Acceptability of a dyadic Tai Chi intervention for older people living with dementia and their informal carers

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3 informal carers

1 Abstract 2 Exercise is effective in preventing falls amongst older adults. However, few studies have 3 included people living with dementia and their carers and explored their experiences. The aim 4 of this paper is to explore what affects the acceptability of exercise interventions to better meet the needs of people with dementia and their carers as a dyad. Observations, field notes 5 6 containing participants and instructor's feedback, and focus groups with 10 dyads involved in 7 Tai Chi classes for 3 or 4 weeks in two sites in the South of England were thematically 8 analysed to understand their experiences. Findings suggest that dyads' determination to 9 achieve the benefits of Tai Chi facilitated their adherence, whereas a member of the dyad's low sense of efficacy performing the movements during classes was a barrier. Simplifying 10 class content and enhancing the clarity of instructions for home-based practice will be key to 11 12 support the design of future exercise interventions. 13

14 Keywords: exercise, qualitative, dyad, community-dwelling, falls

1 Acceptability of a dyadic Tai Chi intervention for older people living with dementia and their informal carers 2 Dementia is estimated to affect 46.8 million people worldwide (Alzheimer's Disease 3 International, 2015), with advancing age being an important contributor to its prevalence 4 (WHO, 2015). Due to increasing life expectancy and the resultant increase in the number of 5 individuals with dementia this has become a matter of concern (WHO, 2012). The 6 7 progression of dementia has an increasing impact on the individual's cognitive and physical performance, ultimately resulting in more dependency towards their informal caregivers 8 9 (Alzheimer's Society, 2015). This increase in dependency not only impacts on the person but also on the informal carer (henceforth "carer") and wider family and friends potentially 10 affecting social, health and financial circumstances (Alzheimer's Research UK, 2015). 11 12 Falls have an additional and direct impact on an individual's autonomy and quality of life (National Institute for Health and Care Excellence, 2013). A variety of interventions 13 (including Vitamin D supplementation, exercise, environmental, and multifactorial 14 interventions) have been attempted to reduce the risk factors for falls amongst older people 15 living in the community. Exercise, including Tai Chi, and home safety interventions have 16 been effective in reducing the risk of falls (see Gillespie et al., 2012). In most of these 17 studies, however, people living with dementia have been excluded even when they are more 18 19 likely to experience a fall (Shaw, 2003). However, when people living with dementia in the 20 community have been included, exercise related activities have been shown to be potentially useful for this purpose reducing around one third the risk of falling (Burton et al., 2015). Tai 21 Chi in particular shows promise for preventing falls among people living with dementia 22 23 (Nyman & Skelton, 2017). However, there is a lack of high quality randomised controlled trials (RCTs) with blinded assessors that focus on exercise, including Tai Chi, among 24 community dwelling older people living with dementia and their carer as a dyad. 25

1	Exercise interventions have been tested for their impact on behavioural and
2	psychological symptoms in dementia, as well as on physical and cognitive function (i.e.,
3	Fleiner, Dauth, Gersie, Zijlstra, & Haussermann, 2017; Hamilton et al., 2017; Öhman et al.,
4	2016). However, recent systematic reviews of such studies have identified inconsistent results
5	due to differences in settings (i.e., community vs long term care), exercise types (i.e., using
6	one or different type of exercises as well as exercise alone or in combination with other
7	interventions), and doses (Abraha et al., 2017; Laver, Dyer, Whitehead, Clemson, & Crotty,
8	2016; Rao, Chou, Bursley, Smulofsky, & Jezequel, 2014; Öhman, Savikko, Strandberg, &
9	Pitkälä, 2014). Lessons learnt from previous exercise interventions involving community
10	dwelling people living with dementia suggest that uptake facilitators are health care
11	professionals' advice (Chong et al., 2014; Suttanon et al., 2012), the provision of enough
12	detailed information about the intervention (Frederiksen, Sobol, Beyer, Hasselbalch, &
13	Waldemar, 2014), and the use of positive phrasing in recruitment materials (Hawley-Hague,
14	Horne, Skelton, & Todd, 2016). Characteristics of the intervention such as a group-based
15	format (Chong et al., 2014; Dal Bello-Haas et al., 2014; Hawley-Hague et al., 2016), the
16	possibility of adapting the intervention to participants' needs (Chong et al., 2014),
17	affordability (Chong et al., 2014; Hawley-Hague et al., 2016), and the abilities of the
18	instructors to create a bond with participants influence their perceived attractiveness of the
19	intervention (Hawley-Hague et al., 2016). Participants' characteristics also has an impact on
20	acceptance in terms of personal motivations (Hawley-Hague et al., 2016), positive attitudes
21	towards exercise (Chong et al., 2014; Suttanon et al., 2012) or the perceived benefits,
22	including the value of research and the potential reduction of caregiver burden (Suttanon et
23	al., 2012) and the expected impact on cognition (Chong et al., 2014).
24	Interventions designed to enhance well-being amongst people living with dementia
25	and their informal carers are relatively recent (Van't Leven et al., 2013). Dyadic exercise

- 1 interventions, where both the person living with dementia and the carer participate together,
- 2 however, have been well received and feasible in the community (Chew, Chong, Fong, &
- 3 Tay, 2015; Suttanon et al., 2013; Yao, Giordani, Algase, You, & Alexander, 2012; Yu et al.,
- 4 2015). The involvement of both members has been found particularly relevant in exercise
- 5 interventions to ensure safety and promote enjoyment (Dal Bello-Haas et al., 2014; Logsdon,
- 6 McCurry, & Teri, 2005; Suttanon et al., 2012; Yao et al., 2012).
- 7 Tai Chi is a mind-body exercise originated from China and based on the Taoist
- 8 Philosophy (Fetherston & Wei, 2011). Different styles of Tai Chi have been developed (i.e.,
- 9 Chen, Yang, Sun, Wu) keeping most of the essential principles, but adopting different
- 10 characteristics (i.e., intensity) (Fetherston & Wei, 2011). Previous research suggests that Tai
- 11 Chi could be as effective and cost-effective or more than alternative exercises targeting falls
- prevention amongst older people living with or without dementia; and could attract better
- adherence as a 'normal' activity practiced by people of all ages and not just frailer older
- adults (Nyman & Skelton, 2017). However, there is little research exploring the use of Tai
- 15 Chi amongst people living with dementia in the community (Barnes et al., 2015; Burgener et
- al., 2008; Yao et al., 2012). Only Yao et al. (2012)'s pilot study (the most similar to our
- study, using an adapted simplified Yang Style form) used Tai Chi in isolation. In this study
- participants attended 100% of the group sessions; however, those were only delivered twice a
- week for 4 weeks, whereas 84% adhered to the home-practise component which lasted 12
- additional weeks. In two other studies, adherence was around 72-75% to classes delivered 3
- 21 times a week over 18 or 40 weeks, but Tai Chi was not delivered in isolation which makes it
- 22 difficult to differentiate what effects were due to Tai Chi (Barnes et al., 2015; Burgener et al.,
- 23 2008). In all three cases as no qualitative methods were used, there is no way to explain the
- reasons for participants' engagement or disengagement with Tai Chi.

An underuse of qualitative methods has generally been observed in RC1s of
healthcare interventions (Drabble, O'Cathain, Thomas, Rudolph, & Hewison, 2014). While
more recently some RCTs have incorporated a qualitative component in their evaluation, this
has not been the case in feasibility studies (O'Cathain, Thomas, Drabble, Rudolph, &
Hewison, 2013). To our knowledge, only one trial testing exercise in people living with
dementia (Barnes et al., 2015) reported an amendment to their study protocol to implement
qualitative data analysis, although results have not been reported to date. Acceptability has
occasionally been reported by authors following their perceptions about participant's
satisfaction with interventions or providing participants' anecdotal comments (e.g.,
Saravanakumar, Higgins, Van Der Riet, Marquez, & Sibbritt, 2014; Yao et al., 2012). The
need to listen to participants' opinions and perceptions regarding their involvement in Tai Chi
interventions had already been highlighted (Saravanakumar et al., 2014), as it could help to
understand the relevance of the intervention and identify ways of making it more appropriate
for them. In this paper the acceptability of a Tai Chi intervention is explored using
observational and focus groups data. This Tai Chi intervention is the Pilot Intervention Phase
of the TAi ChI for people with demenTia (TACIT Trial). The aim of this study was to obtain
information on the feasibility of a Tai Chi intervention for people living with dementia in the
community, taking part together with an informal carer. The main objective was to identify
any practical issues with the Tai Chi intervention that may reduce participants' acceptability
of the intervention. Sharing the lessons learnt in this study could facilitate people living with
dementia and their carer's adherence to Tai Chi and to similar exercise interventions designed
for such dyads.

23 Methods

Prior to data collection for this study, ethical approval was received from NHS (IRAS Project ID: 209193) and the trial was registered (ClinicalTrials.gov ID: NCT02864056).

Recruitment Strategy

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- 2 Recruitment took place between October and December 2016. Potential participants 3 were initially identified and approached by three National Health Service (NHS) Trusts in the 4 South of England, as well as by the research team using Join Dementia Research (JDR) 5 website where people living with dementia can express their interest in taking part in research. Additionally, the study was advertised locally, allowing potential participants to 6 7 contact the research team directly to express their interest in the study. Once participants made initial contact (or after referral) to the research team, further information about the 8 9 study was posted or emailed to them. Recruitment materials included a Leaflet, a Key Facts Sheet and a Participant Information Sheet. These materials provided information regarding 10 balance, falls prevention, Tai Chi and the implications of getting involved in the study for 11 12 each member of the dyad. Confidentiality, voluntary participation, data protection and consent procedure were also described within the Participant Information Sheet. Potential 13 participants were also provided with a visual representation of the different steps involved in 14 the study. This study was presented as a falls prevention and balance improvement exercise, 15 which was informed by the main outcome measures, and aim of the RCT. At least 48 hours 16 after receiving this information an initial telephone screening was conducted to ascertain 17 eligibility. A total of 53 people were contacted by the research team and of these 10 dyads 18 19 (instead of 14 initially planned at this stage) were successfully recruited into the study (see 20 Figure 1).
- 21 [Figure 1 here]

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Participants

Demographic characteristics of participants included in the study are provided in
Table 1. The inclusion criteria for participants were: A diagnosis of (mild-to moderate)
dementia, be aged 65 years or older, live in their own home, be able to practice standing Tai

- 1 Chi and have a carer available who would provide support during the assessments and at
- 2 home and during the group-based Tai Chi classes. The exclusion criteria were: People with
- 3 Lewy Body dementia or Parkinson's disease, receiving end of life care, those with severe
- 4 dementia symptoms according to the The Mini-Addenbrooke's Cognitive Examination (M-
- 5 ACE) (Hsieh et al., 2015) (cut off point M-ACE <15) or sensory impairments, those already
- 6 practising Tai Chi or who would not be able to attend weekly classes. However, after
- 7 finishing the Pilot Intervention Phase, on re-analysis of M-ACE scores it was revealed that
- 8 three participants included in this phase of the study were in fact ineligible (scores between
- 9 10-15), which was reported to the Sponsor. Nevertheless, all of the participants were able to
- take part in the classes and provide feedback and no one was put at risk from participating in
- the study. A subsequent request was sent to the Research Ethics Committee to lower the M-
- ACE threshold score to 10 or above for the next phase of the study, which was approved.
- 13 [Table 1 here]

Procedure

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- 15 The ten dyads recruited were split in two groups, according to their proximity to the venues.
- 16 In Site 2 participants were invited to attend 4 classes (once a week) and practise at home for
- 20 minutes a day for 3 weeks as planned. The length of classes and home practice was set up
- to imitate the Trial Phase of the study where participants would be encouraged to do so to
- build up over 50 hours of exercise dose (Sherrington et al., 2008). Due to the slower
- 20 recruitment and restricted time-frame, however, participants in Site 1 were invited to join the
- 21 study for 3 weeks only and an extension was not offered. As the aim of this study was to
- 22 obtain qualitative feedback on the experiences of participants to help develop the RCT phase,
- 23 the impact of participants receiving 3 or 4 classes on research outcomes was not measured.
- 24 The classes were to run over 4 weeks to allow the study of the acceptability of the classes, the

1 home-visit conducted by the instructor, the home-based practice and the data collection

2 methods used during dyad's involvement in the study in the short term.

The Tai Chi course was specifically designed and made simple for people to follow, including several repetitions of the movements both in and between classes (during home-practice). Corrections were given to all in class, without excluding any participant, and providing an explanation regarding the importance of ensuring a safe practice. Health and safety protocols were put in place to guide the instructor on what to do in the event of a fall during a class and to allow the instructor know about participants' health conditions before the first class. Classes were led by a professionally trained Tai Chi instructor with experience of working with older participants living with and without dementia. Both pilot groups were led by the same instructor. Venues were chosen after checking their suitability against various criteria: Size (able to accommodate between 14-20 people), maintenance conditions, accessibility by car and/or public transport, time slots availability, flexible booking, availability of onsite kitchen facilities and general accessibility within the venue (i.e., lifts and toilets).

Both venues were spacious, had well maintained wooden floors, heating systems, and used a combination of natural and artificial lighting. Classes were delivered during working days around midday on a weekly basis, following advice from the Public and Patient Involvement (PPI) advisory group that was involved in the TACIT Trial's design (see Appendix A for a description of this meeting). Participants were asked to arrive 10 minutes before the scheduled time of the class, take part in 45 minute Tai Chi classes and engage in conversation for 45 minutes after the Tai Chi class over a cup of tea/coffee and cake. Every session therefore required participants' involvement for up to 90 minutes. Before starting each class, participants had the chance to talk to other participants and the instructor. During the classes participants generally practised in silence and with no or only occasional verbal

- 1 guidelines from the carer to the person living with dementia. Participants were expected to
- 2 stand for the duration of the class to challenge their balance, but they were free to sit before
- and at the end of the session. Each class had the same structure formed by warm-ups,
- 4 patterns, relaxation and socialising. Classes consisted of copying the instructor's movements.
- 5 Each pattern (formed by several movements) was slowly repeated two or three times by the
- 6 instructor, depending on dyads' performance, whilst participants mirrored him. Participants
- 7 responded mostly non-verbally (i.e., with laughs) to the instructor's jokes and interactions.
- 8 Only in a few occasions there was a verbal interaction between dyads and with the instructor.
- 9 Classes developed in a friendly and relaxed atmosphere, where participants kept mostly
- 10 focused on the instructor and received regular positive feedback. After the classes
- participants interacted with each other and with the instructor whilst enjoying some
- refreshments.

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Additionally, dyads were asked to practise Tai Chi at home for 20 minutes a day after the first class. Participants were told that they could compensate their practise over the week (i.e., one day practice 30 minutes instead, and the next only 10; or split their 20 minutes practice in 2 slots of 10 minutes if this could fit better in their routines). A booklet was provided to act as a prompt for participants' home practise, reminding participants how to perform the movements. This booklet contained several pictures of each pattern, supported by explanatory text below each picture.

Dyads were supposed to receive a home-visit from the instructor during the second week of their participation in the study to ensure a safe practice at home and complete an action and a coping plan. However, in practice, only 6 out of 10 received this visit due to time constraints and various reasons. One of the dyads withdrew from the intervention after the first class; a second dyad joined the group a week later and the home-visit had to be postponed because of the person living with dementia not feeling well, but then was never re-

scheduled because was ill for the rest of her participation in the study. For the other two 1 2 dyads, their location was quite far from the Instructor's and they were not able to arrange a 3 suitable time for both to meet. A non-compliance report was filled for this and sent to the 4 Sponsor. Nobody was injured during home-practice and from this experience we learnt that for the future Trial Phase of this study, classes lead by the same instructor would need to start 5 at least two weeks apart and home-visits would only take place after the two first weeks of 6 7 class practice. This way we could ensure enough time for the instructors to conduct these home-visits without fail. Additionally, information given to the participants has been revised 8 9 to make clear there is to be no home-practice until the home-visit is made. Although four dyads did not receive the intervention fully as per the protocol, they were not exposed to 10 undue risk given the very safe intervention they are being asked to do (Tai Chi) in their home 11 12 environment that they are very familiar with. We have not had any experience of there being any risks to account for in any of the home visits in the Pilot Intervention Phase or the ones 13 conducted so far during the RCT phase. 14 The action plan was introduced to identify a suitable time for home-practice and the 15 coping plan to develop strategies to overcome possible barriers to home-practice (Chase, 16 2015). Action and coping plans are techniques used to facilitate behaviour change (National 17 Institute for Health and Care Excellence, 2014), in this study to facilitate participants' 18 19 practice of Tai Chi at home. The action plan is the document where both members of the 20 dyad specify which days of the week, at what times (morning/afternoon/evening), for how long, where specifically and with whom will they practise Tai Chi. The coping plan is the 21 document where both members of the dyad identify the anticipated barriers for practising Tai 22 23 Chi at home. For each barrier anticipated, they are requested to provide a way of overcome it and keep to the plan. 24

- During the study period, one dyad from each Site withdrew from the intervention
- 2 (20% withdrawal rate). Both dyads, however, decided to carry on providing research data.
- 3 As reflected in Table 2, six dyads attended all the classes offered and only one dyad attended
- 4 less than 50% of the classes (33%).
- 5 [Table 2 here]

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Data Collection Process

Field notes were used during participants' involvement in the classes to capture what was observed in the research context (Austin & Sutton, 2014; Patton, 2013) and to record participants and instructor's feedback. During the classes, qualitative semi-structured observations were made over the two study sites following a semi-structured checklist template (see Appendix B for qualitative checklist). Each observation started with an initial description of the venue, participants' interaction, and spatial distribution in the room. To capture changes within sessions, observations were split in three blocks (1st: 0-15 minutes; 2nd: 15-30 minutes; 3rd:30-45 minutes). The observational schedule captured examples of participants' interactions, engagement (as interest and sustained attention) (Kinney & Rentz, 2005), attitudes towards Tai Chi, positive and negative affect (Watson, Clark, & Tellegen, 1988), communication (as expressions of pleasure, sadness, self-esteem, and normalcy) (Kinney & Rentz, 2005), and psychological needs satisfaction (Deci & Ryan, 2000). Data collected by the researcher observing the sessions were quotes (where possible) or a description of what was happening in the intervention context. Sessions were not video or audio-recorded as the instructor opposed this. However, to ensure the appropriateness of the qualitative observation tool created for this study, two authors (first and last) took notes (following guidelines provided by the first author in an observational codebook) during sessions organised in Site 1, which were later compared to refine the observational data collection tool. At the end of each class, during the 45 minutes allocated to socialise, the first

- 1 author interacted with the participants and the instructor individually and they provided their
- 2 feedback about the session. This feedback was not audio-recorded but the researcher took
- 3 notes whilst participants were providing their feedback or immediately after to avoid altering
- 4 their accounts.

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Focus group data were collected immediately after the last class (3rd or 4th depending

of the Site), and both lasted around one hour taking place in the same venue as the Tai Chi

class. All dyads attending the last class (n=7, 3 dyads in Site 1 and 4 dyads in Site 2) were

involved in these focus groups. Two researchers facilitated each joint dyadic focus group

(last and first authors in Site 1 and first and third in Site 2) and ensured the focus group

schedule was followed. Topics covered included (see Appendix C for focus group

schedule): Experience of taking part in Tai Chi classes and at home, their willingness to

continue and their experience of taking part in research. This was audio-recorded and

professionally transcribed verbatim, to ensure the accuracy of participants' accounts. First

author attended all the sessions and was present in both focus groups. This researcher was in

touch with participants weekly so they were sharing their experiences with a familiar person.

Ethical Issues

Due to the progressive nature of dementia process consent procedure was followed (Dewing, 2008), meaning that participants were verbally asked about their willingness to carry on taking part in the study at key points in the study, as well as the researcher looking

for verbal cues that confirmed consent to participate.

During the data collection process participants were informed any data collected would be anonymised so their identities or any personal details would not be disclosed, participants' non-verbal communication, particularly for participants living with dementia was checked during their interactions with the researchers. Participants provided informed consent to take part in the study and focus group during the baseline home-visit, when they

- 1 were asked to summarise back to the researcher what the study was about and what they
- 2 would be doing as part of their participation in the study to check their ability to provide
- 3 informed consent. However, to ensure their willingness to continue taking part in the study,
- 4 process consent was sought at each interaction with the researcher. This was also verbally
- 5 checked before and after the focus group. Should any participant have declined to carry on
- 6 with their participation in the study, up until the point when their data would have been
- 7 anonymised, their data would have not been analysed. During the focus group, all
- 8 participants were given an equal opportunity to share their experiences, with occasional direct
- 9 invitations from the researcher to contribute to the conversation. To facilitate participants'
- 10 living with dementia's involvement in the conversation, printed copies of focus group
- 11 questions were provided in A4.

Data Analysis Strategy

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Thematic analysis was used to identify common trends in systematic qualitative observations of the classes, field notes containing participants and instructor's views during their involvement in the study and the content of the focus groups. Methodological (observation, feedback and focus group) and data sources (participants, instructor and researchers) triangulation were used to ensure credibility. Data were analysed together following the 6 steps described by Braun and Clarke (2013) for thematic analysis: a) Audio files from focus groups were professionally transcribed verbatim, double-checked and anonymised (UK Data Archive, N. D.); b) Reading and re-reading the transcripts to get familiar with the data; c) Coding all the data sets inductively, looking for salient units of meaning (Saldaña, 2016) in the manifest content expressed by participants, and developed a codebook with inclusion and exclusion criteria and examples for each code. A large number of codes were identified after this process and, after revision, very similar codes were merged; d) Themes were searched amongst the codes; e) Themes were reviewed to make sure

- they were representative of the codes contained; and f) Themes were defined and named.
- 2 Data sets and the analytical process were managed using NVivo.11 (QSR International Pty
- 3 Ltd., 2012). One author (first) coded the whole data set, and once the initial codes had been
- 4 identified, and refined (merging very similar codes), a coding booklet was developed. This
- 5 booklet was provided to the second author, who double coded 10% of each type of data
- 6 collected to enhance rigour. Coding was compared to refine the coding framework.

7 Results

The intervention was well received by the majority of participants (9 out of 10 dyads) who expressed a willingness to carry on practicing Tai Chi after the study (see Table 1 for participants' characteristics). The remaining dyad was unable to continue participating in the pilot and withdrew after the first class due to health issues.

Two main themes were identified: intervention's characteristics and participants' reactions to the intervention (as reported in Table 3). Direct quotes presented contain participant identification numbers and a "C" when mentioned by a carer or a "P" if was mentioned by a person living with dementia. An "O" indicates this was heard during an observation or observed and described by the researcher, "FG" in the context of a focus group, and "F" when providing feedback at the end of the class. A summary of barriers, facilitators and improvements suggested to enhance the acceptability of the intervention by participants, the instructor or the research team are provided in Table 3.

[Table 3 here]

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Intervention's Characteristics

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

2	example quotes). Both people living with dementia and their carers stated that they were able
3	to understand him as he was using clear speech and a calm tone of voice. During the classes,
4	the instructor made use of examples from his private life to create rapport with participants
5	(i.e., sharing comments made by his daughter), but also used examples from everyday life to
6	describe the movements during the classes (i.e., "is like drinking a cup of tea" (O)). He
7	regularly provided positive feedback during the classes to encourage participants'
8	engagement in the activity and reassured the participants when they verbalised difficulties
9	while doing Tai Chi at home or during classes. Sometimes this positive feedback was given
10	when some participants were struggling to perform the movements or doing them incorrectly.
11	This approach was chosen by the instructor for this study to facilitate their engagement and
12	was positively perceived by one of the carers during a focus group:
13	when he's doing the exercises, he says, oh, that's good, yes, that's right, you're doing it
14	right there, butyou know they're not really but he's just encouraging (02001C-
15	FG).
16	Corrections, however, were mostly made as a general comment not directed to
17	individual participants (i.e., "golden rule: your knees very slightly bent go forward and your
18	heels stay in the ground" (O)), unless participants had expressed a particular difficulty in
19	performing a movement. The instructor reinforced participants' home-practice by providing
20	positive feedback (i.e., "I can see some of you have been practising" (O)).
21	The instructor adapted the intervention to participants' needs and responded to their
22	requests (i.e., introducing breathing while practising one movement, as requested by a carer
23	during the class) to make the intervention accessible for both people living with dementia and
24	their carers. He emphasised the need of participants to focus only on their own performance.

Instructional methods. All participants valued the instructor (see Table 3 for

1 Class and home-based Tai Chi practice. Occasionally participants performed better 2 when attempting a move for the second time during a class. However, more frequently 3 participants (mostly people living with dementia) carried on practising the movement in the 4 opposite direction, bending too much forward or pausing their engagement in the activity. During the first class participants living with dementia stood closer to their carers, however in 5 the classes that followed three of the carers in Site 2 practised in front, leaving the person 6 7 living with dementia to work individually behind them. At home, eight out of ten dyads reported that they had managed to do some practice. 8 9 Dyads who did not report any practice were the one dyad who withdrew after the first class and another dyad that attended all the classes but was not able to practice due to an 10 unexpected lack of time. 11 12 Two carers verbalised their difficulties motivating the person living with dementia to do things, which had an impact on their home-practise meaning that they did not manage to 13 do any practise or not more than 20 minutes during one week. However, only one participant 14 living with dementia struggling to practice at home had experienced difficulties following the 15 classes, instead focused on doing the warm ups ("you do get quite a bit of benefit in that" 16 17 (02004C-FG), "But our warm-ups is Tai Chi in my mind" (02004P-FG)). The lack of guidance and confidence when practising at home was the main issue 18 19 raised by participant dyads. Particularly carers felt like the "blind leading the blind", which 20 led one of the carers to stop practising at home, whilst the person living with dementia carried on alone, convinced that any practice would be positive for her. The booklet in all the cases 21 was perceived as not useful, unclear and with inconsistent (picture-description) instructions 22

which failed to show the progression of the movements (see Table 3 for example quotes).

Participants' Reactions to the Intervention

Subthemes contained by this overarching theme relate to the way participants responded to the intervention in terms of their: a) feelings toward the intervention and their dyadic participation; and b) interaction with others (see Table 3).

Feelings towards the intervention and their dyadic participation. Before starting the classes and after the first class half the dyads were particularly passionate and enthusiastic about the opportunity of taking part in Tai Chi, whereas the rest were more neutral in their behaviours and expressions. Generally, participants had neutral and positive feelings towards the intervention ("a good addition to my life" (02005P-F)). All participants shared their enjoyment of the intervention and the socialising component, when providing feedback (see Table 3 for example quotes). However, only occasionally they verbalised this satisfaction during the class (i.e., "I like it!" (01002P-O)). In site 2, participants expressed their content non-verbally at the end of the class by clapping the instructor.

Tai Chi was perceived as a different activity that participants were not familiar with, however, this had no impact on participants' enjoyment and engagement in the activity ("It's strange from another tasters that I went to, but I like it" (02003P-FG)). Tai Chi is an activity that carers see themselves doing with their partners to improve or maintain their physical condition unlike other types of exercise, and both enjoy doing.

Carers did not find their joint participation to be a burden. Only one expressed it had been hard as a carer although he would keep going for the person living with dementia and the possibility of meeting with other carers. Similarly, only one participant living with dementia seemed to react negatively towards the intervention, feeling "distressed before going" (02006C-F)) to the sessions as reported by the carer.

During the classes, all participants were focused in the session, looking at the instructor and copying his movements. Three participants expressed they had experienced

1	difficulties following the classes after the first session, one due to their fear of falling and
2	two because they struggled during sessions when copying more complicated patterns. It was
3	clearly observed, however, that an additional participant, who did not report any difficulties,
4	also struggled copying some of the movements. One of the participants living with dementia,
5	on the contrary, according to the instructor and first author's observations got more into the
6	intervention and was able to follow the class without verbal prompting from the carer. Carers
7	engaged in the intervention reported no difficulties in copying the movements during the
8	classes. Generally, participants appear to enhance their perceptions of competence during
9	sessions and with practice, feelings of the "flow" and getting other benefits of the
10	intervention. Participants' progress was already noticeable in the second class when half of
11	the participants living with dementia and carers anticipated the movements taught by the
12	instructor. Finally, three non-serious and non-severe, and expected adverse events
13	experienced by participants were rated as definitely/probably/possibly related to the
14	intervention: dizziness - reported by two participants living with dementia and pain -reported
15	by a carer and attributed to previous conditions, which did not impact on their willingness to
16	carry on practising Tai Chi.
17	The most important facilitators of participants' engagement in the intervention were
18	the benefits perceived by both members of the dyad after taking part in the intervention: a)
19	relaxation; b) exercise for health benefits -increasing activity levels, keeping muscle supple;
20	c) body awareness-"it makes you think about what's going on in your body while you're
21	doing this" (01004P-FG); d) brain stimulation; and e) balance improvement. Taking part in
22	the intervention was perceived as a source of pride in itself.
23	Interactions with others. During the classes, most of the interactions were initiated
24	by the instructor as he was the one leading the session. However, participants reacted to the
25	instructor's comments frequently with smiles and laughs. In both sites only occasionally

there was an interaction between members of the same dyad, for instance, in the form of non-

2 verbal interactions expressing mutual understanding. When the carers started a verbal

3 interaction this was always in a soft and comfortable way to ensure the person living with

dementia was all right or to support the instructions provided by the instructor. At the end of

the class participants were able to engage in informal conversation with other dyads and the

instructor.

7 Discussion

The aim of this study was to understand what is influencing the acceptability of Tai Chi amongst people living with dementia and their carers and how this could be enhanced. Findings suggest that Tai Chi is perceived by people living with dementia of mild-to-moderate severity and their carers as an enjoyable activity that they can readily carry out together. Carers play a key role in supporting people living with dementia's involvement in the classes and facilitating home-practice, therefore content and supporting materials must be carefully adapted so both members feel comfortable when practicing at home. Once incorporated in their routines, Tai Chi could be an enjoyable and mutually beneficial activity.

Caution is required in supporting the acceptability of Tai Chi as a falls prevention intervention, as recruitment was challenging. An important reason for this is that eligible participants felt that they were not at risk of falls (Hawley-Hague et al., 2016) and as such that a falls prevention intervention was not for them. This has been a common problem in that participants rate exercise intervention designed to reduce falls as important for other people (Haines, Day, Hill, Clemson, & Finch, 2014). In this study there were also participants who did not feel at risk of falls, which is consistent with the findings of another study with older participants (Yardley et al., 2006). For this reason, in the RCT phase of the TACIT Trial we have changed our strategy to take the emphasis away from falls to general health and well-being.

Class-Based Practice

The intervention was widely accepted by participants who particularly adhered to the class-based component. Consistent with previous exercise research, the qualities of the instructor (Hawley-Hague et al., 2016), the creation of a warm and failure-free environment (Barnes et al., 2015) and the socialising component (Wu et al., 2015) have been positively valued by participants and influenced their adherence to the study.

Researchers observed participants living with dementia that at times struggled to copy

the instructor; however these participants only reported their enjoyment of Tai Chi. One reason for this might be that they felt able to do the Tai Chi well-enough and so report that they found the experience enjoyable. This could be partially supported by previous research suggesting that participants' enjoyment of the intervention could be critical for their sustained participation in falls prevention interventions (McPhate et al., 2016). Previous studies have also found apathy in participants with lack of insight to their dementia symptoms (Aalten et al., 2006). This could explain a lack of awareness about their performance during the classes and their tendency not to communicate their difficulties. However, participants' enjoyment of the socialising component could have impacted more positively on their acceptability of the intervention, as the satisfaction of the social need seemed to be crucial for people living with dementia (Maki, Amari, Yamaguchi, Nakaaki, & Yamaguchi, 2012).

Low sense of efficacy performing the movements perceived by the carer or the person living with dementia could have an impact on participants' willingness to carry on taking part in the intervention. Both dyads who expressed this lack of competence ended up not willing (or not being able, due to health issues) to attend further sessions. In light of these results, tailored support from the instructor (Chong et al., 2014; Day, Trotter, Donaldson, Hill, & Finch, 2016; Pitkälä et al., 2013) in becoming aware of these perceptions could facilitate their adherence to the exercise intervention. Having successful experiences and verbal

- 1 encouragement from the instructor, however, could have enhanced most participants' efficacy
- beliefs (Bandura, 1977) which in turn have been shown to be a predictor of perseverance and
- 3 adherence (Alharbi et al., 2016).

Home-Based Practice

The home-based component was generally well perceived by participants who included Tai Chi practice in their routines. However, their acceptability was challenged due to their difficulties remembering the Tai Chi movements at home, which was not improved by the use of the home-exercise booklet. Such difficulties could have potentially impacted on participants' adherence to the home-based component. Our results expand on previous research findings suggesting the use of memory aids such as exercise booklets with images and explanations to support home-practice (Connell & Janevic, 2009; Logghe et al., 2011; Logsdon, McCurry, Pike, & Teri, 2009; Prick et al., 2014; Suttanon et al., 2013) and highlight the need for additional support so participants can perceive movements' progression.

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

Dyadic Approach

In this study the use of a dyadic approach was accepted by both people living with dementia and their carers. This finding concurs with previous studies where a dyadic

- approach had been used to facilitate people living with dementia's adherence to exercise
- 2 interventions (Teri et al., 2003; Yao et al., 2012). Results from the current study suggest that
- 3 this dyadic approach could not only facilitate their adherence to the intervention, but enable
- 4 people living with dementia's inclusion in these interventions. In the same way, feedback
- 5 from carers reinforce the use of this dyadic approach in the context of dementia as it gives
- 6 them the opportunity to discover enjoyable activities which could evolve to shared interests.
- 7 These would be of particular relevance when these common activities could be helpful for
- 8 carers (to experience their role more positively) and the person living with dementia (to feel
- 9 competent and empowered) (DiLauro, Pereira, Carr, Chiu, & Wesson, 2015; Lamotte, Shah,
- Lazarov, & Corcos, 2016). Another strength of this dyadic approach highlighted by carers is
- that both, they themselves and the person living with dementia benefit from taking part in Tai
- 12 Chi. This perceived benefit could potentially mean carers are willing to carry on practising
- after their involvement in the study, which would also be of benefit for the person living with
- dementia (Lamotte et al., 2016). In contrast to some reports in the literature (Wesson et al.,
- 2013; Woods et al., 2016), carers did not perceive their involvement in this study as a burden.

Strengths and Limitations

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- Our results describe for the first time how people living with dementia and their carers
- respond to a Tai Chi exercise intervention. This study is the first of its kind to use qualitative
- methods to understand how appropriate a Tai Chi intervention is for people living with
- 20 dementia and their carers. The use of a dyadic approach to gather the views of participants
- 21 living with dementia and their carers, has enabled carers to support the researcher by
- rephrasing questions and inviting the person living with dementia to provide their views
- during the focus groups, as found in previous research (Nyman, Innes, & Heward, 2016;
- 24 Prick et al., 2014) and in the TACIT Trial PPI advisory group.

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This study has a number of limitations. First, the quality of the observations may have been impacted by the fact that the Tai Chi classes were not video-recorded (as the instructor did not consent for him or participants to be recorded during classes). The researcher may have missed some participants' reactions whilst they were taking notes on different participants. Second, feedback from the two dyads who withdrew from the intervention was limited because one did not agree to take part in the final focus group, and the other dyad was not feeling well after their holiday period. An interview with the dyad that withdrew during the first class could have provided more insight into ways of facilitating their acceptability of the intervention. Third, time to collect participants' views at the end of the class was also limited, however, capturing how people feel in that specific moment (after practising Tai Chi) could be particularly relevant in the context of dementia as recall could be facilitated by interviewing participants in their natural environment where they were taking part in the activity (Nygård, 2006). Lastly, during one of the focus group participants living with dementia could have felt uncomfortable by hearing their carers commenting they are not always able to provide accurate responses. Although people living with dementia did not seem to respond verbally or non-verbally to this, this could have silenced their voices.

Practical Implications

This study highlights three main aspects which should be considered in designing future exercise programs for people with dementia. First, the use of a dyadic approach in exercise interventions could be beneficial for both the person living with dementia and the carer at an individual level, but also facilitate their uptake of the intervention, as this would provide them with a potential common interest. Second, the combination of class and homebased practice could be advantageous to reinforce participants' social support networks as well as strengthen dyadic relationships and facilitate the acceptability of the intervention by feeling an increased competence. Third, instructors' awareness of dementia and adapted

- 1 instructional methods in class and support materials at home facilitates participants'
- 2 acceptability of the classes. For this reason, it must be taken into account that booklets with
- 3 images and descriptions might be insufficient for people living with dementia and their carers
- 4 when facing unfamiliar movements such as those of Tai Chi. In this case, simple, clear and
 - when possible, dynamic prompts (i.e., DVD) are advised.

Future Research

Future research investigating the acceptability of Tai Chi should consider the inclusion of participants from different ethnic backgrounds and with different relationships with the person living with dementia (other than spouse). In this study, informal carers were sought to be recruited independently from their relationship with the person living with dementia. However, only one dyad was not formed by a couple and in all cases the person living with dementia was living with the informal carer, which could have influenced their acceptability of the intervention and particularly their availability to take part in home-based practice. Similarly, the impact of the size of the group on dyads acceptability was only explored in two small groups, which could be less cost effective in community settings. The acceptability of larger groups formed by dyads rests unexplored in the context of exercise interventions for people living with dementia and their informal carers.

18 Conclusion

In summary, this novel study contributes to our understanding of the experiences, needs and preferences of people living with dementia taking part in exercise interventions with their carers. Intervention's characteristics and participants' reactions to the intervention might impact on their acceptability of exercise interventions. A series of improvements have been suggested by participants, instructor and the research team to facilitate the engagement of people living with dementia with different levels of performance (i.e., reducing the amount of content to be delivered) and support home practice (i.e., adjusting materials).

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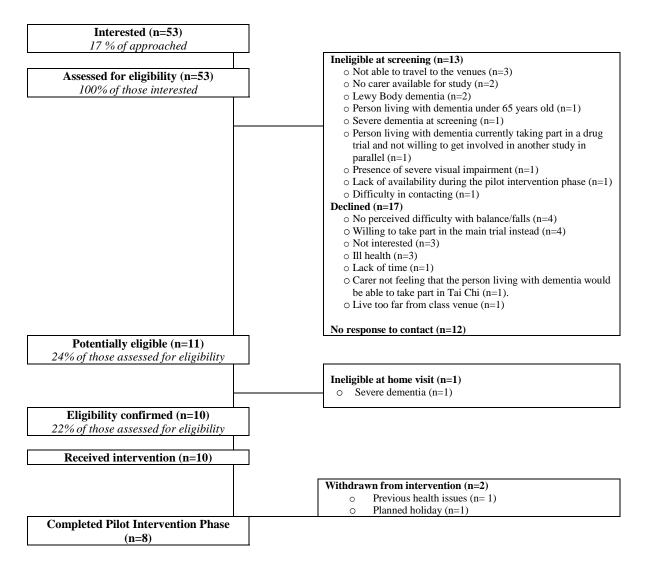
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1 Figure 1. Flow diagram of participant recruitment.

Table 1

Baseline Demographic Characteristics

Participant	Item	Frequencies o	r means (Standard Deviations	(SD))
		Site 1 (n=4)	Site 2 (n=6)	Total
People Living	Gender			
With	Male	2	3	5
Dementia	Female	2	3	5
Dementia	Mean age (SD)	73.75 (0.96)	81.17 (5.04)	78.20 (5.39)
	Relationship status	75175 (61,76)	01117 (01017)	70.20 (0.03)
	Married / Civil partnership	3	5	8
	With partner	1	0	1
	Widowed	0	1	1
	Current living situation	· ·	1	1
	Living with family/friends	4	6	10
	Level of education	·	· ·	10
	Primary	0	2	2
	Secondary	2	$\frac{1}{2}$	4
	Higher education college /			•
	university	1	0	1
	Further education /	1	3	2
	professional qualification	1	2	3
	Ethnicity			
	White	4	6	10
	Dementia type	·	~	
	Alzheimer's	3	6	9
	Mixed Alzheimer's &			
	Vascular	1	0	1
	Mean number of months	21 (22 22)	25 67 (20 56)	22 00 (24 07)
	diagnosed with dementia (SD)	21 (22.23)	25.67 (28.56)	23.80 (24.97)
	Other chronic conditions			
		2	4	
		(Claysoma biob message	(Fibromyalgia ² and stroke/	
	Yes	(Glaucoma, high pressure and headache/hypertension/	prostate cancer and	7
			diverticulitis ³ /neuralgia ⁴ /	
		sarcoidosis1)	hypertension)	
	No	1	2	3
	Uses a walking aid?			
	No	4	6	10
	Mean prescribed daily			
	medications (SD)	3.5 (1.29)	5.5 (4.32)	4.7 (3.47)
	Falls in the last year?			
			1/	
	Yes	0	1 (minor injury)	1
	No	4	5	9
	Falls in the last month?	0	1 (minor injum)	1
	Yes		1 (minor injury)	
	No Frequency of moderate PA	4	5	9
	practise			
	Everyday	1	2	3
	3 times per week	1	0	1
	2 times per week	$\overset{1}{2}$	1	3
	Weekly	0	1	1
	Rarely/never	0	2	2
	Frequency of vigorous PA	v	_	-
	practise			
	Monthly	1	0	1
	Rarely/never	3	6	9

¹ Sarcoidosis is a disease "characterized by the formation of immune granulomas" in any organ affected (Strookappe et al., 2015, p. 701). If present, symptomatology generally disappears spontaneously or with adequate treatment without further consequences for the patient (Judson, 2015).

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² Fibromyalgia is a syndrome characterised by chronic "widespread pain" and possibly other physical (i.e., "muscle stiffness") and psychological ("memory and concentration" difficulties) manifestations (NHS, 2016).

³ Diverticulitis is an infection caused by bacterial accumulation in "small bulges that stick out of the side of the large intestine" which is generally cured after dietary, pharmacological or (rarely) surgical intervention (NHS, 2014).

⁴ Neuralgia is the pain caused by nerve irritation or damage (Shelat, 2016).

Table 1 Continued

Participant	Item	Frequenc	ies or means (Standard Deviat	ions (SD))
		Site 1 (n=4)	Site 2 (n=6)	Total
People Living With Dementia	Previous experience practising Tai Chi? No Mean confidence about	4	6	10
	being able to practise Tai Chi for at least 20 minutes per day (SD) ⁵ Mean intention to practise	1.75 (0.96)	2.67 (1.21)	2.3 (1.16)
	Tai Chi for at least 20 minutes per day (SD) ⁶	2.25 (0.96)	2.17 (0.75)	2.2 (0.79)
Carers	Gender			
	Male	2	2	4
	Female	2	4	6
	Mean age (SD)	69.25 (1.5)	74.5 (5.96)	72.40 (5.28)
	Relationship with the person living with dementia			
	Spouse/partner	4	5	9
	Other Live with the person living with dementia	0	1 (niece)	1
	Yes	4	6	10
	Relationship status			
	Married / Civil	3	6	9
	partnership			
	With partner Current living situation	1	0	1
	Living with family/friends Level of education	4	6	10
	Primary	0	1	1
	Secondary	1	2	3
	Higher education college/university Further	2	1	3
	education/professional qualification Ethnicity	1	2	3
	White Previous experience practising Tai Chi?	4	6	10
	No Mean confidence about	4	6	10
	being able to practise Tai Chi for at least 20 minutes per day (SD) ⁵ Mean intention to practise	1.33 (0.58)	1.17 (1.17)	1.89 (1.05)
	Tai Chi for at least 20 minutes per day (SD) ⁶	1.33 (0.58)	2 (1.1)	1.78 (0.97)

⁵ Participants were asked to rate their confidence using a Likert scale from 1 (true) to 7 (false), where 1 was the best score –showing participants' confidence about being able to practise for 20 minutes per day.

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⁶ Participants were asked to rate their intention using a Likert scale from 1 (likely) to 7 (unlikely), where 1 was the best score –showing participants' intention to practise for at least 20 minutes per day.

Table 2 Dyads' Attendance to the Classes in the Pilot Intervention Phase

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

¹ Due to previous health issues.

² Due to a traffic accident blocking traffic.

³ Due to planned holiday. ⁴ Due to illness.

Table 3

Barriers, Facilitators and Improvements Suggested to Increasing Participant's Acceptability of Tai Chi

Theme / Subtheme	Facilitators	Barriers	Improvements suggested (by)
Interventions characteri Instructional methods Instructional methods Instructional sp mm care con the care with		• Amount of content delivered during the classes (Participants). As that was only a short course. I think if you'd concentrated on the warm-ups, to be perfectly honest (02004C-FG); Yeah (02003C-FG); Because you getyou do get quite a bit of benefit in that (02004C-FG); Yeah (02001C-FG); Yeah (02003C-FG); And these people here are pretty limited, you know(02004C-FG); Yeah (02003C-FG); you know, they can't help it, but they'll only grasp so much. And I think toto concentrate on a few movements every weekwould benefit them (02004C-FG);if you're gonna go to the few that probably do grasp	• Reduce the amount of content to be delivered during the classes to adapt the intervention to participants with more difficulties copying the movements (Instructor and participants).

¹ Direct quotes are coded with the participant number and a "C" if provided by a carer or a "P" if provided by the person living with dementia. An additional code is used to mark the context where data was collected: during observations ("O"), feedback provided at the end of the class ("F"), or during the focus group ("FG").

Table 3 Continued

Theme / Subtheme	Facilitators	Barriers	Improvements suggested (by)
	<instructor>'s so good that it's really brought it home to me what the various movements are (02004P-FG)he's a good man, isn't he (02001P-FG) an excellent instructor who made the classes fun (01002P-FG).</instructor>	The ones that can't are the ones that really need the help, aren't they really. (02004C-FG); ()I picked hold of them reasonably well, but you have to realise everyone's got their own limitations (02004C-FG).	
	 Adaptation of the classes to participants' needs or requests (Instructor and researcher). 	The worry I got is if it, um, if it progressed and it was more complicated, how she would cope	
	Tai Chi is about you, this is your Tai Chi () everybody has different flexibility, different hips. Please don't worry about looking as anybody else (Instructor-O).	with the complicated bits (01003C-FG); I would have expected that <instructor> would manage that side of things. I don't think he's going to push people beyond what</instructor>	
	The instructor says in the next class it was planned to introduce something new, but comments he'll not do this, to adapt the class to the group's needs (Researcher notes).	 they could be expected to reasonably do (01004C-FG). Lack of tailored support to individuals who kept performing the movements wrong after correction (Observed by 	 Approach participants
	02001C asks the instructor "what's the breathing with that one?" —The instructor responds to 02001C's question "that's actually a good thing, let's do it incorporating breathing"—and at the end of the practise the instructor adds "I like questions, questions are good!" (Researcher	researcher). Keeps doing the movement in the wrong direction, stays on a side (Researcher - O). I got muddled up there (01004P-O) (and we could see this). <instructor> said actually she did it right but only got footwork</instructor>	individually if required copying the movements closer and in front of them to support their individual and safe practice (Research team).

Table 3 Continued

Theme / Subtheme	Facilitators	Barriers	Improvements suggested (by)
	 "Breathing makes me dizzy" (01004P-O) – <instructor> said not to focus on breathing then (Researcher notes).</instructor> Provision of regular positive feedback (Observed by researcher). Good stuff, your movement is great (to 01002P), everybody's movement is great; You're doing great <02004P>; Excellent, that's good, that's perfect, wonderful (Instructor –O) Creation of a reassuring, failure free and warm class environment (Observed by researcher). Use of everyday life examples to facilitate copying the movements and create rapport with participants (Observed by researcher). 	slightly wrong (in heel not in toe). Second time she still didn't confidently do it and got stuck again (Researcher - O).	
Class-based Tai Chi	 raising your hand as if you're taking your cup of tea;like asking for money;Imagine you are riding a horse (Instructor –O). Movements' repetition - most of the movements were practised twice (Participants and researcher). Misses some parts of the pattern (the 	 Unexpected or unavoidable difficulties to attend the classes: traffic accident, ill-health, planned holiday period (Research team). 	_

Table 3 Continued

Theme / Subtheme	Facilitators	Barriers	Improvements suggested (by)
	for 45 minutes (Participants and researcher).	During classes: coughing, stopping practice because of fear of falling or feeling stiff (Observed by researcher).	• Instructor's closer relationship with participants to know the reasons they have to stop their practice during classes and provide any support required to facilitate their continued engagement (Research team).

Table 3 Continued

Theme / Subtheme	Facilitators	Barriers	Improvements suggested (by)
	(02002C-FG). And the actual venue itself, do you think this is a good venue or do you think we could try and? (Researcher); Oh yes. Yes (01004P-FG); Yes (01004C-FG); Yes. Very good (01002P-FG). It's ideal (01002C-FG). A car park and a, and a nice room, small (01002P).		
Home-based Tai Chi	 Timings (Participants and researcher). Length of the classes (Participants and researcher). I think that's perfect the timingAnd the time of the day and the length of time (02003C-FG); Yes (02001C-FG); By the time my wife gets up, it is anyway [laugh] (02004C-FG). Group sizes (Participants and researcher). Allocation of socialising time at the end (Participants and researcher). Carers supporting practice (Participants). Role of routine (Participants). 	 Early start of home-practice (Participants). Booklet (overwhelming and unclear) (Participants) 	 Provide the booklet in smaller volumes (Participants). Delay home practice at least two weeks after starting the
	I find everything's easierlife is routine in our household, and it, and it works very, very well (01002C-FG); Yeah (01002P-FG); That's interesting I'm afraid we're quite the	unclear). (Participants) Negative feelings raised by the home-exercises booklet. "I felt depressed" (01004P-F) when she was not able to follow the	two weeks after starting the class-based practice, so participants are more familiar with the movements and carers feel more confident to

Table 3 Continued

Theme / Subtheme	Facilitators	Barriers	Improvements suggested (by)
	opposite (01004C-FG); Yeah I find routine helps me (01004P-FG); We don't have a lot of routine. We We, we found it far better to do the Tai Chi in the mornings after breakfast <01004P> gets tired towards the end of the day so, you know, we listen to the news and things But if, um, if we had a, a shopping day and got up, had	booklet. The class sessions were very good but at home we found the book slightly overwhelming and perhaps a DVD of <instructor> would have been more helpful. (01003C-FG) "Booklet not helpful, need a DVD" (02002C-F).</instructor>	guide the person living with dementia (Participants and research team). • Create a DVD as requested by participants or provide a crib sheet to guide their practice (Participants and instructor).
	breakfast and went out and came back, those are the days we, we might have given it a miss So itI, Iroutine is important, um, but it, it depends how busy you are (01004C-FG); Yes (01004P-FG). It's good, isn't it, this time of year when the winter's coming on and, um, to help people, er,you know, the people who are caring to, um, exkeep exercising without having to go out time. Well, apart from the lessons, obviously, um(02003C-FG); It becomes the routine really doesn't it? (02004C-FG)() It's fitting it in what we do, isn't it (02001C-FG). Importance of repetition to improve practice and get the benefits of the intervention (Participants). It's the, it's the repetition that's the	 The book I foundI'm not as good as I was at reading and the book was difficult for me to comprehendYeah, I'd like to have had him [Instructor] on the screen in front of me so I could copy him [laughs] (01002P-FG); II, I basically think it's that we haven't had enough practice. We have done one session here(01002C-FG). Carers' lack of confidence guiding the person living with dementia (Participants). Difficulty remembering (how to start) the movements/practice (Participants). The very first weeks participants felt home-practice was difficult as 	• Allow at least two weeks between the start of classes lead by the same instructor to facilitate home-visits scheduling (Instructor).

Table 3 Continued

Theme / Subtheme	Facilitators	Barriers	Improvements suggested (by)
	importantpart of it (01002P-FG). Just when heyou, you practice over and over againI mean, it's much better than you saying, well, do this and then, and then the next minute you've forgotten all about it (01004P-FG). • Participants' determination to achieve perceived benefits (Participants). [Home practice]Um, not every day, I must say [laughs], but mostly we have, yes. Um, and yes, I found that beneficial and in I don't know that, um, weI don'tsome of the things are probably not, um, we're notWe're not probably doing them properly And I, and I do forget(01004P-FG); And us [laughs] (01003C-FG); Yeah. I do forget whether you should be going up there or down there or, you know, and if But then somehow it doesn't really seem to matter all that much [laughs] (01004P-FG); It's still doing us some good (01003C-FG). • Participants' pointing to unexpected events as barriers to practice and being positive providing ways to overcome these difficulties and do the practice (Instructor).	they could not remember what they had been doing in class (Instructor-F). So one session, and then you go home and you're doing four different things and you've got to do it for so many different times. It was a bit like the blind leading the blind. () Then try to guide somebody else with something you're not sure about (01002C-FG). once you've started the restafter a couple of movements the rest actually falls into placeIt's starting it that's the difficultYour first action is the difficultyAt home, in the lounge, you're stood there and youI didn't really know We did get into itbut starting was hard (01002P-FG). Carers' discontinued engagement in practice due to their lack of confidence (Participants). 01004P reports being practising alone after 01004C stopped practising because he was not sure he was doing the movements right (01004P-F).	Ask carers about ways of getting over people living with dementia's lack of motivation (Research team).

Table 3 Continued

Theme / Subtheme	Facilitators	Barriers	Improvements suggested (by)
	visits were useful to clarify and make home-practice easier (Participants).	 Instructor's time constraints to arrange home-visits (Instructor). Carers' difficulties to motivate the person living with dementia to do things or to carry on practising for 20 minutes (Participants). But, er, as I said to you, we could do the movement, got to do the movethe warm-ups fairly quickly and, er, we did them alright. So we concentrated on the warm-ups more than anything else, to be perfectly honest. When it got to the actual Tai Chi, er, we never really got the hang of that completely. But the warm-ups, yes, it was(02004C-FG); Yeah, that's what we did (02004P-FG);it was quite good. So we concentrated on giving warm-ups a little more extra time so that, you knowwe tried to get to 20 minutes but, um(02004C-FG); But our warm-ups is Tai Chi in my mind (02004P-FG); Well, it is Tai Chi, <02004P>, yeah, yes (01004P-FG); Well, call it Tai Chi because it sounds much better than warm-ups (02004P-FG); [laugh] Yeah, well, it was (02004C-FG); Did anyone else 	Prompt participants to fill in their action and coping plans or use a duplicate system to

Table 3 Continued

Theme / Subtheme	Facilitators	Barriers	Improvements suggested (by)
Douti sin ont's voc	t ions	 do the timer, do you know? I found this business of not being able to concentrate for too long (02003C-FG). Participants' not filling their action and coping plans (Instructor). Finding time to practice (Participants) 	reduce instructor's work load during home-visits (Instructor).
Participant's reactor to the intervention		 Feeling sceptical about the 	Reassure participants who
Feelings towards the intervention and their dyadic Table 3 Continued	intervention as a facilitator for people living with dementia's involvement in Tai Chi practice (Participants). 01004P and 01003P report that they would not have joined the class without	 intervention (Participants). Perception of Tai Chi as an "awkward activity" (Participants). Carers feeling hard to take part in the intervention (although the socialising component would compensate this effort) (Participants). Perception of Tai Chi as not appropriate for people living with dementia at more advanced stages, or as being less beneficial for them 	 Reassure participants who express this and explain them the potential benefits of practising Tai Chi (Research team). Reinforce the idea that practice is more important than the number of patterns performed, to avoid participants feeling that they are not practising enough (i.e.,
	 Carers not feeling burden in taking part together with the person living with dementia and providing support at home (Participants). Rewarding for both members of the dyad (Participants). 	(Participants). I've enjoyed it. I've enjoyed it to a point but I've found it hard work being a carer. And, um, but if it helps me wife, so it's all very well, yeah. Um, er, it's nice to meet	if they are only practising the warm-ups at home and they feel this is beneficial to them, there is no need to feel like they should be doing all the patterns) (Research team).

Table 3 Continued

Theme / Subtheme	Facilitators	Barriers	Improvements suggested (by)
	 Willingness to carry on practicing Tai Chi or reengage in previously practised exercises (i.e. Pilates) (Participants). Discovery of a new pleasurable activity to practice together (Participants). They keepall these people, they sort of say, oh, you've got to do about sixty minutes a day of somethingenergetic, get your heart moving and all that. But, you know, I couldn't do that, butas I say, I like this movement (02001C-FG). Thoroughly delighted and enjoyed the experience () I have got my carer at home and he's so updated and he's now able to do Tai Chi every single day () he's getting better () I love doing the exercises with <02004C> (02004P-FG). Well, I thought they wereI enjoyed them that's firstly you know. Er, also, um, I alsoand learnt something from them really. () But I've enjoyed it (02003P-FG); I have very much enjoyed the experience and would like to continue. (01004P-FG). 	people, come out and meet people. I think that's why we all kept coming, to meet somebody (02002C-FG); Yeah, I think we all felt that, didn't we? (02004C-FG); Yeah, we did, yeah (02001C-FG); It's nice to meet like-minded people in the same situationand you feel you're not alone reallythat there's other people with the same sort of problems (02004C); That's right (02002C-FG); Yeah, I've enjoyed it. I thought it was quite nice (02001C-FG). And, of course, some people are more, unfortunately, afflicted by this dementia, aren't they? (02004C-FG); Yeah (020002C-FG); So they're not gonna respond quite so well. I mean, <02004P>'s quite good at the moment but, um, er, going forward it's gonna get very much harder (02004C-FG); Yeah (02003C-FG); So whether anyone with quite bad dementia could really benefit from it, I don't know, er. (02004C-FG); I think if they start it earlier(02003C-FG); I	

Table 3 Continued

Theme / Subtheme	Facilitators	Barriers	Improvements suggested (by)
	 Participants' autonomy to engage in class-based practice (Researcher notes). Attribution of a beneficial effect to their Tai Chi practice (Participants). 	think they can, <02004C>. (02004P-FG).	
	 Joint participation and enjoyment (Participants). Participants' familiarity with the Tai Chi movements over session, allowing them to anticipate the movements (Researcher notes). Participants' perceived progression in practice, getting more into Tai Chi and feeling the "flow" (Participants). Comments after 3 classes, he's felt more "getting into it", he was "flowing more" (Observational notes). I think the exercises ultimately with people with dementia could help with balance (01002P-FG). May I say the one thing I have noticed, I love to do my bit of gardening and I rather love to go out and inspect everything daily. And to go into my greenhouse, for instance, I'm very much more careful with my legs. And I have said quietly to myself, um, thank you 	 Previous health issues (Participants and research team). Adverse events (i.e., feeling dizzy) (Research team). Participants' difficulties to engage in the intervention in a non-familiar (class-based) environment without supports nearby (Participants). for some reason, I can do the exercise [at home], which I had difficulty with [in class], that's with my feet andand my balance. () But I think just being at home and, you know, having something nearby that ifthat if I happened to get a little bit dizzy I can put my hand out. My grandma's chair is down near me (02004P-FG); Yeah, that's true (02004C-FG); () And for that reason, I love doing the exercises with <02004C> (02004P-FG). 	• Instructors should be aware of participants' health conditions and provide them a tailored advice on how to practice depending on these conditions or adverse events experienced during their practice. Similarly, more contact at the end of the session with participants will allow instructors to identify possible difficulties linked to home or class-based settings and provide tailored recommendations to facilitate participants' adherence to the intervention (Research team).

Table 3 Continued

Theme /	Facilitators	Barriers	Improvements suggested (by)
Subtheme			

Tai Chi, because it has helped me so much with balance. (02004P-FG). I think if, if one can feel that you...slowly...a slow benefit, an im...improving benefit of better balance perhaps, even feeling better within yourself...I, I feel a little bit better after having done it. Um... (01004C-FG); Yes, I think it does... Yeah (01004P-FG); But it... I think if you, if you put a lot of effort into it and you think, well, I just feel the same as I did before... (01004C-FG); [Laughs] (01003C-FG);...then you think, well, you know... So you've got to see a reward. It's, you know, the effort and the reward's got to come from it (01004C-FG); Yeah ...It ma...it makes you think about what's going on in your body while you're doing this. That's how I feel. You know, or, or...it... Oh, sorry. I don't know. Yeah. [Laughs]. (01004P-FG).

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

Table 3 Continued

Theme / Subtheme	Facilitators	Barriers	Improvements suggested (by)
Interaction with others	 Well, wewe do quite a bit, don't we, but you need to feel you've gone out somewhere and do some exercises, it sounds pretty basic but that's what it's all about really isn't itcoming together and doing something that breaks the week up [laugh] (02004C-FG). Creation of a semi-circle of chairs before starting the first class to encourage participants' conversations whilst waiting for the rest of participants (Researcher notes). Allowing time at the end of the sessions for participants' socialisation was perceived as something positive particularly for carers (Participants). Involving participants in their coffee/tea preparation (Researcher notes). When participants laugh at the instructor's jokes they look at each other (Observational notes). 		-

1	Appendix A
2	PPI Advisory Group Meeting
3	
4	The advisory group was formed of four people living with dementia, and six carers (four of
5	them spouses of the four people living with dementia). Of the four people living with
6	dementia there were two male and two female. The two carers who were not accompanied
7	by their relatives living with dementia were both females. In one of the PPI groups organised
8	to inform the design of the trial, they were asked to review a 14 font size, double line spacing
9	and bold letters document containing the Focus Group schedule was provided to each
10	member of the group. The researcher explained briefly the context where the questions
11	would be formulated. Participants of this group where asked about the appropriateness of the
12	questions, as well as if they would feel comfortable responding these questions in front of

not provide any negative comment on the questions. Two of them asked if those questions

their family members (person living with dementia or carer). Participants of this group did

would be handed out to the participants or asked verbally instead, they found more appropriate to formulate the questions to participants. One of the participants reported it was

not a problem for him (carer) to talk openly in positive or less positive terms in front of his

wife (person living with dementia). The rest of the group agreed. This carer also advised to

ask first the dyad if they are happy to take part in a joint interview.

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1	Appendix B				
2	Qualitative Semi-structured Checklist for Observation of Tai Chi Classes				
3					
4	R	Research s	tage: Pilot Intervention Phase		
5	D	Pate:		Session number:	
6	S	tarts at:		Ends at:	
7	I	nstructor:			
8	R	Research S	lite:	Venue:	
9	N	lumber of	participants attending the session:		
10	P	articipant	ts' names:		
	Γ	Dyad ID	People living with dementia	Carers	
		T ()	T		
11	1. <u>N</u>	lotes on th	ne Intervention Setting		
12	Venu	e descripti	On [Physical environment: accessibility to the building, Tai Chi room's flo	oring conditions, windows, type of lighting, size of the room, temperature of the	
13	room, oth	er objects in the roo	om].		
14					
15					
16	Intera	action amo	ngst (and affect) participants before the in	tervention starts [Affect shown by participants at their arrival to the	
17	session, d	yads interactions, is	nteraction with members of other dyads when they arrive in the venue].		
18					
19					
20	Partic	cipants' / S	pace distribution in the room [Map of participants of	istribution in the room	
24		1		•	
21					
22	Sessi	on structur	re as introduced by the instructor:		

1. Notes on participants'...:

Observation: 1 (0-15 min) / 2 (15-30 min)/ 3 (30-45 min)

Interactions			
With the other member of the dyad	Positive -	- Negative -	Neutral
Kind of responses provided by people living with dementia to the carers Verbal/ non-verbal expressions of support acceptation/rejection and positive/negative responses to the carer.			
Kind of support provided by carers Verbal communication speed and tone, physical support provided (i.e., area of physical contact, soft/brusque movements), Examples of disempowerment and/or infantilization.			
With other participants Interest	Positive -	- Negative -	Neutral
Camaraderie between peers Interest shown towards other participants and verbal or non-verbal interactions established with them (i.e., "making eye contact, smiling or acknowledging" support from peers.			
With the instructor	Positive -	- Negative -	Neutral
Initiated by participants Verbal or non-verbal interactions and their purpose.			
Instructor's rapport			
Interaction started by the instructor Purpose of these interactions and speed and tone used. Examples of positive feedback.			
Tailored comments for people living with dementia or carers Presence or absence of tailored comments for (a) specific dyad(s). If present, purpose/content of those. Instructor's response to participant's comments (i.e., examples of verbal/ non-verbal acknowledgement, appreciation), establishment of eye contact with participants when they are talking to the instructor			
Engagement			
Participants' engagement Examples of verbal/non-verbal signs of active/passive engagement/non-involvement (i.e., they are able to sustain attention for 10 minutes/ need prompting to sustain their attention in the activity/ interact with peers or instructor and are able to return to the activity and refocus).			

Attitudes towards Tai Chi	
Verbal/non-verbal positive / negative / neutral attitudes Verbalizations on expected benefits/harms from practising Tai Chi, or positive/negative feelings while performing the movements.	
Affect (during/after Tai Chi)	
Positive — interested, excited, strong, enthusiastic, proud, alert, inspired, determined, attentive, active. Negative — Distressed, upset, guilty, scared, hostile, irritable, ashamed, nervous, jittery, afraid. Agitation, angry, feeling anxious. Confusion.	
Communication	
Verbal Pleasure Displeasure Sadness Self-steem – satisfaction, pride. Normalcy - feeling good about being in a group activity.	
Non-verbal Pleasure – relaxed body language Displeasure – tense body language Sadness Self-steem – satisfaction, pride. Normalcy - feeling good about being in a group activity.	
Psychological needs	
Competence Ability to perform the exercises.	
Relatedness Closeness with the other member of the dyad and sense of belonging to the group.	
Autonomy Freedom of act to choose if they want to perform a movement with/without additional support (i.e., chair), stop performing a movement if they do not want to do it or if they feel tired. Describe if any member of the dyad is not allowing this freedom of act to the other member.	

2 Other notes:

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Appendix C 1 2 Focus Group Schedule 3 Before starting the focus group ✓ Set up the room: place chairs in circle, confirm drinks are provided. 4 ✓ Test video and audio recording equipment. 5 ✓ Check preliminary questions and ball pens are ready. 6 ✓ Provide name badges to participants. 7 ✓ Check every participant knows what will happen and accept to be recorded. 8 9 Introduction Housekeeping – fire, loos, stretching legs. 10 I would like to thank you all for coming today. My name is ____ and my assistant____. 11 We are both researchers at ______. Today _____ will be taking notes and helping 12 me if I forget anything. 13 Over the last few weeks you have been taking part in Tai Chi classes and practising Tai Chi 14 15 at home as part of our research project. We feel that the best way to improve the sessions and 16 the Tai Chi practise at home is talking with you about your opinions and experiences of taking part in it. It is particularly important for us to gather the views of those of you who 17 have dementia, and also those of your family member or friend. Even if you have not been 18 able to attend all the classes or do the exercises at home, your views and opinions are still 19 very valuable to us. 20 21 To learn from your experiences, we are going to conduct a group discussion. Your participation in this group is voluntary, so if you prefer not to participate you are completely 22 free to leave. However, we value all your opinions and would like to hear them. Whatever 23 you say in this group will be confidential and used only for this research project. We will 24 25 audio record this discussion in order to help us produce an accurate written record of this meeting and make sure that the record is an accurate version of your views. Any information 26 that might disclose your identity will be anonymised in the written record. If we use any 27 quotes from your contributions in research conferences, publications or events, we won't 28 29 include any information that could identify you personally. We will also video record this conversation, just to make easier for us to identify who is talking at each time. Is it OK with 30 everyone to audio and video record this discussion? (Check consent) 31 32 During this discussion I will ask you a few questions. There are no right or wrong answers, just different opinions that we would like to hear. Please feel free to state what you really 33 34 think, even if you disagree with others but please respect their views. I would appreciate if 35 <name of participants living with dementia > could give their opinions first, and then family 36 members or friends. It is important that only one person talks at a time as this makes it easier for the discussion to be clearly recorded and for <researcher's name> to take notes. Can I ask 37

- 1 you to say your names in order, so we will be able to recognise your voices in the recording?
- 2 (Check every participant says his/her name). Thank you.
- 3 This discussion will last around an hour or an hour and a half. If you want to have some
- 4 refreshments, please feel free to help yourselves during the conversation. Half way through
- 5 the conversation I will ask if you would like to have a short break. So we will be able to have
- 6 a pause and the restart the conversation if you need so.
- 7 Are there any questions before we start?
- 8 Before starting the group discussion, we would like you to consider the three topics that we
- 9 will be discussing:
- 1. What has helped you to take part in Tai Chi in the classes and at home?
- 2. How could the Tai Chi have worked better for you in class and at home?
- 3. How would you describe your experience of taking part in Tai Chi together with your family member, friend or neighbour?
- These 3 questions are written on this paper (hand out). You do not need to write your name
- on this page, so your thoughts will be anonymous. However, I would like to ask <carers
- names> to write a C on the right corner of your paper, please. Just to be able to differentiate
- which member of the dyads' responses come from. We would like you to note down your
- answers. This might help in our conversation as people can forget what they want to say in
- the group conversation. Should you need any support in writing, just let < focus group
- 20 facilitator name> or < focus group assistant> know. You don't have to share everything you
- 21 write down, but we will collect these anonymous papers at the end of the group discussion.

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EXPERIENCE OF TAKING PART IN TAI CHI

1. Tell me about your experience of taking part in the Tai Chi classes.

[Prompt: Some images of people doing Tai Chi classes]

- o Enjoyment:
 - What did you like about the Tai Chi classes?
 - What did you not like about the Tai Chi classes?
- o Participation:
 - What helped you to take part in the Tai Chi classes?
 - What if anything, made taking part in the Tai Chi classes more difficult?
 - How did you feel about taking part in a group activity? E.g. keen, anxious, uncertain?
- o Improvements:
 - How could the classes be improved to make it easier for you to participate?

1	• Length of the session?
2	• Frequency?
3	• Intensity?
4	• Timing and venue?
5	• Explanations, support and guidance (by the Tai Chi instructor)?
6	2. Tell me about your experience of doing the Tai Chi exercise at home.
7	[Prompt: Hold up the Booklet that was provided for people to take home and follow]
8	
9	o Participation:
10	How did you do the Tai Chi exercises at home?
11	 How often did you practise the Tai Chi exercises at home?
12 13	 How many minutes did you practise the Tai Chi exercises at home?
14	What helped you do the Tai Chi exercises at home?
15	Did anything stop you doing the Tai Chi exercises at home?
16	Enjoyment:
17	• What did you like most about the Tai Chi exercises at home?
18	What did you not like about the Tai Chi exercises at home?
19	 Home visit by Tai Chi instructor:
20	How did you feel about the home-visit by the Tai Chi instructor?
21	o Booklet:
22	 How did you find the booklet for guiding you while doing the Tai Chi
23	exercises at home?
24	Was it easy to follow?
25	 How could the booklet have worked better for you?
26	
27	WILLINGNESS TO CONTINUE
28	3. Do you feel there have been any changes to your health or wellbeing since taking
29	part in the Tai Chi exercise?
30	o Benefits and harms:
31	 Do you think there has been any benefit to you from taking part in the
32	Tai Chi classes?
33	 Do you think there has been any harm to you from taking part in the
34	Tai Chi classes, or has anything not worked so well?
35	
36	4. How did you feel about carrying out Tai Chi with your family/friend member?
37	
38	5. Would you be willing to carry on practising Tai Chi?
39	o Why/ why not?
40	

EXPERIENCE OF TAKING PART IN RESEARCH

- 2 6. Tell me about your experience of taking part in this research.
 - O How did you find the first interviews and tests (at baseline)?
- 4 o How did you find filling in the weekly log of your Tai Chi exercise?
 - o How did you find filling in the falls calendar?
 - o How did you feel about being observed while doing the Tai Chi Classes?
 - O How did you feel about the weekly telephone calls with the researcher?
- 8 O How could this research be improved for you to make it easier to take part in?

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DOUBTS AND COMMENTS

- 7. Is there anything else you would like to let us know?
- 8. Are there any questions you would like to ask us?
- 13 <u>Conclusion</u>
- 14 I would like to thank you all again for coming today and sharing your opinions with us. Your
- views will help us improve Tai Chi classes for others to take part.
- 16 If you have further questions or you want to share any information personally regarding the
- 17 Tai Chi sessions or the research, please contact me (provide Researcher's e-mail and contact
- 18 number).
- 19 At the end of the focus group
- 20 ✓ Seek verbal process consent.
- ✓ Collect preliminary questions sheets.
- ✓ Check and secure video and audio recording equipment.
- ✓ Tidy up the room.