

Barriers, motivators and facilitators of physical activity in people with dementia and their family carers in England: Dyadic Interviews

Nicolas Farina<sup>1\*</sup>, Alice Williams<sup>2</sup>, Kirsty Clarke<sup>3</sup>, Laura J. Hughes<sup>1</sup>, Serena Thomas<sup>4</sup>, Ruth G. Lowry<sup>5</sup>, and Sube Banerjee<sup>1</sup>.

<sup>1</sup>Centre for Dementia Studies, Brighton and Sussex Medical School, <sup>2</sup>Medical Education, Brighton and Sussex Medical School <sup>3</sup>Global and Public Health, Brighton and Sussex Medical School <sup>4</sup>Research and Development, Sussex Partnership NHS Foundation Trust, <sup>5</sup>School of Sport Rehabilitation and Exercise Sciences, University of Essex.

\*Corresponding author.

*Acknowledgements*

Thank you to the Alzheimer's Society and their support through their partnership program. In particular, we would like to acknowledge the support received from Tim Wilkins. The research team acknowledges the support of the National Institute for Health Research Clinical Research Network (NIHR CRN).

This research would not have been possible without the time and effort of the participants that took part in this study.

The MODEM study is funded by the UK Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR). Beyond approval for our original proposal, neither funding body has had any influence over the design of MODEM, the collection, analysis or interpretation of data, or the writing of this manuscript.

## Abstract

**Introduction:** Physical activity may have a number of physical and mental health benefits for people with dementia and their carers. However, there is limited evidence about factors that influence physical activity participation in these groups. This study therefore looks at the barriers, facilitators and motivators of physical activity in people with dementia, from both the perspective of the person with dementia and their carer.

**Method:** Thirty participants (15 sets of community-dwelling people with dementia and their family carers) were recruited from the South East of England. The participants took part in semi-structured dyadic interviews about their views of physical activity. Interviews were analysed using inductive thematic analysis at an individual level and comparisons were made between the groups.

**Results:** Common motivator themes across persons with dementia and family carers were emotional and physical wellbeing, and social connectedness. Physical health was seen as a common barrier in both groups. Physical activity in the person with dementia was encouraged and supported by the family carer. For the carer, their caring role, and limited time acted as barriers to their participation.

**Conclusion:** Themes such as social connectedness, positive emotion and health were seen as key motivators to physical activity, which indicate that people with dementia and carers use physical activity as a means to maintain and improve their quality of life. Supporting family members to better facilitate such activities could encourage physical activity in people with dementia.

**Keywords:** dementia, exercise, family, caregivers, attitudes, cognitive impairment

## Introduction

The benefits of physical activity across the lifespan are well established. For those with conditions such as dementia, physical activity may improve function (Forbes et al., 2015) and mood (Bowes et al., 2013). Importantly, physical activity may improve cognition (Farina et al., 2014), even at low frequency (<150 minutes per week) (Groot, Hooghiemstra, Raijmakers, van Berckel, & Scheltens, 2016). However, due to the heterogeneity in the designs of Randomised Controlled Trials (RCTs), the general consensus is that further research is needed (Farina et al., 2014; Forbes et al., 2015; Groot, Hooghiemstra, Raijmakers, et al., 2016; Öhman et al., 2014). Variation of intervention, duration, intensity and control group (to name a few) may explain why some physical activity RCTs do not slow cognitive decline above controls (e.g. de Souto Barreto et al., 2017; Lamb et al., 2018). Evidence from observational studies suggests that physical activity is seen as meaningful, enjoyable, and that it may improve wellbeing for people with dementia (Cedervall et al., 2014; Eggermont & Scherder, 2006; Moyle et al., 2011).

Despite the potential benefits of physical activity for the person with dementia, this population are less physically active than cognitively healthy older adults (Boyle et al., 2015; Zanco et al., 2016), often leading largely sedentary lives (van Alphen, Volkers, et al., 2016). There appears to be a shift in physical activity preferences after developing dementia, with the majority of people with dementia not participating in any organised physical activity (>92%) (Watts et al., 2013), and often opting for activities such as walking (Winchester et al., 2013). Given the holistic benefits of leading an active lifestyle, it is important to establish why people with dementia are physically active, or not, and what may limit or encourage them to exercise. A systematic review on this topic identified 82 barriers, motivators and facilitators for physical activity in people with dementia (van Alphen, Hortobágyi, et al., 2016). Though it should be noted that these conclusions are limited by their being derived from only seven studies, of which only two were focussed on primarily identifying facilitators, motivators or barriers of physical activity (Malthouse & Fox, 2014; Suttanon et al., 2012). In addition, one of these studies was in relation to participation of a specific home-based exercise program (Suttanon et al., 2012), rather than physical activity more broadly. Irrespective, of the sources of data included within this systematic review, sample sizes were generally very small, five of which had 10 or fewer participants (including carers).

One reoccurring theme is the importance of the carer in motivating, supporting, and facilitating, physical activity in the person with dementia (van Alphen, Hortobágyi, et al., 2016). Carers of people with dementia also appear to participate in less leisure-time physical activity such as formal exercise than non-caregivers (Fredman et al., 2006). However daily accumulated physical activity does not decline when a caring role is adopted, due to increased amounts of household-related activity undertaken in this role (Fredman et al., 2008, 2009). To our knowledge no research has explored the barriers, motivators and facilitators of physical activity in carers of people with dementia.

To date, there is a limited amount of research that explores the barriers, facilitators and motivators for people with dementia to participate in physical activity. The literature from carers of people with dementia is even more sparse. Our primary aim in the work reported here was to explore the barriers, motivators and facilitators toward physical activity of people with dementia and their carers living in England. The study aimed to understand the similarities and differences in themes discussed between the two groups.

## **Methods**

### ***Participants***

This study was nested within the MODEM project (Comas-Herrera et al., 2017). People with dementia and their family carers were recruited from the South East of England. Participants were identified through individuals that have previously expressed interest in research, clinical referral from local memory assessment services, self-referral through Join Dementia Research (<http://joindementiaresearch.nihr.ac.uk/>), or self-referral through community groups. Participants were required to have a clinical diagnosis of dementia. Participants in this sub-study were required to have capacity to consent and be able to speak conversational English. Participants were not excluded based on the amount of physical activity they participated in.

### ***Design***

A series of dyadic semi-structured interviews were completed with the participants. A pragmatic approach was taken, allowing participants to choose whether they participated in separate interviews or joint interviews, each of which has its own benefits and drawbacks as

methodologies (Eisikovits & Koren, 2010). Interviews were carried out between January 2018 and January 2019.

### ***Topic guide***

The topic guide was developed by reviewing existing literature on the topic and through discussions amongst a team of multi-disciplinary researchers. The person with dementia and carer were asked a common set of questions about their views regarding physical activity, the benefits and drawbacks of participation, alongside their personal likes and dislikes of physical activity. No effort was made to draw out themes directly associated with barriers, motivators and facilitators if the participants did not raise them. Participants were however asked about how their respective situation (i.e. living with cognitive impairment and providing care) influenced their physical activity participation. The topic guide for the carer did not require them to make a judgement about their family members views on physical activity.

For the purposes of this study, we adopted the definition that physical activity is “*any bodily movement produced by skeletal muscles and results in energy expenditure*”, so it covers occupational, sports, and household activities (Caspersen et al., 1985). The interviewer would prompt participants on this during the interviews, as and when needed.

### ***Measures***

A series of measures relating to participants’ demographics, health and wellbeing were captured during the broader study. The outcomes used here were:

- Demographics: Age, gender, marital status, ethnicity, carer-person with dementia relationship, diagnosis of dementia (self-report).
- The standardised mini-mental state examination (sMMSE) (Molloy et al., 2005) was used to assess the degree of cognitive impairment in all of those with dementia. A score of 26-29 indicates questionable dementia, 21-25 indicates mild/early dementia, 11-20 indicates moderate dementia, and a score of 0-10 indicates severe dementia (Pernecky et al., 2006).
- A single item from the 12-item Medical Outcomes Study Short-Form Health Survey (SF-12) (Ware Jr et al., 1996) was used to summarise participant health status.

## ***Procedure***

The interview was a semi-structured interview which took place in the participant's home at a time that was convenient for them. Present were the interviewer, person with dementia and their caregiver (a family relative). Capacity was assessed in all people with dementia, consent was obtained from all participants that had capacity, those without capacity were not eligible for inclusion in this study.

For pragmatic reasons, the person with dementia was allowed to answer the questionnaires independently or with assistance of the carer. The interviewer asked the questions on the topic guide, probing further when needed. Participants were given the opportunity to provide any further information they felt was important and then they were thanked, and the interview was terminated.

Interviews typically lasted around 15-30 minutes and were recorded using an encrypted voice recorder. Following the interview, each recording was downloaded onto cross-platform audio software (Audacity 2.3.0, 2018) and transcribed by an independent researcher (AW, KC).

## ***Analysis***

Demographics, health, and cognitive outcomes are reported descriptively, both as a whole sample but also within dyads.

Analysis of interviews was completed based on Braun and Clarke's Thematic Analysis guidelines (Clarke & Braun, 2017). Primarily, an inductive approach was used, meaning codes and themes were identified by what was seen in the data, allowing the coding framework to closely match the data set. These themes were then deductively grouped into themes of "barriers", "motivators" and "facilitators". The researchers leading the coding for each participant group (i.e. person with dementia and the carer) were blind to each other's coding, minimising bias.

## ***Ethics and Rigour***

Ethical approvals were obtained from the Social Care Research Ethics Committee, London.

ST (Female, early 20s, Research Assistant) led the qualitative interviews. AW led the transcription for the person with dementia, KC led the transcription for the carer. AW and KC are both female, early 20s, and are currently training in medicine. Both AW and KC met with an independent researcher (LH) to ensure that the coding and thematic analysis was accurate and clear. NF reviewed the themes and coding and discussed these with LH. Efforts were made, when appropriate, to compare the initial themes between the person with dementia and the carers, and to ensure that terminology used was consistent.

## **Results**

Fifteen participant dyads were recruited to the study. The person with dementia was on average 77 years old (SD=5.8), with the carers slightly younger on average (M= 71, SD =11.1). The majority of carers were spouses to the person with dementia (n=12, 80%), and 13 carers lived with the person with dementia (87%). All participants, except one, were White British. The median self-reported health (based on a single SF-12 item) was “very good” for the person with dementia and “good” for the carer. See Table 1 for a summary of participant characteristics.

Themes and subthemes are reported independently for the person with dementia and the carer. Please see Figure 1 for an overview of these themes.

### ***Person with Dementia***

Two barriers (Physical health and cognitive impairment), four motivators (emotional wellbeing, physical wellbeing, social connectedness, and family encouragement), and one facilitator (family support) theme were identified.

### ***Barriers***

***Physical health.*** It was clear that physical health, and in particular, mobility, acted as the main barrier for the person with dementia to participate in physical activity; often describing how

they would like to do exercise, but that their existing health conditions prevent them from doing so (Table 2; A1 and A2). Not only did physical health influence the amount of activity performed, it also influenced the intensity.

**Cognitive impairment.** The decline in cognition characteristically seen in people with dementia had a negative effect on physical activity for a number of reasons. Due to cognitive decline, a number of people with dementia stated that they often forget the actions they need to perform for certain activities (Table 2; B1) and that they struggle to follow instructions (Table 2; B2), even if they have been participating in that activity for considerable time.

### ***Motivators***

All participants with dementia were able to recognise the benefits of being physically active, reported as improvements to emotional and physical wellbeing, and social connectedness. Other factors were identified (such as *walking the dog, feeling of achievement*) though they did not come out as themes. Whilst there was also some nuance to how participants saw physical activity, some felt that structured leisure physical activity (i.e. exercise) was more beneficial than routine physical activity, and therefore the motivators may not be equal across activity types. For example, “*I think structured is more productive in getting you to a goal. Unstructured is better than not doing it at all*” (Male, person with dementia, 160107SB1)

**Emotional Wellbeing.** When discussing their motivations toward activity involvement, the participants all reported the association of activity and positive emotions. Enjoyment was the most common emotional process mentioned (Table 2; C1).

The sub-theme of emotional wellbeing also captured feelings of normality (Table 2; C2), and fulfilling the participants competitive nature (Table 2; C3).

**Physical wellbeing.** It was common for the person with dementia to identify that being physically active has physical health benefits (Table 2; D1 and D2).



***Social connectedness.*** Meeting new people and keeping in touch with friends was another motivator that appeared important to participants with dementia. People with dementia often stated that the social side of exercise was what they looked forward to (Table 2; E1) and often contributed to their positive emotional wellbeing (Table 2; E2).

***Family encouragement.*** There was evidence that some of the carers (i.e. family) provided encouragement to participate in physical activity (Table 2; F1). However, the living arrangements of the family members (i.e. proximity to the person with dementia) affected the extent to which family members were able to encourage physical activity participation, for example; “[I don’t receive encouragement from] the rest of my family because they don’t live locally” (Male, person with dementia, 151125EB1)

### ***Facilitators***

***Family support.*** Alongside the family playing a role providing encouragement for the person with dementia, family members were important in facilitating physical activity, usually by providing the means to be physically active. This was typically related to the extent to which cognitive impairment acted as a barrier to physical activity. Carers tended to act as a chaperone and companion, whether it be travel to carry out the physical activity (as the participant is no longer able to drive by themselves) (Table 2; G1), or to go out for a walk (as their sense of direction has declined). This indicates that without the presence of the carer, physical activity would be further limited.

It was sometimes acknowledged that without this facilitation from the family member, then some activities might not be possible.

### ***Family Carers***

Three themes concerning barriers (Physical health, time, and caring role) and three concerning motivators (emotional wellbeing, physical wellbeing, and social connectedness) were identified in the interviews with carers of people with dementia. Overall many carers discussed that being physically active was important and/or enjoyable to them with positive benefits.

However, it is important to acknowledge that carers understood that they were participating in low intensity, habitual physical activity, but in fact felt they should be doing more strenuous activities.

*“I feel I ought to be more physically active. I realise I’m not getting enough um, exercise but I always say well you know dashing around chasing grandchildren counts as a form of exercise”* (Female, caring for spouse, 160107SB1)

### **Barriers**

**Physical health.** Physical health was seen as a limiting factor by carers, with increasing age and reduced energy playing an important role for many (Table 3; A1). There was also a fear of overexertion and the consequences of this such as tiredness (Table 3; A2) and pain. However, in some cases, the importance of physical activity meant that carers felt that overcoming these barriers were necessary and achievable, for example, *“[it’s] only aches and pains, that’s all, but you can get over that”* (Female, caring for spouse, 180919ST1)

**Time.** One of the main limitations discussed by carers was time.. Participants felt that finding the time to fit physical activity into their daily routine given other activities and duties was difficult (Table 3; B1 and B2). Lack to time as a theme was usually non-specific, though could be associated with increased burden due to their caring role (see below).

**Caring role.** The caring role was seen as a limitation on the carer’s ability to be as physically active. Caring role is very much interlinked with the time subtheme, though can be differentiated, based on carer’s stating providing care rather than time more generally as a barrier. Participants were unable to do as much or to do things on their own like they used to. This was mainly discussed as not wanting or able to leave the person with dementia alone at all, or for too long (Table 3; C2 and C3). In addition, supporting the person with dementia being active inhibited their own physical activity (Table 3; C1 and C4).

## *Motivators*

***Emotional wellbeing.*** The non-physical benefits of being physically active were discussed by carers as important in driving their motivation to take part in physical activities. Many participants discussed that being able to do physical activity was important for simply getting out of the house. This was often described as a way to escape, to de-stress, and to relax (Table 3; D1 and D2).

***Physical wellbeing.*** For most carers the physical benefits of taking part in physical activity were an important factor in their motivation to be active. Carers perceived that being physically active had general health benefits (Table 3; E1), though specific benefits were also sometimes cited (Table 3; E2).

More specifically, physical activity was seen as important for ageing well. It was perceived that being physically active helped to keep carers active and feeling young and fit. There was also a perception that it would aid longevity (Table 3; E3).

***Social connectedness.*** Being able to socialize was also an important factor for many carers. Taking part in physical activities allowed carers to meet up with others and meet new people, other than the person with dementia (Table 3; F1). However, physical activity was also seen at times as a way to enhance communication between the carer and the person with dementia (Table 3; F2).

## ***Contextual notes***

Cognitive impairment for the person with dementia meant that insight into their diagnosis, and its impact on their physical activity habits, were affected. It became noticeable throughout the study that a number of the people with dementia did not believe that the condition had affected them at all. Nonetheless, during the subset of joint interviews there were occasions when the carer would prompt the person with dementia, reminding them of decreased activity.

### *Similarities and differences between themes identified the person with dementia and the carer*

For both the person with dementia and carer, themes related to barriers and motivators were identified. For barriers, both groups identified that their physical health often acted as a barrier to physical activity. Only carers identified that a lack of time and their caring role acted as a barrier, whilst participants with dementia also described that their cognitive impairment limited their participation. Motivators between groups were largely consistent, describing the benefits to their physical and emotional wellbeing, as well as feelings of social connectedness as being key motivators. Participants with dementia did however, note that encouragement of family members acted as a motivator. Finally, only people with dementia identified facilitators during the interviews, more specifically the role of the family in supporting their physical activities.

### **Discussion**

This study looked at the barriers, motivators and facilitators of physical activity in people with dementia and carers from South East England. This research expands on the limited evidence about the barriers, motivators and facilitators of physical activity from people with dementia, and is the first study to look at this topic in carers of people with dementia. The dyadic nature of the interviews also provides us novel data where contextual information remains constant between dyads, thus providing the ability to explore differences between the two groups.

Broadly, the themes identified by the person with dementia and their carer were consistent. Both groups identified social connectedness, and mental and physical wellbeing as key motivators. In addition, physical health was a key barrier. These themes are in line with those previously highlighted in people with dementia, and in older adults more generally (Baert et al., 2011; Gothe & Kendall, 2016; Han et al., 2016; Karssemeijer et al., 2018; Schutzer & Graves, 2004; Silverman, 2019; van Alphen, Hortobágyi, et al., 2016). Notably, neither group cited condition enhancing benefits (i.e. improving cognition, or reducing carer burden) as key motivators. However, physical activity was described as a means of feeling normal. Old age and the onset of dementia can often result in a change in their social routines, thus losing their self-image. It has previously been reported that people with dementia want to maintain continuity in life (Daley et al., 2013; Phinney, 1998), including their lifestyle behaviours

(Menne et al., 2002). Thus, participation in physical activities provides a sense of continuity, whilst also shifting focus from being a patient to being a physically capable individual (Beattie et al., 2004).

For the person with dementia, cognitive impairment was seen as a key barrier to their physical activity participation. Cognitive impairment resulted in a number of potential barriers to physical activity including being unable to drive, getting lost, and forgetting when planned physical activities were scheduled. Van Alphen and colleagues identified some of these barriers in their systematic review (van Alphen, Hortobágyi, et al., 2016). Dementia may make physical activity participation more difficult due to cognitive impairment, though previous literature suggests that cognitive function is not consistently associated with physical activity levels (Stubbs, 2014). This could be due to mediating factors such as coping mechanisms, perceived importance of physical activity, and available social support. For example, the present study also indicates that family carers often encouraged and facilitated physical activity for the person with dementia, ensuring that they can attend exercise groups or support them in completing that activity. This reflects two types of social support, instrumental support and companionship support, respectively (Wills & Shinar, 2000). The significance of the carer in motivating and supporting physical activity in people with dementia is a theme raised previously (Hobson, 2017; van Alphen, Hortobágyi, et al., 2016). Social support features in Michie et al.'s taxonomy of behavioural change techniques in general (Michie et al., 2013), and carers have an important place in behaviour change techniques to increase physical activity in people with dementia specifically (Nyman, 2019). This 'partnership with carers' has been identified as an area for future research (Nyman, 2019). It is possible that additional strategies could be adopted, utilising Michie et al.'s taxonomy, such as using prompts and cues (Michie et al., 2013). Within the context of dementia, overcoming cognitive impairment barriers by using memory prompts or calendars has previously been used (Wardt et al., 2019). Such an approach, might benefit people without social support, or reduce the onus on existing family members, though ultimately, the effectiveness of prompts and cues may well decline as cognitive impairment increases.

Compared to people with dementia, the barriers, motivators and facilitators of physical activity of carers are explored less in the literature. Caring for the person with dementia acted as a barrier, because they felt that they could not leave them alone to participate in physical activity. Caring for others has been previously identified as a barrier to physical activity in older adults (Baert et al., 2011). Exclusively, the carer group identified lack of time as a barrier, which

supports previous evidence that carers feel that they have a lack of time (Commissaris et al., 1995), and less time for leisure activities (Ory et al., 1999). However, it is worth acknowledging that lack of time is commonly raised as a barrier to physical activity in older adults generally (Baert et al., 2011; Chao et al., 2000; Costello et al., 2011; Gobbi et al., 2012). Even when people are sufficiently active, time is perceived as a barrier, despite their tendency to prioritise exercise over other activities (Costello et al., 2011). Ultimately, due to their caring responsibilities, it is likely that carers struggle to achieve a desired (both personal goal and health recommendation) level of physical activity. Even when carers incorporated physical activity into their caring role, through participating in physical activity with the person with dementia, carers identified that this physical activity was somewhat limited (i.e. intensity or duration) to suit the needs of the person with dementia. Despite the reported difficulties, there were obvious benefits for joint physical activity with the person with dementia, with some carers citing that it provided meaningful conversations between the dyad.

It was evident that purposeful physical activity was somewhat inhibited by being a carer, the family carer was able to identify that they remained highly active in terms of household activity, thus supporting previous evidence (Fredman et al., 2008; Fredman, Doros, Ensrud, Hochberg, & Cauley, 2009). For some carers this was seen as “enough” physical activity, though others were unclear about whether their habitual physical activity was adequate in terms of health benefits or whether more intense activity was needed. This has potential implications about how physical activity is presented to carers, being able to both acknowledge the benefits of habitual physical activity, but also the benefits of more intense activity to reduce carer stress (McCurry et al., 2010) and burden (Hirano et al., 2011; Holthoff et al., 2015; Lowery et al., 2014; Orgeta & Miranda-Castillo, 2014).

It is important to recognise the limitations of the study. First, the findings only reflect the views of a small group of people with mild to moderate dementia with capacity to consent living in the community and their carers. The sample therefore excludes those with more severe dementia and those without the capacity to consent who are likely to differ systematically in their views from those included in this study. This will limit the generalisability of the study findings, further work is needed with those with more severe dementia and those without identifiable family carers. Second, only one participant was from a minority ethnic group, barriers and motivators may vary cross-culturally and further work is needed to understand these in people with dementia and family carers from black, Asian and other minority ethnic groups. Third, participants involved may well have had stronger opinions (positive or negative)

about physical activity just through their choice to participate in the research. Fourth, in the four interviews where both the carer and person with dementia were present in the same interview, this dynamic may have inhibited either participant expressing personally held views that might have upset their family member. Fifth, the recruitment area of participants may have also influenced the findings. Two-thirds of all households in the South East of England have access to a green space of at least 20 hectares within two kilometres (McKernan & Grose, 2007). There is likely to be geographic variation in terms of leisure and sporting clubs/facilities, thus affecting both the accessibility and types of physical activities. A range of social and economic factors can contribute to physical activity participation (Farrell et al., 2014), potentially influencing potential perceived barriers, motivators and facilitators. Last, the themes reported here likely do not reflect all barriers, motivators and facilitators of physical activity in these groups, and likely represent perceived prominent factors. Certainly, the systematic review by Van Alphen et al. (2016) identified a range of other factors associated with physical activity in people with dementia; albeit from heterogeneous sources.

Further research is needed to understand physical activity habits (including barriers, motivators and facilitators) in both people with dementia and their carers. An emphasis on quantitative research methods in particular will help understanding the size and direction of relationships. To date, there has been no research that has investigated the relationship of physical activity habits between person with dementia and carer dyads, as the emphasis is usually the person with dementia alone (Mc Ardle et al., 2019; Watts et al., 2013; Winchester et al., 2013). Caution needs to be taken in how we capture physical habits and other variables, particularly in people with dementia. Apart from a few notable exceptions (van Alphen, Volkers, et al., 2016), there is a focus on capturing physical activity habits through self- or proxy-report questionnaires in people with dementia, without evidence of validity. However, many of these questionnaires may not be accurate and introduce bias (Farina et al., 2019; Middleton et al., 2018).

## 5. Conclusions

This study provides supporting evidence of motivators, barriers and facilitators of physical activity in people with dementia and their family carers. In adopting a dyadic approach, we were able to better observe variability in attitudes towards physical activity when certain contextual factors remain consistent. While there are some themes that are consistent between both the person with dementia and their carer, there are particular unique barriers that affect

both groups. The relationship between the person with dementia and the carer and physical activity is a complex one, with the carer providing encouragement and support for the person with dementia to be physically active, this might be beneficial to them or add additional strain to their caring role. As such, the data illustrates the interlinked nature of physical activity habits between the two groups, and recommendations to one group, invariably influence the other. This may mean that healthcare professionals who want to primarily promote physical activity of the person with dementia could achieve this by supporting the carer more generally, or by facilitating the carer's own physical activity. It is clear that an accessible message about the importance of physical activity is needed, acknowledging the benefits of habitual and low intensity physical activities.

*CRedit author statement*

**Nicolas Farina:** Conceptualization, Methodology, Formal analysis, Writing – Original Draft, Writing – Review & Editing, Supervision, Project Administration. **Alice Williams:** Formal analysis, Writing – Review & Editing. **Laura J. Hughes:** Formal analysis, Writing – Review & Editing. **Serena Thomas:** Investigation, Writing – Review & Editing. **Kirsty Clarke:** Formal analysis, Writing – Review & Editing. **Ruth G. Lowry:** Conceptualization, Writing – Review & Editing. **Sube Banerjee:** Conceptualization, Writing – Review & Editing, Funding Acquisition

*Data statement*

For ethical reasons data associated with this study are not available online. Data will be made available upon reasonable request.

*Conflict of interest statement*

The authors declare no conflicts of interest.



### *Acknowledgements*

Thank you to the Alzheimer's Society and their support through their partnership program. In particular, we would like to acknowledge the support received from Tim Wilkins. The research team acknowledges the support of the National Institute for Health Research Clinical Research Network (NIHR CRN).

This research would not have been possible without the time and effort of the participants that took part in this study.

The MODEM study is funded by the UK Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR). Beyond approval for our original proposal, neither funding body has had any influence over the design of MODEM, the collection, analysis or interpretation of data, or the writing of this manuscript.

Accepted manuscript

## 6. References

- Baert, V., Gorus, E., Mets, T., Geerts, C., & Bautmans, I. (2011). Motivators and barriers for physical activity in the oldest old: A systematic review. *Ageing Research Reviews, 10*(4), 464–474. <https://doi.org/10.1016/j.arr.2011.04.001>
- Beattie, A., Daker-White, G., Gilliard, J., & Means, R. (2004). ‘How can they tell?’ A qualitative study of the views of younger people about their dementia and dementia care services. *Health & Social Care in the Community, 12*(4), 359–368. <https://doi.org/10.1111/j.1365-2524.2004.00505.x>
- Bowes, A., Dawson, A., Jepson, R., & McCabe, L. (2013). Physical activity for people with dementia: A scoping study. *BMC Geriatrics, 13*(1), 129. <https://doi.org/10.1186/1471-2318-13-129>
- Boyle, C. P., Raji, C. A., Erickson, K. I., Lopez, O. L., Becker, J. T., Gach, H. M., Longstreth Jr., W. T., Teverovskiy, L., Kuller, L. H., Carmichael, O. T., & Thompson, P. M. (2015). Physical activity, body mass index, and brain atrophy in Alzheimer’s disease. *Neurobiology of Aging, 36*, Supplement 1, S194–S202. <https://doi.org/10.1016/j.neurobiolaging.2014.05.036>
- Caspersen, C. J., Powell, K. E., & Christenson, G. M. (1985). Physical activity, exercise, and physical fitness: Definitions and distinctions for health-related research. *Public Health Reports, 100*(2), 126–131.
- Cedervall, Y., Torres, S., & Åberg, A. C. (2014). Maintaining well-being and selfhood through physical activity: Experiences of people with mild Alzheimer’s disease. *Aging & Mental Health, 0*(0), 1–10. <https://doi.org/10.1080/13607863.2014.962004>
- Chao, D., Foy, C. G., & Farmer, D. (2000). Exercise Adherence among Older Adults: Challenges and Strategies. *Controlled Clinical Trials, 21*(5, Supplement 1), S212–S217. [https://doi.org/10.1016/S0197-2456\(00\)00081-7](https://doi.org/10.1016/S0197-2456(00)00081-7)
- Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology, 12*(3), 297–298. <https://doi.org/10.1080/17439760.2016.1262613>

- Comas-Herrera, A., Knapp, M., Wittenberg, R., Banerjee, S., Bowling, A., Grundy, E., Jagger, C., Farina, N., Lombard, D., Lorenz, K., & McDaid, D. (2017). MODEM: A comprehensive approach to modelling outcome and costs impacts of interventions for dementia. Protocol paper. *BMC Health Services Research*, *17*(1), 25. <https://doi.org/10.1186/s12913-016-1945-x>
- Commissaris, C., Jolles, J., Verhey Jr, F. R. J., & Kok, G. J. (1995). Problems of caregiving spouses of patients with dementia. *Patient Education and Counseling*, *25*(2), 143–149.
- Costello, E., Kafchinski, M., Vrazel, J., & Sullivan, P. (2011). Motivators, Barriers, and Beliefs Regarding Physical Activity in an Older Adult Population. *Journal of Geriatric Physical Therapy; La Cross*, *34*(3), 138–147.
- Daley, S., Newton, D., Slade, M., Murray, J., & Banerjee, S. (2013). Development of a framework for recovery in older people with mental disorder. *International Journal of Geriatric Psychiatry*, *28*(5), 522–529. <https://doi.org/10.1002/gps.3855>
- de Souto Barreto, P., Cesari, M., Denormandie, P., Armaingaud, D., Vellas, B., & Rolland, Y. (2017). Exercise or social intervention for nursing home residents with dementia: A pilot randomized, controlled trial. *Journal of the American Geriatrics Society*, *65*(9), E123–E129.
- Eggermont, L. H. P., & Scherder, E. J. A. (2006). Physical activity and behaviour in dementia A review of the literature and implications for psychosocial intervention in primary care. *Dementia*, *5*(3), 411–428. <https://doi.org/10.1177/1471301206067115>
- Eisikovits, Z., & Koren, C. (2010). Approaches to and outcomes of dyadic interview analysis. *Qualitative Health Research*, *20*(12), 1642–1655. <https://doi.org/10.1177/1049732310376520>
- Farina, N., Hughes, L. J., Watts, A., & Lowry, R. G. (2019). Use of Physical Activity Questionnaires in People With Dementia: A Scoping Review. *Journal of Aging and Physical Activity*, *27*(3), 413–421. <https://doi.org/10.1123/japa.2018-0031>

- Farina, N., Rusted, J., & Tabet, N. (2014). The effect of exercise interventions on cognitive outcome in Alzheimer's disease: A systematic review. *International Psychogeriatrics / IPA*, 26(1), 9–18. <https://doi.org/10.1017/S1041610213001385>
- Farrell, L., Hollingsworth, B., Propper, C., & Shields, M. A. (2014). The socioeconomic gradient in physical inactivity: Evidence from one million adults in England. *Social Science & Medicine*, 123, 55–63. <https://doi.org/10.1016/j.socscimed.2014.10.039>
- Forbes, D., Forbes, S. C., Blake, C. M., Thiessen, E. J., & Forbes, S. (2015). Exercise programs for people with dementia. In *Cochrane Database of Systematic Reviews*. John Wiley & Sons, Ltd. <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD006489.pub4/abstract>
- Fredman, L., Bertrand, R. M., Martire, L. M., Hochberg, M., & Harris, E. L. (2006). Leisure-time exercise and overall physical activity in older women caregivers and non-caregivers from the Caregiver-SOF Study. *Preventive Medicine*, 43(3), 226–229. <https://doi.org/10.1016/j.ypmed.2006.04.009>
- Fredman, L., Cauley, J. A., Satterfield, S., Simonsick, E., Spencer, S. M., Ayonayon, H. N., & Harris, T. B. (2008). Caregiving, Mortality, and Mobility Decline: The Health, Aging, and Body Composition (Health ABC) Study. *Archives of Internal Medicine*, 168(19), 2154–2162. <https://doi.org/10.1001/archinte.168.19.2154>
- Fredman, L., Doros, G., Ensrud, K. E., Hochberg, M. C., & Cauley, J. A. (2009). Caregiving Intensity and Change in Physical Functioning Over a 2-Year Period: Results of the Caregiver-Study of Osteoporotic Fractures. *American Journal of Epidemiology*, 170(2), 203–210. <https://doi.org/10.1093/aje/kwp102>
- Gobbi, S., Sebastiao, E., Papini, C. B., Nakamura, P. M., Valdanha Netto, A., Gobbi, L. T. B., & Kokubun, E. (2012). Physical inactivity and related barriers: A study in a community dwelling of older brazilians. *Journal of Aging Research*, 2012.

- Gothe, N. P., & Kendall, B. J. (2016). Barriers, motivations, and preferences for physical activity among female African American older adults. *Gerontology and Geriatric Medicine, 2*, 2333721416677399.
- Groot, C., Hooghiemstra, A. M., Raijmakers, P. G. H. M., van Berckel, B. N. M., Scheltens, P., Scherder, E. J. A., van der Flier, W. M., & Ossenkuppele, R. (2016). The effect of physical activity on cognitive function in patients with dementia: A meta-analysis of randomized control trials. *Ageing Research Reviews, 25*, 13–23.  
<https://doi.org/10.1016/j.arr.2015.11.005>
- Groot, C., Hooghiemstra, A., Raijmakers P, van Berckel, B., & Scheltens, P. (2016). *The effect of physical activity on cognitive function in patients with dementia: A meta-analysis of randomized control trials- ClinicalKey*. Ageing Research Reviews.  
<https://www.clinicalkey.com/#!/content/playContent/1-s2.0-S1568163715300349?returnurl=http%2F%2Flinkinghub.elsevier.com%2Fretrieve%2Fpii%2FS1568163715300349%3Fshowall%3Dtrue&referrer=https%2F%2Fwww.ncbi.nlm.nih.gov%2F&scrollTo=%23hl0001194>
- Han, A., Radel, J., McDowd, J. M., & Sabata, D. (2016). Perspectives of people with dementia about meaningful activities: A synthesis. *American Journal of Alzheimer's Disease & Other Dementias*<sup>®</sup>, *31*(2), 115–123.
- Hirano, A., Suzuki, Y., Kuzuya, M., Onishi, J., Ban, N., & Umegaki, H. (2011). Influence of regular exercise on subjective sense of burden and physical symptoms in community-dwelling caregivers of dementia patients: A randomized controlled trial. *Archives of Gerontology and Geriatrics, 53*(2), e158–e163. PsycINFO. <https://doi.org/10.1016/j.archger.2010.08.004>
- Hobson, N. (2017). *Perceived Barriers to Exercise among Older Adults with MCI and Early Dementia* [Master's Thesis]. University of Waterloo.

- Holthoff, V. A., Marschner, K., Scharf, M., Steding, J., Meyer, S., Koch, R., & Donix, M. (2015). Effects of Physical Activity Training in Patients with Alzheimer's Dementia: Results of a Pilot RCT Study. *PLoS ONE*, *10*(4). <https://doi.org/10.1371/journal.pone.0121478>
- Karssemeijer, E. G. A., de Klijn, F. H., Bossers, W. J. R., Rikkert, M. G. M. O., & van Heuvelen, M. J. G. (2018). Ranking Barriers, Motivators, and Facilitators to Promote Physical Activity Participation of Persons With Dementia: An Explorative Study. *Journal of Geriatric Physical Therapy* (2001). <https://doi.org/10.1519/JPT.0000000000000210>
- Lamb, S. E., Sheehan, B., Atherton, N., Nichols, V., Collins, H., Mistry, D., Dosanjh, S., Slowther, A. M., Khan, I., Petrou, S., & Lall, R. (2018). Dementia And Physical Activity (DAPA) trial of moderate to high intensity exercise training for people with dementia: Randomised controlled trial. *BMJ*, *361*, k1675. <https://doi.org/10.1136/bmj.k1675>
- Lowery, D., Cerga-Pashoja, A., Iliffe, S., Thuné-Boyle, I., Griffin, M., Lee, J., Bailey, A., Bhattacharya, R., & Warner, J. (2014). The effect of exercise on behavioural and psychological symptoms of dementia: The EVIDEM-E randomised controlled clinical trial. *International Journal of Geriatric Psychiatry*, *29*(8), 819–827. <https://doi.org/10.1002/gps.4062>
- Malthouse, R., & Fox, F. (2014). Exploring experiences of physical activity among people with Alzheimer's disease and their spouse carers: A qualitative study. *Physiotherapy*, *100*(2), 169–175. <https://doi.org/10.1016/j.physio.2013.10.002>
- McArdle, R., Del Din, S., Donaghy, P., Galna, B., Thomas, A., & Rochester, L. (2019). Factors That Influence Habitual Activity in Mild Cognitive Impairment and Dementia. *Gerontology*, 1–12. <https://doi.org/10.1159/000502288>
- McCurry, S. M., Pike, K. C., Logsdon, R. G., Vitiello, M. V., Larson, E. B., & Teri, L. (2010). Predictors of Short- and Long-Term Adherence to a Daily Walking Program in Persons With Alzheimer's Disease. *American Journal of Alzheimer's Disease and Other Dementias*. <https://doi.org/10.1177/1533317510376173>

- McKernan, P., & Grose, M. (2007). An analysis of accessible natural greenspace provision in the South East. *Forestry Commission*.
- Menne, H. L., Kinney, J. M., & Morhardt, D. J. (2002). 'Trying to Continue to Do as Much as They Can Do' Theoretical insights regarding continuity and meaning making in the face of. *Dementia*, 1(3), 367–382. <https://doi.org/10.1177/147130120200100308>
- Michie, S., Richardson, M., Johnston, M., Abraham, C., Francis, J., Hardeman, W., Eccles, M. P., Cane, J., & Wood, C. E. (2013). The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: Building an international consensus for the reporting of behavior change interventions. *Annals of Behavioral Medicine: A Publication of the Society of Behavioral Medicine*, 46(1), 81–95. <https://doi.org/10.1007/s12160-013-9486-6>
- Middleton, L. E., Black, S. E., Herrmann, N., Oh, P. I., Bechar, L., Middleton, L., & Lanctot, K. L. (2018). VALIDITY OF PHYSICAL ACTIVITY SCALE FOR THE ELDERLY AMONG PEOPLE WITH MCI OR MILD DEMENTIA. *Alzheimer's & Dementia*, 14(7, Supplement), P942–P943. <https://doi.org/10.1016/j.jalz.2018.06.1232>
- Molloy, D. W., Standish, T. I., & Lewis, D. L. (2005). Screening for Mild Cognitive Impairment: Comparing the SMMSE and the ABCS. *The Canadian Journal of Psychiatry*, 50(1), 52–58. <https://doi.org/10.1177/070674370505000110>
- Moyle, W., Venturto, L., Griffiths, S., Grimbeek, P., McAllister, M., Oxlade, D., & Murfield, J. (2011). Factors influencing quality of life for people with dementia: A qualitative perspective. *Aging & Mental Health*, 15(8), 970–977. <https://doi.org/10.1080/13607863.2011.583620>
- Nyman, S. R. (2019). Which Behavior Change Techniques Are Effective in Promoting Physical Activity Among Older People With Dementia? A Call for Research Into Three Underexplored Avenues. *Journal of Aging and Physical Activity*, 27(4), 441–445. <https://doi.org/10.1123/japa.2018-0301>
- Öhman, H., Savikko, N., Strandberg, T. E., & Pitkälä, K. H. (2014). Effect of Physical Exercise on Cognitive Performance in Older Adults with Mild Cognitive Impairment or Dementia: A

Systematic Review. *Dementia and Geriatric Cognitive Disorders*, 38(5–6), 347–365.

<https://doi.org/10.1159/000365388>

- Orgeta, V., & Miranda-Castillo, C. (2014). Does physical activity reduce burden in carers of people with dementia? A literature review. *International Journal of Geriatric Psychiatry*, 29(8), 771–783.
- Ory, M. G., Hoffman, R. R., Yee, J. L., Tennstedt, S., & Schulz, R. (1999). Prevalence and Impact of Caregiving: A Detailed Comparison Between Dementia and Nondementia Caregivers. *The Gerontologist*, 39(2), 177–186. <https://doi.org/10.1093/geront/39.2.177>
- Pernecky, R., Wagenpfeil, S., Komossa, K., Grimmer, T., Diehl, J., & Kurz, A. (2006). Mapping scores onto stages: Mini-mental state examination and clinical dementia rating. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, 14(2), 139–144. <https://doi.org/10.1097/01.JGP.0000192478.82189.a8>
- Phinney, A. (1998). LIVING WITH DEMENTIA From the Patient's Perspective. *Journal of Gerontological Nursing*, 24(6), 8–9. <https://doi.org/10.3928/0098-9134-19980601-06>
- Schutzer, K. A., & Graves, B. S. (2004). Barriers and motivations to exercise in older adults. *Preventive Medicine*, 39(5), 1056–1061. <https://doi.org/10.1016/j.ypmed.2004.04.003>
- Silverman, M. (2019). 'We have different routes for different reasons': Exploring the purpose of walks for carers of people with dementia. *Dementia*, 18(2), 630–643. <https://doi.org/10.1177/1471301217699677>
- Stubbs, A. (2014). Reducing mental illness stigma in health care students and professionals: A review of the literature. *Australasian Psychiatry*, 22(6), 579–584. <https://doi.org/10.1177/1039856214556324>
- Suttanon, P., Hill, K. D., Said, C. M., Byrne, K. N., & Dodd, K. J. (2012). Factors influencing commencement and adherence to a home-based balance exercise program for reducing risk of falls: Perceptions of people with Alzheimer's disease and their caregivers. *International Psychogeriatrics*, 24(7), 1172–1182. <https://doi.org/10.1017/S1041610211002729>



- van Alphen, H. J. M., Hortobágyi, T., & van Heuvelen, M. J. G. (2016). Barriers, motivators, and facilitators of physical activity in dementia patients: A systematic review. *Archives of Gerontology and Geriatrics*, *66*, 109–118. <https://doi.org/10.1016/j.archger.2016.05.008>
- van Alphen, H. J. M., Volkers, K. M., Blankevoort, C. G., Scherder, E. J. A., Hortobágyi, T., & van Heuvelen, M. J. G. (2016). Older Adults with Dementia Are Sedentary for Most of the Day. *PLOS ONE*, *11*(3), e0152457. <https://doi.org/10.1371/journal.pone.0152457>
- Wardt, V. van der, Hancox, J., Pollock, K., Logan, P., Vedhara, K., & Harwood, R. H. (2019). Physical activity engagement strategies in people with mild cognitive impairment or dementia – a focus group study. *Aging & Mental Health*, *0*(0), 1–8. <https://doi.org/10.1080/13607863.2019.1590308>
- Ware Jr, J. E., Kosinski, M., & Keller, S. D. (1996). A 12-Item Short-Form Health Survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care*, *34*(3), 220–233.
- Watts, A., Vidoni, E. D., Loskutova, N., Johnson, D. K., & Burns, J. M. (2013). Measuring Physical Activity in Older Adults With and Without Early Stage Alzheimer’s Disease. *Clinical Gerontologist*, *36*(4), 356–374. <https://doi.org/10.1080/07317115.2013.788116>
- Wills, T. A., & Shinar, O. (2000). Measuring perceived and received social support. *Social Support Measurement and Intervention: A Guide for Health and Social Scientists*, *4*, 86–135.
- Winchester, J., Dick, M. B., Gillen, D., Reed, B., Miller, B., Tinklenberg, J., Mungas, D., Chui, H., Galasko, D., Hewett, L., & Cotman, C. W. (2013). Walking stabilizes cognitive functioning in Alzheimer’s disease (AD) across one year. *Archives of Gerontology and Geriatrics*, *56*(1), 96–103. <https://doi.org/10.1016/j.archger.2012.06.016>
- Zanco, M. F., Moraes, H., Maranhão Neto, G., Laks, J., Deslandes, A. C., Zanco, M. F., Moraes, H., Maranhão Neto, G., Laks, J., & Deslandes, A. C. (2016). Assessing cardiorespiratory capacity in older adults with major depression and Alzheimer disease. *Jornal Brasileiro de Psiquiatria*, *65*(1), 1–8. <https://doi.org/10.1590/0047-2085000000096>

Table 1. An overview of participant characteristics for each dyad.

	Person with dementia	Carer
Age, years	77.3 (SD = 5.77)	70.6 (SD =11.08)
Gender: Male	10 (66.7%)	5 (33.3%)
Ethnicity: White British	14 (93.3%)	15 (100.0%)
sMMSE	22.5 (SD = 5.55)	-
Dementia diagnosis: Alzheimer's disease	9 (60.0%)	-
Relationship to person with dementia:	-	-
Spouse		12 (80.0%)
Son/Daughter		2 (20.0%)
General health status (SF-12):		
Excellent	1 (7.1%)	4 (26.7%)
Very Good	4 (28.6%)	6 (40.0%)
Good	8 (57.1%)	5 (33.3%)
Fair	1 (7.1%)	0 (0.0%)

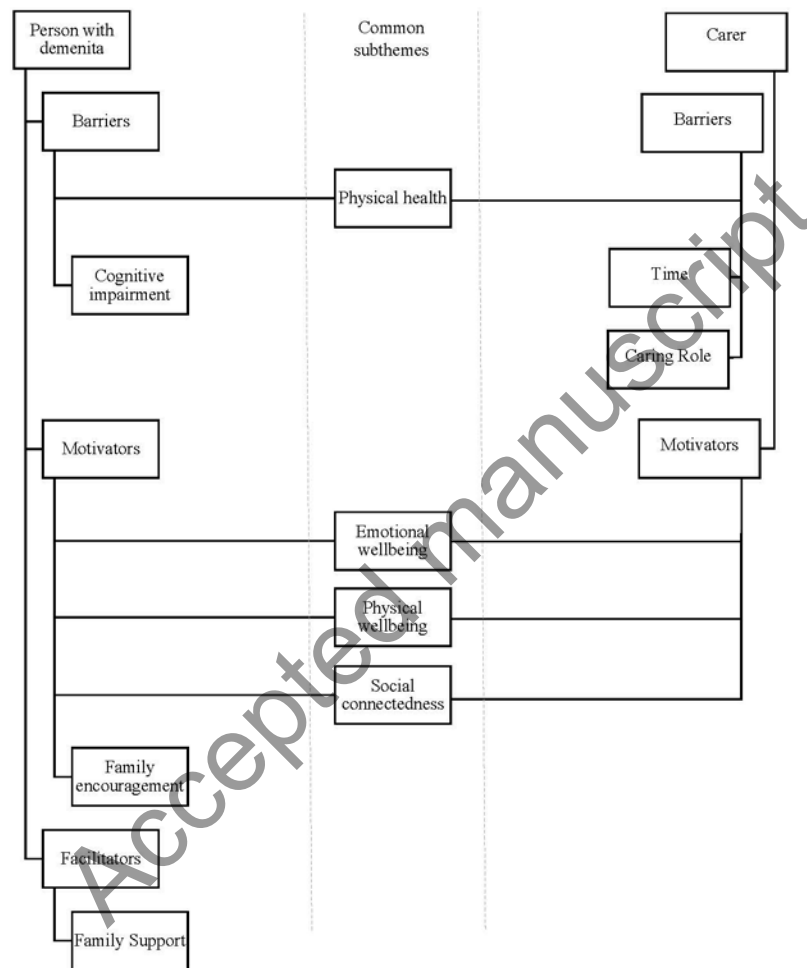


Figure 1. An overview of the themes identified during the dyadic interviews.

Table 2. Example quotes from participants in relation to barriers, motivators and facilitators of physical activity in people with dementia.

Theme	Subtheme	Example
Barriers	Physical health	<p>A1: <i>“but if [I was] more mobile I would probably start going to play football”</i> (Male, person with dementia: 180709ST1)</p> <p>A2: <i>“you want to get to the gym but your blooming leg isn’t letting you do it as often as you want to”</i> (Male, person with dementia, 160107SB1)</p>
Barriers	Cognitive impairment	<p>B1: <i>“I don’t think you (indicating toward spouse) would go swimming, [it would] be too difficult, changing and everything, using lockers”</i> (Female, caring for spouse, 151112SB1)</p> <p>B2: <i>“Erm, there are times when I... not quite sure what I should be doing, and then I think ‘oh Christ that’s the dementia coming in”</i> (Male, person with dementia, 180803ST1)</p>
Motivators	Emotional Wellbeing	<p>C1: <i>“oh the sheer enjoyment of whatever I am doing, I wouldn’t do it if I didn’t enjoy it”</i> (Female, person with dementia, 180529ST1)</p> <p>C2: <i>“It makes me feel that occasionally I feel normal”</i> (Female, person with dementia, 151125EB1)</p> <p>C3: <i>“, “and I um, I enjoy doing it, so I enjoy the sports, I enjoy doing the exercise... and um, and I’ve always been err, a pretty competitive sort of person. So when I’m at the gym, um, I record what I am doing so I am making a comparison between, um, what I’ve done this time with that particular exercise compared with the last time.”</i> (Male, person with dementia, 160107SB1)</p>

Motivators	Physical wellbeing	<p><i>D1: "I think it not only helps with your weight, helps with your health, it helps with your breathing, it's good for your heart..." (Male, person with dementia, CX145)</i></p> <p><i>D2: "because I do it I'm fitter and you know good form..." (Male, person with dementia, 180803ST1)</i></p>
Motivators	Social connectedness	<p><i>E1: "...it keeps you fit, it keeps you in touch with people" (Female, person with dementia, 180529ST1)</i></p> <p><i>E2: "...I've known them, oh gosh, years and years...years of being with people the same people, same room, erm, and it's an outing, and we always go and have a cup of coffee and moan and groan" (Female, person with dementia, 151125EB1) (Responding to why they think Pilates has the greatest impact on their quality of life)</i></p>
Motivators	Family encouragement	<p><i>F1: "I mean that's the main thing is encouragement, 'come on mum' isn't it? (laughing). I don't... I don't sit around too much, well I don't think I do, erm, but they certainly help, they certainly help, and they certainly encourage you." (Female, person with dementia, 180529ST1)</i></p>
Facilitators	Family support.	<p><i>G1: "I now rely on people or especially (wife) to run me about..." (Male, Person with dementia, 181018ST1)</i></p>

---

Table 3. Example quotes from participants in relation to barriers, motivators and facilitators of physical activity in carers.

Theme	Subtheme	Example
Barriers	Physical health	<p>A1: <i>“Only my age I suppose you get to a certain age and you are not as active as you once used to be but other than that you just accept it and if it takes you twice as long to do it it’s not really that important is it?”</i> (Male, caring for spouse, 171003GS1)</p> <p>A2: <i>“if I do too much, anything like what I used to do, I then have some days of absolute total exhaustion um which is a real drawback mentally and physically”</i> (Female, caring for a parent, 180404ST1)</p>
Barriers	Time	<p>B1: <i>“I used to go down to the gym umm quite a bit and umm I just don’t have the time for that now. Um...it seems I used to go out a lot more I don’t go out as much as I used to”</i> (Female, caring for a parent, 180529ST1)</p> <p>B2: <i>“...time really you know, finding, it’s fitting it in with everything else you do”</i> (Female, caring for spouse, 160812MC1)</p>
Barriers	Caring role	<p>C1: <i>“It’s because he can’t walk very fast or can’t walk very far it stops me from doing it sometimes, you know? Where I would go out, but he want to come with me... so it does hold me back a bit yeah”</i> (Female, caring for spouse, 160812MC1)</p> <p>C2: <i>“I can’t leave [spouse name] for as long as I used to. If I do, do anything I have to write down on a piece of paper what time I will be back, because [spouse name] will forget by the time I’ve gone out</i></p>

*the door, where I've gone, what I'm doing and what time I will be back. But it does restrict you” (Male, caring for spouse, 171003GS1)*

*C3: “It has reduced the time available and options because I can't leave [person with dementia] alone for longer than an hour. So does limit the distance I can walk... probably doesn't limit swimming because we've got the swimming pool next door. But um yeah it's mostly walking that is limiting” (Male, caring for spouse, 151125EB1)*

*C4: “I don't get as much active aerobic walking on the whole because obviously with somebody of nearly ninety we walk much more slowly” (Female, caring for parent, 180404ST1)*

Motivators      Emotional Wellbeing

*D1: “I just like getting out and about, I get bored I think” (Female, caring for spouse, 180503ST1)*

*D2: “I think it's absolutely essential for me, I'm very aware that the times if I'm getting really stressed or depressed...I just need a good long walk and I've always been like that and it clears my head as well as making me feel better” (Male, caring for parent. 180404ST1)*

Motivators      Physical wellbeing

*E1: “I think physical activity improves your life, yes. I think it helps to prolong your life I think it helps you generally be healthier” (Female, caring for parent, 180529ST1)*

*E2: “I think it’s very important for physical wellbeing... And also keeping your weight down a little bit (laughter) and for your heart... I mean it’s got all positive attributes yeah” (Female, caring for spouse, 180604ST1)*

*E3: “I mean it helps to make you live longer, keeps you flexible um stops you having heart attacks, strokes, that sort of thing...keeps your weight down” (Female, caring for spouse, 160812MC1)*

Motivators      Social  
connectedness

*F1: “...you get to meet people as well. You get to see people you’ve not seen in a while and probably have a chat... because otherwise when you walk in, I have only you (indicating person with dementia) to talk to really haven’t I really?” (Female, caring for spouse, 180503ST1)*

*F2: “...it [physical activity] gives you something to talk about otherwise it’s quite easy to just sit there in silence” (Female, caring for spouse, 180919ST1)*

---

Accepted manuscript