



Exploring experiential differences in everyday activities – A focused ethnographic study in the homes of people living with memory-led Alzheimer's disease and posterior cortical atrophy

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ABSTRACT

Background: Supporting ageing in place, quality of life and activity engagement are public health priorities for people living with dementia, but little is known about the needs and experiences of community-dwelling people with rarer forms of dementia with lesser known symptoms. Posterior cortical atrophy (PCA) is a rare form of dementia usually caused by Alzheimer's disease but which is characterised by diminished visual processing (rather than a dominant memory problem), which poses challenges for maintaining independence and accessing appropriate support.

Methods: This study used a comparative qualitative design and focussed ethnographic methods to explore experiential differences in activity engagement for 10 people with the most common, memory-led presentation of Alzheimer's disease and 10 people with posterior cortical atrophy within their everyday home environments.

Results: While the data collection revealed much rich variation in individual and contextual factors, some tentative high-level differences in the experiences of everyday activities could be drawn out, seemingly attributable to the different diagnoses' differing dominant symptoms. These included people with posterior cortical atrophy being less likely to use environmental cues to initiate activities, and more likely to withhold from asking for support because of preserved insight into the impact of this on carers. This lack of initiation of activities could be misinterpreted as apathy. People with posterior cortical atrophy also were discouraged from engaging in activities by disorientation within the home, and difficulties localising, identifying and manipulating objects. People with the more common, memory-led presentation of Alzheimer's disease exhibited more memory-based difficulties with engaging with activities such as forgetting planned activities, where to locate the items required for an activity and the steps involved. Despite these distinct symptom-led challenges, all participants and their family members demonstrated resourcefulness and resilience in making creative adaptations to support continued engagement in everyday activities, supporting the widely reported management strategies of people with dementia of the Alzheimer's type more generally.

Conclusions: These findings offer helpful insights into some the differing impacts dementia related visual and memory impairments can have on everyday activity engagement, which will be helpful for others navigating these challenges and the health and social care practitioners working with people affected by these conditions. The findings also highlight the vast individual variation in the multitude of individual and contextual factors involved in everyday activity engagement, and suggest important areas for future work utilising methods which are similarly high in ecological validity and accessibility as the home-based focussed ethnographic methods utilised here.

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Background

Posterior cortical atrophy – a lesser known dementia with lesser known symptoms

Dementia is an umbrella term for a large number of diseases which result in progressive cognitive impairment, and its wide-reaching impacts on individuals, families, health and social care systems and society are well-documented (Nichols et al., 2022). The most common cause of dementia is Alzheimer's disease, for which the most significant risk factor is age and the leading symptom most often memory loss, and as a result, the research and support landscape for people affected by many rarer forms of dementia, which are more likely to affect people at an earlier age and be characterised by atypical symptoms, is often sparse (Millenaar et al., 2016; Svanberg, Spector, & Stott, 2011; Tookey, Greaves, Rohrer, & Stott, 2021). Posterior cortical atrophy is one such rarer form of dementia which is usually younger in onset (affecting people before the age of 65) and which – while usually caused by Alzheimer's disease - predominantly affects people's ability to process visuo-perceptual and visuospatial information (Crutch, 2014; Crutch et al., 2012; Shakespeare, Yong, Foxe, Hodges, & Crutch, 2015). The various causes and ways of classifying posterior cortical atrophy are considered complex, and as a result much of the research into the condition is of a biomedical orientation seeking to better define and describe the symptoms associated with the condition, and there is a noticeable lack of research which explores how people who receive a diagnosis of posterior cortical atrophy experience it. Related to this, the majority of the existing literature on posterior cortical atrophy can be considered to focus on losses, or deficits, feeding into the normative narrative surrounding dementia which can leave little space for the acknowledgement of how people can and do live with the diagnosis and find ways to manage the specific nature of difficulties they are experiencing. This is an important consideration drawn out in the context of Alzheimer's disease more broadly (e.g. Beard, 2004; Beard, Knauss, & Moyer, 2009), and one which would be worthwhile to extend within the context of posterior cortical atrophy in which the symptom profile and challenges being managed and worked around may be of a different nature. Diversifying the discourse of dementia more generally and acknowledging the different impacts of different diagnoses may also help us to move away from such one-directional narratives such as that of victimhood and loss (e.g. Beard et al., 2009). The little that is known about the lived experience of people with posterior cortical atrophy leads to – due to the aforementioned complexity and lack of understanding of it – an often-convoluted diagnostic journey, lack of awareness among the public and professionals, and an absence of appropriately tailored support (Crutch et al., 2017; Harding et al., 2018). This is a pattern noted in other rarer forms of dementia too, for example in frontotemporal dementia and the primary progressive aphasia, and calls for tailored support that is aligned to the specific experiences and needs of those affected have been made (e.g. Morhardt, 2011; Morhardt, O'Hara, Zachrich, Wieneke, & Rogalski, 2019). While clinical anecdotes and case reports suggest profoundly impactful effects of a diagnosis of posterior cortical atrophy on daily life, there is very little existing research into the subjective experience of people affected which would be essential to inform interventions and support provision to enable people to live as well as possible with the diagnosis. Existing research focused on characterising the impairment profile of people with posterior cortical atrophy suggests that people with posterior cortical atrophy experience profound difficulties navigating and orientating within their immediate physical environment (Day et al., 2022; Yong et al., 2018; Yong et al., 2020) and the limited existing research exploring their lived experience suggests a wide range of resulting psychosocial ramifications of this including impacts on sense of identity, independence, roles and responsibilities, due specifically to their dementia-related visual impairment, as opposed to the dominant memory problems that may underpin similar difficulties reported by

people with more typical presentations of Alzheimer's disease (e.g. Caddell & Clare, 2010; Harding et al., 2018; Harris & Keady, 2009). There are broader motivations for extending this knowledge base too – for example knowing more about how these specific visual problems associated with posterior cortical atrophy impact the ways in which people affected are able to engage with the different activities that matter to them could also provide important insights about the secondary visual symptoms many people with more typical presentations of memory-led Alzheimer's disease may experience later in their disease course, when they may be less able to communicate them (Firth et al., 2019; Paxton et al., 2007).

Public health priorities in dementia care – ageing in place and activity engagement

Despite widespread excitement in the biomedical field around recent developments with disease modifying treatments for dementia (e.g. Edwards & Corkill, 2023), we are still without a cure for dementia-causing diseases, or treatment options which show consistent abilities to meaningfully plateau the progression of the disease. While this is the case, it is imperative that the public health priorities for people living with dementia which are centred around maintaining as good a quality of life as possible and ageing in place, remain front of mind and top of research agendas (e.g. Brittain, Corner, Robinson, & Bond, 2010; Chung, Ellis-Hill, & Coleman, 2017; Vayda, Patterson, & Whitehouse, 2010). One aspect of this is supporting people with dementia to remain living at home, and while there are widely recognised economic and social benefits of this, it is also the preferred option for most of the general population, whether they have a diagnosis of dementia or not, who all seek to maintain their independence as far as is possible (Brittain et al., 2010; Mokhtari et al., 2012; Robinson, Brittain, Lindsay, Jackson, & Olivier, 2009).

Another priority area in supporting people with dementia to live well is maintained engagement in activities, which is associated with a wide range of positive psychological outcomes for people living with dementia. A loss of independence in activities of daily living is associated with lower quality of life for anyone, regardless of any diagnostic label they may or may not have, and can be increasingly likely for people living with dementia (Chan, Slaughter, Jones, & Wagg, 2015). Engagement with meaningful activities promotes wellbeing and meets fundamental psychological needs including the maintenance of meaningful relationships and connectedness, fostering a sense of control, satisfying needs for creativity, providing opportunities to work towards goals and offering continuity in one's sense of self and identity (Han, Radel, McDowd, & Sabata, 2016; Nyman & Szymczynska, 2016). Relatedly, in their 2009 study, Harris and Keady highlighted the importance of the ongoing construction and renegotiation of selfhood and identity for people with younger onset forms of dementia and the significance of these transitions for their ongoing wellbeing and adjustment, further emphasising the importance of understanding and supporting continued engagement with activities for people with dementia. Menne, Kinney, and Morhardt (2002) also identified this motivation to sustain a sense of continuity within everyday life for people in the early stages of dementia and conceptualised it within the context of Atchley's (1989) Continuity Theory of Ageing which posits that as we age, we are motivated to maintain consistency and a sense of connection with our history in both our sense of self and our social patterns. As suggested by Park and Folkman (1997), this motivation can arise from or be strengthened by a desire to make meaning of a traumatic situation (e.g. a dementia diagnosis) in which there is significant distress due to the situation's profound discrepancies with the person's long-established global sense of meaning, how their world works and who they and others consider themselves to be within this. Recreational activities can also help to reduce behavioural indications of unmet needs such as apathy, agitation and irritability (Kolanowski, Fick, & Buettner, 2009), further testament to the potential of engagement with activities to meet

fundamental psychological needs for people. The importance of supporting ongoing activity engagement for people living with dementia in the community is now widely accepted and as such is reflected in policy recommendations and healthcare guidelines for dementia care (NICE, 2018; WHO, 2020).

However, the majority of existing research exploring independence in activity engagement for people living with dementia in the community has largely been conducted with people with memory-dominant dementias, and has tended to focus on self-reported levels of functional independence in a standardised set of activities of daily living (Giebel, Sutcliffe, & Challis, 2015; Prizer & Zimmerman, 2018). Research of this orientation may also artificially separate individuals with dementia from the relational contexts within which they carry out most of their activities, and may underestimate the essential roles carers and others play in the activity engagement of people with dementia in their everyday lives (Morhardt & Spira, 2013). Unstructured observations in naturalistic settings can add an ecologically valid lens to understanding peoples' lived experience, providing opportunities for researchers to observe the many and varied roles people living with dementia may occupy at home, and to be directed towards objects and activities of significance and meaning to participants in their everyday lives, many of which are so because of their connections to peoples' life histories (Angrosino, 2007; Briggs, Askham, Norman, & Redfern, 2003; Higginbottom, Pillay, & Boadu, 2013; Huizenga et al., 2023; Nygård, 2006). Observing in this way also enables enriched opportunities for witnessing people with dementia living 'in the moment', an approach Keady et al. (2022) suggests offers opportunity for a more contextualised, deeper and revealing appreciation of the lived experience of people with dementia, in allowing for the observation of multi-sensory, relational and embodied aspects of engagement with activities (rather than individual, retrospective and solely verbal reports). In addition, and with specific reference to verbal reports, Kindell, Keady, Sage, and Wilkinson (2017) have highlighted the utility and meaningfulness of naturalistic conversation (as opposed to structured interviews) as a data source, including for those with rarer forms of dementia such as frontotemporal dementia and primary progressive aphasia. Collecting data within everyday settings like the home environment, like Huizenga et al. (2023)'s walking interviews and home tours, enables unanticipated insights into what matters most to participants, beyond the bounds of any researcher-imposed constraints, and can offer an authenticity and ecological validity to findings that may not emerge from structured interviews or questionnaires. Data of this kind is likely to be most helpful and applicable in informing interventions to support people to live well with dementia at home, and may be particularly important and revealing for those with rarer forms of dementia with atypical symptoms (like those with posterior cortical atrophy) who may otherwise be grouped in with a wider dementia population and be at risk of an exacerbated lack of acknowledgement and appreciation of the specifics of their symptoms, lived experience and preferences.

In this study we sought to understand how everyday activities are challenged and supported for people with posterior cortical atrophy and a comparative sample of people with the more common, memory-dominant presentation of Alzheimer's disease, within their everyday home environments.

Methods

Study design

This study used a comparative qualitative embedded multiple case study design (Baxter & Jack, 2008; Yin, 2018) drawing on focussed ethnographic methods. Focussed ethnography is a pragmatically-derived and time-efficient variation of classic ethnography, which can give researchers insight into lived experiences that would otherwise be difficult to access (Knoblauch, 2005; Simonds, Camic, & Causey, 2012). It is increasingly used in healthcare and educational settings where

prolonged immersion in the field is challenging (e.g. because of resources, participant burden) (Knoblauch, 2005; Wall, 2015). Despite the shorter amount of time spent in the field, the intensity and volume of data collected in focused ethnography is often enhanced by technological aids (e.g. video/audio recordings) (Knoblauch & Schnettler, 2012; Pink & Morgan, 2013; Simonds et al., 2012; Wall, 2015). Further details of the methodological approach and rationale have been reported elsewhere (Harding, Sullivan, Yong, & Crutch, 2021).

Ethnographic approaches are increasingly recommended to increase accessibility in research participation for people living with dementia, even for those in the milder stages (Briggs et al., 2003; Hubbard, Downs, & Tester, 2003; Ludwin & Capstick, 2016). Observing participants in their everyday contexts offers particular promise for capturing the experiences of people with posterior cortical atrophy given the varied challenges they experience in interacting with the physical environment (Harding et al., 2018). Home-based observational methods can also be particularly inclusive for those with a diagnosis of Alzheimer's disease because of their common language and memory impairments, which may impair the communication of personal experience in a more traditional interview.

Sample and setting

Participants were recruited via the Cognitive Disorders Clinic at the National Hospital for Neurology and Neurosurgery, University College London Hospitals NHS Foundation Trust, a specialist hospital clinic and www.raredementiasupport.org the Dementia Research Centre at University College London Queen Square Institute of Neurology, an affiliated research centre, both of which see patients/participants affected by a range of typical and rarer forms of dementia. Participants had to have capacity to consent to the study, a diagnosis of posterior cortical atrophy (Crutch et al., 2017) or the more common, memory-led form of Alzheimer's disease (Dubois et al., 2014) and an accompanying family member, friend or other caregiver. The first author (EH) visited each participant on one occasion, in their homes for approximately 9 h on a single day, usually arriving at the home between 9 and 10 am and departing between 6 and 7 pm (with breaks).

Ethical considerations

Ethical approval for the study was granted by the National Research Ethics Service Committee – London Queen Square (approval number: 06/Q0512/81). Participants were given sufficient time to read and consider the Participant Information Sheet and written informed consent was obtained, and ongoing consent was assessed during the visits due to their extended length. The unstructured nature of the visits also posed ethical challenges in terms of unforeseen and incidental video footage being captured. Participants were given the opportunity to request the deletion of any video footage throughout the visit, during a debrief at the end of the visit, and during a follow up call one week after the visit. There were also ethical considerations in terms of the emotional impact on and ensuring the safety of the researcher. An amendment to an existing departmental protocol for researchers conducting home-visits was made to accommodate these. Specifically, these amendments included two-hourly reporting to a duty senior member of staff and a debrief telephone call with a member of senior staff once the researcher had completed each home visit.

This study was conducted in accordance with the Consolidated criteria for REporting Qualitative research criteria (Tong, Sainsbury, & Craig, 2007).

Data collection

The primary source of data collection was video recordings made of participants' interactions with the physical environment and informal interviews with the researcher throughout the observation period,

which were recorded using 360-degree cameras (4 K; 360FLY) and wearable clip-on cameras (VEHO HD; MUVI). This data collection was supported by observational field notes which were taken throughout the visit by EH. These consisted of brief notes taken by hand throughout the visit related to anything not captured by the video recording (e.g. other sensory data such as temperature within the home, researcher impressions and assumptions), and were typed up fully within 24 h. Visual ethnographic maps were also sketched during the visit to capture the layout of the home and anything significant about how participants had used the space (e.g. a favourite chair, a particularly challenging route within the space) (Causey, 2017). A small set of standardised measures were also administered by the researcher during the home visit including the Mini Mental State Examination (MMSE - Folstein, Folstein, & McHugh, 1975) and measures of quality of life (QoL-AD - Logsdon, Gibbons, McCurry, & Teri, 1999), activities of daily living (Johnson's ADL Scale - Johnson, Barion, Rademaker, Rehkemper, & Weintraub, 2004) and neuropsychiatric symptoms (Neuropsychiatric Inventory-Questionnaire (NPI-Q) - Kaufer et al., 2000). These were collected to help characterise the nature of the different difficulties across the two groups by some standard 'comparable' measure, with a view to contextualising these scores using the more nuanced primary qualitative data described above.

Data analysis

Data analysis was primarily conducted by EH and supported by the qualitative data analysis software Atlas.ti (v.7). Analysis involved an iterative process of organising, classifying, interpreting, triangulating, pattern-searching and naturalistic generalisation informed by established methods for analysing ethnographic and qualitative case study data (Roper & Shapira, 2000; Yin, 2018). Data was digitised, labelled and indexed before a process of re-immersion and re-familiarisation began, with memos about emerging analytic ideas created throughout. Codes were applied and then grouped accordingly, and recurring patterns and themes in the data were sought, with cases constantly compared throughout, and attention being paid to negative cases. In order to maintain the individual 'caseness' of each observation throughout the reductive coding process, index cards of individual participants' data were created, which could be viewed alongside each other simultaneously and in different combinations, for example by gender, level of independence in activities of daily living, disease stage, and both within and across diagnostic groups (see Fig. 1 for an anonymised example). These index cards allowed analytic thinking and diagramming at a more abstract thematic level across the cases, while ensuring each individual case was held in mind throughout.

Once it was felt that this more abstract thematic account of the data offered a coherent overall representation of the main patterns, each individual case was revisited and written up in thick description (Geertz, 2008), as a final verification exercise to confirm the comprehensiveness of the themes.

As recommended by Briggs et al. (2003), joint data viewing sessions with other members of the research team (KY, MPS, PC, SC) provided opportunities for EH's interpretations and assumptions to be discussed and alternative interpretations to be considered.

Results

Sample characteristics

Ten individuals with posterior cortical atrophy (6 male; 4 female) and 10 individuals with memory-led Alzheimer's disease (5 male; 5 female) took part. Fourteen participants lived with their spouse; two with their spouse and teenage or young adult daughters; two with their spouse, daughter, son-in law and grandchildren; one participant was widowed and lived with his daughter and granddaughter; and one participant lived with his spouse and a lodger. Participants' homes were

in a variety of rural and urban locations across the United Kingdom and were a mixture of houses and flats. Participants' ages ranged from 55 to 88 overall, with participants with a diagnosis of posterior cortical atrophy being aged 55–79 and participants experiencing the more common memory-dominant presentation of Alzheimer's disease being aged between 68 and 88. Summary demographic and disease duration information is displayed in Table 1, and further individual-level information is available in Table 2.

Qualitative findings

The qualitative data was organised into three themes: 1) Independent initiation of activities and actual or assumed apathy; 2) Disentangling diagnostic difficulties - seeing and perceiving, remembering and knowing; and 3) Tailoring supportive strategies. Each theme is described below with illustrative examples and data extracts including relevant contextual information about participant's age, gender, diagnosis and MMSE score (to provide a general sense of level of cognitive impairment), in parentheses.

Independent initiation of activities and actual or assumed apathy

Before activity engagement even began, differences in participants' motivation and ability to independently initiate activities were observed, as well as how these were interpreted and responded to by family carers. Due to the posterior cortical atrophy symptom profile and the consequent difficulty in interacting with the physical space and objects within it (see Theme 2 below), the majority of people with this diagnosis had profound difficulty in independently initiating the activities they wanted to pursue. Eleanor,¹ a retired nurse who had been diagnosed four years previously and had recently relocated with her partner to live nearer close friends summed this up when she said:

I suppose the biggest problem for me these days is my eyes – because once you can't see it shuts a few doors, it shuts off everything else for you. (74 years old, posterior cortical atrophy, MMSE: 20.)

This difficulty in independently initiating activities was sometimes misinterpreted by carers as apathy, or a lack of motivation. A number of carers of people with posterior cortical atrophy (including Eleanor above) reported their family member as demonstrating apathy on the Neuropsychiatric Inventory, and this appeared in many cases to be when the person with dementia was not able to initiate many activities, but those same individuals would often express (verbally or nonverbally) a keen interest in things they would have liked to be able to do. For example, Eleanor explained:

I would like to go out for walks on my own, I would like to drive a car, I would like to have a life...I miss that freedom, when you've been independent ...you miss it when it goes.

This apparent discrepancy between perceived and actual interest in activities was particularly notable among several people with posterior cortical atrophy who mentioned not wanting to request too much support with activities for fear of being a burden to family members who were already managing a greater share of the household responsibilities. During our household tour Maurice, a retired print floor manager who had spent much of his career working very long hours and who described himself as thriving on the busy-ness of that, explained that he was motivated to donate his collection of computer magazines to a school or community group who could use them since he could no longer read due to his posterior cortical atrophy symptoms, but expressed his frustration that this was something he wouldn't be able to coordinate himself, and a reluctance to ask his wife for help as she was already doing so much to support him. Lillian, a former model who described herself as very sociable and as really missing being able to independently

¹ All names have been changed

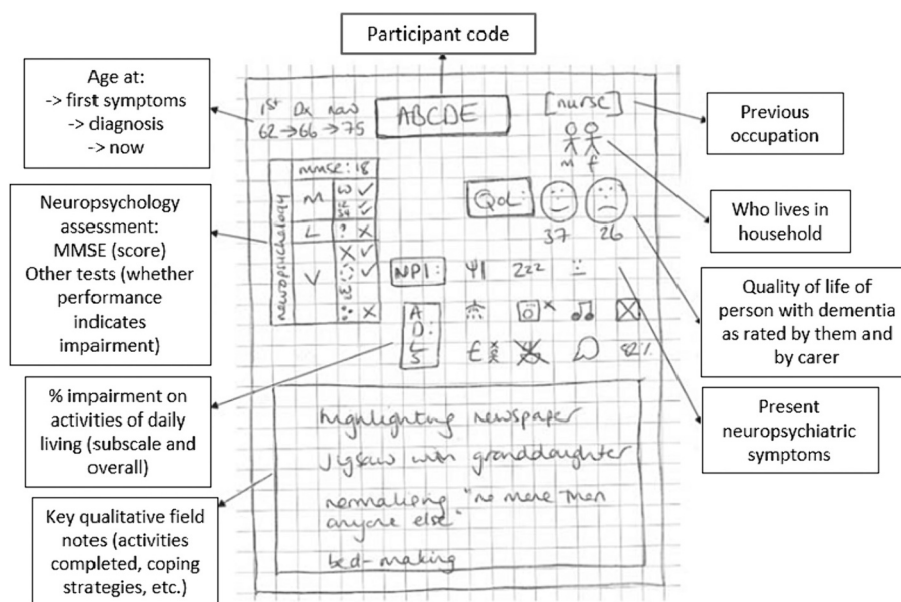


Fig. 1. Anonymous example of index card.

Table 1
Summary demographic information.

| | Posterior cortical atrophy | Memory-led Alzheimer's disease |
|--|----------------------------|--------------------------------|
| Number of participants | 10 | 10 |
| Gender (male/female) | 6/4 | 5/5 |
| Age (years – mean ± SD ^a) | 67.6 ± 8.28 | 76.7 ± 6.13 |
| Years since subjective onset (years – mean ± SD) | 7.1 ± 3.14 | 6.5 ± 4.36 |
| Years since diagnosis (years – mean ± SD) | 3.3 ± 1.95 | 3.1 ± 2.26 |
| Years between subjective onset and diagnosis (years – mean ± SD) | 3.8 ± 2.68 | 3.4 ± 3.61 |
| MMSE (mean ± SD) | 17 ± 5.55 | 20.1 ± 5.45 |

^a Standard deviation (SD).

get herself into town to see and speak to local friends, was another participant with a posterior cortical atrophy diagnosis who was rated as demonstrating apathy on the Neuropsychiatric Inventory, and someone who had a great deal of difficulty with many daily tasks due to her dementia-related visual problems, but who demonstrated nonverbally on several occasions her keen interest in various activities and interactions – for example when she independently went to inspect the ingredients her husband had taken out for dinner, and when she spent a long period in the morning using various cosmetic creams and products to get herself ready for the day.

Participants with the more common, memory-led presentation of Alzheimer's disease appeared to differ, in that they were largely physically capable of doing what most activities involved, but were less likely to independently initiate such activities. Some had to be encouraged to participate, for example Wendy – who lived in a large house over four floors with her husband and two cats and had been diagnosed with Alzheimer's disease six years previously – was repeatedly prompted by her husband with a shortlist of activities she enjoyed and tasks she'd expressed wanting to finish (e.g. gardening, cross-stitch). At points Wendy would pause in the garden and her husband would mention, for example, that she had said she wanted to move a item of garden furniture around, and ask if that was something they should do now, which with Wendy's agreement, prompted their next activity.

Other participants with memory-led Alzheimer's were motivated to engage in a certain type of activity (e.g. something helpful), but without

necessarily having a clear sense of what that activity might be or entail, for example, Richard, a retired IT management consultant who now spent long periods watching the news on television, regularly asked his wife what he could do to help, and agreed to tasks such as folding the laundry despite being unsure how to complete this. In this case Richard's wife demonstrated what he needed to do with a few items before checking Richard felt ok to continue with the others, to which Richard responded that he did before taking a larger pile of items upstairs to hang and fold.

Another way participants with the more common memory-led form of Alzheimer's disease initiated and engaged with activities distinctly from those with posterior cortical atrophy was via environmental cueing. Often the physical environment would provide a cue which seemed to encourage engagement of the person with memory-led Alzheimer's disease in a given activity, for example when Betty – one of the oldest participants in the study who lived in the suburbs with her partner of 20 years and who had a number of mobility issues - looked out into the garden from her favourite chair in the conservatory and this prompted conversations about the range of outdoor sports she had enjoyed many years previously such as tennis and swimming.

Those with posterior cortical atrophy did not appear to demonstrate this environmental cueing towards activities, possibly because of their difficulties in accurately perceiving the environment and the objects within it, but also what appeared to be relatively well preserved internal, self-initiated motivation towards activities, memory for how activities should be executed, and the ability and inclination to articulate when help with doing so might be required. For example, Maurice had a good recollection of and continued interest in the many metalworking projects he had worked on using a lathe, and was independently motivated to take me to have a look at photos of those on his computer in another room.

Disentangling diagnostic difficulties

Once an activity had been decided upon, differences were also identified in terms of the difficulties people with posterior cortical atrophy and more memory-led Alzheimer's disease experienced in executing them. Engagement with activities was challenged for all participants by difficulties with navigation and orientation within the home, and these challenges were accompanied by difficulties finding, recognising and using objects, but these were underpinned by the different symptoms people were experiencing according to their

Table 2
Individual demographic information.

| Pseudonym | Gender | Diagnosis (posterior cortical atrophy – PCA; memory-led Alzheimer's disease – AD) | Age at time of interview | Years since subjective onset | Years since diagnosis | Years between subjective onset and diagnosis | MMSE | Living situation (other inhabitants; housing type) |
|-----------|--------|---|--------------------------|------------------------------|-----------------------|--|------|---|
| Alan | M | PCA | 64 | 12 | 2 | 10 | 5 | with wife; house |
| Eleanor | F | PCA | 74 | 12 | 8 | 4 | 20 | with partner; house |
| Lilian | F | PCA | 70 | 8 | 6 | 2 | 14 | with husband; house |
| Martin | M | PCA | 73 | 6 | 2 | 4 | 19 | with wife; house |
| Maurice | M | PCA | 79 | 6 | 3 | 3 | 17 | with wife; house |
| Oscar | M | PCA | 56 | 7 | 2 | 5 | 19 | with wife and two daughters; house |
| Paul | M | PCA | 79 | 6 | 3 | 3 | 14 | with wife; retirement flat |
| Rhian | F | PCA | 55 | 3 | 2 | 1 | 15 | with husband and two daughters; house |
| Sally | F | PCA | 64 | 9 | 3 | 6 | 19 | with husband; house |
| Simon | M | PCA | 62 | 2 | 2 | 0 | 28 | with wife; house |
| Anita | F | AD | 88 | 4 | 2 | 2 | 27 | with husband; house |
| Betty | F | AD | 88 | 5 | 5 | 0 | 15 | with husband; house |
| Brian | M | AD | 75 | 17 | 4 | 13 | 30 | with wife; house |
| Helena | F | AD | 75 | 7 | 6 | 1 | 10 | with husband, daughter, son-in-law and two grandchildren; house |
| Lionel | M | AD | 76 | 5 | 0 | 5 | 22 | with daughter and granddaughter; flat |
| Mandy | F | AD | 72 | 2 | 2 | 0 | 19 | with partner; converted bungalow |
| Mark | M | AD | 68 | 4 | 2 | 2 | 21 | with wife; house |
| Mike | M | AD | 73 | 3 | 0 | 3 | 21 | with wife and lodger; house |
| Richard | M | AD | 77 | 12 | 7 | 5 | 16 | with wife; house |
| Wendy | F | AD | 75 | 6 | 3 | 3 | 20 | with husband; house |

diagnosis. These challenges impacted how both groups engaged with household chores as well as recreational activities.

Here we use illustrative examples relating to: finding the right rooms and objects within them; household chores (e.g. washing up, laundry); and recreational activities (e.g. gardening, reading and watching television) to exemplify the difference challenges experienced.

Difficulties with seeing and perceiving

For those with posterior cortical atrophy, these difficulties in engaging with activities appeared to be due to common challenges with seeing and/or perceiving visual and spatial information about the environment, which had knock-on effects on their abilities to engage with and manipulate the environment and objects within it.

Finding the right room: For example, people with posterior cortical atrophy demonstrated difficulties with recognising which room they were in currently and/or where a designated room they wanted to reach was. Sally, a retired civil servant in computer engineering who had first noticed symptoms nine years previously, demonstrated her disorientation when she asked during the initial walk around tour:

Am I in the wrong room? Are we in the orangey coloured room? (64 years old, posterior cortical atrophy, MMSE: 19.)

Finding things: Those with posterior cortical atrophy also had observable difficulties with finding things, whether that was because of them not being able to see the item they were looking for (even if it was right in front of them) or more global difficulties with navigating and orienting to objects and spaces within the home. The wife of one participant with posterior cortical atrophy who had previously had a very technical job installing sound systems and who continued to express a real keenness to do practical, hands on tasks around the home and garden commented:

He'll stand in front of the towel rail saying 'where are the towels?' (Wife of Alan, 64 years old, MMSE: 5.)

Washing up and laundry: A common perceptual problem for those with posterior cortical atrophy that impacted their effective engagement with activities was the phenomenon of struggling to perceive their

whole visual field at once. Martin who along with his wife had worked in education for many years and who had previously shared a large proportion of household tasks with her, demonstrated this when he was drying up and putting crockery away – he left some items in the bottom right hand corner after working quite thoroughly and consistently through the rest, as if not 'seeing' that section of the board at all.

Gardening: The participants with posterior cortical atrophy also demonstrated difficulties with identifying or recognising objects, or telling them apart from one another. For example, Alan could manage leaf-clearing on the front driveway, but had to be supervised in the back garden because he could not tell the dead leaves apart from those which were still growing.

Reading: The activity that was most commonly and consistently challenging for those with posterior cortical atrophy was reading. Simon, a retired IT consultant who maintained a keen interest in computers and technology, described it as lettering 'all merges into one lump and doesn't seem to be what I'm looking for' (62 years old, male, posterior cortical atrophy, MMSE: 28).

Watching television: The participants with posterior cortical atrophy also had more observable difficulties with accurately handling or manipulating objects, for example with reaching for, grasping, or putting down objects, in ways which impacted their engagement with everyday activities. When describing how it felt to try to move his hand to pick something up in front of him, Maurice explained 'My fingers don't belong to me' (79 years old, posterior cortical atrophy, MMSE: 17). When describing using the remote control, Eleanor, who also had posterior cortical atrophy, had difficulty spatially orienting her thumb to the 'On' button of a simplified, specially adapted television remote control. The 'On' button was green, and Eleanor articulately talked through what she knew she needed to do, but she had to make several attempts before she managed to get her thumb to touch the button she was aiming for.

Difficulties with remembering and knowing

In contrast, the respondents with memory-led Alzheimer's disease seemed to demonstrate and report challenges remembering how to do a given activity, or where they were in the process of it, as having a bigger

impact on their activity completion.

Finding the right room: In contrast to those with a diagnosis of posterior cortical atrophy, participants with the more common memory-led presentation of Alzheimer's seemed to have little difficulty accurately perceiving areas around the home, and any disorientation or inefficiencies in moving around it seemed to be more attributable to memory difficulties. Examples of this included having forgotten where we had been, with Wendy asking about several rooms 'have we been in here already?' during our initial walk around (75 years old, female, memory-led Alzheimer's disease, MMSE:20).

Finding things: In contrast to those with posterior cortical atrophy, the people with more memory-led Alzheimer's disease often demonstrated having forgotten what they were looking for or where they had put something as the main barrier to finding things. When making coffee and crumpets, Brian who had received his diagnosis of Alzheimer's disease four years previously despite still maintaining an MMSE score of 30, appeared to experience some confusion and difficulties with sequencing his actions, as well as recalling where things were kept – for example he left several cupboards open, the tap running and the kettle off its stand.

Washing up and laundry: For people with memory-led Alzheimer's disease, difficulties with washing up and laundry appeared to be due more to issues with sequencing and orientation to the task, as opposed to the more visual-spatial difficulties people with posterior cortical atrophy more commonly experience. For example, Helena, a 75-year-old lady with Alzheimer's disease who had recently returned from Italy with her husband where they had lived for several decades in order to be closer to family, engaged in hanging laundry but needed to be prompted several times throughout. Once she had started the activity, she had no difficulty evenly hanging or laying out the laundry items, but showed some difficulty with sequencing the different steps of the task, for example, by hanging some already dry items back out.

Gardening: Similarly, disorientation to task (rather than any problems with visual perception) was noted during gardening for those with memory-led Alzheimer's disease, for example, when Wendy was gardening, she had no difficulty in discriminating between the many different plants in the garden and demonstrated this by telling me many of their names, but on several occasions became disoriented to the tasks she was doing with them (e.g. watering).

Reading: The impact the more dominant memory symptoms of people with more typical Alzheimer's disease had on reading included difficulties following storylines and recalling details about different characters. For example, Anita, a retired special educational needs teacher and primary carer for her husband who was registered blind, had continued reading but admitted she no longer recalled the details of the stories she read, though she did recall if she liked and had a good feeling about a book, which would often prompt her to re-read it (88 years old, memory-led Alzheimer's disease, MMSE: 27).

Watching television: Mandy, who had memory-led Alzheimer's disease and worked part-time in a local garden centre, spent the majority of the home visit watching television. Her dominant memory problems were evident when she asked her partner if they had a television in their bedroom - as she could not remember - and in her asking repeated questions about the television show we were watching (72 years old, memory-led Alzheimer's disease, MMSE: 19).

Tailoring supportive strategies

In the same way that the underlying nature of the difficulties varied, so too did the strategies employed to help support activity engagement, though there was also overlap particularly regarding carers providing hands on assistance and guidance.

Supportive strategies in posterior cortical atrophy: Generally, those living with posterior cortical atrophy would use techniques to simplify or familiarise the visual input associated with an activity. Common strategies included:

- (i) Adaptations to the environment – for example notes or labels with key words, colour contrast, more evenly distributed lighting to minimise shadows and night lights guiding the way to the bathroom;
- (ii) Intrapersonal factors such as: persevering and taking more time, relying more on other senses like touch (e.g. feeling for a chair) and retained abilities such as relatively preserved memory. For example, when describing her strategy for keeping items in a familiar place, Sally commented:

All my underwear and socks and things are in these cupboards... they've always been there so I know where they are. (64 years old, posterior cortical atrophy, MMSE: 19.)

- (iii) Interpersonal strategies like asking for or receiving physical assistance or verbal guidance from a family member, though who these were initiated by and for (e.g. whether requested or spontaneously offered) could be contingent on a range of relational factors including previous relationship dynamics, people with posterior cortical atrophy's concerns about being a burden or wanting to minimise strain for their carer, longstanding patterns and preferences for doing things independently vs. interdependently and communication styles and approaches within dyads.

Most of these strategies seemed to relieve visual processing difficulties by introducing sensory cues to aid particular tasks while also minimising task-irrelevant visual information.

Supportive strategies in memory-led Alzheimer's disease: Supportive strategies to prolong engagement in activities for those with memory-led Alzheimer's disease sometimes also relied on simplification and familiarity, but in contrast to the respondents with posterior cortical atrophy, more often with the aim of aiding recall, or compensating for executive dysfunction or attentional impairments. For example, for those with memory-led Alzheimer's disease, simplification often meant breaking tasks down into smaller steps and repeating instructions. Strategies were also more often based around reminding and prompting (e.g. written and verbal reminders, or physical demonstrations as reminders). Participants with memory-led Alzheimer's disease also often needed reorienting to a task if they had become distracted or confused about the sequence midway through. For example, Helena's husband explained how tasks needed to be broken down if Helena was to remain engaged in cooking, when he explained:

If you say do this, get the water, put the water, pick the pasta, get the pasta...if you direct her she can do it, but she wouldn't be able to organise the steps. (Husband of Helena, 75 years old, memory-led Alzheimer's disease, MMSE: 10.)

Negotiating supportive strategies – understanding, awareness, assumptions and communication: people living with dementia and their carers' understandings of their condition and symptoms was an important determining factor in how support strategies were negotiated and delivered. Owing to the relatively well-preserved memory and insight that is characteristic of posterior cortical atrophy, these participants could usually offer an articulate account of their symptoms and in most cases had shared with their family members who were, as a result, very informed about how their difficulties impacted their day-to-day interactions with the environment. However, there were a few cases where couples did not have such an open dialogue, and in these cases, carers appeared more likely to (mis)attribute their family member's posterior cortical atrophy-related difficulty to some form of memory or executive function problem. When Lilian mistook her gym shoes for her boots, her husband commented 'It's the recall' (Husband of Lilian, 70 years old, posterior cortical atrophy, MMSE: 14).

The carers of participants with memory-led Alzheimer's disease were often less able to have these conversations owing to their relatives' memory problems or lack of insight, but they tended to demonstrate much more of a general understanding about the key symptoms of

Alzheimer's disease, which informed the way they supported their family members' engagement.

Discussion

This study has offered an original contribution of a focused ethnographic home-based study of how everyday activities are experienced, challenged and supported for people with posterior cortical atrophy or the more common presentation of Alzheimer's disease in which memory problems are the dominant issue. Participant's often symptom-specific and creative and resourceful responses to the challenges faced, in the context of a paucity of literature which looks beyond the cognitive impairments which characterise posterior cortical atrophy, have highlighted key areas of need, specifically the need for understanding of how these specific symptoms impact the abilities of people with posterior cortical atrophy to engage with the activities they want to, and as an extension of this, the tailored support people with posterior cortical atrophy may need in order to remain engaged with the everyday activities which matter to them, and to live as well as possible with the condition. The resourcefulness and creativity of people living with dementia and their families in developing supportive strategies to manage the range of different symptoms represented in this study have additionally provided insights into how this kind of symptom-specific support may be developed and delivered – and namely the importance of consolidating the learning and experiences of people with lived experience in navigating these challenges – such that the wellbeing, quality of life and other fundamental psychological needs of people living with dementia can be promoted (Han et al., 2016; Nyman & Szymczynska, 2016).

Diagnosis-related differences in activity engagement and supportive strategies

The challenges and strategies that participants with posterior cortical atrophy described and demonstrated were more often visually and/or spatially related than the more memory-oriented ones for those with Alzheimer's, and these different difficulties and strategies relating to activities were in line with the existing literature about the clinical presentations of each diagnosis. Key presenting symptoms which have been identified in the literature and were corroborated by observations of the posterior cortical atrophy participants in this study included: difficulty with complex skilled actions and dressing (consistent with ideomotor and dressing apraxia); loss of reading ability (alexia); difficulty writing and distinguishing left from right (consistent with elements of Gerstmann's syndrome); difficulty perceiving objects and space; perceiving the visual field in a fragmented way and difficulty orientating in familiar environments (Crutch, 2014; Crutch et al., 2012; Mendez, Ghajarania, & Perryman, 2002; Tang-Wai et al., 2004; Yong et al., 2014; Yong, Rajdev, Shakespeare, Leff, & Crutch, 2015).

One of the difficulties most commonly observed in the those with memory-led Alzheimer's disease during everyday activities was disorientation to task, and this is also fitting with existing literature, which suggests this is underpinned by attentional, executive function or memory deficits (Baddeley, Baddeley, Bucks, & Wilcock, 2001; Chiu et al., 2004). Respondents with posterior cortical atrophy, while often motivated and oriented to tasks, were often unable to initiate or execute them. This is compatible with previous findings documenting the relative strengths in memory and insight people with posterior cortical atrophy show compared to those with memory-led Alzheimer's disease (Charles & Hillis, 2005; Mendez et al., 2002; Tang-Wai et al., 2004). These preserved functions were also key in permitting the shared decision-making relating to ongoing activity engagement witnessed during the observations. That this was possible for those at varied stages of a posterior cortical atrophy diagnosis perhaps suggests unique opportunities for dyadic interventions in this population. This also highlights the importance of considering retained capabilities as well as

impairments in order to build a full picture of the illness experience. This may in turn empower those who are adapting and coping well by recognising their efforts, highlighting their resilience and fostering their self-efficacy (Kobiske & Bekhet, 2018; Whelan, Teahan, & Casey, 2020).

Another barrier to activity engagement for those with Alzheimer's were the difficulties participants had with locating the items required for activity engagement, and this has been reported as a common problem for people in the mild to moderate stages of dementia (Hamilton, Fay, & Rockwood, 2009). The participants with posterior cortical atrophy also experienced difficulties with misplacing and finding objects owing to the specific visual and spatial symptom profile, and this is compatible with empirical literature reporting full or partial Balint syndrome, which includes difficulty with visually guided reaching (e.g. optic ataxia), with perceiving more than one object at a time (simultanagnosia) and voluntary eye movements (oculomotor apraxia) (Tang-Wai et al., 2004). Another way objects related differently to activity engagement for the two populations was that objects could cue activity engagement for those with memory-led Alzheimer's. For the participants with posterior cortical atrophy, however, their difficulties accurately perceiving objects in combination with their retained intentional and motivational capacities meant this environmental cueing was less common but also not so necessary to prompt engagement. These diagnostic differences have implications for intervention design as, for example, an activity intervention involving prompt objects may work for people with memory-led Alzheimer's disease but be less supportive for someone with posterior cortical atrophy, highlighting the need for increased awareness of diagnostic variation and tailored information and support (e.g. Morhardt, 2011; Morhardt, O'Hara, Zachrich, Wieneke, & Rogalski, 2019).

Further highlighting the complexity of the varied underlying cognitive profiles and corresponding observable symptoms of the participants here, there were several examples of family members misattributing the difficulties in those with posterior cortical atrophy. This could include a carer claiming that the person living with dementia could not remember where something had been put or was not concentrating enough on a visual stimulus to perceive it properly, both of which are symptoms more typically associated with memory-led Alzheimer's disease. This perhaps reflects dominant discourses around dementia, and stresses the need for these to be more representative of the varied profiles of symptoms of different dementias. This has particular implications for people with rarer presentations such as posterior cortical atrophy, as it can contribute to an already convoluted diagnostic journey (Harding et al., 2018) and impact the provision of appropriate support, when symptoms do not correspond with public and professionals' prior assumptions and knowledge (McIntyre et al., 2019). A key misattribution in the group with posterior cortical atrophy was the potential for family members to underestimate how motivated someone so-diagnosed was to engage in activities. Participants with posterior cortical atrophy often showed profound difficulty in initiating activities independently, and in couples where there was a tendency towards a lack of communication for any reason, this difficulty with initiation could be misperceived and reported by carers as an example of apathy, even when their family member had expressed (verbally or nonverbally) their own motivation and interest in a certain activity or topic. This was in contrast to the participants with memory-led Alzheimer's, who appeared much more likely to exhibit apathy in the classic sense, and as is indicated in the empirical literature (Landes, Sperry, Strauss, & Geldmacher, 2001; Starkstein, Petracca, Chemerinski, & Kremer, 2001). This is a further example of how important it is that specific knowledge of the condition and how it may impact activity engagement is made available to those supporting people with posterior cortical atrophy, especially considering their essential role in facilitating activities.

Explicating the specific challenges of these different diagnoses of dementia is important and in line with calls within the existing literature in order to facilitate the development of tailored support and interventions for those with less common forms of dementia and atypical

symptoms, and will help to meet public health priority outcomes regarding meaningful participation for all people with dementia (Morhardt, 2011; Morhardt et al., 2019; NICE, 2018; WHO, 2020). We hope that doing this while also acknowledging the steps people living with posterior cortical atrophy and memory-led Alzheimer's disease are already taking to manage these challenges and continue to engage with activities of meaning, builds on this in not only identifying needs and losses, but also broadens out the dominant discourse to acknowledge the resilience and resourcefulness that people with dementia demonstrate in finding ways to live as well as they can in the face of these challenges, and in doing so, moves away from a dominant victimhood-oriented narrative (e.g. Beard, 2004; Beard et al., 2009). The drive to find ways around these challenges that have been documented and shared via this study are in line with existing literature and theory which suggests that people with dementia and their families are motivated to find continuity in their ways of being, activities of interest and things that matter to them in a process of ongoing construction and maintenance of identity and selfhood, and that this addresses fundamental psychological needs we all share (e.g. Atchley, 1989; Han et al., 2016; Harris & Keady, 2009; Huizenga et al., 2023; Menne et al., 2002; Nyman & Szymczynska, 2016).

Limitations: samples and snapshots

Conducting the observations within the home environment may have contributed to some sampling bias in that dyads who were not managing so well may have been less comfortable with being observed and may have declined participation, limiting representativeness. However, even if these findings represent the coping and problem-solving strategies of people living with dementia who are uncharacteristically well-supported and engaged, or an 'ideal type', then this may still make useful contributions to intervention design and the development of support provision for those not coping so well. Another way in which our sample may have been biased is in terms of socioeconomic status, with most participants having a high level of education, occupational status, and financial security. All these factors could impact adjustment and adaptation in the face of these diagnoses and future work with more representative groups will be valuable.

The nature of the activities observed was limited due to the timing of visits and sensitivity; for example, activities like dressing, toileting and sleep were not directly observed in this study. Finding ways to access experiences that are ecologically valid, ethically sound and sensitive remains a challenge.

Focused ethnographic methods are particularly suited to producing findings in a timely way and in settings within which prolonged immersion is difficult. Related to this, one perceived limitation of focused ethnographies is the suggestion that they are 'quick and dirty' and can fail to capture the richness of a context (Vindrola-Padros & Vindrola-Padros, 2018; Wall, 2015). While the current findings may only be able to represent 'partial realities', within those, they highlight issues of importance to the population studied, with a greater breadth and depth of authenticity owing to the multiplicity of data sources integrated (Causey, 2021). While the data collection period in the current study was relatively brief in ethnographic terms, it was also intense in terms of volume, and this intensity was matched by the rigour of the data analysis. The transparency and depth with which we have reported the analytic process here and elsewhere (Harding et al., 2021) increases the trustworthiness with which these findings can be interpreted and addresses the common criticism relating to the poor reporting standards of focused ethnographic studies (Vindrola-Padros & Vindrola-Padros, 2018).

While the focus here was on experiential differences according to diagnosis, it is important to acknowledge the limitations of (particularly qualitative) comparative research and the potential to over-identify differences between groups and to under-recognise both commonalities across groups and differences within them. While group differences

in experience were the focus of this paper and some could be noted according to the differences in dominant symptoms, it is important to acknowledge that there were also numerous idiosyncratic contextual and other factors which shaped participants' experiences of everyday activity. While not the focus of this paper, a more detailed exploration of the way any differences are mediated by multiple and intersecting individual, relational and contextual factors would be a worthwhile avenue of future work.

Reflexivity

It is important to address that the observations outlined here will have been informed by the research environment in which this study was designed and conducted, notably a department which specialises in the diagnosis and therefore distinction of differing forms of dementia. The assumptions inherent within this environment will have contributed to the lens through which participant actions were observed and interpreted. This, and its interaction with the lead researcher's positionality – as a social scientist – was carefully considered throughout data collection, analysis and interpretation, and these considerations inform both the limitations outlined above, and suggestions for further work to explore the experience of activities through a selfhood-oriented (rather than diagnostic-oriented) lens.

Implications for research and practice

Future ethnographic and/or observational research exploring the lived experiences of people with different types of dementia in their familiar everyday environments over time, given the progressive nature of the condition(s) would provide an ecologically valid lens on the disease progression and how the challenges and supportive strategies associated with everyday activities develop and are adapted to (Marshall & Hutchinson, 2001; Phinney, 2006). For example, rather than capturing snapshots of individual experience in the unfamiliar context of a clinic or lab setting, longitudinal observational research at home may more reliably build a picture of the nuances of everyday life with dementia in the relational context in which it is lived, and particularly of the variation and fluctuation of the good days and bad days that many people living with dementia and their families describe characterising what is often oversimplified as a one-directional trajectory of decline (e.g. Morhardt & Spira, 2013; Rockwood, Fay, Hamilton, Ross, & Moorhouse, 2014). In addition, given the range of everyday activities engaged within the current study, future work which explores the meanings of these everyday activities for people living with dementia would provide a useful indication as to where to target interventions to support the activity engagement of people living with dementia in the community.

Further qualitative work and observational research, in particular, may help to acknowledge the value of the voices of people living with rarer forms of dementia in research and increase accessibility in research participation, while also offering insights into the unique strengths and capabilities of those with posterior cortical atrophy (and other atypical presentations of dementia), which can facilitate their problem-solving (Hellström, Nolan, & Lundh, 2007; Marshall & Hutchinson, 2001).

Further work which explores the potential for adaptation of the physical environment to support activity engagement for people with posterior cortical atrophy – perhaps informed by creative adaptations like those observed in the current study – would be worthwhile.

These findings highlight a pressing need for health and social care professionals to have improved awareness of posterior cortical atrophy and increased ability to provide tailored information and support to affected families that acknowledges the particular challenges of dementia-related visual impairment and the relative strengths that people living with it demonstrate. The dominant difficulties that people with posterior cortical atrophy reported having in interacting with the physical environment may mean there is increased scope for physical aids and adaptations to support their activity engagement and

participation and in turn, their psychological wellbeing more broadly. In addition, the relatively well-preserved insight, memory and language functions of people with posterior cortical atrophy may indicate that psychosocial interventions could hold particular promise in those instances where supported engagement via physical aids and adaptations is not possible.

The many and varied adaptations and supportive strategies that all participants demonstrated – particularly those with posterior cortical atrophy for whom information and guidance relating to the condition was limited – served to highlight the creativity, resourcefulness and resilience of those affected by different dementias and their families. Acknowledging the value of the expertise-by-experience of people living with dementia by disseminating these self-made strategies and adaptations could have important benefits for others facing the challenges associated with these diagnoses.

Conclusions

This study has provided new insights into the different ways initiation of and engagement with everyday activities can be challenged and supported for people with memory-led Alzheimer's disease or posterior cortical atrophy within their home environments. It has contributed new knowledge by highlighting the visually-based challenges people with posterior cortical atrophy face when undertaking everyday tasks at home, as well their unique strengths in articulating and communicating their experiences of these atypical symptoms, and how this permits creative problem solving jointly with family members. These findings should be supportive of people living with dementia, their families, healthcare professionals and practitioners in encouraging ongoing activity engagement and, in turn, psychological wellbeing, in ways tailored and attuned to differing dementia symptoms.

Ethics approval and consent to participate

The study was approved by the National Research Ethics Service Committee – London Queen Square. (Approval number: 06/Q0512/81) and all methods were carried out in accordance with the Declaration of Helsinki and all relevant guidelines and regulations. All participants provided written informed consent to participate.

Consent for publication

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Authors' contributions

Emma Harding contributed to study design, data collection, data analysis and writing of the manuscript.

Mary Pat Sullivan contributed to study design, data analysis and writing of the manuscript.

Paul M Camic contributed to data analysis and writing of the manuscript.

Keir XX Yong contributed to study design, data analysis and writing of the manuscript.

Joshua Stott contributed to writing of the manuscript.

Sebastian J Crutch contributed to study design, data analysis and writing of the manuscript.

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Emma Harding: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Supervision, Writing – original draft, Writing – review & editing. **Mary Pat Sullivan:** Conceptualization, Formal analysis, Investigation, Methodology, Supervision, Writing – review & editing. **Paul M. Camic:** Methodology, Supervision, Writing – review & editing. **Keir X.X. Yong:** Conceptualization, Data curation, Investigation, Methodology, Project administration, Supervision, Writing – original draft, Writing – review & editing. **Joshua Stott:** Methodology, Supervision, Writing – review & editing. **Sebastian J. Crutch:** Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Supervision, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no competing interests.

Data availability

The datasets generated and/or analysed during the current study are not publicly available due to the nature of the data (video/audio recording) and their containing identifiable information that could compromise the privacy and confidentiality of research participants. Anonymised time logs and selected other data are available from the corresponding author on reasonable request.

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