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Perspectives of People with Mild to Moderate Cognitive Impairment and Their Caregivers about Physical Activity and Exercise for Fall Prevention: A Qualitative Study

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Abstract: Older adults with cognitive impairment are at high risk of experiencing falls. Although no specific fall prevention guidelines presently exist for this population, exercise programmes to prevent falls are recommended. Limited literature exploring what older adults with mild to moderate cognitive impairment think about or how they make sense of the need for such programmes exists. This study explored the perspectives of older adults with mild to moderate cognitive impairment and their caregivers about exercise and physical activity in the context of fall prevention. Underpinned by Interpretive Phenomenological Analysis, qualitative semi-structured interviews were undertaken with nine community-dwelling adults (>65 years) with mild to moderate cognitive impairment and their caregivers (N = 6). Three themes of acceptance, denial, and accommodation were identified. The fluctuating concept of 'self' appeared to influence individual decisions to exercise or be physically active and what sort of physical activity to undertake more than any practical barriers. We suggest that healthcare professionals emphasise the concept of personhood, listening to and reinforcing biographic narratives of older adults living with cognitive impairment to foster a sense of autonomy, and shared decision-making while emphasising fall prevention activities that older adults with cognitive impairment might like to engage with.

Keywords: cognitive impairment; older adults; falls prevention; physical activity; exercise; caregiver perceptions



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1. Introduction

Progressive cognitive impairment that affects the ability to function independently is a clinical component of the overarching term 'dementia' [1]. Typically the following components of mental activity are impaired: language, memory, visuospatial skills, personality, and cognition [2,3], and this substantially affects daily function [2,4]. Older adults with cognitive impairment are at higher risk of experiencing falls, with risk ranging from 2–8 times greater risk than older adults without cognitive impairment, and incidence rates of 20–65% within a year reported [5].

Management following a fall incurs a high cost and is an issue for policymakers, healthcare providers and many personnel involved in looking after older adults with dementia, including family members [6,7]. For a person with dementia, there are numerous multi-factorial, intrinsic and extrinsic fall risk factors [8], such as lighting, environmental hazards, co-morbidities and polypharmacy, as well as cognitive impairment [9]. Postural instability is also linked with the risk of falling [10]. An older systematic review has suggested that interventions that focus on postural stability have the potential to reduce

falls among older adults with dementia [9], with more recent systematic reviews and meta-analyses suggesting that exercise programmes may assist with minimising falls in community-dwelling older adults with mild to moderate cognitive impairment [10,11]. Additionally, the current literature suggests the inclusion of multi-type exercises, targeting flexibility, strength, balance and aerobic training may assist in preventing falls [5,11,12].

While specific fall prevention and management guidelines do not exist for older adults with dementia [13], generic guidelines are available for example, the Assessment and Prevention of Falls in Older People—NICE Guideline [14] and recently Montero-Odasso et al. [15] published the World Guidelines for Falls Prevention and Management for Older Adults: A Global Initiative. These latter authors recommend fall risk stratification, assessment, management and interventions, use of an Assessment and Treatment Algorithm to ensure the care is person-centred, and that healthcare professionals and service providers across health and social contexts be involved in fall prevention work. Further, these authors make a "strong recommendation that community dwelling older adults with mild cognitive impairment and mild to moderate dementia should be offered an exercise programme to prevent falls GRADE:1B", with Grade:1B denoting a strong recommendation, with the benefits of an intervention clearly outweighing the risks and burdens, which should be applied to most patients. [15] (p. 26). However, there is limited literature exploring what adults with mild to moderate cognitive impairment think about these programmes and how they make sense of the need for such programmes in their life. One such study reported on factors influencing adherence to a home-based balance class for reducing fall risk [16]. Results showed that education on why exercise is important, caregiver support and commitment affect adherence. However, this study did not explore attitudes towards group-based physical activity programmes, nor was there an in-depth analysis of participants' sense-making.

More recently, studies have begun to explore caregivers' perceptions about the benefits of exercise and physical activity for adults with mild to moderate impairment [17–19]. Evidence shows that the family caregiver's perception of the importance of and engagement in physical activity is associated with the person with dementia's engagement in physical activity [17]. However, irrespective of whether caregivers are professional or family, both believe that a potential reduction in the burden of care might arise from the person with dementia engaging in physical activity [17,18]. Moreover, minimisation of distress has been found in professional caregivers when the person with dementia engages in physical activity [19]. This study aimed to add to this growing body of literature and to gain insight into the collective perspectives of older adults with mild to moderate cognitive impairment and their caregivers about exercise and physical activity.

2. Materials and Methods

The study was part of a larger exploratory mixed-method research (MMR) study. The theoretical lens of the overall MMR study was underpinned by a pragmatist approach [20]. Such an approach facilitated integration of the different types of knowledge generated from within its embedded studies.

This embedded qualitative study was used Interpretive Phenomenological Analysis (IPA). The theoretical background for the analysis of data in this study was derived from a constructivist understanding that acknowledges human experiences develop and occur within cultural and social contexts [21]. IPA is a flexible and holistic approach that offers a way to gain insight into the lived experience and how individuals make sense of that experience [22]. IPA facilitates the exploration of the subjective and contextual nature of individuals' perceptions of significant health-related experiences. The genealogy of IPA is linked to Husserl's ideas of consciousness (personal experiences) and hermeneutics (interpretation) and is idiographic (uses a detailed approach to analysis) [22,23]. For the purposes of this research, we were interested in how participants with cognitive decline thought of themselves with respect to the concepts of physical activity. The larger study was approved by the University of Otago Human Ethics Committee (Health) (H14/035).

2.1. Participants

Potential participants were community-dwelling adults (N = 13) aged 65 years or older with mild to moderate cognitive impairment who had completed earlier components of the larger MMR study. Participants for the larger study were recruited from a dementia daycare center and via advertising from the local Alzheimer's Society to their memberships. Participants were informed of the purpose of the research and that this work formed part of one of the authors' (N.M.) Ph.D. studies.

All participants provided signed consent to participate in the larger study, and all were supported by caregivers. The diagnosis of cognitive impairment was either determined by the participants' general practitioner or via self-reported memory loss. All participants with mild to moderate cognitive impairment or self-reported memory loss needed to have scored 10–28 out of 30 on the Mini-Mental State Examination (MMSE) prior to starting the larger study. The MMSE is a frequently used screening tool when assessing cognitive function, with its psychometric properties comprehensively investigated (test-retest reliability (0.80–0.95)) [24–27]. A license to use the MMSE was obtained from Psychological Assessment Resources, Inc., Lutz, FL, USA, with a screening of potential participants undertaken by N.M.

Eleven of the thirteen participants from the larger study indicated a potential interest in participating in this latter aspect of the study. Nine participants with a range of MMSE scores, a range of ages and a mix of genders were purposefully approached to participate in this qualitative aspect. The remaining two participants were not approached because of the presence of unrelated ill health at the time the interviews were being conducted. The nine participants were contacted by N.M. (a physiotherapist and Ph.D. student) about the semi-structured interview and provided with an information sheet about the current interview study. If verbal consent to participate was obtained, a date, time and venue for the face-to-face interview were scheduled.

2.2. Data Collection

Within this paper, the term participants have been used to describe participating older adults with cognitive impairment, and 'caregiver' for the support person/significant other, chosen by the participant, who was central to the care of the participant. Caregivers were able to provide information about the person for the person as needed. All participants and caregivers were interviewed at the same time. Initially, interviews (n = 2) were conducted by two of the research team (L.H. and N.M.) until it was ascertained that (i) questions asked elicited sufficient breadth and depth of information to answer the aim of the study; and (ii) N.M. was sufficiently confident to continue independently. On the day of the interviews, the participant and the caregiver provided signed informed consent to be interviewed. Three interviews occurred in a private room at the University, five were interviewed at the participants' respective homes, and one participant was interviewed at a mutually agreed place in the community. Each interview was audio-recorded, lasted about one hour, and commenced with a reiteration of the aims of the study and what they were agreeing to with respect to their data, followed by the semi-structured questions (see Table 1). The semi-structured interview questions were drawn from previous similar studies [16,28,29] and via discussions with the research team. These questions guided the discussions. The actual sequence of questioning changed according to how the interview developed and with respect to where participants and caregivers wished to focus, thus facilitating the exploration of their experiences. At the conclusion of the interview, participants were provided with an NZD 25 grocery voucher as an acknowledgement of their time, travel and/or parking costs.

Table 1. Semi-structured interview questions.

Demographic Questions:

Participant Gender, Age, Long-Term Conditions, Caregiver Age, and Relationship Between Participant and Caregiver

Topics Explored:

Tell me about your balance?

Tell me about the times you have lost your balance or nearly had a fall?

How do you think you could improve your balance?

How do you think physical activity or exercise might help you?

What would help you to exercise or do physical activity regularly?

What would stop you from exercising or do physical activity regularly?

Where would you like to do the exercise or physical activity?

2.3. Data Analysis

In IPA, the analysis aims to understand the meaning participants ascribe to their worlds [23] and is influenced by the researchers' own interpretations of the participants' experiences, sometimes termed a double hermeneutic [29,30]. IPA requires repeated interaction with the transcripts [23]. The research team consisted of four females and one male researcher. Three of the team are experienced qualitative researchers with a combined experience of more than 50 years. Four team members are physiotherapists, and one is a registered nurse. Four have lived experience of supporting a family member with mild to moderate cognitive impairment. IPA acknowledges that these aspects of the researcher's identity are integral to the interpretation of the data.

Audio files were transcribed by one author (N.M.) and facilitated immersion in the data and recall of the interview setting and atmosphere. Following Smith and Osborne's [23] process, multiple readings of one transcript were undertaken independently by two researchers (N.M. and L.H.). This included notation of the researcher's reflection, insights, interpretation of the language used by the participants and caregivers and the context made in one margin, and identification of potential emergent themes capturing the essence of what the participants and/or caregivers were discussing in the other margin. As the aim of this study was not to compare data between participants and caregivers, participant and caregiver data from the same interview were analyzed collectively. However, nuances or differences in opinion were noted and coded as appropriate. Themes from the transcript were then listed in Word and analysed to connect and cluster themes. As IPA is an iterative process, the researcher then returned to the transcript to check their interpretation against the raw data.

Discussion occurred between four of the researchers (N.M., L.H., M.P. and A.W.) about the emergent themes until a consensus was reached. Excerpts of participants' and caregivers' words captured by the themes were extracted, matched, and tabulated with clustered emergent themes. Each theme was then named and described in the context of the study. One researcher (N.M.) then individually and iteratively analysed each remaining transcript. Clustered themes from each transcript were collated, and connections, such as similarities and differences, were observed between themes. Re-reading of raw data, in light of new emergent themes, also occurred [23,31]. Interpreted themes were grouped across the analyses and discussed between researchers to reach a consensus on grouping and names [23,30]. IPA does not advocate data saturation; however, no new themes arose after the seventh interview and all nine interviews contributed to the rich phenomenological insight [32]. A summary of the preliminary results of the analysis was presented in plain language to participants and caregivers for feedback. This form of stakeholder check resulted in no modification of the analysis.

3. Results

All nine participants approached agreed to participate in the qualitative interviews. Of these nine participants, six were accompanied by a family caregiver to provide support.

Five participants had a confirmed diagnosis of dementia, two of frontotemporal lobe dementia, and three unspecified. Six participants had mild cognitive and three moderate cognitive impairments based on the MMSE score. Participants also reported having the following long-term conditions: hypertension, lung disease, diabetes and musculoskeletal conditions. Three had a history of falling (confirmed by their family caregiver) in the last 12 months, but all were able to ambulate independently, with two participants requiring the use of a walking stick for outdoor activities. Three participants regularly participated in group activities (walking and pétanque), groups not specifically designed for people with cognitive decline. The remaining participants engaged in either group or individual physical activity on an ad hoc basis. Four participants lived in the community, and five in independent units within a retirement village.

Of the participants who chose to have a caregiver support them, all chose to have a family caregiver at the interview. The age range of the caregivers was between 65–76 years. Two caregivers had one or more medical conditions, including hypertension, diabetes, heart disease, back pain, arthritis and respiratory problems. All caregivers were female and a spouse to the respective participant. Table 2 provides participant and caregiver demographics.

Participants					Caregivers			
Name	Gender	Age (Years)	MMSE Score	#LTCs	Name	Age (Years)	#LTCs	Relationship
Alden	Male	71	14	0	Sabrina	67	0	Spouse
Bradley	Male	79	28	1	Edith	65	>4	Spouse
Raymond	Male	76	27	0	Hayley	70	1	Spouse
Ashley	Female	91	22	0	ŇA	NA	NA	NA
Daisy	Female	78	22	3	NA	NA	NA	NA
Dane	Male	82	24	2	Elisa	62	0	Spouse
Hazel	Female	90	20	0	NA	NA	NA	NA
Earl	Male	78	16	3	Kelsie	76	0	Spouse
Zain	Male	74	21	1	Ioana	70	1	Spouse

Table 2. Characteristics of participants and caregivers.

Notes: NA—Not applicable; Name—Pseudonym name; MMSE—Mini-Mental State Examination; #LTCs—Number of long-term conditions.

Three themes of 'awareness', 'denial' and 'accommodation' were iteratively interpreted from the data and explained participants' lived experience of behaviour towards physical activity or exercise and their caregivers' experience of encouraging participants to be physically active. Participants' 'awareness' of changes to their cognitive health (perceptualmotor control, memory and learning, attention, executive function, social cognition, and language ability) [33] and subsequent changes in motor skills, and their accommodation or denial of these changes, vacillated over time, both within moments of a day and across days. The accommodations made by participants changed depending on their understanding, i.e., 'awareness' of their own cognitive health (an acceptance-denial-accommodation continuum). When participants were aware that they were experiencing some change to their cognitive function and accommodating of these, they used different coping strategies when they were less aware but accepting or when aware but in denial. The fluctuating 'self', therefore, impacted decisions to engage in physical activity or exercise and what physical activities to undertake, more so than any practical barriers. Altered cognitive and physical health changed the participants' psychological perception of 'self', and this altered perception impacted their daily activities and decision-making about undertaking those everyday activities.

3.1. Awareness

The degree of perception participants had of their cognitive and physical decline was dependent on their current level of 'awareness'. However, awareness and then denial, or awareness and acceptance, were not necessarily consistent. For example, some participants were aware of and accepted some changes as being a part of cognitive decline; however,

conversely, other changes were not accepted as being part of altered cognitive function. Therefore, awareness of both cognitive and physical change was evidenced in fluctuating ability to complete a specific task. These changes were described as a gradual deterioration over time, making completion of tasks difficult. One caregiver shared her observation of a participants' decreasing ability to concentrate and follow instructions, reflecting how deterioration of these cognitive skills prevented daily task completion. "I [have] observed that it is very hard for you to eliminate distraction and stay on task and focus on what you [are] doing" (Sabrina, caregiver).

Participants also recognised the concurrent deterioration of physical health, as tasks required more effort and resulted in fatigue. Some participants recognised that their reaction time when responding to an unforeseen perturbation, for example, the "response on...catching of the foot [is] slower" (Dane, participant) than it used to be and that "coordination, it seems becoming more affected" (Raymond, participant). Others discussed the use of assistive devices, such as a walking stick, helping them to walk even though they could not walk the same distances as previously and that it was important "to go out, otherwise you will deteriorate" (Hazel, participant). The increasing difficulty of completing more complex physical tasks, such as traversing uneven terrain or climbing a ladder in the same manner as previously, was frequently noted by the caregivers. "He is fine with walking...[but] climbing the step ladder, [he] needs to [have someone] hold [it]. It [the ladder] shakes [because] he is a bit shaky" (Sabrina, caregiver).

Generally, participants and caregivers agreed that more strenuous physical activities should be of short duration, as everything took more cognitive and physical effort and required an "enormous amount of energy" (Kelsie, caregiver) to just complete the usual tasks. Other caregivers noted the "fatigue" (Edith, caregiver) and of their clients being "'hopeless' in the afternoon" (Hayley, caregiver). Earl (participant) similarly said his "sleep pattern had changed" and that meant he needed to go to bed early to cope with the physical demands of everyday life.

Multiple incidents of near physical misses, or accidents, helped improve awareness of a change in cognitive health and motor skill for some of the participants. Some reported feeling consistently unstable with quick turning or that they regularly missed changes in elevation of the footpath.

As the level of awareness decreased for participants, caregivers became hyper-aware of the link between the deterioration of cognitive and physical systems and the impact of each system's deterioration on the other system. Elisa talked about how the reduced "rhythm of the body movement" affected her husband since his diagnosis with dementia and "it spread slowly into the other areas of his life" (Elisa, caregiver). While Hayley (caregiver) reported, "obviously, [there] is a strong relationship between mental efficiency and physical...ability. There is too much [of an] association". These escalating effects of each systems' deterioration on the other system raised concerns for caregivers about the ability of participants to safely complete activities of daily life. For example, Hayley (caregiver) shared an experience where her husband got lost taking the dog for a walk one day.

Not that long ago he did not do his normal walk, he went a different way, [to a] different place. [It] took him [a bit] longer [to get home]. I thought he was lost. Nobody else knew that. So, you know, as you get worse, [and] what we know is [it is] going to happen, [I think] it would be better [for you to be] doing exercise with people rather than alone. (Hayley, caregiver)

3.2. Denial

Denial arose from an initial phase of perception (awareness) about the cognitive and secondary physical changes being experienced by participants. "Denial" suggested that the participants had difficulty "admit[ting] the truth or reality of something unpleasant" [34], in this instance, changes in cognitive and physical health. Denial, a common defence mechanism, was used by participants to protect themselves as they noticed the changes in their cognitive health. As new changes in physical and cognitive health were noticed,

new coping strategies to mitigate these further changes were implemented. Examples of denying physical changes but with sufficient awareness to implement coping strategies were illustrated by the following participants. When they were asked about balance with walking activities, they suggested that it was "all right" (Daisy, participant) and "reasonably good" (Ashly, participant) if completed "with some caution" (Alden, participant), while Dane (participant) suggested "it [walking] is not a problem when on the flat floor indoors" despite the distance and places where they walked being curtailed. They were aware of change, but there was limited insight that physical changes might be due to pathological changes in the brain. For example, Dane knew he was experiencing a decline in balance (postural stability), but he did not consider these changes to be "a great problem [but] more an annoyance". Many of these episodes of instability were observed by the caregivers, and they felt that the frequency of these events increased progressively over time. Sometimes, participants attached the cause of an instability episode to an impairment in, for example, vision, but the caregiver would dispute this attribution:

As an outside observer [there is] nothing [to] tell me why you trip. However, several times when it happened, [although] it does not happen a lot. Sometimes when it happens, you said to me 'it is my progressive lenses I do not see the depth properly of things'. (Elisa, caregiver)

Denial of cognitive change was also evident. Some participants recognised the change in cognitive function as a normal part of the ageing process rather than having experienced any changes in cognitive health. Participants thought about what they had achieved in life and were grateful for the good things they had achieved. For example, one participant described the numerous successful things in her life, such as "rais[ing] seven children" but suggested that now "it was time for [her] to rest" because she was just physically tired from completing daily tasks because of her age (91) (Ashley, participant). Caregivers also discussed participants' denial about cognitive changes. For example, when physical activities or exercises to keep the brain active were discussed in one interview, Raymond (participant) displayed and expressed discontent with his caregiver because she was explaining that his memory issues had got worse over time. Raymond stated, "I feel agitated now [that you are talking about me in this way]". Another caregiver raised how the participant's speech had also been affected, making communication frustrating, an assertion not readily agreed to by the participant:

He has trouble Ig words in the right order. [It is] not bad, but sometimes you [name of participant] get frustrated because you want to say something, but it does not come out the way that you want [it] to come out. Moreover, it is not every time, it is out of the blue. (Edith, caregiver)

However, over longer periods of time, and as awareness of 'self' also decreased, the effectiveness of coping strategies to mask changes diminished. Denial of decreased cognitive health in conjunction with limited awareness, made completing everyday tasks difficult. Dane's caregiver spoke of his difficulty in attempting to organise his thinking and make decisions by himself. She shared a conversation that Dane had previously had with her reorganising his furniture to make navigation around the room easier. Dane had asked her, "How do I organize my furniture to make [my] life easy and comfortable?" She realised that he was struggling with organising and planning the proposed furniture rearrangement but was in denial about not being able to do it himself. She recognised that "he could not think through" the required planning and organisation for undertaking the task and that "he could not make those [decisions] for himself" (Elisa, caregiver).

Denial was also linked with 'social withdrawal'. Participants withdrew socially as they were afraid that if changes became obvious to others, it would lead to 'stigmatisation' and 'labelling' of themselves by others in their social networks. This was especially evident when discussing group-based exercise classes. For example, Alden said he did "not want to be in the group. I just do not want [to do that]" while Raymond said he felt "embarrass[ed]" to potentially be labelled when other people discovered or attributed some of his behaviours

to his Alzheimer's diagnosis. Raymond disclosed that while he had discussed his diagnosis with his local bowling colleagues, he still found it a hard thing to do as it was awkward, despite knowing many others had been diagnosed with Alzheimer's themselves. He felt uncomfortable since he had disclosed his diagnosis as "people [that he did not know] had started to greet him". He also did not wish to attend groups with other people who had been diagnosed with Alzheimer's because it was confronting.

I don't want to associate with [them because]...they might be worse than I am. I am not comfortable with doing that [as it might be challenging for me to see the deterioration I will experience in the foreseeable future]. (Raymond)

3.3. Accommodation—Acceptance and Adjustment

Participants accepted and adjusted to their new 'self' by varying degrees over time. This is a concept known as accommodation. For the participants, it involved both acceptance of and adjustment to changes in cognitive health and concurrent physical decline. Participants' discussion suggested 'accommodation' was achieved via acceptance of the cognitive changes, which in turn facilitated an ability to adjust to the change/s. Several participants suggested that being in nature and doing activities that had a purpose and were meaningful to them encouraged exercising. For example, one couple "walk[ed] to the supermarket rather than take a car or bus and carr[ied] the groceries" even though they realised the groceries were "quite heavy" (Alden, participant and Sabrina, caregiver). They described it as "a good exercise". Alden liked to walk and "bend down to pick up the [rubbish] along the road". Both Dane and Hazel (participants) also enjoyed walking in nature and relished the "beautiful environment" while "listening to the birds cheeping".

Every new change in cognitive and physical health was seen as a "challenge" that triggered the formulation of new strategies so participants could maintain quality of life. Strategies kept altering as awareness changed. Each strategy required new learning by the participants (changed schemas), and this included activities in which they had previously participated. Routines were considered important and could help participants preserve autonomy. This was recognised by the caregivers who provided participants with strategies to overcome short-term memory loss so that they could remember the tasks to be completed during that day. Reminders included a "phone call" (Elisa-caregiver) during the day, or a "note" or "lists" (Hayley-caregiver) placed strategically around the home. Elisa explains how she supported Dane to be on time and at the right place for his interview:

We have a strategy for Dane coming down here [to interview place] today to meet up with you. The night before I talked to him on the telephone. I got him to write on a piece of paper [that] he need[ed] to catch the bus, and he had to be [at interview place] by this time. [I then asked him to] put [the note] on his breakfast tray. (Elisa, caregiver)

Acceptance of changes in cognitive and physical health was not, however, easy. Participants were in a quandary as to whether they should push themselves to do more physical activity or exercise and maintain physical conditioning or gracefully accept physical deterioration and use assistive devices such as a cane. This fluctuating 'self' expressed by many of the participants was illustrated by Ashley. She believed the changes she experienced were related primarily to age and the raising of her seven children and not to cognitive decline, but she simultaneously recognised that maybe she should just accept who she is now rather than whom she was:

I have realised that I have to help myself. I have to push myself a bit more [to exercise]. ... I do not know, maybe I should push myself a bit more [and] be more enthusiastic [to do exercise and attend an exercise group but] then I think 'Why I do this silly thing?'. I am 91 years old and should accept the fact that I am 91. But, I honestly do not know.

(Ashley, participant)

Even so, Ashley is, and wants to remain, independent. She liked her "body to [function] properly" and "that is the main push" to keep persevering with exercise. She suggested that

"once my [exercise] routine is established, I'll keep it going." (Ashley). Participants suggested that, despite the deterioration in physical performance and cognitive health, they believed that exercise could keep them "fit", "increased strength", and stimulated and facilitated the development of social connectedness with a spouse, friends, or pets, or acquaintances. 'Exercise' provided participants the ability to maintain who they identified their 'self' to be.

If I did not have a little dog, I would not bother going walking alone in the park unless my wife says, "Let's have a walk". [But] I have company, my dog is my company and so we enjoy [going for walks together]. ... I [am] still interested in doing [activities] that keep my body fit, because I like to be fit. (Raymond, participant)

4. Discussion

This study explored the lived experience of older adults with mild to moderate cognitive impairment of being physically active. The use of an Interpretive Phenomenological Approach facilitated an in-depth exploration of the participants' and caregivers' experiences. Participants considered many activities to constitute physical activity, which is consistent with the broad definition of physical activity [35]. Moreover, being physically active was generally good but not specifically because of their current cognitive health. Physical activity, consisting of discrete specific exercise (e.g., walking), was also influenced by insight. Three themes of acceptance, denial, and accommodation (an acceptance–denial-accommodation continuum), with the fluctuating 'self' impacting on decisions to exercise or be physically active and what sort of physical activity to undertake or encourage, more so than any practical barriers.

The fluctuating 'self' evidenced in the lived experience of the participants has similarly been discussed in other current international literature exploring peoples' experiences of a recent diagnosis of mild dementia. For example, in Taiwan, as fluctuating interpretations and the maintenance of a sense of self [36], or in the United Kingdom, as "being a stranger to oneself and sense making" [37] (p. 489). The idea of a fluctuating 'self' may suggest that people who have been diagnosed with mild to moderate dementia are experiencing a disruption to their sense of self and selfhood or are undergoing "biographical disruption" [38,39] to their "personhood" [40–42] which results in the adjustment to existing, or the creation of new, schemas of identity and structured frameworks for participating in life [43].

Personhood encompasses the ideas of a sense of self (my perception of characteristics that define me) or self (who and what I am) [44,45], selfhood (past, present and future me or self-continuity) [46], and identity (how I think others perceive me) [44], and are used to describe and discuss how a person sees themselves and integrates and interacts with their wider world [41,42]. While the findings of this study have been presented in a necessarily linear way and are reflective of an acceptance-denial framework [47], the labelling of the findings in this way nonetheless prompts deeper thinking about how healthcare professionals may better support choices about physical activity by people who have been diagnosed with dementia. Specifically, being cognisant of suggesting physical activities that support a person's concept of who they are, are more likely to be acceptable to that person. For example, dog walking or engaging in light repairs around the home. People with dementia and their caregivers are willing and able to contribute to implementing appropriate and relevant fall prevention strategies if healthcare professionals develop collaborative and shared decision-making therapeutic alliances [48]. A discussion tool to facilitate such a collaborative discussion has been developed [49].

Viewed from the acceptance-denial framework, "denial" can play an important part in the process of adaptation and acceptance [47] and is a coping strategy used during a life-altering experience, such as the diagnosis of dementia [50]. Understood from a biopsychosocial perspective, people who have high expectations of themselves might view the diagnosis of dementia as a sign of weakness and may seemingly "deny" observed changes or impairments [50]. However, the observance of a person in "denial" may be related to other processes [50], such as decreased cognitive reserves or stigmatisation.

Decreased cognitive reserve [51] can be understood through the neuropsychological model, which suggests that limited self-awareness in dementia reflects damage in the right parietal and frontal lobes [48], which causes loss of insight and awareness [52]. Findings from the current study illustrated that the participants attempted to explain the changes they experienced as part of a normal, natural ageing process. Or from an outsider's perspective, participants lacked awareness and insight about links between brain damage and dementia and observed changes in areas such as physical ability or memory. This lack of awareness is particularly seen in people with more severe dementia [53] and may impact their ability to recognise and justify the relevancy of a choice that older adults with dementia might make [54] in relation to physical activities to engage. For example, an intervention that is constructed for a group of people with mixed cognitive abilities will provide stimulation for older adults with dementia through constructive and inclusive engagement [55]. This, however, requires that those with no or less altered cognitive ability understand and have respect for those with the greater altered cognitive ability to avoid labelling and stigmatisation. This would enable older adults with dementia to participate in a more meaningful way with others, but only if said exercise class was deemed 'relevant' to the identity of the individuals. In addition, modifying the environment, for example, locating the intervention in a person's home, may also foster participation in physical activities by older adults with dementia [54].

Stigmatisation arises from being labelled by peers and others [56], and the consequences of stigmatisation are a complex individual experience. In early-stage dementia, individuals may feel limited in their ability to contribute in a meaningful way to complete roles and tasks and pursue social interaction or indeed engage in physical activities [37]. Disease manifestation and social environments interact to affect personal identity and, ultimately, how a "sense of self" impacts others, for instance, the outward appearance or ability of a person [57]. Concurrently, recognition by another (potentially ignorant person) that someone with a particular diagnosis differs from the norm in ways that have social significance [58] can lead to labelling. Labels usually have a negative social meaning [59–61]. Findings from the current study suggested participants were worried and anxious about what they might say or do, especially if it was something considered to be socially unacceptable. When this feeling of being labelled is repeated over time, an internalisation process occurs, resulting in lowered self-esteem, decreased social support, changed family dynamics and diminished emotional wellbeing [62]. In some instances, labelling may cause the development of anxiety [63] and depression [59].

The major consequence arising from labelling among stigmatised older adults, who have been diagnosed with dementia, is separation or marginalisation. Separation becomes more likely when the reactions of others to differences in appearance and demeanour, lead to a pronounced sense that others are treating them differently [58]. This can be seen in the current study, where participants became more socially withdrawn from others even though they had been diagnosed with the same condition. These findings are akin to a previous study that found that people who had not accepted their diagnosis displayed a high level of avoidance behaviours [59] or social withdrawal [37]. Social withdrawal may weaken social networks and result in an increasing loss of cognitive and social stimulus [64,65]. Based on the Continuity Theory [66], older adults with health conditions, in this instance with mild to moderate cognitive impairment, adapt to the changes in their health and social circumstances by preserving and establishing an external life that supports their internal ideas of life. For example, in terms of the findings, older adults with mild to moderate cognitive impairment are looking for activities that are enjoyed and give them pleasure; at the same time, they are looking for meaningful activities that could stimulate and facilitate the development of social connectedness.

4.1. Clinical Implications

Circling back to the notion of personhood discussed earlier, it is this concept that could be useful for healthcare professionals to be cognisant of during interactions with

people with mild to moderate cognitive impairment. As Dewing [40] suggests, how interactions with older adults with dementia have undertaken either privilege the person (person-centred, encompassing more than just the individual) or the disease (a biomedical approach). It could be argued the role of healthcare professionals is to listen to [47] and reinforce and strengthen the biographic narratives of people living with mild to moderate cognitive impairment.

Our results suggest that healthcare professionals could bolster a sense of autonomy and independence in decision-making while emphasising activities that older adults with mild to moderate cognitive impairment like to engage with [67]. The freedom to choose activities that have personal meaning and are considered relevant is likely to be considered more acceptable to older adults. Furthermore, health professionals need to be cognizant that participation in group exercise classes with 'similar others' may be too confronting for some older adults with cognitive decline and respond empathetically by providing alternative community-based options for maintaining or increasing physical activity.

4.2. Strengths and Limitations

Sensitivity to context was demonstrated by ensuring participants felt at ease, that their narrative was listened to carefully and empathetically, and by taking care with the interpreted meaning of the data during the analysis. Rigour was founded on the degree of iteration undertaken and the level of idiographic engagement with the phenomena. Independent inter-coder auditing was also used to ensure the validity of the coding along-side cross-referencing the themes back to the original data and asking participants and caregivers for feedback on the themes.

Despite these strengths, several factors limit the generalizability of our results. The participants' cognitive function ranged from mild to moderately altered. From our perspective, participants with mild impaired cognitive function were more independent and eloquent in providing responses compared to the participants with moderate cognitive impairment. This difference might be because the participants did not feel comfortable expressing their feelings to a relative stranger with limited time to develop a trusting relationship. This could be an area of future study.

We were unable to confirm a specific diagnosis of dementia in four of the participants despite the participants being recruited either from a dementia daycare programme or from a newsletter to members of the local Alzheimer's association. Participants consented for us to contact their general practitioner to establish a specific diagnosis. Despite repeated attempts to contact these participants' general practitioners, we did not receive a response. Given the reported co-morbidities of the participants, it is unlikely, but still possible, that the cause of cognitive decline was for reasons unrelated to dementia.

A further limitation is that we did not ascertain the level of past engagement in physical activity of either the participants or the caregivers. It is possible these past experiences may have shaped current attitudes and behaviours [68]. Finally, only family caregivers were interviewed in this study, and therefore, these findings may not necessarily apply to professional caregivers.

5. Conclusions

We explored the perspective of older adults with mild to moderate cognitive impairment and their caregivers about exercise and physical activity and found their perceptions to be complex and changing. We identified three dispositions that participants appeared to fluctuate between—acceptance, denial and accommodation. Each of these states of self impacted, in the moment, participants' decisions to exercise or be physically active and what sort of physical activity to engage in. Our findings suggested that older adults with mild to moderate cognitive impairment sought activities that were enjoyable and gave them pleasure; at the same time, they were seeking meaningful activities that stimulated and facilitated the development of social connectedness. We recommend that healthcare professionals are flexible and person-centred in their approach to fall prevention exercises

and programmes. Healthcare professionals are well positioned to listen to and reinforce the bio-graphic narratives of older adults living with cognitive impairment to foster a sense of autonomy and shared decision-making while emphasising fall prevention activities that older adults with cognitive impairment might like to engage with.

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