

Exploring the Lived Experiences of Physical Activity in Community-Dwelling Adults Living With Dementia and Their Carers

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People living with dementia have the same right to well-being as anyone else, including physical activity. Yet, physical activity levels among people with dementia are lower than in the general population, and while the physical activity health benefits are well established, little is known about how people living with dementia experience physical activity. To explore these physical activity experiences, we visited six community settings in one English county and conducted informal interviews with 18 people who were either living with dementia and community dwelling ($n = 4$), caring for or who had cared for someone with dementia ($n = 10$), or providing a support service for people living with dementia and their carers ($n = 4$). Findings highlight both the challenges and facilitators presented by organized groups, service provider skills and qualities, and environmental factors. Additionally, these factors were influential in shaping the physical activity experience of people living with dementia. The findings may be relevant for people providing or planning support services, commissioners, policymakers, and researchers.

Keywords: experience, meaning, movement, well-being

Key Points

- People providing and planning services, commissioners, and policymakers should take time to consider a range of options and environments for physical activity.
- It is important for people living with dementia and carers to be involved in research and planning that may influence their well-being.

Dementia is an overarching term used to describe progressive cognitive decline. There are over 920,000 people living with dementia in the United Kingdom, and this number is expected to reach one million by 2024 (Witterberg et al., 2019). Although not exclusively an older person's disease, most people living with a dementia diagnosis are aged 65 years and older, with 61% of those living in the community (Social Care Institute for Excellence, 2020). Additionally, there are an estimated 120,000 people living with dementia who are living alone in the United Kingdom (Alzheimer's Society, 2019).

As a progressive and at present incurable disease, preserving or enhancing the well-being and/or quality of life of those living with dementia and their carers is an important goal (Alzheimer's Society, 2021). However, a survey conducted by the Alzheimer's Society (2019) found that one in six people living with dementia said they would not do certain activities because they felt they would not be welcomed or accepted. Factors, such as poor accessibility, a lack of reasonable adjustment to meet the needs of people living with dementia, and experiences of stigma influenced by perceptions and attitudes in the wider community, can lead to social exclusion and significant reductions in opportunities to take part in activities that others may take for granted (Walsh et al., 2017). Exploring how people living with dementia and their supporters experience physical activity may shed light on the factors that

support or challenge people in maintaining or enhancing quality of life. As reflected in national dementia policy in the United Kingdom (Department of Health, 2009), "living well," which the Alzheimer's Society (2019) highlights, should include access to personalized activities that contribute to leading a fulfilled life.

Physical activity is an umbrella term for many types of bodily movement, encompassing everyday/lifestyle activity (e.g., walking, gardening), exercise, and sport, although these terms are often used interchangeably (see Pedersen & Saltin, 2015). The benefits of physical activity are well established, including its association with improved health (Bangsbo et al., 2019; Ding et al., 2020). Considering its contribution to health and well-being, recommendations for physical activity participation are now published in many countries, with consistent messaging about the importance of adults achieving 150 min of moderate-intensity activity each week (Bull et al., 2020). Despite the researched benefits and published physical activity guidelines, levels of physical activity are suboptimal, and among people living with dementia, levels of activity are often much lower when compared with the general population (Boyle et al., 2015; Zanco et al., 2016). Studies have shown that physical activity can benefit people living with dementia in numerous ways, from improving physical function (Forbes et al., 2015; Potter et al., 2011); cognition (Farina et al., 2014; Wang et al., 2012); and mood (Bowes et al., 2013); to supporting well-being (Nyman & Szymczynska, 2016). The need for physical activity to be personally meaningful, enjoyable, and pleasurable and to create feelings of achievement has also been demonstrated to be important for people living with dementia (Cedervall et al., 2015; Farina et al., 2021; Moyle et al., 2011). People living with dementia may want to continue with longstanding

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activities that may have been interrupted by diagnosis and/or symptom-related obstacles (Malthouse & Fox, 2014). However, linked to the Alzheimer's Society (2019) survey findings and evidence of the risk of social exclusion, people living with dementia may, for a variety of reasons, feel or be unable to (re)engage with those activities.

Relationships with family and friends can be important in motivating, supporting, and facilitating physical activity in people living with long-term conditions, including dementia (Birtwistle et al., 2021; Farina et al., 2021; van Alphen et al., 2016). With over three quarters of people living with dementia receiving support from an unpaid carer (Alzheimer's Society, 2014), it is perhaps unsurprising that spouse or partner carers are identified as central to supporting the person living with dementia to remain, or become more, active (Cedervall et al., 2015). Encouragement, facilitation, and experience can also be influenced by service providers, instructors, and session leaders (Farina et al., 2021; Roland & Chappell, 2015).

Well-being is likely to be a relevant and often-used goal with respect to *doing* physical activity and *being* physically active. The Care Act (Department of Health & Social Care, 2014) promotes the idea that well-being is difficult to define as it should be personal to each individual and based upon their own priorities, needs, and circumstances. This approach reflects the more flexible definition of physical activity (which is further discussed below) and the acknowledgement that meaning, enjoyment in physical activity, and its impact on well-being are likely to be informed by factors, such as individual contexts, aspirations, and resources. Although a contested term, quality of life is persistently related to well-being and is associated with the individual's view of life as well as the context of the culture and value systems in which one lives (World Health Organization, 2012).

Many studies in the past two decades have examined the association between physical activity and the risk of dementia and/or the management of so-called dementia symptoms (e.g., Blondell et al., 2014; Najar et al., 2019). Largely using longitudinal and/or quantitative research designs, these studies have rarely, with some notable exceptions, included the relationship between the lived experience of physical activity and engagement. One study that did explore this found that lifestyle activity in people living with Alzheimer's disease (the most common type of dementia) may provide a better experience than structured or formal exercise (Malthouse & Fox, 2014). Building on these findings, Piggitt (2020) defined physical activity in a way that embraces all kinds of movement and participation in activities in cultural spaces and introduced the idea that physical activity is affected by multiple influences, including, for example, personal interests, emotions, and relationships. The overarching aim of this study is to explore the lived experiences of physical activity in people living with dementia and their carers.

Methodology

Research Paradigm

This research design takes an interpretive approach and recognizes the body as more than a biological entity, with the potential for diversity in individual experiences, which are negotiated through social and cultural contexts (Palmer et al., 2018; Phoenix & Tulle, 2018). In their examination of the term "lived experience," McIntosh and Wright (2019) described it as a widely used and interpreted notion across a range of scholarly disciplines and nonacademic organizations denoting engagement or involvement with people in real-world contexts (e.g., Croucher et al., 2017; Neale, 2016; Wright, 2016). The incorporation of lived experience

in the aim of this study is epistemically applicable as an experiential and empathetic way of gathering aspects of life (McIntosh & Wright, 2019) in relation to physical activity and dementia.

Participant Recruitment

Owing to the number of carers supporting people living with dementia and their importance to the lives of those they care for (as identified in the opening section), the experiences of carers are included in this review, with the term carer aligning with the National Health Service (NHS) definition as anyone who provides unpaid care and support (NHS England, 2021). Similarly, due to the relevance of service providers to physical activity experiences, such providers are also included in this study.

The first author, as principal researcher, contacted dementia support service providers in one English county and ascertained whether their services met the criteria of being provided in a community location, aimed at people living in the community, and involved an element of physical activity, even if this was not at every session. Six community groups met these criteria, and after an initial conversation, the session leaders invited the researcher to attend a session to talk to attendees and service providers about the study, share the participant information sheet, and ask any questions they may have about taking part. The researcher approached people living with dementia, carers, and service providers. Not everyone attending sessions wished to talk about the study, and not everyone the researcher spoke to consented to being part of the study. Written informed consent was obtained by each person taking part in the study (further details on the consent process are detailed below). Eighteen consultation participants were recruited, including four people living with dementia, four service providers, and 10 people who either care for or have cared for someone living with dementia. Further details about participants are provided in Table 1.

Methods

Conversations were used as the method of collecting data. These were purposeful yet informal in nature, aiming to create more relaxed communication, leading to potentially more naturalistic data (Swain & King, 2022). A semistructured topic guide was used with open-ended questions including asking about experiences of and influences on physical activity, what was important to them about physical activity, and how dementia may or may not influence engagement. Curiosity-driven questions based on participant responses encouraged elaboration (Smith & Sparkes, 2017). Approaching qualitative data generation in an informal way is not a new approach, having gained traction in ethnographic anthropological research in the 1920s. The approach continues to be used more recently (e.g., Densley, 2013; Thomson & Trigwell, 2018). This method has been used both as a complementary approach alongside other methods and as a standalone method, and as Swain and King (2022) advocated, it can be an appropriate method in everyday situations where people talk. We do not therefore suggest this method is suitable in every scenario but find that this approach meets well with the aim of this study, our paradigmatic assumptions (discussed earlier), our ethical quest for inclusivity, and the settings within which we collected our data.

The audio from conversations was not recorded due to their public and fluid nature. Contemporaneous notes were taken, and detailed field notes were written up after leaving the field. The use of recording is keenly debated, and as Rutakumwa et al. (2020)

Table 1 Participant Information

ID	Participant type	Dementia diagnosis	Setting and physical activity
1	Person with dementia	Vascular dementia	Refreshments and tai chi at a community hall
2	Person with dementia	Frontotemporal dementia (early-onset)	Refreshments and tai chi at a community hall
3	Person with dementia	Alzheimer's disease	Refreshments and various indoor activities at a leisure center
4	Person with dementia	Vascular dementia	Refreshments and various indoor physical activities at a community hall
5	Carer	N/A	Refreshments and tai chi at community hall
6	Carer	N/A	Refreshments and various indoor physical activities at a leisure center
7	Carer	N/A	Refreshments and various indoor physical activities at a leisure center
8	Carer	N/A	Refreshments and various indoor physical activities at a leisure center
9	Carer	N/A	Refreshments and various indoor physical activities at a community hall
10	Carer	N/A	Refreshments and various indoor physical activities at a community hall
11	Carer	N/A	Refreshments and movement to music at a community hall
12	Carer	N/A	Refreshments and movement to music at a community hall
13	Carer	N/A	Refreshments and movement to music at community hall and walks from the venue
14	Carer	N/A	Refreshments and movement to music at community hall and walks from the venue
15	Service provider	N/A	Managing leisure and culture programs including providing occasional dementia support cover including various indoor physical activities at leisure and community venues
16	Service provider	N/A	Providing leisure and culture programs including providing occasional dementia support cover including various indoor physical activities at leisure and community venues
17	Service provider	N/A	Providing dementia support sessions including various indoor physical activity options at leisure and community venues
18	Service provider	N/A	Providing dementia support sessions including various indoor physical activity options at leisure and community venues

Note. N/A = not applicable.

highlighted in their comparative analysis, in certain circumstances, such as open environments, not recording may be the best approach to reduce participant nervousness and attempting to level the power distribution between the researcher and researched. Furthermore, they found that data captured from notes can be comparable to transcripts in terms of quality and rigor, but researcher care and training are important. As an early-career researcher, the first author has undertaken a variety of qualitative methods, including both recorded and unrecorded interviews and world café, and is well practiced at note-taking. The second author is very experienced in participatory research approaches and provided support and guidance throughout the study. As with the conversation approach, the decision to take notes and not record was informed by the contextual factors highlighted earlier, for example, the settings and inclusivity.

With inclusivity at the core of our approach, conversations were conducted during the dementia support groups and sometimes took place over several meetings. Physical activity offered during groups varied and included, for example, seated exercise, singing with actions, parachute games, tai chi, new age kurling, boccia, balloon games, a walk outside, and tabletop sports. The number of conversations with each participant varied according to their attendance at sessions, their time availability, the information shared during the conversation(s), the well-being of the participant, for example, reducing the mental burden, and rapport with the researcher. As a minimum, each participant was spoken to once over the course of their participation in the group they attended (typically 90 min). The researcher visited each of the six locations a minimum of two times to collect data.

Data Analysis

Field notes formed the data for this study. Our approach to data analysis was informed by Braun and Clarke's (2019) reflexive thematic analysis, in that the analytic process was organic and recursive, moving forward and backward through data familiarization, coding, theme development, and then writing up. The first author spent time familiarizing herself with the field notes, immersing herself in the data through reading and rereading. Coding was used to interpret meaningful segments of data concerning lived experiences of physical activity and to generate initial codes. After initial code development, the first author reviewed these codes and began to construct themes. Codes and themes were subsequently discussed with the second author, who acted as a "critical friend" (Smith & McGannon, 2018), constructively challenging initial interpretations and suggesting alternatives, strengthening the analytic process, and supporting the refinement of themes.

Ethical Considerations

Ethical approval for this research was granted by the University of Lincoln Human Ethics Committee (ref: 2021_7030). Noting the inclusive consent process for people living with dementia advocated by Dewing (2008), people wishing to take part were asked to give informed consent; mental capacity to do so was assumed unless otherwise indicated as per the Mental Capacity Act (2005), and consent was revisited verbally on each meeting occasion. The participant information sheet identified the conversations with a

purpose approach and note-taking may take place during these conversations; again, both things were revisited on each meeting occasion. Our inclusive approach extended into the consideration of how to collect data in this study (discussed earlier) and led to the selection of informal conversations, note-taking, and field notes. It was the intention to be part of the groups attended and provide a relaxed informal environment where conversations could happen during the normal activities of each group setting, for example, over a cup of coffee or during a game of kurling.

Having provided the background context and aim of this study in addition to details of the research design, we now present the results and discussion. These are presented as a combined section to aid in the exploration of the lived experiences of physical activity among the study participants.

Results and Discussion

Based on the reflexive thematic analysis of the data from the field notes, we constructed four themes: (1) groups as a space for connection and support, (2) skills and qualities of service providers, (3) carers are important but experience challenges, and (4) environmental factors.

Groups as a Space for Connection and Support

Our study highlighted the importance of places and spaces where people living with dementia and their carers could meet, and where physical activity and movement could be enjoyed in relaxed, non-stigmatizing, and encouraging environments. Carer participants highlighted that many days spent without activity or outside interaction left the person living with dementia sitting or sleeping. Having a group to attend provided motivation to go out, to meet people, and to move and be physically active. Resonating with the extant literature, groups were also identified as a space where both people living with dementia and carers gain perspective on their own experiences and help people to be socially connected and experience the camaraderie of being “in it” together (Yu & Smartwood, 2012), feeling empowered by the group and its activity (Hobden et al., 2019; Mmako et al., 2020; Motta-Ochoa et al., 2021; Sondell et al., 2021), and promoting a sense of fellowship (Söderhamn et al., 2014).

Participant 16, a service provider, described in the consultation how carers feel that they can “breathe” when attending a group, knowing they are supported, understood, and the person living with dementia is safe. For the same reason, groups can also provide a source of respite, where a carer may leave the person for a short while (Yu & Smartwood, 2012).

The data highlighted the importance of a wider definition of physical activity and where that activity can take place, emphasizing social connection and fun along with physical movement. The lack of recognition of the importance of a wider definition, incorporating a range of benefits outside of physical activity, presented a challenge for some service providers in the consultation, who commented that funding was often attached to government physical activity guidelines, but poignantly, one provider (Participant 15) remarked:

How do you measure a smile?

Participant 1, who is living with vascular dementia, stated that she enjoyed coming to the tai chi group she attended, highlighting both the social aspects and the reduced feelings of stigma, commenting that she had found:

People you can laugh with and a chance to do something good for me.

Signs of well-being were observed, including joyful facial expressions, expressions of pleasure, laughter, and confident social mixing during groups and specifically during the various physical activity opportunities. One carer (Participant 9) expressed how taking part in activity with a group made their relative living with dementia become more animated and supported an increase in communication, positive emotion, and indications of well-being. People were noted by a service provider (Participant 15) as “being in the moment,” who went on to describe seeing “initial fear turn to peace.” In the same way, carers expressed how the person living with dementia was keen to come to the group, obviously looked forward to it, and enjoyed taking part in the activities. All carer participants mentioned the importance of a routine, such as having familiar places to attend on the same days each week.

Group activities also provided an opportunity for people living with dementia, carers, and service providers to talk about sporting interests; lively conversations took place about attending football matches and watching sport on television. This coheres with the literature in demonstrating the enjoyment felt from an autobiographical perspective as a past/present participant or fan (Carone et al., 2016). However, service providers (Participants 15, 17, and 18) also highlighted how reminiscence may not always produce positive emotions and sensitivity to people’s sense of loss in their physical and cognitive abilities, for example, was essential.

In acknowledging the importance of group situations, the study identified that most of the groups visited had been created either by service providers as part of funded services, by volunteers, or established by individuals as part of friendships developed from formal groups. The ethos and content of the groups were shown to be important features, both in terms of the group environment on its own and as a positive space for physical activity, which leads onto the next theme, concerning the skills and qualities of service providers.

Skills and Qualities of Service Providers

Service providers may be paid staff or volunteers, but their perspectives highlighted their fulfillment from providing dementia support and activity groups:

[Providing sessions is] the proudest thing I’ve ever done.
(Participant 17, dementia support group session leader)

We would argue that fulfilled providers can indicate their suitability for the role working with people living with dementia and carers and could associate with the embodiment of positive qualities. Service providers emphasized how they felt their skills were based on awareness and acknowledgment of the diversity and difference among different group members. This was, they said, central to their approach to planning and delivering sessions—being able to adapt the physical activity element in the moment, for example. Continuity was an important feature, for example, continuity of staff, venue, and time of the week—supporting people living with dementia to develop confidence. The importance of empathy, both from the perspectives of service providers and participants, was consistently highlighted and was also noted in a study on dementia-friendly swimming by Hobden et al. (2019).

People living with dementia and carers explained how, with the encouragement of service providers, they were able to be more positive about what they could do and could potentially achieve more than might have initially been assumed. The view among service providers was that there was always some form of physical activity a participant could do and always something to enjoy, such as tapping feet along to music. This was noted in one person living with dementia who rarely communicated verbally, but her family

carer (Participant 8) noted that when participating in a game of tabletop golf, she followed the progress of participants as well as recognizing the nuance of the game, as indicated by her facial expressions and humorous gestures when her relatives and service providers missed shots. The importance of the mix of skills and qualities of service providers was powerfully conveyed by a carer (Participant 6), who had been feeling alone following his relative's dementia diagnosis and worried that they would become socially isolated as people would not understand her changed behavior. Emphasizing the empathy and understanding he felt from one service provider and realizing he was not on his own, he stated that:

She saved my life.

Scholars have noted how the enhanced skills and abilities of service providers may improve the physical activity experience for attendees. For example, verbal and nonverbal communication and cues (Hancox et al., 2019; Mc Parland et al., 2017), tailoring of exercises (Hancox et al., 2019), and maintaining rapport with participants' and understanding of their needs (Vseteckova et al., 2020). Taking time to plan sessions may reduce the likelihood of problems occurring, while preparing well in advance of session commencement may provide time for training and delivery refinement (Mc Parland et al., 2017). This again highlighted the issues that can arise where short-term funding may provide less time for planning and disrupt service provider consistency and the building of routines (Mc Parland et al., 2017).

Carers Are Important but Experience Challenges

Carers who are unpaid and caring for people living with dementia are more likely to provide many hours of care and support over 24-hr periods. All the participants in the consultation were related to the person they were caring for, with the majority being the spouse of the person living with dementia and therefore the coresident. Carers have needs of their own, and in line with existing research, two carer consultees (Participants 5 and 9) remarked how their own health concerns were impacted both by and on the caring role. Relatedly, van Alphen et al. (2016) highlighted how the health and commitment of carers can be a challenge to the accessibility of physical activity for those living with dementia.

Our study demonstrated how the support provided by group activities was important to carers. Several expressed how being a carer made it difficult to look after themselves, and one carer (Participant 6) described trying to "divorce" themselves from their loved one who was living with Alzheimer's disease to achieve a momentary break from their caring role. In terms of physical activity, several studies have reported findings involving the role of carers as facilitators of physical activity (Barrado-Martín et al., 2019; Cedervall & Åberg, 2010; Farina et al., 2021; Malthouse & Fox, 2014). Furthermore, the demands of the caring role mean that opportunities for the carer to be physically active are often limited. Research has identified the positive physical activity experiences that carers have when either taking part with the person living with dementia or when participating on their own (Batsch & Mittelman, 2015; Carone et al., 2016; Long et al., 2020). Facilitative factors were particularly noted by the carers in our study, with several saying that their relative living with dementia may be less inclined to do any physical activity if they did not encourage them to go to activities, accompany them and join in, and/or support attendance by driving them to activities:

I bring her every week. If we didn't come [to the support group], she would likely not do a lot ... she enjoys it and

usually joins in [with activities] when we are here. (Participant 6, carer of person living with Alzheimer's disease)

This also links back to Piggin's (2020) broader definition of physical activity and the relevance of emotions and relationships to our experience. Furthermore, in their tai chi dementia study, Barrado-Martín et al. (2021) identified how carers may find it difficult to relax during activity sessions; this was also something identified by one carer (Participant 5) who described herself as "on edge" throughout an activity. Despite this challenge, both the carer and person living with dementia (Participant 2) attended regularly, both engaged in the activity, and stayed to socialize afterward. There was a mutual expression of how getting out and doing some activity was important to their lives, and because of the young-onset diagnosis of Participant 2, partaking in meaningful activities was felt to be especially important as they had recently left employment.

Environmental Factors

Environmental factors were relevant to indoor and outdoor spaces and highlighted the broader influences on physical activity experience and engagement in people living with dementia. The suitability of indoor venues was an issue raised by two service providers. In their experience, there were several environmental features that were identified as important, including acoustics, ventilation, outside noise, and accessibility. Service providers reflected that community leisure centers, although used for groups, were not always appropriate locations, and challenges included not being offered a suitable space, awareness that participants may have had previous connections with the place, which may not be conducive to joining a new group or activity, and finally, that community leisure centers can be busy, loud, large, and lack appropriate signage and are therefore environments that people may find unsettling.

Outdoor environments have been discussed in the literature in relation to physical activity (Brookfield et al., 2017; Ellingsen-Dalskau et al., 2021; McDuff & Phinney, 2015). The outside environment was an important and enjoyable space for activity for many of the people taking part in the study, especially those with gardens and pets. However, changes to mobility, balance, and cognitive abilities caused time outdoors to be more challenging. For example, one person living with vascular dementia (Participant 4) described how much they had enjoyed their garden and being outdoors, but due to a series of falls, was now more hesitant about going outdoors. His carer (Participant 10) reinforced the feeling that he may be losing interest due to fear of falling and increasing forgetfulness, but that adjustments to access and the support of others may be positive influences. Other carers also described the loss of interest they had seen in the person living with dementia, in some cases thinking that tiredness may be a reason and wondering how they might negate this. One person living with vascular dementia (Participant 1) explained how concerned she was becoming about where she lived and how this may influence her independence once she was no longer able to drive. She shared her experience of walking along the busy road being unpleasant and the distance to the bus stop being hindered by a lack of safe crossing points. She said she felt that:

There is no quality of life in inaccessibility.

Walking has been found to be a potentially preferable form of activity for people living with dementia (McDuff & Phinney,

2015). Alongside garden and home activities, walking fits with the notion of lifestyle activity, and as previously discussed, this type of activity may provide a better experience for people living with dementia than more structured activities (Malthouse & Fox, 2014). However, one carer of a person living with frontotemporal dementia (Participant 5) mentioned how difficult she now found walking with the person she cared for, with concerns regarding sensory impairments, a changed gait, and the associated risk of falling. Another carer (Participant 6) talked about the uneven nature of paths when using a stick and the lack of space for a wheelchair, leading to a loss in the previous enjoyment of outdoor activities, including shopping. In their consideration of the challenges posed by their near environments, two participants stated that they had thought about moving into a more urban location; however, this may create other challenges for a person living with dementia, who is unfamiliar with the environment.

Concurring with some of the aspects raised in our study, Brookfield et al. (2017) noted the environmental impact of outdoor design features, such as footpaths and resting places, and recommended that environmental planners consider such issues and make an effort to identify and advertise accessible walking routes.

Limitations and Avenues for Future Research

Our study took place in one large rural county in the East of England, which may be considered a limitation. Furthermore, we only used one method of data collection, in the form of conversations with purpose. Wider recruitment and a larger participant sample, in addition to the use of multiple methods, would be of benefit to future research to expand and extend some of the themes highlighted. Challenges in accessing and engaging with physical activity related to the rural nature of the area where the study took place. The extent to which people can access opportunities for physical activity and continue to use “naturally occurring” opportunities for physical activity/lifestyle activity (e.g., walking), infrastructure support, such as transport, and the availability of activities are factors that have not received significant research attention. Moreover, how people felt about place was also highlighted in our study. The influence of place and rurality on physical activity experiences and how place may support or create obstacles to physical activity in those living with dementia and their carers are underresearched and merit further exploration.

Research including more underrepresented groups, such as those with rarer forms of dementia or advanced dementia, is important but may require enhanced ethical considerations and consideration for innovative and inclusive methodologies. As highlighted by a carer of someone living with an early-onset and rare form of dementia explained during the consultation, there is so much to learn and appreciate about someone living with these forms of dementia and different considerations when it occurs earlier in life.

The wider system of stakeholders may provide further understanding of the influences on physical activity experience. For example, local leisure providers, age-friendly officers, dementia support workers, and local government staff were not participants in this study. These wider perspectives could all be relevant to the appreciation of the influence of place when living with dementia and, furthermore, when engaging in physical activity.

Finally, we acknowledge that group experience may be relevant to many of our findings, with or without the inclusion of physical activity. While we see these findings as relevant to the conversation about movement in its broadest sense as well as well-

being when living with dementia, there is scope for more in-depth research exploring the relationship between group environments, physical activity, and the experiences of people living with dementia.

Conclusion

This study has explored the lived experiences of physical activity for people living with dementia and family carers. It has illuminated some of the important aspects relevant to how people experience physical activity. This has included highlighting the positives that can arise from engaging in physical activity in all its forms, some of the things that can both facilitate and challenge participation, and the experience for people living with dementia and their wider support network. There are, however, several gaps in understanding, and this provides scope to develop research into more specific contexts in which dementia is experienced, different diagnoses, and the progression of the disease. Importantly, this study highlights the significance of including people living with dementia in research to represent diversity in, for example, culture, ethnicity, experiences of dementia, and carers in research, and to consider how such research may then be translated into practice so that it is meaningful for all.

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References

- Alzheimer's Society. (2014). *Dementia UK report*. <https://www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-uk-report>
- Alzheimer's Society. (2019). *Alzheimer's Society's view on carer support*. <https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/carers-support>
- Alzheimer's Society. (2021). *The later stage of dementia*. <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/late-stage-dementia>
- Bangsbo, J., Blackwell, J., Boraxbekk, C.J., Caserotti, P., Dela, F., Evans, A.B., et al. (2019). Copenhagen consensus statement 2019: Physical activity and ageing. *British Journal of Sports Medicine*, 53(14), 856–858. <https://doi.org/10.1136/bjsports-2018-100451>
- Barrado-Martín, Y., Heward, M., Polman, R., & Nyman, S.R. (2019). Acceptability of a dyadic tai chi intervention for older people living with dementia and their informal carers. *Journal of Aging and Physical Activity*, 27(2), 166–183. <https://doi.org/10.1123/japa.2017-0267>
- Barrado-Martín, Y., Heward, M., Polman, R., & Nyman, S.R. (2021). Adherence to the class-based component of a tai chi exercise intervention for people living with dementia and their informal carers. *Journal of Aging and Physical Activity*, 29(5), 721–734. <https://doi.org/10.1123/japa.2020-0119>
- Batsch, N.L., & Mittelman, M.S. (2015). *World Alzheimer report 2012. Overcoming the stigma of dementia*. Alzheimer's Disease International (ADI). <https://www.alzint.org/u/WorldAlzheimerReport2012.pdf>
- Birtwistle, S.B., Jones, I., Murphy, R., Gee, I., & Watson, P.M. (2021). “Do what you can with a happy heart”: A longitudinal study of patient

- and family members' lived experiences of physical activity post-myocardial infarction. *Disability and Rehabilitation*, 44(14), 3661–3670. <https://doi.org/10.1080/09638288.2021.1878560>
- Blondell, S.J., Hammersley-Mather, R., & Veerman, J.L. (2014). Does physical activity prevent cognitive decline and dementia?: A systematic review and meta-analysis of longitudinal studies. *BMC Public Health*, 14(1), Article 510. <https://doi.org/10.1186/1471-2458-14-510>
- Bowes, A., Dawson, A., Jepson, R., & McCabe, L. (2013). Physical activity for people with dementia: A scoping study. *BMC Geriatrics*, 13, Article 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, W.T., Jr., Teverovskiy, L., Kuller, L.H., & Thompson, P.M. (2015). Physical activity, body mass index, and brain atrophy in Alzheimer's disease. *Neurobiology of Aging*, 36(Suppl. 1), S194–S202. <https://doi.org/10.1016/j.neurobiolaging.2014.05.036>
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11(4), 589–597. <https://doi.org/10.1080/2159676X.2019.1628806>
- Brookfield, K., Ward Thompson, C., & Scott, I. (2017). The uncommon impact of common environmental details on walking in older adults. *International Journal of Environmental Research and Public Health*, 14(2), Article 190. <https://doi.org/10.3390/ijerph14020190>
- Bull, F.C., Al-Ansari, S.S., Biddle, S., Borodulin, K., Buman, M.P., Cardon, G., et al. (2020). World Health Organization 2020 guidelines on physical activity and sedentary behaviour. *British Journal of Sports Medicine*, 54(24), 1451–1462. <https://doi.org/10.1136/bjsports-2020-102955>
- Carone, L., Tischler, V., & Denning, T. (2016). Football and dementia: A qualitative investigation of a community based sports group for men with early onset dementia. *Dementia*, 15(6), 1358–1376. <https://doi.org/10.1177/1471301215600239>
- Cedervall, Y., & Åberg, A.C. (2010). Physical activity and implications on well-being in mild Alzheimer's disease: A qualitative case study on two men with dementia and their spouses. *Physiotherapy Theory and Practice*, 26(4), 226–239. <https://doi.org/10.3109/09593980903423012>
- Cedervall, Y., Torres, S., & Åberg, A.C. (2015). Maintaining well-being and selfhood through physical activity: Experiences of people with mild Alzheimer's disease. *Aging & Mental Health*, 19(8), 679–688. <https://doi.org/10.1080/13607863.2014.962004>
- Croucher, K., Quilgars, D., Baxter, D., & Dyke, A. (2017). *Housing and life experiences: First interviews with a qualitative longitudinal panel of low income households*. Joseph Rowntree Foundations.
- Densley J. (2013). *How gangs work: An ethnography of youth violence*. Palgrave Macmillan.
- Department of Health. (2009). *Living well with dementia: A national dementia strategy*. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf
- Department of Health & Social Care. (2014). *General responsibilities and universal services*. <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#chapter-1>
- Dewing, J. (2008). Process consent and research with older persons living with dementia. *Research ethics*, 4(2), 59–64. <https://doi.org/10.1177/174701610800400205>
- Ding, D., Varela, A.R., Bauman, A.E., Ekelund, U., Lee, I.M., Heath, G., Katzmarzyk, P.T., Reis, R., & Pratt, M. (2020). Towards better evidence-informed global action: Lessons learnt from the Lancet series and recent developments in physical activity and public health. *British Journal of Sports Medicine*, 54(8), 462–468. <https://doi.org/10.1136/bjsports-2019-101001>
- Ellingsen-Dalskau, L.H., de Boer, B., & Pedersen, I. (2021). Comparing the care environment at farm-based and regular day care for people with dementia in Norway—An observational study. *Health & Social Care in the Community*, 29(2), 506–514. <https://doi.org/10.1111/hsc.13113>
- Farina, N., Rusted, J., & Tabet, N. (2014). The effect of exercise interventions on cognitive outcome in Alzheimer's disease: A systematic review. *International Psychogeriatrics*, 26(1), 9–18. <https://doi.org/10.1017/S1041610213001385>
- Farina, N., Williams, A., Clarke, K., Hughes, L.J., Thomas, S., Lowry, R.G., & Banerjee, S. (2021). Barriers, motivators and facilitators of physical activity in people with dementia and their family carers in England: Dyadic interviews. *Aging & Mental Health*, 25(6), 1115–1124. <https://doi.org/10.1080/13607863.2020.1727852>
- Forbes, D., Forbes, S.C., Blake, C.M., Thiessen, E.J., & Forbes, S. (2015). Exercise programs for people with dementia. *Cochrane Database of Systematic Reviews*, 2015(4), Article CD006489.
- Hancox, J.E., van der Wardt, V., Pollock, K., Booth, V., Vedhara, K., & Harwood, R.H. (2019). Factors influencing adherence to home-based strength and balance exercises among older adults with mild cognitive impairment and early dementia: Promoting activity, independence and stability in early dementia (PrAISED). *PLoS One*, 14(5), Article e0217387. <https://doi.org/10.1371/journal.pone.0217387>
- Hobden, T., Swallow, M., Beer, C., & Denning, T. (2019). Swimming for dementia: An exploratory qualitative study: Innovative practice. *Dementia*, 18(2), 776–784. <https://doi.org/10.1177/1471301218768372>
- Long, A., Di Lorito, C., Logan, P., Booth, V., Howe, L., Hood-Moore, V., & van der Wardt, V. (2020). The impact of a dementia-friendly exercise class on people living with dementia: A mixed-methods study. *International Journal of Environmental Research and Public Health*, 17(12), Article 4562. <https://doi.org/10.3390/ijerph17124562>
- 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>
- McDuff, J., & Phinney, A. (2015). Walking with meaning: subjective experiences of physical activity in dementia. *Global Qualitative Nursing Research*, 2, Article 233339361560511. <https://doi.org/10.1177/2333393615605116>
- McIntosh, I., & Wright, S. (2019). Exploring what the notion of 'lived experience' offers for social policy analysis. *Journal of Social Policy*, 48(3), 449–467. <https://doi.org/10.1017/S0047279418000570>
- Mc Parland, P., Cutler, C., & Innes, A. (2017). The challenges of implementing and evaluating a pilot music and movement intervention for people with dementia: Innovative practice. *Dementia*, 16(8), 1064–1068. <https://doi.org/10.1177/1471301216642342>
- Mmako, N.J., Courtney-Pratt, H., & Marsh, P. (2020). Green spaces, dementia and a meaningful life in the community: a mixed studies review. *Health & Place*, 63, Article 102344. <https://doi.org/10.1016/j.healthplace.2020.102344>
- Motta-Ochoa, R., Incio-Serra, N., Boulet, A., Fu, D., Frantz, A., William, M., & Blain-Moraes, S. (2021). Mouvement de passage: Creating connections through movement among persons with dementia. *Dementia*, 20(7), 2573–2596. <https://doi.org/10.1177/14713012211004009>
- 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>
- Najar, J., Östling, S., Gudmundsson, P., Sundh, V., Johansson, L., Kern, S., Guo, X., Hällström, T., & Skoog, I. (2019). Cognitive and physical activity and dementia: A 44-year longitudinal population study of

- women. *Neurology*, 92(12), e1322–e1330. <https://doi.org/10.1212/WNL.0000000000007021>
- Neale, B. (2016). Introduction: young fatherhood: Lived experiences and policy challenges, *Social Policy & Society*, 15(1), 75–83.
- NHS England. (2021). *Who is considered a carer?* <https://www.england.nhs.uk/commissioning/comm-carers/carers/>
- Nyman, S.R., & Szymczynska, P. (2016). Meaningful activities for improving the wellbeing of people with dementia: Beyond mere pleasure to meeting fundamental psychological needs. *Perspectives in public health*, 136(2), 99–107. <https://doi.org/10.1177/1757913915626193>
- Palmer, V., Tulle, E., & Bowness, J. (2018). Physical activity and the ageing body. In S.R. Nyman, A. Barker, T. Haines, K. Horton, C. Musselwhite, G. Peeters, C.R. Victor, & J.K. Wolff (Eds.), *The Palgrave handbook of ageing and physical activity promotion* (pp. 531–549). Palgrave Macmillan.
- Pedersen, B.K., & Saltin, B. (2015). Exercise as medicine—Evidence for prescribing exercise as therapy in 26 different chronic diseases. *Scandinavian Journal of Medicine & Science in Sports*, 25, 1–72. <https://doi.org/10.1111/sms.12581>
- Phoenix, C., & Tulle, E. (2018). Physical activity and ageing. In J. Piggan, L. Mansfield, & M. Weed (Eds.), *Routledge handbook of physical activity policy and practice* (pp. 264–273). Routledge.
- Piggan, J. (2020). What is physical activity? A holistic definition for teachers, researchers and policy makers. *Frontiers in Sports and Active Living*, 2, Article 72. <https://doi.org/10.3389/fspor.2020.00072>
- Potter, R., Ellard, D., Rees, K., & Thorogood, M. (2011). A systematic review of the effects of physical activity on physical functioning, quality of life and depression in older people with dementia. *International Journal of Geriatric Psychiatry*, 26(10), 1000–1011. <https://doi.org/10.1002/gps.2641>
- Roland, K.P., & Chappell, N.L. (2015). Meaningful activity for persons with dementia: Family caregiver perspectives. *American Journal of Alzheimer's Disease & Other Dementias*, 30(6), 559–568. <https://doi.org/10.1177/1533317515576389>
- Rutakumwa, R., Mugisha, J.O., Bernays, S., Kabunga, E., Tumwekwase, G., Mbonye, M., & Seeley, J. (2020). Conducting in-depth interviews with and without voice recorders: A comparative analysis. *Qualitative Research*, 20(5), 565–581. <https://doi.org/10.1177/1468794119884806>
- Smith, B., & McGannon, K.R. (2018). Developing rigor in qualitative research: Problems and opportunities within sport and exercise psychology. *International Review of Sport and Exercise Psychology*, 11(1), 101–121. <https://doi.org/10.1080/1750984X.2017.1317357>
- Smith, B., & Sparkes, A.C. (2017). Interviews: Qualitative interviewing in the sport and exercise sciences. In B. Smith & A.C. Sparkes (Eds.), *Routledge handbook of qualitative research in sport and exercise* (pp. 103–123). Routledge.
- Social Care Institute for Excellence. (2020). *Dementia: At a glance*. <https://www.scie.org.uk/dementia/about/>
- Söderhamn, U., Aasgaard, L., & Landmark, B. (2014). Attending an activity center: Positive experiences of a group of home-dwelling persons with early-stage dementia. *Clinical Interventions in Aging*, 9, 1923–1931.
- Sondell, A., Lampinen, J., Conradsson, M., Littbrand, H., Englund, U., Nilsson, I., & Lindelöf, N. (2021). Experiences of community-dwelling older people with dementia participating in a person-centred multidimensional interdisciplinary rehabilitation program. *BMC Geriatrics*, 21(1), Article 341. <https://doi.org/10.1186/s12877-021-02282-y>
- Swain, J., & King, B. (2022). Using informal conversations in qualitative research. *International Journal of Qualitative Methods*, 21, 1–10. <https://doi.org/10.1177/16094069221085056>
- Thomson K.E., & Trigwell K.R. (2018). The role of informal conversations in developing university teaching? *Studies in Higher Education*, 43(9), 1536–1547. <https://doi.org/10.1080/03075079.2016.1265498>
- van Alphen, H.J., Hortobagyi, T., & van Heuvelen, M.J. (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>
- Vseteckova, J., Dadova, K., Gracia, R., Ryan, G., Borgstrom, E., Abington, J., Gopinath, M., & Pappas, Y. (2020). Barriers and facilitators to adherence to walking group exercise in older people living with dementia in the community: A systematic review. *European Review of Aging and Physical Activity*, 17(1), Article 15. <https://doi.org/10.1186/s11556-020-00246-6>
- Walsh, K., Scharf, T., & Keating, N. (2017). Social exclusion of older persons: A scoping review and conceptual framework. *European Journal of Ageing*, 14(1), 81–98. <https://doi.org/10.1007/s10433-016-0398-8>
- Wang, H.X., Xu, W., & Pei, J.J. (2012). Leisure activities, cognition and dementia. *Biochimica et Biophysica Acta*, 1822(3), 482–491. <https://doi.org/10.1016/j.bbadis.2011.09.002>
- Witterberg, R., Barraza-Araiza, L., & Rehill, A. (2019). *Projections of older people with dementia and cost of dementia care in the UK 2019–2040* [CPEC Working Paper 5]. www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf
- World Health Organization. (2012). *The World Health Organization quality of life (WHOQOL)*. <https://www.who.int/tools/whoqol>
- Wright, S. (2016). Conceptualising the active welfare subject: Welfare reform in discourse, policy and lived experience. *Policy and Politics*, 44(2), 235–252. <https://doi.org/10.1332/030557314X13904856745154>
- Yu, F., & Swartwood, R.M. (2012). Feasibility and perception of the impact from aerobic exercise in older adults with Alzheimer's disease. *American Journal of Alzheimer's Disease & Other Dementias*, 27(6), 397–405. <https://doi.org/10.1177/1533317512453492>
- 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>