in the present study only effect of instructors' gender on adherence to Tai Chi intervention among PWD could be evaluated.
9. Study-II evaluated baseline factors associated with adherence to Tai Chi intervention among community dwelling PWD with multiple linear regression analysis being conducted to examine the associations. Participants only from intervention arm (N = 42) were included as adherence to Tai Chi exercise was being examined. TACIT trial design placed a few restrictions to the approach adopted in this study. Participants in TACIT trial intervention arm (N = 42) restricted number of predictive variables to only four for adherence to Tai Chi class exercise among PWD. As a rule of thumb 10 participants per variable were required for regression analysis (VanVoorhis & Morgan, 2007). Had the sample been larger predictive value of more variables e.g., gender, long term health conditions other than dementia, living with family and friends or alone, confidence (self-efficacy) may have been explored.

8.9 Future Research

Future research may attempt to validate ICECAP-O for PWD in care homes or residential facilities. In addition, Tai Chi exercise intervention may be conducted at a larger scale (multisite) across a larger geographical area. This will provide opportunity to recruit larger samples which will facilitate understanding of predictors and factors associated with adherence to exercise intervention in PWD. Such larger studies could also examine the influence of the instructor or class size on selected variables including enjoyment.

PWD's and carer's health issues which in the present study were found to be a major cause of non-adherence to Tai Chi exercise intervention may be considered at the planning phase of exercise interventions to enhance their exercise adherence. Behaviour Change Techniques (BCTs) may be incorporated in exercise interventions to improve adherence among PWD. Nyman et al. (2019) reported that BCTs involving cognitive processes may not be effective for PWD due to their cognitive impairment. Therefore, they suggested inclusion of non-cognitive BCTs including implicit behaviour learning (which does not involve cognitive processes), behaviorist approach or choice architecture (which involves encouraging people to choose healthy behaviors) or cognitive strategies may be adopted along with partnership of carers to reap the benefits of BCTs to promote physical activity among PWD. The role and characteristics of the instructor in facilitating adherence to exercise intervention among PWD may also be explored in detail. Home-based Tai Chi practice may also be included in future studies for carers of PWD as it has shown to have a positive effect on QoL of PWD therefore, it may be extended to carers of PWD as well. Interventions longer than twenty weeks may provide an opportunity to attend exercise intervention to those who have missed the exercise classes or practice due to practical reasons. Exercise interventions may make alternative class arrangements to compensate for the exercise sessions missed due to genuine reasons such as health issues. Some PWD missed Tai Chi classes due to their carers health issues as well, therefore, future dyadic exercise interventions may have more than one carers recruited to support PWD alternately in case of non-availability of one. Longer than 20 weeks exercise interventions for community dwelling PWD may compensate for the missed exercise classes and facilitate adaptation to exercise behaviour to reap its benefits. Previous studies suggest that the first six months are important for older adults to attend to exercise classes (Stigglebout, Hopman-Rock, Crone, Lecher, & Van Mechelen, 2006). It will change their attitude towards exercise and develop commitment to exercise if their expectations are met (Hawley-Hague et al., 2013). However, it is also evident that older adults discontinue participation in an exercise program within the first six months (Jancey et al., 2007). Therefore, future studies may pay attention to designing at least six months long exercise interventions and ensure maximum overall attendance of participants to improve adherence and subsequent benefits.

8.10 Summary

The present research made novel contributions in knowledge by providing evidence of i) good psychometric properties of ICECAP-O, ii) viability of Tai Chi exercise intervention, iii) barriers in adherence to Tai Chi exercise intervention among community dwelling PWD, and iv) positive effect of adherence to Tai Chi exercise intervention on QoL of PWD and their carers. The evidence filled the major gaps in knowledge regarding assessment of QoL, and adherence to a Tai Chi exercise intervention among community dwelling PWD, and positive effect of adherence to Tai Chi exercise intervention on QoL of PWD and their carers. The findings will be helpful for future research and policy regarding assessment of QoL of community dwelling PWD and improvement in QoL of PWD and their carers. Next chapter will provide a complete summary of this research.

9 Conclusion

The aims of the present PhD were to validate a scale that measures actual attributes of QoL, identify factors that affect adherence to a Tai Chi intervention and QoL of PWD and their carers, and assess the effect of adherence to a Tai Chi exercise intervention on the QoL of PWD and their carers. To measure QoL, the ICECAP-O was selected as it measures actual attributes of QoL of Life (Coast, Peters et al., 2008). Existing QoL measures for PWD were either health-related or only focused on factors associated with QoL instead of measuring actual attributes of QoL. The ICECAP-O was already validated for use with older adult population (Coast, Peters et al., 2008) however, it was not validated for PWD. Therefore, to utilize it in the present PhD it was validated at first and subsequently used with PWD and their carers as well to assess their QoL. It was found to be a valid and reliable measure of QoL for community dwelling PWD. Adherence to Tai Chi intervention was considered in terms of percentage of Tai Chi classes attended and Tai Chi home practice during the 20 weeks intervention period. Health conditions of PWD and their carers was found to be a major factor negatively affecting adherence to Tai Chi intervention among PWD. Higher level of adherence to Tai Chi intervention was found to have a positive effect on the QoL of PWD and their carers. Moreover, spousal carers were found to be major positive contributor in PWD's QoL and carer burden was major negative contributing factor in carers' QoL.

The present PhD was divided into three sub studies to achieve its aims. Study-I aimed to validate the ICECAP-O for PWD. ICECAP-O was found to have good face validity in terms of participants' readability and comprehension of the scale, and it was feasible to administer with 100% completion rate and no difficulty reported by participants while completing the scale. Study sample was diverse in terms of their educational background and severity of dementia (i.e., M-ACE) scores. The findings provided good evidence that the scale is comprehensible, and feasible to administer with community dwelling PWD with diverse attributes. ICECAP-O was also found to have acceptable internal and test re-test reliability. There was some evidence of its construct validity in terms of convergent and discriminant validity. The Confirmatory Factor Analysis showed a good fit as well. ICECAP-O as a valid measure of QoL among community dwelling PWD will be very useful in future research related to QoL of PWD as it has four advantages highlighted by Nyman et al. (2021) over other existing QoL scales for PWD: 1) it is a brief measure of QoL having only five items which makes it quick and easy to complete by PWD; 2) each of its items measure a separate attribute of QoL identified as important by older adults; 3) it can be self-reported by PWD and so avoid proxy bias; and 4) as a generic scale its scores are comparable to those of cognitively intact older adults. Therefore, its validation is a valuable addition in the existing measures of QoL of PWD.

Study-II aimed to explore patterns, predictors, and factors of adherence and causes of non-adherence to Tai Chi intervention among PWD. Adherence was considered in terms of percentage/frequency of Tai Chi classes attended during the 20 weeks intervention phase. Non- adherence was considered in terms of absence from Tai Chi classes. Additionally, association between home-based and class-based Tai Chi practice was also explored. PWD's overall or incremental increase in adherence session wise did not reflect any specific patterns. Likewise, group adherence also shown to have randomly increased and decreased around sessions 5-8 and 15-18. Causes of these changes in group adherence patterns were unknown, which warrants further exploration of patterns of group adherence to Tai Chi intervention among PWD in future research. Moreover, at baseline physical activity of PWD was found to be a major predictor of adherence.

During the intervention phase the major cause of non-adherence was found to be PWD and carers health conditions. Health related issues of PWD and their carers were also found to be inversely related to PWD's adherence to Tai Chi intervention. The study population was vulnerable with complex health issues (Desai et al., 2012), which affected their adherence to Tai Chi intervention. Additionally, the sample was recruited as dyads, therefore, PWD's attendance of Tai Chi classes was largely dependent on carers attendance. Carers' extended non-attendance due to their health issues would have affected PWD adherence negatively. However, PWD's adherence to Tai Chi classes and home-based Tai Chi practice was found to be strongly associated in a positive direction. Moreover, PWD's intention and confidence to come to Tai Chi classes mid-way intervention phase was found to be inversely associated with their adherence to Tai Chi classes. It may either be due to self-reporting bias of PWD or any unforeseen circumstances which PWD were unaware of at the time of reporting. The intention-behaviour gap to participate in physical activity was reported to be 46% among older adults (Rhodes & de Bruijn, 2013). This highlights investigation of intention-behaviour gap to participate in exercise intervention among PWD as well.

Identification of health conditions of PWD and their carers as a main factor inversely affecting adherence to Tai Chi intervention among PWD was a major contribution to knowledge regarding factors associated with adherence to exercise interventions among PWD. Previous evidence suggested a positive association between good health and adherence to exercise among cognitively intact older adults (Rivera-Torres et al., 2019; Picorelli et al., 2014; Findorff et al., 2009). However, there was gap in the knowledge regarding association of good health or health condition with adherence to exercise intervention among PWD. Therefore, the present findings have added to knowledge in this regard. The finding will help to enhance PWD's adherence to exercise interventions in future as health conditions have been found to be major factor affecting adherence among PWD negatively. By keeping these conditions in consideration arrangement of compensatory classes can maximize adherence to exercise interventions among PWD.

Study-III aimed to explored factors associated with QoL of PWD and their carers, association of baseline QoL of PWD and their carers with their adherence to Tai Chi intervention, association of adherence to Tai Chi intervention with their QoL at post-intervention, and effect of higher level of adherence to Tai Chi intervention on QoL of PWD and their carers. Adherence for PWD was considered in terms of percentage of class attendance and that of home-based practice. Adherence for carers was in terms of percentage of class attendance only. Among factors affecting QoL of PWD, spousal carers were found to have a positive association. This may be due to awareness of spousal carers of the care needs of PWD and providing them care accordingly enhancing their QoL. QoL of carers was mainly affected by carer burden. This may be because of being excessively indulged in caring responsibilities and being left with lack of personal time and activities associated with QoL. Moreover, correlational analysis indicated small non-significant associations of baseline QoL with adherence and that of adherence with QoL at post-intervention among both PWD and carers. Association of QoL with adherence may be small and non-significant due to exercise adherence being a complex and multifaceted phenomenon, involving various factors. As it was highlighted in study-II of the present PhD that health conditions of PWD and their carers affected adherence to Tai Chi intervention negatively. Therefore, QoL was not found to have a strong significant association with adherence of participants to Tai Chi intervention. Likewise, small, and non-significant association of adherence to Tai Chi intervention may be due to skewed distribution, however, further median split analysis suggested positive affect of higher level of adherence to Tai Chi intervention on QoL of both PWD and their carers may be by adjusting the skewed distribution. Identification of positive effect of higher adherence on QoL of PWD and their carers is a vital addition in knowledge regarding QoL of PWD and their carers. The findings highlighted that Tai Chi could be a great contributing factor in improving QoL of PWD and their carers. Therefore, it may be utilized in research and policies pertaining to improvement in QoL of PWD and their carers.

9.1 Personal Impact

The approach adopted in the present thesis was post-positivism which required a neutral and impartial role of the researcher during data collection and data analysis procedures. Data collection and analyses were carried out objectively using objective measures and statistical procedures, including a small component of the thesis in which readability and comprehension of the QoL scale was assessed. Participants in this component of the study were asked to read out each item of the scale and response options aloud and tell what they understood from it. During these interviews the researcher remained as a silent observer without interrupting or giving any cues to interpret the items. The researcher maintained her impartiality and neutrality. It was ensured that the researcher would not impact the data collection or analysis process in any way.

For data collected in the RCT, the researcher was blind to the treatment the participants received (i.e., allocation into control or intervention arm), therefore the researcher bias was not involved in the data collection or analyses processes. However, having taken all the measures to ensure objective, unbiased, and neutral conduction of the research the researcher might have had some personal impact on the participants. The researcher having the background of clinical psychology had an empathic understanding and listening skill to make the participants comfortable during data collection sessions. This may have impacted them positively and motivated them to continue in a relaxed manner. Pre- and post-intervention data collection sessions on average took two hours each, during which the data was collected through forms, questionnaires, and performance tests, which were recorded objectively. However, the participants informally talked about their life experiences or things they liked to discuss. The data collection sessions seemed to be an opportunity for them to be heard, understood, and reassured that their self-hood is of core importance. It was not a hectic exercise or monotonous activity. All participants enjoyed the data collection sessions and expressed their appreciation for the researcher for making it a pleasant experience. Another researcher conducted focused groups for her PhD in which opinions from participants were taken about their experience during data collection sessions. The participants provide positive feedback on the data collection process. This reflects that the researcher made a positive impact on participants during her interaction with them, which may have encouraged or motivated them to continue.

9.2 Future Research Directions

Future studies may focus on extending the study design to various PWD populations such as those residing in care homes, with severe sensory motor impairments, or wheelchair bound. Culturally and educationally more diverse population may be recruited by expanding the locale of the study. BCTs may be utilized to enhance adherence to class and home-based Tai Chi intervention (Borek et al., 2019). If participants have to be recruited as dyads (i.e., PWD along with their carers) it is better to recruit more than one carers who may replace one another in case of any unforeseen circumstances to avoid interruption in PWD’s adherence to intervention. Interventions may consider health conditions of PWD and their carers as a vital factor negatively affecting adherence to intervention, therefore, compensatory additional exercise sessions may be arranged for the participants. Effect of home-based Tai Chi practice on QoL of carers may also be explored. As higher adherence to Tai Chi intervention has shown to have positive effect on QoL of participant in the present study, therefore, factors which may contribute enhancing adherence to Tai Chi intervention may be explored including objective (such as conditions of Tai Chi class venues, and area of home where Tai

Chi is practice) and subjective factors (for example characteristics of Tai Chi instructor, carers, and group to which PWD is part of).

9.3 Practical implications

Findings of present PhD may be extended to research linked to QoL of community dwelling PWD and their carers. As a QoL scale ICECAP-O involving actual attributes of QoL has been validated, which may be useful for policy formulation and research designs concerning QoL of community dwelling PWD. Moreover, carer burden has been found to have negative effect on carers' QoL, which could be counter affective for PWD's QoL, therefore, policies and research may focus on exploring ways to reduce carer burden to enable them to provide care to their loved ones efficiently. The findings may also be utilized in exploring factors and predictors associated with QoL of PWD and their carers. The study may also benefit research involving predictors and facilitators of adherence to Tai Chi intervention among PWD, which may help in improving adherence to Tai Chi intervention and reaping benefits associated with it.

Future exercise interventions aiming to improve QoL of PWD and their carers may focus on arranging longer than 20 weeks intervention. Because physiological adaptations to exercise take longer among older adults it is likely that longer interventions might better improve their physiological and physical capacity (e.g., McPhee et al., 2016). This in turn might have greater effect on their QoL. In addition, interventions of longer duration have been shown to result in long-term behaviour change (Middleton et al., 2013). Recruitment of participants as dyads (i.e., PWD + their carers) in exercise interventions will be useful as carers not only assist and facilitate PWD in adhering to intervention (Peach et al., 2017), but they personally benefit from the intervention as well. In addition to class attendance and minutes of home-based exercise practice per week, it will be useful to set objectives of each exercise session and each week of home practice. Instructors must keep a record of objectives achieved by the participants in exercise classes and home-practice given that specific, measurable, attainable, relevant, and time bound goals have been suggested to increase adherence among PWD (Lorito et al., 2020). Moreover, interventions may include group formats as they have been found to be positively associated with exercise adherence among PWD may be due to an opportunity to socialize, compete, or follow role models (Di Lorito et al., 2020). It may also give carers a chance to feel free from the caring responsibilities and social inclusion for both PWD and the carers, as they can see PWD independently participating along with them in the same activity (Camic et al., 2013).

9.4 Summary

Findings of the present PhD are a novel contribution in existing knowledge. QoL of PWD and their carers have been studied extensively. A scale which measures actual attributes of QoL has been validated for PWD, previously no such measure of QoL was available for PWD. Therefore, it was a valuable addition in previously available measures of PWD’s QoL. Factors associated with QoL of PWD and their carers were also explored which augmented the previous findings for example spousal carers have positive effect on PWD’s QoL as compared to all other carers and carer burden has negative effect on carers’ QoL. Likewise, evaluation of factors associated with adherence to Tai Chi intervention highlighted general health conditions of PWD and their carers as a major negative factor affecting adherence to Tai Chi intervention among PWD. The PhD will be a positive contribution in improving QoL of community dwelling PWD in the times to come. Because a QoL scale which measure actual attributes of QoL has been validated for PWD for the first time, which can be used to measure improvement in QoL of PWD in intervention studies. Likewise, a promising Tai Chi intervention to improve QoL of PWD and their carers has been identified, which is a valuable addition in the existing interventions aimed at improving QoL of PWD and their carers.

Moreover, health conditions of PWD and their carers were identified as a major negative contributing factor in adherence to Tai Chi intervention among PWD, once addressed effectively it will help to promote adherence among PWD and enable them to benefit from interventions. Likewise, carer burden was found to affect carers' QoL negatively, which highlighted the need to reduce carer burden to improve their QoL.

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Appendices

Appendix A. ICECAP-O Scale

Quality of Life Assessment

By placing a tick (✓) in ONE box in EACH group below, please indicate which statement best describes your quality of life at the moment.

1. Love and Friendship

I can have **all** of the love and friendship that I want ☐

I can have **a lot** of the love and friendship that I want ☐

I can have **a little** of the love and friendship that I want ☐

I cannot have **any** of the love and friendship that I want ☐

2. Thinking about the future

I can think about the future **without any** concern ☐

I can think about the future **with only a little** concern ☐

I can only think about the future **with some** concern ☐

I can only think about the future **with a lot** of concern ☐

3. Doing things that make you feel valued

I am able to do **all** of the things that make me feel valued ☐

I am able to do **many** of the things that make me feel valued ☐

I am able to do **a few** of the things that make me feel valued ☐

I am unable to do **any** of the things that make me feel valued ☐

4. Enjoyment and pleasure

I can have **all** of the enjoyment and pleasure that I want ☐

I can have **a lot** of the enjoyment and pleasure that I want ☐

I can have **a little** of the enjoyment and pleasure that I want ☐

I cannot have **any** of the enjoyment and pleasure that I want ☐

5. Independence

I am able to be **completely** independent ☐

I am able to be independent in **many things** ☐

I am able to be independent in **a few things** ☐

I am **unable** to be at all independent ☐

Appendix B: Ethics Approval for ICECAP-O Validation Study.

Bournemouth University

Research Ethics Checklist

Reference Id	13879
Status	Approved
Date Approved	16/06/2017

Researcher Details

Name	Iram Bibi
Faculty	Faculty of Science & Technology
Status	Postgraduate Research (MRes, MPhil, PhD, DProf, DEng)
Course	Postgraduate Research - FST
Have you received external funding to support this research project?	No

Project Details

Title	Psychometric validation of ICEpop (Investigating choice experiment for preference of older people) CAPability measure for Older people (ICECAP-O) for people with Dementia
Proposed Start Date of Data Collection	17/04/2017
Proposed End Date of Project	31/07/2019

Original Supervisor	Samuel Nyman
Approver	Research Ethics Panel

Summary - no more than 500 words (including detail on background methodology, sample, outcomes, etc.)
see attached document

External Ethics Review

Does your research require external review through the NHS National Research Ethics Service (NRES) or through another external Ethics Committee?	No

Research Literature

Is your research solely literature based?	No

Human Participants

Will your research project involve interaction with human participants as primary sources of data (e.g. interview, observation, original survey)?	Yes
Does your research specifically involve participants who are considered vulnerable (i.e. children, those with cognitive impairment, those in unequal relationships—such as your own students, prison inmates, etc.)?	Yes
Is a DBS check check required?	Yes
Does the study involve participants age 16 or over who are unable to give informed consent (i.e. people with learning disabilities)? NOTE: All research that falls under the auspices of the Mental Capacity Act 2005 must be reviewed by NHS NRES.	No
Will the study require the co-operation of a gatekeeper for initial access to the groups or individuals to be recruited? (i.e. students at school, members of self-help group, residents of Nursing home?)	Yes

Will it be necessary for participants to take part in your study without their knowledge and consent at the time (i.e. covert observation of people in non-public places)?	No
Will the study involve discussion of sensitive topics (i.e. sexual activity, drug use, criminal activity)?	No

Are drugs, placebos or other substances (i.e. food substances, vitamins) to be administered to the study participants or will the study involve invasive, intrusive or potentially harmful procedures of any kind?	No

Will tissue samples (including blood) be obtained from participants? Note: If the answer to this question is 'yes' you will need to be aware of obligations under the Human Tissue Act 2004.	No

Could your research induce psychological stress or anxiety, cause harm or have negative consequences for the participant or researcher (beyond the risks encountered in normal life)?	No
Will your research involve prolonged or repetitive testing?	No
Will the research involve the collection of audio materials?	Yes
Is this audio collection solely for the purposes of transcribing/summarising and will not be used in any outputs (publication, dissemination, etc.) and will not be made publicly available?	Yes
Will your research involve the collection of photographic or video materials?	No
Will financial or other inducements (other than reasonable expenses and compensation for time) be offered to participants?	No

Please explain below why your research project involves the above mentioned criteria (be sure to explain why the sensitive criterion is essential to your project's success). Give a summary of the ethical issues and any action that will be taken to address these. Explain how you will obtain informed consent (and from whom) and how you will inform the participant(s) about the research project (i.e. participant information sheet). A sample consent form and participant information sheet can be found on the Research Ethics website.
The research is related to the psychometric validation of a capability based Quality of Life scale ICECAP-O for people with dementia therefore the sample must involve people with dementia which is a form of cognitive impairment. However only those participants will be included in the study who have the mental capacity to consent to participate. The researcher will assess the capacity of participants to consent in the light of Mental Capacity Act 2005 description of the person having capacity to consent. In addition to that Audio recording will be used during the qualitative interviewing of people with dementia in order to examine their understanding and readability of the ICECAP-O scale, which has shown to be valid for the general older population but has not been validated for people with dementia. The audio recording of the qualitative interviewing will help us determine content validity and readability of the scale for people of dementia without which a scale cannot be considered valid for the targeted population. In case of data collection from participant's home the researcher will provide detailed information about the address and contact details of participant to the supervisor and will remain in contact via mobile phone with her supervisor during lone working. The lone working protocol will be followed

Final Review

Will you have access to personal data that allows you to identify individuals OR access to confidential corporate or company data (that is not covered by confidentiality terms within an agreement or by a separate confidentiality agreement)?	No
Will your research involve experimentation on any of the following: animals, animal tissue, genetically modified organisms?	No
Will your research take place outside the UK (including any and all stages of research: collection, storage, analysis, etc.)?	No

Please use the below text box to highlight any other ethical concerns or risks that may arise during your research that have not been covered in this form.
The study may involve lone working for data collection in some cases where it is not feasible for the participants to come to the University. In that case lone worker protocol (attached) will be followed to avoid any possible risks.

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

Appendix C. Participant Demographic Sheet for ICECAP-O Validation Study

Psychometric validation of ICECAP-O for people with Dementia.

ADRC
Ageing & Dementia
Research Centre
Bournemouth University

Participant Demographic Sheet

Participant Number ☐☐☐

1. Are you a male or female?
   - a. Male ☐
   - b. Female ☐

2. What is your date of birth? ______________________

3. Which best describes your current situation?
   - a. Living alone ☐
   - b. Living with family/ friends ☐
   - c. Living in sheltered housing ☐

4. What was your highest level of education?
   - a. None ☐
   - b. Primary ☐
   - c. Secondary ☐
   - d. Higher education college / university ☐
   - e. Further education / professional qualification ☐

5. Which best describes your ethnicity?
   - a. White ☐
   - b. Asian ☐

c. Black ☐
d. Mixed ☐
e. Chinese ☐
f. Other European ☐
g. Any other ☐

6. What type of dementia have you been diagnosed with?
    a. Alzheimer’s ☐
    b. Vascular ☐
    c. Mixed Alzheimer’s & Vascular ☐
    d. Other*: ☐
    e. *Please specify: ____

7. When were you diagnosed with dementia? Provide month and year as accurately as possible:

Month: ________________________ Year: ___________

Appendix D. Participant Informed Consent Form for ICECAP-O Validation Study

Title of project: Quality of life questionnaire for people with Dementia

Researcher: Iram Bibi, Postgraduate Researcher, Bournemouth. Contact number 07801890259. Email address: ibibi@bournemouth.ac.uk

Supervisor: Dr Samuel Nyman, Department of Psychology and Ageing & Dementia Research Centre, Bournemouth University, email address: snyman@bournemouth.ac.uk

Please Initial

I have read and understood the participant information sheet for the above research project.	
I confirm that I have had the opportunity to ask questions.	
I understand that my participation is voluntary.	
I understand that I am free to withdraw up to the point where the data are processed and become anonymous, so my identity cannot be determined.	
During the task I am free to withdraw without giving reason and without there being any negative consequences.	
I understand that there are two different parts of the study; questionnaire-based part, and interview-based part.	
I understand that I can take part in any one part of the study or both the parts collectively.	
I understand that if I agree to participate in the interview-based part of the study my interview will be audio recorded.	
I understand that if I agree to participate in the questionnaire-based part of the study I will have to commit for two separate data collection sessions with an interval of two weeks.	
I understand that if I agree to take part in both the interview and questionnaire-based parts of the study I will complete few forms and an interview (audio recorded) in first session and I will participate in the second session after two weeks to complete only one questionnaire.	
I understand taking part in the interview part of the research will include being recorded (audio) but that these recordings will be deleted once transcribed.	
Please select and initial one of the following three options	
1. I agree to take part in the questionnaire-based part of the study (two data collection sessions).	
2. I agree to take part in the interview-based part of the study.	
3. I agree to take part in both questionnaire and interview-based part of the study (two data collection sessions)	

Please Initial

Should I not wish to answer any particular question(s), complete a test or give an interview, I am free to decline.	

I give permission that de-identified information collected in this study may be shared with other researchers to support other research in the future. I understand that I cannot be identified from this information.	
I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the outputs that result from the research.	

Name of participant Date Signature

Name of person taking consent Date Signature

Appendix E. Lone Worker Protocol followed during Data Collection.

Lone worker protocol

Describe the Activity being Risk Assessed: Lone working.

Location(s): Wessex Region.

Persons at potential Risk (e.g. consider specific types of individuals)

- Postgraduate Researcher –PGR– (staff/student).
- Members of the public.

Potential Hazards:

Hazard	Severity of the hazard	How Likely the hazard could cause harm	Risk Rating
General travelling	High	Low	Medium
Participants living with dementia's behavioral challenges	Low	Low	Low
Sudden illness or emergency	High	Low	Medium
Researcher’s distress	Medium	Low	Low
Lone working	High	Low	Medium
Animals	Medium	Low	Low
Tocacco fumes	Medium	Low	Low

Any Control Measures Already In Place:

Hazard	Control measure(s)
General Travelling	• The supervisor will know which kind of transport the PGR will be using for each visit/observation. • When possible an estimation of departure and arrival times will be provided by the PGR. This information will be available through the PGR’s outlook calendar. • The researcher will prepare the route to the venue/participant’s home in advance, as well as the public transports available, to avoid stop and asking or getting lost (safest and fastest routes will be preferred). • Whenever possible, the PGR will stick to well-lit, busy areas where she can be clearly seen and where she can clearly see other people. And will stay alert to her surroundings at all times to avoid potential dangers.

Participants living with dementia's behavioral challenges	• If during a home visit: Participants will be offered the possibility to stop for a while, arrange an alternative moment to carry out the interview/visit/measurements or withdraw with no negative consequences for their participation in the TACIT Trial. • Home-interviews/data collection: will be conducted in the presence of an informal carer.

Hazard	Control measure(s)
Sudden illness or emergency	• The PGR will report this immediately, or as soon as possible thereafter to the supervisor. • A University mobile phone has already been provided to the PGR to report any incidences and be accessible during lone working. The PGR will make sure this device is appropriately charged before lone working. • A key word will be agreed with the supervisor to report high risk of incidence.
Researcher’s distress	• A PGR's supervisor will be available for debriefing after activities conducted under lone working, in case this is needed. • Counselling advise will be sought at the University if persistent distress is manifested by the Postgraduate Researcher.
Lone working	• Lone working will be avoided whenever it is possible. • At the first sign of potential danger the PGR will make a speedy exit from the home/venue where the lone working is taking place. • The PGR will formally report any incident occurred under lone working. • Any incidents during lone working activities will be reported to PGR's supervisors immediately or as soon as possible thereafter (according to its importance). When necessary, these will be raised in supervisory team meetings. • Ageing and Dementia research Center (ADRC)’s Administrator and the supervisor will know the whereabouts of the researcher and what she is doing. They will have access to PGR’s outlook calendar where venue/participant’s details, address, contact number and starting/end times will be specified. • The researcher will inform via outlook calendar, text message or call the supervisor after leaving the venue/home being visited. • If the researcher does not contact the research team after the home visit estimated duration, a supervisor will try to establish contact by phone with the researcher. If unsuccessful, he will try again 5 minutes later. If contact is neither established, then will contact the participants as necessary. • Confrontation with participants will always be avoided.

Animals	• Participants will be asked to place them in a different room for the duration of the researcher's visit to their home. • If the researcher is confronted by an aggressive animal or she feels unsafe because of its presence, she will not put herself in risk. Visit will be rearranged, if possible, to a more suitable moment when this animal will not be in the same room as the researcher.
Tocacco fumes	• If participants smoke, they will be asked not to do so in presence of the PGR.

Estimating the Residual Risk (e.g. remaining risk once existing control measures are taken into account)

Choose a category that best describes the degree of harm which could result from the hazard and then choose a category indicating what the likelihood is that a person(s) could be harmed.

	Slightly Harmful (e.g. minor injuries)	Harmful (e.g. serious but short-term injuries)	Extremely Harmful (e.g. fatality, long-term injury or incurable disease)
Highly Unlikely	Trivial Risk ☐	Tolerable Risk ☐	Moderate Risk ☒
Unlikely	Tolerable Risk ☐	Moderate Risk ☐	Substantial Risk ☐
Likely	Moderate Risk ☐	Substantial Risk ☐	Intolerable Risk ☐

Person who did Assessment:	Iram Bibi	Date:	D/M/Y
Checked By:	Samuel Nyman	Date:	D/M/Y

Appendix F. TACIT Trial Participant Information Sheet.

The TACIT Trial

TAi ChI for people with dementia
PARTICIPANT INFORMATION SHEET

Thank you for taking some time to read this information sheet. We are a team of researchers led by Dr Samuel Nyman at Bournemouth University and we are interested in improving the health and wellbeing of people with dementia.

The ancient form of gentle exercise known as Tai Chi might be a good way to improve a person's health and wellbeing. ***Can Tai Chi improve the health and wellbeing of people with dementia?***
We really don't know and that is why we want to do this study.

If you have any questions about this study please contact:
Yolanda Barrado-Martín on **07801 890258** or
ybarradomartin@bournemouth.ac.uk
Or Michelle O'Brien on 01202 962771
(Mondays - Thursdays), or visit:
www.bournemouth.ac.uk/tai-chi

To find out we will need up to 150 people with dementia and their carers to take part in our study. Half of the people in the study (75 people with dementia and their carers) will receive a course of Tai Chi, and the other half will not. During the study, we will assess the health and wellbeing of those taking part so that we can compare results between the two groups over 6 months. If you think you might be interested in taking part, please read on….

Put off by long documents?

- We have provided a separate 1 page "Key Facts Sheet" that provides a summary of all the information in here.
- Please at least read the summary Key Facts Sheet to get an idea of what this study is about and what you will be asked to do if you agree to take part.
- Please contact us on the details above to find out more; we will be happy to talk to you about taking part even if you cannot do all the things asked for in this document.

Some background information

Dr Samuel Nyman at Bournemouth University and his team want to test whether Tai Chi improves the health and wellbeing of people with dementia and their informal carers. Of particular interest is testing whether Tai Chi can improve people's balance while standing and moving around. We are looking for people both **with** and **without** balance difficulties to take part in this study. You may not be experiencing any balance problems yourself but by taking part in this study, you will provide important information to us and help improve services for people with dementia.

What is Tai Chi ?

Tai Chi is an ancient form of gentle exercise which originated in China. Tai Chi combines smooth and continuous body movements with deep breathing and mental concentration. Tai Chi is recommended by the NHS and the UK Department of Health as a gentle way to promote exercise in older people. This form of exercise is thought to be particularly suited for people with dementia as the movements are slow, gentle and repetitive.

Who can take part in this study?

This study relies on recruiting participants in pairs. People with a confirmed diagnosis of dementia are invited to take part provided they meet certain other criteria and provided they have a carer who is also willing to take part with them, to make up the pair.

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 the study, your ongoing treatment will not be affected in any way. Even if you do decide to take part, you can choose to withdraw from the study at any time, and you won't have to give a reason for withdrawing if you don't want to. Please take time to read this information carefully. Discuss it between yourselves and with your family, friends or your General Practitioner (GP) if you wish and please ask us if anything is not clear, or if you would like more information.

What will happen to us if we take part?

An illustration briefly describing what the study involves is provided below. Simply put, the study involves two visits from a researcher (an initial visit and a 'follow-up' visit approximately six months later) and weekly completion of diaries plus phone calls with the researcher in between the two visits. A researcher from the TACIT team will arrange to visit you at home or at another suitable location. It is important that both the person with dementia and the carer are present for this initial visit. The researcher will explain the study in full 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 complete a standard questionnaire with the person with dementia, designed to assess mental abilities relating to memory, attention and language. The questionnaire takes about ten minutes to complete and the results will allow the researcher to confirm whether or not the person with dementia is suitable to take part in the study. If the results of the assessment indicate that you are not able to take part in the study, the researcher will explain this to you.

If the results of the assessment indicate that you are suitable to take part, the researcher will ask you some questions about your background, medical history and ask you to do a short test on your ability to judge where things are in your environment. Both of you will be invited to perform some balance tests (see below) and complete some questionnaires. The questionnaires are designed to find out about your general wellbeing, fear of falling (for the person with dementia) and experience as a caregiver (for the carer). The questionnaires for the person with dementia will be completed through interview with the researcher. The carer will complete the questionnaires themselves. The questionnaires will take around 10 minutes to complete.

The balance tests

Good balance while standing upright is an important part of our health and wellbeing, and is linked to our ability to do daily tasks independently and having confidence to go outdoors on our own. The researcher who visits you will be trained in the safe administration of a number of different tests to assess your balance. The researcher will carefully explain and demonstrate each assessment, and will stand next to you for each one in case you need support while standing. Safety will be of utmost importance and should the researcher at any time be concerned that you might fall during an assessment, they will tell you this and stop that task and move on to the next one. However, each assessment is routinely used in daily NHS practice and safe to do at home, and so it is unlikely that anyone in this study will not be able to do them.

One of the tests involves standing up from a seat, walking a few paces, and then returning to sit down. It takes around 5 seconds to 2 minutes to complete, depending on mobility. Both members of the pair will be invited to perform this test.

A second test also involves sitting and standing, as well as other movements to assess your balance such as standing with your eyes closed, picking up an object from the floor while standing, looking over your shoulder and standing on one foot. This test takes around 15 to 20 minutes to complete and only the person with dementia will be invited to perform this test.

A third (and final!) balance test involves standing for 30 seconds firstly on the floor and then on a foam rubber mat, and is designed to assess the extent to which you sway while standing still. Both members of the pair will be invited to perform this test which takes just a couple of minutes to complete. Some of the tests require the test subject to wear a small, lightweight monitor (about the size of a matchbox) on a strap around the waist. The monitor accurately measures a range of different movements and is harmless.

Keeping a falls calendar

As well as balance we want to record whether or not people fall. We will provide you with a calendar and invite you to make records of any falls you experience on that calendar. The research team will telephone you each week to ask about any falls you have recently had. The calendar will invite you to make records of any falls you experience. Every month, you will be asked to return the calendar to the research team by post. You don’t need to worry about postage costs because postage-paid envelopes will be provided to you. When the research team receives a calendar, they will look at the information contained and may telephone you to get some additional details. For example, if a calendar indicates that a participant has fallen, the researcher will telephone to find out how the fall occurred and whether the fall caused an injury or not, and collect further information, such as if you needed to go into hospital or receive extra help at home.

Which group will we be in?

An important feature of this type of study is that participants are allocated to groups at random. Half of the people in the study will be allocated to the ‘Tai Chi group’ and the other half will be allocated to the ‘no Tai Chi group’. To find out if Tai Chi improves balance, we need to make sure that the two groups both have similar people in them, so that we can make a fair comparison at the end of the study. For example, the comparison wouldn’t be fair if all of the people in the ‘Tai Chi group’ had only very minor symptoms of dementia while the people in the ‘no Tai Chi group’ had much more severe symptoms. This is why we use a computer to randomly allocate participants to the groups, so that the two groups are balanced and well matched. This means that neither you nor the researcher will be able to choose whether you are in the ‘Tai Chi group’ or in the ‘no Tai Chi group’.

After the initial visit, a computer will ‘decide’ which group you are in. **If you want to take part in this study therefore, it’s important to realise that you won’t be able to choose your group**. We need data from both groups in order to answer our question and so the data you provide is equally valuable to us, regardless of which group you are in. You will be informed by letter which group you are in.

What happens if we are in the ‘Tai Chi group’?

If you are allocated to the Tai Chi group, you will receive a letter confirming where the Tai Chi classes will be held and the name and contact details of your instructor. The Tai Chi course is delivered over a period of about 5 months and is designed for both the person with dementia and their carer. The course is made up of weekly Tai Chi classes, held at a local accessible venue, and weekly home-based Tai Chi exercises for you both to practice at home. The classes will be delivered to around seven pairs of participants and will last for around 90 minutes: 45 minutes for Tai Chi and 45 minutes for informal discussion.

Some of the classes will be observed by a researcher from the TACIT team, who will make notes on how the classes are delivered and may even take some photos and video footage. The photos and video will be used to assess how well the instructor delivers the class and whether anything could be improved. The video is not intended to be used for public broadcast and will be kept securely and confidentially by the researcher. The researcher will also talk to some participants about their experience of taking part in the classes and make notes.

We would like the opportunity to talk in more detail to some participants about what they thought of the Tai Chi course. With your permission, we may invite you to take part in an interview with a researcher at your home toward the end of the Tai Chi course.

After the first 2-3 classes, the Tai Chi instructor will visit you at home to teach you both how to do the home-based Tai Chi exercises. An information booklet will be provided. **It is important that you do not practise Tai Chi at home until the Tai Chi instructor has visited you at home (after the first 2-3 classes) to ensure all safety precautions have been made**.

The instructor will ask you to perform the exercises for twenty minutes each day at a convenient time and place (in the lounge in the morning, for example). It is important for us to know how much Tai Chi exercise you do at home, so pairs allocated to the Tai Chi group will be asked to fill in a Tai Chi exercise record, which will be used to tally up the number of hours of home-based Tai Chi you complete over the study period. The instructor will collect the records from you in person when you attend the weekly Tai Chi classes. The Tai Chi course does not replace any other treatment. Any usual treatment you receive will continue unaffected.

What happens if we are in the ‘no Tai Chi group’?

Participants allocated to the ‘no Tai Chi group’ will continue with their usual daily activities throughout the study period. Remember that the data we collect from people in this group is equally important to us. If you are allocated to this group, you will still be asked to complete the weekly diaries and return them on a monthly basis, and be telephoned occasionally by the researcher if further information is required.

When does our involvement in the study end?

You will be involved in the study until around six months after the initial visit, when a researcher will visit you at home again to perform the ‘follow-up’ visit. This visit will be similar to the initial visit: the researcher will ask you both some questions about your medical history, invite both of you to perform the same balance tests as before and complete the same questionnaires as before plus a further questionnaire about your willingness to pay for Tai Chi.

What are the benefits of taking part?

We really don’t know if Tai Chi will help to improve the health and wellbeing of people with dementia, so we can’t say with any certainty that you will benefit personally from taking part in this study. You will certainly be helping us to answer a question which might lead to improved treatment for people with dementia and their carers in future, and you might regard that as being beneficial in itself and any significant changes to your health over the past six months.

What are the risks and disadvantages of taking part?

We don’t foresee any major risks in taking part in the study. Tai Chi is a relatively safe practice but could cause sore muscles, sprains, or dizziness if done too vigorously. Some people may be unsteady on their feet and at risk of falling over while taking part in the balance tests or while practising Tai Chi. However, the risk of this happening is very low as each assessment is very quick and easy to do, and will be closely supervised by a trained professional. For example, for the test when standing on a foam mat, you will only need to stand on the mat for 30 seconds and the researcher will be standing right next to you. Likewise, Tai Chi is a very safe form of gentle exercise and is designed to help people improve their balance and reduce their risk of falling, and you will be shown how to do this by a trained professional. In the unlikely event that someone falls during this study, there are a set of instructions the trained researcher will follow during a home visit. Tai Chi instructor will follow these same instructions during classes and you will be given these to follow at home as well.

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.

What if relevant new information becomes available?

A committee has been set up to look at all the information that is gathered about the participants in this study. It will ensure that any concerning issues are investigated. If the study is stopped for any reason you will be told why. If any new information which might affect your participation in the study becomes available, you will also be informed.

What if there is a problem?

Complaints: If you have a concern about any aspect of this study, please speak to someone in the research team who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure.

Harm: We don't expect any harm to come to you as a result of participating in this study. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against your NHS Trust but you may have to pay your legal costs. There are no special compensation arrangements in place. The normal NHS complaints mechanisms will still be available to you.

If a member of the study team (including the Tai Chi Instructor) has any concerns regarding your welfare, he/she will advise the Chief Investigator immediately to determine whether your GP, or the local adult safeguarding service, should be contacted.

Private insurance policies: Please note that it is your responsibility to check if taking part in this study affects the terms and conditions of any private insurance policies that you hold.

What will happen if we don't want to carry on with the study?

You are free to withdraw from the study at any time without your medical care or legal rights being affected. If you want to withdraw from the study a 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 don't want to. The study relies on recruiting people in pairs, so if one of you becomes unwilling to carry on, you may have to be withdrawn from the study.

If you do withdraw from the study at any stage, information collected about you during the study may still be used unless you ask for it not to be.

Will our taking part in the study be kept confidential?

All information collected about you during the course of your participation will be kept strictly confidential and in accordance with the Data Protection Act 1998. Your medical records will remain within the establishments which usually maintain them (your GP or local hospital for example) but may be reviewed by members of the research team to confirm your eligibility to take part and to gather information regarding any hospital admissions during the study period if needed. The Peninsula Clinical Trials Unit (PenCTU, part of the University of Plymouth) and members of the research team at Bournemouth University will prepare the study data collected about you for analysis.

Your name and other identifying information will be removed from any study data before being transferred to either party so that you cannot be identified from the data. Your contact details (name, address, telephone number) will be provided to PenCTU to enable collection of some information by post. These details will be stored separately from the de-identified study information on secure computers accessible only to authorised members of PenCTU.

Paper-based information will be stored in locked offices, in locked filing cabinets and information kept on computers will be stored securely on a system maintained by either the University of Plymouth or Bournemouth University.

Authorised people from Southern Health NHS Foundation Trust, Dorset HealthCare University Foundation Trust, Bournemouth University or PenCTU may need to review your medical records to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research team.

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, anonymised information collected during the study will be made available to other researchers under an appropriate data sharing agreement, but it will not be possible to identify you personally from 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 study, we will prepare the study results (this normally takes several months) and send you a summary of the findings. The study results 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.

If the results of this study indicate that Tai Chi does improve balance in people with dementia then a larger trial will be planned to see if improved balance does indeed reduce the rate of falling.

Who is organising and funding the research?

The study is being led by Dr Samuel Nyman, a Principal Academic with a special interest in physical activity and dementia care at Bournemouth University. The study is funded by a grant awarded by National Institute of Health Research (NIHR) as part of his Career Development Fellowship.

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 *<enter REC>*. 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

Appendix G. TACIT Trial Key Fact Sheet.

We would like to invite you to consider taking part in a research study. It aims to find out if practicing a gentle form of exercise known as Tai Chi can be helpful for people with dementia's health and wellbeing.

ADRC Ageing & Dementia Research Centre Bournemouth University
NHS Dorset HealthCare University NHS Foundation Trust
Southern Health NHS Foundation Trust
Solent NHS Trust
Alzheimer's Society Leading the fight against dementia

Why would I want to take part in the study?

- You will be helping with research to find out if Tai Chi is beneficial for people with dementia.
- Half of those that take part will be provided with free Tai Chi classes from a qualified and experienced instructor.
- You will have regular contact from the research team and receive a home visit at the beginning and end.

What is Tai Chi?

- Tai Chi is an ancient form of gentle exercise which originated in China.
- It is recommended by the NHS as a gentle way to promote exercise in older people and is thought to be particularly suited for people with dementia as the movements are slow, gentle, and repetitive.

Can Tai Chi improve the health and wellbeing of people with dementia?

- We don't know and that is why we need this research study to see if Tai Chi does improve health and wellbeing, and particularly balance, of people with dementia.
- We aim to recruit 150 pairs of participants; each pair includes a person with dementia and their carer.
- Half of the people who take part will receive their usual care and will practice Tai Chi for 5 months while the other half will just receive their usual care.
- By comparing information collected from both groups of people, we will be able to decide whether the Tai Chi course is beneficial. Both groups are equally important.

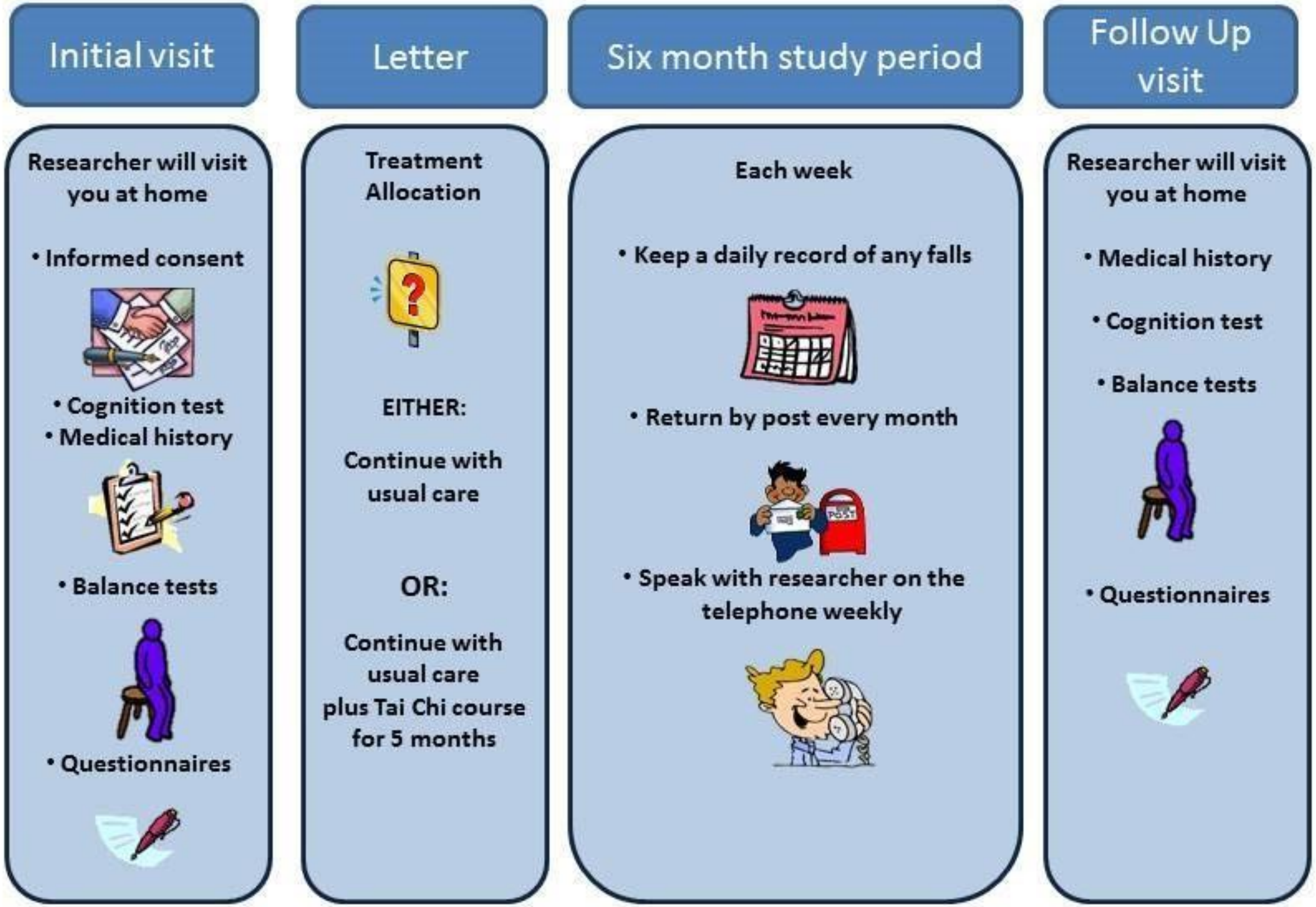
What will happen if I take part in the study?

- All participants in the study will be visited at home twice by a researcher: once at the start of the study and once again after 6 months.
- The researcher will collect information from both the person with dementia and the carer at these visits and both will be asked to perform some simple and easy balance assessments.
- In between the two visits participants will be asked to keep a daily record of any falls they experience, and researchers will phone participants each week to find out more details and see how they are getting on. A summary is shown in a flowchart overleaf.

What if I have questions?

Please contact the research team at Bournemouth University: Telephone Yolanda Barrado-Martín on **07801 890258** or ybarradomartin@bournemouth.ac.uk, or Michelle O'Brien on 01202 962771 (Mon - Thurs)

IRAS Project ID: 209193 NCT02864056 RCT Key Facts Sheet version 2.1 dated 30.01.2017



Initial visit

Researcher will visit you at home

- Informed consent
- Cognition test
- Medical history
- Balance tests
- Questionnaires

Letter

Treatment Allocation

EITHER:

Continue with usual care

OR:

Continue with usual care plus Tai Chi course for 5 months

Six month study period

Each week

- Keep a daily record of any falls
- Return by post every month
- Speak with researcher on the telephone weekly

Follow Up visit

Researcher will visit you at home

- Medical history
- Cognition test
- Balance tests
- Questionnaires

Appendix H. TACIT Trial Advertisement.

Dementia study volunteers needed

BU Bournemouth University

BUDI Bournemouth University Dementia Institute

The TACIT TRIAL
TAi Chi for people with demenTia

Seeking Volunteers!

We need your help for a new research project that will test whether Tai Chi is of benefit to those living with dementia and their carers.

If on reading this leaflet you can help, please contact
Yolanda Barrado-Martin on **07801890258**
or **ybarradomartin@bournemouth.ac.uk**
Or Michelle O'Brien on **01202 962771** (Mondays-Thursdays).

Bournemouth University's Ageing and Dementia Research centre is running free Tai Chi classes for people with dementia, and their informal carers, on a Friday morning at The Hub in Eastleigh.

After a home visit by a researcher, participants get to attend the class, run by a qualified and experienced Tai Chi instructor, once a week for several weeks. After the 45-minute class, there is time to chat over tea and coffee.

The instructor also makes home visits to encourage the people with dementia and their carers to practise Tai Chi outside the classes.

What does the carer need to do?

Carers will need to provide the researchers with information - and help participants with dementia attend the Tai Chi classes and perform the Tai Chi exercises at home.

What will happen with the results of this study?

The results will be used to develop the main trial, involving 150 people with dementia and their carers, which will compare the effects on people who do Tai Chi for five months with those who have not. This will provide important information as to whether Tai Chi benefits people with dementia.

For more information please contact:

Yolanda Barrado-Martín on 07801890258 or ybarradomartin@bournemouth.ac.uk, or Michelle O'Brien on 01202 962771.

Appendix I: PWD's Percentage of Attendance (including withdrawal Participants)

Table 23:

PWDs' patterns of adherence to Tai Chi intervention classes in terms of their overall percentages of attendance (inclusive withdrawn participants) (N = 42).

S. No	Participants ID	Group	No. of sessions offered	No. of sessions attended	% of attendance
1	03003P	1	20	6	30
2	03005P	1	20	9	45
3	03006P	1	20	19	95
4	02002P	2	11	4	36
5	02004P	2	12	6	50
6	01002P	2	20	16	80
7	01008P	2	20	16	80
8	03007P	3	20	0	0
9	03008P	3	11	9	82
10	01015P	3	1	1	100
11	01021P	3	16	16	100
12	01006P	4	12	6	50
13	01009P	4	20	18	90
14	01012P	4	20	20	100
15	01022P	4	18	13	72
16	01023P	5	20	19	95
17	01025P	5	20	13	65
18	01031P	6	12	12	100
19	01034P	6	20	4	20
20	01035P	6	20	20	100
21	01036P	6	20	17	85
22	01039P	6	20	18	90
23	01043P	6	WT	WT	WT*
24	01045P	6	20	20	100
25	01055P	6	19	4	21
26	01047P	7	20	15	75
27	01049P	7	12	3	25
28	01052P	7	20	17	85
29	01053P	7	20	18	90
30	01064P	7	19	16	84
31	01059P	8	20	18	90
32	01057P	8	20	12	60
33	01062P	8	20	8	40
34	01066P	8	20	19	95
35	01076P	8	15	10	67
36	01070P	9	16	13	81
37	01072P	9	16	3	19
38	01075P	9	16	9	56
39	01080P	9	3	2	67
40	01067P	10	2	2	100
41	01078P	10	2	2	100
42	01081P	10	7	6	86

Average attendance of all participants: M (SD); min-max (%) = 69.19 (29.95); 0-20 (0-100%)

*The dyad was allocated to the intervention arm; however, they completely withdrew from the study before session one.

PWDs' (N = 42) patterns of adherence are presented in Table 17 in terms of their overall percentage of class attendance over the 20 sessions. It includes all those participants who at some point withdrew from the study. Percentage of participants' attendance ranged from 0-100. Percentage of attendance was calculated in terms of number of classes attended against number of classes offered. Only one participant had 0% (03007) who were offered 20 classes but did not attend any class. They neither withdrew nor attended classes therefore they were excluded from further analyses as they were considered an outlier. Eight participants had 100%. Among them three participants attended twenty classes, one participant attended all the sixteen offered classes. Remaining four participants who had 100% withdrew from study at some point. Two among them were offered 2 classes, which they attended before their withdrawal. Likewise, one participant was offered one class and one participant was offered 12 classes which they attended before withdrawal.

Appendix- J: PWD's Percentage of Attendance (excluding withdrawal Participants)

Table 24:

PWDs' patterns of adherence to Tai Chi intervention classes in terms of their overall percentages of attendance (withdrawn participants excluded) (N = 30).

S. No	Participants ID	Group	No. of sessions offered	No. of sessions attended	% of attendance
1	03003P	1	20	6	30
2	03005P	1	20	9	45
3	03006P	1	20	19	95
4	01002P	2	20	16	80
5	01008P	2	20	16	80
6	03007P	3	20	0	0
7	01021P	3	16	16	100
8	01009P	4	20	18	90
9	01012P	4	20	20	100
10	01022P	4	18	13	72
11	01023P	5	20	19	95
12	01025P	5	20	13	65
13	01034P	6	20	4	20
14	01035P	6	20	20	100
15	01036P	6	20	17	85
16	01039P	6	20	18	90
17	01045P	6	20	20	100
18	01055P	6	19	4	21
19	01047P	7	20	15	75
20	01052P	7	20	17	85
21	01053P	7	20	18	90
22	01064P	7	19	16	84
23	01059P	8	20	18	90
24	01057P	8	20	12	60
25	01062P	8	20	8	40
26	01066P	8	20	19	95
27	01076P	8	15	10	67
28	01070P	9	16	13	81
29	01072P	9	16	3	19
30	01075P	9	16	9	56
Average attendance of all participants: M (SD); min-max (%) = 70.33 (28.72); 0-20 (0-100%)					

Table 18 presents patterns of PWD's (N = 30) adherence to Tai Chi classes in terms of their overall percentages of class attendance, however, it excludes those participants who at some point withdrew from the study. Percentage of attendance was calculated in terms of number of classes attended against total number of classes offered. As recruitment was an ongoing process during the trial, therefore participants were allowed to join even if they had missed initial few sessions. In addition, participants' absence from sessions resulted in varied number of classes attended against number of sessions offered. Percentages of attendance ranged from 0-100. Only one participant (03007) had 0%, they were offered 20 classes but they did not attend any. They neither withdrew from study nor attended any classes therefore they were excluded from further analyses being considered an outlier. Four participants had

100% among them three were offered 20 classed and they attended all, while one attended all the offered 16 classes.

Appendix- K: Percentage of Group Attendance

Table 26:

Patterns of each group's percentage of attendance over 20 sessions.

Groups	N	% Of participants (dyads) attending per session (1-20)																				Average Participation
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	
1	6	100	67	100	100	67	100	67	33	67	33	33	33	33	33	67	33	67	33	33	33	57%
2	8	75	100	100	75	50	38	38	13	50	63	75	67	100	100	100	100	100	100	0	100	72%
3	8	50	67	50	50	67	67	67	33	67	67	33	50	50	50	50	50	50	50	50	50	53%
4	8	100	100	100	50	100	100	100	75	50	50	75	75	67	67	67	67	100	100	100	100	82%
5	4	100	100	100	100	100	100	100	100	100	100	100	100	100	50	50	50	0	50	50	50	80%
6	16	83	57	86	100	100	100	71	71	71	71	64	64	67	67	67	67	58	42	67	67	71%
7	10	50	60	50	70	80	90	80	100	80	80	80	60	100	88	75	100	75	50	75	63	75%
8	10	75	100	88	88	75	80	70	70	50	40	70	60	60	70	30	50	60	60	60	70	66%
9	8	67	33	67	25	75	25	67	33	67	67	67	33	33	67	67	67	-	-	-	-*	54%
10	6	100	100	0	100	100	100	0	100	100	100	-	-	-	-	-	-	-	-	-	-*	80%

*In group 10 all participants withdrew from study while in group nine all participants were absent in last four classes.

Table 20 provides information on attendance during each session for each group as well as the total attendance rate. There were 10 sub-groups in the intervention arm. Participants were allocated to the groups according to their close proximity to the class venues. There were three main sites of exercise classes i.e., Southampton, Dorset, and Portsmouth, and seven different class venues. Average attendance per group ranged from 53%-82%. Participants of group 10 attended only first 10 sessions however, all participants withdrew from rest of the sessions. Whereas, all participants of group nine were absent in last four sessions (i.e., 17-20). Reasons of participants' absence from sessions in group three (i.e., four dyads) with lowest attendance rates (i.e., 53%) were mainly acute health conditions of participants including; "breathing issues of PWD" due to which the dyad could not attend any session (03007), PWD’s “cold and flu” due to which the dyad could attend only one session and withdrew from study in 6th session (01015), “carer not feeling well” (03008), however they withdrew from study in session 15 due to carer’s unavailability. Group four (4 dyads) with highest attendance rate (i.e., 82%) had 100% attendance in 10 sessions and 75% attendance in three sessions. Reasons for participants’ absence in group four were predominantly dyads’ health issues including; PWD’s headache and dizziness (suspected to be related to medication) (01006), PWD’s hospital appointment, and carer’s cataract surgery (01009), PWD’s carer’s flu (01022).

Appendix- L: Causes of non-adherence.

Table 27: *Categories of causes of non-adherence to Tai Chi intervention among PWDs.*

PWD ID	Causes of non-adherence and number of sessions affected (n)							Total no. of absents	Total sessions offered	% of overall attendance
	PWD's health	Carer's health	PWD's medical appointment	Carer's medical appointment	PWD SAE*	Holidays	Others** / Unknown			
03003	2	10	2	-	-	-	-	14	20	30
03005	11	-	-	-	-		-	11	20	45
03006	-	-	1	-	-	-	-	1	20	95
02002	6	1	-	1	-	1	-	7	11	36
02004	-	-	-	6	-	-	-	6	12	50
01002	-	1	-	-	-	2	1	4	20	80
01008	-	-	1	-	3	-	-	4	20	80
03007	20	-	-	-	-	-	-	20	20	0
03008	-	1	-	-	-	-	1	2	11	82
01015	-	-	-	-	-	-	-	-	1	100
01021	-	-	-	-	-	-	-	-	16	100
01006	5	-	-	-	-	-	1	6	12	50
01009	-	1	1	-	-	-	-	2	20	90
01012	-	-	-	-	-	-	-	-	20	100
01022	2	3	-	-	-	-	-	5	18	72
01023	1	-	-	-	-	-	-	1	20	95
01025	7	-	-	-	-	-	-	7	20	65
01031	-	-	-	-	-	-	-	-	12	100
01034	14	1	-	-	-	1	-	16	20	20
01035	-	-	-	-	-	-	-	-	20	100
01036	-	-	-	-	-	2	1	3	20	85
01039	-	-	-	-	-	-	2	2	20	90
01043	WT	WT	WT	WT	WT	WT	WT	WT***	0	0
01045	-	-	-	-	-	-	-	-	20	100
01055	15	-	-	-	-	-	-	15	19	21
01047	1	-	-	-	-	3	1	5	20	75
01049	-	4	-	-	-	5	-	9	12	25
01052	1	-	-	-	-	-	2	3	20	85
01053	-	-	-	-	-	-	2	2	20	90
01064	-	-	-	-	-	-	3	3	19	84
01059	-	-	-	-	-	2	-	2	20	90
01057	-	-	-	-	-	2	6	8	20	60
01062	-	-	-	-	-	5	7	12	20	40
01066	-	-	-	-	-	-	1	1	20	95
01076	-	-	-	-	-	3	2	5	15	67
01070	-	-	1	-	-	2	-	3	16	81
01072	1	11	-	-	-	-	1	13	16	19
01075	-	1	-	-	-	1	5	7	16	56
01080	-	-	-	-	-	-	1	1	3	67
01067	-	-	-	-	-	-	-	-	2	100
01078	-	-	-	-	-	-	-	-	2	100
01081	-	-	-	-	-	-	1	1	7	86
M (SD) min-max	6.61(6.43) 1-20	3.40(3.89) 1-11	1.20(.44) 1-2	3.50(3.53) 1-6	6(-) 6	2.41(1.37) 1-5	2.23(1.92) 1-7	6.09(5.05) 1-20	51.71(6.26) 0-20	69.07(29.89) 0-100

*Serious Adverse Event (SAE).

** Causes which were very specific to individual cases and couldn't be categorized.

*** The dyad completely withdrew from the study from the first session onwards.

Appendix-M: Distinction between TACIT trial and Present Thesis.

Table 1:

Distinctions between present thesis and the TACIT trial and contribution of present researcher in both.

S.No.	Domains	Present PhD	TACIT trial
1	Aims	1. Validation of a generic QoL scale - the ICECAP-O - for PWD. 2. Investigation of adherence to Tai Chi exercise intervention among PWD. 3. Effect of adherence to Tai Chi exercise intervention on QoL of community dwelling PWD and their carers.	1. To test the effectiveness of Tai Chi to improve postural balance among community dwelling PWD. 2. To assess the feasibility of conducting a definitive trial to reduce falls (Nyman et al., 2018).
2	Objectives	**Primary objectives were:** 1. To determine construct validity, face validity (in terms of readability and comprehension), feasibility of administration, test retest (external) and Cronbach alpha (internal) reliability, and factorial structure (in terms of confirmatory factor analysis) of a generic QoL measure the ICECAP-O for community dwelling PWD. 2. To assess patterns, baseline predictors, factors associated with adherence during intervention phase, causes of nonadherence to class-based Tai Chi exercise intervention and comparison of adherence to home and class-based Tai Chi practice among community dwelling PWD. 3. To assess factors associated with QoL of PWD, association of baseline QoL with their adherence to home and class-based Tai Chi practice, and effect of adherence to home and class-based Tai Chi exercise on their QoL. **Secondary objectives were:** 1. To assess factors associated with QoL of carers of PWD. 2. To investigate the association between carers' baseline QoL and their adherence to class-based Tai Chi intervention.	**Primary objective was:** 1. To assess the effect of a Tai Chi intervention, delivered in addition to usual care, on the dynamic balance of older people with dementia compared to usual care alone. **Secondary objectives were:** 1. To compare functional balance, static balance, fear of falling, global cognitive functioning, visual-spatial cognitive functioning, quality of life, and the number and rate of falls, fallers, and injurious falls between patients in the intervention and control groups. 2. To compare dynamic balance, static balance, quality of life, and carer burden between carers in the intervention and control groups. 3. To determine the acceptability and safety of the intervention for patients and carers in the intervention group. 4. To assess feasibility of key aspects of the study design (i.e. recruitment, consent, randomisation, suitability of outcome measure data and methods of data collection) to inform the design a future clinical and cost-effectiveness definitive trial.

		3. To assess effect of adherence to class-based Tai Chi exercise intervention on QoL of carers of PWD at the follow-up.	(TACIT trial unpublished protocol, version 4.4. dated 8/06/2018, p.14)
3	Outcome and contribution of present researcher.	1. Psychometric validation of generic QoL measure the ICECAP-O for community dwelling PWD. 2. QoL of community dwelling PWD measured with a generic QoL measure ICECAP-O, which was earlier validated for them. 3. Adherence to Tai Chi exercise intervention among PWD.	**The primary outcome was:** 1. Difference in performance at follow-up between the two arms on the Timed Up and Go* (TUG) test (Podsiadlo & R ichardson,1991) by PWD at six months post-baseline (TACIT trial unpublished protocol, version 4.4. dated 8/06/2018, p.14). The present researcher collected this data. **The Secondary outcome were:** 1. PWD – balance tests: • **Difference in score on the Berg Balance Scale** (BBS) (Berg et al., 1989) between the two arms at six months post-baseline. The present researcher collected this data. • **Difference in postural sway** performance between the two arms while standing on the floor and on a foam mat (Taylor et al., 2014) at six months post-baseline. The present researcher collected this data. • *PWD – structured interview scales:* • **Difference in score on the Iconographical Falls Efficacy Scale** (Icon-Fes, short form) (Delbaere et al., 2011) between the two arms at six months post-baseline. The present researcher collected this data. • **Difference in score on the Mini-Addenbrooke's Cognitive Examination** (M-ACE) (Hsieh et al., 2015) between the two arms at six months post-baseline. The present researcher collected this data. • **Difference in score on the Statue task** (Reed et al., unpublished thesis) between the two arms at six months post-baseline. The present researcher collected this data.

- **Difference in score on the ICEpop CAPability measure for Older people** (ICECAP-O) (Coast et al., 2008) between the two arms at six months post-baseline. The present researcher collected this data.
- **Difference in number and rate of falls** prospectively recorded up to six months post-baseline between the two arms (binary outcome measure). An unblind researcher collected this data who also had her PhD came from the TACIT trial.
- **Difference in the number and rate of fallers** (people that have fallen at least once) between the two arms (binary outcome measure). An unblind researcher collected this data who also had her PhD came from the TACIT trial.
- **Difference in the number and rate of injurious falls** between the two arms (count data). An unblind researcher collected this data who also had her PhD came from the TACIT trial.

2. Carer – balance tests:
    - **Difference in TUG*** (Podsiadlo & Richardson 1991) performance between the two arms at six months post-baseline. The present researcher collected this data.
    - **Difference in postural sway*** performance between the two arms while standing on the floor and on foam (Taylor et al., 2014) at six-months post-baseline. The present researcher collected this data.
3. Carer – structured interview scales:
    - **Difference in score on the ICECAP-O*** (Coast et al., 2008) between the two arms at six months post-baseline. The present researcher collected this data.

- **Difference in score on the Zarit Burden Interview (short-form)*** (Higginson et al., 2010, Mancini et al., 2011) between the two arms at six months post-baseline. The present researcher collected this data.

The pilot phase feasibility outcomes were:

1. **Feasibility of recruitment method:** Detailed information about the recruitment rate of dyads, including numbers approached, excluded, or declined (with reasons for declining where given) will be recorded. The present researcher along with another researcher collected this data
2. **Acceptability of the TACIT Tai Chi intervention:** During the intervention pilot phase. Another researcher collected this data.
3. **Acceptability of the methods for data collection:** During the intervention pilot phase. Another researcher collected this data.

The RCT phase feasibility outcomes were:

1) **Feasibility of recruitment method:** Detailed information about the recruitment rate of dyads, including numbers approached, excluded, or declined (with reasons for declining where given) will be recorded. An unblind researcher collected this data who also had her PhD came from the TACIT trial.
2) **Acceptability of the methods for data collection:** During the RCT phase, field notes will be made by the researcher as to the acceptability to dyads of the diary and telephone-based data collection methods. The number of missing diaries and telephone interviews will be recorded. An unblind researcher collected this data who also had her PhD came from the TACIT trial.

			3) **Adherence to the TACIT Tai Chi intervention (for participants in the intervention arm only):** Dyads' class attendance will be recorded each week during the intervention period by the instructors. Dyads will also complete a weekly exercise diary to record how many minutes of Tai Chi they have carried out at home outside the classes. In addition, qualitative data will be collected. A researcher will observe 10% of the classes and make qualitative observations in relation to class-based adherence (including group social cohesion, participant enjoyment and engagement, rapport with the instructor and socialising and peer support at the end of each session). Informal feedback from dyads and instructors will be sought at the end of each session and recorded using fieldwork notes. At around week 16 of the Tai Chi intervention, joint interviews will be conducted with a purposive sample of around 15 dyads in their homes and will focus on adherence to the intervention and in particular the home-based Tai Chi exercises (including any wider benefits of the intervention to the PWD and carer beyond improving balance) (TACIT trial unpublished protocol, version 4.4. dated 8/06/2018, p.16-18). Class attendance was recorded by the instructors and weekly Tai Chi home-practice diaries were handed over to the instructors in next session. An unblind researcher collected qualitative data who also had her PhD came from the TACIT trial.
4	Participants	1. All participants (community dwelling PWD and their carers) from the trial (N = 83). 2. 59 community dwelling PWD (N= 54 for test-retest reliability of ICECAP-O, N= 5	Community dwelling PWD and their carers (N= 83 i.e., N= 42 intervention arm, N= 41 control arm).

		participants for face validity of ICECAP-O. See study- I for detail) from outside the trial.	
6	Baseline and follow-up data	**The following baseline data from TACIT trial was used in the present Thesis:** 1. PWD’s Mini Addenbrooke’s Cognitive Examination scores (M-ACE) (study-I, II). 2. PWD’s (study-I) and carers’ ICECAP-O scores, study- III). 3. PWD’s Statue-test scores (study-I). 4. PWD’s Berg Balance Scale scores (study-I). 5. Carer’s Zarit burden Interview short form scores. 6. Demographic information: • Presence/absence of any long-term health condition other than dementia among PWD (study-I, III). • Question from PWD: “If offered the opportunity I intend to do Tai Chi for at least 20 minutes every day for the next five months?” It was answered on a seven-point Likert scale where 1 represents agree while seven represents disagree (study-II). • Question from PWD: How often do you usually do moderate physical activity? (Examples include brisk walking, bike riding, dancing and, swimming) The respondents had to select one out of six options i.e., every day, 2 times per week, 3 times per week, weekly, monthly, rarely/never (study-II). • PWD’s age, gender, use of walking aid, living arrangements (i.e., living with family and friends or living alone), relationship with carer (i.e., spouses or others), (study-III). • Carer’s age, gender, care burden, relationship with PWD (study-III).	**The following data was collected at baseline:** 1. PWD’s M-ACE scores (data utilized in present thesis). 2. PWD’s and carers’ demographics (some of this data utilized in present thesis, detail in the preceding column). 3. PWD’s Icon-FES scores. 4. PWD’s and carer’s ICECAP-O scores (data utilized in present thesis). 5. PWD’s Statue test scores (data utilized in present thesis). 6. PWD’s postural sway test. • On firm surface. • On foam. 7. PWD’s Time Up and Go test scores. 8. PWD’s Berg Balance Scale (data utilized in present thesis). 9. Adverse events caused by performance on balance tests. 10. Carer’s Postural sway test scores 11. On firm surface 12. On foam 13. Carer’s Time Up and Go test scores 14. Carer’s Zarit burden Interview short form scores (data utilized in present thesis). The present researcher collected all the above data for TACIT trial. **The following data was collected at follow-up:** 1. PWD’s M-ACE scores. 2. PWD’s Icon-FES scores. 3. PWD’s and carer’s ICECAP-O scores (data utilized in present thesis). 4. PWD’s Statue test scores. 5. PWD’s postural sway test. • On firm surface. • On foam.

		The present researcher collected the above TACIT trial baseline data. Note: Rationale for using the above-mentioned baseline data from TACIT trial is explained in the rationale and hypotheses sections of all the sub-studies. **The following follow-up data from the TACIT trial was used in the present study:** 1. PWD’s and carers’ ICECAP-O scores (study-III). The present researcher collected the above TACIT trial follow-up data.	6. PWD’s Time Up and Go test scores. 7. PWD’s Berg Balance Scale. 8. Adverse events caused by performance on balance tests. 9. Carer’s Postural sway test scores • On firm surface. • On foam. 10. Carer’s Time Up and Go test scores 11. Carer’s Zarit burden Interview short form scores. 12. Exit interview from PWD and carer. 13. Researcher’s observation about unblinding by participants during the data collection process. The present researcher collected all the above data for TACIT trial.
7	Intervention phase data	The following data from intervention phase of the TACIT trial was used in sub-study-II of the present thesis: 1. TACIT trial Class attendance: • PWD’s percentage of Tai Chi classes attended against classes offered. • Carer’s percentage of Tai Chi classes attended against classes offered. • Dyad’s percentage of Tai Chi classes attended against classes offered. • Discrepancies between PWD and carer’s percentage of attendance. Tai Chi instructors collected PWD’s and carers’ class attendance. 2. Home practice TACIT trial data: • PWD’s percentage of minutes Tai Chi practiced at home against minutes of Tai Chi expected to be practiced (i.e., 20 minutes each day for 20 weeks). Tai Chi weekly home practice diaries were shared with Tai Chi instructors in the next Tai Chi class/session. Carers assisted in reporting weekly home practice. Dyads were instructed to keep record of daily Tai Chi practice per week.	1. Detail of class attendance, home practice, and qualitative data collected during intervention phase is as above in S. No. 3 column: TACIT trial, heading: The RCT phase feasibility outcomes, sub-heading: Adherence to the TACIT Tai Chi intervention (for participants in the intervention arm only). Tai Chi instructors collected PWD’s and carers’ class attendance and home practice data, while qualitative data was collected by an unblind researcher. 2. Midway data based on the five representative statements of PWD and carers was collected by an unblind researcher. The statements were rated on seven-point Likert scale, where 1 represented agree and 7 represented disagree. Three among the five statements were utilized in the present thesis (detail is given in the preceding column). The statements were as follows: • I enjoy coming to Tai Chi classes. • I am confident that I can come and take part in a Tai Chi class every week for the next 10 weeks if I wanted to.

		3. Midway data based on the following representative statements of PWD which were rated on seven-point Likert scale, where 1 represented agree and 7 represented disagree: - I enjoy coming to Tai Chi classes. - I am confident that I can come and take part in a Tai Chi class every week for the next 10 weeks if I wanted to. - I intend to come to a Tai Chi class every week for the next 10 weeks. Note: carer's midway data was not utilized in the present study as focus of study-II was only evaluation of PWD's adherence to Tai Chi exercise intervention. An unblind researcher collected the midway TACIT trial data.	- I intend to come to a Tai Chi class every week for the next 10 weeks. - Handing my home exercise log to the Tai Chi instructor each week motivates me to practice Tai Chi at home. - I use the alarm clock to remind me to practice Tai Chi at home. An unblind researcher collected the midway TACIT trial data.
8	Data analyses	The following data analyses were exclusive to the present thesis, these were not carried out in the TACIT trial. 1. Psychometric validation of ICECAP-O. 2. Patterns of adherence to Tai Chi exercise classes among PWD. 3. Factors associated with Tai Chi class adherence among PWD. 4. Causes of nonadherence to Tai Chi exercise classes among. 5. Association between home-based and class based Tai Chi adherence among PWD. 6. Effect of adherence to Tai Chi exercise classes on QoL of PWD. 7. Effect of adherence to Tai Chi home-practice on QoL of PWD. 8. Effect of adherence to Tai Chi exercise classes on QoL of carers of PWD. 9. Factors associated with QoL of PWD. 10. Factors associated with QoL of carers of PWD.	ICECAP-O was only administered on PWD and their carers at baseline and follow-up. A t-test was conducted to see if PWD and carers in intervention arm differed on QoL at follow-up. Effect of adherence on QoL wasn't measured in the TACIT trial. Only both groups were compared for different variables.
9	Novel contributions	1. Psychometric validation of ICECAP-O for PWD. 2. PWD's acute health issues were found to be a major cause of non-adherence/absence from Tai Chi classes	The novel contributions of the present thesis were unique and independent from the TACIT trial.

3. A dose-response effect was established between adherence to Tai Ch exercise and QoL among PWD i.e., the higher the adherence the better the QoL.

Appendix-N: Distinction between Data of TACIT trial and Study-I

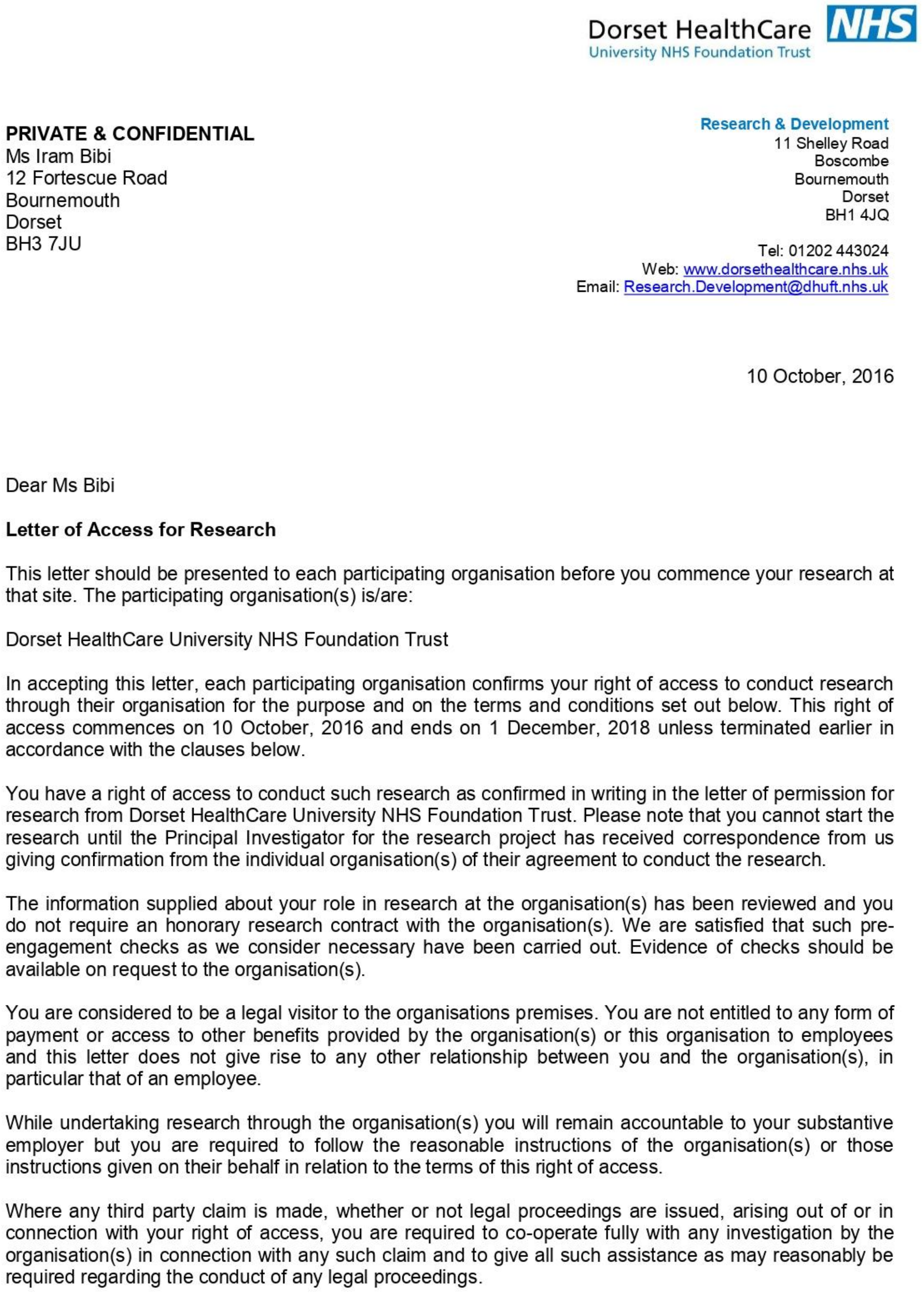
Table 8:

Distinction between new data, and data derived from the TACIT trial for study-I, along with difference in utilization and reporting of ICECAP-O in both.

Study-I components	Study-I	TACIT trial (N = 83)
	Data derived from TACIT trial (N = 83)	
Construct validity	PWD's Mini Addenbrooke's Cognitive Examination scores (M-ACE) (Hsieh et al., 2015).	Difference in score on the Mini-Addenbrooke's Cognitive Examination (M-ACE) (Hsieh et al., 2015) between the two arms at six months post-baseline.
	PWD's baseline ICECAP-O (Coast et al., 2008) score	ICECAP-O (Coast et al., 2008) between the two arms at six months post-baseline.
	PWD's Statue-test scores (Reed et al., unpublished thesis)	Difference in score on the Statue task (Reed et al., unpublished thesis) between the two arms at six months post-baseline.
	PWD's Berg Balance Scale (Berg et al., 1989)	Difference in score on the Berg Balance Scale (BBS) (Berg et al., 1989) between the two arms at six months post-baseline.
	Question from PWD: Presence/absence of any long-erm health condition other than dementia among PWD.	Question from PWD: Presence/absence of any long-erm health condition other than dementia among PWD. (Recorded, not used).
Confirmatory factor analysis	Data derived from TACIT trial (N = 83)	
	ICECAP-O	As above
Cronbach alpha reliability	ICECAP-O	As above
Test-retest reliability	New data (N = 54)	
	PWD's Mini Addenbrooke's Cognitive Examination scores (M-ACE)	-
	ICECAP-O	-
Face validity	New data (N = 5)	
	PWD's Mini Addenbrooke's Cognitive Examination scores (M-ACE)	-
	ICECAP-O	-

Note: The present researcher collected all data mentioned in column two and three of the above table.

Appendix-O: Letter of Access for Researcher



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PRIVATE & CONFIDENTIAL
Ms Iram Bibi
12 Fortescue Road
Bournemouth
Dorset
BH3 7JU

10 October, 2016

Dear Ms Bibi

Letter of Access for Research

This letter should be presented to each participating organisation before you commence your research at that site. The participating organisation(s) is/are:

Dorset HealthCare University NHS Foundation Trust

In accepting this letter, each participating organisation confirms your right of access to conduct research through their organisation for the purpose and on the terms and conditions set out below. This right of access commences on 10 October, 2016 and ends on 1 December, 2018 unless terminated earlier in accordance with the clauses below.

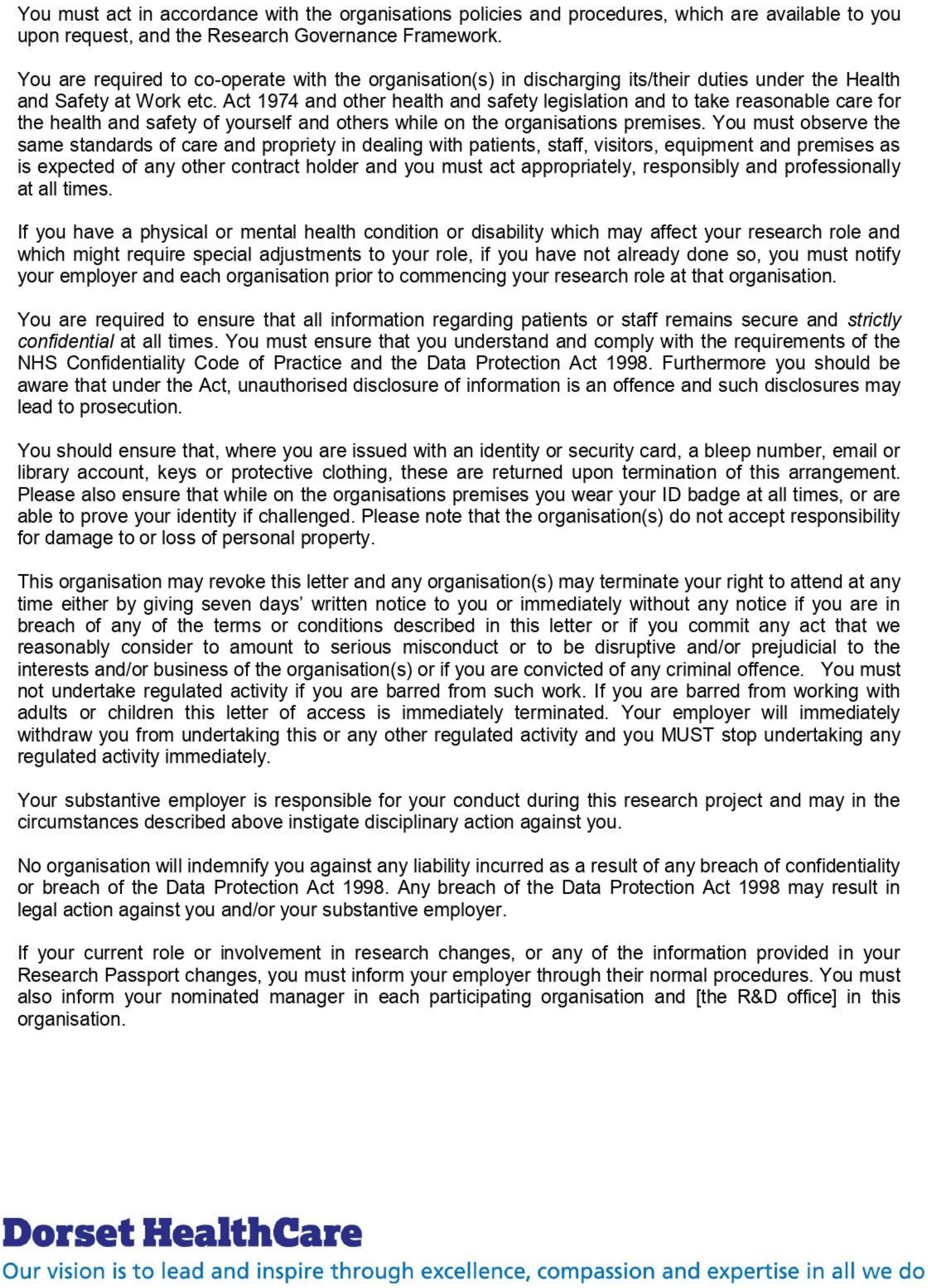
You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from Dorset HealthCare University NHS Foundation Trust. Please note that you cannot start the research until the Principal Investigator for the research project has received correspondence from us giving confirmation from the individual organisation(s) of their agreement to conduct the research.

The information supplied about your role in research at the organisation(s) has been reviewed and you do not require an honorary research contract with the organisation(s). We are satisfied that such pre-engagement checks as we consider necessary have been carried out. Evidence of checks should be available on request to the organisation(s).

You are considered to be a legal visitor to the organisations premises. You are not entitled to any form of payment or access to other benefits provided by the organisation(s) or this organisation to employees and this letter does not give rise to any other relationship between you and the organisation(s), in particular that of an employee.

While undertaking research through the organisation(s) you will remain accountable to your substantive employer but you are required to follow the reasonable instructions of the organisation(s) or those instructions given on their behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by the organisation(s) in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.



You must act in accordance with the organisations policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with the organisation(s) in discharging its/their duties under the Health and Safety at Work etc. Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on the organisations premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and each organisation prior to commencing your research role at that organisation.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the organisations premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that the organisation(s) do not accept responsibility for damage to or loss of personal property.

This organisation may revoke this letter and any organisation(s) may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of the organisation(s) or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

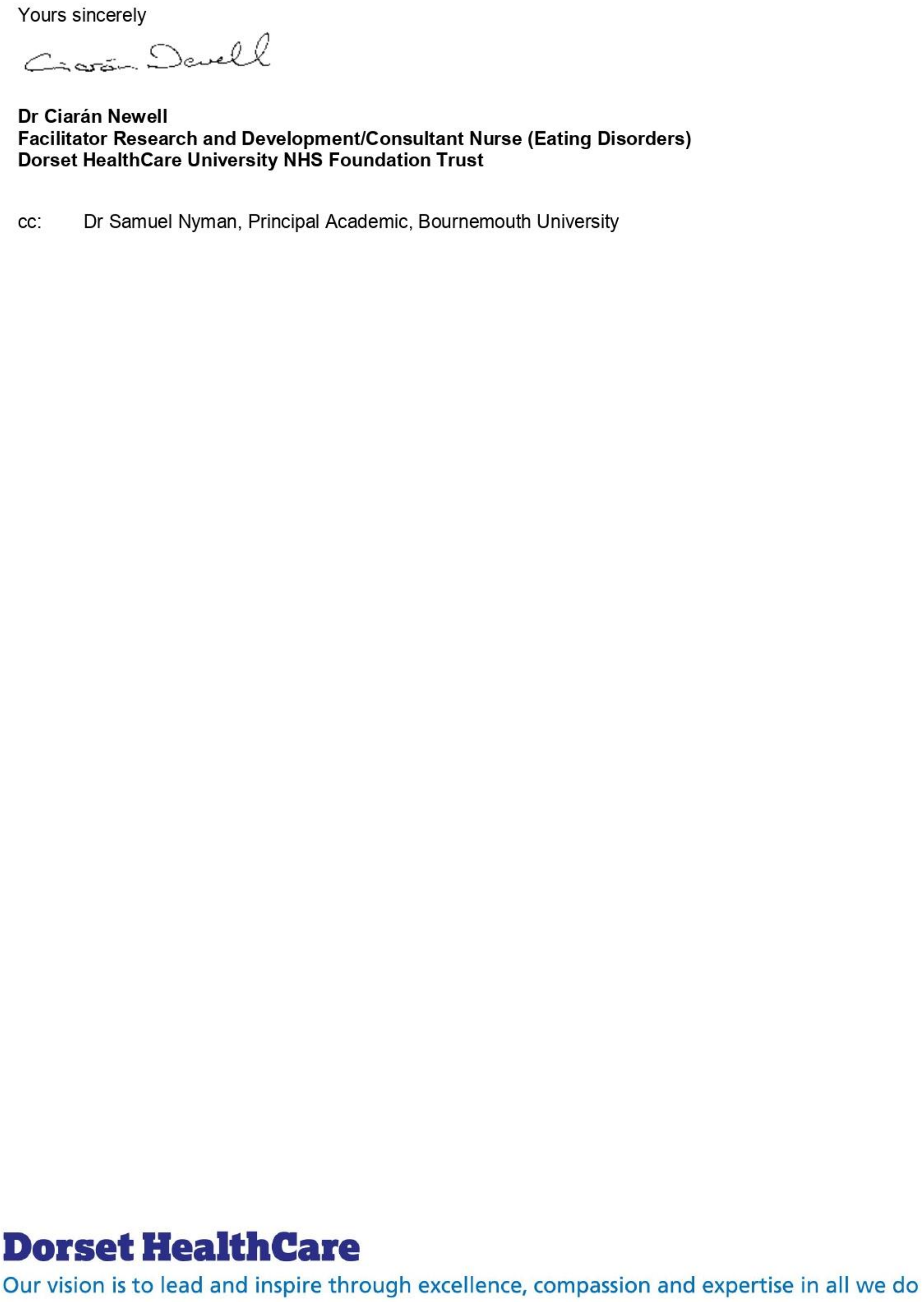
Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

No organisation will indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in each participating organisation and [the R&D office] in this organisation.

Dorset HealthCare
Our vision is to lead and inspire through excellence, compassion and expertise in all we do

A



Yours sincerely

Ciarán Newell

Dr Ciarán Newell
Facilitator Research and Development/Consultant Nurse (Eating Disorders)
Dorset HealthCare University NHS Foundation Trust

cc: Dr Samuel Nyman, Principal Academic, Bournemouth University

Dorset HealthCare
Our vision is to lead and inspire through excellence, compassion and expertise in all we do

Appendix- P: Letter of Access for Research TACIT

Southern Health NHS
NHS Foundation Trust

Ms Iram Bibi
Bournemouth University
Department of Psychology
Talbot Campus
Fern Barrow
Poole
BH12 5BB

Recruitment Department
Hawthorn Lodge
Moorgreen Hospital
Botley Road
West End
Southampton
SO30 3JB

Tel: 023 8047 5103

www.southernhealth.nhs.uk

18TH August 2016

Dear Iram

Letter of access for research – TACIT

I am pleased to offer you an honorary research contract in Southern Health NHS Foundation Trust. I should be grateful if you would sign the attached three contracts, keep one yourself and return the other two to the above address. We will send a copy of the contract to your substantive employer.

The contract if accepted by you begins on 18TH August 2016 and ends on 1st December 2018 unless terminated earlier in accordance with the clauses in the contract. Please note that you cannot start the research until the Principal Investigator has received a letter from us giving permission to conduct the project.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and the organisation Dr Peter Phiri prior to commencing your research role at the Trust.

We will not reimburse any expenses you incur in the course of your research unless we have agreed to do so by prior arrangement. Similarly, we accept no responsibility for damage to or loss of personal property.

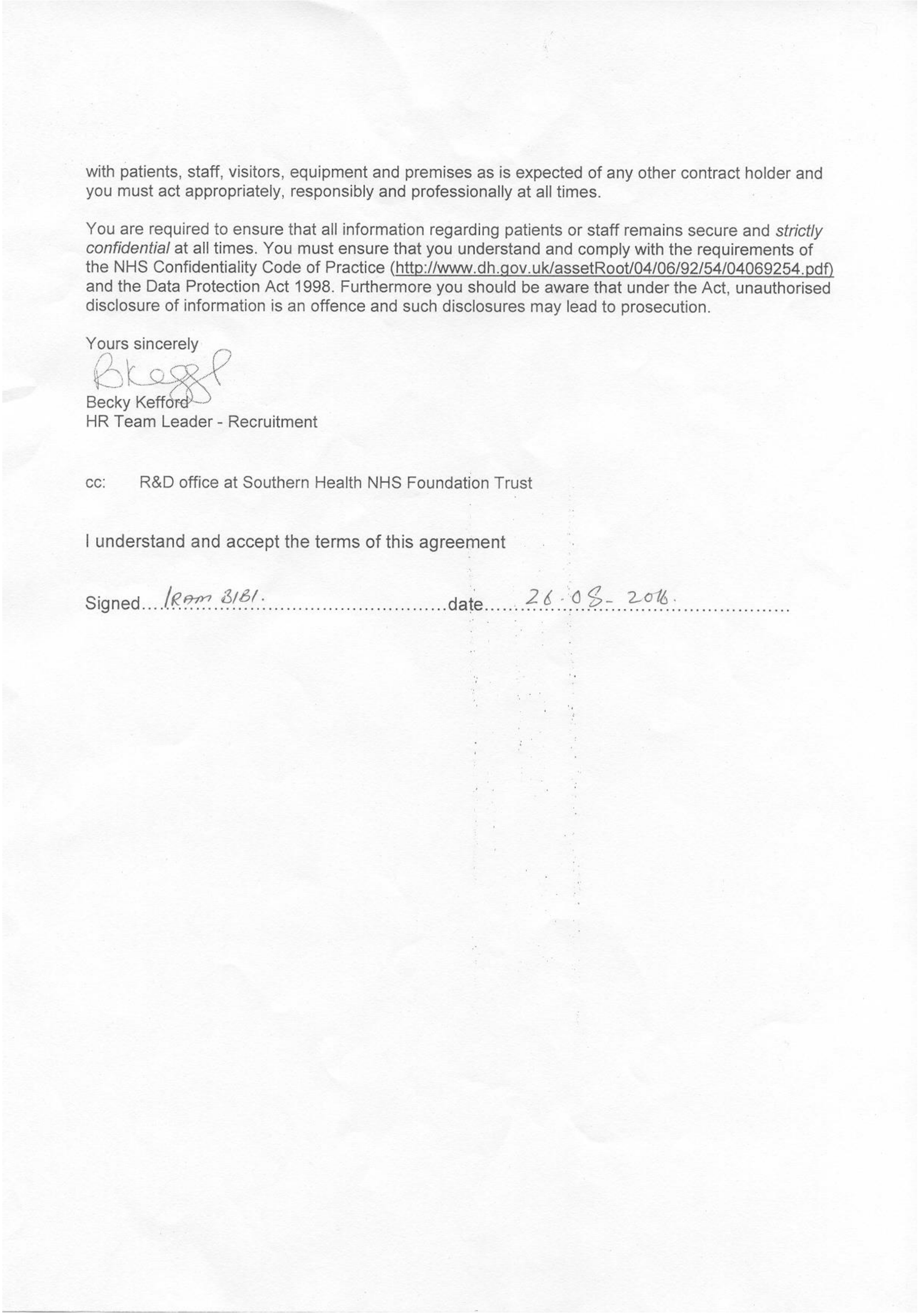
Your Research Passport Form may be subject to random checks carried out by us within the lifetime of the project. The information it contains must therefore remain up to date and accurate.

If your circumstances change in relation to your health, criminal record, suitability to work with adults or children, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform your employer through its normal procedures. You must also inform your nominated manager in this NHS organisation.

You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this honorary research contract is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

You are required to co-operate with Southern Health NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Southern Health NHS Foundation Trust premises. You must observe the same standards of care and propriety in dealing

An NHS Teaching Trust with the University of Southampton
Trust Headquarters, Maples, Tatchbury Mount, Horseshoe Drive, Calmore, Southampton SO40 2RZ



with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Yours sincerely

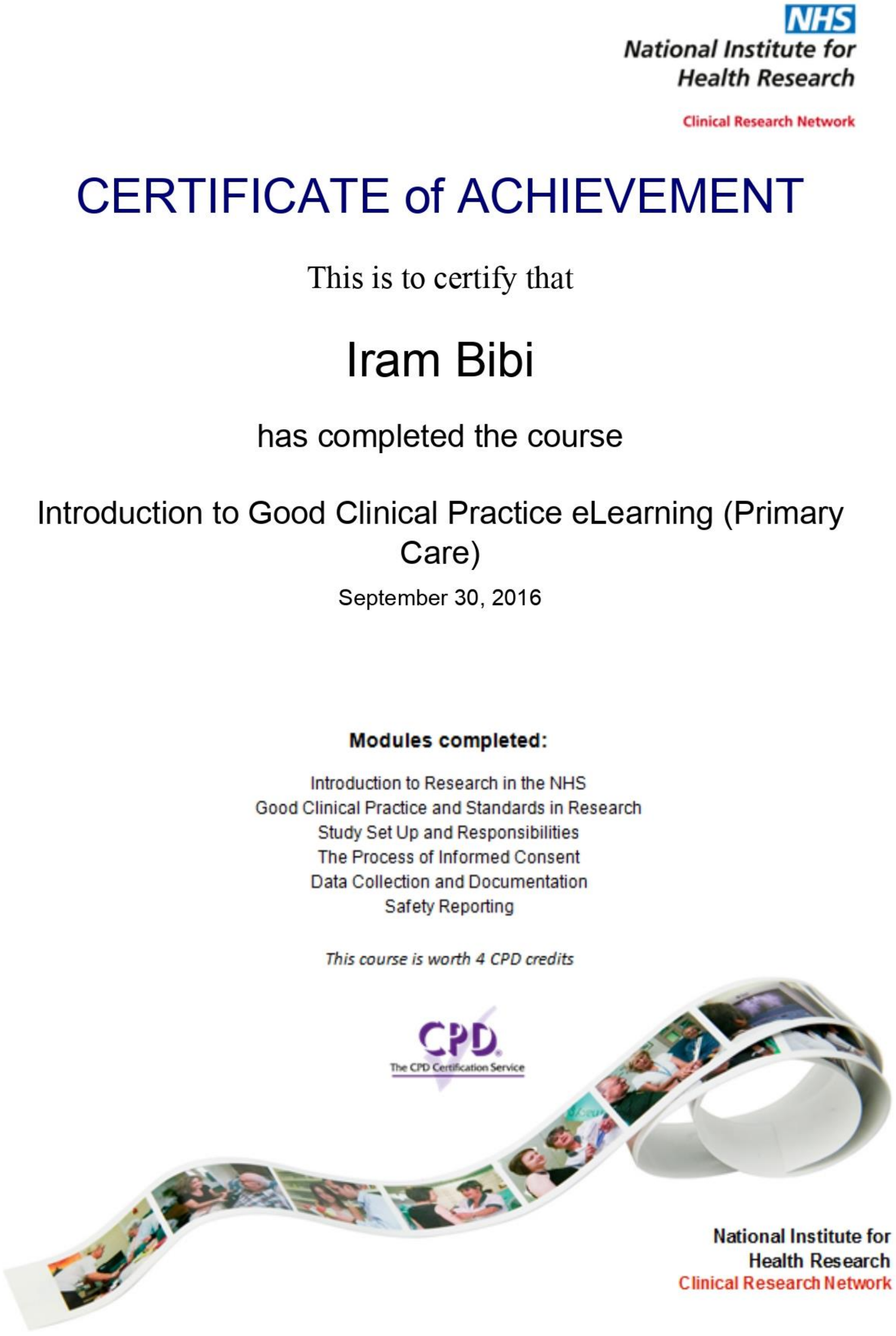
Becky Kefford
HR Team Leader - Recruitment

cc: R&D office at Southern Health NHS Foundation Trust

I understand and accept the terms of this agreement

Signed… IRAM BIBI. ……date… 26.08.2016. ……

Appendix- Q: Introduction to Good Clinical Practice eLearning (Primary Care)



NHS
National Institute for
Health Research
Clinical Research Network

CERTIFICATE of ACHIEVEMENT

This is to certify that

Iram Bibi

has completed the course

Introduction to Good Clinical Practice eLearning (Primary Care)

September 30, 2016

Modules completed:

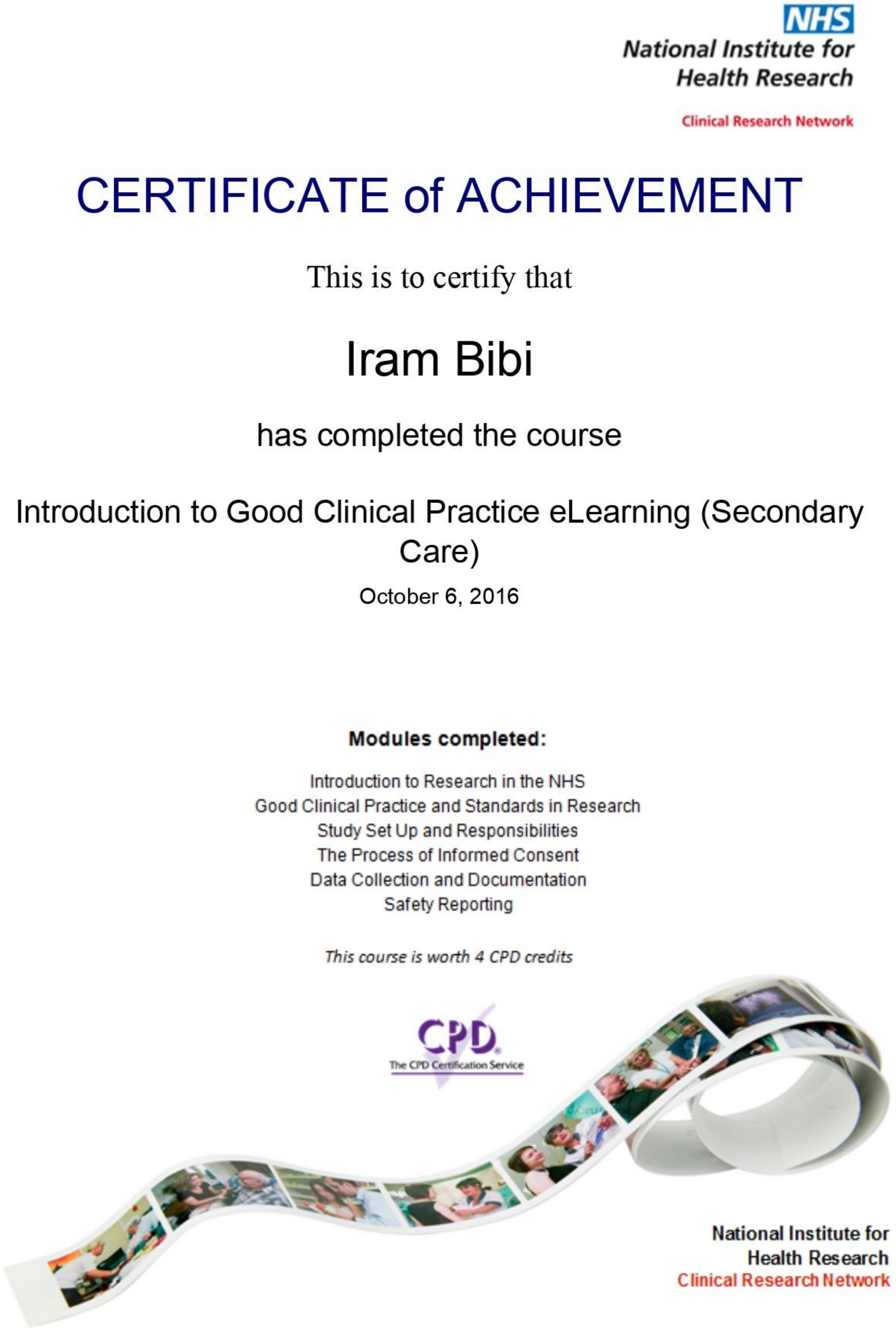
Introduction to Research in the NHS
Good Clinical Practice and Standards in Research
Study Set Up and Responsibilities
The Process of Informed Consent
Data Collection and Documentation
Safety Reporting

This course is worth 4 CPD credits

CPD
The CPD Certification Service

National Institute for
Health Research
Clinical Research Network

Appendix- R: Introduction to Good Clinical Practice eLearning (Secondary Care)



NHS
National Institute for Health Research
Clinical Research Network

CERTIFICATE of ACHIEVEMENT

This is to certify that

Iram Bibi

has completed the course

Introduction to Good Clinical Practice eLearning (Secondary Care)

October 6, 2016

Modules completed:

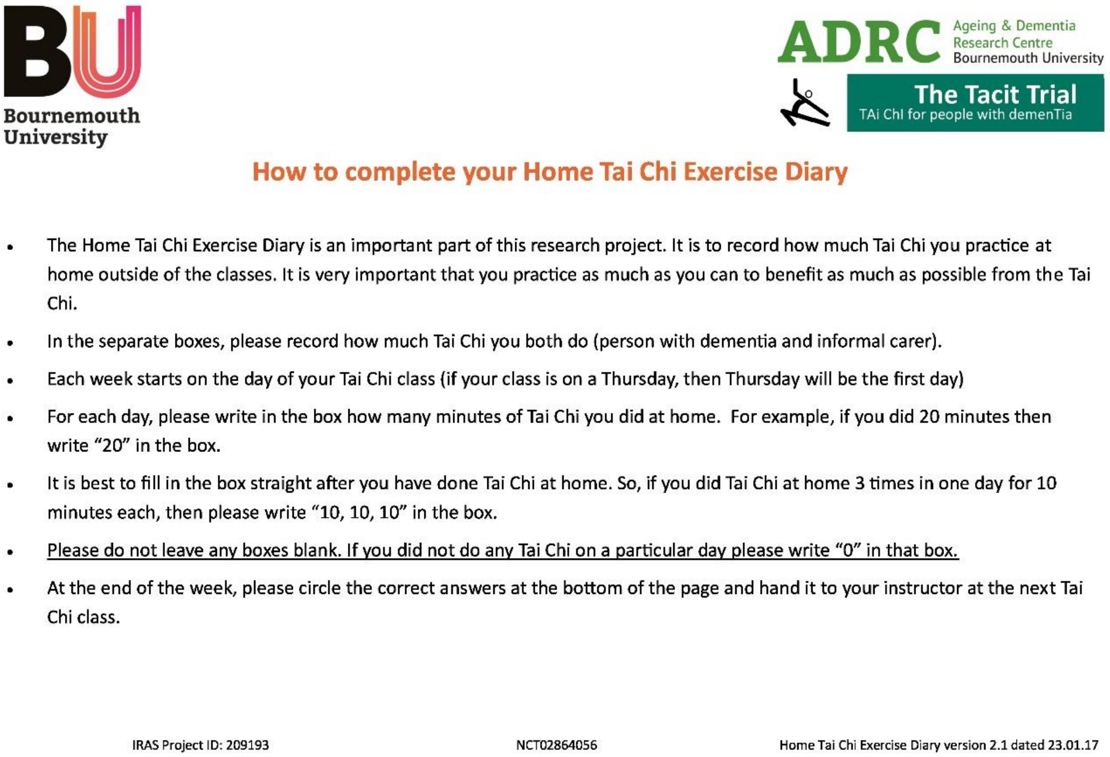
Introduction to Research in the NHS
Good Clinical Practice and Standards in Research
Study Set Up and Responsibilities
The Process of Informed Consent
Data Collection and Documentation
Safety Reporting

This course is worth 4 CPD credits

CPD
The CPD Certification Service

National Institute for
Health Research
Clinical Research Network

Appendix-R: Tai Chi Exercise Home Practice Diary



Bournemouth University

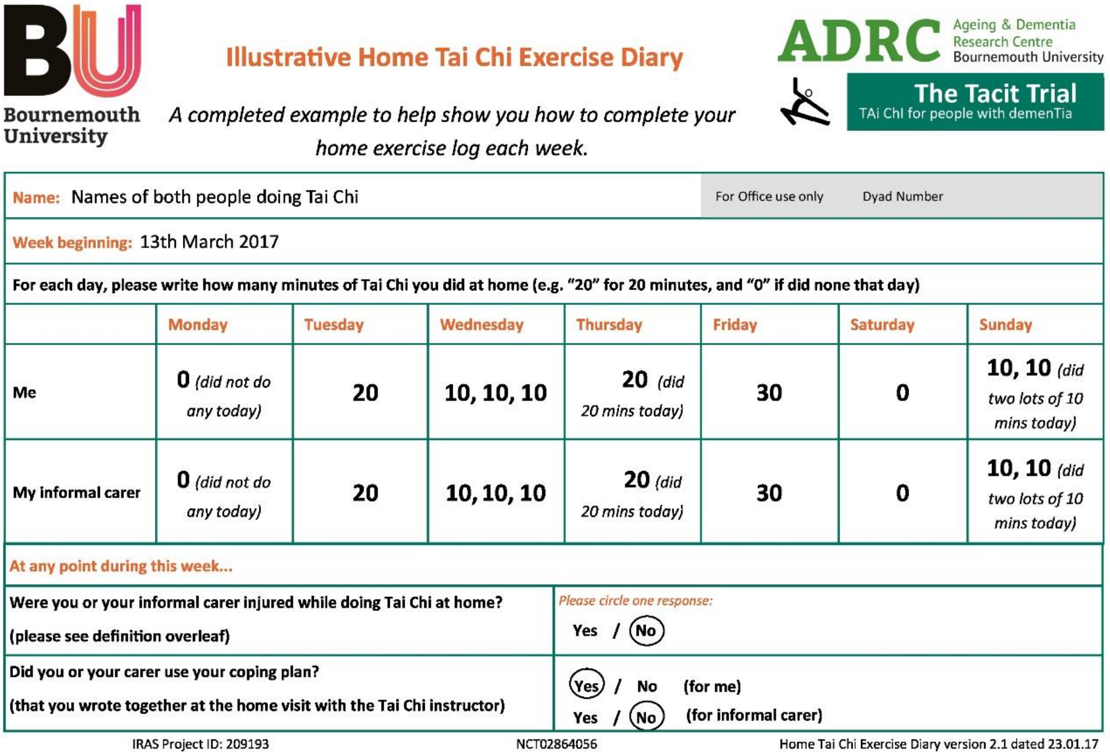
ADRC Ageing & Dementia Research Centre Bournemouth University

The Tacit Trial
TAi ChI for people with demenTia

How to complete your Home Tai Chi Exercise Diary

- The Home Tai Chi Exercise Diary is an important part of this research project. It is to record how much Tai Chi you practice at home outside of the classes. It is very important that you practice as much as you can to benefit as much as possible from the Tai Chi.
- In the separate boxes, please record how much Tai Chi you both do (person with dementia and informal carer).
- Each week starts on the day of your Tai Chi class (if your class is on a Thursday, then Thursday will be the first day)
- For each day, please write in the box how many minutes of Tai Chi you did at home. For example, if you did 20 minutes then write "20" in the box.
- It is best to fill in the box straight after you have done Tai Chi at home. So, if you did Tai Chi at home 3 times in one day for 10 minutes each, then please write "10, 10, 10" in the box.
- Please do not leave any boxes blank. If you did not do any Tai Chi on a particular day please write "0" in that box.
- At the end of the week, please circle the correct answers at the bottom of the page and hand it to your instructor at the next Tai Chi class.

IRAS Project ID: 209193 NCT02864056 Home Tai Chi Exercise Diary version 2.1 dated 23.01.17



Bournemouth University

Illustrative Home Tai Chi Exercise Diary

A completed example to help show you how to complete your home exercise log each week.

ADRC Ageing & Dementia Research Centre Bournemouth University

The Tacit Trial
TAi ChI for people with demenTia

Name: Names of both people doing Tai Chi — For Office use only Dyad Number

Week beginning: 13th March 2017

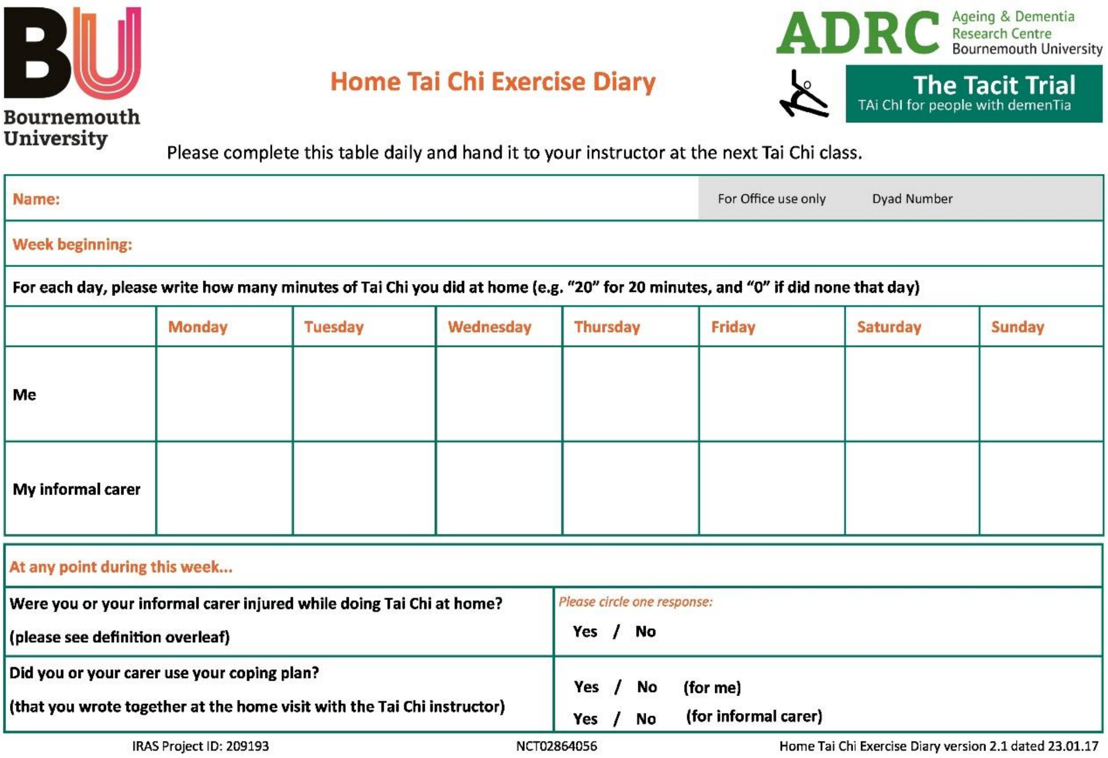
For each day, please write how many minutes of Tai Chi you did at home (e.g. "20" for 20 minutes, and "0" if did none that day)

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Me	**0** *(did not do any today)*	**20**	**10, 10, 10**	**20** *(did 20 mins today)*	**30**	**0**	**10, 10** *(did two lots of 10 mins today)*
My informal carer	**0** *(did not do any today)*	**20**	**10, 10, 10**	**20** *(did 20 mins today)*	**30**	**0**	**10, 10** *(did two lots of 10 mins today)*

At any point during this week...

Were you or your informal carer injured while doing Tai Chi at home? **(please see definition overleaf)**	*Please circle one response:* **Yes / [✓ No]**
Did you or your carer use your coping plan? **(that you wrote together at the home visit with the Tai Chi instructor)**	**[✓ Yes] / No (for me)** **Yes / [✓ No] (for informal carer)**

IRAS Project ID: 209193 NCT02864056 Home Tai Chi Exercise Diary version 2.1 dated 23.01.17



Bournemouth University

ADRC Ageing & Dementia Research Centre Bournemouth University

The Tacit Trial
TAi ChI for people with demenTia

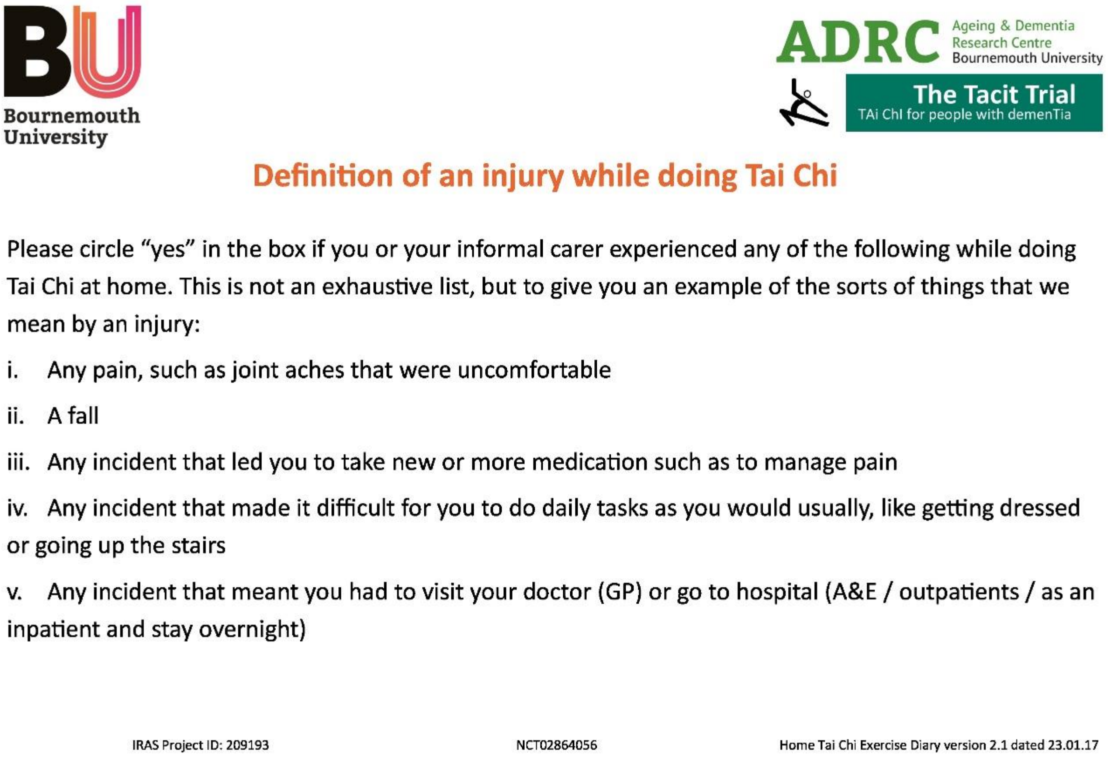
Home Tai Chi Exercise Diary

Please complete this table daily and hand it to your instructor at the next Tai Chi class.

Name:					For Office use only	Dyad Number	
Week beginning:							
For each day, please write how many minutes of Tai Chi you did at home (e.g. "20" for 20 minutes, and "0" if did none that day)							
	Monday	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**	**Sunday**
Me							
My informal carer							

At any point during this week...	
Were you or your informal carer injured while doing Tai Chi at home? **(please see definition overleaf)**	*Please circle one response:* **Yes / No**
Did you or your carer use your coping plan? **(that you wrote together at the home visit with the Tai Chi instructor)**	**Yes / No (for me)** **Yes / No (for informal carer)**

IRAS Project ID: 209193 NCT02864056 Home Tai Chi Exercise Diary version 2.1 dated 23.01.17



Bournemouth University

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The Tacit Trial
TAi ChI for people with demenTia

Definition of an injury while doing Tai Chi

Please circle "yes" in the box if you or your informal carer experienced any of the following while doing Tai Chi at home. This is not an exhaustive list, but to give you an example of the sorts of things that we mean by an injury:

i. Any pain, such as joint aches that were uncomfortable

ii. A fall

iii. Any incident that led you to take new or more medication such as to manage pain

iv. Any incident that made it difficult for you to do daily tasks as you would usually, like getting dressed or going up the stairs

v. Any incident that meant you had to visit your doctor (GP) or go to hospital (A&E / outpatients / as an inpatient and stay overnight)

IRAS Project ID: 209193 NCT02864056 Home Tai Chi Exercise Diary version 2.1 dated 23.01.17