‘I’m still that person in there but I can’t make it work’: capturing the day-to-day impacts of a diagnosis of Posterior Cortical Atrophy

Emma Harding

A thesis submitted to University College London (UCL) for the degree of Doctor of Philosophy

Dementia Research Centre
Queen Square Institute of Neurology
University College London

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Declaration

I, Emma Harding, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.
Acknowledgements

I am so grateful to the many people who have supported and encouraged me throughout my PhD journey and for the ESRC-NIHR and Dementia Research Centre funding which has allowed me to carry out work that I am so proud of.

I would firstly like to thank my supervisors – Professors Seb Crutch and Mary Pat Sullivan who have provided a wealth of guidance, support, expertise, and patience in deciphering many of my panicked ramblings. Seb, for always meeting me where I am, for being a reassuring voice of clarity and perspective, and for offering me so many wonderful opportunities. Mary Pat, for countless enriching conversations about tiny data segments, broad theoretical implications and everything in between. I would like to also thank Dr Susie Henley and Professor Paul Camic who offered helpful steers when examining my upgrade. Paul has continued to generously offer his time and expertise and I have valued our conversations so much.

I have been privileged to work with many wonderful colleagues at the Dementia Research Centre, as part of the Created Out of Mind residency, and in the Seeing What They See, Vision in Dementia, Rare Dementia Support and RDS Impact study teams, and will always be grateful for how encouraging and receptive colleagues from all disciplines have been to my work. I have so appreciated my brilliant ‘5th floorer’ colleagues and the many debriefs about work and life which have really kept me going through some tricky moments. Special thanks to Keir Yong for help with a million and one questions (great and small); to Rachel Woodbridge for camaraderie in those early PhD days (and beyond); to Suzie Barker for many hours spent checking in on me during those long home visits; and to Elizabeth Halton for much reassurance and many words of wisdom.

I am so very grateful to my friends and family, who I feel so lucky to have, and who have demonstrated immense patience and understanding throughout my many
months of preoccupation and unresponsiveness, and who have cheered me on at all stages. Special thanks to my mum and Martin for their never-ending support and love; to Alix for always championing me; and to Chris, for being a source of unwavering support and encouragement throughout the highs and lows.

I would also like to thank members of the PCA support group – our conversations continually remind me of the value of and need for research into the rarer dementias, and finally, I am indebted to everyone who so openly and generously invited me into their homes and participated in this research – it has been a privilege to collect such rich data which has been so impactful and inspiring on a personal level, too.
Abstract

Supporting people to age in place and ensuring good quality of life for people living with dementia (PLWD) are public health priorities, but little is known about the needs and experiences of community-dwelling people living with rarer dementias. Posterior cortical atrophy (PCA) is a rare form of dementia which predominantly affects visual processing, and is currently mostly understood from a biomedical perspective.

Theoretically underpinned by the Stress Process Model, in phase I of this PhD study I sought to better understand the lived experience of a diagnosis of PCA using dyadic interviews. The interviews revealed a convoluted diagnostic journey, difficulties in interacting with the physical environment (e.g. locating objects) and wide-ranging psychosocial ramifications (e.g. interdependence), but also the resourcefulness dyads were showing in responding to these difficulties, and the complexity of the relational contexts this stress process was happening within.

I sought to better understand the complexity of these intersecting physical and psychosocial environments in phase II with a series of all-day home-based observations of people living with PCA and typical, memory-led Alzheimer’s disease. This phase was theoretically underpinned by relational citizenship and used an embedded case study design with focussed ethnographic methods (including participant observation, conversational interviews, field notes and video recording).

Participants’ ways of being in, engaging with, and acting on the world were challenged differentially by diagnosis and according to disease stage. Despite this, all participants were finding ways to continue engaging with their environments and in meaning-making via various activities. The main findings are encapsulated in three themes: (1) The fun and the function of activities; (2) Reciprocities of care, and (3) The constitution and continuity of (a changing) self. Implications for research, theory and practice are discussed, relating to meaningful versus
measurable activities, the acknowledgement of diagnostic differences, and enduring expressions of selfhood for PLWD.
Impact statement

I hope the impact of this PhD study will span academia and beyond, and take a number of forms.

Methodologically, this PhD study is novel in its use of focused ethnographic methods (including video recording) during extended home-based observations with PLWD. I hope that in justifying and thoroughly reporting this approach and its accessibility for this particular population, and in reporting ecologically valid findings with practical implications, that this work may encourage other researchers to adopt similar methods. Perhaps in other rare dementia cohorts, but also in other groups who may be marginalised or excluded from more traditional research paradigms.

Another aspect of relative novelty in this work is its exploration of the subjective lived experience of people affected by a rare form of dementia. In demonstrating the value of this kind of approach for highlighting the specific needs of individuals with these specific symptoms, I hope this work will have impact by encouraging other research which champions the lived experience in addition to a biomedical understanding of the dementias and other diseases more typically studied through a biomedical lens.

I hope my findings will also contribute towards the wider theoretical conversation about how the voices, experiences and personhood of PLWD can best be valued, enabled and recognised, by not solely relying on theoretical approaches which are dementia-centric and/or decline-focused. I hope to achieve the above impacts by writing up my PhD research for publication in peer-reviewed theoretical, methodological and empirical academic journals and to continue to present my findings at relevant academic conferences.
I consider the findings to also have applied value, in demonstrating the importance of recognising atypical presentations of dementia and their specific sets of symptoms, but also in demonstrating the potential value of enduring engagement in meaningful activities for all PLWD. I plan to maximise the impact of these findings by publishing in professional practice journals and by giving talks to varied health and social care professionals at training events. Given the huge demands on health and social care professionals’ time I also hope to digitise some key findings and recommendations (e.g. on a webpage, in video clips) in order to make engagement with these outputs most accessible to the professionals diagnosing and supporting people affected by these conditions in their everyday practice.

I hope these findings also hold practical value for PLWD, and will seek to enable this impact by presenting these findings to regional and national support groups for PLWD, which I will endeavour to record so that they can be available for ongoing dissemination and for those who are unable to attend meetings.

In being firmly grounded in participants’ everyday experiences within their naturalistic settings, I would argue that the data generated in this PhD study is also accessible and highly relatable. I believe it could be especially powerful and resonant for public engagement and other creative or artistic outputs, which could bring these findings to a broader audience and hopefully have impact by contributing to enriching public discourses and perceptions of dementias.
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<td>AD</td>
<td>Alzheimer’s disease</td>
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<tr>
<td>ADL(s)</td>
<td>Activity(ies) of Daily Living</td>
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<tr>
<td>AIDS</td>
<td>Acquired immune deficiency syndrome</td>
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<tr>
<td>CBD</td>
<td>Corticobasal degeneration</td>
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<tr>
<td>CJD</td>
<td>Creutzfeldt–Jakob disease</td>
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<tr>
<td>CMT</td>
<td>Cambridge Memory Tests</td>
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<tr>
<td>COREQ</td>
<td>Consolidated criteria for reporting qualitative research</td>
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<tr>
<td>CSF</td>
<td>Cerebrospinal fluid</td>
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<tr>
<td>DIY</td>
<td>Do it yourself</td>
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<tr>
<td>DLB</td>
<td>Dementia with Lewy bodies</td>
</tr>
<tr>
<td>EH</td>
<td>Emma Harding</td>
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<tr>
<td>ESRC</td>
<td>Economic and Social Research Council</td>
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<tr>
<td>FTLD</td>
<td>Frontotemporal lobar degeneration</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>IADL</td>
<td>Instrumental Activities of Daily Living</td>
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<tr>
<td>IQ</td>
<td>Intelligence quotient</td>
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<tr>
<td>LPA</td>
<td>Logopenic progressive aphasia</td>
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<td>MMSE</td>
<td>Mini mental state examination</td>
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<td>MPS</td>
<td>Mary Pat Sullivan</td>
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<tr>
<td>NICE</td>
<td>National Institute for Clinical Excellence</td>
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<td>NIHR</td>
<td>National Institute for Health Research</td>
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<tr>
<td>NPI</td>
<td>Neuropsychiatric Inventory</td>
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<td>NPI-Q</td>
<td>Neuropsychiatric Inventory Questionnaire</td>
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<tr>
<td>OT</td>
<td>Occupational therapy</td>
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<tr>
<td>PAMELA</td>
<td>Pedestrian Accessibility Movement Environment Laboratory</td>
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<td>PET</td>
<td>Positron emission tomography</td>
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<tr>
<td>PCA</td>
<td>Posterior cortical atrophy</td>
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<td>PLWD</td>
<td>People/person living with dementia</td>
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<td>QoL</td>
<td>Quality of life</td>
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<td>QoL-AD</td>
<td>Quality of Life in Alzheimer’s disease</td>
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<td>RW</td>
<td>Rachel Woodbridge</td>
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<td>sRMT(w)</td>
<td>Short Recognition Memory Test for Words</td>
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<td>tAD</td>
<td>Typical Alzheimer’s disease</td>
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<td>UCL</td>
<td>University College London</td>
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<td>VOSP</td>
<td>Visual Object and Spatial Perception</td>
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This PhD project: context and roadmap

About the author

After leaving school I completed a Foundation Diploma in Art and Design at Chelsea College of Art, hoping to merge my interests in the arts and in helping people to become an art therapist. My interest in other people steadily became more and more centre stage, and after finishing my course I went to study Psychology at Royal Holloway University of London – one of the only BSc courses which positively encouraged applications from students with an arts background.

After completing my degree in 2011 I joined a small psychology practice where I stayed for 4 years, eventually moving from doing the room bookings to managing the practice’s 12 psychologists who were seeing 140+ service users per week. In my conversations with service users, I became increasingly interested in how people described their experiences – the varied and rich narratives of the difficulties they were facing and the impacts these were having on them and those around them, and the ways people conceptualised these difficulties along a broad spectrum from diagnostic labels through to everyday issues and struggles that anyone might face. I found conversations with the practice psychologists enriching and illuminating, and was particularly interested in the work of those coming from an existential approach. Something about the centrality of meaning-making, and the reframing of psychological problems as an essential part of the rich experience of human existence felt very significant to me. Interactions with service users who had a diagnosis of dementia and their families highlighted to me how care and support are often jointly negotiated, and also interested me in terms of assumptions about what is possible for people affected by dementia, and the tensions sometimes in how cognitive abilities and emotional wellbeing were differentially appraised and prioritised.

At one point I was helping to transcribe some research interviews for one of the psychologists which had been conducted with people living with a diagnosis
terminal cancer using object elicitation, and it was this privileged access to what felt such significant and richly layered storytelling which really cemented my want to return to academia.

I was delighted to take up a Research Assistant post at the Dementia Research Centre at University College London in 2015, at the time as the only psychologist with expertise mostly in qualitative approaches, as part of the ESRC-NIHR funded Seeing What They See study team. The five years that have followed have been a hugely significant professional and personal journey for me, peppered with occasional bumps in the road and many a crisis of confidence, but ultimately an incredibly rewarding and stimulating experience in a department of wonderful and supportive colleagues I feel very lucky to work alongside and know.

The ESRC-NIHR funded ‘Seeing What They See’ project

This PhD project was conducted within the ESRC-NIHR funded project ‘Seeing What They See: compensating for visual dysfunction in Alzheimer’s disease’, funded as part of the ESRC-NIHR Living Well with Dementia Initiative in 2012 (ESRC, 2017). The project was an interdisciplinary and multi-site project to explore the nature and impact of cortical visual dysfunction for people with dementia, with a view to developing an intervention to support the challenges faced. The project involved psychologists, occupational therapists, neuropsychologists, engineers and social gerontologists working across University College London (UCL), Brunel University London, Nipissing University in Canada and the London School of Hygiene and Tropical Medicine. The study involved participants with typical, memory-led AD (tAD) and PCA, a rare type of dementia which mostly affects the back of the brain and a person’s ability to process visuoperceptual and visuospatial information. The three work streams within the project were:

- Neuropsychology-led: characterising the nature of the cortical visual impairment of both groups with standardised neuropsychology tasks;
• Engineering-led: assessing navigational and object-localisation abilities of people with PCA and tAD in a controlled laboratory environment – Pedestrian Accessibility Movement Environment Laboratory (PAMELA) at UCL;
• Social science-led: exploring the day-to-day impacts of cortical visual dysfunction in participant’s home environments using interviews, walk-around tours and focused ethnographic observations.

This PhD was conducted within the social science stream of the overarching project.

This PhD project – a roadmap

Here I will briefly outline my whole PhD project which will hopefully provide helpful overall context before the main body of the PhD thesis begins.

The context and background and the gaps in the literature

PCA is a rare kind of dementia and as such, and in line with typical research trajectories, much of what is known about it currently is centred around defining the disease profile and course. So while it is well documented that it has a very different profile to typical memory-led dementia – that being that it is largely the visual processing centres of the brain which are affected, at least in the earlier stages of the disease – little is known about how people experience the particular set of symptoms associated with it. In line with what has been published about the neuropsychological and neuropsychiatric profiles of PCA, and the associated levels of functional impairments in activities of daily living (ADLs), it is perhaps possible to infer how people living with the condition may be affected day-to-day, but prior to this PhD project there was no published qualitative research about the subjective experience of living with PCA. And why is it important to explore what the condition is like for people? This is important for informing how people with PCA can be best supported to live at home with a good quality of life (QoL) for as long as possible, and also because there is every reason to expect that the difficulties faced by – and therefore the support needed by – people with this condition will vary from that of
those with more typical presentations of dementia. Also, better understanding visual problems in this population who are uniquely able to articulate their experiences (because of relatively well-preserved memory and language skills) may help to better understand the visual problems which those with tAD may experience later on in their disease course, when communicating those can be more challenging. It was hoped that understanding the nature and impacts of the challenges associated with dementia-related visual impairment would inform the development of an aid or adaptation for people experiencing these symptoms, to support them in living well at home. The Stress Process Model (Pearlin et al., 1990; Judge, Menne and Whitlatch, 2010) was the dominant theoretical underpinning as this first stage of this PhD study began, this was selected because stress and coping are well-established frameworks for exploring the impacts of dementia on those affected, the model acknowledges a broad range of contextual factors in determining stress, and has previously been used in intervention studies.

Assumptions

Based on published literature on the clinical presentation and ADL function in PCA, it was assumed that the main issues people would be having would be with navigating, reading, driving, reaching, recognising objects and where they were in space and so on; in short, in interacting with the physical environment. What this study hoped to add was understanding of the symptoms through an ecologically valid lens (i.e. how they played out in people’s everyday lives) and how they were experienced by people in their own words.

What did I do?

In the first phase of this PhD project I asked people, in dyads, in their home environments, how the condition impacted them in their daily lives. I asked them in pairs because I wanted to acknowledge that an experience of a dementia happens in a relational context, not just affecting the person with the diagnosis but their close others too. I also anticipated this might be helpful as people with PCA can have some concurrent difficulties with memory and language, and so may have had
some difficulty with elements of reporting their accounts at times. I asked them at home anticipating that the specifics of their everyday environments would be significant and helpful for contextualising and understanding any specific difficulties that were reported, and I used in-depth semi-structured interviews to allow any unanticipated insights to emerge. At this point I was still mostly hoping to get a picture of stressors within the physical environment with a view to contributing towards developing a physical aid or adaption to help people with PCA in their interactions with the physical environment.

*What did I find?*

In terms of participants’ experiences of the condition up to the point of the interview, I found that the diagnostic journey had been convoluted and a cause of significant stress for most dyads. In terms of day-to-day life, participants reported that there were a number of stressors in the physical environment as expected, but also that these all had varied and wide-reaching psychosocial ramifications, and were being responded to in intuitive and resourceful ways already by families, in the absence of any specific guidance or recommendation.

Having seen the intersecting nature of the physical and psychosocial environments, I realised I could not look at the impact on the physical environment and the psychosocial ramifications separately without undermining the real-world and real-time complexity of people’s everyday lives. Any intervention or adaptation that may be developed to support people would need to be developed with this in mind and be able to be implemented within it. I had also learned that people were already being incredibly responsive and creative in coming up with their own tailored solutions and workarounds for the daily difficulties associated with the condition, and these too mostly emerged from or were implemented at the intersection of these two environments. The findings had also confirmed some of the compatibilities of the Stress Process Model with the breadth of factors involved in determining the stress experienced, but had also highlighted some limitations of the two adaptations of the model considered here, specifically in terms of the
significance of the physical environment in shaping the stress process and also the potential issues with considering the person living with dementia (PLWD)'s stress process separately from that of their family member, when in the interviews they had appeared to be very much interrelated and jointly negotiated. At this point relational citizenship (Kontos, Miller and Kontos, 2017) became one of the central theoretical approaches which seemed to align with the findings, particularly in terms of the relational context within which care was provided and stress was experienced and its conceptualisation of embodied selfhood. These seemed relevant and fitting with what the interviews had revealed about the impacts that challenges with embodied action had had for identity and role maintenance.

**Deciding on the next phase**

It was clear I was some way away from being ready to start feeding my findings into thinking about developing some sort of practical tool at this point and that there was much more to be known about this layered complexity – the complexity of people’s individual contexts and environments alongside their individual disease profiles, previous life experience, etc. – and a need for improved recognition of what people were already doing in response to these stressors. To understand more about what people might need, it seemed I needed to know more about what their days were like – how these varied difficulties, strategies, different actors and the framing context all played out and interacted in everyday life, in the naturalistic settings people spent their time in. I had asked what it was like to have PCA, now I needed to get closer to seeing what it was like and how it was experienced, by spending time with people in their homes.

**Evolving research questions**

My research questions developed from ‘What is the stress process for people living with PCA?’ to ‘How are difficulties and coping strategies negotiated in real-time in the layered and intersecting physical and psychosocial everyday environments of people living with PCA?’, and home-based observations seemed the most appropriate means by which to explore this question and others relating to it. As
very little home-based observational work has been conducted in the everyday environments of people living with a diagnosis of dementia, and in order to gain a better understanding of those impacts which were specific to the dominant visual processing problems in PCA, I also included a comparison group of people with typical memory-led dementia.

**What did I do in phase II?**

Using a comparative embedded multiple case study design, I did a series of all-day, home-based participant observations, in the homes of 10 people living with PCA and 10 people living with tAD. I asked if I could observe as typical a day as it was possible to have with a researcher present, and attempted to account for the impact of my being there throughout in a reflexivity journal, as will be reported on below. A range of focussed ethnographic methods were used including participant-observation, audio and video recording and qualitative observational field notes. These were collected alongside quantitative measures of participants’ neuropsychological profiles, functional impairment status and QoL, to provide an opportunity for juxtaposing and triangulating these varied data sources to see what the combination of them may have been able to add to my overall interpretations.

My research questions were about interactions with the physical environment [e.g. Which areas of the home were people struggling with? How were objects used to support activities?], the everyday impacts of the diagnosis on the psychosocial environment [e.g. How and by who is care delivered and accepted? How were roles negotiated and maintained?], and questions that sit of the intersection of the two [e.g. particular objects that were meaningful for people, or areas of the home they found especially stressful or anxiety-inducing].

**Evolving research questions**

After completing two pilot visits, I had realised that neither of the participants I had observed (Martin and Maurice) were spending much time at all trying and

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2 All names have been changed
repeatedly having difficulty with various activities and also that the mix of activities undertaken over the course of the day was broad. As a result, I realised that I was not going to see an obvious, distinct and universal need for an intervention by observing people at home. As the observations continued this was confirmed, that participants had largely either stopped doing things that were very difficult or too high risk, or had started to find their own varied ways around doing a broad range of activities, for example, using visual cues or asking a family member for help. I was conscious too that temporality had been a significant framing factor in the dyadic interviews, but that here I was seeing people at one particular time point and that, given the insidiousness of the disease, that abilities were always changing and being adapted to and that the likelihood of me catching an activity at the moment it became difficult and before any strategies had been developed to deal with it was very small with the methods I was using. The research questions became focused around the mix of activities people were doing, and how those were both challenged and supported, in those naturalistic settings. Particularly activities outside of the essential ADL tasks such as hobbies and leisure activities, as these had emerged as important in the dyadic interviews but my largely symptom-led approach, the interview format and theoretical underpinnings had possibly weighted my exploration towards more functional activities. I had started to see by observing that people’s daily lives were not mostly made up of set functional tasks – once people finish attending clinic appointments, getting dressed, having meals and the other essential ADLs, they still had the majority of the day left to fill, and that made up most of the time I was privileged to be spending with participants. So with the same overarching aim of understanding the day-to-day impacts of the conditions I shifted more towards asking what that time was like. At this point it became less solely a study of deficits and strategies in action in the intersecting psychosocial and physical contexts and more a holistic study of the mundane and the ordinary. Essentially, what were people spending their days doing? What filled the hours of the day? And how were those things done and why? And ultimately, what could I learn from what people were already doing to cope in their usual,
ordinary environments, which might have been able to inform how others also living with these conditions could best be supported? Spending this amount of time with people meant much of it was this ‘ordinary’ time, and this allowed me to learn about what people choose to do with it, what mattered most to them, and their own preferences and priorities for activity engagement, rather than those which might be presumed as important and imposed by existing measures of activities which are, by nature, the more easily measurable ones (e.g. ADLs). These sorts of ordinary daily activities were also arguably just the sort which could be expected to have a strong bearing on priority outcomes such as QoL and wellbeing, particularly perhaps for people like these participants who had relatively recently (and often unexpectedly) retired, and who had been preparing and planning for a new ‘ordinary’ centred more around having time to spend doing the things they enjoyed.

The data collection and analysis (both ongoing and iterative) throughout these unstructured home-based observations became guided by four questions pertaining to what people were (and were not) doing, how and why:

- Which activities was this person motivated towards throughout the visit?
- How was that activity challenged?
- How was that activity supported?
- Why was this activity prioritised/selected/important?

**What did I find in phase II?**

In asking these questions within the home environments of people living with PCA and tAD, I identified some group level differences in how various activities were challenged and how they were supported. For example, for those with typical AD, activities were mostly challenged by memory-related difficulties such as the forgetting of instructions, disorientation and difficulties in sequencing during tasks. For those with PCA, tasks were mostly challenged by visual processing problems such as difficulty recognising or locating objects, or proprioceptive difficulties such
as orienting oneself to an object or navigating to a certain space within the home. Accordingly, activities were mostly supported by reminders and reorientation to task and by hands on physical assistance or verbal instruction for those with tAD and PCA respectively. But for the questions about the which activities people were doing and why, I observed more similarity and overlap, with any differences among these seeming to occur not just according to disease type but various other dimensions of individual differences such as personality, disease severity, quality of existing relationships, living situation, and so on. I had also realised the difficulty and perhaps unhelpfulness of categorising and drawing boundaries around what counts as an ‘activity’, given the breadth of differences in abilities people displayed owing to their disease severity and other factors. In wanting to take account of all expressions of motivation towards an activity and to take an inclusive approach to any observed examples of agency, I had broadened the ‘activity’ construct out to ‘doing’, and was essentially asking about what it is that we are doing when we’re doing, or overall, the ‘what’s and ‘how’s and ‘why’s of doing for people with a diagnosis of a dementia. Three major themes were constructed and considered to offer a comprehensive account of the major over-arching findings across both groups in relation to this question, and will be discussed and grounded in data from both groups, and those are: (1) The fun and the function; (2) Reciprocities of care; (3) The constitution and continuity of a changing self.

**What does this tell us and why is it useful?**

Taken together, the findings will firstly be discussed in terms of how daily activities are differentially challenged and can be differentially supported for people living with both memory and visually-led dementias. Then finally, why recognising the extant priorities, preferences, motivations and meaning-making of those living with and supporting someone with a diagnosis of a dementia should be a centre-stage priority for researchers, so that people living with these conditions can be best supported to continue to act with agency and engage meaningfully in their everyday environments.
Aims and Objectives

The central aim of this PhD study is to explore and gain some understanding of the lived experience of PCA.

This aim will be met using the following objectives:

- **Phase I**: Gain novel insights into the day-to-day experiences of PCA by conducting the first in-depth semi-structured interviews with people living with PCA and their family carers (both as a dyad and individually) about the stressors and coping strategies associated with living with the condition, facilitated by a walk-around tour of the home environment;

- **Phase II**: Conduct the first home-based observational study in a naturalistic setting of people with PCA and a comparison group of people with tAD, to offer an ecologically valid lens on the day-to-day experiences of people with both conditions. Specifically, exploring the challenges, coping strategies and meaning-making associated with day-to-day activity engagement using focussed ethnographic data collection tools and techniques, in order to gain a rich volume of data in a relatively and necessarily short time period.
Chapter 1: General Introduction

In this section I will provide the context and rationale for this PhD project by introducing PCA as a rare form of dementia and summarising what is already known about it, as well as highlighting the current gaps in knowledge which this study aims to fill.

1.1 Biomedical introduction to dementia, Alzheimer’s disease and posterior cortical atrophy

Although this is a social science PhD study, here I will firstly introduce dementia, Alzheimer’s disease and PCA from a biomedical perspective, as this reflects: the balance of research enquiry into PCA to date which has been very biomedical; the context in which I completed this work (this is the first social science study undertaken at the dominantly biomedical Dementia Research Centre, UCL); and the interdisciplinary nature of the Seeing What They See project in which this work is situated.

1.1.1 Wider context and rationale

Dementia is widely acknowledged as one of the biggest public health challenges of our time. There are currently thought to be approximately 850,000 PLWD in the UK, and this is set to rise as the population ages (e.g. Ferri et al., 2005). Current estimates are that 1 in 14 people over 65 are affected by dementia and this rises to 1 in 6 people over 80 (Jorm and Jolley, 1998). Dementia is characterised by progressive cognitive impairment which has wide-reaching impacts on the individuals affected by the conditions, their families, health and social care systems and society as a whole (Etters, Goodall and Harrison, 2008). There are huge direct and indirect economic costs associated with the necessary provision of care, but also personal costs in terms of the impact dementia can have on individuals’ quality of life and social relationships. Dementia is also the condition that people over 50
fear most, and stigma and misconceptions about the condition and the diseases which cause it are widespread (Milne, 2010; Swaffer, 2014).

While we are without a cure for dementia-causing diseases, the public health priorities for PLWD are centred around maintaining as good a quality of life as possible. Understanding the complexities of dementia-causing diseases and their impacts is of essential importance in both the search for a cure but also in building the knowledge base about how best to support people currently affected by the conditions. A necessary part of this process is increasing understanding of atypical presentations of dementia, and in recent years the widespread heterogeneity which exists underneath the umbrella term of dementia has been increasingly acknowledged. As well as the typical amnestic presentation of dementia, studies have reported on dementia presentations characterised by alternative predominant symptoms including altered personality and behaviour, language impairment and problems with processing visual information – as is the case in PCA which is the focus of this PhD thesis. It is likely that people experiencing different patterns of atrophy and therefore different sets of symptoms, will also experience different challenges, and as a result need tailored support strategies. Condition-specific education and information will also be key for equipping PLWD and the health and social care professionals supporting them to most effectively manage the difficulties associated with these diagnoses.

One of the central personal challenges dementia poses is the loss of independence PLWD experience as cognitive decline progresses and everyday tasks become increasingly difficult, and dependency on others for assistance with ADLs can have a significant impact on quality of life (Andersen et al., 2004). This relates to another relevant public health priority – ageing in place – not only are there indisputable economic and social benefits of PLWD remaining at home, it is also the preferred option for most PLWD, who seek to maintain their independence as far as is possible (Brittain et al., 2010; Mokhtari et al., 2012; Robinson et al., 2019). Better understanding how different presentations of dementia impact people in their
home environments will be crucial in informing the development of interventions to facilitate ageing in place for this population. Before outlining how I attempted to address part of this need, I am first going to offer some introductory background about what dementia, Alzheimer’s disease and PCA are, including: what causes them and how they are diagnosed, how they progress and how they are characterised in terms of symptom presentation.

1.2 What is dementia?

Dementia is an umbrella term describing an acquired syndrome which manifests as progressive decline in a range of cognitive domains. This includes memory loss and problems with thinking and planning, and leads to increased dependence and significant impairment in functioning in a range of everyday tasks (Cummings and Benson, 1983; Rossor, 1994; Qiu, Kivipelto and von Strauss, 2009). Dementia is caused by physical diseases of the brain which result in neuronal cell death, and there can be a number of different diseases responsible for causing this atrophy. The most common pathological disease which causes dementia is Alzheimer’s disease, but there are many other potential causes including (but not limited to): vascular dementia, dementia with Lewy bodies (DLB), frontotemporal lobar degeneration (FTLD), corticobasal degeneration (CBD), Creutzfeld Jakob disease (CJD) and Acquired Immunodeficiency Syndrome (AIDS) dementia (e.g. Van Der Flier and Scheltens, 2005). These diseases can be difficult to distinguish from each other clinically as symptoms which present quite similarly can be underpinned by different atrophy-causing diseases, and there can also be simultaneous overlap of multiple pathologies in some cases which can complicate things further (e.g. Jellinger and Attems, 2008). Knowing which pathology is underlying someone’s dementia presentation is important for PLWD, families and professionals’ understandings of the symptoms as they happen, but also in order to anticipate how things may progress, which is essential for care planning and management. This thesis focuses on people with a diagnosis of PCA (which can be caused by a
number of different underlying disease processes but most commonly AD), and people with a diagnosis of tAD, and I will introduce both now.

### 1.2.1 Alzheimer’s disease

Over 100 years ago Alois Alzheimer first identified the amyloid plaques and neurofibrillary tangles in one of his patients which are now acknowledged as characterising Alzheimer’s disease – the most common cause of dementia in people over the age of 65 (Van Der Flier and Scheltens, 2005). Here I will provide some background on exactly what Alzheimer’s disease is or looks like (i.e. pathology), how and who gets AD (i.e. epidemiology, genetics and other risk factors), how it is diagnosed, how it progresses and current treatment approaches.

#### 1.2.1.1 What causes AD and who gets AD?

There are two neuropathological features which are the defining characteristics of AD and they are extracellular amyloid β-protein deposits and intracellular neurofibrillary tangles (Braak and Braak, 1991; Selkoe, 2001). Together these cause a loss of neurons and the synapses which connect them over time (Terry et al., 1991; Gómez-Isla et al., 1996), which ultimately results in progressive atrophy of areas of the cerebral cortex (Chan et al., 2003). The hippocampus in the medial temporal lobe is one of the areas most drastically affected in typical AD (e.g. Braak and Braak, 1991).

Understanding what causes AD is complicated – with age being the biggest risk factor for AD, the majority of people with AD are older, and this highlights the possible role of biological age-related changes in the development of dementia, and also potentially that various lifestyle and environmental factors may accumulate over the lifespan and contribute in some way to the development of dementia (e.g. Qiu et al., 2009). Vascular risk factors for AD have been identified including smoking (Peters et al., 2008), obesity (Kivipelto et al., 2005) and high blood pressure (Kivipelto et al., 2001). There are also protective factors which can guard against the development of AD including physical activity (Rovio et al., 2005) as well as psychosocial protective factors such as a higher educational level (Karp et al., 2004) and greater occupational complexity (Andel et al., 2005). Although age is a
major risk factor, about 5% of people with dementia have what is called young or early onset dementia (arbitrarily defined as symptom onset before the age of 65 – see Rossor, Fox, Mummery, Schott, and Warren, 2010), which equates to about 42,500 people in the UK, according to current estimations. Studies of AD (and dementia more broadly) are often stratified according to whether the disease is early or late onset, and it has been found that underlying AD pathology is more strongly associated with dementia in the younger old than the oldest old (e.g. Savva et al., 2009). This suggests that there may be other factors contributing to dementia in the oldest old and further illustrates the importance of factoring in age when studying variations of dementia, and the potential importance age may have for the implementation of future interventions to treat dementia and its symptoms.

A very small proportion of AD cases (just over 600 families worldwide) with predictable and markedly earlier age of onset have a genetically inherited form (familial AD) which can be caused by an autosomal dominant mutation in, for example, the amyloid precursor protein (APP) on chromosome 21 (Chartier-Harlin et al., 1991) and genes including the presenilin-1 gene on chromosome 14 (Janssen et al., 2003) and presenilin-2 gene on chromosome 1 (Mann et al., 1997; Campion et al., 1999; Sampson, Warren and Rossor, 2004). For most people however, AD is sporadic (i.e. not directly inherited from a parent), though there are also a number of genetic risk factors which have been identified for sporadic onset AD. These genetic risk factors can interact with each other and various environmental and lifestyle factors to increase or reduce the chance of a person developing AD. The gene which has the greatest impact on the development of sporadic AD is apolipoprotein E (APOE) which is found on chromosome 21 and is involved in handling fats in the body (e.g. cholesterol) (Okuizumi et al., 1994; Qiu, Kivipelto and von Strauss, 2009). Other genes responsible for fat metabolism, immunity and inflammation and transport within cells are also thought to influence the development of AD, but to a lesser extent than APOE and research is ongoing (e.g. Badea et al., 2019; Leonenko et al., 2019).
1.2.1.2 Diagnosing AD

The early signs and symptoms of AD are usually the insidious onset of memory problems which eventually progress to a more global cognitive deficit with multiple domains affected (Cummings and Benson, 1983; McKhann et al., 1984). Diagnosis is not clear-cut however, and the presence of the characteristic plaques and tangles described above can only be established with certainty on post-mortem or by biopsy. Certain clinical and neuropsychological assessments can be done to diagnose probable AD, and a diagnosis of possible AD may be given when there is an atypical presentation, or progression not accounted for by other co-morbid dementia-causing diseases (NINCDS-ADRDA; McKhann et al., 1984). There have been recent efforts to refine and revise diagnostic criteria and to increase sensitivity earlier in the disease course, and as a result these criteria now include episodic memory impairment as the leading core diagnostic feature in combination with at least one supporting biomarker (Dubois et al., 2007). Biomarkers include medial temporal lobe atrophy identified via structural brain imaging, amyloid deposition as identified by positron emission tomography (PET) imaging or by a low Aβ42 concentration and high t-tau concentration in cerebrospinal fluid (CSF), or the presence of a genetic mutation in the presenilin 1 or 2 or APP genes (Dubois et al., 2007; 2010).

While it is true that most people with AD experience predominant memory problems, especially in the early stages, this refinement of the diagnostic criteria potentially contributes to the possible under-recognition of those atypical forms of AD in which visual processing problems (i.e. PCA) or language problems are the leading feature (e.g. Galton, Patterson, Xuereb, Hodges, 2000). This under-recognition can also contribute to these atypical forms of dementia being under-researched, as the defining characteristics of the populations are less well specified. Efforts to explicate the complexity and heterogeneity of AD presentations have included: the suggestion of a frontal variant of AD mostly affecting executive function (e.g. Johnson, Head, Kim, Starr, and Cotman, 1999); the identification of an association between AD pathology and word finding pauses in the absence of any
major issues in syntax or comprehension, which occur in the logopenic variant of primary progressive aphasia (Mesulam et al., 2008); and as is most relevant here, the dominant visuospatial and visuoperceptual impairments which characterise the atypical visual variant of AD, which has come to be known as PCA (e.g. Cogan, 1985; Benson, Davis and Snyder, 1988; Mackenzie Ross et al., 1996; Suárez-Gonzáles et al., 2015).

Although typical AD is considered a mostly amnestic syndrome, the current diagnostic criteria refers to potential secondary impairments in visuospatial ability, non-amnestic language and executive function (McKhann et al., 2011). While there is evidence of, for example, visuospatial and visuoperceptual deficits presenting early on in course of AD for some patients (e.g. Almkvist, 1996; Binetti et al., 1998; Caine and Hodges, 2001; Quental, Brucki, and Bueno, 2013), these deficits are mostly anticipated as a feature of more moderate AD (Grady et al., 1988). Leading visuospatial or visuoperceptual symptoms would usually be indicative of an atypical syndrome such as PCA (as I will describe), and it is worth noting that people with young onset AD are more likely to demonstrate a non-amnestic clinical presentation, with one study finding a third of young-onset AD patients showing impairments in vision, praxis, language or executive function, over and above memory (Koedam et al., 2010).

1.2.1.3 The progression of AD
A commonly used framework for understanding how the clinical presentation of AD changes over time is Reisberg’s (1999) 7 Stages of Alzheimer’s disease. The stages outline the sorts of difficulties a person with AD may have at the stages of no, very mild, mild, moderate, moderately severe, severe and very severe cognitive decline. The mild stages describe minor unremarkable memory problems and occasional losing of things around the house, through to problems with planning, organising, word-finding and remembering new names, which are noticeable to doctors and family members, through to more profound short-term memory impairment such as forgetting what one had for breakfast and elements of one’s life history, as well
as increasing difficulty with complex tasks such as managing finances, at the moderate stage. Stages 5-7 (moderately severe, severe and very severe) see a functional shift whereby people begin to need assistance with all daily tasks, confusion becomes significant and there may be wandering and personality or behavioural changes, before the final stages where a person may lose the ability to communicate or respond to their environment and require constant care.

1.2.1.4 Current treatment approaches for AD

While there is no cure for AD to stop the disease process overall, there are treatments available which can slow down memory loss and other cognitive symptoms for a limited period. Medications which are usually most effective in the mild-moderate stages of the disease are cholinesterase inhibitors (e.g. galantamine, rivastigmine, donepezil) and these are thought to work by slowing down the breakdown of acetylcholine which is a neurotransmitter considered to be important for memory and thinking processes (e.g. Jann, 2000; Lopez et al., 2002). Memantine may be used in the moderate-severe stages and is thought to work by regulating another neurotransmitter, glutamate, which may contribute to neuronal cell death (e.g. Winblad et al., 2007).

In summary, while much is known about amnestic AD in general (and even regarding the subjective experience, as will be discussed below) there is much still to be learned about the varied presentations of AD and particularly, the subjective experience of those lesser known forms. The benefits of increasing understanding of the varied clinical presentations of AD cannot be overstated: better characterisation will mean better categorisation and more specific and sensitive inclusion criteria for intervention trials; it may also permit the selection of more attuned and appropriate outcome measures for participants who may be dealing with very different dominant symptom profiles, as well as improving accurate and timely diagnosis which can then be followed by the necessary provision of tailored, syndrome-specific post-diagnostic support and information (e.g. Crutch et al.,
One such lesser known dementia syndrome is PCA, which I will now outline.

1.2.2 Posterior Cortical Atrophy

PCA is a syndrome characterised by a predominant and relatively selective decline in visual processing abilities – irrespective of any problems with eye health – and other cognitive functions which are associated with the posterior regions of the brain (Cogan, 1985; De Renzi, 1986; Benson, Davis and Snyder, 1988; Caine, 2004; Kirshner and Lavin, 2006; Crutch et al., 2012; Crutch, 2014; Maia da Silva et al., 2017). The corresponding neuroanatomical features are atrophy of predominantly the occipital, parietal and occipito-temporal regions (Lehmann et al., 2011b; Borruat, 2013; Maia da Silva et al., 2017). The term was first introduced by Benson and colleagues (1988) when they reported on five patients with dominant impairments in higher-order visual functions such as localising and recognising objects and signs of Balint’s and Gerstmann’s syndrome, along with memory function which was impaired but relatively well preserved in comparison to the leading visual symptoms. The patients all showed associated atrophy in parieto-occipital areas (Benson, Davis and Snyder, 1988). Other early studies of PCA looked mainly at the clinical and neuroimaging profiles of the condition and these are still the leading approaches taken to researching PCA, along with work to characterise the neuropsychological profile of the syndrome (e.g. Berthier, Leiguarda, Starkstein, Sevlever, and Taratuto, 1991; Borruat, 2013; Cogan, 1985; De Renzi, 1986). AD has been identified as the most common cause of PCA, with the characteristic amyloid plaques and neurofibrillary tangles present in the posterior regions of the brain of those affected (e.g. Hof and Morrison, 1990; Kirshner and Lavin, 2006; Tang-Wai et al., 2004). Because of this, PCA is often considered an atypical variant of AD – sometimes referred to as the visual or bi-parietal variant of AD (e.g. Bokde et al., 2001; Galton et al., 2000; Levine, Lee, and Fisher, 1993; Mackenzie Ross et al., 1996; Schott et al., 2006; Suárez-González et al., 2015) and there have been suggestions that PCA should be considered as being on a continuum of phenotypic variation in
AD (e.g. Stopford et al., 2008; Maia da Silva et al., 2017). However, there are also other known causes of PCA including DLB, corticobasal degeneration (CBD) and prion disease (e.g. Mendez, Ghajarian, and Perryman, 2002; Renner et al., 2004; Seguin et al., 2011; Tang-Wai et al., 2003), and there are arguments too for the consideration of PCA as its own distinct syndrome with its own set of diagnostic criteria (Mendez et al., 2002; Tang-Wai and Mapstone, 2006). Further still, there is the suggestion that there may be both dorsal and ventral manifestations of PCA, depending on which cortical processing stream is most affected, for example people with PCA who have more trouble seeing where things are would be considered to have a predominantly dorsal stream PCA (with damage to the parietal lobes), and those who have more trouble seeing what things are, a predominantly ventral version, with more damage to the occipito-temporal regions (Mishkin and Ungerleider, 1982; Goodale and Milner, 1992; Mackenzie Ross et al., 1996). A third subtype in which the striate cortex and early visual processing is most affected has also been suggested (Galton et al., 2000). Research seeking to confirm these syndromic variations is mixed however (e.g. McMonagle, Deering, Berliner, and Kertesz, 2006), and often conducted with single participants or small samples. A group study of PCA showed that although there are deficits associated with occipital and temporal lobe damage, such as achromatopsia (problems seeing colours), hemianopia (blindness over half the field of vision), visual agnosia (problems recognising or interpreting visual information) and prosopagnosia (impaired recognition of faces), that the overall pattern across the group was of a consistent, disproportionate deficit in dorsal processes (the ‘where’ stream) processes, relative to ventral (the ‘what’ stream) or primary visual processes (McMonagle et al., 2006).

It is clear that further work is needed, and that much like in AD, there is considerable within-syndrome variability and heterogeneity and much still to be agreed and confirmed about the varied ways PCA can present and be classified. This only strengthens the argument for more research which could offer further clarity about the complexity of the condition and equip those affected by and researching PCA to better understand the nature of the problem they are faced with.
The behavioural phenotype of PCA mostly involves visuospatial and visuoperceptual impairment, features of Balint’s (simultanagnosia – difficulty seeing more than one item at a time, oculomotor apraxia – impaired voluntary controlled eye movements, optic ataxia – impaired visually guided reaching and grasping) and Gerstmann’s syndrome (acalculia – inability to perform calculation, agraphia – inability to write, left-right disorientation, finger agnosia – inability to recognise fingers), as well as alexia (inability to read) and apraxia (Kirshner and Lavin, 2006; McMonagle et al., 2006a; Crutch et al., 2012; Borruat, 2013; Maia da Silva et al., 2017). Longitudinal studies indicate that while memory, language and executive function are relatively well preserved in the early stages, that PCA tends to progress to more global cognitive impairment (Levine, Lee and Fisher, 1993; McMonagle et al., 2006; Maia da Silva et al., 2017). The symptom profile can also vary according to the underlying cause of the PCA, for example the experience of visual hallucinations (observed in up to 25% of PCA patients – Josephs et al., 2006), and dystonia could indicate an underlying cause of DLB or CBD (Crutch et al., 2012). The cognitive profile of PCA can also include some language impairment – specifically, people with PCA have been shown to demonstrate some overlap with people with logopenic progressive aphasia (LPA) on tasks of non-word repetition, phonemic fluency and prosody processing (Crutch et al., 2013b).

1.2.2.1 What causes PCA and who gets PCA?

Studies which look at CSF biomarkers (amyloid and tau depositions) have reported similar concentrations in PCA compared with AD (Baumann et al., 2010; De Souza et al., 2011), which supports the assertion that PCA is most often caused by underlying AD pathology. However, the patterns of distribution are known to be broadly different, but studies attempting to delineate exactly how different they are and in which ways show inconsistent findings and use small sample sizes. Some studies have shown differences in amyloid plaques and neurofibrillary tangles in people with PCA compared to people with typical amnestic AD (Levine, Lee and Fisher, 1993; Mackenzie Ross et al., 1996; Hof et al., 1997), while other studies have found no differences in the distribution of plaques (Renner et al., 2004; Tang-Wai et al.,
These discrepancies are likely down to similar issues as already noted with regard to studying PCA populations, including the rarity of the condition, misdiagnosis or misclassification, earlier age of onset, variation in assessment methods, and so on.

It is difficult to establish the prevalence of PCA with certainty because of the rarity of the condition itself meaning it is likely underdiagnosed. Variability in the diagnostic criteria used across sites and studies is also an issue, as well as misdiagnosis and misclassification. Several single centre studies have been conducted, but the transferability of their findings is unclear, and the different samples owing to different centre specialisms exacerbate this problem. A study by Snowden et al., (2007) identified that 5% of 523 patients with AD who presented to one specialist cognitive disorders centre had a visual presentation of AD and a study by Croisile (2004) identified 4% of 154 people presenting to a memory clinic as having PCA. The condition’s early age of onset (e.g. McMonagle et al., 2006; Mendez et al., 2002) may also contribute to the lack of representative figures based on inaccurate diagnosis, although studies have identified patients being diagnosed at a range of ages (40-86 years; Tang-Wai et al., 2004). Gender distribution is also unclear, as some studies have reported no difference in the prevalence between the genders (e.g. McMonagle et al., 2006; Mendez et al., 2002; Renner et al., 2004), while others have reported PCA as disproportionately affecting women (e.g. Snowden et al., 2007; Tang-Wai et al., 2004).

There is currently no evidence to suggest a directly inherited form of PCA but similarly as with tAD, genetic risk factors have been identified. Findings to date have been mixed, and until Schott et al.’s 2016 study of 302 patients, sample sizes are often small. Some studies have reported significant differences in the APOE status of people with PCA or a visual presentation of AD compared to people with amnestic AD (Schott et al., 2006; Snowden et al., 2007), however other studies have reported lesser or no difference in APOE between those with PCA and amnestic AD (Mendez et al., 2002; Migliaccio et al., 2009; Tang-Wai et al., 2004). These
disagreements may have reflected the difficulty with consistent classification and categorisation of PCA (and AD to an extent) owing to rarity and inconsistencies in diagnostic and inclusion criteria, and studies with larger samples are needed for more conclusive results. Schott’s 2016 study provided evidence for specific genetic risk factors for PCA in a large sample and with replication, these findings hold much promise for further developing understanding of how various genetic factors can contribute to the wide-ranging phenotypic variance in AD, and ultimately why some people develop the visual variant that is PCA.

1.2.2.2 Diagnosing PCA

There are two sets of diagnostic criteria which are commonly used in research studies and clinical settings (Mendez et al., 2002; Tang-Wai et al., 2004). They specify core features for a diagnosis of PCA as: insidious onset and gradual progression; the presentation of visual deficits in the absence of ocular disease; relatively preserved episodic memory, verbal fluency and personal insight; presence of symptoms including visual agnosia, simultanagnosia, optic ataxia, ocular apraxia, dyspraxia and environmental disorientation and aspects of Gerstmann’s syndrome; and absence of a stroke or tumour. Additional supportive features for a diagnosis include alexia, ideomotor apraxia, agraphia, acalculia, early onset of symptoms (i.e. before the age of 65) and supportive neuroimaging evidence of posterior cortical atrophy (Crutch et al., 2012; Maia da Silva et al., 2017; McMonagle et al., 2006; Mendez et al., 2002; Tang-Wai et al., 2004). Historically there have been slight differences in definitions of PCA, possibly owing to the rarity and range of different clinical centres’ experiences of and exposure to PCA, which have potentially contributed to some of the inconsistencies in studies of PCA outlined above. In response to this, consensus criteria for classifying PCA at both the syndrome and disease level has recently been established via the international collaboration of the PCA Working Party (consisting of researchers representing 23 institutions in 9 counties) (Crutch et al., 2017), to assist the classification of different manifestations of PCA in a range of research settings, to ultimately improve both the knowledge base and clinical care and support provision for those affected.
1.2.2.3 The progression of PCA

Firth et al. (2019) recently conducted the first major longitudinal investigation of the anatomical and cognitive changes in over 100 PCA participants with up to 6 annual assessment visits, and showed earlier decline in tests sensitive to visuospatial dysfunction in people with PCA than in people with a diagnosis of tAD, and the reverse for tests of memory.

Crutch and colleagues at the Dementia Research Centre at UCL have also published a version of Reisberg’s 7 stages document but for people with PCA, developed in consultation with Rare Dementia Support members (Crutch, Walton, Carton and Shakespeare, n.d.). The document describes early visual symptoms such as difficulty judging distances when driving and slower typing on a keyboard, to problems with reading, dressing and managing money, before people become ‘functionally blind’ and require help with virtually all daily tasks, and eventually displaying a more global cognitive impairment similar to that seen in AD more generally.

1.2.2.4 Current treatment approaches for PCA

Options for medications to reduce the impact of the symptoms of PCA depend upon the underlying disease causing the syndrome, and anecdotally, many patients with an AD pathology find medications designed for AD useful in slowing their symptoms for a time.

1.2.2.5 The imaging profile of PCA

As indicated by the syndrome name, brain imaging has identified cerebral atrophy particularly in the posterior brain regions of people with PCA. Studies have identified reduced grey matter volume in the occipital, posterior parietal and posterior temporal regions in people affected by PCA, in comparison to healthy controls (Lehmann et al., 2011b; Migliaccio et al., 2009; Migliaccio et al., 2012; Whitwell et al., 2007).

When comparing PCA and tAD, studies have also found lower grey matter volume in the occipital and bilateral posterior parietal regions of the PCA group (Lehmann et
al., 2011b; Whitwell et al., 2007). Studies using diffusion tensor imaging (DTI) have also identified changes in white matter in posterior brain networks of people with PCA (Migliaccio et al., 2012), with a case study by Duning et al. (2009) suggesting the involvement of the occipital lobe particularly early on, consistent with the predominant visual symptoms people with PCA experience. Manning et al. (2015) showed differences in the shape of the hippocampus of people with PCA compared to tAD (irrespective of volume) which seemed to account for the differences in episodic memory function seen in the two groups (i.e., that for people with PCA this was less affected).

Functional imaging studies of people with PCA (e.g. SPECT, PET) have also identified differences in functional activity in the posterior regions including the occipital, parietal and temporal cortices, relative to healthy controls and people with tAD (Nestor et al., 2003; Gardini et al., 2011; Kas et al., 2011; Rosenbloom et al., 2011). Interestingly, studies have also showed differences in function in the frontal eye fields of people with PCA compared to healthy controls, perhaps relating to the optic ataxia which is commonly observed in PCA (Crutch et al., 2012). Studies have also been mixed with regards to amyloid deposition – some have shown it to be increased in occipital and parietal regions of PCA patients relative to tAD patients (Migliaccio et al., 2012; Tenovuo, Kemppainen, Aalto, Någren, and Rinne, 2008), whereas others have found no differences in amyloid burden among the two groups (De Souza et al., 2011; Rosenbloom et al., 2011).

These discrepancies are compatible with those seen also in post-mortem assessments of the pathology underlying PCA. Taken together with evidence of overlap of cortical thickness and grey matter volume in some areas in cases of PCA, tAD and LPA, this might suggest that these syndromes are best considered as points on a non-discrete, non-distinct continuous spectrum of AD (Migliaccio et al., 2009; Ridgway et al., 2012). These discrepancies and mixed findings highlight that more work is needed to understand PCA at an anatomical level, as well as in terms of clinical presentation and impact on functional status and other outcomes.
1.2.2.6 The neuropsychological profile of PCA

A significant amount of the existing literature on PCA is aimed at characterising the neuropsychological profile associated with the syndrome. This is important for further understanding the possible varied presentations within the PCA syndrome and for moving towards greater detection of the differential underlying pathologies that can be responsible for PCA, in terms of how they may be identified at diagnosis, how they progress and ultimately, how they may respond to treatments. Further specifying the neuropsychological profile of PCA is also of critical importance for educating families and professionals so that they can better understand and respond to the challenges associated with the condition (Crutch et al., 2013a). McIntyre et al.’s (2018) interviews and focus groups with social workers and occupational therapists highlighted the need for this, with their findings that in the absence of training about the lesser known possible features of dementia such as the visual problems seen in PCA, health and social care professionals may interpret novel or unfamiliar symptoms using their existing understandings of symptoms considered to be more typical of dementia, for example memory difficulties, disorientation and behavioural problems. Some of the most prominently acknowledged deficits in PCA relate to impairments in the processing of visuospatial and visuoperceptual information. These include alexia, neglect (failure to acknowledge visual stimuli), features of Balint’s syndrome (simultanagnosia – difficulty perceiving more than one item at once, oculomotor apraxia, optic ataxia, environmental agnosia – inability to recognise familiar environments) and Gerstmann’s syndrome (acalculia, agraphia, finger agnosia, left/right disorientation) (Andrade et al., 2010; Charles and Hillis, 2005; McMonagle et al., 2006; Mendez et al., 2002; Renner et al., 2004; Tang-Wai et al., 2004; Whitwell et al., 2007). Of those features, in their 2006 group study of 19 people with PCA, McMonagle et al. (2006) identified the following as the most consistently observed: agraphia, alexia, simultanagnosia and optic ataxia. Other features McMonagle and colleagues (2006) reported included agnosia for objects, faces and colours.
More specifically, higher order visual processing problems such as spatial and object perception are reported more commonly in PCA than early visual processing problems such as enhanced visual crowding (the inability to recognise objects in clutter) and seeing line, form, colour and motion accurately, but the latter are thought to make some contribution to the former (Crutch et al., 2012; Crutch and Warrington, 2009; Crutch and Warrington, 2007; Farah, 2000; Heider, 2000; Levi, 2008; Mendez, Shapira, and Clark, 2007; Qiu and Von Der Heydt, 2005; Warrington, 1986) and corresponding AD pathology in the occipital lobe has been observed (Hof et al., 1997; Metzler-Baddeley et al., 2010). People with PCA have shown early visual processing problems such as difficulty localising, maintaining fixation on and tracking a single point or object in space which may contribute to the observed visual disorientation people with PCA commonly experience, something which has a significant functional impact, affecting a person’s ability to (e.g.) reach for an object or walk across a room unaided (McCarthy and Warrington, 1996; Kaida et al., 1998; Langdon and Thompson, 2000; Chan et al., 2003). A perhaps counter-intuitive observation and example of the complexity of the syndrome is that some PCA patients show improved localisation and perception of things which are smaller and/or moving (Coslet, Stark, Rajaram, and Saffran, 1995; Crutch et al., 2011, 2013; Midorikawa, Nakamura, Nagao, and Kawamura, 2008; Saffran, 1995; Stark, Grafman, and Fertig, 1997). In keeping with this inverse size effect and a tendency to focus on small segments of the visual field at a time, people with PCA show difficulties in perceiving whole scenes (Perry and Hodges, 2000; Shakespeare et al., 2013), describing a somewhat fragmented field of vision (e.g. Berthier et al., 1991; Crutch, 2014; Maia da Silva et al., 2017) and complain of having particular difficulty when reading large font, such as newspaper headlines (Crutch et al., 2011).

People with PCA have also showed impaired performance on various neuropsychological tests of form perception, including: shape discrimination, shape detection, orientation discrimination, contour integration, form coherence, visual field detection and colour perception (Chan, Crutch, and Warrington, 2001; Lehmann, Barnes, et al., 2011a; McMonagle et al., 2006; Mendez, Mendez, Martin,
Smyth, and Whitehouse, 1990; Metzler-Baddeley et al., 2010; Pelak, Smyth, Boyer, and Filley, 2011; Tang-Wai et al., 2004; Wakai et al., 1994; Whitwell et al., 2007), which again, can all have profound functional impacts when trying to perceive objects in the day-to-day environment. As well as visual disorientation, people with PCA also show higher order visuospatial impairments which challenge their abilities to represent the spatial relationships between objects (rather than struggling with localising a single object) and to guide their actions accordingly (e.g. Binetti et al., 1998; Freedman and Dexter, 1991; Mendez, 2001; Warrington and James, 1967) and a range of studies have shown people with PCA to demonstrate impaired performance on tasks assessing visuospatial function (Benson, Davis and Snyder, 1988; Mackenzie Ross et al., 1996; Mizuno et al., 1996; Stark, Grafman and Fertig, 1997; Delazer et al., 2006; Tenovuo et al., 2008; Videaud et al., 2009; Metzler-Baddeley et al., 2010; Lehmann, Barnes, et al., 2011a).

Object recognition is another commonly impaired neuropsychological function for people with PCA (e.g. De Renzi, 1986; Benson, Davis and Snyder, 1988). One form of this is apperceptive agnosia, in which people are unable to assemble or perceive the sensory information they are receiving into a coherent representation of a whole object (Warrington, 1985), and several studies have demonstrated this in PCA (Hof and Bouras, 1991; Wakai et al., 1994; Aharon-Peretz et al., 1999; Galton et al., 2000; McMonagle et al., 2006). Apperceptive agnosias are much more commonly responsible for impairments in object recognition for people with PCA than associative agnosias are, which arise from intact perceptual representations of objects in combination with a loss of meaning (McMonagle et al., 2006; Mendez et al., 2002; Warrington, 1985). People with PCA also demonstrate prosopagnosia which is a disproportionate difficulty in recognising faces (relative to other objects) (Mendez et al., 2002). Being a relatively early and common symptom, it has been suggested as a supportive diagnostic feature of PCA, though it occurs in combination with other visual agnosias and early visual processing problems (Aharon-Peretz et al., 1999; Sala, Spinnler, and Trivelli, 1996; McMonagle et al., 2006; Mendez et al., 2002; Tang-Wai et al., 2004; Wakai et al., 1994).
The visual processing problems that people with PCA experience have a drastic impact on their performance IQ which is typically 30-40 points lower than their verbal IQ scores, and they demonstrate similarly impaired performance on constructional tasks such as clock-drawing (McMonagle et al., 2006; Crutch et al., 2012). Although episodic memory and linguistic skills are relatively well preserved in the early stages of PCA, these go on to be more affected in the later stages when the neuropsychological profile of PCA becomes more globally impacted and comparable to a tAD presentation (e.g. Sala et al., 1996; Levine et al., 1993; McMonagle et al., 2006).

There are also non-visual neuropsychological features associated with PCA which reside in the posterior regions of the brain. These include difficulties with calculation, spelling and praxis (e.g. Aharon-Peretz et al., 1999; Delazer et al., 2006; McMonagle et al., 2006; Kas et al., 2011).

Although language can often be referred to as being relatively well preserved in PCA, there are documented language features associated with the condition which can be experienced from the point of symptom onset (McMonagle et al., 2006; Mendez et al., 2002; Migliaccio et al., 2009). These include anomia (inability to recall the names of everyday objects) and problems with comprehension, phonemic fluency (ability to list words beginning with a given letter) and word retrieval (Crutch et al., 2013b; Magnin et al., 2013; Tang-Wai et al., 2004).

Similarly, while memory and executive function are sometimes reported as the preserved cognitive domains for people with PCA, there are also mixed and complex findings related to those (as with language) (Lehmann, et al., 2011b; McMonagle et al., 2006; Mendez et al., 2002; Rosenbloom et al., 2011; Tang-Wai et al., 2004; Whitwell et al., 2007). Ahmed et al. (2016) have shown that people with PCA can show impaired memory at initial clinical presentation relative to controls, and Trotta et al. (2019) have shown that people with PCA demonstrate deficits in both verbal and visuospatial working memory beyond that of people with tAD. The common discrepancies across studies may arise from differences in inclusion
criteria, classification and stage of disease as well as the test materials and control groups used, and the interpretation of these findings is further challenged by typically small sample sizes (sometimes single case studies). Further studies like that of Trotta et al. (2019) which break down functions into their visual and other (e.g. verbal) components are needed to further explicate the specific characteristics of the cognitive profile(s) of people affected by PCA.

1.2.2.7 The gaps in the literature

The specific cognitive profile and early age of onset make it seem likely that people with PCA will have unique and specific needs in terms of care and support, and that the particular symptoms will have distinctive impacts on their everyday lives. However, as this review of the literature so far is testament to, there is very little existing research into the day-to-day impacts of a diagnosis of PCA or the subjective experience of people affected. This is perhaps owing to a combination of its relatively recent discovery and its rarity, with much current literature aiming to better characterise the condition with the long term aims of developing therapeutic interventions.

Several recent papers offer some insight into how daily life may be affected, for example Shakespeare et al. (2015) identified the specific ADLs which were severely affected for people with PCA compared to those affected by AD, and these were everyday skills including writing, using the telephone and making a hot drink, and self-care tasks including dressing. The AD group in the study were more impaired on tasks associated with memory and orientation and motivation. Other research which speaks to the subjective experience of people with PCA are studies about the associated neuropsychiatric symptoms. Suarez-Gonzales et al. (2016) reported on a similar neuropsychiatric profile for people with PCA as in tAD, with participants most commonly experiencing depression, anxiety, apathy, and irritability. Isella and colleagues’ (2015) study highlighted the particular significance of anxiety for people with a diagnosis of PCA, finding a significantly higher proportion of people
experiencing anxiety and significantly higher levels of anxiety in their PCA group than the AD group.

Clinical anecdotes and case reports can be helpful for giving a sense of the ways symptoms are experienced and noticed in everyday life but, by definition, are idiosyncratic. Berthier (1991) described a patient becoming unable to read and write and struggling with calculation and the manual handling of objects as well as experiencing what they described as piecemeal perception (i.e. simultagnosia). In their 2012 case report Migliacco et al. described a patient who had had repeated minor car accidents involving vehicles on the left-hand side. Difficulties with reading are frequently described as some of the most disabling and distressing symptoms for people with PCA (Crutch, 2014; Maia da Silva et al., 2017; Yong et al., 2014a, 2014b), and while the nature of these deficits are well-specified in the neuropsychological literature (Yong et al., 2014a, 2014b; Yong et al., 2015), what is known about the impact of difficulty reading and how it manifests for people is largely confined to single case reports or clinical anecdotes. For Ruis and colleagues’ (2012) patient this manifested initially as losing lines when reading, whereas Crutch (2014) describes a person affected by PCA noticing that he could more easily read the headlines on others’ newspapers across a train carriage than his own.

Prior to this PhD project there was no published qualitative research on the subjective experience of living with a diagnosis of PCA. Given the specific and atypical symptom profile and early age of onset, a qualitative approach could be considered to be particularly helpful, as it permits the emergence of unanticipated insights and is particularly suited to exploratory work (e.g. Fine and Deegan, 1996; Gerson and Horowitz, 2011).

The value of a qualitative approach to the study of the subjective experience of dementia has been demonstrated by numerous reviews in relation to typical, memory-led dementia, highlighting important aspects of the illness journey relating to identity and self, continuity, ongoing adaptation to change, renegotiation of roles and the significance of personal and contextual resources such as one’s outlook and
personality characteristics and one’s physical environment and interpersonal relationships (e.g. Caddell and Clare, 2010; Górska, Forsyth, and Maciver, 2018; La Fontaine and Oyebode, 2014), and the relevant areas of that existing literature for this study will be further described in the next section.

There is also an encouraging and growing body of qualitative literature focused on young onset dementia in particular, which explicates some of the particular challenges related to employment issues, family care and financial responsibilities, and sense of independence and changing roles that are particularly pertinent when symptoms start before the age of 65 (e.g. Harris and Keady, 2009; Roach and Drummond, 2014; Svanberg, Spector, and Stott, 2011; Van Vliet et al., 2017). Further still, qualitative research has begun into other rarer forms of dementia and the specific challenges associated with them. Examples in the case of frontotemporal dementia include the particular significance of maintaining dignity and the complexity of understanding the reasons for perceived changes in interpersonal relationships when a lack of insight is one of the defining symptoms of the condition (e.g. Griffin, Oyebode, and Allen, 2016; Sagbakken et al., 2017).

In being one of the first known qualitative studies of the lived experience of PCA (along with a parallel PhD study completed as part of the ‘Seeing What They See’ project – see Woodbridge, 2018), this PhD project hopefully makes a timely contribution to the broader research efforts to better understand and better support all those living with or affected by a form of dementia.

1.2.3 Cortical visual dysfunction in tAD

Knowing more about the visual problems associated with PCA could also provide important insights about how people with tAD may experience the secondary visuospatial and visuoperceptual symptoms they have also been shown to demonstrate, though often later in their disease course (Grady et al., 1988; Almkvist, 1996; Binetti et al., 1998; Caine and Hodges, 2001; Paxton et al., 2007; Quental, Brucki and Bueno, 2013). Because these are secondary in tAD, by the time
they occur people affected will often likely have more significant concurrent memory and language impairments, which may inhibit their abilities to communicate them. However, visuospatial and visuoperceptual functions have been shown to predict instrumental ADL (IADL) performance for people with dementia, highlighting the importance of these cognitive skills for everyday functioning (Hill, Bäckman and Fratiglioni, 1995; Glosser, Gallo, et al., 2002b; Jefferson et al., 2006; Fukui and Lee, 2009). Understanding more about how these sorts of impairments affect everyday activities for people with PCA could therefore potentially inform the development of supportive interventions for people experiencing similar difficulties in the later stages of tAD as well.

1.3 Dementia: the subjective experience

As there is currently no published qualitative work on the subjective experience of PCA, here I will review some of the literature on the lived experiences of people with more typical memory-led forms of dementia in areas relating to the emergent areas of interest of this PhD study, namely: self and identity; couples coping; objects and the environment; temporality; and activities.

1.3.1 Self and identity

There is a broad consensus that dementia can pose a threat to a person’s sense of self (e.g. Clemerson, Walsh, and Isaac, 2014; Sabat, 2001; Tolhurst, Weicht, and Kingston, 2017), though there is a lack of clarity around exactly what definitions of ‘self’ and ‘identity’ encompass (Caddell and Clare, 2010). Components of self and/or identity which are commonly conceptualised in the literature include a person’s preferences, roles, interests, life history, personality, values, sense of self-worth, sense of control and the various environments one constructs or inhabits (e.g. home, workplace) (e.g Askham, Briggs, Norman, and Redfern, 2007; Brittain, Corner, Robinson, and Bond, 2010; Dröes, 2007; Harris and Keady, 2009; Kitwood and Bredin, 1992; Menne, Kinney, and Morhardt, 2002; Moyle et al., 2014; Sabat, 1998; Zgola, 1987). Despite the challenges to a person’s sense of identity a
dementia diagnosis can pose, people remain motivated to preserve their sense of themselves and there is evidence for elements of self and/or identity persisting throughout all stages of dementia (Kontos, 2004; Harris and Keady, 2009; Caddell and Clare, 2010).

Particularly pertinent to this study’s emergent focus on activities, numerous studies have explored how activity engagement relates to sense of self for PLWD. Many researchers acknowledge the activities that someone engages in to be constitutive of their sense of self – there is a sense that we are the things we do – and in engaging in activities as being a central way in which one’s identity is developed, expressed and communicated to others (e.g. Andrew, Phillipson and Sheridan, 2019; Christiansen and Bryan, 1999; Hasselkus, 2002; Menne et al., 2002; Roland and Chappell, 2015; Topo, Kotilainen and Eloniemi-Sulkava, 2012; Zgola, 1987). Activities can be considered meaningful and significant to a person to the extent that they reflect fundamental elements of one’s sense of self such as values, interests, routines, life history and previous roles (e.g. Chung, 2004; Hammell, 2004; Harmer and Orrell, 2008; Kuosa, Elstad, and Normann, 2015; Menne, Johnson, Whitlatch, and Schwartz, 2012; Moyle et al., 2014; Nygård and Borell, 1998; Nyman and Szymczynska, 2016; Öhman and Nygård, 2005; Phinney, Dahlke, and Purves, 2013). In this sense, continued engagement in those sorts of meaningful activities becomes a way for a PLWD’s identity to be preserved and maintained. This sense of continuity is important for one’s sense of autonomy, something which is argued as perhaps especially significant when coping with the challenges and disruptions a diagnosis of dementia can bring (Nygård and Borell, 1998; Öhman and Nygård, 2005; Phinney, 2006; Phinney, Chaudhury and O’Connor, 2007; Han et al., 2016; Kaufmann and Engel, 2016). The inevitable difficulties that PLWD can have in maintaining engagement with such significant and constitutive activities is one of the ways in which the sense of identity or self can be threatened (Travers et al., 2015). Activities may become particularly important as a means of sustaining personhood as dementia progresses and a PLWD necessarily becomes less reliant on their cognitive and rational capacities and more so on pre-reflective ways of
being such as perceiving, doing, moving and feeling, and perhaps particularly those habitual taken-for-granted activities which have been of long-time importance (Kitwood and Bredin, 1992; Davis, 2004; Phinney, Chaudhury and O’Connor, 2007). In her 2004 ethnographic study in a long term care facility, Kontos captured this in describing residents’ ‘being-in-the-world’ as the means by which their selfhood was able to engage meaningfully with the environment around them.

One particular way in which impaired activity completion is reported to challenge one’s sense of self is in terms of feelings of competence, autonomy and mastery (Andrew et al., 2019; Nygård and Borell, 1998; Hammell, 2004; Davies-Quarrell et al., 2010; Kaufmann and Engel, 2016; Øksnebjerg et al., 2018; Harding et al., 2019). The ability to successfully complete an intended and important activity relates closely to a person’s sense of self via a sense of agency and the ability to manipulate or exert some control over one’s everyday environment (Bartlett and O’Connor, 2007; Brittain et al., 2010; Chung, 2004; Chung, Ellis-Hill, and Coleman, 2017; Kitwood and Bredin, 1992; Nygård and Borell, 1998; Zgola, 1987). Feelings of loss of agency and control over one’s environment was reported by Norman et al. (2004) to be one of the most distressing changes for PLWD as they adjusted to their dementia diagnosis. In being focused around the disruptions to identity and activity caused by dominant memory difficulties and other impairments associated with dementia generally, it is unclear how representative of the dominant visual difficulties that people with PCA face these existing findings are. While concepts such as sense of self and identity and defining activities would seem to be of universal importance, it seems likely that the mechanisms by which these are disrupted could be different for people with PCA, making the overall experience of the condition and its impacts worth exploring.

1.3.2 Couples coping

There have been calls for more research which assesses the impact of dementia in a relational context and a steady increase in research which considers the family or couple as a unit when exploring the lived experience and management of a
dementia diagnosis in everyday life (e.g. Davies, 2011; Hellström, Nolan, and Lundh, 2005, 2007; Molyneaux, Butchard, Simpson, and Murray, 2012; Phinney, 2006; Svanberg et al., 2011; Tolhurst et al., 2017).

Notions of a shared ‘us’ identity and of couplehood have gained traction, with researchers explicating how the multiplicities of experiences of a dementia diagnosis and the challenges posed by it are navigated and negotiated by families over time (e.g. Hellström et al., 2007). Studies of couples’ subjective experiences highlight the resilience, resourcefulness and team-based approach that many couples apply to coping with a diagnosis of dementia (Bielsten and Hellström, 2019). Davies (2011) described the collaborative nature of the journey that couples take and the commitments made to maintaining an ‘us’ identity, as well as how a resources-based approach which maximizes on the social capital families have was essential in supporting couples to do this. Molyneaux et al. (2012) similarly described an inherent reciprocity and mutuality in how couples reported on their experiences of the diagnosis and Davies (2011) reports on the enduring companionship and affection that couples were committed to maintaining. However despite this dyadic approach being well documented, many psychosocial interventions – even those developed to be administered to couples – can still take an individualized and symptom-focused approach to outcomes (e.g. aiming to reduce caregiver burden and depression or improving PLWD functional status). Encouraging a dyadic approach to research in this context is not to deny that there are challenges and changes – Davies (2011) and Tolhurst et al. (2017) both acknowledge fluctuations in the balance or levels of reciprocity that are possible as dementia progresses – but there is often a sense of a shared responsibility for dealing with this as Chung et al. (2017) and Phinney et al. (2006) have illustrated, when describing the motivation of family carers to compensate for the losses experienced by working to sustain the personhood of a PLWD.

One way this is achieved is via the essential roles that carers or family members play in supporting PLWD to engage in meaningful activities (e.g. Chung et al., 2017;
Carers provide support in a range of ways including adapting the environment, providing hands on support, selecting or suggesting activities and providing instructions or verbal guidance (e.g. Edvardsson, Petersson, Sjogren, Lindkvist, and Sandman, 2014; Majlesi and Ekström, 2016; Merrick et al., 2016; Phinney, 2006; Vikström et al., 2005). Inherent in this dyadic support is an ongoing negotiation of preferences, motivations, priorities and opinions, and carers and their partners have been shown to differ in the outcomes they prioritise. For example, carers have been shown to prioritise activity for the mental and physical stimulation it can provide (e.g. Edvardsson, Fetherstonhaugh, and Nay, 2010; Harmer and Orrell, 2008; Roland and Chappell, 2017) whereas PLWD may value activity engagement more for the sense of personhood it can foster. For PLWD, it can be a way to relate to past interests and roles, reinforcing a sense of identity, of feeling valued, a sense of belonging, a way of harnessing self-esteem and as providing an opportunity to feel both interested and interesting (e.g. Edvardsson et al., 2010, 2014; Harmer and Orrell, 2008). Another key point of negotiation as far as activity engagement is concerned involves differing perceptions of risk and how it weighs up against the sense of independence a PLWD may gain from completing a given activity (e.g. Brittain et al., 2010; Chung, 2004; Chung et al., 2017; Öhman and Nygård, 2005). Despite the increasingly acknowledgment of the importance of the relational context of the dementia experience, the methods used to investigate this can occasionally still be somewhat unbalanced in their accessibility for or acknowledgement of both members of a dyad, with carers often interviewed individually about the impact of the diagnosis on the relationship. For example, in Holdsworth and McCabe’s (2018) review of 11 studies of the impact of the diagnosis on the relationship, eight were based on data collected from carers only, two from the perspective of the PLWD and one from the perspective of the couple, and this was a single case study (Bakker et al., 2010).
Findings from studies which explore the impact on couple relationships are also mixed. Merrick et al. (2016) reported on the co-construction of the sense-making processes couples were embarking on in order to adapt and adjust over time, from the shared foundations that the couples were starting from to the inherently interactional nature of the flexible scaffolding that was provided to support the PLWD over time. Robinson, Clare and Evans (2005) looked slightly earlier on in the process than I am, to consider how couples co-constructed their experience of receiving and adjusting to the diagnosis. They too found that couples embarked on joint processes – in this case in order to make sense of the diagnosis, to cope with loss and to begin to adapt their lives in the face of the changes to the roles and identity the diagnosis had brought about. Wawrziczny et al. (2016a, 2016b) also conducted dyadic interviews but further along into the disease progression, and through these identified how the continued impact of symptoms eventually led to a deterioration of marital interactions, as behaviours around symptoms moved more from being protective to controlling, and a process of struggling to adapt, eventually leading to feelings of unfamiliarity and separation characterising the dyadic dynamic. These interactional processes involved in the joint adaptation and adjustment to losses and challenges while trying to preserve and protect a sense of ultimate togetherness in the face of fear and uncertainty were supported in Wadham et al.’s (2016) meta-synthesis of qualitative studies looking at couples’ shared experiences of the impact of dementia on their relationship and couplehood. Wadham et al.’s (2016) review explicated the complex and nuanced nature of some of these interactional processes in detailing how changes in the balance of power can have implications for both members of the couples’ shared and individual identities, and how couples work jointly to protect each other’s sense of identity and role, and the empathy and sensitivity required in doing so. These findings perhaps point to complex and sometimes contradictory experiences between dyads and over time, and similarly to the clinical and neuropsychological literature on PCA above, this work is also often limited by its small sample sizes – in the case of qualitative work owing often to the richness, volume and intensity of
data, and the necessarily limited generalisability. This therefore only builds the case, given the complexity, for more research further exploring the nuanced experiences of dyads coping with dementia, using methods which permit the exploration of not just the independently-reported perspectives of each member of the dyad but how those processes are navigated jointly, in real-time, in a naturalistic home setting.

1.3.3 Objects and the environment

Considering the dominant visual and spatial symptom profile in PCA and studies’ reports of the initial clinical presentation, it was anticipated that the physical environment would pose significant challenges for people with PCA, and there is a broad existing literature on the potential impacts of objects and the environment for people with memory-led dementia. The literature on the supportive potential of objects spans assistive technology (e.g. Fleming and Sum, 2014); object-handling as a health-promoting activity (e.g. Camic, Hulbert, and Kimmel, 2019); familiar personal objects as a tool for continuity of personhood as transitional objects or in the context of memory boxes (e.g. Gulwadi, 2013; Stephens, Cheston and Gleeson, 2013); and the role of the spatial organisation of objects in assisting with activity completion for PLWD (Majlesi, Ekström and Hydén, 2019). The importance of the environment in dementia care more broadly is also widely acknowledged, with recent reviews addressing its impact on behavioural and psychological symptoms, physical activity, cognitive function, social engagement, everyday activities and wellbeing (e.g. Anderiesen et al., 2014; Marquardt, Bueter and Motzek, 2014; Soril et al., 2014; Chaudhury et al., 2017; Dröes et al., 2017; Woodbridge et al., 2018). In recognition of this acknowledged importance, in 2013 Keady et al. proposed a new bio-psycho-social-physical model of dementia, building on the biopsychosocial model which had been dominant for many years prior. A large proportion of this work on physical spaces and objects in dementia care is based in communal public settings or in residential care settings, where spaces are often more uniform or consistent. So while objects and spaces are clearly important influencing factors in a multitude of outcomes for PLWD, there has been relatively little empirical work.
exploring the objects and spaces within the home environments of community-dwelling PWD and a particular paucity of this for people with PCA, or other rarer forms of dementia. This seems an especially important area of knowledge to contribute to considering that most PLWD reside in their own homes and that policy prioritises ageing in place for PLWD for as long as possible (e.g. Aminzadeh, Dalzie, Molnar, and Garcia, 2010; Brittain et al., 2010; Chung et al., 2017).

Further stressing the importance of greater understanding of the how the physical home environment is experienced by PLWD is the wide acknowledgement that adaptation of the home environment can become necessary for the continued engagement with activity of PLWD over time, and that families and PLWD have difficulty navigating the tensions between making necessary changes and maintaining the familiarity of the environment, which many consider to be helpful (Allen, Cain, and Meyer, 2019; Andrew et al., 2019; Fæø, Husebo, Bruvik, and Tranvåg, 2019; Førsund et al., 2018; Han et al., 2016; Nygård and Öhman, 2002; Nyman, Innes, and Heward, 2017; Phinney et al., 2007). Objects have been described as able to both help and hinder PLWD’s ongoing engagement in that they can act as prompts for activity engagement and also that specially adapted objects can minimise the demands on the PLWD in using them (e.g. Bartlett and O’Connor, 2007; De la Cuesta and Sandelowski, 2005; Majlesi and Ekström, 2016; Öhman and Nygård, 2005). On the other hand, objects which cannot be used effectively anymore can act as reminders of lost abilities and be detrimental to a PLWD’s sense of competence (e.g. Bartlett and O’Connor, 2007; De la Cuesta and Sandelowski, 2005; Majlesi and Ekström, 2016; Öhman and Nygård, 2005).

The home environment itself is also acknowledged to be important for the construction and representation of identity and constitution of self, something which can be challenged by the onset of a dementia diagnosis. One way this occurs is in the presence of objects which refer to long-held interests or past achievements and experiences (Hocking, 1997; Öhman and Nygård, 2005; Aminzadeh et al., 2010; Brittain et al., 2010; Topo, Kotilainen and Eloniemi-Sulkava, 2012; Edvardsson et al.,
Homes are complex, layered with personal and existential meanings and are considered to play a vital part in the construction of continuity of self which can be disrupted when dementia-related difficulties compromise a person’s ability to engage with it (e.g. Kontos, 1998; Nygård and Borell, 1998; Dyck et al., 2005; Førsund et al., 2018; Fæø et al., 2019). Environments’ qualities of taken-for-grantedness, and their potential for providing opportunities for sense-making can become challenged for PLWD, and the embodied experience of navigating it can then in turn disrupt and challenge the sense of self and identity that it has long constituted (e.g. Nygård and Borell, 1998; Phinney and Chesla, 2003; De la Cuesta and Sandelowski, 2005; Førsund et al., 2018). The role of such constituting objects and one’s pre-reflective bodily way of being in, doing within and moving around the home and other familiar environments are claimed to potentially become more significant as engagement with activities is challenged by the progressive cognitive impairment associated with the diagnosis (Nygård and Borell, 1998; Brittain et al., 2010; Lloyd and Stirling, 2015). Something which is often inherent in studies such as this, which refer to the long-held interests of a PLWD or their life-history and the environment’s potential to endorse those, is an assumption about dominant difficulties with remembering, which the environment can support. A critical contribution of this study will be how such difficulties are experienced by people with a distinctly different profile of dominant impairment, for whom remembering may be a relative strength, and physical engagement with the environment and objects within it a particular and distinct challenge.

1.3.4 Temporality

Another key concept which seems of inevitable significance when studying any neurodegenerative disease is temporality, and the existing literature about the subjective experience of dementia addresses the impact or experience of temporality in multiple ways. The progressive nature of dementia is the unifying factor across all types, and the progressive difficulties people have with engaging with their everyday environments in the ways they are used to are well
documented (e.g. Dröes, 2007; Lloyd and Stirling, 2015; Chung, Ellis-Hill and Coleman, 2017; Fæø et al., 2019). Published studies are almost always sensitive to the stage of the disease, whether in the sense that they stratify their sample accordingly, or more explicitly in that they are concerned with issues which are considered particularly relevant to people in either the early or advanced stages, for example adjustment to diagnosis in the early stages and adjustment to care home admission in the later stages. Another temporal consideration is the age of onset which for people with PCA and other rarer forms of dementia is usually earlier (i.e. before the age of 65). This too is acknowledged within the exiting literature, in terms of the specific challenges it can bring including negotiating financial commitments, existing caring responsibilities for children/parents and disruption to employment status (e.g. Williams, Dearden and Cameron, 2001; Beattie et al., 2002; Harris and Keady, 2009; Davies-Quarrell et al., 2010; Clemerson, Walsh and Isaac, 2014; Roach and Drummond, 2014; Andrew, Phillipson and Sheridan, 2019). The literature also details the temporal-relevance of the sorts of activities PLWD desire to maintain engagement in, something established above which can make an important contribution to one’s sense of self and identity (e.g. Nygård and Borell, 1998; Öhman and Nygård, 2005; Davies-Quarrell et al., 2010; Menne et al., 2012; Kaufmann and Engel, 2016; Tolhurst, Weicht and Kingston, 2017). At the time of life at which early onset dementia begins, these sorts of activities of importance which could be prone to disruption might relate to a person’s career, the leisure activities they are planning to start spending more time on (e.g. in retirement), or the family caregiving or other voluntary work they have planned (e.g. Öhman and Nygård, 2005; Roach and Drummond, 2014; Nyman and Szymczynska, 2016; Andrew, Phillipson and Sheridan, 2019).

Another temporal element captured in the literature on the lived experience of dementia is the motivation to maintain continuity, normality and find an ongoing sense of coherence amid what is a continual process of change (e.g Menne, Kinney and Morhardt, 2002; Nygård and Öhman, 2002; Kuosa, Elstad and Normann, 2015; Kaufmann and Engel, 2016). This relates to a wide range of aspects of everyday life,
including the ordinariness of everyday activities (Nygård and Öhman, 2002), and although it is arguably something which spans the whole of the illness experience, studies focusing on it tend to be concentrated towards the earlier years, perhaps when change seems most drastic. Any experience of dementia is situated within a person’s (and their families’) life history and context, and PLWD and their families have been shown to work to connect the person’s current day-to-day experience to their social biography, whether they are living in the community or in a residential care home setting (e.g. Bury, 1982; Phinney, 2006; Askham et al., 2007; Moyle et al., 2007, 2014; Davies, 2011; Kuosa, Elstad and Normann, 2015). There can be a gradual transition over time from attempts at maintaining a wide range of activities and tasks, to the central task of maintaining one’s sense of personhood and of being in the world as the dominant priority (Nygård and Borell, 1998; Phinney, 2006; Phinney, Chaudhury and O’Connor, 2007). Evardsson, Fetherstonhaugh and Nay (2010) describe a combination of flexibility and sameness that need to be continually renegotiated and recalibrated over time. Owing probably to broader issues such as funding, researcher contracts and research hierarchies, there is very little longitudinal work exploring the subjective experience of a dementia diagnosis over time, which would potentially shed significantly important insights on how these processes are negotiated throughout the disease course.

Though these transitions can often be framed as wholly negative, perhaps understandably given the progressive nature of the condition and in line with the narrative of decline which has dominated the dementia literature landscape, this in the moment drive to maintain normality which has been outlined is said by some to illustrate some sense of hope. The very attitude of ‘getting on with life’ can be considered as a positively oriented, proactive enactment of retained abilities and capacities (e.g. Kitwood and Bredin, 1992; Nygård and Borell, 1998; Davis, 2004; Øksnebjerg et al., 2018). This reflects a broader shift in the literature away from notions of decline and loss and towards recognition of what remains for PLWD. The significance of this acknowledgement of the ability to adapt over time and the wide-reaching implications a conceptual shift such as that can have are captured in the
inclusion of items relating to ‘adaptation’ in QoL measures in recent years (Missotten, Dupuis and Adam, 2016). Considering temporality as something which all dementias have in common, it will be of interest in the current study to see how what is an inevitable progression may vary in the details of its trajectory, for people with a rarer form of dementia and distinctive pattern of symptoms as seen in PCA.

1.3.5 Activities

The existing literature on activities in the dementia research field falls broadly into three areas: research aimed at understanding the functional status of PLWD in terms of their ADL performance; research looking at the efficacy of meaningful activity engagement as a psychosocial intervention for PLWD; and research exploring the subjective meaning of activity engagement for PLWD.

1.3.5.1 Activities of Daily Living (ADLs)

ADL scales are measurement tools widely used in clinical practice and in research to determine the level of functional impairment of a PLWD. They are situated within a biomedical framework of dementia in which functional decline is considered an inevitable feature of any neurodegenerative disease. They are used to screen for the presence of dementia, monitor its progression and assess the impact of therapeutic interventions. Tasks measured by the scales can be divided into ‘basic’ and ‘instrumental’ ADLs. Basic ADLs are those self-care tasks such as toileting and bathing which are most resistant to dementia, and which a person is likely to be able to continue to do for much longer than instrumental tasks which are more complex (e.g. making a phone call, preparing a meal). IADLs are therefore more vulnerable to being affected earlier on in the course of the disease (e.g. Barberger-Gateau et al., 1992, 1999; Andersen et al., 2004; Sikkes et al., 2009; Sikkes and Rotrou, 2014).

People living with more typical dementia have widely documented increasing impairments in the execution of ADLs (e.g Barberger-Gateau et al., 1992; Vernooij-Dassen, 2007; Mokhtari et al., 2012). There is very little research on ADL function
for people living with PCA, but they have been shown to have greater impairments in everyday skills such as writing letters and self-care activities such as dressing, compared to people with AD who show more impairment in tasks requiring memory and motivation for completing tasks (Shakespeare et al., 2015), which begins to set the scene for the sorts of varied experiences people with PCA may have compared to those with tAD, in terms of their everyday interactions within their home environments. Glosser and colleagues (2002b) helped to develop understanding of exactly how the visual perceptual system could contribute to deficits in ADL function (in addition to the memory and executive function deficits which are usually studied) when they showed that impaired function in discriminating object shapes was associated with impaired performance on visually mediated IADLs including driving and recognising familiar faces. These findings suggest that people with PCA can be expected to perform more poorly on ADLs dependent on visually guided actions, and it is difficult to think of many ADLs which do not rely heavily on accurate perception and movement. However, there is no published research to date on how these symptoms and the changes they cause are experienced by people with PCA in their home environments, what they mean for those affected and how any impairments are responded to and negotiated by them and those they live with, a gap this PhD study hopefully contributes some knowledge to.

1.3.5.2 Meaningful activities

While the ADL literature is necessarily concerned with an essential set of tasks that feature in most people’s daily lives, alongside this there has been a growing literature around the concept of meaningful activity for PLWD – both in terms of what constitutes it and what the benefits of it can be. Meaningful activity interventions have been shown to be beneficial for PLWD both in terms of reducing a range of behavioural and psychological symptoms such as anxiety, depression and anxiety but also in terms of increasing positive outcomes such as QoL (e.g. Allan and Killick, 2000; Chung, 2004; Davies-Quarrell et al., 2010; Hewitt et al., 2013; Hydén, Lindemann and Brockmeier, 2014; Travers et al., 2015).
Activity which is individually tailored has been shown to be especially effective, in fact, significantly more so than that which is delivered uniformly across a group. Sauer, Fopma-Loy, Kinney and Lokon, (2016) found that person centred artistic activities which were delivered one-to-one, by facilitators who had been trained to encourage and endorse a person’s sense of autonomy and personhood, resulted in higher engagement and pleasure ratings and lower disengagement ratings, when compared to a traditional visual arts activity. In addition, a systematic review by Travers et al. (2015) highlighted the strongest evidence for individualised activities for a range of behavioural and psychological symptoms of dementia; increasing pleasure and interest as well as music-based activities being helpful for agitation reduction, depression and anxiety; and reminiscence therapy improving mood and cognitive functioning. The added benefits of individually tailoring meaningful activities for people is compatible with Chung, Ellis-Hill and Coleman’s (2017) assertion that meaningful activities are important because of the opportunity they provide for personal meaning making and the expression of personal preference and choice that they provide. Given this emphasis on the importance of activities tailored to individuals, it is perhaps surprising that the vast majority of the research into the benefits of meaningful activities is on those delivered in groups, usually within residential care settings. This perhaps contributes to the widely acknowledged difficulties in defining what constitutes meaningful activity as this is, as suggested, very individually variable (e.g. Marshall and Hutchinson, 2001; Hammell, 2004; Menne et al., 2012). This is supported by the definition used by Travers’ et al. (2015) which was endorsed by PLWD and carers, and states that ‘activities can be meaningful if an activity is somehow significant to, or valued by, the person and provides enjoyment, a sense of purpose, belonging or achievement.’ (p.168).

1.3.5.3 Meaning of activities

The importance of maintained engagement in meaningful everyday activities is widely accepted and that is reflected in policy recommendations and healthcare guidelines for dementia care (e.g. National Institute for Clinical Excellence – NICE,
2019; World Health Organisation – WHO, 2019). It is perhaps this policy level endorsement of activity which drives efforts to offer and develop activity programmes within residential care settings. However, this third approach to studying activities can perhaps help to understand how it is that activities are meaningful, in studying PLWD’s own subjective experiences of their naturally occurring everyday activities and their significance. These are the sorts of activities and day-to-day experiences that this study is interested in exploring for people with PCA, those which people are motivated to engage in and which by that definition are inherently meaningful, within the unique and individual everyday environments in which they are undertaken.

It has been asserted that humans have an innate need for occupation (Zgola, 1987; Wilcock, 1995) and the importance of continued engagement in the idiosyncratic ordinariness of everyday activities when living with a diagnosis of dementia is widely acknowledged (e.g. Nygård and Öhman, 2002; Öhman and Nygård, 2005; Phinney, Chaudhury and O’Connor, 2007; Nyman, Innes and Heward, 2017; Andrew, Phillipson and Sheridan, 2019). Ordinary, familiar activities and practices can act as ‘resting places’ and can provide opportunities for being connected to, collaborative and comfortable with familiar others (Nygård and Borell, 1998), and PLWD mostly remain motivated to continue to do as much as they can for as long as they are able. How this validating familiarity may be experienced by people who have difficulty recognising elements of their physical environments such as those with dominant cortical visual symptoms is as yet unknown, and of key relevance for people with PCA. Activities which were previously taken-for-granted are acknowledged as becoming disrupted for PLWD and can gain new significance - they can be seen as core components of everyday life once people are faced with the associated challenges of their diagnosis (Nygård and Borell, 1998; Menne, Kinney and Morhardt, 2002). The disruption that PLWD can face to their everyday routines and practices (e.g. household chores, family finances) is one of the key changes they and their partners report being aware of and noticing as the symptoms of dementia onset (Norman et al., 2004), and PLWD and their family members are motivated to
begin strategising to support the prolonged engagement of these activities even in the early stages of the disease (Phinney, 2006). Further emphasising the significance of activities for PLWD, engagement in them has been described as an essential component of a ‘good life’ for PLWD (Edvardsson et al., 2014) and was a key concept in Dröes and colleagues (2017) operationalisation of the ‘social health’ domain of the updated WHO definition of health for PWD. Further supporting this, a scoping review of 16 qualitative studies about the activities people with cognitive impairment (dementia-related and other) want to continue to be able to master reported those which upheld participants’ senses of independence and their social values and roles as being most meaningful (Lindqvist et al., 2016). This only strengthens the need for developing understanding of how those familiar activities may be disrupted differently for people with a range of atypical presentations of dementia.

1.4 Summary

Dementia is a major public health concern and carries significant economic and social costs for individuals affected by the condition, health and social care services and society as a whole. AD is the most common cause of dementia, but there is much still to be delineated about the varied manifestations of AD and particularly, how atypical presentations impact those living with the condition now, for whom any successful search for a cure would be too late. PCA is one such atypical variant of AD, mostly affecting people’s ability to process visuoperceptual and visuospatial information. The existing knowledge base about PCA details the neuropsychological, neuropathological and imaging profiles of the disease. While clinical anecdotes and case reports suggest profoundly impactful effects of the diagnosis on the day-to-day lives of people, this has not yet been studied with qualitative methods, which could offer unique insights into participants’ subjective experiences in their own words.
Here I have outlined some of the key empirical literature which emerged to be of relevance for framing and informing both phases of this PhD study and my interpretations of the data, as my research questions were refined from the broad psychosocial impacts of a diagnosis of PCA to the ‘how’s, ‘what’s and ‘why’s of activities for people with PCA and tAD, within their everyday home environments.

1.5 Theoretical underpinnings (phase I) – The Stress Process Model

Here I will introduce one of the key theoretical frameworks which underpinned the dyadic interview phase of the study, before later discussing how this and other theoretical approaches helped me to understand the findings overall, as well as how the findings illuminated some possible limitations in the versions of the model I will describe, or in the parameters of its application.

The Stress Process Model was selected as an initial framework for this PhD work as it is a model which – by definition – considers the stress and coping associated with a dementia diagnosis within a temporal context (i.e. as a process) which seems of fundamental importance in order to acknowledge the inherent degenerative nature of the condition of dementia. More broadly, a stress and coping approach to the study of dementia is a well-established and often-used conceptual framework in the field (e.g Gilhooly et al., 2016; Kramer and Vitaliano, 1995; Norman et al., 2004). There are many varied everyday impacts of a dementia diagnosis acknowledged as stressors which can pose a threat to a person’s quality of life and well-being. Stressors are broadly considered to be demands or pressures on a person – these could be financial, social, emotional or practical – and stress results when these demands are appraised as exceeding a person’s available resources. The various cognitive, emotional and/or behavioural strategies people employ to try to manage these demands are considered coping strategies, and much attention has been given over the past few decades, particularly to understanding what contributes to
caregiver stress and what facilitates carers’ abilities to cope with stress, which is considered so important because of the huge societal contribution informal carers make in caring for their loved ones with dementia at home (Haley et al., 1987; Allen et al., 2017). The dominance of the stress-coping approach is evidenced in the numerous reviews of literature about stress and coping in dementia noted by Gilhooly et al. (2016). There are multitudes of existing studies exploring the chronic and particular psychological, socioemotional and practical stressors and strains faced by carers of people with dementia (Borden, 1991; Kim and Schulz, 2008) and also the nature and efficacy of the many practical, emotional, psychological and social coping strategies which can mediate this (Kneebone and Martin, 2003; Cooper et al., 2012; Li et al., 2012).

This dominance of the stress/coping approach was appealing as a framework for this first phase of this PhD study, given the exploratory nature of this work. It seemed important to be able to situate any findings within a broad empirical literature, specifically as these findings would be a first contribution to the knowledge base about the specific subjective experience of people with this atypical form of dementia with such a distinctive symptom profile. This distinctiveness of the PCA symptom profile also increased the appeal of such a broad conceptual framework as stress and coping – the framework is widely adopted in the wider sphere of research into chronic health conditions and caring (e.g. Ben-Sira, 1984; Cannon and Cavanaugh, 1998; Karademas, Karamvakalis and Zarogiannos, 2009; Sirois, Molnar and Hirsch, 2015), so seemed wide-reaching enough from the outset for these findings to be contextualised within, as opposed to a theoretical framework which had in-built assumptions of more typical presentations of dementia (e.g. older age, dominant memory impairment) underpinning it. Other elements considered important in a theoretical framework for this phase were sensitivity to the temporal context and a multi-faceted recognition of the many different and potentially complex contributing factors for different individuals within the situation (and how those may change over time). The Stress Process Model (Pearlin et al., 1990; Judge, Menne and Whitlatch,
2010) was selected as it takes a global approach to the illness experience – acknowledging the many and varied factors which can both cause or contribute to stress but also those which can mediate it. It takes account of the person living with or caring for someone with dementia in a complex context, which was considered essential here, considering the added complexities of dementia when experienced at an earlier age (e.g. employment factors, family care commitments, financial commitments). It was also hoped that in being a process model, the Stress Process Model would acknowledge the ongoing adaptation and response to changing conditions of the illness as an inherent part of the experience.
Figure 1.1: Stress Process Model for caregivers (Pearlin et al., 1990)
As this phase took a dyadic approach, I drew on two variations of the Stress Process Model – one developed for carers of PLWD (Pearlin et al., 1990 – see Figure 1.1) and a later adaptation concentrated on capturing the stress process of PLWD (Judge, Menne and Whitlatch, 2010 – see Figure 1.2). First I will introduce Pearlin et al.’s (1990) version developed to model the stress process of caring for a family member with dementia. The aim in developing it was that it could help to draw together some of the vast existing literature on stress and coping for dementia caregivers in which reference to any theoretical lens was often vague or lacking. It was also a topic being explored from a range of sometimes disparate methodological approaches. The challenges of such disjointed and disparate work in one field according to Pearlin and colleagues (1990), is that it can lead to such diversity of approach and outlook that findings are not easily integrated or related to each other, which can ultimately inhibit the development of the knowledge base as a whole. The Stress Process Model meets this aim with its broad range of constructs and factors which would span many areas of biopsychosocial inquiry into stress and coping, and its ability to do this is further reflected in its common use within intervention studies (e.g. Menne, Judge and Whitlatch, 2009; Schulz et al., 2002).

The model outlines four conceptual domains of the stress process and Pearlin et al. (1990) emphasise the importance of the model capturing how these components relate to each other – that being another inherent part of acknowledging stress as a process – not just how the stress changes over time but also how different components related to it impact each other and the stress itself throughout that time. The four domains and examples of their multiple sub-components are:

- **The background and context of stress** – Pearlin et al. (1990) outline a range of key characteristics of caregivers which can influence how stress manifests and is shaped throughout the caregiving experience including demographic factors such as socioeconomic status, age, gender and occupational status. Also included are factors about the pre-existing...
relationship between the caregiver and the person they are supporting – the length and quality of that relationship – as well as any comorbid health conditions the person being cared for has. The availability of support programs and networks is also included here, including family networks and community-based support services, in terms of the nature and frequency of contact possible, however the authors make clear the distinction between the size or shape of this network and the actual support which is delivered by or drawn from this network, with the latter being captured as a mediator. Said another way, theoretical access to support is a key contextual and background factor in terms of its potential impact, but the practical engagement with this kind of support is acknowledged to be widely variable for a range of reasons, and it is that which can be more determining in how stress is experienced over time;

- **The stressors** – these are described as the actual elements, conditions, experiences and activities that cause stress for people, whatever form that stress takes, whether financial worries, feelings of depression or experiencing exhaustion. Stressors are split into primary and secondary not to reflect any hierarchy of importance but rather the stage within the process that stressors emerge – again with the aim of better understanding the process of stress, and what contributes to it and when. Primary stressors mostly relate directly to the care needs of the PLWD and include factors such as the level of cognitive impairment of the PLWD, behavioural difficulties, the dependency of the PLWD (and importantly this refers not just to the amount of help needed but also how this is accepted or otherwise received by the PLWD), carer feelings of burnout and also the changes in the relationship resulting directly from the diagnosis. Secondary stressors refer to those which emerge as a result of the continuity and intensity of the primary stressors over
time, and include role strains such as family conflicts, employment and economic disruption, and the impact on a caregiver’s social and recreational life as a result of their caregiving responsibilities. Secondary stressors can also include intrapsychic strains which refer to the caregiver’s self-concept and own psychological state such as changes in sense of mastery, self-esteem and the possibility of feelings of depression;

- **Mediators of stress** – Pearlin and colleagues (1990) outline two categories of mediating factors, coping and social support, and these feature in the model by way of acknowledging that the stress process is not a deterministic unidirectional path from stressors to outcomes, and ultimately that not all of those faced with the same stressors in the same context will experience the same stress-related impact. The coping category refers to the varied ways a caregiver might behave, or practices they might undertake in order to either manage the situation which is causing the stress, to manage the stress symptoms the situation has caused or to manage the meaning of the situation in order that it does not feel so threatening. The second mediating factor is social support, referred to earlier, and this is described as the extent to which people make use of or are offered the support which is available within those family and community networks they have access to. These can have direct impact on primary and secondary stressors but can also influence how these relate to each other and how they eventually contribute to caregiver outcomes overall;

- **Outcomes/manifestations of stress** – the outcomes or effects of the stress process outlined by Pearlin and colleagues (1990) relate to both the physical and mental wellbeing of caregivers and ultimately how able they are to continue with their caregiving activities and to sustain
themselves in their role as caregiver, all of relevance when considering the stress process and its impact on caregivers at both the individual but also societal levels. The authors also acknowledge the interacting processes that can happen even within the outcomes components of the model, in acknowledging that emotional wellbeing can influence how physical health problems are responded to, and the two together can contribute differentially to the sustainability of the caregiving role overall.
Figure 1.2: Stress Process Model for PLWD (Judge, Menne and Whitlatch, 2010)
More recently the Stress Process Model has been adapted in order to acknowledge and attempt to help understand the stress process as experienced by PLWD (Judge, Menne and Whitlatch, 2010). This made a Stress Process Model framework of particular relevance for the dyadic interview study conducted here as inherent in the development of the model was an acknowledgement that a dementia diagnosis is never experienced by one person in isolation. Like Pearlin et al., (1990) Judge, Menne and Whitlatch (2010) sought to create a version of the model that encompassed the complex and global nature of factors which influence an iterative stress and coping process which is experienced over time, from diagnosis to the later stages of cognitive impairment. The adapted model was developed as a response to a growing focus on the personhood of PLWD and increasing acknowledgement of the contribution PLWD can make in communicating their own experiences first hand (rather than via informant proxy ratings). Judge et al. identified an encouraging increase in work of this kind, but that this (like the literature concentrated on caregiving before it) was often lacking a comprehensive theoretical model which would permit systematic and thorough investigation of the varied factors contributing to or otherwise featuring in the stress process of PLWD.

The iteration of the model for PLWD overlaps in many ways with Pearlin et al.’s (1990) version of the Stress Process Model for caregivers, with primary stressors divided into objective and subjective stressors, allowing for the possible lack of insight of PLWD in the more advanced stages of their condition, and those factors which may then be most representatively captured by objective measures (e.g. cognitive status) or informants (e.g. behavioural problems). The subjective stressors are those which are the PLWD’s direct emotional and psychological consequences of their own experience of their symptoms. Judge, Menne and Whitlatch (2010) described an assumption of the ordering of events here, specifically that the objective strains are primary, occurring directly because of the symptoms, and that the subjective strains are secondary, and consequences of the PLWD’s appraisal of
the impact of the symptoms. This is another example of the temporal sensitivity of the model. Other differences include the inclusion of health history in the background and contextual factors in Judge’s model to acknowledge how prior or pre-existing physical and mental health issues can affect the illness experience for PLWD. Like Pearlin et al.’s (1990) iteration of the model (though not captured in the figure) the Stress Process Model for PLWD divides intrapsychic strain into global and situational strains, for example to distinguish between a PLWD feeling a generally low sense of mastery overall, versus a low sense of mastery relating to a specific skill or hobby they were previously very adept at. One difference worth noting is the internal mediator of ‘care values’, which refers to PLWD’s thoughts and feelings about being independent and concerns about being a burden.

Another addition to Judge’s model which seems relevant for the sample here is the possibility for knowledge of the illness to mediate stress for PLWD, something perhaps particularly challenging for those living with a rarer form of dementia about which knowledge may be limited. Also included in Judge and colleagues (2010) iteration of the model and not in Pearlin and colleagues’ (1990) version is ‘living arrangement’ within the background and contextual factors domain. The addition of living arrangement is particularly relevant for this study as – although in the model it is not explicitly stated that this refers to or incorporates the physical environment – a key aim of this study was to explore the potential of the physical environment to contribute to and/or mediate the stress process, because of the prominent visuospatial and visuo perceptual symptoms people with PCA experience. Another part of the rationale for using the model was also to test its compatibility with our findings related to the stress process of dyads, rather than individuals as separate entities involved in the same process.
1.6 Epistemology, ontology, paradigm

Before outlining what I did, it is important to be explicit in establishing the epistemological, ontological and paradigmatic assumptions and positioning of this PhD project and to situate that within the broader research context. Questions such as ‘what is the nature of reality?’ and ‘what is my relationship to what can be known, as a researcher (and person)?’ and ‘how can I find out what there is to be known?’ are essential in informing any methodological decisions made and therefore important to document and justify (e.g. Guba and Lincoln, 1982; Denzin and Lincoln, 2002; Denzin, 2017).

Historically, dementia has been considered first and foremost from a biomedical perspective, as a biological disease which needs to be better understood in order that a cure can be found. This conceptualisation of dementia as a naturally occurring biological phenomenon has lent itself to it being studied predominantly within the positivist paradigm which underpins all natural sciences research. Inherent ontological and epistemological assumptions of this approach being that there is a singular reality and that with the rigorous use of standardised methods of measurement, this truth can be known, understood and the events related to it can be reliably explained and predicted. This assumption that phenomena can be objectively measured is naturally compatible with a quantitative approach methodologically. While it is fitting that any therapeutic intervention to disrupt the biological process of dementia-causing diseases will need to be approached from a positivist angle utilising these dominant methods of the natural sciences, while we are without a cure, there is also a pressing call to social scientists to address the needs of those living with the condition for whom a cure – whenever it comes – would be too late, but for whom the right support, right now, could be life-changing.

Despite the initial dominance of a positivist perspective in general dementia research, there is now an encouragingly increasing body of research exploring the
experiences of people affected by dementia which sits within a constructivist or interpretivist paradigm. A constructivist paradigm is not concerned with finding a singular truth but rather exploring the varied meanings and understandings people hold and construct about their own experiences (Guba and Lincoln, 1982; Denzin and Lincoln, 2002; Nygård, 2006). A constructivist and/or interpretivist positioning is much more compatible with a qualitative methodology, one which is more concerned with the quality of experience than any measurable elements of it, and which is sensitive to context, compatible with my research questions and agenda to better understand people’s lived experiences, within their everyday environments (e.g. Guba and Lincoln, 1982; Denzin and Lincoln, 2002). Over the past two decades there has been a steady but slow increase in interest in the specific experiences of people with younger onset dementia more broadly and in some less common subtypes (e.g. Harris and Keady, 2009; Griffin, Oyebode and Allen, 2016; Sagbakken et al., 2017; Spreadbury and Kipps, 2019), and this is a trend I am excited to be a part of. With this being a first attempt at exploring the experiences of people living with PCA in their own words and in their own everyday environments, it seemed that an approach which inherently acknowledges the subjectivity within individual accounts and a multiplicity of possible interpretations was important (Guba and Lincoln, 1982; Holloway and Todres, 2003). Additionally, a qualitative research approach is considered to be especially helpful when little is known about a phenomenon as is the case here, as it gives the opportunity for unanticipated insights to emerge (e.g. Denzin and Lincoln, 1995; Pope and Mays, 1995; Corbin and Strauss, 2008; Goodson and Vassar, 2011; Slevitch, 2011).

In this study, implicit in the questions I am asking is the acknowledgement that people will have rich, individually varying subjective experiences of their situations about which they are the experts, and within this interpretivist paradigm, if I acknowledge that the participants in my study are constructing their own versions of reality via their own interpretations and meaning-making about their experiences, I must also acknowledge that in any attempts to research those
experiences, as a social scientist, I am also interpreting their realities as part of mine, and it is only through that process of interpretation that I can accumulate or posit any assumed knowledge of the meanings of the experiences of the participants in this study (Hammersley, 2008; Higginbottom, Pillay and Boadu, 2013). This means essentially that my data is therefore my construction of these participants’ constructions, and as such these are necessarily layered interpretations (Geertz, 2008). A major way the constructivist and interpretivist approaches differ from the positivist therefore is in their consideration of what the researcher brings to a study, and this will be carefully considered in the 5.9 Reflexivity section (5.9) of my General Discussion below. This intersubjectivity and layering of interpretations is key beyond just the participant-researcher relationship too, as people are acknowledged to live in social contexts where their perceptions and interpretations of the world have to co-exist alongside and are informed by those of others in their social network. There is also a need therefore to try to take account of these multiple others’ perspectives, and even when those accounts are at odds with one another, it is important to hold in mind that the aim is not to determine which is accurate, rather to see how those valid and varied interpretations co-exist, are negotiated and guide action and behaviour in the real world in this social context, in order to build a more accurate picture of experience as it is lived (Angrosino, 2007; Simonds, Camic and Causey, 2012).

1.6.1 Mixed methods

Although this PhD project was approached predominantly from a qualitative perspective, I also collected a large volume of quantitative data during the home-based observational phase (II) and think it is also important to mention my positioning in relation to that. Parts of these data were used to characterise our sample in terms of their symptom profile, general levels of well-being and functioning, and this was helpful for both comparability with other studies and for data triangulation purposes within this one. But a selection of the quantitative data was also used in exploratory mixed methods data triangulation discussions which
are narratively detailed in Chapter 4. Having such rich contextual data about people’s day-to-day activities and experiences alongside standardised measures of various features of their everyday environments offered a unique opportunity to juxtapose these and to explore any (in)compatibilities or emergent patterns of interest that each data source could illuminate in the other. However, given the inductive nature of this project overall, to prevent the quantitative data from overly steering or otherwise shaping the interpretation of the qualitative data, these reflective discussions happened once I had already coded all of the qualitative data and familiarised myself with it. As the qualitative data was primary and this mixed methods data triangulation secondary and explorative, it is presented towards the end of this thesis (Chapter 4).
Chapter 2: Phase I – Interviews

2.1 Methods

Here I will outline the methodological approach to the first phase of this study including: the research questions, methodological justification, ethical considerations, recruitment and consenting procedures, quality assurance processes, and data collection and analysis procedures.

2.1.1. Research questions

The research questions for the phase I interview study were broad and exploratory as follows:

1. What are the daily stressors that people with PCA/tAD and their carers experience (e.g. activities, areas of the home)?

2. What are the particular daily stressors caused by visual impairments?

3. What immediate, short term and longer term strategies (environmental, psychological, and social) do people with PCA/tAD and their carers use to cope with their symptoms and stresses?

4. How does the person with PCA/tAD and carer dyad continually adjust in the face of decline (e.g. first symptoms noticed, diagnosis, managing day-to-day)?

5. How can person-centred/family-centred interventions be best tailored and implemented (e.g. timing of intervention, length of engagement, accessibility, location, single or multi-component)?

---

This phase of this PhD study has since been written up and published – see Harding et al., 2018, and for the full manuscript see Appendix 14.a
2.1.2 Methodological justification – semi-structured dyadic interviews

There has been a long tradition in dementia research of informant ratings, usually by spousal or professional carers, because of the progressive impairments in language and memory function associated with dementia and assumptions about how that may limit the reliability with which PLWD can report on their experiences (e.g. Hubbard, Downs and Tester, 2003; Moyle et al., 2007). However, this has changed over relatively recent years, with increasing acknowledgement of the contributions PLWD can and should make to research for and about them (e.g. Snow et al., 2005; Carpenter, Kissel and Lee, 2007; Dröes, 2007; Trigg, Jones and Skevington, 2007; Nazarko, 2015). A key priority of this phase of the study was to maximise the relative abilities of those with PCA to reflect on and communicate their experiences, and to contribute to recent efforts to increasingly view the experience of dementia through a relational lens. Semi-structured interviews allow participants some opportunity to determine the scope and breadth of the interview findings, by elaborating and expanding on areas of the interview topic guide which are of particular relevance or significance to them (Corbin and Morse, 2003; Low, 2013; Hofisi, Hofisi and Mago, 2014). Though they can be resource-heavy, and require in-the-moment flexibility and adaptation on the part of the researcher in responding to new avenues opened up by participant responses, semi-structured interviews also offer possibilities to capture wide individual variation in the subjective meanings made of experiences, which can be particularly valuable when a research area is either very complex or when relatively little is already known about it, as was the case here (Corbin and Morse, 2003; Low, 2013; Hofisi, Hofisi and Mago, 2014). This being said, it is important to bear in mind that interviews (when conducted without any concurrent observation) are usually retrospective, in that they are capturing the meanings participants recall having made, or are making on reflection, of their past experiences (Silverman, 1998).

It was partly this reliance on retrospection and recollection, along with a keenness to understand the illness experience within a relational context, which encouraged
the use of dyadic interviews. As well as offering participants support in recalling their experiences, dyadic interviews can offer insights into interactional processes, such as how accounts of experiences are co-constructed, how the presence of a familiar other can foster a sense of ease and confidence, as well as offering increased time for the processing and formulation of responses, and how comments from one participant can prompt reflections from another (Morgan et al., 2013). For example, Molyneaux and colleagues (2012) used a dyadic interview approach to better understand how couples work together to co-construct their experiences of dementia, and in this work identified the shifting couple identity and interactional processes such as normalising and reframing the experience in light of a shared past. Additionally, Hydén and Nilsson (2013) suggested that asking questions jointly to couples offers unique insights in how they position themselves in terms of each other and their relationship, in the ways they formulate their responses to the interviewer but also in how they confer and decide on their positioning together in the moment. In their study this revealed the ways that couples were showing perseverance and determination in trying to continue to be able to talk about their experiences from the position of being a ‘we’. Polak and Green (2016) have suggested that dyadic interviews may be especially helpful when studying complex interactive processes relating to healthcare such a decisions about medication-taking, and I would argue that the ongoing adjustment to a diagnosis of a dementia (perhaps particularly a rarer and atypically-presenting one) could be considered a similar kind of complex interactional process, and so one that may also benefit from a data collection process which capitalises on these kinds of jointly negotiated and co-constructed narratives.

Despite these strengths, there are also acknowledged limitations in dyadic interviewing, such as participants withholding information which they do not wish to reveal to their fellow participant, as well as risks to confidentiality and privacy being breached within the interview, if one participant shares something on behalf of the other which they would wish not to have shared (Allmark et al., 2009;
Morgan et al. 2013). The interactional processes permitted by dyadic interviewing can also pose problems, such as when one partner answers on behalf of the other and when a researcher notices themselves feeling inclined to ‘take sides’ with one participant’s account more than the other (Allmark et al., 2009; Morgan et al. 2013). The identified weaknesses of a dyadic approach suggested that dyadic interviews used in combination with individual interviews would allow for the most thorough accounts possible of the illness experience as it is experienced by individuals within their relational contexts.

2.1.3 Ethical approval, confidentiality, consent

Ethical approval for the study was granted by the London-Queen Square Research Ethics Committee. Participants were given sufficient time to read and consider the Participant Information Sheets and informed consent was obtained (see Appendix 1 for copies of the Participant Information Sheets and Consent Forms). At the end of the interviews and observations, the attending researchers (RW and MPS for 6 sets of 3 interviews; EH and RW for 14 sets of 3 interviews) conducted a short debrief providing further information and contact details in case of any issues or causes for concern related to the study and a follow up call was made one week later in case any concerns had arisen since.

It was explained that confidentiality would only be breached in the event that the researchers had concerns that someone was at risk of harm, but that we would always attempt to discuss this with participants first where possible.

2.1.4 Quality assurance

Ongoing discussions in the literature acknowledge both the complexity and necessity of assuring the quality of qualitative research. Establishing validity in qualitative research is widely acknowledged to be a difficult and challenging endeavour, and emerging consensus asserts the value of concepts such as authenticity, trustworthiness, sensitivity and utility over those more traditionally
associated with validity of research in the natural sciences (e.g. Morse and Field, 1995; Creswell and Miller, 2000; Whittemore, Chase and Mandle, 2001; Morse et al., 2002). It is now widely accepted that traditional quantitative methods for determining reliability and validity in the scientific research tradition do not apply to qualitative, often interpretive research in the social sciences (e.g. Guba and Lincoln, 1982; Hammersley, 2008), with this relying heavily instead on self-conscious reflective practice throughout.

Here I draw on a notion of rigour in qualitative research suggested by Morse et al. (2002). Morse et al. (2002) identified five verification strategies for attaining reliability and validity in qualitative research which require consideration by the researchers throughout all stages the research process, as opposed to the more traditional notions of criteria for reliability and validity that are often determined post hoc by readers of the research only. Table 2.1 outlines these five verification strategies and where or how they are addressed in the design, conductance and write up of this phase of the study.
### 2.1.4.1 Verification strategies

Table 2.1: Five verification strategies for attaining reliability and validity in qualitative research (Morse et al., 2002)

<table>
<thead>
<tr>
<th>Verification strategy</th>
<th>Explanation</th>
<th>How or where demonstrated in the current study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Methodological coherence</td>
<td>Ensuring congruence between research question and methods</td>
<td>Background (Stress Process Model) Methods (design/sampling, i.e., community-based sample; data collection, i.e., individual and dyadic interviews in order to gain both shared and individual perspectives; data analysis, i.e., qualitative approach for study of little known topic)</td>
</tr>
<tr>
<td>Appropriate sampling</td>
<td>Participants who best represent or have knowledge of the research topic</td>
<td>Methods (design/sampling, i.e., community-based sample; data collection, i.e., individual and dyadic interviews in order to gain both shared and individual perspectives; broad range of disease severity)</td>
</tr>
<tr>
<td>Collecting and analysing data concurrently</td>
<td>Establishing an iterative interaction between what is known and what one needs to know</td>
<td>Methods: moving between data collection and data analysis, including: - memo-writing (keeping an ongoing log of analytical thoughts and ideas); - amendments to interview schedule (adding questions/prompts to further explore emerging areas of interest, e.g., role changes); - field notes (written together by the two interviewing authors—MPS and RW or RW and EH—immediately after the interview to document initial responses and reflections on the data collected)</td>
</tr>
<tr>
<td>Thinking theoretically</td>
<td>Constant, cyclical process of checking that emerging ideas are reconfirmed in new data</td>
<td>Methods: moving between data collection and data analysis, including: - memo-writing (keeping an ongoing log of analytical thoughts and ideas); - amendments to interview schedule (adding questions/prompts to further explore emerging areas of interest, e.g., role changes); - field notes (written together by the two interviewing authors—MPS and RW or RW and EH—immediately after the interview to document initial responses and reflections on the data collected)</td>
</tr>
<tr>
<td>Theory development</td>
<td>Moving between micro-perspective to macro-conceptual/theoretical understanding</td>
<td>Results (major and subthemes, supporting quotes and explanatory commentary) Discussion (compatibility with existing literature, e.g., empirical—relationship impact and theoretical—utility of the Stress Process Model; research and clinical practice implications; suggestions for future work, e.g., other rare dementia populations)</td>
</tr>
</tbody>
</table>
2.1.4.2 COREQ

To further establish the quality of this phase of the study, it was conducted in accordance with the COnsolidated criteria for REporting Qualitative research criteria (COREQ – Tong, Sainsbury and Craig, 2007 – see Appendix 16).

2.1.4.3 Member checking

Member checking is the process of presenting findings from qualitative research studies to respondents or participants and inviting their feedback and is a means of checking that the findings resonate with and constitute an accurate representation of their subjective experiences. The advantages and disadvantages of member checking are much contested, (Sandelowski, 1993; Harvey, 2015) and details of the debate are beyond the scope of this chapter, but several issues are particularly relevant here. Firstly, and perhaps of particular significance in the case of any study in which the participants are experiencing progressive cognitive impairment, there is the potential issue that participants may have incomplete or inaccurate recall of their original account(s). Secondly, events which have taken place since the participants provided their original accounts may have altered their perceptions or views in some way and in turn, how they would now choose to respond to the same questions – something which also may be of increased likelihood for people living with a progressive diagnosis for whom things are (by definition) changing all the time. For these potentially confounding reasons, in this study I sought external validation of the main findings from the interviews via two support groups for people with PCA and their carers (i.e. an equivalent population to the study sample), but none of whom had participated in the study. The findings were presented to both groups before their feedback and comments were invited, and there was a general consensus across both groups that the themes outlined were compatible with their own experiences. As a result, many support group
members provided their own examples of experiences which showed overlap and coherence with the study findings and even later into the support group meeting, several referred back to the interview findings by way of endorsing their applicability more broadly.

2.1.5 Sample

Participants were recruited via the Specialist Cognitive Disorders Clinic at the National Hospital for Neurology and Neurosurgery, University College London Hospitals NHS Foundation Trust. Inclusion criteria were for people to have a confirmed diagnosis of PCA and an accompanying family member or familiar other who was willing to participate in the interviews with them.

Twenty individuals with PCA (12 female; 8 male) took part in the interviews, and the mean age was 68 years (7.66 SD). Scores on the Mini Mental State Examination (MMSE – Folstein, Folstein and McHugh, 1975) ranged from 10 to 29 (mean=20.05; SD=6.54), indicating mild to moderate dementia. Twenty family carers took part (10 female; 10 male); in 18 cases, this was a spouse, in one case the dyadic relationship was mother–daughter and in the other case it was aunt–niece. One spouse (female) opted not to take part in an individual interview but did participate in the dyadic one. Only one participant lived alone. The number of years since diagnosis ranged from 0 to 12 (mean=3.31; SD=2.75), and the number of years since subjective onset ranged from 2 to 14 (mean=6.39; SD=3.26).

Summary demographic and disease duration information are displayed in Table 2.2, and individual participant information\(^3\) in Table 2.3.

---

\(^3\) All names have been changed
Table 2.2: Summary demographic and disease duration information - Phase I Interviews

<table>
<thead>
<tr>
<th>Description</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants (PWD/Carers)</td>
<td>20/20</td>
</tr>
<tr>
<td>PLWD age (years – mean ± SD)</td>
<td>68 ± 7.46</td>
</tr>
<tr>
<td>PLWD gender (male/female)</td>
<td>8/12</td>
</tr>
<tr>
<td>Carer age (years – mean ± SD)</td>
<td>63.71 ± 9.21</td>
</tr>
<tr>
<td>Carer gender (male/female)</td>
<td>10/10</td>
</tr>
<tr>
<td>Years since subjective onset (years – mean ± SD)</td>
<td>6.39 ± 3.16</td>
</tr>
<tr>
<td>Years since diagnosis (years – mean ± SD)</td>
<td>3.31 ± 2.66</td>
</tr>
<tr>
<td>Years between subjective onset and diagnosis (years – mean ± SD)</td>
<td>3.38 ± 3.18</td>
</tr>
<tr>
<td>MMSE (mean ± SD)</td>
<td>20.05 ± 6.38</td>
</tr>
</tbody>
</table>
Table 2.3: Individual participant demographics and disease duration information

<table>
<thead>
<tr>
<th>PLWD name (gender)</th>
<th>Carer name (gender)</th>
<th>Age at time of interview</th>
<th>Years since subjective onset</th>
<th>Years since diagnosis</th>
<th>Years between subjective onset and diagnosis</th>
<th>MMSE</th>
<th>Carer age at interview</th>
<th>Relationship w/carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Betty (F)</td>
<td>Elliott (M)</td>
<td>80</td>
<td>4</td>
<td>4</td>
<td>0</td>
<td>10</td>
<td>84</td>
<td>Married</td>
</tr>
<tr>
<td>Sally (F)</td>
<td>Linda (F)</td>
<td>75</td>
<td>6</td>
<td>4</td>
<td>0</td>
<td>15</td>
<td>48</td>
<td>Mother and daughter</td>
</tr>
<tr>
<td>John (M)</td>
<td>Annabelle (F)</td>
<td>58</td>
<td>7</td>
<td>4</td>
<td>3</td>
<td>11</td>
<td>52</td>
<td>Married</td>
</tr>
<tr>
<td>Susan (F)</td>
<td>Terry (M)</td>
<td>70</td>
<td>14</td>
<td>2</td>
<td>12</td>
<td>22</td>
<td>73</td>
<td>Married</td>
</tr>
<tr>
<td>Amanda (F)</td>
<td>Mark (M)</td>
<td>58</td>
<td>5</td>
<td>4</td>
<td>1</td>
<td>22</td>
<td>59</td>
<td>Married</td>
</tr>
<tr>
<td>Bob (M)</td>
<td>Sarah (F)</td>
<td>60</td>
<td>7</td>
<td>4</td>
<td>3</td>
<td>10</td>
<td>57</td>
<td>Married</td>
</tr>
<tr>
<td>Lilian (F)</td>
<td>Robert (M)</td>
<td>67</td>
<td>6</td>
<td>4</td>
<td>2</td>
<td>20</td>
<td>67</td>
<td>Married</td>
</tr>
<tr>
<td>Fearne (F)</td>
<td>Harry (M)</td>
<td>68</td>
<td>7</td>
<td>3</td>
<td>4</td>
<td>23</td>
<td>67</td>
<td>Married</td>
</tr>
<tr>
<td>Camilla (F)</td>
<td>Jack (M)</td>
<td>71</td>
<td>6</td>
<td>3</td>
<td>3</td>
<td>12</td>
<td>73</td>
<td>Married</td>
</tr>
<tr>
<td>Trudy (F)</td>
<td>Edward (M)</td>
<td>59</td>
<td>5</td>
<td>4</td>
<td>1</td>
<td>18</td>
<td>62</td>
<td>Married</td>
</tr>
<tr>
<td>Katrina (F)</td>
<td>Phillip (M)</td>
<td>61</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>28</td>
<td>63</td>
<td>Married</td>
</tr>
<tr>
<td>Molly (F)</td>
<td>Diane (F)</td>
<td>74</td>
<td>14</td>
<td>12</td>
<td>2</td>
<td>22</td>
<td>50</td>
<td>Aunt</td>
</tr>
</tbody>
</table>

* Data not available
<table>
<thead>
<tr>
<th>Name</th>
<th>Relationship</th>
<th>Age</th>
<th>Gender</th>
<th>Age</th>
<th>Gender</th>
<th>Age</th>
<th>Gender</th>
<th>Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maurice</td>
<td>M</td>
<td>77</td>
<td></td>
<td>4</td>
<td></td>
<td>3</td>
<td></td>
<td>Married</td>
</tr>
<tr>
<td>Pam</td>
<td>F</td>
<td>78</td>
<td></td>
<td>-</td>
<td></td>
<td>-</td>
<td></td>
<td>Married</td>
</tr>
<tr>
<td>Alison</td>
<td>F</td>
<td>57</td>
<td></td>
<td>-</td>
<td></td>
<td>-</td>
<td></td>
<td>Married</td>
</tr>
<tr>
<td>Nigel</td>
<td>M</td>
<td>74</td>
<td></td>
<td>2</td>
<td></td>
<td>-</td>
<td></td>
<td>Married</td>
</tr>
<tr>
<td>Stuart</td>
<td>M</td>
<td>68</td>
<td></td>
<td>4</td>
<td></td>
<td>1</td>
<td></td>
<td>Married</td>
</tr>
<tr>
<td>Patrick</td>
<td>M</td>
<td>75</td>
<td></td>
<td>4</td>
<td></td>
<td>4</td>
<td></td>
<td>Married</td>
</tr>
<tr>
<td>Stan</td>
<td>M</td>
<td>71</td>
<td></td>
<td>5</td>
<td></td>
<td>0</td>
<td></td>
<td>Married</td>
</tr>
<tr>
<td>Steven</td>
<td>M</td>
<td>59</td>
<td></td>
<td>10</td>
<td></td>
<td>0</td>
<td></td>
<td>Married</td>
</tr>
</tbody>
</table>

### 2.1.6 Data collection

A comparative sample of people living with tAD (n=17) and their family carers (n=17) were also interviewed for analysis and reporting elsewhere. For the purposes of clarity and transparency, I have tabulated the data collected during phase I below, and summarised if and how it features in this PhD project. Below the table, I have provided more information about the primary data sources in this PhD.
Table 2.4: Phase I data types

<table>
<thead>
<tr>
<th>Data source</th>
<th>Features in this PhD project?</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview data (PCA)</td>
<td>Yes</td>
<td>Findings – Interviews (section 2.2)</td>
</tr>
<tr>
<td>Field notes (PCA)</td>
<td>Yes</td>
<td>Findings – Interviews (section 2.2)</td>
</tr>
<tr>
<td>Demographics (PCA)</td>
<td>Yes</td>
<td>Sample (section 2.1.5)</td>
</tr>
<tr>
<td>Walk-around tour (PCA)</td>
<td>Yes</td>
<td>Findings – Interviews (section 2.2)</td>
</tr>
<tr>
<td>Neuropsychology assessment (PCA)</td>
<td>Yes</td>
<td>Mixed methods data triangulation (section 4.1)</td>
</tr>
<tr>
<td>Self-report measures (PCA)</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Interview data (tAD)</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Field notes (tAD)</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Demographics (tAD)</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Walk-around tour (tAD)</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Self-report measures (tAD)</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Neuropsychology assessment (tAD)</td>
<td>No</td>
<td>N/A</td>
</tr>
</tbody>
</table>

2.1.6.1 Interviews

Individual and dyadic interviews were conducted at participants’ homes (by EH and RW or MPS and RW) and dyads were interviewed together first and then separately. The dyadic interviews allowed for capturing the dyads’ shared experience and their co-constructed narratives, (e.g. Taylor and De Vocht, 2011; Morgan et al., 2013) and also offered some insight into their interactions, including where there were discrepancies or disagreements and how those were negotiated. The dyadic interviews also allowed the family carer to supplement the person with PCA’s account in the case of any additional, secondary memory impairment. The following individual interviews also offered the opportunity for individuals to provide information they might not have felt comfortable to disclose in the presence of
their family member, as discussed above (Morgan et al., 2013). The order of the interviews – the dyadic first followed by the individual – was in part decided on to enable efficient reporting of the couple’s shared history. It seemed important to start with the shared history, to get to know a little about the dyads and their context and background before asking about the diagnosis and its impact, and appropriate and efficient to ask people about this together, to avoid too much duplication and (as above) to allow caregivers to support the PLWD in case of any difficulty in communicating the history because of any additional memory or language impairments. The order also worked well as it meant that any points of disagreement or discrepancies could be followed up individually with each member of the dyad. The interview schedule (see Appendix 2) covered contextual factors (drawing on those outlined in the Stress Process Model) including personal, marital and occupational history as well as the current family and living situation, the diagnostic journey in terms of what had first been noticed and the process of seeking and eventually receiving a diagnosis, and eventually the daily difficulties and coping strategies within the home environment, including any particularly troubling symptoms, any areas of the home that were particular helpful or difficult to navigate and any activities particularly impacted. In total, interviews lasted between 3 and 4 hours per dyad. Audio files of the interviews were transcribed, and a subsample checked for quality. All names and place names were changed.

2.1.6.2 Field notes
Field notes were also made at the end of the interview, about anything not captured in the audio recording – for example anything notable about the physical environment, as well as any initial analytic thoughts (memos).

2.1.6.3 Demographics
Demographic information was collected about PLWD and carers including age, gender, occupational history, living situation and other health conditions (see Appendix 3a and 3b).
2.1.6.4 Walk-around tour

The home visit also involved a walk-around (Emmel and Clark, 2009; Clark and Emmel, 2010) of areas of the home posing particular challenges to participants or where they had implemented assistive strategies. Walk-around tours and interviews can facilitate researcher understanding of how a space is lived in and used by participants, and can offer insights into how everyday life and tasks are embedded within the environment in which they are lived (Emmel and Clark, 2009; Clark and Emmel, 2010). The method can also add to the participant’s ability to shape the interview (and in turn the findings) as they can make choices about where to direct the researcher, and also allows participants to show things rather than to have to solely articulate them (and showing items can facilitate articulation, too) (Emmel and Clark, 2009; Clark and Emmel, 2010). Walking interviews can also prompt the researcher to ask questions they may not have considered in a contained setting, and can provide opportunities for unanticipated insights or contradictions to happen, rather than just be referred to or declared by participants (Emmel and Clark, 2009; Clark and Emmel, 2010).

2.1.6.5 Neuropsychology

All PCA participants had previously (within 6 months) completed a selection of neuropsychological tests of memory, language and visual processing skills (visuoperceptual and visuospatial). The tests and participant scores are described and discussed in Chapter 4.

2.1.6.6 Measures

Participants completed self-report measures of ADL function (Johnson et al., 2004), QoL (QoL-AD, Logsdon et al., 1999), carer burden (Zarit, Reever and Bach-Peterson, 1980) and relationship impact (Dyadic Relationship Scale, (Sebern and Whitlatch, 2007), to be analysed and reported on elsewhere.
2.1.7 Data analysis

Interview transcripts and field notes were uploaded into Atlas.ti qualitative data analysis software (version 7). The data were analysed using thematic analysis (Braun and Clarke, 2006), which was selected owing to its flexibility and accessibility. Thematic analysis is a method for identifying patterns and themes in data sets. Data is organised and analysed before the themes and patterns identified are reported on in a way that describes the data in rich detail, and sometimes offers a level of interpretation too (Braun and Clarke, 2006). In this phase of the study, because of its exploratory nature and the little amount known about the subjective experience of PCA, I primarily concentrated on articulating a broad account of patterns and themes which offered a complete and coherent account of the full data set, with richness coming from this breadth of description, rather than a more interpretive and detailed analysis of a few select themes within the data set.

Although the noticing of apparent patterns and areas of interest began during data collection, the first stage of formal analysis was familiarisation with the data and this was achieved with multiple read-throughs of the transcripts and field notes. This familiarisation, along with the research questions and the existing literature on stress and coping in dementia, informed the development of an initial coding framework. Codes are meaningful labels which can be assigned to data segments which capture something which is of relevance or interest in the data. This coding framework was flexible, and new codes were added as required, following discussion and agreement among the research team. Each dyads’ set of three interviews (person with PCA, family carer and joint) constituted one case for analysis, and the cases were divided among the two authors EH and MPS. Coding is the initial fine-grained organisation of data which later allows broader-level themes and patterns to be identified. Once all 60 transcripts had been assigned initial codes, the codes were sorted into broader themes. The search for themes spanned the coded segments of the whole data set and was hierarchical – there were some broad themes identified and sub-themes within them were created where
applicable. Once candidate themes were identified they needed to be reviewed and refined – some were merged, some discarded, some became major instead of sub themes and vice versa, and groups of themes were reorganised too. There were two steps to this process of refinement – the coded data segments within themes had to be compared to one another to ensure the themes themselves were coherent, and then themes needed to be considered in terms of the whole data set, to assess whether they were individually representative across the whole data set and if the combination of all the themes together offered a coherent picture of the full data set. Analysis was an iterative process of moving between the data set, the coded segments, the thematic maps and analytic memos.

2.2 Findings

Participants described a wide range of ways in which having a diagnosis of PCA and the atypical symptoms associated with it contributed to their experience of stress over time. They also outlined and demonstrated various strategies that they and close others had developed and employed in response to these varied challenges. Overall the findings comprise three central themes which relate to and capture some of the condition-specific characteristics of living with PCA, and these were: (1) a difficult journey to diagnosis; (2) managing interactions with the physical environment – this included affected ADLs, navigating the outside world and use of aids and adaptations; and (3) implications for the psychosocial environment – such as maintaining independence and adopting a ‘one day at a time’ approach to coping with the ongoing challenges. Within and across these key themes, there were key temporal considerations – these were due in part to the transitions associated with the time/stage of life that most participants were affected at, but also more broadly due to the inherent change over time associated with any neurodegenerative condition. The illness experience was framed throughout by numerous contextual and background factors such as previous or existing relationship quality, personality
factors and participants’ living situations (e.g. intergenerational households, rurality).

2.2.1 Theme 1: The journey to diagnosis

The first theme relates to the complexities involved in getting an accurate diagnosis of PCA – something which all participants referred to, illustrating that the stress process actually begins before people may consider themselves as a PLWD or a caregiver, and perhaps especially so in the case of rarer dementias such as PCA which are harder to recognise and diagnose. Early symptoms were often described as unusual, incongruous or hard to pinpoint, and often people wondered with hindsight whether odd happenings some years previously had in fact been an indication of symptoms starting. Even though initial signs were confusing and did not point to a clear cause, they were nevertheless taken as an indication that something was clearly wrong. Often, struggles with very familiar activities were first noticed:

> Everything was hard for about a year, and [I was] beginning to feel there’s something not right here, because I couldn’t work out sort of basic things.

(Fearne, 68, female, PCA, MMSE: 23)

For this participant it appears that the stress was two-fold, there was the stress of not being able to do things, but another layer to this was realising that this meant something was wrong but with no clear idea about what that might be. In describing ‘everything’ being hard, and even ‘basic’ things, this participant seemed to be talking about what could be considered a global sense of functional impairment, and this pervasiveness of even early difficulties was a commonly reported experience.

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5 As in this case, all names have been changed, and all direct quotations will be followed by the following information in brackets: (Participant name, age at time of interview, gender, dementia diagnosis, MMSE score /30 at time of interview)
Other common signs and symptoms to be first noticed were in relation to workplace activities, for example difficulties reading financial accounts or using a computer, difficulties with driving (e.g. with the glare of headlights, or judging distances) and problems with reading or changes in handwriting. This provides an example of how contextual factors such as age and employment status could shape the stress process, and participants would often describe the broader implications of having difficulties at work, where there was often an extra level of responsibility and risk if mistakes were made. Many participants were in fairly senior roles at the time their symptoms began, and difficulties at work seemed to also cause stress in terms of their perceptions of others’ judgements of their capabilities, which added an additional layer of stress to the intrapsychic role strains they were also often feeling about personal hobbies and other activities being affected. The emerging difficulties with such everyday and taken-for-granted tasks was very unsettling for participants and a primary source of stress in and of itself. Participants and their families often attributed these challenges to eye-health issues in the first instance and the difficulties presented in stark contrast to the short-term memory problems usually first noticed in people with tAD (Barnes et al., 2015). The majority (n=19) of individuals initially consulted eye-health professionals such as their high street opticians, and this often led to various inconclusive tests and onwards referrals (e.g. to optometry or ophthalmology). This highlighted the complexity of the supportive context people had access to, and how its varying suitability could mediate the stress process – accessing support of what turned out to be the wrong kind was often reported as contributing an extra layer of stress and frustration because of the disappointment of having thought that much needed answers were getting closer.

Most dyads described the lack of knowledge of the condition among the varied health professionals they had contacted as a major contributor to the stress they experienced over the months and often years it took before an accurate diagnosis was given. This is compatible with the findings of McIntyre et al. (2018) following
their interviews and focus groups with a range of health and social care professionals, who expressed a need for more training and education about the lesser known symptoms of dementia such as dementia-related visual impairment. The participants’ experiences with health professionals is a good example of the individuals other than the PLWD and caregivers themselves, who may play a role in the stress process and broader illness experience of those affected by dementias. For some participants (n=10), the whole diagnostic process was complicated by concurrent eye-health issues, which only served to further delay diagnosis and appropriate referrals (e.g. to neurology). The majority of the group (n=17) also reported frustration and further stress arising from their contact with their general practitioner (GP) because of a lack of answers or appropriate and timely onward referrals. Because of the rarity of the condition, even once a referral had been made to a neurologist, an accurate diagnosis of PCA was still not guaranteed:

> That would have saved me a lot of trouble if I had believed myself. And it took ages, we went through about five or six neurologists... Nothing. It was just dreadful because I kept thinking if I tell them what’s wrong, what’s happening and the symptoms, they’re bound to know... And nobody knew.  
>  
> (Katrina, 61, female, PCA, MMSE: 28)

It was a striking minority of participants (n=3) who reported a diagnostic journey that was timely and efficient, and when this had been the case, this was mostly attributed by participants to either their own thorough and careful information seeking (mostly online) or to the ‘pot-luck’ of their GP’s professional or personal connections. The remaining majority of dyads (n=17) all felt that they had had to persist in the search for a diagnosis for an unacceptably long time – at a time which was already stressful, and that this had only exacerbated the stress they were already experiencing.

These findings across this group of PCA participants build on Ruis et al. (2012) reporting of the delay to diagnosis experienced by the participant in their case report, and adds to Borruat’s (2013) reporting of the often delayed diagnosis for
people with PCA, by describing how such a delay is subjectively experienced by the families involved. This fits with broader empirical literature which reports on the difficulties of, but also the benefits and necessity of, prioritising the early and accurate diagnosis of dementia for individuals, families and society as a whole (Leifer, 2003; Robinson, Canavan and O’Keeffe, 2014; Spreadbury and Kipps, 2019). Samsi et al. (2014) have reported on the anxiety and uncertainty that PLWD and their families can experience when waiting for assessment and diagnosis even when in the appropriate referral channels, and these findings highlight the particular added stresses people with PCA can face in terms of getting an accurate diagnosis. This is owing largely it seems to the rarity of the condition and its atypical symptom profile which can contribute to a lack of professional (and public) awareness. This highlights how important having knowledge of a health condition is and in line with this, many participants explicitly described the sense of relief they experienced when they eventually did receive their diagnosis (n=11).

Building on from this, many participants reported a lack of accessible information about what the diagnosis would mean, and what to expect after the diagnosis had been given, highlighting that stress could be layered and relate to numerous factors simultaneously, which is a particular compatibility and strength of the Stress Process Model. This dearth of information provision following a dementia diagnosis has also been reported in the literature, both in relation to those adjusting to a diagnosis of tAD (Bunn et al., 2012; Clemerson, Walsh and Isaac, 2014) but also young-onset dementia specifically (Wawrziczny, Pasquier, et al., 2016b). This phase of the study therefore adds to the knowledge base in outlining a particular type of rare dementia for which post-diagnostic support and information needs development. The rarity of PCA and the resulting lack of knowledge among healthcare professionals could also be an ongoing source of stress over time in that those living with the diagnosis regularly found themselves to be the experts on their condition. They were often better informed about PCA than many of the health and social care professionals they came into contact with, and as a result of this they
spent time educating others and repeatedly explaining the syndrome and its symptoms. This was another potential source of stress as participants described this impacting the sense of trust and confidence they had in their interactions about ongoing care. This is an example of the important distinction in Pearlin et al.’s (1990) Stress Process Model between available support as a contextual factor, which is acknowledged even earlier on in the process than when support is accessed, and the potential for any available to support to actively mediate the stress process, which is contingent on how tailored and applicable the available support is.

2.2.2 Theme 2: Interactions with the physical environment

In being predominantly visual, the nature of the symptoms meant that difficulties in effectively interacting with the physical environment was the primary issue for most participants day-to-day. This included interactions both within and outside the home environment, with activities requiring macro and micro actions (e.g. navigating between rooms through to signing a form), and those completed independently and with others.

Every participant mentioned the multiple challenges they faced in completing self-care tasks, most prominently dressing and cooking. Specific difficulties with dressing included finding or selecting clothes or shoes, orienting them and using fastenings:

\[I\text{ do struggle a bit sometimes in working out which way round shirts go... If it’s all in a big heap, which it generally is, it’s just a question of I will perhaps turn it round, sort of, two or three times before I work out where the collar is.}\]

\[(Nigel, 74, male, PCA, MMSE: 29)\]

This participant captured the primary strain caused directly by their symptoms and the resulting functional impairment, despite his normal levels of cognitive functioning according to his MMSE score. The persistence this participant described in keeping trying was also representative of the majority of the group, and it
seemed as though this approach to managing the difficulties could arise as a result of a number of different factors. These included personality type, but also the extent to which people prioritised their independence to mediate the stress of any emerging perceived dependence, as well as their existing relationship dynamic.

These problems with dressing were exacerbated by difficulties with locating the wardrobe and folding or replacing items accurately. Common strategies for dealing with dressing difficulties included family members providing hands on or verbal assistance and by decluttering, reorganising or otherwise simplifying the bedroom environment or dressing area. Most of the PCA group offered articulate and insightful accounts of the specific visuoperceptual and visuospatial processing problems that were underpinning their difficulties, and these were in contrast to that which is reported in the empirical literature about people with tAD, for whom problems with dressing may be more attributable to difficulties with sequential task performance and attention (Namazi and Johnson, 1992). The people with PCA interviewed for this study were similarly articulate about their choices and preferences around dressing activities and clothing, and remained interested in and motivated to initiate dressing activities, which may be in contrast to those with tAD whose dressing behaviour is more commonly thought to be disrupted by temporal disorientation and a lack of motivation (Teri et al., 1989). It is interesting to consider how the Stress Process Model accounts for retained skills, and whether cognitive status can also mediate as well as directly cause stress, as seen in many examples in this study. With cooking and food or drink preparation activities, the typical problems that were reported were with locating ingredients or equipment in the kitchen, reading labels or recipes, using appliances, and confidently and safely handling hot materials. As with other household tasks, some participants attempted to use strategies which increased the visual saliency of aspects of the environment or objects within it, such as labelling cupboards or putting a raised brightly coloured sticker on the start button of an appliance. The effectiveness of these strategies varied significantly person to person and over time, and there was an increasing
tendency for those with PCA to retreat from those household activities such as cooking or cleaning which could no longer be completed or facilitated safely. As with dressing activities, when these sorts of problems are reported in the literature for people with tAD, they are more often attributed to impairments in other cognitive domains including declining executive function skills (Perry and Hodges, 1999).

Something which seemed to be of particular significance to the participants were the difficulties they were having with a wide range of activities relating to their hobbies and interests, including reading, do-it-yourself (DIY), sports and arts activities. The particular impact of difficulties with leisure activities seemed heightened by the typically young age of onset, as participants were either approaching retirement age, had recently retired or were in the process of reducing their working hours, and as a result were allocating increasing time to leisure activities:

"I think we thought we’d be going out to theatre and travelling, and things more, whereas I’m planning in 2015 to make it the year I’m going to go to the matinees, try that. But, travelling has virtually stopped. We were going to take John’s mother to the Christmas markets, thinking, well, with her help, I can probably get John on and off the train, but it... with her breaking her hip, that’s another thing, another holiday went because of that, and so we thought, this is the time, this will be the time in our life that we need to travel, and this is the time in life, for one reason or another, we can’t... Yes, I think we thought this would be the golden years."

(Carer of John, 58, male, PCA, MMSE: 11)

This quote provides an example of the commonly reported shared, dyadic secondary strains experienced in terms of changed plans and lost opportunities for recreational activities, something which seemed in this sample to be exacerbated by the relatively early age of onset. This is also perhaps an example of how important it may be to consider the subjective weighting of situational strains – it is perhaps intuitive to consider global strains as the sum of many smaller and specific
situational strains, but as demonstrated here, situational strains can be of relatively different levels of importance (i.e. here, reduced recreational activities outside of the home are particularly significant) and it would seem the extent of this would be key in determining their impact on any stress process. The shared nature of the strain here – the way it is referred to as the couple’s appraisal of the situation is also fitting with much of the literature which explores couplehood and shared dyadic processes in coping (e.g. Robinson, Clare and Evans, 2005; Merrick, Camic and O’Shaughnessy, 2016), and this perhaps raises questions about the distinctness of stress processes between carers and PLWD at least for some couples, such as some of those interviewed in this study.

The negative impact of having to retreat from or renegotiate hobbies and leisure activities is consistent with other empirical work, which highlights some of the areas of people’s lives which are significant contributors to their quality of life, which can be challenged by a diagnosis of a dementia (Thorgrimsen et al., 2003). However, the barriers participants faced to the ongoing engagement with hobbies in the current sample were largely due to the specific visuospatial and visuoperceptual deficits, which is in contrast to much of the empirical work on the pursuit of meaningful activities for people with tAD. For example, in work by Giebel, Challis and Montaldi (2017) carers described those with tAD as having difficulties predominantly with the initiation of activities rather than the actual performance of them. Differences in the specific nature of any ADL-related dependencies (e.g. initiation, performance) could arguably contribute differentially to the overall stress process, strengthening the case for theory and empirical work which incorporates a thorough breakdown of the components of a given concept of interest, whether that be ADL function, or stress, and so on.

Outside of the home environment, all participants had difficulties with navigating the external environment either on foot, by car or on public transport. Particular challenges were with navigating uneven surfaces and kerbs, judging the distance of
approaching cars, wayfinding through crowds, reading signs, maps or digitally displayed travel information boards, general orientation and using stairs or escalators:

*I’m usually quite okay here but the minute I step outside the door it all goes mad... Life goes a bit strange, yes... even inside the village can be a bit strange but definitely when I go catching buses and dealing with... interacting with people, in general, no, it’s not great, not great... I don’t know what happens but it goes mad, yes. Not all the time and not every time but I’m much less comfortable and avoid, now, going unless I really need to go into town.*

(Katrina, 61, female, PCA, MMSE: 28)

This quote provides an example of coping strategies firmly rooted in the physical environment, in this case in avoidance of certain spaces, and many of the coping strategies reported were centred around adjusting the physical environment, given the dominant difficulties participants had in engaging with it. The extent of Katrina’s difficulties appear even more striking considering that her cognitive function is in the normal range according to her MMSE score, and this was characteristic of the very early debilitating impact of the visual symptoms associated with PCA. As coping is relatively under-specified in the Stress Process Model, compared to the factors contributing to stress, further development of the model which expands upon the varied social and emotional but also particularly the practical, physical coping strategies could be a helpful future direction, not only for those with PCA but also for PLWD more broadly, given the widely acknowledged potential for the physical environment to improve functional capacity (e.g. Marquardt, Bueter and Motzek, 2014; Woodbridge et al., 2018). This example also illustrates the great insight which was characteristic of the sample in this study, particularly striking given the profound impairment in day-to-day functioning which was being described. This is one example of how encouraging it is that the version of the Stress Process Model for PLWD recognises and values PLWD’s subjective experience of their objective functional impairments as in doing so, implicitly acknowledges that the two can be disparate, as shown here.
Participants often described trying to rely on accompaniment and familiar routines to support their navigation of the external environment, for example using a preferred route (even if it took longer) and also environmental cues which could be helpful, such as using a particular shop or lamppost as a landmark when navigating. However, there were significant challenges posed to any strategies for navigating the external environment because of its changeability – a disruption in public transportation or a lorry blocking the view of an environmental cue could cause the person with PCA to easily become disoriented or lost. It is important to note however that, for most, this was usually not due to forgetfulness, distractibility or another issue relating to executive function deficits as might be expected in cases of tAD (Chiu et al., 2004; Pai and Jacobs, 2004), but because of problems with accurately perceiving the visual information about the environment, which would in turn help the individual to work out where they were in relation to their target destination.

The difficulties that participants described having with interactions within their physical environments are fitting with the range of neuropsychological deficits documented in people with PCA in the empirical literature. Deficits such as visual crowding, simultagnosia, spatial navigational problems and apraxia (Mendez, Ghajariania and Perryman, 2002b; Tang-Wai et al., 2004a; Yong, Shakespeare, Cash, Henley, Nicholas, et al., 2014b) are all compatible with the issues people in this phase of the current study described with locating and manipulating objects, reading and dressing activities.

As outlined throughout, participants were responsive and adaptive in finding ways to simplify and familiarise the physical environment in order to ameliorate some of the stress they were experiencing, but an inevitable part of this adjustment process involved withdrawing from certain activities at some point. An additional challenge for participants to navigate was the continuing, ongoing uncertainty and unpredictability associated with the disease symptom profile. This meant that any
difficulties were rarely reliably ever-present (n=16). This uncertainty was further exacerbated by the reported lack of disease-specific information provision and guidance that was mentioned earlier in relation to the diagnostic journey. A sub-section of the sample had tried out or were using off-the-shelf aids and adaptations developed for people with eye-health related visual impairment, for example a symbol cane (n=3), and some had been in touch with the Royal National Institute for the Blind regarding visual aids (n=5). However, most participants were taking a self-initiated, largely trial-and-error approach to the development and implementation of homemade strategies owing to the atypical, unpredictable and continually changing nature of the symptoms, demonstrating their creativity and resilience in the face of often confusing and unpredictable progressive symptoms. This process of trialling and developing their own strategies was rife with uncertainty, and carers described their worries about not knowing if things would work, why they might not and for how long they might continue to work:

Camilla can still read, so if it’s just one word it’s okay... but we’ve done different colour coding [on shampoo/conditioner bottles] and this sort of stuff but then she forgets which colour’s which. So it’s not, you know, it seems to be simple... but then there’ll be some other obstacle along the way.

(Carer of Camilla, 71, female, PCA, MMSE: 12)

This quote from a family carer provides a good example of the inherent complexity of the progressive cognitive decline that PCA involves, whereby strategies implemented to compensate for the dominant visual symptoms may rely on other cognitive functions (e.g., memory) which may also be impacted, even if to a lesser extent, but also increasingly over time. There was also a sense of relentlessness captured in many caregivers’ accounts of their continual adaptation, and the importance of the temporal context of the stress process will be addressed more fully below, in terms of how comprehensively temporal factors are accounted for within the model itself. This serves as a good example of the ongoing changes that were experienced even at the within-domain-level (i.e. with cognitive
status/functional impairment in this case) and the associated implications those changes had for coping strategies which would hopefully, eventually mediate stress. This quote was also characteristic of many participant’s accounts in which there was an inherent ‘we-ness’ in the way they described the illness experience – this participant describes the strategies ‘we’ have tried, even though it was he who developed and implemented that particular strategy. This perhaps is another example which raises questions about the distinctiveness of the stress process for individuals within the dyad, and the importance of considering areas of overlap in the illness experience, or how the two stress experiences of the members of the dyad may or may not at times overlap and interrelate. The example just given was in contrast to those whose memory performance was still within the normal range at the time of the interviews (n=9) – these participants were able to and so frequently did rely on their recollections and the familiarity of their environment to help them navigate their way or to find something they needed. These participants would often close their eyes and/or feel their way in order to minimise any potentially confusing visual information, another example of cognitive and functional capacities being able to mediate (as well as contribute to) stress.

In their recent work, Allen, Cain and Meyer (2017) described a similar trial-and-error approach that community-dwelling carers and PLWD were taking to adapting their home environments, as required by the progressive nature of the disease, however these were usually triggered by – and designed to ameliorate – the difficulties associated with the dominant memory problems associated with tAD (e.g., using labels as reminders).

The participant above, like many others in their statements, made implicit reference to the temporal context this was all happening within, which in itself was another stressor. In referring to what his wife could ‘still’ do, this family carer appeared to demonstrate an anticipation and acknowledgement of the decline that would continue over time. This awareness of the progression of the disease is something
commonly reported throughout the dementia literature in general (Roach et al., 2008; Harris and Keady, 2009). In the case of PCA though, this concern about inevitable progression was coupled with a relative paucity of accessible knowledge or professional guidance as to exactly how the disease would progress, which appeared to add another layer in exacerbating the stress. This highlighted nuances in the mediating factor of knowledge about the illness, by distinguishing knowing the diagnosis from knowing the prognosis, and this layering of stress regarding what was being experienced in the moment and the role of anticipatory stress will be further explicated in the ‘One day at a time’ subsection (2.2.3.1) below.

2.2.3 Theme 3: Psychosocial implications

All participants described broader psychosocial ramifications arising from these day-to-day difficulties with interacting with the physical environment, and these included reconciling threats to one’s sense of independence and the stress that came with the necessary contemplation of an uncertain short-term and long-term future.

A key psychosocial implication of the profound difficulties people were having with within the physical environment was the impact on their sense of independence:

_I think that is the worst thing I can do nothing for myself so all the time you’ve got to ask somebody._

(\textit{Susan, 70, female, PCA, MMSE: 22})

This quote provides an example of how an objective primary stressor such as reduced functional status manifested as a subjective stressor too for this participant, in terms of their perceived dependency.

For almost all participants, the go-to strategies used to facilitate the completion of daily activities (and mediate the stress associated with them) involved the provision of physical assistance from family members, friends or carers and/or reallocation of some responsibilities or renegotiation of tasks within the dyad or family. Over time,
this facilitation by others and the profound impairment people with PCA showed in initiating or completing tasks alone, often resulted in increasing feelings of dependence on others:

One of my big problems is frustration that I can’t do things I want to do. I don’t need to do them but because I’ve always been able to do them it really irks me to have to phone my son up and say, come and put this together for me.

(Patrick, 75, male, PCA, MMSE: 29)

This example illustrates a common phenomenon reported across the interviews—the way this perceived dependency lead to changing roles and responsibilities within families. This quote provides a clear example of how the subjective stress of a sense of role captivity, feeling unable to do things, and the feeling of stuck-ness and frustration that can cause, can then lead on to secondary family role strain as this PLWD (like many others) had to ask another member of the family to complete something on his behalf. The quote also captures the intra-psychic strain in terms of the reduced self-efficacy this person felt as this was a task (furniture assembly) they had previously been very accomplished at, and still retained interest in and motivation towards. How much secondary strain this dependency caused for people though was mediated by an interacting range of mediating factors. These were both internal, such as care values and resistance for feelings of dependence in this case, but also social support as this participant (like many others) did have a support network of people who were willing and able to support them in such activities.

The age of onset was one of the contextual factors framing the stress process for many participants, specifically in the sense that younger people with PCA often seemed to find it more difficult to adjust to being dependent on their partner or family members. Personality factors and previous relationship quality were other background and contextual factors which could mediate how readily this primary stress became secondary strain. Some couples appeared to have always had very interdependent relationships and overlapping interests, while other participants
reported how important having their independence was, and often these were members of dyads who had some quite separate interests and largely different social networks to each other, beyond family relationships. All of this came together to impact both how the stress was coped with and the psychosocial repercussions of this. An example of the variation in relationship quality and dynamic and how these could mediate how the stress of the condition was experienced and managed comes from the one couple in the sample who were relatively recently married (<5 years). They described their biggest challenges as being with the organising of the household responsibilities, though they felt able to emotionally support each other well. In the context of the rest of their interview it seemed that this was perhaps owing to the fact that their household roles and routines were less well-established than their emotional closeness, as they had only relatively recently begun to share a home. This type of emotional and social support was often a joint endeavour with each member of the dyad contributing. The complexity of factors influencing dyadic dynamics above and beyond their place in coping with the stress arising from the diagnosis warrants further focused investigation, especially in light of the mixed existing literature about how relationships are affected by a diagnosis of dementia.

The age of onset being earlier in PCA than with tAD contributed to a range of psychosocial implications too. In terms of their employment status, individuals had often been at the peak of their careers, in a position of great responsibility and regarded by themselves and others as someone skilled and knowledgeable at what they did. In addition to or as an alternative to this, many were also in a critical position of responsibility within the family system, perhaps with childcare responsibilities for their grandchildren, financial commitments regarding their adult children’s university fees, and caring responsibilities for their own elderly parents. These sorts of activities and the roles they represented for people were often key in defining individuals’ senses of self and identity:

...he does all the ironing and everything now. And I say, no, that’s my job... I had always done it, you know. [He] was always working and I had
the children and everything, and just did it... And I must admit, I sit here now and I think, I can’t do anything.

(Camilla, 71, female, PCA, MMSE: 12)

This quote provides an example of how contextual factors such as age and occupational role could shape the secondary strain that was experienced, in terms of these family and work-related role strains. The threat that a diagnosis of dementia and the associated decline in functioning can pose for a person’s sense of identity and independence is well documented throughout the extant literature, but this has previously mostly been studied in the context of functional capacity being disrupted by memory problems (Clare et al., 2008; Harris and Keady, 2009) rather than the predominant cortical visual deficits seen here.

Concerns about the person with PCA’s perceived dependency also had implications for carers in terms of how best to provide help and support, and often this manifested as situational secondary intrapsychic strain with carers questioning their competence in supporting the PLWD’s reduced functional status. Many of them (n=13) outlined the concerns they had about their competencies in taking on the new role of caregiver, and reported stress associated with the uncertainty of knowing how and when to best provide help. For many this was reported as trying to strike a balance between getting things done, protecting against their family member’s feelings of frustration, and encouraging or facilitating their ongoing independence, demonstrating how PLWD’s intrapsychic strains could also be experienced by carers on behalf of their loved ones.

The stress and strain that participants with PCA experienced because of the impact the symptoms were having on their identity, role and independence seemed to be exacerbated by their relatively intact long-term memory function, and ability and inclination to reflect on and compare their previous experiences with their current capacity. This perhaps also highlights that the division between objective and subjective stress required for people with tAD is perhaps not so applicable for those
with atypical, non-amnestic presentations of dementia such as PCA, whose subjective appraisal of their abilities was more often aligned with their objective functional status than not. This could be a cause of stress in itself, as when reflecting on themselves, their previous achievements and their declining abilities, they could become concerned about being a burden to their partner or wider family, and most (n=15) participants alluded to this, or stated it explicitly. However, these relatively well-preserved capacities were also able to contribute to relieving some of the stress for couples who took an interdependent or ‘teamwork’ approach to managing the difficulties, via continued collaboration and joint problem solving, and this too was the case for most couples (n=16). This illustrates the nuance of how cognitive status can influence the stress process, and the potential for both cognitive strengths and relative weaknesses to both mediate and exacerbate stress.

In the minority of cases in which not such a team-based approach was adopted (n=4), this seemed to be because of contextual or mediating factors relating to either: previous relationship quality (e.g., living fairly independent lives); personality (e.g., pride and/or stubbornness); or the primary stressor of the cognitive decline of the person with PCA (e.g., poor memory for shared events or impaired ability to express oneself verbally). There were several ways this dominant ‘teamwork’ approach or sense of navigating the illness experience together was made apparent, including in shared story-telling during the dyadic interviews and in the corresponding and complimentary accounts provided in the individual interviews which followed.

However, there were also occasional discrepancies in the accounts of the person with PCA and their family carer. Sometimes these were differing recollections of events (e.g., a family occasion, first symptom onset) and often these would seem to be easily explained by a concurrent memory impairment, but in other cases, the discrepancies were more complicated to tease apart. One example of this was when the individual members of the dyad offered differing accounts of the person with PCA’s functional ability. In one specific case, a daughter assured us that her mother
was purposefully trying to not let us, the researchers, realise the extent of her impairment, by insisting she was still completing a range of household chores, and that this discrepancy could be explained as an exercise in self-presentation. In another case, a man with PCA and his wife disagreed about whether or not he could safely go for a walk unattended—the man’s wife considered his wayfinding abilities to be too compromised, while he considered her to be unnecessarily monitoring him and disproportionately concerned. Another way divergence in accounts occurred was when day-to-day difficulties with tasks and activities were attributed to different underlying symptoms. For example, one man with PCA put his problem with navigating the stairwell at a relative’s house down to the area being ‘dim’ and ‘dark’, whereas his wife put this down to him not correctly remembering where he was:

...you still get lost on that landing...So it’s a square area with four closed doors where does he go? And he never knows...like where is it, where on earth is it? So he can’t retain the information...this is like every single time...he is walking down those steps for the first time.

(Carer of John, 58, male, PCA, MMSE: 11)

Although these discrepancies were not the common pattern in the interviews, they serve to highlight the importance of acknowledging any potential differences in perspectives, and how these could pose challenges for dyads and families in the day-to-day understanding of, and responses to, the symptoms and their impacts.

Again cementing the ‘team-work’ approach as the dominant one, despite these occasional discrepancies, many individuals with PCA (n=11) explicitly expressed the extensive gratitude they felt, or how ‘lucky’ they considered themselves in having their spouse/family carer. There was also a tendency to normalise any symptom-specific dependency as one of many ways in which they and their family member were working together to manage life’s challenges:

If you get married, sickness and in health, you have to keep to these things... I’m old-fashioned enough to think... you know, if it were me, he
would look after me, I have no doubt... So, you know, what I think, and this is what I say to him, we’re married, we’re two parts of a whole, so in many ways it affects me, because then when you are supposed to be as one, as a whole... then you have to look after the other half of you, and, you know, by keeping one half healthy, helps the other half.

(Carer of Stan, 71, male, PCA, MMSE: 27)

This seemed to be a manifestation of one of the three coping strategies that Pearlin et al. (1990) outlined – in reframing the meaning of the caregiving role and activities in order to mediate the stress associated with it.

I suggested above that relatively well preserved insight and memory functions in people with PCA promoted a continuation of closeness and collaboration between dyads, via joint problem solving and a sharing of burden, potentially contrasting with previous studies involving participants with young-onset but memory-led dementias. Baikie (2002) reported a loss of joint decision making in marital relationships where one partner has dementia, while separateness made up part of an overarching theme in a study by O’Shaughnessy, Lee and Lintern (2002) about the impact of dementia on the marital relationship. Similarly, Wright (1991) has described how a lack of awareness or insight can contribute to discrepancies in the accounts of people with dementia and their spouses about their experiences of tension within the relationship, and also how this can feed into an overall reduction in shared meaning-making about the illness experience. An example of this within this phase of the current study was one of the male participants who demonstrated concurrent memory problems along with his dominant visual processing deficits, whose wife commented:

Everything’s more flat, yes. And he’s got no sense of time, so whereas before... he would go... oh yes... this is the year that she said was our silver wedding anniversary... now he’s got to rely on the children to say... we’d better do something about it... I found it painful.

(Carer of John, 58, male, PCA, MMSE: 11)
This carer seems to be describing the kind of relational deprivation that the Stress Process Model proposes as a primary stressor resulting directly from the PLWD’s symptoms and associated behaviours.

However, there are also reports in the literature of couples living with memory-led dementias taking a continued teamwork approach (Bunn et al., 2012) and of a sustained reciprocity in PLWD’s consideration of the others’ needs (Merrick, Camic and O’Shaughnessy, 2016), which aligns more with the findings here. This serves as a useful reminder of the need to avoid making assumptions about how symptoms relate to relationship trajectories and the unidirectional nature of care delivery. The findings of the current study, when situated in the extant literature, make the important points that the dementias progress in different ways for different people (all with their own complex contexts), and that, given this variation, that states of separateness or connectedness, or teamwork versus independence, do not apply discretely and exclusively to a group of people with one diagnosis and not to another. It is probable that the participants with PCA interviewed here will progress to have more memory difficulties over time, which may potentially pose additional challenges to shared meaning-making, and that those in the early stages of more typical dementias are increasingly being shown to be able to reflect reliably and accurately on their own experiences and abilities (Menne, Kinney and Morhardt, 2002; Merrick, Camic and O’Shaughnessy, 2016), something which is an essential component of joint problem solving and shared decision making.

Another important factor to consider is the sociocultural context within which research questions are framed and studies are carried out. As quality of life is increasingly prioritised over life expectancy, and as cures for dementias remain elusive, attention has shifted to notions of supporting people to live well with dementia, with a key component of this being preserving the personhood of PLWD and more recently still, the couplehood of dyads living with a diagnosis. Acknowledging the person or the family and not just the disease has also
encouraged a welcome shift in focus away from the documenting of deficits and losses, towards attempts to capture the whole breadth of lived experience as attempted here: the possible positives, strengths, closeness and resilience too (Hellström, Nolan and Lundh, 2007; Molyneaux et al., 2012). The Stress Process Model approach is compatible with this approach as although it essentially models a stress (i.e. negative) process, it focuses on a wide range of layered contextual and mediating factors, many of which preceded the diagnosis itself, and even with regards to the secondary strains associated with the condition, makes reference to the rich lives PLWD and their families have had by acknowledging the potential impact of a diagnosis of a dementia on one’s work, social and family roles and responsibilities.

2.2.3.1 ‘There isn’t a plan B’ – One day at a time

Looking beyond diagnosis and to the longer term, ongoing coping with the diagnosis, it appeared that uncertainty and a lack of knowledge persisted over time as an almost continual source of stress, particularly with regards to what people should expect and how the symptoms would progress:

*There’s little point in thinking about the future because, in that sense, one would have to have a model of what the future may hold and therein lies part of the difficulty, that I can’t map that future and make any choices.*

*(Steven, 59, male, PCA, MMSE: 27)*

This had a big impact on how equipped many couples felt to effectively plan for the future and as a result, many described taking a conscious decision not to think about it. An essential part of this decision making seemed to be a sense of purposelessness on dwelling on something which was inevitably going to progress and which people were unable to change, which often left participants experiencing a lack of control:

*Every now and again I get down, mainly because if I think too long about what the future holds then... it’s counter-productive...It’s going to*
happen. There’s nothing you can do about it. You know, it’s like one of those things. It’s nothing... it’s all... you can give a problem a lot of thought if there’s an answer; right, do we do this or do we do that? Right, think about it a long time, perhaps worry about it for a couple of days. Right, let’s do that. With this, there isn’t... What’s Plan B? You haven’t got a Plan B. And that’s this situation. There isn’t a Plan B.

(Nigel, 74, male, PCA, MMSE: 29)

This was a fairly commonly reported approach to managing the stress of the lack of control and inevitability of the disease progression, and was adopted by some couples but also by some PLWD and caregivers individually. It seems as a mediator of stress it would be captured within the version of the Stress Process Model for PLWD as life orientation, and within coping in the version of the Stress Process Model for caregivers. Both of these are acknowledged to be mediating factors for the stress caused by the impact of the diagnosis, though the specific future-oriented and anticipatory nature of the stress that they mediated could perhaps be more explicitly outlined in both versions of the model.

In shifting their focus away from what they perceived to be a difficult and uncertain future, many described their approach as one of ‘keeping going’ and ‘getting on with things’, with almost all dyads outlining their efforts to maintain normality as far as possible (n=17):

When she [my wife] got her head around what she had, she said, there’s nothing I can do about it, we’ve just got to get on with it. And we just carried on as normal...When it crops up, I deal with it, but 99% of the time, we just carry on as normal...I mean, obviously you gradually get worse and worse, but, you know.

(Carer of Trudy, 59, female, PCA, MMSE: 18)

This family carer’s comment captures the complexity and significance of the temporal context in describing the simultaneous day-by-day approach that was co-existing alongside the broader acknowledgement and anticipation of ongoing
decline over the long term. There were several reports of this approach of living in the moment being endorsed or encouraged by health professionals too:

*She [doctor] just looked at him and... put her hands on his legs and said, just live your life...just go on and live your life, that’s all you can do.*

*(Carer of Patrick, 75, male, PCA, MMSE: 29)*

This comment also seemed to refer to the inevitability of the progression of the disease and to confirm the absence of a cure, in positing that continuing to ‘go on' and to ‘live your life' are the only options open to patients confronted with the diagnosis. Perhaps this also acts as a reflection of the lack of published guidance and knowledge about the progression of the disease and what to expect, which would enable or assist with longer term care planning and management. This is corroborated by recent papers which report on the challenges families and health and social care practitioners face in finding tailored, evidence-based, disease-specific information and practical advice about PCA (McIntyre et al., 2018; Wilson et al., 2016). The lack of a cure and inevitable progression of the disease can perhaps explain the weighting of both adaptations of the Stress Process Model towards the causes and contributors to stress as opposed to the mediators and coping strategies, which are fewer and less well defined in both versions. Given that this phase of the study has highlighted both how impacting a lack of knowledge about the condition can be at all stages of the disease, but also how resourceful people were in finding ways (practically and emotionally) to carry on anyway, suggests that coping and mediating factors are potentially really promising and worthwhile areas of both versions of the Stress Process Model for future development.

Opting to take a day-by-day approach to coping seemed to be both preferred and required due to the ever-changing nature of the symptom profile as the disease progressed. Individuals and families were continually responsive, and most described the need to be attuned to the necessary ongoing adjustments and adaptations required by the continual change characteristic of the condition (n=16):
Yes, as I say, if I let my mind go there [the future], I will probably collapse in a heap, so I find it’s best just to deal with things as they present, and just try and think one step ahead, and not too far, because, as I keep being told, every individual with the disease is different, and they can make no... they’ve got no crystal balls to see into the future, about exactly how it’s going to pan [out] for any... one person.

(Carer of Stuart, 68, male, PCA, MMSE: 23)

The overarching sense of needing to balance the maintenance of normality in the face of diagnosis-related changes that require ongoing adjustment is also commonly reported throughout the qualitative literature on dementia (Menne, Kinney and Morhardt, 2002; O’Shaughnessy, Lee and Lintern, 2010; Bunn et al., 2012; Molyneaux et al., 2012). A decision to focus on the ‘here and now’ is also widely reported, and often attributed to the uncertainty or discomfort associated with thoughts about the future, in line with what has been reported here (O’Shaughnessy, Lee and Lintern, 2010; Bunn et al., 2012). These similarities with existing literature perhaps highlight the ultimate temporal element – the progressive nature that is common to all variations of AD and the dementias more broadly. Theoretically, in being a process model, the Stress Process Model has an inherent sensitivity to temporality, in acknowledging that various factors interact over time and in particular orders to shape the stress experience for those affected, but taking the current findings into account seems to suggest that incorporating PLWD and caregiver’s individual temporal orientations into the model could be a useful development in further understanding how these varied factors are experienced and responded to in a relational context over time.

2.2.4 Summary

Here I have outlined the temporally-bound impacts of the day-to-day subjective experience of PCA, from the first noticed symptoms, throughout the challenge of getting a diagnosis, and in the ongoing management of the stress associated with various aspects of the condition – particularly the lack of awareness and knowledge
of the condition and how it will progress. I have also described some of the common challenges faced in interactions with the physical environment and the psychosocial implications of these challenges and how they are dealt with – usually collaboratively and necessarily creatively – by the dyads and families affected, made possible by the relative strengths within the unique cognitive profile of symptoms, and required because of the lack of specifically tailored information and guidance available.

The Stress Process Model was useful in helping to understand the findings in terms of their comprehensiveness and acknowledgement of the broad range of contextual, background and intra- and interpersonal factors involved in shaping the stress process. In taking a process approach, the two variations of the model were compatible with the significance of the temporal context in how stress seemed to be experienced – i.e. from the early stages of seeking a diagnosis through to the ongoing day-to-day management of the condition and associated symptoms, as reported in the interviews. The two adaptations of the model were also useful in providing a framework for thinking about both the situational and subjective impacts of the illness experience, but the interview findings also illuminated some ways in which these versions of the model were perhaps limited, with regards to how well they could account for the overlap and interrelation of individual dyad member’s stress processes and in the lack of explicit acknowledgement of the ability of the physical environment to mediate stress, which is where much of the stress for the participants in this phase of the study arose. There are also emerging questions about how compatible the model’s weighting towards stress rather than coping is with the current findings, given the broad range of supportive strategies and responsive adaptation people with PCA and their family members reported or demonstrated, and again, their often joint approach to problem solving. The broader applicability and potential limitations of the Stress Process Model will be discussed further later in relation to findings from both phases I and II. The model’s helpful divisions of the broad range of factors which can influence the stress
process, while helpful for the purposes of theorising and very much compatible with the findings of phase I, informed the design of phase II by encouraging the further exploration of how all these factors are negotiated in real-time in a real-world setting.
Chapter 3: Phase II – Home-based observations

3.1 The next steps – from phase I to phase II

At this stage I had gathered insights into some of the specific difficulties people with PCA can have, as well as the varied strategies they had responsively developed to manage those difficulties. The fact that these both seemed to be happening at the intersection of the physical and psychosocial environments, highlighted the importance of exploring the intersection of these two environments further, if the complexity of how these difficulties were jointly negotiated and responded to in real-time, in a real-world context was going to be more fully understood.

I had seen first-hand the value of conducting interviews within the home environment for the ecologically valid insights and illustrations of how these difficulties and coping strategies were situated within the everyday environment. To build on these findings, I set out to conduct a series of all-day home-based observations to further understand the day-to-day impacts of a diagnosis of PCA and will fully detail my methods and methodological justification below. There is only one peer-reviewed home-based study involving someone with PCA (a single case study) to date, to my knowledge (Samra et al., 2019), so I hoped this study would add to a much needed knowledge base about the real-world impacts of PCA on day-to-day life. As there is also a relative lack of observational research conducted with people living with more typical presentations of dementia in their own homes, I included a comparison group of people with tAD in this next phase. My research questions had developed from ‘What is the stress process for people living with PCA?’ to ‘How are difficulties and coping strategies negotiated in real-time in the layered and intersecting physical and psychosocial everyday environments of people living with PCA?’. These now specifically related to
interactions with the physical environment [e.g. Which areas of the home were people struggling with? How were objects used to support activities?], the psychosocial implications of the diagnosis for daily life [e.g. How and by who is care delivered and accepted? How were roles negotiated and maintained?] and questions that sit of the intersection of the two [e.g. particular objects that were meaningful for people, or areas of the home they found especially stressful or anxiety-inducing]. However, after completing the pilot visits with two participants with PCA (Martin and Maurice), it became clear that neither of the two were spending much time repeatedly trying and failing at activities, and also that the mix of activities undertaken over the course of the day was broad. As the observations continued this was confirmed, in that participants had largely either stopped doing things that were very difficult or too high risk, or had started to find their own varied ways around doing a broad range of activities, whether that was for example, using visual cues or asking a family member for help. The research questions became focused around the mix of activities people were doing, and how those were both challenged and supported, in their naturalistic home environments. Particularly activities outside of the essential ADL tasks, such as hobbies and leisure activities, as these had emerged as important in the dyadic interviews (e.g. with Patrick explaining that he did not need to do DIY, but wanted to), but were perhaps underexplored owing to the largely symptom-led approach I was taking at that time, the interview format, and the theoretical underpinnings which possibly all weighted the data more heavily towards ADL-type functional activities. The data collection and analysis (both ongoing and iterative) throughout the remaining unstructured home-based observations eventually became guided by four questions pertaining to what people were (and were not) doing, how and why:

- Which activities was this person motivated towards throughout the visit?
- How was that activity challenged?
- How was that activity supported?
Why was this activity prioritised/selected/important?

In terms of theoretical framing, while I anticipated that temporality would remain key, it seemed as though moving beyond this weighting towards stress, to a theoretical approach oriented more towards enablement and empowerment might help more with framing and understanding the data in phase II. Particularly focusing on the PLWD’s varied ways of (still) doing things as a move away from the more dominant deficit approach, to capitalise on the perseverance, responsiveness and adaptation that the dyadic interviews had revealed. Having seen the hugely determining value of dyadic factors I also wanted to build on the Stress Process Model’s acknowledgment of care partner-PLWD relational factors to a model more encompassing of relationality more broadly, and finally to adopt a theoretical approach that considered action within the environment as key, because of the leading PCA symptoms. At this point relational citizenship (and the associated conceptualisation of embodied selfhood) became an important theoretical framework to consider the next phase within. Here I will introduce the approach before later reflecting on its ability to help understand the findings of the home-based observations.

3.2 Theoretical underpinnings (phase II) – Relational citizenship

Relational citizenship is one of the most recently developed of a group of theoretical models posited as an alternative to the dominant biomedical discourse around dementia, which is largely deficit-led, focused on impairments and losses and in doing so, assumes a gradual loss of self and therefore personhood, as dementia progresses (Kontos, Miller and Kontos, 2017). This dominant deficit-model discourse was borne out of a cerebral-centric sociocultural and historical context, in which the brain was recognised and celebrated as the seat of one’s consciousness, intellect, agency and ultimately self, and much of this remains the case in our hyper-cognitive society today. Proponents of these alternative theories argue that this assumption can in fact lead to PLWD being marginalised and
excluded, when the inevitable progressive loss of memory and communication skills threaten a person’s ability to advocate on their own behalf and to express their needs and wishes (Askham et al., 2007; Baldwin, 2008; Chung, Ellis-Hill and Coleman, 2017; Bosco et al., 2018). Assumptions about personhood relying on intact cognitive capacity are claimed to be an unhelpful product of a dominant hyper cognitive discourse which prioritises rationality, language, intentional goal-directed action and functional capacity over a person’s fundamental essence and other varied ways of being in and acting on the world (e.g. Nygård and Borell, 1998; Sabat, 1998; Shilling, 1999; Davis, 2004; Killick, 2004; Kontos, 2004; Sabat et al., 2011; Boyle, 2014). As a reaction to this, theoretical and empirical work which emphasises the embodied nature of selfhood has emerged, and this acknowledges bodily movement and expression as being just as agentic and capable of enacting and constituting selfhood (Kontos, 2004, 2005; Boyle, 2014; Lloyd and Stirling, 2015). Lloyd and Stirling (2015) describe the will to move through space as perhaps the most essential way in which one recognises themselves as a person, and action is seen as a motivated and agentic enactment of one’s identity and sense of self (e.g. Kontos and Martin, 2013; Boyle, 2014; Lloyd and Stirling, 2015).

Kitwood has been credited with being responsible for the biggest shift in thinking in this area as it relates to dementia care with the development of his model of personhood, and advocacy for person-centred care (e.g. Kitwood, 1997a, 1997b, 1997c; Kitwood and Bredin, 1992; Bartlett and O’Connor, 2007). Personhood is concerned with the moral recognition of PLWD as unique and valued individuals and pushes back against those traditional notions of personhood which over-emphasise the importance of rationality and autonomy in the construction of self (Higgs and Gilleard, 2016). Kitwood’s (1997) theory suggests that recognition of a person’s personhood is of vital importance for wellbeing, and promotes and prioritises the fostering of trust, respect and recognition for and of PLWD. Some of the processes by which Kitwood suggested this can be achieved include: opportunities to be involved in life in ways that feel meaningful (whether action
based or not), fostering self-esteem, maintaining a sense of identity via continuity with the past and consistency in the present, delivering person-centred rather than illness-centred care, interacting in ways that foster collaboration, validation and facilitation and recognizing a person’s uniqueness, their life history and competencies (Kitwood, 1997a, 1997b, 1997c; Bartlett and O’Connor, 2007; Kaufmann and Engel, 2016). Although a welcome departure for many from the dominant discourse which preceded it, the theory of personhood has faced some criticism for being too individualistic. Even though it acknowledges the PLWD a social context (e.g. care environment), the theory can be considered to be somewhat unidirectional in terms of how it accounts for the delivery of care. Its defining aim – that a status of equal respect is bestowed upon a PLWD – in itself implies that the endorsement of one’s personhood is something that is only granted by another person recognising (and bestowing) it. This speaks to potential power imbalances, as it places the responsibility for the recognition of the personhood of PLWD in the hands of others, and suggests a general lack of reciprocity, in implying that PLWD can receive this recognition of their personhood without outlining how they may be able to assert this themselves. This is one of the central criticisms that has spurred the development of relational and citizenship approaches to dementia care (e.g. Higgs and Gilleard, 2016; Tolhurst, Weicht and Kingston, 2017). Although a further welcome development, relationship-centred approaches to dementia care have also faced criticism, for focusing solely on relationships relating to care, which by definition also has inbuilt power imbalances, and neglecting the other relationships which people with all stages of dementia have, which are not only concerned with their receiving of care (e.g. Nolan et al., 2004; Bartlett and O’Connor, 2007; Kontos, Miller and Kontos, 2017).

Kontos, Miller and Kontos’ (2017) relational citizenship seeks to redress the imbalance of power and marginalisation that PLWD can endure because of this emphasis on the rational and intellectual foundations of selfhood, and its essential reliance on a person’s communicative capacity, in order for them to express and
claim their rightful status as active citizens. To do this, Kontos and colleagues propose a model of citizenship which is relational, and which acknowledges the importance of interdependence and reciprocity in dementia care and beyond, and every PLWD’s right and ability to contribute and connect to the social context around them – particularly those in the later stages, for whom the traditional routes of communication and self-expression may be compromised (Nolan et al., 2002; Dupuis, Wiersma and Loiselle, 2012; Kontos, Miller and Kontos, 2017). Buron’s work (2008) suggests that a main source of the threat to personhood for PLWD in the earlier stages are the reactions and responses of others to them, highlighting the importance of considering the broader social context, something which both relational and citizenship approaches aim to do more explicitly. In the relational citizenship approach, the relational contexts of interest are not just between the PLWD and their care-providers, but with other individuals and groups, as well as larger societal institutions and powers, and this forms a central tenet of the theory in acknowledging PLWD first and foremost as people, rather than as representing a diagnostic status. In its conceptualisation of citizenship, the model is concerned with PLWD’s rights to freedom from discrimination and social exclusion, as well as opportunities for active participation in life, as fully as possible. Enabling and acknowledging the capacities of PLWD is of fundamental importance in this.

Another foundational principle of the model is the acknowledgement of the role of the body in self-expression, communication and agency. Kontos and other proponents critique the mind-body dualistic approach which is endorsed by assumptions that expressions of selfhood rely on cognitive capacity for self-reflection and rationalised action (e.g. Kitwood and Bredin, 1992; Davis, 2004; Kontos, 2004, 2005; Bartlett and O’Connor, 2007; Kontos and Martin, 2013; Boyle, 2014; Kontos, Miller and Kontos, 2017; Tolhurst, Weicht and Kingston, 2017; Bosco et al., 2018).

A person’s movements and capacity for sensation as well as their inhabiting of their body are all acknowledged within the relational citizenship approach as crucial in
constituting the self and affirming one’s being in the world, as well as playing a central role in the reciprocal and interdependent processes of social connectedness (Kontos, 1998; Kontos, 2004, 2005; Kontos, Miller and Kontos, 2017). This acknowledgement of embodied forms of selfhood demotes the dominant idea of one’s cognitive and intellectual capacities as the sole manifestation and vehicle of one’s personhood and identity, and raises the body’s status in doing so. The model promotes the appreciation of pre-reflective and unconscious bodily movements and expressions as ones of selfhood, so that actions which are not articulated or rationalised hold status and offer PLWD at all stages a means by which they can be recognised, can communicate and can otherwise contribute. Davis (2004) and Phinney and Chesla (2003) endorse this idea that there are many ways of engaging with the world which do not exist on the basis of cognitive awareness, reason and rationality including being, moving and doing. The body is said to both constitute and manifest selfhood, and can be considered a vehicle for agentic action and a means of engaging with the world and others which offers coherence and continuity, at a time of cognitive disruption (e.g. Kontos and Martin, 2013; Kontos, Miller and Kontos, 2017).

The two central tenets to the theory of relational citizenship both made it seem a helpful theoretical framework for this next phase of the study. Firstly, a focus on relationality – having seen in the dyadic interviews how interrelated and overlapping both members of the dyads’ stress and coping processes were. Secondly, the status Kontos grants to embodiment and action, as opposed to solely intellectual and rational mental capacities, in representing and constituting one’s expressions of selfhood. This seemed particularly interesting to explore in relation to people with PCA given the significant challenges they can face in their embodied interactions within the physical environment.

Kontos and colleagues (2017) developed the model and intended its application primarily for PLWD in the advanced stages who are in receipt of direct care, and I was interested to explore the applicability of the model in the earlier stages of the
disease course, when informal care is being delivered at home. Also in earlier onset dementia when individuals’ citizenship status had likely recently been at its peak, and relatively unthreatened leading up to the point of their diagnosis (i.e. less commonly impacted by mobility, accessibility and other health-related issues and disadvantages that may be associated more commonly with older age).

3.3 Methodological underpinnings (phase II) – home-based observations, qualitative case studies and focussed ethnography

3.3.1 Methodological justification – home-based observations

The Phase I interviews had revealed the numerous and profound difficulties people were having in their interactions with the physical environment, and I had also seen first-hand the immense value of conducting these interviews within the environment of interest, as the space and objects within it prompted and enriched participants’ interview responses. Extended observations within the home environment seemed a natural next step for furthering my explorations of how these difficulties played out and were negotiated in the intersecting physical and psychosocial environments, in an ecologically valid way. I will now explain how I conducted the study and the methodological decisions I made which led me to explore the central concept of activity engagement in the everyday environments of people with these two different diagnoses of dementia, and how this activity engagement related to people, things and the ever-changing temporal context it was happening within.

The importance of observations in naturalistic settings for helping to add an authentic and ecologically valid lens to understandings of peoples’ lived experience has been illuminated and endorsed by the work of Nygard (2006) and Briggs et al. (2003) who highlight the potential of context to prompt and support participants’ communications about their experiences. Further still, Simonds, Camic and Causey
(2012) consider a contextualist epistemology essential to any study which is focused on the meanings participants make, because meanings are situated and constructed within contexts, and most clearly revealed through the actions and communications which take place in them. Participants' everyday contexts also provide opportunities for researchers to see them in the varied roles they may occupy at home, as opposed to (for example) the role of patient they may be more likely to occupy when attending a clinic or lab setting (Briggs et al., 2003; Nygård and Borell, 1998; Nygård, 2006). Something of particular interest given the dominant symptom profile of the PCA group was interaction with objects, and in their 2019 study of the role of the spatial organisation of objects in activity engagement in three settings (a residential home, day centre and residential care setting), Majlesi, Ekström, and Hydén stressed the importance of taking a contextualist approach in studying activity, in order to gain a fuller understanding of how the context itself contributes to the formulation and execution of action. Observations in participants’ own familiar contexts also increase opportunities for them to steer researchers towards the things of meaning and significance in their home and everyday life (Angrosino, 2007; Higginbottom, Pillay and Boadu, 2013). Simonds, Camic and Causey (2012) and Silverman (1997) critique an over-reliance on interviews in qualitative research and – especially when the subject of interest relates to activities – endorse ethnographic methods which allow a researcher to observe this ‘doing’ in real-time. Nygard (2006) talks about ‘reflecting while doing’ and ‘showing by doing’, and how observations of activities in real-time offer another route to asking and knowing about participants’ naturalistic interactions, within their everyday contexts.

Unstructured observation in a naturalistic setting also encourages the careful consideration and exploration of much which might be considered mundane and ordinary. That which is of key importance in providing the texture and richness to lived day-to-day experiences, and which may seem too trivial for researchers to ask about in interviews, or for participants to report to them (e.g. Angrosino, 2007; Knoblauch and Schnettler, 2012; Pink and Morgan, 2013). This method makes
visible and elevates much of what is taken-for-granted and often considered small-scale, to a position of worthwhile study and attention, and helps to build a fuller picture of the complexities of everyday life as it is lived (e.g. Geertz, 2008; Pink and Morgan, 2013; Roper and Shapira, 2000). Stake (1978) goes further in stressing the value of this immersion in the ordinary lives of participants, in suggesting that it not only provides researchers with rich experiential learning about their participants' everyday lives, but that it also helps when communicating these findings to others. He asserts that the common humanity we all share – participants, researchers across different disciplines, and the broader public included – is ultimately an experiential one, and that writing about these ordinary personal experiences and sharing them is a most understated but powerful tool for bringing to light and enriching others’ understandings of social problems.

Home-based observational methods certainly seemed best suited for better understanding these daily interactions in the environment for people with PCA but additionally, because of there being relatively little home-based observational work with PLWD in general, it was decided that including a comparative group of people with tAD could be helpful for situating and making sense of the findings. It was considered that the method may also be particularly inclusive for those with a diagnosis of tAD because of their dominant language and memory impairments. Many argue that the dominance of positivist investigations of dementia has, over time, contributed to the marginalisation of the voices of people living with the condition, specifically because of an over-emphasis on people’s symptoms, which then leads to PLWD being considered (intentionally or not) within a deficit-model framework, and predominantly in terms of what they cannot do or are not able to offer (e.g. Nygård, 2006; Goodson and Vassar, 2011; Ludwin and Capstick, 2017). Two of the most commonly known symptoms of dementia are memory loss and language difficulties, two things considered essential for the communication of personal experience, for example, in an interview. This has meant that even within qualitative research (which is predominantly interview-based), PLWD are still rarely
the sole or major contributors to research about their experiences, and ethnographic approaches are increasingly recommended to increase accessibility for research participation, even for PLWD in the milder stages (e.g. Briggs et al., 2003; Hubbard, Downs and Tester, 2003; Goodson and Vassar, 2011; Ludwin and Capstick, 2017). Having seen some discrepancies in accounts during the initial interview phase and in line with recommendations of Briggs et al. (2003), Bond and Corner (2001) and others, I was encouraged to adopt an approach which allowed for a multiplicity of voices and interpretations to be expressed and recorded, in ways most accessible and inclusive for all participants, regardless of their particular symptomatic profile.

There are many challenges and potential weaknesses identified in taking an approach which relies heavily on extended participant observation in everyday contexts however, and particularly when there are sensitive health issues (discussed here and below in section 5.8). These include the duality of roles of the researcher, who may also feel a need to provide additional help and support, the emotional burden on the researcher, the need to be attentive and flexible in negotiating emerging data while holding research questions in mind, the need to be perceptive and sensitive in obtaining ongoing informed consent, and the need to be reflective about the impact of the researcher’s presence and assumptions on the observed environment (e.g. Briggs et al., 2003; Watts, 2011). In her acknowledgement of the respective strengths and weaknesses of both interviews (as discussed earlier in section 2.1.2) and observations (as discussed here), Low (2013) calls for the triangulation of multiple methods and data sources in order to increase the robustness and richness of analytic accounts. In the remainder of this chapter I will describe the different methodological approaches I drew on in this phase of the study and the multiple data sources I was able to triangulate as a result.
3.3.2 Methodological influences

My study design and protocol was informed by qualitative case study and focused ethnographic methodological approaches, and I will now outline some of the essential features of those and the specific data collection and analytic techniques which informed my study, before justifying the rationale for the combined approach I have taken.

3.3.2.1 Qualitative case study

A qualitative case study approach is most fitting for studying and describing complex real-world phenomena, usually asking ‘how’ or ‘why’ questions. The phenomenon is studied in context because it is heavily context dependent and the two cannot be easily separated out, and there are usually many interrelated variables which cannot be controlled or manipulated (e.g. Stake, 1978; Baxter and Jack, 2008; Yin, 2017). Case studies are often not so much oriented towards theory generation, as towards accurately and richly describing the particular case(s) being studied. They can include one or multiple cases, and a case can be an individual, organisation or an event. Case studies can include qualitative and quantitative data, and some guiding theoretical propositions set out in advance are usually encouraged, or considered to strengthen the approach.

I mostly drew on the methodological approaches outlined by Yin (2017) and Stake (1978, 1995) – Yin mostly for the design and some analytic techniques, and Stake mostly for the underlying epistemological positioning, as well as some additional analytic techniques. According to Yin (2017), a multiple case design can be used when the researcher is looking to make comparisons, and cases can have multiple sub-units of analysis embedded within them. The research questions and theoretical positioning should be pre-specified unless the case study is exploratory, in which case only the purpose of the research needs to be clearly defined at the outset. The context-specific study findings are related to broader theories as part of the process of analytic generalisation. Piloting can be an essential part of the
process of deciding where to focus and any amendments required to the study protocol. Multiple case studies can allow for literal and theoretical replication and these are important analytic processes for naturalistic generalisation – this is the researcher testing if their interpretations are evident more broadly in the case being studied (literal) and in other similar cases and not in other dissimilar cases (theoretical).

The researcher needs to be an attentive listener and to pay careful attention to the setting, but also to their own impact on the context. Maintaining some sense of distance is encouraged to facilitate the researcher’s recognition of their own biases as are efforts to control for them (e.g. by being open to the unexpected emerging). Rather than formal structured interviews, guided natural conversations are encouraged, as this permits the researcher to focus on whatever is emerging as significant, while also eliciting responses which are as natural as possible. Similarly, with the observational elements, researchers are required to make a conscious choice about where to selectively attend.

Data analysis is essentially a cyclical process which involves examining, categorising, combining and testing the data, to ensure the interpretations made give as accurate an account as possible of the case(s). Analysis should be thorough and systematic – attending to all evidence and proposing alternative explanations – and a general analytic strategy should be thought through and articulated. A helpful part of this process is finding ways to display or organise the data so that patterns, insights and key concepts can more easily be noticed and interpreted (e.g. tabulating, visualising, making data matrices, combining qualitative and quantitative data). It is important for researchers to evidence their thinking and workings and to create an evidence trail, so that their interpretations can be traced.

There is no specified formula for analysis which is acknowledged as being both very freeing but also potentially difficult to navigate – especially for novice researchers – and Yin suggests starting points to help a researcher start ‘playing’ with the data in
order to begin to get a sense of where they may want to focus. I found the following suggestions particularly helpful:

- Juxtaposing data from two different people;
- Organising data into different themes and sub themes;
- Making a matrix of categories and assembling evidence;
- Visual displays such as flow charts and other graphics;
- Writing memos (all the way through data collection and analysis) about what the researcher thinks they might be observing (i.e. lightbulb moments), which may help to consolidate ideas for future ways of looking at or interrogating the data.

Yin (2017) also suggests a number of possible general analytic strategies, and I found the following most useful in my analysis:

- Working the data from the ground up – This involves the researcher immersing themselves in the data to notice key concepts and their possible relationships (Yin, 2017). Coding can help with this process as it encourages the abstraction of data and can make patterns clearer (quantitative data can also help with this). This means being inductive and letting the data and what is noticed in it drive the analysis;
- Developing a case description – This requires organising the case study data according to some sort of a descriptive framework, under headings which the researcher considers relevant to the case and to telling the story of it (Yin, 2017). This is so that patterns which seem salient and intuitive can be thoroughly considered and articulated.

Finally, Yin suggests the following 5 analytic techniques:

- Pattern matching (within and/or across cases);
- Explanation building (adding causal links to the above);
- Time-series analysis (temporal pattern matching e.g. ‘X always precedes Y’);
- Logic models (testing out predicted series of cause and effect events on the data);
- Cross case synthesis - applying any of the above to multiple cases.

Stake (1978, 1995) takes a more constructivist approach and endorses the use of only qualitative data as a possibility in case study research. Stake takes a flexible stance on when and how data collection and analysis each begin and interact over the course of the research project. He encourages an emerging and increasing focus on more refined areas of interest as the study progresses, and for research questions to be reformulated as required. Stake is also less prescriptive in his suggestions for analytic strategies, in suggesting two which are broadly more flexible, and stating that researchers need – via their experience and reflection on working with data of this kind – to find the strategies which are most compatible with their ways of working and thinking. The two strategies Stake outlines are:

- Categorical aggregation - this involves intuitively grouping and tallying elements and features of the data according to some sort of system of categorisation that seems natural and fitting, in order to identify meaningful patterns in complex data. Stake differentiates his proposed ‘categorical’ aggregation from the more standardised, objective and sustained aggregation that traditional scientific research methods can propose;
- Direct interpretation – relying even more heavily on intuition and an inductive approach, with this technique Stake advocates researchers directly interpreting meanings that are apparent to them in the data they are observing or collecting, by asking themselves the question ‘What did that mean?’.
Stakes describes a researcher’s need to take apart and deconstruct moments and events in order to look at them closely, before putting them back together with some new understanding and interpretation of the meaning that is inherent in them, and these are his two suggested techniques for achieving such understanding.

### 3.3.2.2 Focused ethnography

Focussed ethnography is a pragmatically-derived and time-efficient variation of classic ethnography, designed to lead to findings which have some practical application (Roper and Shapira, 2000). It is increasingly used in healthcare and educational settings where prolonged immersion in the field is perhaps not possible (e.g. because of resources, participant burden) (Knoblauch, 2005; Wall, 2015). The method shares many features with classic ethnography, and its central aims remain to learn by experience and immersion in a real-world context, about the socially constructed meanings and practices of a specific cultural group, and how those guide action (Knoblauch, 2005). For pragmatic reasons though, the focusedness of the time period is also reflected in the focusedness of the research questions (though these can and should still evolve and develop over time), and in the selection of a cultural group who are not completely unknown or unfamiliar to the researcher (e.g. Knoblauch, 2005; Simonds, Camic and Causey, 2012; Higginbottom, Pillay and Boadu, 2013). As in classic ethnography, these evolving questions are shaped by the data collection and analysis happening in parallel as soon as the researcher enters the field. Despite the shorter amount of time spent in the field, the intensity and volume of data collected is often enhanced by technological aids (e.g. video/audio recordings) (Knoblauch, 2005; Knoblauch and Schnettler, 2012; Pink and Morgan, 2013; Wall, 2015).

Key methods of data collection for use in focused ethnographic research include:

- Participant observation (this is primary and places significant demands on the researcher in terms of social, intellectual and methodological
flexibility; this may be documented in field notes with or without the assistance of supplementary video or audio recording);

- Informal interviewing (this aids rapport-building by following the natural flow of conversation);
- Mapping (sketches of the field based on the researcher’s experience of the space);
- Object or photo elicitation (this provides an anchor or prompt for personal reflection and can be researcher- or participant-initiated);

(e.g. Morse and Field, 1995; Roper and Shapira, 2000; Goodson and Vassar, 2011; Simonds, Camic and Causey, 2012; Higginbottom, Pillay and Boadu, 2013; Spradley, 2016).

The richness and volume of data generated by ethnography makes organising and indexing it a major priority (Roper and Shapira, 2000). Developing strategies for the selection and transcription of the most relevant data is key, and an analytic strategy needs to be custom built for the needs of each project - there is no ‘one size fits all’ approach (e.g. Knoblauch, 2005; Angrosino, 2007). Data collection and analysis happen concurrently, and memos should be written throughout. Memos should contain the researcher’s thoughts and emerging ideas about the data and any patterns noticed, and are helpful for the refinement of research questions over time, and the eventual identification of patterns and key concepts (Roper and Shapira, 2000; Miles, Huberman and Saldana, 2013). Analysis is a process of breaking up or segmenting the raw data into smaller chunks before rebuilding these into patterns and key concepts, and this process is also cyclical and iterative (Jorgensen, 2015). The analytic process should encompass identification, classification, categorisation, and eventually move towards the formulation of abstract and explanatory patterns (depending on if the analysis is a descriptive search for patterns, or a theoretical search for meaning in the patterns) (e.g. Roper and Shapira, 2000; Angrosino, 2007; Higginbottom, Pillay and Boadu, 2013).
Analysis begins with coding, requiring the researcher to reduce down and simplify their data segments by assigning meaningful labels to them. These codes are also a helpful housekeeping tool as they allow the quick identification of relevant segments of data on a given topic (Roper and Shapira, 2000). Codes are then combined to make broader and more general categories. Here begins a process of comparing and contrasting in order to verify any emerging patterns or key themes among the data segments, as well as points of divergence. This comparing and contrasting is one iteration of the constant comparison that should continue throughout analysis, in which emerging assumptions and analytic ideas about the data and what it means can be tested. The eventual aim is to abstract this enough to develop and articulate a coherent and comprehensive set of themes which fit the data collected, and which provide a more overarching picture of what has been identified as happening in the data. One challenge when moving towards more theoretical generalisations is how to simultaneously ensure there is an accurate interpretation of the specific situation(s) which have been observed (an emic perspective – concerned with the participants’ worldview) at the same time as relating it to the relevant theoretical ideas (the etic perspective – the perspective of the researcher, informed by their knowledge of the broader literature and theoretical context) (Roper and Shapira, 2000; Angrosino, 2007; Hammersley, 2008; Higginbottom, Pillay and Boadu, 2013).

Specific tools that should be utilised throughout the data collection and analytic processes include: being open to negative cases and using them to test any emerging patterns, the use of rival explanations and the integration and triangulation of the varied data sources (Roper and Shapira, 2000; Angrosino, 2007; Hammersley, 2008; Simonds, Camic and Causey, 2012). Where video data is concerned, data viewing sessions can be especially helpful and important. The intersubjectivity of viewing data with colleagues can help with the identification of rival explanations, and facilitate or encourage the gathering of supportive evidence for any tentative or working interpretations. Having video data can also allow micro
analysis of specific moments of interest and offers the researcher some relief from note-taking when they are in the field, which can in turn permit richer interactions with participants (e.g. Fetterman, 2009; Knoblauch and Schnettler, 2012; Pink and Morgan, 2013; Suryani, 2013). Ethnographic studies can include quantitative and qualitative data, and some combination of descriptive text and numbers can also be helpful during the analysis stages, when presenting data in a variety of matrices or tables can help to illuminate patterns and emerging concepts of interest in the data (Roper and Shapira, 2000; Angrosino, 2007). Analysis of any quantitative data however should generally be conducted after the qualitative data analysis, so as not to restrict the researcher in their inductive and selective focus on areas of (emerging) significance (Roper and Shapira, 2000). Interpretations should finally be written up in thick description (Ponterotto, 2006; Geertz, 2008; Hammersley, 2008).

This requires a rich, nuanced, accessible style of narrative writing where the researcher makes explicit the motivations and intentions they are inferring based on their subjective experience of the field, so that observations come to life for readers and can be understood as context-specific meaningful actions and interactions (Wolcott, 2001; Fetterman, 2009). Good ethnographic writing combines a literary style with a firm grounding in the empirical – readers need to be both interested in and able to imagine themselves in the scene being described (Fetterman, 2009; Van Maanen, 2011).

The importance of the role of the researcher as the data collection instrument cannot be overstated in ethnographic research – it is considered of key importance throughout both the data collection and analytic processes (Roper and Shapira, 2000; Higginbottom, Pillay and Boadu, 2013). The trustworthiness and authenticity of the ethnography is seen as inextricably related to the practical knowing the researcher gains via their immersion in the field, and the presence of this in their writing is therefore imperative (Lincoln and Guba, 1985). Keeping a detailed reflexivity journal of the potential impact of any researcher-related factors (e.g. emotional burden, existing assumptions, theoretical positioning) on the data
collection and interpretation is essential (Roper and Shapira, 2000; Simonds, Camic and Causey, 2012). The relationship with theory can be considered more flexible than in the case study approach – theories can guide and shape the initial research questions, but an overly rigid adherence to theory can prevent researchers from being open to unexpected findings emerging. The process of ethnography happens in an iterative dialogue with theory throughout. This may reveal incompatibilities with adopted theoretical positions, and there may not be a straightforward fit between existing theories and emerging findings. An iterative approach to finding theory which is compatible with and/or which seems to explain the findings must be taken (Roper and Shapira, 2000; Simonds, Camic and Causey, 2012; Denzin, 2017).

3.3.2.3 Triangulation and transparency
An extended period of observation also made possible the triangulation of data sources (including qualitative and quantitative data), which proponents of both the case study and focused ethnographic methods suggest can be a helpful step in the processes of verifying and validating findings, when studying complex real-world phenomena (e.g. Stake, 1995; Roper and Shapira, 2000; Denzin, 2017; Yin, 2017). Triangulation is also encouraged in terms of using multiple theoretical frameworks during analysis, a range of empirical literature to situate findings within, and in having multiple researchers intersubjectively explore the data (e.g. Lincoln and Guba, 1985; Denzin and Lincoln, 2002; Denzin, 2017), all of which I sought to incorporate in my data collection and analytic procedures. Roper and Shapira (2000) stress that it is not simply by aggregation of these multiple data methods, theoretical frameworks or researchers that triangulation can be assumed to be working, but that there should be an active process of using, for example, each data source to cross-check and judge the validity of the interpretation of another, and so on. The analytic processes of ethnographic or case study research, in being so subjective and interpretive, can be at risk of appearing mystical, and this can contribute to narratives of qualitative social science research being impressionistic as opposed to systematic and rigorous (e.g. Lincoln and Guba, 1985; Creswell and
Creating an organised and indexed database of evidence alongside thorough and transparent reporting of the process of analysis, including documenting the use of analytic techniques, such as constant comparison and tests of rival explanations, can all help with this (e.g. Stake, 1978; Creswell and Miller, 2000; Angrosino, 2007; Yin, 2017). I will attempt to go some way towards providing this kind of thoroughness and transparency below, in outlining the specific processes of data collection and analysis I embarked on, and in my later reporting of the triangulation of the mixed methods data in Chapter 4.

3.4 Methods

3.4.1 Research questions

Over the course of the observations, my research questions were refined to a specific aspect of the intersecting physical and social environments, and became centred on the enduring engagement in meaningful activities. Engagement in meaningful activities sat at the intersection of these two environments in the sense that activities often required interactions with the physical environment or objects within it, and the process of meaning making about those activities was inherently a psychosocial one. My research questions became:

- What activities did participants do? What activities were they motivated toward/interested in?
- How was engagement in those activities challenged? How was this known/shown? Who noticed/identified this challenge?
- How was engagement in those activities supported? By who/what? At which point in the activity?
- Why were those things important to that person? What purpose did they serve? What was the meaning of them?
3.4.2 Ethical approval, confidentiality, consent

See section 2.1.3 above. For the home-based observations I (EH) conducted the consenting and debriefing for all 20 observational home visits. In addition, owing to the length and unstructured nature of the observations which diverged from the standard department home visit protocol, I, with my supervisors and departmental governance manager developed specific pre- and post-visit assessment forms to identify and document any potential risks and relevant actions (see Appendix 1.d). Key considerations owing to the length of the visit were that I was in touch with an allocated senior member of staff every two hours and that there was an opportunity for a debrief conversation at the end of each visit.

3.4.3 Quality assurance

Many of the issues with establishing validity and quality assurance in qualitative research which applied to the interview data also apply here (see section 2.1.4), and I have completed a corresponding table (Table 3.1) of Morse et al.’s (2002) five verification strategies and COREQ checklist for this phase of the study accordingly (Tong, Sainsbury and Craig, 2007 – see Appendix 16). One additional way the notion of validity was explored in this phase of the study was in the exploratory mixed methods data triangulation sessions (see Chapter 4).

3.4.3.1 Verification strategies


<table>
<thead>
<tr>
<th>Verification strategy</th>
<th>Explanation</th>
<th>How or where demonstrated in this phase of the current study</th>
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<tbody>
<tr>
<td>Methodological coherence</td>
<td>Ensuring congruence between research question and methods</td>
<td>This PhD project – a roadmap (outlining evolution of research questions and methodological decision-making)</td>
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<td></td>
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<td>General Introduction (gaps in the largely biomedical knowledge base and the dominant methodological approaches of existing published studies on PCA)</td>
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<td>The next steps – from phase I to phase II (summary of evolution of research questions and development in methodological thinking following phase I)</td>
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<td>Phase II Methods – Home-based observations (research questions; methodological underpinnings (justification; influences)</td>
</tr>
<tr>
<td>Appropriate sampling</td>
<td>Participants who best represent or have knowledge of the research topic</td>
<td>Phase II Methods - Methodological influences (applicability of focused ethnographic approaches with samples which are not fully unknown/unfamiliar; home-based observational approach increasing accessibility for participants with a range of symptomatic profiles); Sample (i.e. community-based sample; comparative group of tAD to extend contribution to existing knowledge)</td>
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<td>General Discussion – Limitations (potential for sample to represent those affected by tAD or PCA who are coping relatively well; implications for interpretation discussed)</td>
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<tr>
<td>Collecting and analysing data</td>
<td>Establishing an iterative interaction between what is known and what one needs to see</td>
<td>This PhD project – a roadmap (summary of analytic thinking following two pilot home-based observational visits and impact on evolving research questions and focus)</td>
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<td>concurrently</td>
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<td>Phase II Methods – field notes (including analytic memos written in the field); data analysis</td>
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<tr>
<td>Thinking theoretically</td>
<td>Moving between micro-perspective to macro-conceptual/theoretical understanding</td>
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<td>------------------------</td>
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<tr>
<td>Constant, cyclical process of checking that emerging ideas are reconfirmed in new data</td>
<td>Phase II Methods – data analysis (moving between coding of time logs to broader pattern-searching/theme building, back to individual index card summaries, then to written case summaries focused around emergent research questions</td>
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<td></td>
<td>Phase II Findings – presentation of themes supported by data excerpts and explanatory commentary; relating findings to theoretical frameworks throughout (The Stress Process Models; Relational Citizenship)</td>
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<td></td>
<td>General Discussion (compatibility with existing empirical literature; summarising and discussing the broader theoretical implications for The Stress Process Model and Relational Citizenship and other theoretical approaches that may offer alternative understandings of the current study findings; research and clinical practice implications; suggestions for future development)</td>
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<tr>
<td>Theory development</td>
<td>Moving between micro-perspective to macro-conceptual/theoretical understanding</td>
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work, e.g., other rare dementia populations, longitudinal approaches)
3.4.3.2 Member checking

As with the Phase I interview findings, I sought external validation of the main findings from the home-based observations, this time with two presentations of the findings at national PCA support group meetings, with follow up small group discussions. Once again there was a general consensus among support group members at both meetings that the themes outlined here were compatible with their own experiences, while there was also acknowledgment of the complexity and variation of individual living situations and preferences. Many support group members once again provided their own examples of experiences which showed overlap and coherence with the study findings. In this phase I also discussed my overall interpretations and findings at the end of my analysis with two carers whose partners had participated in the study. I also did this informally on an individual basis throughout the observations, when checking I had understood something correctly by way of sense-checking my in-the-moment interpretations.

3.4.4 My approach

The combined methodological approach I used in this phase is perhaps best described as a comparative qualitative embedded multiple case study design drawing on ethnographic methods and analytic techniques. I was encouraged that it was possible to combine these approaches as despite their divergence on the role of theory and the role of the researcher, something which focused ethnographic and qualitative case study approaches have in common is that they are both often acknowledged to be methodologically underspecified or flexible, especially in terms of their analytic processes (e.g. Stake, 1978; Roper and Shapira, 2000; Knoblauch, 2005; Suryani, 2013; Wall, 2015). Demonstrating this, White, Drew and Harry (2009) described the collective researcher’s methodological crisis they had in terms of identifying which method their study was most aligned with, and in their conclusions suggested that a less dichotomous distinction between the two methods may be warranted, owing to the overlap and flexibility of both, a suggestion endorsed by Willis (2007), who describes the methods as more similar.
than dissimilar. Simonds, Camic and Causey (2012) describe the different options of focused ethnographic methods as tools in a toolbox, and they along with Roper and Shapira (2000) and Wolcott (2001) emphasise the importance of choosing the selection of methods most appropriate to the research questions and study sample at hand, and it being the intent of a study, rather than the specific methods used, which ultimately make it ethnographic in nature (i.e. making an ethnographic approach not incompatible with a qualitative case study-informed design). Similarly, Stake (1995) has claimed that case studies are defined by an essential interest in individual case(s), and not necessarily by the methods of enquiry that are utilised. The specific elements I was keen to combine were the comparative element and concurrent individual and group level focus that a qualitative case study approach allows for, along with the immersive and experiential emphasis on the everyday and the ordinary permitted by focused ethnographic methods. Further endorsing this kind of a tailor-made approach, Nygård (2006) and Wall (2015) describe the necessary methodological adaptation and innovation that such heavily context-specific research questions can demand, as well as the exciting possibilities such study designs permit for novel analytic approaches.

This study is also methodologically informed by the work of Briggs and colleagues (2003) who conducted a series of unstructured observations in the homes of community dwelling PLWD. They too had primarily one researcher collecting the majority of data, and emphasised the usefulness of joint data viewing sessions with other team members. They systematically recorded each step of their analytic process and memoed their thoughts about the data throughout, continually relating their interpretations to existing literature as they went along. They began by immersing themselves in the data before moving on to data reduction, which they achieved by coding – assigning broad category labels – to sections of their data. These were then grouped accordingly, before the authors looked for recurring patterns and themes in the data, while constantly comparing case by case throughout, looking for differences as well as similarities.
I will now outline the specific data collection and analysis procedures used, which were informed by the approaches outlined above.

3.4.5 Sample

Recruitment procedures and inclusion criteria were as in the interview phase of the study (see section 2.1.5) only in this phase an accompanying family member, friend or other caregiver was required to be available at the home for the start and majority of the observational visit. Demographic information about participants, their health, employment and relationship status and living situation were collected from informants (see Appendix 3c and 3d), including two items from the Bristol ADL scale (Bucks et al., 1996) about mobility and transfers to supplement questions asked about other health conditions (full ADL functional status was assessed with the ADL scale (Johnson et al., 2004) as outlined below in section 3.4.6.3).

10 individuals with PCA (6 male; 4 female) and 10 individuals with tAD (5 male; 5 female) took part in the observations, in addition to any present family members, friends or visiting others who were all informed of the study and had the right to request the deletion of any video data in which they were captured. Two of the PCA group had taken part in the interviews in phase I, the remainder were new to the study. The mean age of the PCA group was 67.6 years (8.73 SD) and for the tAD group was 76.7 years (6.46 SD) reflective of the typically earlier age of onset of PCA. Scores on the MMSE ranged from 5–28 for the PCA group (mean=17; SD=5.55) and 10–30 for the tAD (mean=20.1; SD=5.45) group, indicating impairment levels spanning severe–no impairment in the PCA group and moderate–no impairment in the tAD group. The number of years since subjective symptom onset ranged from 2–12 for the PCA group (mean=7.1; SD=3.31) and 2–17 for the tAD group (mean=6.5; SD=4.6) and the number of years since diagnosis ranged from 2–8 for the PCA group (mean=3.3; SD=2.06) and 0–7 for the tAD group (mean=3.1; SD=2.38). No participants lived alone – 14 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 mixed of rural and urban locations across the UK and were a mixture of houses and flats.

Summary demographic and disease duration information are displayed in Table 3.2, and individual participant information\(^6\) in Table 3.3.

*Table 3.2: Summary demographic information - Phase II Home-based observations*

<table>
<thead>
<tr>
<th></th>
<th>PCA</th>
<th>tAD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Gender (male/female)</td>
<td>6/4</td>
<td>5/5</td>
</tr>
<tr>
<td>Age (years – mean ± SD)</td>
<td>67.6 ± 8.28</td>
<td>76.7 ± 6.13</td>
</tr>
<tr>
<td>Years since subjective onset (years – mean ± SD)</td>
<td>7.1 ± 3.14</td>
<td>6.5 ± 4.36</td>
</tr>
<tr>
<td>Years since diagnosis (years – mean ± SD)</td>
<td>3.3 ± 1.95</td>
<td>3.1 ± 2.26</td>
</tr>
<tr>
<td>Years between subjective onset and diagnosis (years – mean ± SD)</td>
<td>3.8 ± 2.68</td>
<td>3.4 ± 3.61</td>
</tr>
<tr>
<td>MMSE (mean ± SD)</td>
<td>17 ± 5.55</td>
<td>20.1 ± 5.45</td>
</tr>
</tbody>
</table>

\(^6\) All names have been changed
### Table 3.3: Individual participant demographic and disease duration information - Phase II Home-based observations

<table>
<thead>
<tr>
<th>PLWD name</th>
<th>Gender</th>
<th>Diagnosis</th>
<th>Age at time of interview</th>
<th>Years since subjective onset</th>
<th>Years since diagnosis</th>
<th>Years between subjective onset and diagnosis</th>
<th>MMSE</th>
<th>Living situation (other inhabitants; housing type)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alan</td>
<td>M</td>
<td>PCA</td>
<td>64</td>
<td>12</td>
<td>2</td>
<td>10</td>
<td>5</td>
<td>with wife; house</td>
</tr>
<tr>
<td>Eleanor</td>
<td>F</td>
<td>PCA</td>
<td>74</td>
<td>12</td>
<td>8</td>
<td>4</td>
<td>20</td>
<td>with partner; house</td>
</tr>
<tr>
<td>Lilian</td>
<td>F</td>
<td>PCA</td>
<td>70</td>
<td>8</td>
<td>6</td>
<td>2</td>
<td>14</td>
<td>with husband; house</td>
</tr>
<tr>
<td>Martin</td>
<td>M</td>
<td>PCA</td>
<td>73</td>
<td>6</td>
<td>2</td>
<td>4</td>
<td>19</td>
<td>with wife; house</td>
</tr>
<tr>
<td>Maurice</td>
<td>M</td>
<td>PCA</td>
<td>79</td>
<td>6</td>
<td>3</td>
<td>3</td>
<td>17</td>
<td>with wife; house</td>
</tr>
<tr>
<td>Oscar</td>
<td>M</td>
<td>PCA</td>
<td>56</td>
<td>7</td>
<td>2</td>
<td>5</td>
<td>19</td>
<td>with wife and two daughters; house</td>
</tr>
<tr>
<td>Paul</td>
<td>M</td>
<td>PCA</td>
<td>79</td>
<td>6</td>
<td>3</td>
<td>3</td>
<td>14</td>
<td>with wife; retirement flat</td>
</tr>
<tr>
<td>Rhian</td>
<td>F</td>
<td>PCA</td>
<td>55</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>15</td>
<td>with husband and two daughters; house</td>
</tr>
<tr>
<td>Sally</td>
<td>F</td>
<td>PCA</td>
<td>64</td>
<td>9</td>
<td>3</td>
<td>6</td>
<td>19</td>
<td>with husband; house</td>
</tr>
<tr>
<td>Name</td>
<td>Gender</td>
<td>Age</td>
<td>PCA</td>
<td>SL</td>
<td>SN</td>
<td>Year</td>
<td>Accommodation</td>
<td></td>
</tr>
<tr>
<td>--------</td>
<td>--------</td>
<td>-----</td>
<td>-----</td>
<td>----</td>
<td>----</td>
<td>------</td>
<td>----------------------</td>
<td></td>
</tr>
<tr>
<td>Simon</td>
<td>M</td>
<td>62</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>28</td>
<td>with wife; house</td>
<td></td>
</tr>
<tr>
<td>Anita</td>
<td>F</td>
<td>88</td>
<td>4</td>
<td>2</td>
<td>2</td>
<td>27</td>
<td>with husband; house</td>
<td></td>
</tr>
<tr>
<td>Betty</td>
<td>F</td>
<td>88</td>
<td>5</td>
<td>5</td>
<td>0</td>
<td>15</td>
<td>with husband; house</td>
<td></td>
</tr>
<tr>
<td>Brian</td>
<td>M</td>
<td>75</td>
<td>17</td>
<td>4</td>
<td>13</td>
<td>30</td>
<td>with wife; house</td>
<td></td>
</tr>
<tr>
<td>Helena</td>
<td>F</td>
<td>75</td>
<td>7</td>
<td>6</td>
<td>1</td>
<td>10</td>
<td>with husband, daughter, son-in-law and two grandchildren; house</td>
<td></td>
</tr>
<tr>
<td>Lionel</td>
<td>M</td>
<td>76</td>
<td>5</td>
<td>0</td>
<td>5</td>
<td>22</td>
<td>with daughter and granddaughter; flat</td>
<td></td>
</tr>
<tr>
<td>Mandy</td>
<td>F</td>
<td>72</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>19</td>
<td>with partner; converted bungalow</td>
<td></td>
</tr>
<tr>
<td>Mark</td>
<td>M</td>
<td>68</td>
<td>4</td>
<td>2</td>
<td>2</td>
<td>21</td>
<td>with wife; house</td>
<td></td>
</tr>
<tr>
<td>Mike</td>
<td>M</td>
<td>73</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>21</td>
<td>with wife and lodger; house</td>
<td></td>
</tr>
<tr>
<td>Richard</td>
<td>M</td>
<td>77</td>
<td>12</td>
<td>7</td>
<td>5</td>
<td>16</td>
<td>with wife; house</td>
<td></td>
</tr>
<tr>
<td>Wendy</td>
<td>F</td>
<td>75</td>
<td>6</td>
<td>3</td>
<td>3</td>
<td>20</td>
<td>with husband;</td>
<td></td>
</tr>
</tbody>
</table>
3.4.6 Data collection

I visited participants in their homes for approximately 9 hours each in one sitting, usually arriving at the home between 9-10am and departing between 6-7pm. During this time, I collected a large volume of data, only some of which feeds directly into this PhD project. For the purposes of clarity and transparency, I have tabulated the data I collected below (Table 3.4), and summarised if and how it features in this PhD project. Below the table, I have offered more information about the relevant primary data sources.

*Table 3.4: Phase II data types*

<table>
<thead>
<tr>
<th>Data source</th>
<th>Features in this PhD project?</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic information</td>
<td>Yes</td>
<td>Sample (section 3.4.5)</td>
</tr>
<tr>
<td>Field notes</td>
<td>Yes</td>
<td>Findings – Home-based observations (section 3.5)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mixed methods data triangulation (section 4.2)</td>
</tr>
<tr>
<td>Visual ethnographic mapping</td>
<td>Yes</td>
<td>Findings – Home-based observations (section 3.5)</td>
</tr>
<tr>
<td>Self-report measures</td>
<td>Yes</td>
<td>Mixed methods data triangulation (section 4.2)</td>
</tr>
<tr>
<td>Neuropsychology assessment</td>
<td>Yes</td>
<td>Mixed methods data triangulation (section 4.2)</td>
</tr>
<tr>
<td>Video data</td>
<td>Yes</td>
<td>Findings – Home-based observations (section 3.5)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mixed methods data triangulation (section 4.2)</td>
</tr>
<tr>
<td>Physiological data</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Room dimensions</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Luminance data</td>
<td>No</td>
<td>N/A</td>
</tr>
</tbody>
</table>
3.4.6.1 Field notes

I recorded my field notes on worksheets I had developed for the home visit (see Appendix 2.b) which had a small space for the time on the left hand side to allow me to align these with the video data. Knowing I had the video data to support me, these notes were mostly scribbled key words about what was happening when, who was involved and what we were talking about, and this brevity was helpful for ensuring I was mostly present with the participants and attending to the setting, noticing my thoughts and feelings and reactions rather than directly all my attention to remembering and writing. This was also helpful for rapport-building and ensuring the participants did not feel overly conscious that everything they were doing was being recorded or assessed. Though I did jot down some verbatim quotes which seemed key when I could, and even some initial interpretive or analytical thoughts, these were mostly as reminders to myself of where to focus my attention during analysis or further data collection, or things I should perhaps follow up on. I developed a couple of shorthand codes for myself including those outlined in Table 3.5.

Table 3.5: Field notes shorthand key

<table>
<thead>
<tr>
<th>Symbol</th>
<th>Key</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;&gt;</td>
<td>This is happening repeatedly</td>
</tr>
<tr>
<td>**</td>
<td>This seems key/important/significant and should definitely be revisited</td>
</tr>
<tr>
<td>?? [text]</td>
<td>Emerging analytic thoughts/analytic questions to verify</td>
</tr>
</tbody>
</table>

At the end of the day, either on the train home, once I was home or in two cases the following day, I wrote up what I called my ‘end of the day field notes’. These were not just a fuller version of the time log notes made during the day – there was some interpretation and analytical thinking involved as I wrote up my observations, thoughts and reflections in a way that captured what had seemed significant overall. What I considered to be significant changed over the course of each
individual visit, as well as over the longer term course of all the visits. Over the course of each person’s individual visit, I gradually became more attuned to what was being mentioned repeatedly and what participants seemed most enthusiastic and engaged in talking about or doing. This was sometimes made explicit in participants declaring, for example, ‘that’s what I miss the most’ or inferred by me in response to their enthused facial expression, increased pitch variation, and efforts to demonstrate an activity to me or even involve me in it. An example of the time log and end of day field notes for the participant Maurice are included in the Appendices as an example (see Appendix 6).

3.4.6.2 Visual ethnographic mapping

I drew freehand sketches of the layouts of the main areas of the homes I spent time with the participants in and indicated any points of note about how the participant had used the space during the course of the day, for example, if they had a certain chair that they mostly sat in, or if they made repeated journeys to a particular area of the home (e.g. Maurice carrying his mugs out to the kitchen). An illustrative example is included below (see Figure 3.1).
3.4.6.3 Measures

Three standardised self-report questionnaires were administered to gain a quantified measure of: any neuropsychiatric symptoms which may have been additionally impacting on the observed engagement with daily activities (Neuropsychiatric Inventory-Questionnaire (NPI-Q) – Kaufer et al., 2000); participant’s levels of functional independence in what are considered a standard set of ADLs (Johnson’s ADL Scale – Johnson et al., 2004); and participant’s Quality of Life (QoL-AD – Logsdon et al., 1999). These self-report scale items scores fed into the mixed methods data triangulation sessions (section 4.2), though this happened after the completion of the initial coding of the qualitative data. The mixed methods data was triangulated with a view to better understanding what (if any) qualitative or other information could be useful to supplement or contextualise such scores.
and vice versa, to add richness to the overall interpretation of the data. More
details about the questionnaires used and their administration is as follows, and
copies of all scales are included in the Appendices (see Appendix 4):

- **NPI-Q**: The NPI-Q is a validated brief version of NPI which provides an
  assessment of the presence of 12 neuropsychiatric symptoms over the
  previous month, including hallucinations, delusions, apathy, night-time
  disturbances and depression. It is completed by informants about the
  person they provide care for. Informants first rate if a symptom is
  present (Yes/No) and if it is, how severe the symptom is (mild, moderate
  or severe) and finally how distressing it is for the informant (not
  distressing at all, mildly, moderately, severely, extreme or very severely)
  (Kaufer et al., 2000);

- **Johnson’s ADL Scale**: This is an informant based assessment of
  functional abilities, designed for people with dementia, measuring
  functioning in the following six areas: self-care, household care,
  employment and recreation, shopping and money, travel, and
  communication. Each section has 3-6 items and each item is rated on a
  scale of 0 (no problem) to 3 (no longer able to perform the activity).
  Family carers are asked to rate the current level of functional ability
  relative to that before the PLWD began experiencing symptoms. The
  resultant score represents the level of severity of impairment as either
  none, mild, moderate or severe, and this is calculated overall and by
  subscale (Johnson et al., 2004);

- **QoL-AD**: The QoL-AD is a measure of various aspects of QoL completed
  by an informant and a PLWD (but in both cases refers to the PLWD’s
  QoL). It asks participants to rate areas of physical health, mental health,
  social and financial domains and overall QoL as either poor, fair, good or
  excellent (Logsdon et al., 1999).
3.4.6.4 Neuropsychology

All PCA participants completed a selection of neuropsychological tests of memory, language and visual processing skills (visuoperceptual and visuospatial). The tests and participant scores are described, triangulated and discussed in section 4.2 below (see Appendix 5 for examples of the stimuli).

3.4.6.5 Video data

Video recording was selected as a method of data collection which would allow a rich volume of data to be collected despite the relatively short period I was able to spend in each home, and was considered particularly suitable given the interest in observing people with PCA’s interactions with their physical environment. The video was also used to capture audio data – the informal conversations, verbal interactions and commentaries participants vocalised while doing, reflecting on or storytelling about their engagement with activities, or the objects and spaces associated with them. Video data was recorded on 360 degree cameras (4K; 360FLY) and wearable clip-on cameras (VEHO HD; MUVI). The 360 degree cameras captured the total-scene level of detail, for example how participants were using the space, their proximity to each other and objects, and so on. The wearable cameras were positioned on the participants’ and my collar or lapels to offer an audio-visual approximation of participant’s orientation and view of the world, and also offered useful close up recording of people’s interactions with objects.

3.4.6.6 Luminance, room dimensions, Empatica E4

I captured some measures of the physical properties of the home (room dimensions and luminance levels in each room) and passive physiological data (heart rate, 3-axis accelerometer data, electro dermal activity and skin temperature) using an Empatica E4 wristband on each wrist of the participants (I also wore two of these). This data was collected in line with the interests and concurrent or planned projects within the broader interdisciplinary ESRC-NIHR Seeing What They See project team and will not be further reported on or discussed here.
3.4.7 Data analysis

Here I will outline my particular method for data analysis, which, informed by the analytic techniques described above, was an iterative process of organising, classifying, interpreting, constantly comparing, triangulating, pattern-searching and naturalistic generalisation.

The first step in organising the data once out of the field was digitising it. This involved uploading video and audio files and typing up my time logs, end of day field notes and reflexivity notes. This was important not only to ensure it was safely stored but also so that it would become searchable electronically. It was also an opportunity for me to clarify and expand on any very brief key words or phrases I had noted, and for this purpose it was important that I typed up notes as soon as possible after the visits were completed. Scanning through the video files in order to label them appropriately and typing up the field notes was a really helpful re-immersion exercise – it helped me to keep the data feeling recent and tangible in my mind, reminded me of passing moments that may have seemed more significant on reflection and generally helped to ensure I stayed familiar with the data set.

By this point I was already memoing by building on any emerging analytic thoughts or questions I had had in the field, with the benefit of being able to follow these thoughts through. I also transcribed key moments of video data and audio conversations as I went along, and much of that later became the content for my case summaries (see Appendix 9) and the data extracts which feature in my findings (section 3.5) – this seemed to me to be an example of the intertwined and iterative processes of ethnographic data collection, analysis and write up I had been reading about (and have outlined here).

I used the qualitative data analysis software Atlas.ti (version 7) to help me classify my data segments. I imported all of my field notes (time logs and expanded versions) and applied codes to them to label both what was happening in terms of actions (e.g. ‘washing up’ ‘reading’) but also meanings (e.g. ‘feeling lonely’ ‘blaming
These codes could overlap according to the multiplicities of things going on and the varied meanings appearing to be constructed. This coding was also in part organisation, as these codes served as housekeeping labels, useful for quickly identifying all video data segments that were relevant to a given behaviour, concept or activity of interest (see Appendix 7 for a finalised list of my coding framework and screenshots highlighting examples of how these codes were applied). It was during this initial coding that two concepts which went on to be major components of two of my overarching themes – meaningful activity and preservation of self – were really cemented as key concepts. However, at this point it began to seem that the coding system was constraining my interpretations. I was aware that continuing the coding process would require me to break moments down further and further, but that this was beginning to make me lose the individual and contained ‘caseness’ of the holistic moments I had been immersed in with participants in the field.

At this point I wanted to be able to see whole sub units of analysis’s (i.e. individual participants) data rather than all the individual moments, but if I was going to be constantly comparing and synthesising across individuals I knew I also needed to be able to see all sub units at once, in a format that let me move them around to start playing with the order of them, to see what different combinations and groupings of them revealed to me. Here I began the ‘playing’ with the data that so much of my reading had described. I spent some time developing a method of visual display that would allow me to see some of the basic demographic and quantitative information, but most importantly, a representation of the key qualitative interpretations I was making about each person, in a rich but digestible format, that was manageable enough in size that I would be able to see all 20 sub units at once and easily move them around into different arrangements. I developed what I called my key case summary index cards (see Appendix 8 for pseudonymised versions of these).

These index cards allowed me to start playing with the data in the ways which allowed me to start thinking at a more abstract thematic level, while ensuring I was
holding each individual case in mind and not forgetting to constantly compare as I went.

3.4.7.1 Constant comparison – a working example

An example of how the analytic technique of constant comparison moved the analysis forward was with the activity of television viewing. A number of participants had spent some time watching television during the course of the day but I had very different reflexive notes about the ‘feel’ of that as an activity for different participants. I also noticed my own assumption that spending time in front of the television was passive, and an indication that someone was not being properly stimulated or engaged. When I compared the instances of television watching across individuals, I saw that for Eleanor and Lilian it seemed to be as I had assumed – far subordinate to the activities they expressed that they would have preferred to have been engaging with, whereas for Richard and Mandy, it seemed more a means for genuinely meaningful social interaction. For Richard this was keeping up to date with current affairs, for Mandy this was connecting socially with me and [Mandy’s partner] by chatting and joking repeatedly about what was happening on the screen. These comparisons of the instances of television watching led me to reflect on another comparison that could be made between these two pairs – that of their diagnoses, and eventually to the realisation that Eleanor and Lilian, for whom television watching seemed a much more passive and disengaged activity, also shared the same diagnosis. From here I made comparison with the remainder of the PCA group – were they engaging in passive disengaged activities and if not, why not? This then helped me to develop and articulate my interpretations about dyadic-related factors that could facilitate or act as a barrier to meaningful activity engagement, and an apparent dissociation between intention and action with regard to activity initiation in the PCA group. Constant comparisons also happened within individual sub units, for example following my
interpretation about Mandy’s motivation toward social engagement and Richard’s towards politics and current affairs, I then compared their television viewing with their other activities of the day to see if those same interests were demonstrated in other formats, to confirm my interpretations. Mandy had described liking to attend gym classes and volunteering at the local garden centre because they gave her a chance to chat and to see people, and Richard became most visibly animated and engaged in conversation when we came across a photograph of him involved in a peace protest many years earlier, both of which served to support my emerging interpretations.

The index cards could be easily organised according to dominant symptoms, gender, age, how long participants had lived in their homes, career type, etc., but once I had organised them into these varied formations, the rich qualitative data became my priority for consideration, in combination and comparatively. This allowed me to spot patterns, and to easily test those among other possible combinations or organisations of the cases and sub units of analysis. It also illuminated negative cases much more easily than my initial coding had, as that had broken the data down beyond sub units, so it had felt like an extra layer of intellectual work to keep each data segment’s case identity attached to it, whereas using this method, the moments of interest could not be separated from their case identities, so negative cases stood out much more clearly.

3.4.7.2 Negative cases – a working example

An example of negative cases and how they influenced the analytic process were with Anita and Betty and related to age. They both seemed to take a more accepting stance to their diagnosis and they were the two oldest participants in the study. Seeing them set apart in their outlook in this way informed my consideration of the age of the remaining participants and how it may have been impacting their adjustment to the necessary changes they
had had to make to their activity engagement. It prompted me to consider
the other health conditions that the older participants were dealing with in
addition to their tAD diagnoses, and how they had already been necessarily
limited in their activities prior to their diagnosis of dementia. It also
facilitated my realisation that one of the most significant shifts in activities
that the younger participants had recently faced because of their diagnoses
and their age was leaving employment.

When trying to fully conceptualise the patterns and themes I thought I was seeing
in the data, I then moved away again from individual sub units or cases and started
diagramming. Examples of these working thematic diagrams are included as
Appendix 10 for reference. I had moved towards a more abstract and necessarily
removed account of my data (i.e. patterns and themes, building towards more
naturalistic generalisations) and was feeling confident in this as a coherent overall
account of the main patterns I had interpreted from the observations. At this point,
it seemed that revisiting each individual case and writing them up in thick
description, in the format of answers to what I had eventually established as the
final iteration of my evolving research questions, would serve as a helpful, final
verification exercise. These case summaries are included as Appendix 9 for
reference.

Finally, something which happened throughout the data collection and analysis was
triangulation. As well as in the dialogue with theory and multiple data sources
outlined above (section 3.3), there was triangulation in the analysis stage as
multiple different data sources and my interpretations about them were juxtaposed
and used to test one another. There was also triangulation of investigators, as I
viewed data segments and my final thematic overview with four colleagues, all from
slightly different academic disciplines. We discussed and debated our different
interpretations and in case of interest, the nature of some of these conversations is
captured in the mixed methods data triangulation chapter (Chapter 4).
3.4.7.3 Data deletion

Given that the observations were unstructured, I spent some time at the start, end, and at one week follow up after the visit discussing with participants their rights to request the deletion of any video footage, as none of us could be sure in advance what might be captured within the eventual footage.

3.5 Findings

3.5.1 Case summaries

Each home visit resulted in a rich volume of data, including observational field notes, approx. 20 hours of video camera footage from one 360 degree and two wearable cameras, audio recordings, self-report scale scores and neuropsychological assessment scores. In order to make the data more manageable during analysis (see section 3.4.7), I consolidated the key data for each participant into one digestible document. As part of the data analysis procedure (and once the ‘key’ data had been identified), I created a case summary of approx. 1200 words per participant, i.e. each embedded unit of analysis within the two ‘cases’ under investigation (living with PCA and living with tAD). One is included here as an example and the remaining 19 can be found in Appendix 9 for reference. (I hope that these will help with providing context for each individual case and in bringing the home visits to life):

Example case summary – Martin

[Demographics and quantitative measures and general description of day/house]

Martin was a 73-year-old retired university head of education who had been diagnosed with PCA two years previously after first noticing symptoms four years prior to that. He lived at home with his wife, one daughter and two grandchildren. His MMSE score was 19 indicating moderate impairment and
he performed in the normal range on the memory and language parts of the neuropsychological assessment but showed impaired performance on the visual tasks. He was rated as being moderately impaired overall on ADL function and on the communication subscale, mildly impaired on the self-care subscale and severely impaired on all remaining subscales. Martin and his wife both rated his QoL as good.

What activities did people do? What activities were they motivated toward/interested in?

Martin showed keen interest and engagement in a range of activities throughout the day including bird-watching, dancing with his wife, looking through photo books of his family, reading and highlighting the newspaper, drying up, going out for a walk and preparing lunch. He was also engaged throughout the visit in conversations with [Martin’s wife] about current affairs, their 4 children and many grandchildren and films they had recently seen at the cinema. In interactions with me, Martin was particularly engaged in showing me books of birds, exercise books of the Japanese handwriting he’d studied previously and books of his drawings of canals and waterways from the school trips he’d previously organised.

How was engagement in those things/activities challenged?

Martin’s engaging with different activities was predominantly challenged by his impaired processing of visuoperceptual and visuospatial information. When birdwatching, Martin described that while he could see the bird when flying, it became a lot harder to see when it landed, and [Martin’s wife] added to this that he had much greater difficulty seeing larger birds than smaller ones, explaining ‘he can see the wren but he can’t see the heron’. He also had some difficulty in changing his slippers to shoes ahead of going for a walk in orienting the shoes the right way round and in sequencing, so he ended up putting a left slipper rather than a right shoe on his right foot.
When drying up Martin seemed to miss a couple of items and left them on the draining board, and he had some difficulty unfolding and opening the newspaper in order to read it. When dancing around the kitchen with [Martin’s wife] Martin appeared quite tense and unsure of his movements at times and his conversations with [Martin’s wife] were slightly challenged by his effortful speech throughout the day. When preparing lunch Martin seemed to have some difficulties seeing what was already on the plate and/or inhibiting his behaviour as he continued adding basil leaves to one plate until there was a disproportionate amount.

How was engagement in those things/activities supported?

Martin had slightly moderated his engagement with birdwatching and explained that he no longer went on trips or contributed to the community efforts in bird conservation but still enjoyed looking at and feeding the birds in the garden and at photos of them in books and on a Christmas card his son had sent him which he remarked on several times throughout the day. Martin and [Martin’s wife] were continuing to engage with dancing by applying similar simplification strategies to this, they were no longer going to local dance classes where partners would change around because Martin worried about not keeping up and therefore ‘letting people down’, but the two continued to dance at home in their kitchen. With the shoe/slipper confusion, [Martin’s wife] oversaw this and gave verbal instructions to Martin which he appeared to have some difficulty interpreting but which worked eventually. Martin persevered with the newspaper unfolding rather than asking for any help, and [Martin’s wife] sensitively and tactfully commented that everything looked OK and he was probably all done when she noticed (and indicated to me separately) the surplus basil leaves Martin had added to one of the lunch plates.
Why were those things important to that person? What purpose did they serve? What was the meaning of them?

Many of the activities Martin engaged in were long standing interests of his, e.g. birdwatching, dancing, reading and highlighting the newspaper and meal preparation. Continuing to participate in these activities seemed to offer Martin some maintenance of his identity and previous roles he had had within the household and the community. When talking of the community campaign to protect a certain type of a bird, he expressed some sadness as not being able to contribute to this in the same way he had previously and explained that causes such as that needed people to get involved and make the effort. While activities such as that and dancing had previously been much more participatory and contributory, it seemed as though the purpose of them had shifted somewhat towards this preservation of interests, because of the difficulties in engaging in the way Martin had previously. Similarly, within the household, [Martin’s wife] described how Martin had – counter to traditional gender roles – always been the one to prepare the food and had taken a great deal of time and care over the presentation of dishes (as he did on that day). Activities seemed to serve the purpose of maintaining these interests and at the same time, were achieved in a way that maintained Martin’s identity, independence and dignity as far as possible (i.e. in not drawing unnecessary attention to Martin’s difficulties) – [Martin’s wife] often deferred to Martin’s expertise and opinion and decision making and the two had a very intellectually balanced conversation about their shared interests throughout the day, they were also both equally grateful to the other for their contributions (e.g. Martin’s preparation of lunch and [Martin’s wife]’s of dinner). It seemed the preservation of engagement in activities offered them opportunities to also maintain the strong social connection they had always had. Another role Martin appeared to be preserving was that of teacher and educator, as when looking at the
various books which documented these long standing interests of his (birds, waterways, Japanese) he took time to teach me about them.

Engagement in meaningful activity was not a predefined area of interest before the observations began but it emerged over the course of the observational home visits as an area of everyday life that was at the intersection of the physical and psychosocial environments, and both significant to participants and impacted by their diagnoses (i.e. relevant to the overarching aims of this PhD study). The case summaries are therefore each structured around the same following 5 questions as in the example above:

- Who was being observed (essential demographic information and participant characteristics for context)?
- What activities did they do? What activities were they motivated toward/interested in?
- How was engagement in those activities challenged?
- How was engagement in those activities supported?
- Why were those things important to that person? What purpose did they serve? What was the meaning of them?

3.5.2 Observations about activities

Here I will describe what I observed in terms of some of the key symptoms and strategies demonstrated by each group, as they related to engagement with meaningful activities, before moving on to discuss my interpretations of what was observed. This section will essentially be a group-level consolidation of the information falling under Questions 3-4 in the case summaries: How was engagement in things/activities [of interest] challenged? How was engagement in those things/activities supported?

The stark differences in symptom profiles of the two groups were evident in most cases very soon after my arrival, for example those with tAD were much more likely
to ask repetitive questions about the plan for the day or to need reminding of who I was, where I had come from and what I was there for. On the contrary, those with PCA were much more likely to seem to recall me and the purpose of the visit but would more often have difficulty seeing or grasping my hand to shake it, or with leading me to the part of the home where we would begin filling in the paperwork. Now I will present some contrasting examples of how the observed difficulties (and any support strategies) manifested in relation to engagement with meaningful activities over the course of the day for the two diagnostic groups, supported by excerpts of the data.

3.5.2.1 Not seeing the whole picture / Not remembering all the steps

A common perceptual problem for the PCA group which impacted their effective engagement with meaningful activities was the phenomenon of struggling to see their whole visual field at once, as a full picture. This had been reported in the dyadic interviews, but the observations provided the opportunity to see these symptoms as they occurred in real-time, and allowed participants to offer a real-time verbal description of them, in the context in which they happened. For example, this affected Martin’s engagement with his favourite hobby of bird-watching, as he could no longer perceive some of the larger birds (which took up more of his visual field) but – quite counter intuitively perhaps – had relatively little trouble seeing the smaller birds. His wife explained ‘he can see the wren but he can’t see the heron’ (Martin, 73, male, PCA, MMSE: 19). Martin further demonstrated this inability to ‘see the whole picture’ when he was drying up and putting away items from the draining board - leaving some items in the bottom right hand corner after working quite thoroughly and consistently through the rest, as if not ‘seeing’ them at all.

Interesting parallels can be drawn here with participants in the tAD group doing similar activities to these, but facing different challenges with them. Helena
engaged in hanging laundry but needed to be prompted and then reminded several times to do it by her husband. However, once she had started the activity, she had no difficulty evenly placing the items across the airer, but then showed some difficulty with sequencing the different steps of the task, for example by hanging up some items from the ‘already dry’ pile to air.

3.5.2.2 Not seeing which room it is / Not knowing which room it is

Another common way their dominant visual processing problems impacted the PCA group’s engagement with activities was in difficulties with navigation and orientation within the home, for example the people with PCA demonstrated more difficulties with knowing which room they were in currently and/or where a designated room they wanted to reach was, or how to get themselves there. Sally demonstrated her disorientation when she asked me during our tour ‘am I in the wrong room? Are we in the orangey coloured room?’, explaining that she could not be sure because she could not see the rowing machine that she knew to be in that room (we were in fact in the right room and the rower was on the floor just in front of us both) (Sally, 64, female, PCA, MMSE: 19). Sally appeared to demonstrate well preserved factual knowledge and recollection of the setting, i.e. she could remember where things were in the house but her main difficulties were with those elements of the task(s) reliant on receiving reliable visuospatial and visuoperceptual information about the environment, and interpreting it correctly. This was fairly representative of the group – those with a diagnosis of PCA often had difficulty orienting themselves to spaces, finding their way out of one room and into another and being able to look for things efficiently, even though for the most part they knew where they wanted to look, to get to, or where something should be stored or could be found.

In contrast, members of the tAD group seemed to have little difficulty in safely or accurately navigating around the home per se, and any disorientation or inefficiencies in moving around it seemed to be more attributable to their
underlying dominant memory difficulties. Examples of this included having forgotten where we had already been on our tour, with Wendy asking ‘have we been in here already?’ (Wendy, 75, female, tAD, MMSE:20).

It is not difficult to infer the significant ways in which these kinds of visual processing problems and resulting difficulties with orientation and navigation within the home could challenge activity participation more generally. One participant, Eleanor, summarised the profound impact of the visual problems in particular when she commented ‘the dementia I can sort of fiddle about with but if you can’t see you can’t see’ (Eleanor, 74, female, PCA, MMSE: 20), and seemed to be emphasising the manageability of the other features more characteristic of typical dementia. Disorientation or navigational problems were also an issue for participants when the activity they wanted to engage in was to take place in another area of the home, or when the activity involved materials located in another part of the home.

These challenges that the PCA group had with perceiving the whole visual field or navigating whole physical spaces were accompanied by challenges with interactions with objects too. Specifically, people demonstrated difficulties with finding, perceiving, recognising, reaching for, grasping, putting down and otherwise manipulating the various objects required for their activities of choice, as had been reported in the dyadic interviews. Some examples (and how these differed to the tAD group) will be outlined now.

3.5.2.3 Not seeing an object / Not remembering where it goes

Those with PCA had observable difficulties with finding things, whether that was because of them not perceiving the item they were looking for (even if it was right in front of them), or because of their more global difficulties with navigating and orienting to objects and spaces within the home, all of which posed challenges to their engagement with activities. Importantly though, this was in contrast to the tAD group who had more often forgotten what they were looking for, where they had put something or where it should go.
Examples from the PCA group included Alan’s wife commenting that he would ‘stand in front of the towel rail saying where are the towels?’ and that ‘things [you] tend to see are things in the wrong place, certain things jump out like leaves or crumbs, but looking for a cup in a cupboard of cups it wouldn’t jump out’ (Alan, 64, male, PCA, MMSE: 5).

Difficulties with finding things seemed qualitatively different for those with tAD in that they were much more to do with a dominant difficulty with remembering where things were, or should go, or having trouble holding this information in mind while also carrying out another sequenced task which required concentration and attention. Brian, when making coffee and crumpets, appeared to experience some confusion and some difficulties with sequencing his actions, as well as with recalling where things were kept – he left several cupboards open, the tap running and the kettle off its stand before saying playfully to me when I asked if I could help ‘you can help me look for the food if you like!’ (Brian, 75, male, tAD, MMSE: 30). Once again, the two different groups displayed difficulties with engaging with activities in ways that could appear similar at a surface level, but which throughout the course of more thorough observation, could be attributed to different underlying cognitive deficits.

3.5.2.4 Not telling one object from another / Not remembering the task

The PCA group also demonstrated difficulties with identifying or recognising objects, or telling them apart from one another. For example, Alan could manage leave-clearing on the front driveway, but had to be supervised in the back garden because he could not tell the dead leaves which needed clearing apart from the leaves which were still attached to plants and growing.

In contrast, when Wendy was gardening, she had no difficulty telling the very steep steps up to their treehouse from one another, or in discriminating between the many different flowering plants she was showing me, but she quite often became
disoriented to tasks and had to be reoriented to them by her husband. During our
garden tour [Wendy's husband] had to remind her she’d previously expressed she
was very keen to move a certain piece of furniture they were in the middle of
restoring, and every time he reminded her of this she agreed enthusiastically that
this was the case.

3.5.2.5 Not seeing the letters clearly when reading / Not recalling
the story
The activity that was most commonly and consistently challenged for the PCA group
owing to their perceptual problems was reading. Simon described it as lettering ‘all
merges into one lump and doesn’t seem to be what I’m looking for’ (Simon, 62,
male, PCA, MMSE: 28). As another example, Maurice had previously been a regular
reader of a computing magazine he had a subscription to, and he had stacks of
copies of these magazines throughout the home. He picked one up to look through
during the afternoon, though when I asked if he was able to read the text in the
magazine he explained ‘oh I suppose not, now that you ask’ (Maurice, 79, male,
PCA, MMSE: 17), but continued to flick through nonetheless, once more, suggesting
that there are many more aspects of activities which encourage engagement with
them than simply how able one is to complete them.

These examples were again in striking contrast to the impact the tAD group’s
dominant symptoms were having on their reading experiences. For example, Anita
had continued reading but admitted she no longer recalled the details of the stories
she read (Anita, 88, female, tAD, MMSE: 27). Similarly, Brian’s reading experience
was challenged by his memory problems in that he could not reliably recall the
names and histories of some characters when reading complex books with multiple
intersecting plotlines. He dealt with this by keeping notes for himself inside the
inside cover of the book he was reading that he could refer back to when needed.
3.5.2.6 Seeing what to do with an object / Remembering what to do with an object

The PCA group 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 day-to-day activities. This interaction with objects relies on accurate visual and spatial information about where objects are but also one’s proximity and position in relation to them (proprioceptive information), something else known to be often compromised for people with PCA (e.g. Caine, 2004; Borruat, 2013). The extent of the proprioceptive difficulties experienced in the PCA group were well articulated by 9 of the 10 participants, and their descriptions help to explain exactly how profoundly their symptoms could impact on their abilities to interact with objects and their physical environment confidently and reliably. 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’ and ‘I’m not looking where I should be looking’ (Maurice, 79, male, PCA, MMSE: 17). These examples help to demonstrate just how debilitating this specific combination of symptoms could be, as one might hope to be able to rely on their sense of touch and space if unable to see clearly, but in the PCA group that was often another channel of confused input.

Examples of these sorts of between-group differences in object-manipulation difficulties included using the television remote, for two of the participants who spent significant amounts of the day watching television. Eleanor, who had PCA, 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 (and what she was aiming to do) as she did it, but she had to make several attempts before she accurately managed to get her thumb to touch the button. A transcript of her interaction with [Eleanor’s partner] and the remote control outlines this effortful process:
[Eleanor’s partner]: Normally I would put it on for Eleanor [the TV], but do you want to have a go at putting it on as if I wasn’t here? I don’t know if you want to try?

Eleanor: Well I seem to manage don’t I [orients to ‘gadget corner’ - table with different assistive technology laid out]. See there’s all this other stuff here that throws my eyes a bit - tell me where it is [Eleanor’s partner] please [facing table, tentatively reaches hand forwards]. Is this the flipper?

[Eleanor’s partner]: Yes that’s the flipper

Eleanor: [feels for it] Got that. [Picks it up somewhat awkwardly/uncertainly]

[Eleanor’s partner]: All you have to do is press the green button once

Eleanor: It’s this one up the top isn’t it [pushes silver plastic casing, missing the button]. Well it’s not on

[Eleanor’s partner]: You have to switch it on by pressing the green button

Eleanor: I have done [pushes silver plastic casing again]

[Eleanor’s partner]: Well wait – you have now

Eleanor: I had before

[Eleanor’s partner]: You might’ve switched it off again. Just try pressing it once. If the little red light doesn’t come on you haven’t pressed it properly

Eleanor: I keep pressing little red lights [tilts control vertically to look at it]

[Eleanor’s partner]: Point it at the screen

Eleanor: Well I haven’t got anywhere yet [Eleanor’s partner]

[Eleanor’s partner]: You’re on the right button at the top
Eleanor: Yes I know – I’ve been on that button 3 times

[Eleanor’s partner]: You have to point it at the screen, over there [gestures]. The green button - are you not pressing the green button Eleanor?

Eleanor: Well I can’t see it

EMMA: So is it that sometimes it works and sometimes it doesn’t?

Eleanor: It’s me that doesn’t work! [laughs]

(Eleanor, 74, female, PCA, MMSE: 20)

Throughout, Eleanor demonstrated good awareness of what she was intending to do and good understanding of [Eleanor’s partner]’s instructions, but it was her ability to coordinate her actions in line with these which was challenged, making the process effortful and convoluted.

This differed from Mandy, who had tAD but also spent the majority of the day watching television. Mandy seemed to refer to the difficulty she could have with the task of turning on the television when she said ‘right let’s muck this up’ as she picked up the remote to attempt to turn the television on, but when she managed to make it work first time commented ‘oh, it’s done it itself’ which seemed to suggest some surprise at it having worked and also potentially some uncertainty as to exactly what she had done to make it happen, by implying that it had just turned on automatically (Mandy, 72, female, tAD, MMSE: 19). It seemed as though these intermittent difficulties were more to do with Mandy’s fluctuating memory of how to use the control or with executive functioning deficits challenging Mandy’s ability to grasp the sequencing of the button presses required. Her dominant memory problems were further made evident when she asked her partner if they had a television in their bedroom as she could not remember, and in her repetitive questions and comments to me as we watched television together (e.g. ‘Do you
watch much of this?’ ‘Could you do that? [re: Winter Olympic sport]’ (Mandy, 72, female, tAD, MMSE: 19)).

Simon displayed a similar awareness to Eleanor of what he was aiming to do when he described trying to type a message on his phone, saying ‘I sit there for quite a period thinking where’s the H, I used it just a minute ago’ (Simon, 62, male, PCA, MMSE: 28), highlighting that he knew what he was looking for and also that it was not his memory making things difficult, as he recalled having recently used the key he now needed. Anita on the other hand displayed what seemed more similar to the confusion or poor recollection of steps that Mandy had exhibited, when she answered the telephone, saying ‘Which button do I press? My [registered blind] husband’s better at this than I am...that should tell you something!’ (Anita, 88, female, tAD, MMSE: 27). In making reference to her husband’s visual problems Anita made clear that the problem she was having was not with seeing the buttons.

3.5.2.7 Supportive strategies: making it easier to see / Making it easier to remember

As much as the underlying nature of the difficulties varied by group, so too did some of the supportive strategies employed to help people keep doing the activities that were important to them, but there was also some overlap here – especially regarding carers providing hands on assistance and guidance.

Generally, the group with PCA would use techniques to simplify or familiarise the visual or spatial input associated with an activity. This was achieved in a wide range of ways and involved a range of actors, as reported in the dyadic interviews. Commonly used strategies included adaptations to the environment (e.g. bold and clear notes or labels with key words, colour contrast to make things stand out, more evenly distributed lighting to minimise shadows, night lights guiding the way to the bathroom); intrapersonal factors such as relying more on other senses like memory (e.g. keeping things in the same place - Sally said ‘All my underwear and socks and things are in these cupboards...they’ve always been there so I know where they are’
perceiving and taking more time; and interpersonal strategies like asking for or receiving physical assistance or verbal guidance from a family member. Most of these strategies seemed to serve to relieve the dominant visual processing difficulties by minimising any potentially confusing or otherwise unhelpful sensory input.

Supportive strategies to prolong engagement in activities of interest for the group with tAD sometimes also relied on simplification and familiarity, but in contrast to the PCA group, with the aim of aiding recall or compensating for executive function or attentional impairments, rather than addressing more visuospatial and visuoperceptual deficits. For example, for the tAD group simplification often meant breaking tasks down into smaller steps and repeating instructions, and familiarity often meant keeping things in the same place as they had always been kept. Strategies were also more often based around reminding and prompting (e.g. written and verbal reminders, or physical demonstrations as reminders of what needed doing), speaking more explicitly to the dominant memory difficulties of this group. Participants with tAD also often needed reorienting to a task if they had become distracted or forgotten what they were doing or become 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 despite her sequencing difficulties, 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’ (Helena, 75, female tAD, MMSE: 10).

Although these strategies varied quite distinctly in their format and the symptoms they were trying to support, there were also many factors in why these strategies were arrived at and what their implementation meant for participants which were similar across the groups, or variable according to factors other than people’s
diagnosis, and these will be reported on more fully in the section following this one (3.5.3).

When thinking about how activities were supported, PLWD and their carer’s understandings of their condition and the symptoms it was causing was a really important determining factor in how support strategies were negotiated, developed and delivered. Owing to the relatively well preserved memory and insight that is characteristic of PCA (e.g. Croisile, 2004; Mendez, Ghajarania and Perryman, 2002; Crutch, Yong and Shakespeare, 2016), the PCA group could usually offer a very articulate account of their symptoms and in most cases had discussed this at length with their family members who were, as a result, very informed about the symptoms and how they impacted the person’s day-to-day interactions with their environment. However, there were a few cases where couples did not have not such an open dialogue and this meant that carers were more likely to (mis)attribute their family member’s PCA-related difficulty as owing to some form of memory or executive function problem. When Lilian mistook her gym pumps for her boots, [Lilian’s husband] commented ‘it’s the recall’ (Lilian, 70, female, PCA, MMSE: 14), he also, after Lilian failed to recognise faces shown in photos on an iPad (likely made more difficult/uncomfortable because of the glare), queried how much it was a matter of Lilian’s concentration. This was further demonstrated by Rhian’s husband and daughter who asked a series of questions throughout the day to seemingly test or check Rhian’s memory, such as whether she remembered where a certain room in the house was, which, once we were alone, Rhian (slowly and effortfully, owing to her speech problems) assured me that she did. It was striking that one of the activities Rhian’s family encouraged her to do to fill the time she could no longer spend socialising (much to her disappointment) was playing a word game on an iPad, heavily reliant on visuospatial navigation and accurate perception. This was another example of how the physical and psychosocial environments intersected, as Rhian’s abilities and needs in the psychosocial domain were perhaps underestimated, and she was encouraged to take part in an activity instead which
was heavily dependent on navigating the physical environment, which she had great difficulty with. Somewhat ironically, Rhian’s difficulties with this (owing to her PCA symptoms), actually ended up resulting in her having quite a long social interaction with her daughter, who attended to help her with selecting and moving the correct items across the iPad screen. Here, the two environments intersected in the sense that hands on help and the social interaction which came with it, increased Rhian’s ability to participate. In the PCA group there was therefore a greater ability to give an accurate account of their experiences and also a greater need for this, as their symptoms were so far removed from what one might assume about more typical forms of dementia. These relative strengths in communicating the difficulties echoed those reported on in the interviews. However, also echoing the interview findings, the extent to which this knowledge exchange actually happened was contingent on a range of other psychosocial factors such as different carer’s willingness, openness and motivation to take on board the perspective of their family member (which was in almost all cases very high). The tAD carers were in some cases less able to have these conversations with their family members about their precise experience of their symptoms and the impact, but they also tended to demonstrate much more of a general understanding and assumptions about the key symptoms of AD, which was able to guide the way they supported their family member’s engagement with activities.

I am now going to revert to a slightly earlier step in the process of activity engagement to outline some differences observed in subsections of the groups, relating to how activities were initiated in the first place.

3.5.2.8 Independent initiation of activities and actual or assumed apathy

As well as observing difficulties with the carrying out of daily activities and the coping strategies developed to help with them, I also observed group-level differences in participants’ motivation and ability to independently initiate
activities, and in turn how this was interpreted and responded to by family carers. The groups were not homogenous in this as it varied greatly by stage of disease, but there was a definite trend within each group which was illuminated when they were compared to each other. Because of the PCA symptom profile outlined above and the group’s consequent difficulty in interacting with the physical space and objects within it, the majority had profound difficulty in independently initiating the activities they wanted to. Eleanor 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’ (Eleanor, 74, female, PCA, MMSE: 20), stressing the pervasive impact of her not being able to see and perceive clearly on her ability to orchestrate doing almost anything.

The key distinction between these subsections of the groups was this notion of wanting to do things. So even though the PCA group struggled profoundly to carry out the many meaningful activities just listed, those at all stages of PCA demonstrated well preserved articulation of their preferences regarding activities – they knew what they wanted to do but they could not independently initiate it in many cases. It was perhaps their characteristic relatively well-preserved insight, ability to articulate and memory (compared to the tAD group), (e.g. Croisile, 2004; Mendez, Ghajarania and Perryman, 2002; Crutch, Yong and Shakespeare, 2016) which made the PCA group much more likely to engage with their activities of interest verbally, or socially (if not physically), either by story-telling to me or in conversation with family members or others who were present. This relatively well preserved recollection and articulation also seemed to make the PCA group – in keeping with earlier findings from the phase I interviews – more likely to be joint consultees and decision makers with regards to the delivery and design of strategies to support activities, though the extent to which this happened varied as much according to personality and previous relationship factors as diagnosis, and will be touched on further in the following section.
The tAD group differed on the whole (and again within the group according to stage) in that the participants were mostly physically capable of doing most of what most activities involved, or at least did not have the same profound visual and spatial processing difficulties as a barrier to engaging with spaces and objects, but as a group they were less likely to independently initiate such activities or to express so clearly their motivation towards specific activities. Some had to be encouraged to participate, for example [Wendy’s husband] repeatedly prompted Wendy to decide on a next activity from a shortlist he had put together based on various hobbies she had always enjoyed and specific tasks she had mentioned wanting to get finished (furniture restoration, gardening, cross-stitch).

Others were motivated to engage in something (e.g. something helpful), but without any clear preferences about what that activity might be or entail, for example Richard regularly went to his wife to ask what he could do to help, and agreed to tasks such as folding the laundry even when it became clear he was unsure of how to complete them. For the subsection of tAD participants who demonstrated a lack of activity initiation, this seemed like a quite classic manifestation of apathy, and a proportion of them (n=4) were rated as showing apathy by their caregivers on the NPI. However for the PCA group, of which the same number were rated as showing apathy (n=4), this seemed to be instead a more apparent apathy which could be misinterpreted or misattributed by caregivers – specifically those caregivers who (because of the existing relationship dynamics hinted at above) might have been more likely to take their partner or parent’s lack of engagement at face value as disinterest, without interrogating it further or having those kinds of collaborative conversations about activity preference and support needed as described above. In my (albeit necessarily limited) experience during the course of the home visits, all four of the PCA participants who were rated as exhibiting apathy clearly articulated to me the sorts of activities they would like to be involved in and would be initiating themselves if they were able to. Their debilitating symptom profile seemed to interact with
several possible barriers to them collaborating with their partner to foster the enablement of these activities, whether this was the PLWD not wanting to be reliant or a burden, the caregiver appearing not to be very attuned to, motivated towards or otherwise able to meet the PLWD’s needs regarding activity participation, or some combination of these. As with the other difficulties described above (e.g. problems finding things and manipulating objects) which, despite appearing quite similarly at surface level, were in fact underpinned by very different sets of cognitive impairments, the (mis)interpretation of apathy here seemed to be made possible by this same set of distinct symptoms: relatively well preserved insight, awareness, articulation and motivation to engage coupled with profound impairments in receiving, processing and interpreting visual and spatial information from the environment. The groups also differed here in terms of how this apparent, actual or attributed apathy was responded to – there was less of the joint decision making and collaborative conversation around activity initiation and engagement in the tAD group, especially for those who were further into their disease progression, and where this apparent apathy was attempted to be supported, this often happened via caregivers orchestrating, encouraging or otherwise selecting and supporting activities seemingly on behalf of their family member with AD (as opposed to in conversation with).

Another way the tAD group initiated and engaged with activities which was distinct from the PCA group was via environmental cueing. Often the physical environment would provide some sort of cue which seemed to encourage engagement of the person with tAD in a given activity. This fits with Majlesi’s recent findings (2019) that the spatial positioning of objects, and therefore the order in which PLWD perceive or attend to them, can significantly influence the order in which activities associated with the objects are then completed. The activities and objects engaged with in this study via environmental cueing could be meaningful or seemingly quite arbitrary, and Betty provided good examples of both of these. An example of apparently meaningful environmental cueing was in relation to the garden and
home improvements, which Betty had always had a keen interest in. When looking out to the garden she outlined her plans for developing it as follows:

Betty: I think I must get that door [gate] painted because it’s all in a bit of a mess

EMMA: Which door, the one outside? [i.e. gate]

Betty: Mmhmm. That fence there which we put up – it seems to be going mad

///

Betty: I don’t like that door [gate] it’s all sorts of bits and pieces. I mean I’ve never seen anything made of so many things. It’s stupid isn’t it.

Betty: I’ve started out there because I wanted I don’t know they look a bit tatty out there and that’s my next movement, I mean I’ve got all the flowers and things it’s just a few little bits that I want to do. Ages ago I thought well I’ll put a swimming pool and then I thought, what am I going to do that for? Cause I mean it goes back quite a long way here [gesturing to the length of garden behind us]

EMMA: Do you like swimming?

Betty: mmm. I like lots of things actually because I liked tennis and I liked swimming but now I have to make an effort

EMMA: Right, it’s harder to do things?

Betty: mmm. so I sit and say oh yes I always used to swim a lot [chuckles] never mind, I’ve done it all so it doesn’t matter does it [chuckles]

(Betty, 88, female, tAD, MMSE: 15)

The richness of commentary this environmental cueing encouraged, in which Betty was prompted to refer to both past history and future plans, all spurred on by the noticing of the garden gate, was in contrast to what seemed to be the far more
arbitrary cueing which happened when Betty was still at the table after lunch. The table was covered with a spotted tablecloth, which Betty began to wipe and smooth over as if removing crumbs, but which gradually became a repetitive pattern of her moving her fingers from one dot to another, and another, and so on. Despite the apparent arbitrary nature of this engagement with the environment, Betty did appear to be aware of what she was doing as when she offered to help with tidying up she delayed her assistance saying ‘I’m just doing these dots’ (Betty, 88, female, tAD, MMSE: 15), highlighting again the complex interplay of factors and functions involved in determining one’s actions, movements and behaviours.

The PCA group did not appear to demonstrate this environmental cueing towards activities, possibly because of their difficulties in accurately perceiving the environment around them and the objects within it, but also because of what seemed to be relatively well preserved ‘top-down’ motivation towards activities, memory for how activities should be executed and the ability and inclination to articulate when and how help with doing so might be required.

So far I have been describing observations I made regarding the different ways activities were challenged and supported, and how participants’ motivation to engage with activities manifested and was interpreted differently in the two groups. Now, I will move on to set out my interpretations of what these observations can tell us about what ongoing engagement in activities of choice means to people with these two kinds of dementia, the purpose of it and why it is persevered with, despite the difficulties encountered. Said another way, if the above section (3.5.2) was about the ‘how’s of activities, this following section (3.5.3) will be about the ‘what’s and ‘why’s of activities (Questions 2 and 5 of the case summaries). This section is organised into three overarching themes: (1) The fun and the function; (2) Reciprocities of care and (3) The constitution and continuity of a changing self.
3.5.3 Interpretations about activities

3.5.3.1 Theme 1: The fun and the function

3.5.3.1.1 Introduction

This theme is essentially about the varied purposes of the different activities undertaken – what activities did people choose to spend their time on and what were the purposes of them? The literature on activity in dementia is broadly divided into that which uses a predetermined set of activities (ADLs) as a marker of functional independence in (e.g.) screening and diagnosis of dementia, determining care needs, treatment outcomes and for ongoing clinical evaluations (e.g. Castilla-Rilo et al., 2007; Sikkes et al., 2009; Garrido-Pedrosa, Sala and Obradors, 2017; Smallfield and Heckenlaible, 2017; Koo et al., 2018), and that centred on conceptualising ‘meaningful activities’ and/or implementing therapeutic interventions utilising them to improve outcomes such as agitation and quality of life (e.g. Vernooij-Dassen, 2007; Han et al., 2016; Nyman and Szymczynska, 2016). These research areas are both set against a theoretical context which positions engagement in activities as important for the continued involvement, participation and independence of people as part of healthy ageing (e.g. Havighurst, 1961; Atchley, 1999).

Given that participants in this study engaged in a wide range of activities and for a wide range of reasons, what can the observations above of this variation in activity tell us about what’s important for people in ongoing activity engagement, in their home environments, and if, how and why we should support it? In looking at what this variation in type of activity can tell us, this theme also explores the varying possible outcomes of activities and what these meant to participants – did people want to do things well, quickly, easily, or any which way as long as the activity was of interest and the experience of ‘doing’ was a positive one?
It seems obvious to state that participants were motivated to do activities for ‘fun’, but this seems like an important point to note explicitly given that the activity in dementia literature is so often dominated by the more essential, functional ADL conceptualisation of activities. The interview findings highlighted the particular impact of the symptoms on hobbies and leisure activities of interest, owing largely to the early age of onset of PCA meaning participants had often had to stop working, and this being a time at which they had been preparing to allocate much of their available retirement time to just these sorts of activities. This extended across both groups, and participants of all ages, during the observations, in which there were large portions of the day outside of the completion of essential ADL activities such as washing and dressing, in which people were motivated to and found ways to engage with activities in which they found pleasure, enjoyment, interest, satisfaction, fulfilment and/or other forms of meaning. These included gardening, listening to and playing music, watching television, reading and doing puzzles. For example, Sally spent most of the day listening to music and gardening. In being the non-essential activities, and therefore activities of choice, it was these (often) fun activities which seemed most important and motivating for the majority of participants, and while here I am highlighting the variation and the importance of fun activities undertaken, in the third theme I will outline some of my interpretations about why it seemed that these particular fun activities were important to participants. The varied weightings of importance in the disruption or maintenance of these activities also support the Stress Process Model’s division of global and situational secondary strains, and further build a case for the model’s development to incorporate situational and global coping strategies, like those seen here.

The more ‘functional’ activities completed by participants in both groups included laundry, washing dishes, hoovering and bed-making, and there were indeed some participants who spent most of their day on these sorts of tasks. Of his preference for more ‘functional’ activities, Alan’s wife said:
He’s got his Hi-Fi system there…occasionally he puts his super expensive headphones on and sits in that swivel chair there and listens to a CD there but…he thinks…i think he thinks it’s wrong to sit down and do nothing…he’s sort of always thought he should be doing things and it’s wasting time to sit and relax. So he’ll be up doing what he’s doing now [picking up leaves] rather than sit and listen to music.

And Alan himself explained his own motivations for leave-clearing as follows:

Alan: It’s something…it’s hands on

EMMA: You like that?

Alan: Yes. It’s very satisfying, even when it’s raining, unless it’s too cold

EMMA: Have you always liked the garden?

Alan: Yes but cars. When that went, [shaking head] honestly. That was my existence. It’s just gone

EMMA: Have you always done this [leave-clearing]?

Alan: Yes there’s nothing else to do

EMMA: Did you used to do this?

Alan: No cars

EMMA: So this is a bit of a replacement for that?

Alan: I want to do something

(Alan, 64, male, PCA, MMSE: 5)

Alan was explicit in stating that he wanted to be engaged in doing something, and something hands on, something the leave clearing he is motivated to do currently shares with his previous main pastime of cars. This significance of this motivation in driving Alan’s behaviour was endorsed by his wife’s comment that he was reluctant to sit and listen to music even with the facilities he had for that (e.g. a good chair
and high quality headphones), which might be considered by many to be much more preferable to those of the garden in the rain, which Alan himself declared would not disrupt his leave-clearing.

For a handful of participants, it was actually these sorts of functional tasks which seemed to hold the most meaning, prompting further distinction between the essential ADL tasks that were only a means to an end, and those which served a purpose above and beyond their objective completion. The fun and the functional were not mutually exclusive – activities could be functional and still provide fulfilment, meaning and satisfaction. For example, dressing and grooming appeared to be an important activity which held significant meaning for Eleanor, and not just a case of a task to get finished.

The significance of dressing for Eleanor was captured in this section of field notes I took when on the tour of the home with her partner:

...came into Eleanor’s bedroom where there were labels on the drawers (re: items/colours) and [Eleanor’s partner] said those no longer help/never really did and are more to help her organise Eleanor’s things now than for Eleanor herself; Eleanor all in blue today and there were a selection of blue jackets/cardigans left out on the bed that [Eleanor’s partner] had had to put away; Eleanor very indecisive about what she wants to wear; got completely changed after initial getting ready today; gets frustrated with [Eleanor’s partner] if she tries to help; [Eleanor’s partner] tends to leave her to it and tidy up afterwards now because of frustration but tries to point Eleanor in right direction if possible

(Eleanor, 74, female, PCA, MMSE: 20)

The multiple blue jackets laid out on the bed were an indication of the careful decision-making Eleanor had done about her outfit, as well as how much value she placed on her independence in this activity, further supported by her resistance to [Eleanor’s partner]’s input.
3.5.3.1.2 Choice and preference

Exactly what the prioritised activities were varied a lot across the participants, and the variation in this seemed to relate to the time of life of participants too – they were all retired from full time employment and so all had the majority of their day available as unspecified free time that they could choose what to do with. Very few had fixed commitments which permitted me valuable insight into the nature of those chosen activities, these often being the things people seemed most engaged in or motivated towards. In considering the decisions made around what to do, it was clear the range of activities selected served a range of purposes, and carried a range of meanings for the participants. There was also between-participant variation in which of these categories even the same activities fell into, and in the meanings of them. Reading was one activity which served a differentially fun or functional purpose for participants – difficulties with reading for Simon disrupted his ability to do the family accounts, whereas for Sally and Anita, reading was much more engaged with or missed for the entertainment and enjoyment it provided. For Mandy, watching TV offered an opportunity for social connection and entertainment, whereas for Eleanor it was one of the only things she spent her time doing, and appeared to be low priority and a poor substitute for the work and socialising she would have much preferred to have been able to orchestrate. Overall, participants were as differentially engaged in and motivated towards as broad a range of activities as any of us might be, and the self-determined agency with which people made active selections about the activities they were prioritising seemed to be a one way in which participants expressed their enduring citizenship and selfhood.

3.5.3.1.3 Process over outcome; engagement over efficiency

Another component of this theme of 'The fun and the function' relates to the variation in the preference and purpose of activities but this time in terms of the process of them (as well as the outcome). I observed that it was not only the (functional) output of an activity that was prioritised and gave meaning, but that
the enjoyment and fulfilment (fun) that people gained while engaging with activities were also critical in participants’ selection and support of activities to engage with, across both groups. Things which are often priority outcomes in activities such as how accurately (efficiency) and quickly (speed) they can be completed, appeared to be less of a priority for both groups compared to the sense of enjoyment, purpose, meaning, connection and maintenance of identity that activities could provide. The importance of activity engagement for sense of meaning, purpose, and maintenance of identity will be covered further in the third theme, ‘The constitution and continuity of a changing self’, but here the central point is that in addition to doing things for ‘fun’ (i.e. the end-point or output of an activity is enjoyment, pleasure, interest, etc.), participants in both groups also wanted to have ‘fun’ while doing things, or at least seemed to prioritise the experiential rather than measurable outcomes of activities. A poignant example of this was Alan’s clearing of the leaves in the garden. His fragmented perception meant that he needed to make several laps of the front driveway in order to perceive and clear all of the leaves. This was not a particularly efficient way of the leaves being cleared, owing to his perceptual problems, and it would undoubtedly have been much more efficient for the couple’s gardener to take on this extra task (and he most likely would have used a tool rather than his hands). However, regardless of these inefficiencies, this was now the activity that Alan was spending most of his time doing, illustrating that there was more to be gained from it than the simply functional output of a clearer driveway. More about exactly what Alan may have gained from this activity will be explored in the third theme ‘The constitution and continuity of a changing self’.

The same arguable ‘inefficiency’ was observed with Richard’s loading of the dishwasher, when part way through he began moving items straight from the sink onto the draining board, bypassing the dishwasher altogether. This meant that [Richard’s wife] then had to later return to the task to correct Richard’s attempt, by double checking that everything that needed to be washed had indeed made it into the dishwasher. It would have been much more efficient for [Richard’s wife] to have
completed the task herself in the first instance, so the fact that this is not what happened during the observation attests to there being something else to be gained from Richard’s engagement in this activity, an alternative priority outcome. This pattern of continued engagement despite inefficiencies and alternative priority outcomes also applied to other household tasks that Richard undertook that day including folding laundry and setting the table.

In most cases couples shared these (adjusted) priority outcomes for activities, and sometimes priority outcomes differed from person to person but were compatible, for example Alan’s leave-clearing allowed his wife some time alone to do some admin and errands. Occasionally however, priorities were conflicting or incompatible, as illustrated in the phase I interviews with the example of the gentleman who wanted to go walking alone but whose wife thought it too risky. This could be a source of tension, for example Simon explained it could take him as long as two hours to measure something these days because of his PCA symptoms, something his wife felt he should not ‘waste two hours’ on, but Simon explained ‘I’ve got two hours to waste’ (Simon, 62, male, PCA, MMSE: 28). These different interpretations seemed to reflect the dyad’s different time schedules, in that while [Simon’s wife] was still working, Simon had retired early and now spent most of his time developing strategies to support his ongoing use of the computer at home, for both fun activities like researching holidays and functional activities, such as organising the family’s finances. This was similarly reflected by Maurice and [Maurice’s wife]’s differential interpretations of his afternoon doze – [Maurice’s wife] commented in an aside to me as though it was a relaxing luxury, but Maurice was visibly saddened when he described it as a waste of his time, segueing into a conversation about how much he missed being as busy as he had been in his previous career as a print floor manager.

The way these activities were persevered with despite the observed inefficiencies also highlighted the fact that people’s abilities were changing gradually over time, so it was not the case that someone would suddenly have the specific level of
difficulty that I observed with a given activity, rather that these patterns of difficulty had been developing slowly and insidiously over time, and so any decision-making around what should be persevered with was an ongoing process of negotiation and adjustment, among all parties. Additionally, the sorts of differences in appraisals that have been outlined exemplify those points at which the two variations of the Stress Process Model would need to map onto one another in order to capture this joint negotiation of difficulties and the tensions that can arise more fully.

3.5.3.1.4 Modified modes of engagement
Still wanting to engage in things that were ‘fun’ and enjoyable, and this focus on the process of engaging with an activity rather than solely with whatever the outcome of it might be, saw participants in both groups embarking on modified modes of engagement with activities of interest. Participants were generally more likely to be motivated to prolong their engagement with an activity even if this could not be executed in the same way as it would have been prior to their diagnosis or the onset of symptoms (i.e. even if they could not do it as quickly, independently, or to the same extent as before), and while this was observed in what was essentially a snapshot look at their current day-to-day practices, it was clear this had been a process of gradual adjustment and adaptation over time in all cases. A poignant examples of the differential modes of engagement people were employing to facilitate their ongoing engagement with meaningful activities came from Martin, who had always enjoyed birdwatching, but who was no longer able to reliably see the larger birds and had started having more difficulties seeing birds which were still (as opposed to those in flight). However, Martin still demonstrated a keen interest in birdwatching, in enjoying watching birds in the garden from his kitchen window, by looking through books with detailed illustrations and descriptions of birds, and sporadically, whenever he caught sight of a card his son had recently sent which had an image of a wren on the front, Martin would stop to have a look at it, and pass it to me for me to appreciate too. He had similarly modified his engagement with dancing, something he and his wife had participated in for many
years, most recently at a regular local evening class. On the day of the home visit, Martin and his wife danced together in the kitchen, which Martin’s wife described as being ‘about all we are good for now [laughing]’, capturing the shared nature of their changing engagement with the activity over time. Martin’s wife elaborated that they had stopped attending their class because the format involved swapping partners and with Martin’s PCA symptoms he’d become less confident in leading and turning in the right way, and the worry he felt at the possibility of letting others down (Martin, 73, male, PCA, MMSE: 19). This speaks to the importance of the reciprocal nature of interactions beyond those related to care, as emphasised in a relational citizenship approach and discussed more thoroughly in the following theme below (section 3.5.3.2).

Many participants modified their mode of engagement by engaging socially in the topics or activities they were no longer able to physically engage with. For example, Betty repeatedly described her plans for developing the garden, and also for helping to clear things away after lunch, when her mobility and memory difficulties (and potentially lack of motivation) prohibited her from actualising them. This is perhaps another example of where the principles of a relational citizenship approach can apply, specifically in that it seemed to be participants’ enduring selfhood which prompted this varied but importantly continued engagement with subjects and activities of longstanding interest, despite the challenges of their progressive cognitive impairment.

3.5.3.1.5 Summary: Theme 1

Overall, in this theme I have attempted to capture the varied fun and functional activities participants in both groups were motivated to continue to engage in, within their naturalistic, everyday environments, even if this had to be in necessarily modified ways. I have highlighted the importance of participant choice and preference in the selection of and engagement with activities, given the largely unstructured nature of their days and the free time available either side of the completion of essential ADLs. I have also illustrated how the priority outcomes for
these activities can shift from what they previously were (often away from the functional and further towards the fun), and how variations in perceptions of and preferences about this between PLWD and their family members are negotiated. These findings build on the interview findings by explicating the varied nature of activities engaged with, their desired outcomes, and some of the particular ways engagement with them can be modified over time.

3.5.3.2 Theme 2: Reciprocities of care

This theme outlines how activities were a mechanism by which care could be both delivered and received and importantly, that this did not just happen in one direction. Supporting activity engagement could be considered to be one of the key ways carers were seen to be fulfilling their roles as carer, considering the time and investment assigned to it. Carers were essential in supporting their family member with dementia to continue to engage with doing things that mattered to them. While there is a vast literature on how carers experience the caring role and widespread acknowledgement of the huge contribution carers make (e.g. Donnellan, Bennett and Soulsby, 2015; Feast et al., 2016; Farina et al., 2017), there is relatively little published work on exactly how carers support their loved ones to continue to engage, so this section will hopefully add something to this relative knowledge gap, at least in terms of the support of meaningful activities. I will also outline the ways in which these acts of care were seen to be reciprocal though – engagement in activities was also observed as a key way that PLWD delivered care, or contributed positively to their carer or others in some way. These findings sit against a backdrop of a research tradition which has a long history of positioning people with dementia as passive receivers of care, or a ‘burden’ (e.g. Dunkin and Anderson-Hanley, 1998; Burns and Rabins, 2000; Sabat, 2006) which is thankfully relatively recently shifting towards a context which acknowledges, values and fosters the many and varied possible contributions of PLWD (e.g. Downs, 1997; Bartlett and O’Connor, 2007; Van Vliet et al., 2017). This chimes with a central principle of the relational citizenship approach, regarding the crucial importance of
acknowledging and enabling mutuality and reciprocity in the ways PLWD socially connect. The many and varied ways participants in the current study used activities as a means of contributing to their family carers, as well as to others will be expanded on in this section.

3.5.3.2.1 Essential roles of carers in supporting activities

While some of the supportive strategies people used to enable their continued involvement with activities were implemented individually, the vast majority were continually developed and/or implemented in a dyadic, interactional and ongoing negotiation. On the whole, carers were critical in supporting activities at multiple stages, from selection (e.g. orienting to task) through to execution (e.g. verbal guidance or physical assistance during an activity), for participants across both diagnostic groups. For the most severely affected participants in the tAD group, who displayed greater apathy or were otherwise less independently motivated towards specific activities, this negotiation was markedly less dyadic, highlighting even further the crucial role of carers in supporting ongoing activity engagement, and the importance of acknowledging the relational context within which activities are engaged with (or not). Examples of the sorts of ways carers were commonly involved in supporting activity engagement were carers taking responsibility for orchestrating and selecting the activities their partners engaged in during the day, for example, Helena’s husband coordinated Helena’s engagement with bed-making, laundry, loading and unloading the dishwasher and setting the table. Other participants could select and coordinate their own activity engagement, but needed verbal guidance throughout its execution, for example, Lilian and Martin required verbal cues from their spouses to help them locate items they were looking for. Other carers provided more physical, hands on help such as Paul’s wife guiding Paul to the music room, drawing up a simplified track listing so he could select the pieces he wanted to play and placing the cassette he wanted to listen to into the player. Overall, most often, a combination approach was needed and delivered, for example Richard’s wife verbally reminded Richard of the steps he’d missed when
loading the dishwasher but later provided practical hands on help by moving the items to the correct location herself.

3.5.3.2.2 Balancing priorities, preferences, personalities and circumstances

The critical role carers played in activity engagement was further illuminated by the minority of cases in which this kind of facilitation and support did not result in the PLWD’s participation and engagement in meaningful activities. This is not to say there were carers who did not support or facilitate their partners with activities, and this was never observed, more that in some cases there was an apparent lack of prioritisation of meaningful activities (over and above more essential ADLs such as meal preparation and dressing, for example), or at least to acknowledge that there were differences in the extents to which carers readily and proactively facilitated engagement with meaningful activities. For some participants with PCA, this resulted in minimal engagement with activities which seemed meaningful to them and which they were motivated towards, because of their profound difficulties with independently initiating those activities. On the few occasions that this seemed to be happening, it appeared that this was because either the carer was feeling overburdened and stressed at managing those essential ADLs, let alone more fun activities, or that the carer was not perhaps attuned to the priorities for engagement of the person with PCA, perhaps because of personality style or previous relationship dynamics, or that their priorities were not so overlapping or aligned in the first place. This is an example of where the Stress Process Model could be developed to more fully account for and explore how the stress (and coping) processes of each member of the dyad may interweave and overlap (or not), to facilitate better understanding of how those processes are negotiated in real-time, and particularly, how the acknowledged contextual factor of relationship history feeds into this.

For example, in Eleanor’s case, Eleanor’s partner was showing me a medication pot she had coloured in to make it more visible to Eleanor when she explained:
[Eleanor’s partner]: I’m not very good at caring, Eleanor will tell you this
I’m not very empathetic, but I’m very good at problem solving

Eleanor: Yes I would agree with that [laughter] – I don’t mean that in a
nasty way but she’s a very practical person and she comes, in a way
we’re the opposite end of the spectrum – [Eleanor’s partner]’s very
practical and logical and all the rest of it –

[Eleanor’s partner]: And of course PCA’s not logical at all

(Eleanor, 74, female, PCA, MMSE: 20)

The pair acknowledged their different approaches and skill sets and both confirmed
that this had always been their dynamic and it was not just as a result of the
diagnosis, with Eleanor explaining early on in the home visit ‘we are quite abrasive
with each other, you should know that’. However, this provides an example of how
the diagnosis and the associated challenges can put new demands on long
established relationship dynamics, and how this could contribute to stress for both
parties, for example, the PLWD (Eleanor) in not being able to maximise the
contribution they were used to making and the family carer ([Eleanor’s partner]) in
doubting their competence to fulfil their new role of providing care and support.

3.5.3.2.3 Carer concerns about competence

This also connects back to the importance of carers’ (and others including friends’
and neighbours’) understanding and attribution of the PLWD’s difficulties in
supporting activity engagement. Extending the findings of the interviews in which
the majority of carers (n=13) expressed concerns about how best to help their loved
one, here carers in both groups expressed the same concerns regarding activity
engagement, seemingly owing to the idiosyncratic symptom profiles which were
changing over time, and the complex ways different symptoms overlapped and
intersected. [Wendy’s husband] was concerned that his encouraging Wendy to
cross-stitch was ‘bossy’, and this short transcript details Martin’s difficulties with
taking off his slippers to put his shoes on ready to go for a walk and his wife’s considered approach to best supporting him:

[Martin sits down with his shoes in hand]

Takes left slipper off

Puts left shoe on

Takes right slipper off

Puts right slipper back on]

[Martin’s wife]: No you need your other shoe on [aside to me] I’m not sure that helps really. [To Martin] So take your right slipper off

Martin: This one? [taps right foot]

[Martin’s wife]: Yep

[Martin takes slipper off]

Martin: So what do you want me to do here

[Martin’s wife]: You need your outdoor shoe on, the leather one, the brown one?

[Martin finds slipper and spends some time reorienting and undoing straps]

(Martin, 73, male, PCA, MMSE: 19)

Martin’s wife articulated her uncertainty about how helpful her verbal instructions were being before trying out different descriptors of the object she was trying to guide Martin towards (e.g. colour, material), illustrating the trial and error approach many carers reported having to adopt because of a lack of certainty about the exact
nature of the symptoms and what would most helpfully compensate for them. This perhaps highlights other areas of potential overlap in the two versions of the Stress Process Model – knowledge of illness is acknowledged as a mediator of stress for the PLWD, but does not feature in the caregiver version of the model. A systematic review by Lee, Moore, Candy and Sampson (2017) suggests the importance of knowledge of the illness for carers, in reporting that educational interventions to increase carers’ knowledge can also reduce depression and potentially feelings of stress and burden too. This seems compatible with the current study findings, in which it seemed for carers of the PCA group in particular, that knowledge of the illness and how to best support difficulties could have been an essential mediator on the stress arising from the secondary strain of concerns about competence.

3.5.3.2.4 Wanting to help (as well as be helped)

One of the most common factors which seemed to be a motivator of activity engagement were PLWD’s desires to do things which were of value to others – things which helped others or made a contribution in some way. This challenged dominant narratives in the empirical and theoretical literature which can position PLWD as (only) receivers of care (e.g. Kitwood and Bredin, 1992; Feast et al., 2016), and is much more compatible with a relational citizenship approach which seeks to empower PLWD by acknowledging the enduring agency and desire to act on the world which characterises selfhood. The minimum of motivated activities seemed to be taken up solely for solo entertainment or distraction – all participants seemed motivated to find meaning and purpose in most of the activities they undertook. This often seemed to come from a sense that they had made a contribution to someone or a cause, and participants across both groups were motivated to continue engaging in these sorts of activities even when they became challenged by the specific symptom profiles, as outlined above. Poignant examples of this came from Lilian describing the reciprocal relationship she had with her paid professional carer, and how meaningful she was finding the interactions and activities they undertook together, she said:
She’s absolutely lovely and we’ve become great friends, and because she’s different, she’s very interesting [recalling family history of carer]. She’s lovely. I take her round - I say I take her she takes me - round to [town name] and I take her to places she’s never seen, ‘cause I’ve lived here I know the area.

(Lilian, 70, female, PCA, MMSE: 14)

It is suggested in Lilian’s comment that she was benefitting from her sense that she was contributing to this relationship, and this provides a good demonstration of the inherent reciprocity in caregiving relationships, striking considering that the relationship was originally established for the provision of care to Lilian but is described much more in terms of the bidirectional provision of support and care that the women shared. This and the many other instances of reciprocity in caregiving that were witnessed were good examples of the bidirectional nature of care delivery that the relational citizenship approach advocates for the acknowledgement of. Specifically, that the relational context of care does not only constitute care delivery to PLWD within a social context, but that PLWD are able and motivated to express gestures of care to others, and that their social contexts extend beyond merely care-giving relationships.

Lionel, who had spent many years as a full time carer for his granddaughter with complex health needs, still prioritised administering her medication, checking on her and spending time with her. This prioritisation of activities which were in some way helpful to others was also evident in his daughter’s comment:

All he wants to do is help...do you know sometimes he comes up to me and salutes and says ‘your humble servant is here what can I do for you? ...he’s not interested in doing anything just for himself

(Lionel, 76, male, tAD, MMSE: 22)

Here Lionel’s daughter described his continuing initiation of making the offer to do helpful activities, even if he is unable to initiate the specific activities totally on his own, further stressing the complexity involved in delineating intention, motivation,
action and agency for PLWD. I was fortunate enough to experience the extent of Lionel’s conscientious helpfulness first-hand during the home visit, when he prepared two meals for us all and repeatedly checked with me whether or not I liked all of the ingredients, and if everything tasted OK.

Wanting to make a contribution seemed to be central to one of the modified ways Maurice was continuing to engage with the computing magazines that he could no longer read – he explained to me that he did not want to part with the stacks he had of them because he knew they could be useful to someone else, and talked through his hypothetical plans to arrange to donate them to a computing group who could make good use of them. Maurice also described his frustration at not being able to research or orchestrate this himself, providing one example of how a PLWD’s abilities to enact their citizenship being compromised can result in feelings of disempowerment and a loss of agency, as suggested by Kontos, Miller and Kontos (2017).

3.5.3.2.5 Being part of a team

For several participants, an essential way in which they found the reciprocal nature of activities to be meaningful was in the sense it gave them of being part of a team. Mark described how much he missed his time playing team games including rugby, and spoke very fondly of all of the different jobs he had previously done, from bar work to support himself through medical school, to his eventual post as a consultant paediatric neurologist – a common theme to all of these seeming to be the sense of being part of a team. Mark commented ‘if you work together you can do things’ and reflecting on his and his wife’s joint efforts in current activity management he remarked ‘once you’ve married that’s the team isn’t it?’ (Mark, 68, male, tAD, MMSE:21), articulating the importance of background and contextual factors such as relationship and employment status in framing and determining outcomes, and the critical importance of temporal factors such as age and stage of life which determine those.
Martin also captured this sense of ‘team work’ when reflecting on the community’s efforts to protect the local birdlife, something that he was extremely motivated to be a part of (even if in modified ways, as above), saying:

Emma: Are you a birdwatcher?

Martin: Oh yes, it delights and interests me...Doing that bit of stuff [filling feeders] is a small bit but it gets taken further by other people do a lot more. It’s nice when you can see people have a similar interest and you pass notes on one to another.

EMMA: Have you always been interested in birds?

Martin: Oh a long time. I’m not a real...I’m very happy to let other people take a major role in setting out the wooden, like the wooden cabins?...Yes like birdhouses. It’s a shared effort.

(Martin, 73, male, PCA, MMSE: 19)

Martin outlined how even playing a small part in an activity that he knew mattered to others could foster positive feelings of connectedness and a sense of shared motivation. Together these examples highlight the significance of relationships outside of the caring relationship for PLWD, as suggested in the relational citizenship approach (Kontos, Miller and Kontos, 2017).

3.5.3.2.6 Not wanting to be a burden

Another way this want to help or to provide care as well as receive it manifested was in participants’ concerns about being a burden to their caregivers, and adjusting their expectations or requests around activity engagement in response to this. This develops ideas underpinning existing empirical investigations of burden in the literature, which are usually concerned with the caregiver’s experience of burden, because of their caring role (e.g. Andrén and Elmståhl, 2005; Lea Steadman, Tremont and Duncan Davis, 2007). This too highlighted what an interactive and dyadic process care provision was, in that PLWD acknowledged the critical roles their caregivers played in their own activity engagement, and in wanting to
reciprocate this caregiving, would perhaps limit what they expressed wanting to do in favour of reducing the pressure or strain on their caregiver who was (in all cases) already providing a lot of support.

Brian for example, who was in the very early stages of tAD but very self-conscious of his own cognitive decline, said of he and his wife ‘I’m a burden and she takes the weight of everything’ (Brian, 75, male, tAD, MMSE: 30). The total nature of Brian’s concerns – that his wife takes the burden of everything seems striking given that according to his MMSE score he would be considered to be in the normal range of cognitive functioning. This supports findings from the interview phase in which I suggested that the retained cognitive capacities of people with PCA in part permitted the reflection on one’s abilities and difficulties and could contribute to feelings of being a burden. Seeing this again here, highlights this as something which is not diagnosis-specific, and arguably strengthens the case for the importance of assessing subjective as well as objective impairment/burden, as it appears this can also be a key factor in determining outcomes.

Another example of this came from Lilian who expressed some upset at the fact that she could no longer enjoy some of the shared activities she and her husband had both previously engaged in together, such as going on cruises. She said ‘there are things I can’t do but he could...it must be boring for him because he’s got all his faculties, his mind and his memory and he’s got me tagging along type of thing’ (Lilian, 70, female, PCA, MMSE, 14). Lilian specifically cited her own loss of function as potentially holding her husband back from things they both had enjoyed previously, evidencing the abilities of PLWD (as well as family carers) to experience and be concerned about relational deprivation on behalf of their partner, in the same way that carers were seen to be motivated to act on behalf of the PLWD. This provided another example of PLWD’s enduring contributions to social life and the reciprocity within relationship-centred care which Kontos, Miller and Kontos outline in the relational citizenship approach (2017).
3.5.3.2.7 Research participation

Another way participants seemed to be using activities as a means to be helpful or contributory was in their research participation itself. While all participants had obviously selected research as an activity they were motivated to take part in, for some this seemed to hold particular value, as a newfound activity via which they could make a meaningful contribution and which, importantly, was not only not challenged by, but in fact made possible by their diagnosis and associated symptoms. Paul for example regularly checked with me ‘is this relevant? Do you really want to know all this?’ (Paul, 79, male, PCA, MMSE: 14), showing his conscientiousness about the quality of the data he was providing, as many other participants did too. Wendy summed up the inherently generative motivation for participation which many participants expressed when she said ‘I don’t mind what I do if I’m helping you and other people’ (Wendy, 75, female, tAD, MMSE: 20).

3.5.3.2.8 Existing caregiving responsibilities

As with Lionel’s caregiving of his granddaughter (mentioned above), who his daughter said would be his ‘mastermind subject’, a number of other participants had existing caregiving responsibilities for others, and as a result many of the activities they engaged in during the observation period were inherently acts of care which made a contribution. In fact, Lionel even elaborated on the care of his granddaughter being a way for him to help and support his daughter in saying ‘well for her [daughter] she’s got hard work and she’s sitting down in the evening doing paperwork and things so sometimes she can’t go to sleep before 11 or 12 o’clock’ (Lionel, 76, male, tAD, MMSE: 22). The variation and complexity in each person and families’ situation is illuminated here, and this points also to the fact that for PLWD there was not always just enjoyment and pleasure in their making a contribution, but a real pragmatic need for it, and this only seemed to increase the sense of purpose and meaning derived from these sorts of activities. For example, Anita had previously been a primary carer for her husband who was registered blind, and how this helping relationship had recently shifted was summed up when he explained ‘I
provide the memory and she provides me with eyesight’. One of the activities Anita was motivated towards during the home visit was playing the piano, and it appeared this activity offered Anita an opportunity to contribute something to her husband, as she repeatedly checked with him which songs he’d like her to play, shown here in this transcript:

EMMA: Are you sure you don’t mind playing?

Anita: No of course I don’t!

[Anita’s husband]: I hadn’t heard you play ever in my life until you played at Catherine’s at Christmas when you were playing Christmas carols

Anita: I mean I only strum things dear I don’t play beautifully I’ll just strum away. And you [to Emma] – would you like a little drink? Are you sure dear? I’ll play you a tune. Now this is just playing by ear so you don’t have to clap

[Playing ‘On Top of Old Smokey’ and looking between Emma and [Anita’s husband] and piano, both Anita and [Anita’s husband] singing]

Anita: [to Emma] Do you know this? [to [Anita’s husband]] Come on [Anita’s husband] sing!

EMMA: That was so lovely

Anita: Oh no my dear forget it [chuckles]

EMMA: Are you playing more recently than before?

Anita: I did a lot when I was young – I got to advanced level

EMMA: And you’re only now getting back into it?

Anita: Well yes I suppose so – it’s because he [[Anita’s husband]] likes it so there we are. But this piano my dear my father gave it to my mother in two one so what’s it, 19 something before I was born and it’s a Steinway it’s a beautiful piano so we brought her with us didn’t we
[Anita’s husband]. There’s no tune that you want [Anita’s husband] is there? Have I played all the tunes you wanted darling?

[Anita’s husband]: Well you could play a lot more – take me home again Kathleen?

[plays that]

Anita: Can’t I bring you a little drink dear? [to Emma]

EMMA: Thank you very much that was lovely

Anita: Oh no that’s my pleasure

(Anita, 88, female, tAD, MMSE: 27)

Something that was common to virtually all participants and which can be seen in this exchange and in the examples shared above regarding Lionel, is the care and consideration participants extended to me during the home visits, and this will be expanded upon in the Reflexivity section (section 5.9), but is highlighted here as another way in which participants in both groups demonstrated a want to help or showed reciprocal gestures of care towards others. This felt very poignant with Alan when I accompanied him leaf-picking in the front garden. Despite Alan experiencing profound difficulties with speech production, he persisted to regularly check if I was cold or if I wanted to go inside, despite it taking several attempts each time for him to formulate the sentence. This showed a persistent motivation to socially connect, despite the difficulties involved in communication, and supports the idea of social connectedness as a fundamental component of living well with dementia (e.g. Nyman and Szymczynska, 2016; Dröes et al., 2017; Hansen, Hauge and Bergland, 2017).

3.5.3.2.9 Intention and action

For the most part, the motivation to want to do something helpful came from the person with the diagnosis, and its execution was mostly facilitated by family
members where necessary. However, occasionally, this congruency between intention towards helpful behaviours and eventual contributory action was not so straightforward. An example of this came from Betty, who repeatedly expressed keen motivation to engage in the contributory, helpful activity of tidying up after lunch to help her partner, despite her mobility, motivational and memory difficulties inhibiting her ability to execute this activity in an embodied way, as is seen in this transcript:

[AAfter lunch]

Betty: You’re getting very good at cooking

[Betty’s partner]: [chuckles] well you can take over any time you like. Right I’m going to clear this up

Betty: No I’ll do it

[Betty’s partner]: Well you can help

Betty: No I’ll do it because, I’ve got nothing to do

[Betty’s partner]: Right you put those two in the dishwasher [moves bowls over to her which he eventually puts in the dishwasher]

Betty: [smoothing tablecloth] I’m at your disposal I’ll do whatever you like

[Betty’s partner]: Stand on your head please! For two hours

Betty: [smoothing tablecloth]

[Betty’s partner]: Now how are you getting on?

Betty: I’m doing the dots [on the tablecloth]. I’ll do this [tidying up] darling don’t worry.

[Betty’s partner]: No it’s ok, you can do a bit and I’ll do a bit
Betty: No I’ll do it I like doing it

[Betty’s partner]: [picks up bread]

Betty: Aren’t those enormous slices?

[Betty’s partner]: They are rather. They come from a bakery called Warburton.

Betty: Well you could put them in a plastic box.

[Betty’s partner]: I’m going to but it’s in there [gestures to cupboard]

Betty: Oh I’ll do it for you

[Betty’s partner]: No it’s alright [chuckles]. I’ll tell you what you can do – you can put that in the fridge [passes bottle of wine to Betty]

Betty: I’ll put that in the fridge

[[Betty’s partner] washes up, singing and humming]

Betty: I’ll put the rest away darling

[Betty’s partner]: Oh that’s very kind of you

Betty: I know. I think you’ve done enough

[Betty’s partner]: I’ll just put this away [takes wine from in front of Betty and puts in the fridge]

(Betty, 88, female, tAD, MMSE: 15)

[Betty’s partner]’s responses to Betty’s expressed motivation to help makes this a good example of the bidirectional nature of care delivery, in that he was on some level permitting or enabling Betty’s perception of herself as being helpful by endorsing the possibility of her assisting, and more will be said about the nature and possible meaning of his responses in the final theme.
3.5.3.2.10 Summary: Theme 2

In this theme I have outlined the essential role of carers in facilitating activity engagement, though often, as identified in the interview findings above, this ongoing engagement and participation was seen to be a shared endeavour for the majority of participants in both groups. In the minority of tAD cases where this was less of a jointly negotiated venture, this was still happening within a relational context and still speaks to mostly shared motivations and meaning-making regarding the PLWDs ongoing engagement in meaningful activity. The findings here have extended those of the interviews in identifying some of the manifold ways participants with both PCA and tAD were motivated to engage in activities which offered them an opportunity to make a contribution, beyond just attempting to minimise any sense of being a burden. The varied avenues and mechanisms for this endorse the relational citizenship approach in its recognition of reciprocity which goes beyond dementia-care-related relationships. Exploring the processes by which this was negotiated has highlighted the complex interplay of the sorts of contextual and mediating factors, as outlined by the comprehensive Stress Process Model, such as disease type, stage, living situation and various intra- and interpersonal factors, involved in this.

3.5.3.3 Theme 3: The constitution and continuity of a changing self

3.5.3.3.1 Introduction

The final of the three themes outlines the meaning or purpose of activities for participants in terms of how engagement with activities offered a way for their sense of identity and self to be constituted and represented in and by their everyday environments. I will outline how the objects involved in activities and participants’ interactions with them symbolised and communicated something of participants’ identities and the things that were important to them, also how continuing engagement with these activities and objects (even if not always in quite
the same way as previously) offered some continuity in this sense of identity and self, which could otherwise be disrupted and threatened by the progressive cognitive decline and functional impairment that came with participants’ diagnoses.

3.5.3.3.2 The environment (and objects within it) as self-referential

This first sub-theme refers to the way that the physical spaces and objects associated with meaningful activities were representative of participants’ identities or senses of themselves in some way. I spent long periods of time during each home visit in conversation with participants about various objects and areas of the home, and these often acted as a physical reference point or indicator of the activities that mattered to participants, allowing the communication of some aspect of their history, interests or other aspects of their identities. These objects and spaces could also serve as a marker of how participants’ engagement with activities had changed, owing to their progressive cognitive impairment. For example, in relation to her lifelong reading habit, Sally showed me a post-it on the fridge which had written on it the number of books they had removed from the home now that she could no longer read. This post-it acted as an acknowledgement and reminder of the space this meaningful activity had previously taken up in Sally’s life and home, and she explained ‘well 2000 books have gone. That really pissed me off. But I couldn’t read them. I can’t read. I am reconciled with it but not happy about it. Which is an interesting contradiction’ (Sally, 64, female, PCA, MMSE: 19). For Sally, it seemed she experienced some incongruence at making space to store so many books if she could no longer use them, but this clearly was not an easy decision for her, and she continued to want some physical record of what had been such meaningful objects. Objects were an important reference point for long-standing meaningful activities and interests for Lilian too – she had worked for many years in a chemist and had collected a lot of cosmetics and what she called ‘bits’ (i.e. beauty tools and products) over the years working there, and she repeatedly referenced them as things that ‘us girls have’, making explicit this connection between the things she has and the person she identified as (Lilian, 70, female, PCA, MMSE: 14). Lilian was
persevering with using these various tubes and pots of beauty products, as evidenced by there being many of them open all around the bathroom, though their placement suggested that this had become more challenging, as many were without lids and in slight disarray. She also spent a long time getting ready in the morning, and having previously been a model, seemed to prioritise activities relating to aesthetics including grooming, fashion and interior decorating, and the connection these activities had to her enduring sense of self and identity were clear when she remarked on our individual clothing choices ‘you’re nice and stripy, we’ve all got our things haven’t we? My one’s sparkles’. The way this extended to the environment as a whole is captured in the following transcript as Lilian was showing me around:

Lilian: I used to love all the antique shops and things – do you like the antiques and bits?

EMMA: Have you always liked making the house nice?

Lilian: Yes yes. I miss it – I mean as much as [Lilian’s husband] does what he does, it’s not a woman’s way you know.

EMMA: When you say you miss it, what do you miss?

Lilian: I just miss being the woman around the house, you know. Doing things my way. I do miss it.

EMMA: Do you mean decorating? Or the housework or all of it?

Lilian: Yeah, that’s what you do when you’re at home, don’t you? You do things, whereas I don’t do things anymore and I miss it.

EMMA: I expect especially when you have run a house for a long time

Lilian: This is it, you miss it, I mean [Lilian’s husband] does things in the house and I think why’s he doing that? But you know I have to shut up because I’m lucky I’ve got someone here doing it with me

EMMA: Ah well I’m sure you’d help him if he needed help from you?
Lilian: Yes I’m sure I would but it’s nothing like being your own self is it? I used to like to have all my pictures up on the wall and [touches picture and tells story of holiday and friends they brought it back from]. I used to like it all.

EMMA: Do you not enjoy those things anymore?

Lilian: Oh yes I still like it yes, I can’t do any of it. I used to like little antique places, I’ve been a dressmaker in my time so I could make things and I loved it all.

(Lilian, 70, female, PCA, MMSE: 14)

As many participants did, Lilian spoke not only of these long-prioritised activities as important constitutions of her sense of self but also the objects associated with them as inextricably part of that construction. Lilian quite clearly articulated a strong link between the things she was able to do and her sense of being her ‘own self’, and saw her ability to organise her physical environment and the objects within it in a way that reflected that self as an essential expression of her personhood. This kind of embodied quality to successful expression of selfhood is very in keeping with the conceptualisation of embodied selfhood Kontos, Miller and Kontos (2017) propose in their model of relational citizenship.

Richard provided a good example of the range of objects within the environment that could relate to important activities, from the seemingly mundane and ordinary to the treasured and important; and from significant activities of the past to those planned for the future. Richard’s self-initiated activities were mainly watching the news and reading the newspaper, and he and his wife both described him as someone who had always been very interested in current affairs and politics. This activity seemed key to his identity, and this was reflected in his relationship with a particular object – the newspaper. Richard’s keen engagement with the activity of keeping up to date with the news was exemplified not only by his spending a long time reading the paper on the day of the visit, but also in his expressed desire to keep multiple copies of them for long periods of time for reference. Moving from
the ordinary to the extra-ordinary, Richard’s motivated political actions of the past were encapsulated in a framed photograph on the wall of his and his wife’s bedroom, in it an image of Richard being arrested for his part in a peace protest many years previously. It was when standing in front of this photograph during our tour of the home that an (until then) very quiet Richard first became visibly and verbally engaged in a subject, highlighting the ability of objects in the environment to act as a point of reference for someone’s meaningful engagements with the world, even if that was in reference to previous acts of doing, rather than current ones. Richard was later similarly enthused when we came to photographs of his relatives in the downstairs hallway, and though admitting he had trouble with recalling their names and birth years, described his plans to create a book of the family history at some point in the future – an anticipated and intended activity that also referred to and situated his sense of self, but which was currently constituted within these family photographs.

This was also observed with those with tAD whose behaviour and engagement with doing things or talking about significant activities was more likely to be cued by the environment and objects within it. Sometimes the activities that were cued by the environment seemed arbitrary, for example Betty’s organising of the peas and ‘doing the dots’ on the tablecloth after lunch (discussed above). But insofar as the environment contained objects which were meaningful and related to activities of importance to the PLWD, this was another means by which meaningful engagement with activities of long standing interest could be maintained. For example, whenever she noticed the several vases of flowers throughout the home (which was numerous times throughout the visit), Betty would engage in conversations about the flowers themselves but also about her beloved grandsons who had purchased them. They were objects which offered a means for Betty to engage with her long-standing topics of interest such as gardening and the family she was very proud of, which she was not so able to independently initiate meaningful physical activities in relation to (Betty, 88, female, tAD, MMSE: 15).
For many of the participants, their time of life was also a factor in shaping their environment, which in turn had implications for their activity engagement. For many participants (from both groups) their living situation was currently in or had recently been in a state of flux, and participants described various plans they had to move, declutter, refurbish, reorganise, sort and store things. For many, this in itself was a ‘project’ – an activity they were engaged with and motivated towards. Several dyadic disagreements confirmed that both members of a dyad were equally engaged in the process, making this environmental reorganisation another activity to be jointly negotiated. As well as becoming activities of importance, these planned changes also required decisions to be made about various spaces or objects associated with previous or current meaningful activities. This was also often how the significance of objects associated with meaningful activities was revealed to me in the field – for example, with Maurice and Richard’s resistance to their wives’ plans to remove their stacks of magazines and newspapers, and Wendy and her husband’s very independent plans to separately declutter their (very differently organised) respective studies.

3.5.3.3 Symptom progression and ongoing adaptation
Another aspect of this final theme is about the change in participants’ engagements with activities over time, and how this related to their identity and sense of self. A poignant example of how these changes could be constituted by the environment itself and the activities undertaken within it, came from Sally’s explanation of her regular past time of looking out of the window of their rural bungalow. Sally explained that she would sometimes be on her way to do something or get something, and instead some time later could be found sitting and looking out of the window and appreciating the view instead, and articulated very clearly the meaning of this activity for her in the context of her condition and the associated changes:

*So basically I have places where I can come and sit, some of them are quite strange but I like the ones with the sun or sunset, sunrise and*
sunset are the really good ones. ‘Cause I just like looking at the edge [horizon]. It’s been, can’t remember how long we’ve been here but it’s so familiar, and it’s not gonna shift. I mean the [hills] aren’t gonna fall down. It’s something that is not going to disappear quickly. Because change has always happened quickly but it seems to get quicker. Yes it’s the larger things of the world and the personal ones – there’s a big big difference...I mean the edge of the [hills] isn’t gonna fall off soon, the trees in our garden [aren’t going to fall down], unless [Sally’s husband] fells them! But it’s not permanence because nothing is permanent but it’s a...it’s like an anchor, and that’s one of the things in the future, in terms of what we do as I get worse....so, that’s how it goes, let’s get on with it

(Sally, 64, female, PCA, MMSE: 19)

This example relates to the constituting capacity the environment can have in that the physical external environment, and the activity of sitting and watching the sun rising and setting over it, offered some acknowledgement of and reference to the changes within Sally, but also the possibility for some continuity and comfort, during a period of inevitable change owing to the diagnosis.

Lionel’s daughter described how his changing abilities with regards to the caring activities he undertook for his granddaughter offered a reference point for the progressive impact of his dementia-related symptoms as follows:

But there’s key things that dad is really good at remembering like even with the Alzheimer’s... [granddaughter]’s drugs, because he does [granddaughter]’s cannabis, he wants to be home by four or five o’clock and if we’ve gone somewhere he’ll start to feel a little bit uneasy so you know that kind of thing is actually quite good because the day he becomes blasé about it or forgets that’s when we should be worrying, there are just these key things you know where he’s just on it.

(Lionel, 76, male, tAD, MMSE: 22)

As Lionel’s daughter did, most participants and their family members, when reflecting on their changing ability to engage with activities to date, also extended these reflections into the future, in anticipating what they would be able to do or
not at varied times to come, explicitly acknowledging the fact that things would continue to change and that there would continue to be increasing difficulties with activity engagement over time.

This sense of one’s changing capabilities over time was also implicit in the way supportive strategies to facilitate the engagement with prioritised activities had changed over time. Paul’s ongoing engagement with music (both playing and listening) was facilitated by his wife’s implementation of graded visual aids and adaptations – she had started with a simplified labelling system for Paul’s sheet music and this had developed into incorporating some colour coding with highlighters to make titles stand out more to aid his selection, which had then progressed further to very simple and bold labels with single word instructions for using the different sound systems they had. While all these things had helped for a while, things were now at a stage where many of them were redundant and Paul’s wife had to help in a hands on way to locate particular pieces or to start them playing.

There was also some variation in how these disease-related changes in activity participation were adjusted to, and this seemed to vary just as much by age as by diagnosis, supporting age as a key contextual factor in determining the stress process for PLWD. The oldest participants, who had been some way into this later stage of life before noticing symptoms, seemed to have more of a sense of ease and acceptance of the diagnosis, and this was summed up well by Betty who described having done most of the things she had wanted to do throughout her life, and embracing the relaxed ‘laziness’ she was now indulging in. Members of both diagnostic groups who had been younger when symptoms had onset, seemed more likely to be the ones who expressed a greater sense of frustration or sadness at having to finish work early, or reduce their involvement with meaningful activities such as driving or playing sports (e.g. Alan, Brian, Mark, Eleanor). Participants also often used their experiences of meaningful activities from times gone by or those planned for the future as a way to continue to engage with their long-held interests.
3.5.3.3.4 Motivation to maintain a sense of self and identity

Throughout the home visits, most participants referred multiple times over the course of the day to their sense of themselves or their identity as a continuous construct with some enduring permanence. These assertions of some permanence in participants’ senses of self were also endorsed by family carers, with Martin’s wife putting his recent challenges in the context of his prior history in saying ‘most of your life you didn’t have PCA and you’ve done amazing things’ (once again highlighting the importance of those meaningful activities done previously) (Martin, 73, male, PCA, MMSE: 19) and with Eleanor and her partner’s agreement about her being ‘challenging’, seen in this transcript:

[Eleanor’s partner]: Eleanor described herself very well then by saying she’s challenging

Eleanor: and long may I challenge!

(Eleanor, 74, female, PCA, MMSE: 20)

In expressing her desire to keep being ‘challenging’, Eleanor captured the sentiment expressed by many, of wanting to continue to do things (e.g. communicate) in the ways which characterised her as a person. These and other enduring qualities, either enacted by the PLWD or acknowledged by others, appeared to be testament to the enduring nature of selfhood endorsed by the theoretical work of Kitwood (1997a, 1997b, 1997c) and Kontos, Miller and Kontos (2004, 2005).

Ongoing engagement with activities seemed to be an important way that this sense of self and identity could be maintained and enacted, and when reflecting on his current levels of activity engagement and the support he sometimes required, Brian exemplified this in his comment ‘That’s what I miss – being able to do things’ (Brian, 75, male, tAD, MMSE: 30). Brian’s reflection emphasised the broad and pervasive impact of a changing ability to do things generally, and seems especially noteworthy given that his MMSE score was in the normal range. This arguably supports the
acknowledgement of PLWD’s subjective appraisals of their perceived mastery and dependency, and the prioritisation of meaningful activity engagement interventions improving outcomes for PLWD at all stages of the condition.

This overall drive for the maintenance and preservation of interests, activities and ultimately, identity, was demonstrated in an overarching sense in this continued engagement, but also in one particular strategy almost all participants adopted to cope with the challenges of engaging with everyday activities: perseverance. The majority of participants used perseverance or repeated trying as a supportive strategy for their ongoing involvement with activities of meaning and interest. This was perhaps most poignantly captured by Alan, who had great difficulties with speech production, but persevered countless times in order to tell me various stories right up until I was packing up to leave for the day. As an example, one story was about a helicopter flight he and his wife had taken and he had a great deal of trouble finding the word helicopter, but demonstrated such motivation to find it that this then became a guessing game, with Alan pointing to objects that had a vaguely similar shape to a helicopter’s rotor blades, and erupting into cheers when I eventually guessed correctly. The story he persevered to tell me right at the end of the day was about a particularly exciting Christmas present he had been given, and when he was having too much difficulty finding the name for the present he’d been gifted, he took me to find his wife so that she could complete the story. Relating this back to the discussion of priority outcomes in the first theme above, ‘The fun and the function’, above, arguably neither of these stories constituted ‘essential’, ‘need-to-know’ information, but the profound effort Alan made in order to eventually relay them to me illustrated the significant meaning they held for him, and the potential of this as a motivator for action and communication, despite the challenges faced. This was an example of the ongoing desire for social connection with others, not just related to the diagnosis or to the care needs of the PLWD, but the possibility for PLWD to enact caring and connecting gestures towards others, as many participants seemed motivated to continue to demonstrate.
The adoption of perseverance as a strategy, as well as all the other (mostly relational) supportive strategies already outlined, was contingent on a number of intra- and interpersonal factors such as personality, previous or existing relationship dynamics and individual preferences for things like independence and self-reliance. These factors hugely influenced how challenges were faced, and how support and care strategies were developed, implemented and received, and as such were another way in which the person with the diagnosis and (to varying extents) their family members and/or caregivers, could facilitate or foster this continuity and maintenance of self and identity. As examples of this, regarding their own preferences for independence in activities, Lilian and Eleanor explained:

Lilian: We go abroad and we’ve got friends and one thing and another and that helps, it’s just the not being yourself, can’t change it can you?

EMMA: Can you say any more about that, why you’re not able to be yourself?

Lilian: ‘Cause I’m not able to be, I can’t just say I’m gonna walk down to the hairdressers today and get myself a what’s name to get my hair done or whatever, I’m reliant on people, that’s what it is

(Lilian, 70, female, PCA, MMSE: 14)

Lilian makes explicit in this comment the importance of her independently being able to initiate activities as being essential for her sense of being herself, and this importance of independence in activity execution was echoed in Eleanor’s comment:

Eleanor: 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, which I do vicariously and I’m not complaining...but I miss that freedom, when you’ve been independent as you are now, and as most people are in a lot of their lives, you miss it when it goes...I just wish I could be more functional and get more done.

(Eleanor, 74, female, PCA, MMSE: 20)
Eleanor details the fundamental importance of independence in the choice and execution of activity engagement for her sense of having ‘a life’, and how particularly difficult a change in that independence could be to adjust to, when it had previously been so defining.

A key way the relationship dynamic impacted on this was in the extent to and means by which the caregiver or family member was motivated and able to enact this identity maintenance on behalf of the PLWD, if needed. Observable ways this was achieved during the home visits included carers deferring to the PLWD’s expertise – for example on the day prior to the home visit, Wendy’s husband had asked Wendy for advice on the timings for cooking the meat for dinner in the slow cooker, though she had forgotten having been asked. Wendy then asked about the plans for dinner late in the afternoon during the home visit and her husband explained that they had had the same conversation the night before, which Wendy then asked him to repeat back to her (which he did). Wendy’s husband double checked the timings he had used with Wendy again, and when they tallied with her in-the-moment suggestion, Wendy seemed reassured. Although Wendy was not able to initiate the cooking or recall having had input into the decision-making, in consulting her and in retracing the conversation with her later, her husband had acknowledged her expertise from her years of experience of cooking, and provided an opportunity for it to be recognised, even though Wendy was unable to do this herself.

Other ways carers acted to maintain their partner’s engagement with meaningful activities on their behalf, included eliciting and prioritising their partner’s preferences and choices, and by minimising any diagnosis related difficulties. This sometimes happened by normalising, for example when Oscar struggled with lining the bin with a new bag when making his way through his extensive list of chores, his wife reassured him ‘it’s not you – it’s just always a bit of a faff’ (Oscar, 56, male, PCA, MMSE: 19), suggesting that she too struggled with it and in doing so, dissociating Oscar’s difficulties with it from his diagnosis. Richard’s wife gave two
examples of ways she was seeking to avoid highlighting his difficulties with activity execution, firstly that after a couple of attempts to let him know sensitively that he had missed a step, if he hadn’t taken the feedback on board and adjusted what he was doing (e.g. putting cutlery in the wrong places when setting the table, and moving used mugs and glasses straight from the sink to the draining board and not to the dishwasher) she would leave him to continue and then correct it afterwards. She explained:

‘that’s new, that’s only recently happening [skipping steps with dishwasher]. And even when I was telling him [that the mugs need to go in the dishwasher], it’s like he’s not understanding the command and he’s just carrying on doing what he was doing. So I’ll follow up afterwards, sometimes I’ve done it straight away but then I thought I shouldn’t do that maybe, I’ll do it later, but sometimes it’s just an impulse I just do it and then I think oh no, but mostly it’s depending on what frame of mind I’m in’

(Richard, 77, male, tAD, MMSE: 16)

Richard’s wife describes both her efforts to understand exactly what is going wrong so that she can best support Richard, and also how she consciously tries to postpone her own intervention in the situation, so as not to draw excess attention to Richard’s mistakes. Her comment also captures her concurrent adjustment to Richard’s symptoms over time, and the evolution of her coping strategies over time. Although there were different approaches to this, these examples demonstrate the roles carers could (and mostly did, as and when required) take in supporting their family member to continue to engage in activities, which allowed some continuity in the environments that constituted their changing selves.

3.5.3.3.5 Summary: Theme 3

Here I have outlined various ways in which the activities people do, have previously done, want to do, or plan to do, were seen to constitute their senses of themselves and their identity. The objects and spaces associated with completion of these sorts of meaningful activities in turn were seen as a reference point for these aspects of
people’s identities and in being so, allowed enduring enactment of their selfhood. These findings further support the limitations of the Stress Process Model in the lack of acknowledgement of the physical environment as a mediator of the sorts of stress that can be caused by secondary role strains, relating to one’s recreational and family-based activity engagement, for example. These findings develop the interview findings by expanding understanding of this relationship between objects within the environment and one’s sense of self, as one example of how engagement with the intersecting physical and psychosocial environments shape the illness experience. These findings also support the findings of the interviews and other themes within this results section, in illustrating the potential for this too to be a shared endeavour, sometimes taken on by a family carer on behalf of their partner, whose engagement with the physical environment or cognitive symptom profile more broadly may have challenged their identity maintenance via activity engagement. The findings here have also illustrated that while participants’ abilities to engage with activities were inevitably changing over time, there was an inherent motivation to maintain this sense of self via activity participation, seemingly an example of the enduring selfhood a relational citizenship approach acknowledges. Additionally, that sustaining this was a process involving a complex and context-specific interplay between not only diagnosis and disease stage, but also existing and previous relationship dynamics, and PLWD preferences such as those comprehensively explicated by the PLWD and carer versions of the Stress Process Model.

3.5.4 Overall Summary

In summary, my observations and interpretations suggest that those with PCA had some distinct difficulties with engaging with activities which were important to them, owing to their dominant visuoperceptual and visuospatial symptom profile, which required or responded best to supportive strategies which disambiguated the visual information required for activity completion. These dominant visual processing problems were in contrast to the factors affecting the tAD group’s
engagement with activities, which was more commonly challenged by difficulties with memory, motivation, and executive function related abilities. Overall however, it seemed there was much more which united the two groups than that which distinguished them, and manifold ways that activity engagement varied because of factors other than diagnosis – some related to it (e.g. stage), but others which were parts of the complex context within which the illness experience was being navigated and negotiated (e.g. previous relationship quality, time of life). On the whole, people with both diagnoses were motivated to continue engaging in meaningful activities, even if these had to be done less efficiently or undertaken in slightly different ways than before. While caregivers and/or family members were often essential in this supporting of engagement with activities, people with a diagnosis of a dementia were by no means passive receivers of care, and in fact many of the activities selected were chosen because of the opportunities they offered for the PLWD to be helpful, caregiving or to otherwise enact their selfhood or exercise their citizenship. This ongoing motivation to continue with activities of importance (with help if needed, and in different ways) was a means by which a sense of identity and self could be preserved over time, despite the inevitable progression of the conditions. These findings have extended those of the interviews by further drawing out that which is specific to the subjective day-to-day experience of PCA, and by developing ecologically valid understandings of the particular challenges and purposes of PLWD’s engagement with activities which are, first and foremost, meaningful. What the two phases of findings add to the existing literature and theoretical understandings will now be discussed.
Chapter 4: Mixed methods data triangulation (some reflections)

While the epistemological orientation of this PhD is very much interpretivist, and the data analysis so far largely qualitative, I did also collect a range of quantitative data as outlined in sections 2.1.6 and 3.4.6, and part of the learning process of this PhD study has been around how and if these diverging streams of data can be brought together. In this chapter I will talk through some of the ways the integration of the quantitative data was explored. In the interviews this was limited to characterising the sample and seeing if their neuropsychological profile was in line with what would be expected according to the PCA diagnosis, but in phase II, with a comparative group of participants with tAD and more richly contextual qualitative data, some additional exploratory juxtaposing and ‘playing’ with the data is reflected on.

Critically considering how to integrate mixed methods data seemed like an important endeavour, as mixed methods approaches are becoming increasingly popular in dementia research, but there is little consensus about how these two forms of data can or should be integrated, related to one another, and reported on (e.g. Bryman, 2007; Robinson et al., 2011). Acknowledging that findings of mixed methods studies can be rich but also potentially challenging to interpret, Robinson et al. (2011) calls for more specification and transparency about the means of data collection, integration and analysis in mixed methods studies. Robinson and colleagues (2011) also highlight the particular suitability of mixed methods to capturing the complexity of the dementia experience in a more thorough and comprehensive way, but warn against the uncritical acceptance of such methodological approaches. They argue that this sometimes perhaps occurs because of a lack of formal design in mixed methods research, which they cite as a possible by-product of longstanding tensions among the qualitative and
quantitative research traditions. One of the key recommendations Robinson and colleagues (2011) make to tackle this, is the importance of transparency in reporting one’s analytic process when using mixed methods data, something which I hope to do in this chapter.

O’Cathain, Murphy and Nicholl (2007) ascribed the recent increase in mixed methods research in healthcare services to an acknowledged inability for quantitative methods alone to capture the complexity of health conditions and contexts. In their 2008 review of 75 mixed methods studies funded by the Department of Health, O’Cathain, Murphy and Nicholl reported a common lack of transparency in the way the design was described in mixed methods studies. They also commented on a lack of information about how different data sets were integrated, and that findings were mostly reported as separate standalone components. As a result, they too called for researchers to be more transparent in reporting and justifying their mixed methods designs – particularly the analytic process of the qualitative component (which I have done in section 3.4.7 above) and the integration of data and findings, which I will address here.

In agreement with this, Bryman (2007) has also emphasised the lack of integration of findings in mixed methods studies, and calls for more attention to this in future work. He cites the different timelines and rhythms of quantitative and qualitative research methods as one contributory factor to this, and encourages researchers to be aware of and to plan for this when designing a project schedule. Bryman (2007) also notes that a mixed methods approach is often well justified, before data streams are then handled relatively independently. Bryman (2007) advises that researchers keep their rationale for conducting a mixed methods study in mind when thinking about how to organise data analysis to facilitate better integration. A broader point that Bryman (2007) makes is regarding the status of mixed methods research designs, and what he considers a significant deficiency in appreciation of these methods and (perhaps going hand in hand) particularly in how they are written up and published. Bryman (2007) considers this to be key in perpetuating
this superficiality in the approach to mixed methods research, and presses for the reporting of genuinely integrated accounts in which both forms of data can be seen to speak to one another, are mutually informative, and which researchers use to construct a negotiated account of what has been found, via them. This documentation of the data streams in conversation with one another is what I will aim to achieve in the remainder of this chapter, building towards some tentative examples of what kinds of contributions to findings these two different data types can offer, when genuinely considered together.

Existing mixed methods work has shed important light on some of the potentially pertinent issues and possible insights to be gained. For example, George (2011) collected data using pre- and post-intervention psychometric self-report stress scales, which suggested stress decreased following participation in an intergenerational workshop, and qualitative data from interviews and participant-observations revealed some of the mechanisms by which this had happened (e.g., the workshop fostered a sense of purpose and usefulness and provided opportunities for PLWD to develop relationships with others). Conversely, Windle et al. (2018) showed in their longitudinal evaluation of a visual arts program for PLWD some of the possible discrepancies and inconsistencies that can co-exist in qualitative and quantitative data within the same study. While the participants in their study did not report any improvements in their QoL on standardised measures used pre- and post-intervention, this contrasted with what participants self-reported in the qualitative interviews. There they described the program as stimulating to attend and important for fostering their sense of social connectedness, wellbeing and feelings of inner-strength.

Many of the recently published studies which employ mixed methods relate to intervention design or evaluation – with observational studies taking up a smaller proportion of the literature. Mixed methods studies are also often conducted in residential or healthcare settings and with people with memory-led, typical presentations of dementia (e.g. Sampson et al., 2008; George, Stuckey and
Whitehead, 2014; Moyle et al., 2018). There is a relative lack of mixed methods literature studying people at home in the community and with less common presentations of dementia, or with a younger age of onset. There is some mixed methods data integration in the existing literature on PCA, in the form of clinical case studies, in which a person’s imaging data or neuropsychology assessment scores are presented along with anecdotes of their clinical history, but this has not yet happened systematically and at a group level. By collecting mixed methods data pertaining to different aspects of the day-to-day impacts of an atypical dementia diagnosis in people’s everyday home environments, this study has provided some opportunities to think critically about how these diverging data sources may be able to be brought together, and either reveal insights or illuminate issues of interpretation which, taken together, could make a timely and useful contribution to methodological development and disease-specific knowledge in this area. I will now describe some of the quantitative data and how it was used, specifically: the neuropsychological assessment scores and how these helped with characterising the symptom profile of the samples in this study; some of the exploratory data sessions I had with a number of colleagues to test out ways to bring these two data streams together, and some of the insights that this innovative and creative ‘playing’ with the data revealed.

4.1 Neuropsychological profile – Phase I: Interviews

The following neuropsychological assessment was administered to all people with PCA in the interview study to get a sense of their cognitive difficulties, to support our interpretations of the qualitative interview data. The tests administered and some basic information about them are as follows:

- MMSE: The Mini-Mental State Examination (MMSE) a 30-point questionnaire that is used extensively in clinical and research settings to measure cognitive impairment and commonly to screen for dementia. It examines functions including orientation to time and place, registration
(asking participants to repeat items), attention and calculation, recall, language, ability to follow simple commands and constructional praxis. Administration of the test takes between 5 and 10 minutes and scores are out of 30, with scores of 25-30 considered to indicate normal cognitive functioning; 21-24 as demonstrating mild cognitive impairment, 10-20 indicating moderate cognitive impairment and <10 as severe cognitive impairment, according to the National Institute for Health and Care Excellence (NICE) guidelines (Folstein, Folstein and McHugh, 1975; NICE, 2018);

- Short Recognition Memory Test–Words: The short Recognition Memory Test for Words is a shorter version of the Warrington Recognition Memory Test (Warrington, 1984), in which 25 words are shown individually to participants and they are asked to confirm registration of them. Participants are then shown 25 pairs of words (one pair at a time) and asked to identify the word they were just shown (Camden Memory Tests – CMT; Warrington, 1996);

- Incomplete/Fragmented letters (visuoperceptual): This is a test of object perception in which participants are asked to identify 20 differentially incomplete capital letters (shown individually) (Warrington and James, 1991);

- Dot counting (visuospatial): This is a test of spatial perception in which the participant is asked to count the number of black dots on 10 white cards, shown one after the other (Warrington and James, 1991);

- Concrete synonyms test: The concrete word synonym test consists of 25 target words rated as highly concrete and 25 target words rated low in concreteness. Each is read or shown to participants along with a synonym of higher frequency together with a distractor word of similar frequency, and participants have to identify which of the two alternatives has the same meaning as the target word (e.g. “does
‘marquee’ mean the same as ‘tent’ or ‘palace’?”). The total number of correct answers is recorded (Warrington, Mckenna and Orpwood, 1998).

In the dyadic interview phase, these scores were used primarily to characterise participants’ symptom profiles, and as a means of describing the sample to contextualize the qualitative interview findings. For example, when participants were telling us they may rely more on their memory or other sensory information than any visual input when navigating around the home, it was helpful to be able to use this data to corroborate their reports. This was especially important given the lack of awareness of PCA among professionals identified by McIntyre et al. (2018) but also those affected by the condition – it was important for us to understand for example if something they explained as a memory problem (e.g. ‘he forgets his cup of tea even though it’s right there’) may actually have more likely been underpinned by a visual processing problem, rather than a memory-related one.

See Table 4.1 for the mean scores for the PCA group, along with the number of participants in the group whose scores were below the 5th percentile (indicating impaired performance) according to the normative data sets for healthy people in the same age range (per test). Mean participant scores on the Short Recognition Memory Test for Words, fragmented letters (visuoperceptual) and dot counting (visuospatial) tasks were below the 5th percentile, with mean scores on the concrete synonyms test falling within a normal range (Warrington, 1984; Warrington and James, 1991; Warrington, Mckenna and Orpwood, 1998). About half of participants’ individual scores on the tests of memory (Short Recognition Memory Test for Words) and language (concrete synonyms test) fell below the 5th percentile (n=11 and n=9, respectively), whereas almost all participants’ individual scores on the tests of visuoperceptual (fragmented letters) and visuospatial (dot counting) processing skills fell below the 5th percentile (n=19 and
n=18, respectively) (Warrington, 1984; Warrington and James, 1991; Warrington, Mckenna and Orpwood, 1998).

Table 4.1: Neuropsychological scores of patients with PCA (n=20), in phase I

<table>
<thead>
<tr>
<th>Test</th>
<th>Max. score</th>
<th>Raw score (mean±SD; range)</th>
<th>N &lt;5th percentile cut-off</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short Recognition Memory Test for Words* (memory)^A</td>
<td>25</td>
<td>17.98±4.857 12–25</td>
<td>10</td>
<td>~&lt;5th percentile (cut-off 19)</td>
</tr>
<tr>
<td>Fragmented letters (VOSP)^C (visuoperceptual)</td>
<td>20</td>
<td>1.60±2.703 0–10</td>
<td>19</td>
<td>~&lt;5th percentile (cut-off 16)</td>
</tr>
<tr>
<td>Dot counting (VOSP)^C (visuospatial)</td>
<td>10</td>
<td>2.15±2.961 0–11</td>
<td>18</td>
<td>~&lt;5th percentile (cut-off 8)</td>
</tr>
</tbody>
</table>

*Behavioural screening test supportive of PCA diagnosis
VOSP – visual object and space perception battery
^A Warrington, 1984
^B Warrington, Mckenna and Orpwood, 1998
^C Warrington and James, 1991

The scores show that the PCA sample for the interview study had the characteristic cognitive profile that would be expected – specifically that visuospatial and visuoperceptual functions were disproportionately impaired compared to participants’ memory and language capacities. This informed the interpretation of the qualitative interview data by supporting the proposed thematic findings that people with PCA had wide-ranging difficulties engaging with objects and spaces within their physical home environments, as their difficulties with seeing what and where things are clearly suggested by the neuropsychology data. That their memory and language functions were shown to be relatively spared in the neuropsychology data is also supportive of the suggested finding that these skills being relatively...
retained facilitated people with PCA being able to engage in joint decision-making and creative problem-solving as part of a team with their family carers.

4.2 Neuropsychological profile – Phase II: Home-based observations

The home-based observations offered further opportunities for exploring ways to integrate the quantitative data with the qualitative data, as these involved two different populations with different cognitive profiles. A small selection of neuropsychology tests were administered to broadly characterise the nature of participants’ cognitive impairments, as above, and a selection of tests which assess memory, language and visual and spatial processing were included. A small selection was made to ensure that the cognitive assessment, which can be stressful for participants (e.g. Tolhurst, 2015), did not have a disproportionate impact on the rest of the home visit.

The tests administered and some basic information about them are as follows:

- MMSE: The Mini-Mental State Examination (MMSE) is a 30-point questionnaire that is used extensively in clinical and research settings to measure cognitive impairment and to screen for dementia. It examines functions including orientation to time and place, registration (asking participants to repeat items), attention and calculation, recall, language, ability to follow simple commands and constructional praxis. Administration of the test takes between 5 and 10 minutes and scores are out of 30 with a score of 27-30 indicating normal cognitive functioning, 21-26 indicating mild cognitive impairment, 10-20 indicating moderate cognitive impairment, 10-14 indicating moderately severe and an MMSE score of less than 10 indicating severe cognitive impairment (Folstein, Folstein and McHugh, 1975; NICE, 2018);
• Short Recognition Memory Test–Words: The short Recognition Memory Test for Words is a shorter version of the Warrington Recognition Memory Test (Warrington, 1984) in which 25 words are shown individually to participants and they are asked to confirm registration of the words. Participants are then shown 25 pairs of words (one pair at a time) and asked to identify the word they were just shown (CMT; Warrington, 1996);

• Digit span: A test of working memory in which participants are required to repeat strings of numbers of increasing lengths;

• Naming: Graded-difficulty naming test (naming from verbal description) (see Crutch et al., 2013b);

• Dot counting (visuospatial): This is a test of spatial perception in which the participant is asked to count the number of black dots on 10 white cards, shown one after the other (VOSP – Warrington and James, 1991);

• Figure ground discrimination/Shape detection (early visual processing): This is a test of basic visual perceptual function in which a participant is asked whether or not they can see a series of differentially degraded white ‘X’ shapes in 20 degraded black patterned squares, shown individually (VOSP – Warrington and James, 1991);

• Incomplete/Fragmented letters (visuoperceptual): This is a test of object perception in which participants are asked to identify 20 differentially incomplete capital letters (shown individually) (VOSP – Warrington and James, 1991);

• Symbol acuity: This is a test designed to simplify testing visual acuity in patients who have difficulty in scanning visual arrays such as the letters contained in a typical visual acuity chart. The test contains a number of rows of three different shapes (triangles, squares and circles) decreasing in size and the participant is asked to identify the shapes. Acuity can be recorded as an approximate equivalent to a Snellen acuity score.
(Cortical Visual Screening Test - CORVIST - James, Plant and Warrington, 2001).

This data also acted as a means of characterising the sample which was relevant in informing and validating some of my interpretations about the diagnostic differences between the groups, as well as individual’s particular difficulties. See Table 4.2 for a summary table of scores.

**Table 4.2: Neuropsychological scores of patients with PCA (n=10) and tAD (n=10), in phase II**

<table>
<thead>
<tr>
<th>Test</th>
<th>Max. score</th>
<th>Raw score (mean±SD; range)</th>
<th>N &lt;5th percentile cut-off (/10 unless otherwise specified)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short Recognition Memory Test* for Words (memory)^A</td>
<td>25</td>
<td>14.65±2.55  12.5-20</td>
<td>8</td>
</tr>
<tr>
<td>Digit span* (working memory)</td>
<td>12</td>
<td>7.3±3.635  2-11</td>
<td>3</td>
</tr>
<tr>
<td>Naming (language)^B</td>
<td>20</td>
<td>13.8±6.112  5-20</td>
<td>5</td>
</tr>
<tr>
<td>Figure-ground discrimination (VOSP) (early visual processing)^C</td>
<td>20</td>
<td>14.33±2.906  10-19</td>
<td>8(/9)</td>
</tr>
<tr>
<td>Fragmented letters (VOSP) (visuoperceptual)^C</td>
<td>20</td>
<td>3.56±4.166  0-12</td>
<td>9(/9)</td>
</tr>
<tr>
<td>Dot counting (VOSP) (visuospatial)^C</td>
<td>10</td>
<td>2.9±3.048  0-9</td>
<td>8(/9)</td>
</tr>
</tbody>
</table>
The neuropsychology scores show that more comparable numbers of both groups showed impaired performance on the memory and language tasks, than on any of the visual tasks. While about half of the PCA group showed impaired performance on the tests of language and working memory, almost all demonstrated impaired performance on all three visual tasks. This descriptive data is broadly in line with what would be expected – that people with a diagnosis of PCA show selective and disproportionate impairment of cortical visual functioning. The more similar language and memory function across the groups may also reflect that the PCA group were marginally more impaired overall, and likely slightly further into their disease course than the tAD group, and their average MMSE being slightly lower than the tAD group would support this (17 vs. 20).

It is worth reflecting here that only a short neuropsychology battery was administered. Because we included tests of visuoperceptual and visuospatial perception but, for example, not perception in other modalities, one risk is to over-interpret connections between visual scores and functional abilities or observed behaviours as being visually-mediated. In fact, it is important to remember that cognitive deficits often co-occur because of functions being supported by common or nearby areas of cortex that are undergoing atrophy (e.g. patients who have difficulty seeing where something is also often have difficulty hearing or feeling the location of stimuli) so ‘visual scores’ in our short battery may also act as a proxy for the severity of other perceptual and cognitive impairments, or for disease severity as a whole.
4.2.1 Data sessions

In an effort to address the limitations of some existing mixed methods studies outlined above, along with my supervisors and a small group of fellow researchers from other academic backgrounds (neuropsychology and clinical psychology), we had a number of ‘data sessions’ in which we began to explore creative ways to bring the multiple data types together, to juxtapose them and begin to look at what they may be able to illuminate in each other. This was guided by Bryman’s (2007) suggestion that a team with mixed skill-set specialisms is a key component of mixed methods research which more fully integrates the data and findings from both the qualitative and quantitative components. We saw this as almost a form of ecologically valid discriminant validity, and an opportunity to explore if different data sources could clarify any ambiguities or outliers in others.

We included the qualitative field notes, the video data, the neuropsychology scores and the self-report scale data. It is hoped that these sessions could be considered to meet the following three of nine strategies O’Cathain and Thomas (2006) outlined for combining quantitative and qualitative methods:

- Findings from different methods are checked against each other;
- Qualitative and quantitative research are used together to provide a bigger or richer picture;
- Qualitative research facilitates interpretation of findings from quantitative research.

Here I will try to capture some of what was discussed in those meetings, how they were structured and some of the poignant insights which emerged from them. It is important to state that these conversations were exploratory and inquisitive, partly because of the lack of consensus about how to integrate these different data streams and particularly because of the rich volume of data collected in this study, and the variation in participants’ individual contexts and home settings. As such, I am not proposing that anything illuminated to us in the process of doing this, or any
patterns noticed or issues raised, would transfer beyond the individuals whose data
was under discussion, and sometimes that was data of a whole diagnostic group,
but sometimes it was data relating to a specific individual. The aim in having these
conversations was not to establish guidelines for mixed methods data integration,
rather to see if and how those conversations could work and which issues those
conversations raised, which could in theory, inform further work towards
establishing recommendations and guidelines on the integration of different data
types. During these sessions we moved between data sources and accordingly,
epistemological positions, each of us mainly orienting ourselves within the dataset
we felt most comfortable with, but consciously asking questions related to other
data streams, and making suggestions about what we might expect to see (or not see)
in another data stream, which would corroborate or conflict with our own. For
example, one of the neuropsychologists in the team had suggestions of who they
would anticipate having had particular difficulty reaching for and grasping objects
during the observational home visit in accordance with their neuropsychology
scores, and I as a social scientist had suggestions for which dyads would have
greater discrepancies in their carer and PLWD ratings of the PLWD’s QoL, having
observed variations in dyadic dynamics over the course of the day spent in the
home environment. As mentioned, we asked some questions in which we expected
different data sources to align or agree, and we called these ‘verification queries’.
We also asked what we called ‘discrepant queries’, where we expected data sources
to disagree, and these too were either driven by theory, literature or other data of a
different type in the current set.

Sometimes our predictions and suggestions to each other were validated and
corroborated by data in the other streams which gave us some confidence in our
interpretations, however sometimes we were surprised by what was revealed when
juxtaposing the different data sources, and this then encouraged discussions about
why that might be. Some examples of these types of queries and the insights and
reflections they contributed to are included below.
It is important to mention that for the purposes of this chapter, I did not seek statistical verification for any possible relationships (or lack thereof) between the variables or data points being juxtaposed and as such, any references to possible relationships, dissociations, or trends within this chapter refer to tentative observations made when viewing this data, as it was juxtaposed visually (and as it will be presented here for similar consideration). While statistical tests are invaluable for establishing significant differences between whole groups or variables, here the focus was on exploring new ways to consider data points – which were sometimes collected across multiple modalities, and both qualitative and quantitative in nature – in relation to one another. The sample size here was also manageably small enough that each individual (i.e. each data point) could be considered in terms of the corresponding individual and in light of the other data collected pertaining to that individual (much of which was richly contextual, unstructured and experiential), and this was compatible with the overall case study approach being taken. For the exploratory nature of these data sessions, it was considered important that the quantitative data did not drive or overly shape our interpretations of the qualitative data we were juxtaposing it with, and accordingly, it was thought that formal statistical testing would offer what could be considered a seemingly more objective or verified interpretation of any potential relationships in the data, in a way that did not fit the aims of these sessions. Correspondingly, the qualitative data was also considered at the level of the individual (as well as at the group level) throughout these sessions. This flexibility in exploring the data at both individual and group levels resulted in some useful analytic insights which informed the developing, overarching interpretations of the data in this study, but future work which extends this approach, perhaps exploring some of these issues in larger groups and on a larger scale, could make a worthwhile contribution by also exploring the place of formal statistical tests in similar mixed methods data integration.
4.2.1.1 Example reflections

When triangulating the neuropsychology data, a composite 'Visual function' score was calculated by averaging participants' transformed scores on the three visual tests administered: figure-ground discrimination, dot counting and fragmented letters. This composite score and scores across all other tests (except for the MMSE) were transformed (from 0-100, in which 0 and 100 corresponded to the minimum and maximum score achieved by any participant) in order to better represent each participant’s performance relative to the rest of the group. Because of familiarity with the MMSE, raw scores (i.e. 1-30) were used, as they were considered more easily interpretable than transformed scores would be (i.e. scores from 1-100).

4.2.1.1.1 Memory, vision and diagnosis

![Memory function, visual function and diagnosis](image)

*Figure 4.1: Memory function (as indicated by performance on the short Recognition Memory Test for Words (sRMT(w)) plotted against visual function (as indicated by a composite score across 3 visual processing tasks), by diagnostic group*

When looking at participant’s composite scores on the three visual neuropsychology tasks plotted against their performance on the memory task (see Figure 4.1) we saw that, as expected according to the literature, diagnostic
information, and corroborating the observational data regarding the nature of the difficulties participants were having in engaging with their preferred activities, most of those with a diagnosis of tAD demonstrated better performance on the visual tasks that those with a diagnosis of PCA. There was a similar spread of the scores for each group on the memory task which was perhaps reflective of the PCA group being on average slightly further into their disease course than the tAD group (average MMSE 17 vs. 20).

4.2.1.2 ADL impairment, severity, vision, memory and diagnosis
Looking at the level of functional ADL impairment along with the MMSE, visual composite and memory scores from the neuropsychology assessment (see Figures 4.2-4.4), it can be seen in each plot that more members of the PCA group fall into the half of the group whose ADL function is rated as most impaired by their carers on the ADL scale (Johnson et al., 2004). This distinction is clearest to see with vision on the Y axis, which is fitting with Perry and Hodges (2000) work which reports visual skills to be a stronger predictor of ADL function than memory skills, and also compatible with Shakespeare and colleagues (2015) study which showed that people with PCA showed greater impairment in everyday skills such as writing, using the telephone, than the tAD group who were more impaired on tasks involving memory and motivation. This was consistent with my observations in the field – it had seemed that the visual problems participants with PCA were demonstrating were more pervasive in their disruption of everyday activities in terms of the universality of activities affected, but also in terms of the continual way activities were affected. For example, if someone was having trouble locating objects, that would affect dressing as much as doing jigsaw puzzles and using the phone to call a friend. Participants with tAD may not have always remembered or shown independent motivation to execute certain activities, but often they would if encouraged by a family carer, or if something in the environment cued them to initiate an activity. Regarding the continuity of the impact of symptoms, if someone with PCA was having difficulty perceiving the lines of the racks in the dishwasher,
that difficulty would continue for the duration of the activity, whereas for a participant with tAD, a lack of motivation for a task or memory for location of an object often only needed to be addressed, supported, or facilitated once, before activity engagement could continue undisturbed for a while. However, our discussions about this as a team caused me to explore my observations of the PCA group in more depth – while this pervasive and profound impairment in engaging with activities had been clear during the observations, I realised in discussion that I had considered most participants with PCA to have engaged with a range of meaningful activities which they were motivated towards over the course of the visit. It seemed on reflection that this had been the case because of the largely supportive and facilitative role of carers, and the upheld close communication between participants and their family carers which meant that needs, preferences choices and the specific natures of difficulties became shared knowledge and a shared problem. This was captured across all three themes which were constructed from the qualitative data analysis.

Figure 4.2: % ADL impairment plotted against MMSE(/30), by diagnostic group
Figure 4.3: % ADL impairment plotted against memory (as indicated by the sRMT(w)), by diagnostic group

Figure 4.4: % ADL impairment plotted against visual function (as indicated by a composite score across 3 visual processing tasks), by diagnostic group
4.2.1.3 Severity, ADL impairment and qualitative observations by diagnosis

Juxtaposing the observational field notes with participants’ scores on the MMSE and an ADL measure of functional impairment (see Figure 4.5) also proved a very helpful part of our analytic process.

![% ADL impairment, MMSE score, diagnosis](image)

*Figure 4.5: ADL impairment plotted against MMSE(/30), by diagnostic group*

It was in doing this that we realised that two of the most severely cognitively and functionally impaired participants had in fact spent a large proportion of their day doing ADL type activities (more than many of the others). Alan who had a diagnosis of PCA and the lowest MMSE score of all participants (5), had spent several hours over the course of the day clearing leaves by hand from the front and back gardens. When talking to him about this, he explained to me that he found it satisfying because it was ‘hands on’, before emphatically declaring that he wanted ‘to do something’. This got us as a team thinking about what we measure when we assess functional impairment, factors such as frequency of task completion, efficiency with which things are done, amount of help needed, and how reliably those measurable outcomes may actually be driving activity engagement in people’s own homes. This
complemented the shift in focus in the qualitative data away from just the what difficulties people were having with activities with a view to us developing adaptive aids to support them, and towards gathering a better understanding of what activities people were motivated to continue doing despite any difficulties they were having, and why. The most severely cognitively impaired participant in the tAD group was Helena, and she completed a wide range of household chores over the course of the visit including making the beds, folding and hanging laundry, setting the table and loading and unloading the dishwasher. Once again we saw what we considered to be an apparent lack of correspondence between her MMSE and ADL functioning scores and her actual engagement with those activities in her home environment. This encouraged our thinking along the lines of how Helena’s activity engagement was enabled and why, and was significant in shaping the second theme, ‘Reciprocities of care’, in that Helena’s participation was supported by her husband, but also offered her an opportunity to continue to contribute to the household in many of the ways she always had.

4.2.1.1.4 NPI-rated apathy and qualitative observations

Another important insight that juxtaposing scale data with observational data revealed was regarding reported levels of apathy and observed activity engagement. When looking at the NPI data, the same number of participants in each group were rated as displaying apathy by their carers, but in the light of the observational data this seemed surprising to me in the first instance. I seemed to recall all members of the PCA group having spoken at some length and with some enthusiasm about the varied activities, people, events and subjects they were interested in, suggesting a high level of retained interest and motivation. This is illustrated in Figure 4.6, where extracts from my field notes coded as ‘meaningful/useful/purposeful activity’ have been collated for 3 participants in the PCA group who were rated as displaying apathy on the NPI. There are several possible interpretations of how this data from these two different data sources could be compatible and not in direct conflict – for example apathy can be phasic
and context dependent, and the novelty of the home visit and having a researcher
displaying extended interest and engagement could both have encouraged
individuals to engage and express more interest than they otherwise might have.
However, the point here was not necessarily about reconciling the data sources,
more that it was this juxtaposing of them which caused me to revisit the
observational data to validate and verify my impressions, and this looking more
closely at the two data sources alongside each other, helped to support my
emerging interpretation that the PCA participants – despite maintaining interest in
and motivation to engage in a range of activities – were limited very early on in
their diagnosis in terms of their abilities to enact or instigate these activities,
because of the profound visual and spatial processing problems they were having.
Looking at different data streams alongside each other for both groups further
developed our understanding of the group level differences in how apathy could be
made apparent, or could be interpreted by others, and how this related to activity
engagement.
**Figure 4.6: Extracts of field notes coded as 'Meaningful/purposeful/useful activity' for 3 PCA participants rated as displaying 'Apathy' on NPI**

**ELEANOR**

End of visit field notes:

Career was really important to her – talked about it a lot, v interested in me and our work, would love to still be working
Really motivated to take part in research
V little family support network is EASRI and friends but EASRI totally dependent and reliant bc of needing to navigate the physical environment even though v articulate and engaged and interested and insightful

**LILIAN**

End of visit field notes:

She has lost her sense of self/identity, seems to be because she can’t practically do things/potter/decorate etc around the house anymore and also because she can’t drive/walk into town anymore – feels very reliant on others
She’s always been very sociable and misses that now (you just don’t see anybody here) but maintains it where she can e.g. curiosity re: who is contacting on the phone, in interactions with me (concern re my staying alone, my future career plans, us girls and our fashion preferences)

**PAUL**

On the day observational notes:

Music; loss; playing w others; always in bands
Old house and music
‘can’t do the things they’d like to’ ‘I can play by myself but it’s not the same’
Music room; trumpet player who has died; v upsetting but ‘fantastic to hear a trumpet played the way it should be played’ **key moment**

End of visit field notes:

Time of life and how that impacts...loved working but now retired, loved his years touring w band but friends are getting older now and not so possible any more
POLHA really motivated re research and conscientious about whether or not it’s going to be worthwhile or interesting
The tAD group members rated as demonstrating apathy seemed to do so more in the traditional neuropsychiatric sense of displaying a lack of motivation and interest in initiating activities, but interestingly were often seemingly happy to be engaged in activities orchestrated and supported by their family carers. Helena’s productivity with household chores was always instigated by her husband (though executed by her), and Lionel and Mark both independently approached their family members asking what they could help with. This exercise in data juxtaposing was helpful for developing my analytic thinking in terms of not only which activities were done and why they were important to people, but also how they came to be completed or challenged, and the diagnostic differences underlying these discrepancies.

4.2.1.1.5 QoL, ADL impairment and diagnosis

![Figure 4.7: PLWD-rated QoL (QoL-AD; /max. 52) plotted against % ADL impairment, by diagnostic group](image)

When looking at participants’ self-rated QoL scores in combination with how their family carer rated their ADL functional impairment overall (see Figure 4.7), it appears that there is little relationship between QoL and ADL function or with diagnostic profile, as even though members of the PCA group generally
demonstrated more impairment in ADL function overall, the QoL ratings seem to cover a similar range across both groups. This helped to further endorse my emergent analytic interpretations about the possible dissociation between ability to do activities in a way that would be considered functionally accurate or independent, and overall outcomes such as the general sense of wellbeing that seemed evident during the home visit.

4.2.1.6 PLWD-rated QoL x ADL Scale score x qualitative observations

One of the other ways we juxtaposed these data sources was by viewing the quantitative data displayed in charts with the data points labelled with participants pseudonyms and their index cards to hand. Figure 4.8 shows each participant’s rating of their QoL and their level of functional impairment in ADLs, with the bubble size representing the level of cognitive impairment indicated by MMSE score. The MMSE score was inverted so that the largest bubbles correspond to those participants who were most cognitively impaired.

Figure 4.8: PLWD-rated QoL plotted against % ADL impairment, with bubbles representing MMSE score (larger size indicating greater cognitive impairment), for each diagnostic group
The range of different sized MMSE markers across the whole range of QoL ratings (Y axis), suggested that in this group, QoL was also not related to MMSE score in a unidirectional way. It seemed fitting to me that QoL rating did not appear to be related to ADL function or MMSE in very clear and straightforward way for the participants observed here, as I had experienced a positive and cheering day with the majority of participants who had mostly been in very good spirits. This was perhaps more surprising to colleagues involved in the data sessions, whose notions of the relationship between QoL and functional independence in ADLs may have been primarily informed by existing literature (e.g. Andersen et al., 2004; Giebel, Sutcliffe and Challis, 2015).

These scatter plots and bubble charts also proved useful for considering outliers, and this was another way we asked ‘discrepant queries’ of the data set. Some examples of these were Mandy, who had one of the highest QoL ratings and lowest ADL impairment ratings, despite showing mid-range cognitive impairment according to her MMSE score. This was an example of when quantitative and qualitative data could offer conflicting information, and how further understanding can be developed in the process of trying to reconcile the two data types. While this scatter plot data point seemed to intuitively make sense – that someone having no problem with ADLs would have high QoL – this did not quite fit with my observational field notes, in which I had noted that Mandy showed a number of what seemed to be memory or executive function related difficulties with ADLs, for example with using the remote control, asking repeated questions and difficulty with food preparation. However, Mandy and her family carer both adopted what I described as a ‘normalising’ approach to managing her difficulties – Mandy’s partner had taken over many of the household tasks, but they would both often comment that any difficulty she was displaying was just the same as anybody else might, and when completing the NPI her carer made several comments indicating that Mandy did exhibit the symptom being asked about, but not to a level that needed documenting. This encouraged me to reflect on the use of measures which
rely on caregiver ratings and especially in the PCA group (and with other rarer forms of dementia), when carers themselves may have limited understanding of or knowledge about some of the symptoms being displayed.

Paul was another person who, when data from a range of sources was taken together, my interpretation of his ongoing activity engagement was enriched. He first stood out as an outlier as he had a similar level of overall cognitive impairment and impairment in ADL functioning to the majority of the PCA group, but lower self-rated QoL. This was slightly at odds with my impression of his activity engagement and general coping over the course of the home visit as he had continued to engage in playing his keyboard and I was aware music was a very significant interest of his, both personally and professionally. He also seemed very enthused during our conversations and made many jokes and was very inquisitive about the research study. This semi-surprising low QoL rating being illustrated so clearly by this chart took me back to Paul’s data to explore this more, and helped me bring together two different aspects of the data which had both contributed to the final three themes, but which had not been linked so explicitly. I had known that music was a very important interest of Paul’s and that he, with the help of his family carer, had continued with modified modes of engaging with it, and spent some time during the home visit playing the keyboard. I had also noted how motivated to socially engage Paul was, and how keenly and energetically he chatted to me almost constantly throughout the visit. Drawing this together, I revisited my notes from a conversation we had had about Paul’s music-playing history, and was reminded of his expressing how different playing alone was to playing in a band, and how much he missed the latter. This helped me to think about how some of his priority activities (music and socially connecting) came together, and how it was actually perhaps the most meaningful aspects of his most meaningful activity (the music playing) which had become unsustainable (the social component). This stimulated useful reflections about how even within meaningful activities there is a layer of complexity in terms of the content of the activity as well as how it is delivered or
achieved, and which indirect needs all of this might meet. This helped to cement ideas about the importance of taking a dimensional approach to the measurement or capturing of activity engagement, to best represent the real-world complexity which I had been privileged to observe.

Another example of where comparing quantitative plots against the qualitative observational data was with the overlap of Lilian and Sally in a bubble chart (see Figure 4.9), which plotted memory function (as measured by performance on the sRMT(w)) alongside visual function (as measured by the visual function composite score), again with marker size representing overall cognitive impairment (indicated by MMSE score). The observational home visits with these two participants were very different experiences in terms of their activity engagement but also in many other ways, so I was initially surprised to see them overlapping or equivalent in any way on this bubble chart. Exploring this further helped me to verify some of the thematic findings, such as the importance of shared decision making and communication about participant preferences for activity engagement, and also the idea that couples coping and day-to-day experiences are not solely contingent on or determined by cognitive ability, and that the environments – both physical and social – can have a huge impact, again in keeping with the three themes which emerged from the qualitative analysis.
Figure 4.9: Memory function plotted against visual function, with bubbles representing MMSE score (larger size indicating greater cognitive impairment), for each diagnostic group

4.2.1.1.7 Levels of QoL and impairment in chores vs. fun activities

Having identified an interesting discrepancy between cognitive and functional impairment in ADLs and levels of engagement with them during the home-based observations, I had a further look at the quantitative data which related to ability to do activities (ADL scale – Johnson et al., 2004) and how people rated their QoL in terms of those activities (QoL-AD – Logsdon et al., 1999). In reference to the first theme of the qualitative data analysis, ‘The fun and the function’, I was interested to divide this up further into activities that were more functional (‘household care’ subscale on the ADL scale; ‘chores’ on the QoL-AD – see Figure 4.10) and those that were more for enjoyment (‘employment and recreation’ subscale on the ADL scale; ‘things for fun’ on the QoL-AD – see Figure 4.11), and once again used level of cognitive impairment (MMSE, inverted) to determine the size of participants’ markers.
Figure 4.10: PLWD-rated QoL in the domain of 'chores' plotted against % ADL impairment in 'household care' subscale of ADL scale, with bubbles representing MMSE score (larger size indicating greater cognitive impairment), for each diagnostic group.
What struck me as interesting here at the general group level was that there seemed to be much stronger stratification in the ‘chores’ chart than the ‘fun’ one. In the ‘chores’ chart (Figure 4.10), it seemed quite clear that the majority of the PCA group were more impaired at them and rated their QoL in relation to them lower than in the tAD group. There is a lot more overlap evident in terms of the ‘fun’ chart (Figure 4.11), both in terms of QoL ratings and level of ADL impairment, although it seems that the PCA group were overall more impaired than the tAD group on activities falling into this category, as well as the ‘chores’ activities, and that more of them were rating their QoL more highly in relation to fun activities than chores. As with all of these charts with numbers of this size, what can be concluded about these apparent differences is limited, but this distinction does perhaps make the case for considering different types of activities, and the different functions they
might serve for people, separately. Considering these charts alongside the qualitative observational data, the two seem quite compatible with my experience that the PCA group undeniably seemed to have pervasive difficulties with a range of ADLs, but that the outlook and mood across the group seemed relatively positive and cheerful. Perhaps this was because of an increased tendency towards fun activities, and perhaps the literature shifting towards meaningful activities is a helpful one, given that these activities are (by definition) less well-specified and constrained in the different formats they can take.

4.2.1.1.8 MMSE, diagnosis, level of ADL impairment and qualitative observations

I also looked at participants in order of their cognitive impairment (MMSE score), and this was helpful for verifying what I had observed in terms of the effects of the differences in the dominant symptoms of the participants in each group on their activity engagement. For example, although Martin, Oscar and Sally had the same level of overall cognitive impairment as Mandy, the assistance they required with day-to-day activity engagement was very different, and much more requiring of hands on help, owing to their dominantly visual symptoms. Similarly, Rhian and Betty had the same level of overall cognitive impairment, but Rhian’s presentation was much more visual, and while she could not find the button to turn the kettle on, Betty was able to methodically organise peas into a tidy symmetrical mound. See Figure 14.12 for participants organised by diagnostic group and ordered by MMSE score, with an icon to indicate their level of ADL impairment, and extracts of field notes which illustrate their largely memory/visually based difficulties and strategies. This figure is a somewhat tidier version of the initial freehand drawings I found most intuitive to work with when I tentatively began this process individually, and I have included some original messy sketches of these early attempts at data juxtaposing in the Appendices, in case of interest (see Appendix 11).
Figure 4.12: Participants grouped by diagnosis, ordered by MMSE score, with levels of ADL impairment indicated and excerpts of field notes illustrating visual/memory-based difficulties/strategies.
4.2.2 Summary

This chapter has given some sense of the exploratory and iterative process we went through as an interdisciplinary team, to experiment with finding ways to look at these different mixed method data types in the context of each other, and how insights gleaned via doing so, fed back into the iterative process of moving between different data sources, asking questions of them, and even seemed to verify or encourage further exploration (and eventually richer understanding) of the qualitative data which had largely been independently coded and preliminarily analysed before this exercise took place.

I would stress again that this was exploratory and so has opened up far more questions than it has answered, but hopefully it has triggered enough analytic interest to justify and encourage others to be creative in finding ways to relate mixed methods data and to further the conversation about this. This includes questions relating to data hierarchies, sequencing of processing, and theory versus data-driven enquiry. We played with both here, but there are some unavoidable disciplinary and epistemological variations in relation to these, which would benefit from being made explicit and acknowledged in future studies seeking to merge mixed methods data in this or other ways.

The numbers of participants here were small, which was quite helpful given the rich observational data we had for each person, as it allowed us to continue to consider people at the individual level. This would perhaps be less feasible and/or less interesting in a study with a larger sample with perhaps less qualitative data per participant. The breadth of the data was also often small – when participants are answering on a 1-4 scale there are questions to be asked about how meaningful a difference in experience these scores can really represent – and therefore the value of making interpretations about them, and this perhaps especially applies when looking at a subscale or individual items of interest within a questionnaire. It is also true that we were not systematic in the queries we asked of the data sets – partly
because this was exploratory, but also because the idea of systematising this process may speak to bigger epistemological issues and warrant further consideration in future work.

One final reflection on this process was that as an exercise I found it very helpful for developing my own reflective practice, and better understanding my own intuitive ontological and epistemological positions. It forced me to question and defend my decision-making, to be open to new ways of questioning my interpretations of data, and gave me new appreciation for not just what different insights data obtained by mixed methods can provide about the research topic of interest, but also what these different data streams can say about each other, all of which contributes to building a more nuanced picture of a complex phenomenon. A useful onward step from here would be to consider not just the integration of mixed methods data at the stages of collection and reporting, but also more specifically in terms of how data of both types can be displayed and visualised together during analysis. A very rough initial attempt which draws together some initial ideas I had for this is included in my appendices (see Appendix 12).

I have attempted to map out how these data sessions fit within and across the analytic process during this phase of the study – see Figure 4.13. Colleagues and I also attempted to map out the thinking processes which characterized some of these exploratory data sessions, taking into account those of us who were involved and how questions originated, were asked and responded to, and include a visual representation of that in my Appendices for illustrative purposes (see Appendix 13).
Figure 4.13: Diagrammatic representation of data sessions throughout the analytic process
These examples are by no means exhaustive or comprehensive, but rather a select handful of interesting instances, and although these often speak at the level of the individual, I hope they at least offer a glimpse into the possibilities for mixed methods data from both ends of the qualitative-quantitative spectrum, to shed new light and open up new questions or interpretations of the other, and contribute towards useful analytic development more broadly, whether that is by verifying findings in other data streams or highlighting areas where offering a new angle may extend understanding.
Chapter 5: General Discussion

5.1 Introduction

In this section I will firstly outline the unique contribution this work has made, before discussing the findings of both phases of this PhD study, and how they add to current understandings about: the day-to-day impacts of living with a rare form of dementia which mostly affects vision; and more specifically, how ongoing activity engagement is motivated and supported for people living with PCA and tAD in their home environments. I will situate my central findings in the existing empirical literature under the following headings: diagnosis-related differences – this will focus on the specific challenges a diagnosis of PCA can pose; acknowledging the individual and recognising relationships – this will focus on the intra- and interpersonal factors at play in the relational context of navigating day-to-day life with the condition(s); meaningful and measurable activities – this will focus on the motivations and meanings of activity engagement; and finally temporality – which will acknowledge the inevitable impact of the changing temporal context in the experiences of neurodegenerative conditions such as these. I will then draw out the theoretical implications of this work – how the findings relate to the two dominant theories which framed the study (the Stress Process Model and relational citizenship approaches) and other theoretical approaches which may also help with understanding the findings. I will then reflect on the methodological implications of the home-based observational study in particular, given the novel combination of methods and intensity of data collection. Finally, I will address some limitations of this work and discuss the broader implications for research and practice.

5.2 Original contribution

This PhD project has offered an original contribution to knowledge in being the first qualitative exploration of the day-to-day subjective experiences of people living
with PCA, highlighting the particular challenges faced, such as the prolonged and stressful process of receiving a diagnosis through to the day-to-day management of profound difficulties in interacting with the physical environment. Investigating and observing these difficulties, along with everyday activities of choice, in real-time in people’s own homes, I have been able to consider the interactions and intersections of these physical and psychosocial environments, and to acknowledge the relational context in which the illness is experienced. This has permitted a novel level of ecological validity which complements the largely clinical and lab-based studies of this condition to date, as well as those in typical dementias which often focus later on in the disease course. As I will go on to outline, the findings have also offered opportunities to consider the potential value of theoretical approaches traditionally applied to healthy adults, as well as those usually applied in the later stages of dementia, to those earlier in the course of a rare form of dementia, with a distinctly different dominant symptom profile. The extended duration of observations which were unstructured, has permitted and encouraged authentic contributions and increased the accessibility of participation. I have been able to witness the vast variation and complexity in individual contexts and, using methods drawing on focussed ethnographic principles for the first time with both diagnostic groups, have been able to capture some of the rich nuance and complexity in the ordinariness of everyday life, and gathered insights into the meanings within the mundanity. With the collection of multimodal data in verbal, visual and other domains, I have been afforded the opportunity to triangulate this mixed methods data in creative and innovative ways, to reveal new insights about the significance of different dimensions of activity engagement. These may contribute to broader notions of the practicality and applicability of assessing meaning and measurement of the lived, subjective, day-to-day experiences of people affected by the dementias, and inform interventions to maximise their enduring participation and engagement.
5.3 Diagnosis-related differences

Here I will focus on what the findings have revealed about the specific challenges a diagnosis of PCA can pose, and the differential potential impacts of the different diagnoses on activity engagement. The findings from both phases of this PhD study have highlighted the distinct set of challenges that those with PCA face in engaging with their everyday environment and activities. The challenges and strategies that participants with PCA described and demonstrated in the dyadic interviews and which were observed in the observations were much more often visually and spatially related than in the tAD group, and this unusual symptom profile in itself was a major contributor to stress, because of the convoluted journey to diagnosis the majority of the interview participants had endured. The challenges and strategies observed in the tAD group were much more memory-oriented, with participants demonstrating impairments in remembering which activities they were mid-way through, which they had been allocated or had agreed to take on, how different pieces of equipment worked, and where the necessary items for a given activity were. 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 the neuropsychology assessments, verbal reports and observed activities of the PCA participants in this study were as follows: ideomotor and dressing apraxia (inability to correctly imitate hand gestures, mime tool use or inattention to the left side when dressing), alexia (inability to read), elements of Gerstmann syndrome (e.g. inability to identify own or another’s fingers, inability to write and inability to tell left from right), apperceptive visual agnosia (e.g. difficulty recognising objects or telling them apart) and environmental disorientation (Mendez, Ghajarian and Perryman, 2002; Tang-Wai et al., 2004; Crutch et al., 2012).
One of the problems that the PCA group experienced most severely, and which they described as having most impact on them was difficulty with reading, and this is consistent with published findings about how the visual dysfunction associated with the syndrome effects both reading speed and accuracy (Yong et al., 2014a; Yong et al., 2015). Further evidencing the distinctness of the PCA symptom profile, reading was very differently impaired for members of the tAD group who participated in the observations, and appeared much more representative of episodic and working memory impairment, which is well documented in tAD (e.g. Becker, 1988; Baddeley et al., 1991; Greene, Baddeley and Hodges, 1996; El Haj, Antoine and Kapogiannis, 2015). This was particularly striking in the cases of Brian and Anita whose MMSE scores were still in the range of normal functioning but who both had difficulties recalling details of the books they were reading, and this is consistent with empirical literature showing impaired episodic memory as a hallmark of tAD, evident even in the preclinical stages (e.g. Bäckman et al., 2001; Germano and Kinsella, 2005; Baudic et al., 2006). Another distinct visual symptom reported in the literature for people with PCA is that they perceive the world in a somewhat fragmented way (Crutch et al., 2012, 2013a; Crutch, 2014), and this too was observable during activity engagement, and impacted the efficiency with which activities could be completed. Examples of this included Alan and Maurice having to revisit areas of the garden and carpet when picking up leaves and fluff.

The literature also corroborates that the difficulties participants had and described were underpinned by their different cognitive symptom profiles. Difficulties navigating and environmental agnosia are a widely-reported clinically presenting feature of PCA as a result of impaired processing of visual and spatial information (e.g. Tang-Wai et al., 2004; Crutch et al., 2013a; Crutch, 2014). In contrast, the literature identifies several possible reasons underlying navigational problems for people with more typical AD, including predominant memory deficits (e.g. Monacelli et al., 2003), dementia-specific changes in orientation strategies and in the loss of planning abilities (Passini et al., 2000; Chiu et al., 2004). There is also
evidence suggesting that the visuospatial deficits that can also occur in tAD can be responsible for navigational issues for that group too (Liu, Gauthier and Gauthier, 1991), highlighting the importance of raising awareness and building the knowledge base about visual problems in more typical presentations of dementia more generally, as while these are less dominant, they are indeed possible and even common in the more advanced stages. However, in looking at their performance on the visual subsection of the neuropsychology tests, it seems it was predominantly issues with memory, orientation and planning which underlined any navigational problems for the tAD group in the observational phase of this study. This does however serve to highlight the complexity of discrete diagnoses given the idiosyncrasies and potential overlaps in symptom profiles at the individual level.

One of the difficulties most commonly observed in the tAD group during the phase of observing 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 (e.g. Baddeley et al., 2001; Chiu et al., 2004). The PCA group did not seem to report this disorientation to task during the initial interview stage, as many offered thorough and articulate accounts of the activities they were doing, or wanted to do, and how those had been affected. This was corroborated in the observations when PCA participants showed keen motivation and orientation to task, but would often be prevented initiating or executing them, and this preserved motivation and orientation to task is compatible with previous findings which have documented the relative strengths in memory, insight and language people with PCA show compared to their tAD counterparts (e.g. Mendez, Ghajarania and Perryman, 2002a; Tang-Wai et al., 2004; Charles and Hillis, 2005). These preserved functions were also key in permitting the shared decision making, mutual reflection on the challenges associated with activities, and reciprocal navigations of support delivery relating to ongoing activity engagement that was both reported in the interviews and witnessed in action the observations. That this was possible throughout all stages of the PCA group perhaps suggests unique opportunities for
dyadic interventions in this group, though the fact that this kind of collaborative coping did not characterise every dyad highlights the complexity of this, and the broader interpersonal factors to consider. Generally though, this highlights the importance of considering retained capabilities as well as impairments, and perhaps more broadly, a not solely deficit-based approach, in order to build a full and rich picture of the illness experience, but also to empower those coping well by recognising their efforts and learning from them to improve support for those managing less well.

Another barrier to activity engagement for the tAD group was the frequently observed difficulties participants had with locating the items required for activity engagement, and this is often reported as a common problem for PLWD in the mild to moderate stages by them and their families (Hamilton et al., 2009). The PCA group had also described difficulties with misplacing and finding objects in the dyadic interviews, and the observations and neuropsychology data helped to confirm that these difficulties with localising and manipulating objects was owing to the specific visual and spatial symptom profile of the PCA group, and this is compatible with empirical literature reporting full or partial Balint syndrome, which includes optic ataxia (impaired interactions with objects), visual field defects (blind areas within the normal field of vision) and simultagnosia (inability to perceive more than one object at a time) (Tang-Wai et al., 2004), as common features of PCA. Another way objects were observed to relate differently to activity engagement for the two groups was that objects could act as cues to activity engagement for the tAD group. For the PCA group, because of their difficulties accurately perceiving objects in combination with their retained intentional and motivational capacities, this appeared not so possible nor as required as a facilitator for them to engage. These diagnostic differences have implications for intervention design, as for example, an activity intervention involving prompt objects may work for people with tAD but be less supportive for someone with PCA, highlighting the need for increased awareness of diagnostic variation and tailored information and support.
Difficulties with manipulating objects were also seen in the tAD group and are well documented in the tAD literature, but these more often related to an underlying impairment in one or a combination of cognitive functions including attentional, executive function, or memory capacities (e.g. Mlinac and Feng, 2016). One way these other functions can contribute to impaired ADL functioning is via compromised visual search strategies (Ramzaoui, Faure and Spotorno, 2018), further highlighting that what might be considered as a dissociation of memory and visual impairments in the PCA and tAD groups may be better understood as a common trend rather than as a discrete distinction. It was certainly the case that some PCA participants in both phases of this study showed some memory impairments, and that some members of the tAD group in the observational phase of the study had some difficulty on the perceptual tasks. This complexity and overlap in symptom profiles fits with literature which documents memory impairments at initial clinical presentation for people with PCA (Ahmed et al., 2016) and visual processing deficits contributing to functional impairments in reading and ADLs for people with tAD (e.g. Glosser et al., 2002a, 2002b). This highlights the complexity of these conditions and also the importance of acknowledging individual variation and the specificities of a person’s neuropsychological profile when assessing its impact on engagement with activities and functional capacity more broadly.

The distinct difficulties of both groups in their abilities to find and use objects effectively also seemed to have some broader, unifying implications. Objects in the environment appeared not only to be essential for the execution of many activities but, as reported in the empirical literature, also seemed to play an essential role in constituting both groups of participants’ senses of self and personhood, by representing the activities associated with longstanding hobbies and interests (e.g. Lloyd, 2015; Halpin-Healy, 2017). Participants in both groups demonstrated perseverance in engaging with meaningful objects – even when this had to be in different ways to previously, which can be considered testament to the prolonged
potential of objects to connect people to their hobbies, interests, previous life history and sense of themselves. This perhaps suggests that interventions to support the wellbeing and continued engagement and endurance of personhood of PLWD which incorporate meaningful objects would be worth pursuing.

Further highlighting the complexity and individual variation in the underlying cognitive profiles and patterns of observable symptoms of the participants here, there were examples in both the dyadic interviews and observations of the PCA group of their family members misattributing the difficulties. This could include a carer claiming that their loved one 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 tAD. This perhaps reflects dominant discourses around dementia, and stresses the need for these to be more representative of the varied profiles of symptoms that can accompany different types of dementia, especially given that this is often the background knowledge people have to draw on when they first receive a diagnosis. This has particular implications for people with rarer presentations such as those with PCA interviewed and observed in this study, as it can contribute to an already prolonged and difficult diagnostic journey, when the symptoms do not correspond with prior assumptions and knowledge of a condition. A particularly key misattribution that emerged over the course of the observational home-visits as the research questions became more focused on engagement in meaningful activities, was the potential for family members to underestimate how motivated a person with PCA was to engage in them. Participants with PCA 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 misconstrued as apathy. This was in contrast to the tAD group who were much more likely to exhibit apathy in the classic sense, and as is supported in the empirical literature (e.g. Landes et al., 2001; Starkstein et al., 2001; Phinney and Chesla, 2003; Vernooij-Dassen, 2007). In the PCA group there was what seemed to
be a dissociation between knowing what one wanted to do and one’s ability to initiate or execute that activity owing to the profound visual and spatial processing problems. This prohibited participants’ abilities to act with mastery and agency, though every member of the PCA group could clearly express the activities they were interested in and would have liked to have been able to initiate. This has implications for theoretical conceptualisations of agency and intention which will be expanded on below, but practically, is also a further example of how important specific knowledge of the condition and how it may impact (desired) activity engagement is made available to those supporting people with PCA, especially considering their essential role in the facilitation of activities, demonstrated throughout both phases of this study.

Taken together, these findings about the distinct symptom patterns and possibility for misinterpretation of intention and action highlight the importance of equipping people with PCA, their carers, and the health and social care professionals supporting them with appropriate diagnosis-specific information. Samsi et al. (2014) support this in stressing the importance of relevant, individualised and person-centred diagnostic information for those being diagnosed with a dementia. This would enable an increased understanding of the disease which could inform and assist the development of strategies which target the specific cognitive impairments which underlie any observed difficulties with everyday activities, and importantly minimise the chances of misattribution (e.g. Zgola, 1987). The value and importance of empowering people with knowledge of their/their loved one’s condition is also evident throughout the empirical literature on psychoeducational approaches (e.g. Hepburn et al., 2005; Durepos et al., 2019).

5.4 Acknowledging the individual and recognising relationships

Here I will focus on what the findings have revealed about the intra- and interpersonal factors at play in the relational context of navigating day-to-day life with the condition(s). The findings from the dyadic interviews revealed the
psychosocial implications of the difficulties people with PCA were commonly experiencing, and key ones of those were the threat to one’s sense of self and identity that could come from changes in responsibilities and roles. The home-based observations built on these findings by showing how people with PCA and with tAD were motivated to maintain a sense of self and identity via their ongoing engagement with meaningful activities. This is fitting with a wide body of published work which suggests that maintenance of self and identity is important for PLWD more generally (e.g. Kitwood and Bredin, 1992; Kitwood, 1997; Milte et al., 2016; Hennelly et al., 2018). For example, Askham and colleagues’ (2007) made observations that carers and PLWD considered maintenance of the self in terms of roles and a person’s uniqueness an important task of care at home. Kaufman and Engel (2016) highlighted the importance of independent action, role maintenance and identity management as key features within a model of wellbeing they created based on contemporary empirical observations of the central tenets of Kitwood’s earlier work on personhood. Boyle (2014) has acknowledged the importance of being able to make one’s preferences known and having the opportunities to live in line with one’s values as meaningful ways that continuity of identity can be achieved. The specific role of activities in achieving this aim, identified in the observational phase of this PhD study echoes Chung, Ellis-Hill and Coleman’s (2017) work highlighting the way activities can sustain personhood by maintaining a connection to long-held interests and hobbies. Dröes and colleagues (2017) further endorse this in their conceptualisation of activity engagement and identity maintenance as essential contributors towards their operationalisation of the WHO definition of social health for PLWD.

People’s sense of self and identity and significant roles were also a key determinant in the type of activities they either expressed wanting to do or missed engaging with in the interviews, or those which they were observed continuing to find ways to engage in during the observations. Participants’ personality factors, previous life history, and occupational history were all influential in shaping what these activities
were, and this too fits with much published empirical work (e.g. Zgola, 1987; Christiansen and Bryan, 1999; Hasselkus, 2002; Menne, Kinney and Morhardt, 2002; Öhman and Nygård, 2005; Topo, Kotilainen and Eloniemi-Sulkava, 2012; Roland and Chappell, 2017). For both groups, this was not a solo endeavour in any case, and carers of members of both groups were seen to be essential in supporting activity engagement and in maintaining the PLWD’s sense of self and identity in doing so (though this was to varying degrees, and in some differential ways according to the diagnosis). There is a large body of empirical literature which endorses the critical role carers play in facilitating PLWD’s everyday activities and promoting the personhood of PLWD more broadly (e.g. Sabat, 1998, 2001; Vikström et al., 2005; Phinney, 2006; Dröes, 2007; Chung, Ellis-Hill and Coleman, 2017). The potential implications of misinterpreted apathy in the PCA group which I described above provide a specific example of just how influential carers could be in determining whether and how their loved one engaged with activities which were meaningful and constitutive of their selfhood. In the small number of cases where meaningful activity did not appear to be fully supported by caregivers, this seemed to relate to enduring factors such as personality characteristics and previous relationship quality. The impact of previous relationship quality on the illness experience has been considered in the literature, but often predominantly in relation to carer outcomes such as wellbeing and burden (e.g. Askham et al., 2007; Lea Steadman, Tremont and Duncan Davis, 2007; Ablitt, Jones and Muers, 2009; Quinn, Clare and Woods, 2009). This study hopefully adds important knowledge regarding how previous relationship factors can also influence and shape PLWD-related outcomes, as is proposed in the updated Stress Process Model for PLWD. In most cases however, these were shared endeavours, with couples and families working together as a team to preserve ongoing participation and activity engagement and (as a result) the PLWD’s identity, and there is a growing body of literature looking at how couples cope together, as a unit and in a relational context, rather than as two individuals, which the findings of this study support (e.g. Nolan et al., 2004; Hellström, Nolan and Lundh, 2005; Davies, 2011; Svanberg, Spector and Stott, 2011;
Molyneaux et al., 2012; Boyle, 2014; Tolhurst, Weicht and Kingston, 2017). Exactly how this was reported and observed to be happening could also vary according to the diagnosis and stage of the condition – carers of people in the more advanced stages of tAD were more often observed orchestrating activities for their partner and actively attempting to maintain their partner’s identity on their behalf, rather than in collaboration with them. Where this study can add new knowledge is regarding the slightly more dyadic approach to the navigation of challenges and provision of support afforded by the relatively well preserved insight and memory capacities of the PCA group. This was evident in the PCA groups’ joint story-telling during the dyadic interviews and collaborative communication observed throughout the home visits. This difference in approach highlights the pressing need for an increase in the psychosocial literature on PCA, alongside the biomedical, to acknowledge the potential differences in the subjective lived experiences and optimal coping strategies that can arise from different presentations of dementia. The observed dyadic approaches (and importantly the variation in these) also endorses Phinney’s (2006) view that understanding how families and couples are already coping with dementia related changes in their everyday lives will be an essential component of the development of any interventions to support this further. The impact of previous relationship factors on dyadic coping could also explain some of the mixed findings within the literature, (e.g. Robinson, Clare and Evans, 2005; Brittain et al., 2010; Merrick, Camic and O’Shaughnessy, 2016; Wadham et al., 2016; Wawrziczny, et al., 2016a), building the case for further work which focuses specifically on the mechanisms of couples’ coping and how this may vary across dementia type and time.

One example of the ecologically valid insights that can be revealed by interviewing and observing PLWD and their family caregivers within their relational contexts are the discrepancies in accounts which can emerge. These were key in couples’ explanations of the symptoms, their perspectives, preferences and priorities in the interview phase and in the negotiations of activities, in terms of what should be
supported and prioritised in the home-based observations. Similar differences in accounts and priorities have been described in the literature, emphasising the importance of research designs which take account of multiple perspectives. Harmer and Orrell (2008) identified differences in family member and care staff perceptions of the meaning of activity when compared to PLWD – family members and care staff saw activity as a way to primarily preserve physical and mental function whereas for PLWD, activity had many more purposes, such as being a way to relate to past roles, long term interests and routines; reinforcing a sense of individual social and occupational identity; fostering feelings of belonging; and providing opportunities to be both interested in others and interesting to others. Percival and Hanson (2006) identified carer and PLWD discrepancies in what constituted risk in activity engagement – they found that carers were mostly concerned about risks to physical safety, whereas PLWD considered the biggest risk to be to their personal and social identities (should they not be engaging in activities of importance). The current study findings add to this knowledge by having studied participants within their own homes at a mild to moderate stage. The findings highlight how these different priorities are already being negotiated and navigated by families within their home environments, when the symptoms are less familiar and so more open to interpretation (especially in the pre-diagnostic stage, as reflected in the dyadic interviews), and when the possibilities of activities to engage in and support may be even broader. This work in a community setting and with a diagnostic group with relatively well preserved language and memory functions illustrates the value of studying the ways PLWD and their family cope with some of the most significant stressors for which they are least prepared (symptom onset, the journey to diagnosis), and the ways they are already demonstrating their shared motivations to ensure the enduring enactment of the PLWD’s personhood, at the earliest stages of the disease (and beyond). I have mentioned throughout about the tendency for particular areas of research field to be dominated by studies conducted in residential care settings. Perhaps it could be conceived that this divide, in studying those in the early and late stages so distinctly, contributes to the
potential marginalisation of PLWD, in further distinguishing those who no longer have capacity and are at the more advanced stages, and that approaches to studying lived experience which are more continual in nature, and sensitive to the varied challenges according to different stages, symptoms and situations, could go some way towards addressing this (e.g. Roland and Chappell, 2017).

Another key finding in the observational stage of the current study relating to individuals within their relational contexts was that a key motivator for activity engagement was its potential to provide opportunities for PLWD to make a contribution to others. While the impairments associated with (e.g.) household chore completion, and even the perseverance and strategising to enable the continuation of this had emerged in the dyadic interviews, the home-based observations permitted the underlying motivations driving these activities and the meanings made via them to be more richly revealed. In particular, there was reciprocity in care-giving and receiving, and this is in contrast with the potentially limiting assumptions within the theoretical approaches of person- and relationship-centred care, that it is only directed towards PLWD, rather than acknowledging their capacity to offer and deliver care to others. This is echoed in Majlesi and Ekström’s (2016) interpretation of couple’s baking together, in which they consider the PLWD, in responding to instructions and instructional actions, to be an active and equal collaborator and contributor in the activity. Additionally, this is supported by Lindqvist et al.’s (2016) scoping review, in which one of the identified qualities of activities which people with cognitive impairment wanted to be able to continue to master was those which reduced the negative impact one had on other people, such as the burden of having to remember a partner’s medication needs for them.

The importance of making a contribution for PLWD is widely evident in the qualitative and theoretical literature, but is something which has rarely been considered explicitly in the empirical literature (e.g. Chung, 2004; Harmer and Orrell, 2008; Edvardsson et al., 2014). PLWD’s careers have been highlighted as a way that this has been achieved prior to the diagnosis, and it has also been
suggested that research participation or awareness-raising can offer PLWD new opportunities and avenues for feeling able to continue to make a worthwhile contribution, when this is no longer achievable via employment (e.g. Menne, Kinney and Morhardt, 2002; Menne et al., 2012; Dröes et al., 2017; Øksnebjerg et al., 2018). Another newfound way for PLWD to contribute which is in a sense enabled by their condition is in supporting others in a support group context, something else which was also reported by participants in this study (e.g. Menne, Kinney and Morhardt, 2002; Davies-Quarrell et al., 2010). The significance of previous contributory acts via one’s employment was something which seemed particularly poignant in the dyadic interview phase because of the time of life at which PCA symptoms typically began. The disruption to participant’s employment which had been caused by the symptoms was another major stressor during the difficult time of symptom onset, and contributed to the feelings of role loss and identity threat which have been outlined. The emergent drive to replace this meaningful occupational engagement with (e.g. research participation) observed in the current study could be said to be fitting with Erikson’s (1997) theory of the stages of psychosocial development. Specifically, the crisis of middle adulthood that Erikson outlines (estimated to usually occur between ages 40-59) is one of generativity versus stagnation, and it is proposed that at this time, individuals become concerned with the responsibility they have to contribute to others, whether that be family, friends or wider society. The fact that the theory proposes this can also onset earlier if there is a sudden disruptive change in circumstance, suggest that the theory may also be of relevance to others with those rarer or young onset forms of dementia which are more likely to disrupt work-related transitions (e.g. Harris and Keady, 2009).

The importance of this sense of making a contribution for one’s identity was evident in the current study and has also been stressed by Öhman and Nygård (2005) who suggested that doing things for others is what helps to confirm a person’s sense of being a person at all. Other researchers have described being helpful to others as
fostering a feeling of self-esteem for PLWD, in confirming that one has something to offer, and as a way to promote continuity of self (e.g. Kitwood and Bredin, 1992; Davies-Quarrell et al., 2010; Edvardsson, Fetherstonhaugh and Nay, 2010; Doyle, Rubinstein and Medeiros, 2015; Dröes et al., 2017; Øksnebjerg et al., 2018). Observing people in their home environments and with a range of living situations and family set-ups meant I was privileged to gain rich insights into the existing caring commitments many participants had, and these were revealed as a key way that people used activities to contribute to others, and this too is echoed in the literature (e.g. Phinney, 2006). Other empirical work has described participants offering gestures of care for others when in the more advanced stages in residential care settings, highlighting this as an aspect of meaningful activity which is enduring and worth consideration and exploration across the disease course (e.g. Kontos, 2004; Boyle, 2014; Doyle, Rubinstein and Medeiros, 2015). In her 2004 ethnographic study in a long term care facility, Kontos described the caring and affectionate gestures offered by care home residents to calm their fellow residents down, and the attentive looking and listening to one another which, much like the physical acts of care for others, appeared to help affirm both themselves and their fellow residents. Doyle, Rubinstein and Medeiros, (2015) observed residents being generative via the provision of advice and guidance (e.g. to the researcher – something I also encountered in this study), via enactments or references to their continued roles (e.g. wife, mother), and in their contributory acts to the broader community of the care setting they resided in. Doyle and colleagues (2015) stressed the different formats that generative acts could take, in that they could be actual, intended, conceived, or merely talked about actions, and that the roles people were ‘acting’ in could also be perceived or actual. These manifold dimensions of and dissociations between intentions and actions, talking about and doing, were all also evident in the observational home-visits conducted. In permitting the collection of multiple modes of data, the home visit protocol much expanded the range of manifestations of agency I was permitted to observe. In the interview stage this had been more limited to what was said about what was done, whereas during the
extended unstructured observations I had access to witnessing that which was done, that which was referenced, evidence of that which had previously been done (e.g. photos, souvenirs), that which was planned but not executed, and so on. Doyle and colleagues (2015) also noted that there were not always shared realities between PLWD and their family members or care staff (as in both phases of this current study), but from their interpretivist position considered this irrelevant for their conceptualisation and investigation of generativity. This suggests a need for recognition of intention, as well as action, something I have outlined as particularly important for the PCA group in this study, given their profound impairments in physical interactions with their environments. I would argue that this highlights a need for both flexible and perceptive interpretation by researchers exploring these issues for PLWD, when their possible expressions may be varied and manifold, and Doyle, Rubinstein and Medeiros (2015) outlined the need for the same sensitivity to be applied by family members and care staff, to detect these generative motivations and to facilitate the activity engagement which enables them.

Offering to help and wanting to make a contribution also encompass an inherent sense of reciprocity – a strong theme throughout the current study’s findings and something also captured in the literature. Often this is described in a marital context (and often this was the case in the current study) and involves offers to help with household chores (e.g. Phinney, 2006; Davies, 2011). The fact that this want to contribute was an essential motivator of self-chosen activities at home, suggest that this could also be a potentially meaningful focus of activity interventions for PLWD more broadly.

5.5 Meaningful versus measurable activities

Here I will focus on what the findings have revealed about the motivations and meanings of activity engagement for the participants across the two diagnostic groups studied here. Over the course of this PhD study, my research questions were gradually refined from the day-to-day impacts of the stressors arising from the
visual and spatial symptoms associated with PCA to the meanings, motivations and management of everyday activities for people with PCA and tAD, in their everyday home environments.

Embarking on the pilot home observations, I anticipated mostly observing difficulties with what are considered the typical ADLs, as defined by the literature and measurement scales, however it was clear early on in the observations that there was a much less predictable roster of activities going on within each home environment. Not that participants were not engaging in ADLs, but that they were doing varied amounts and combinations of them (and in addition to many other activities). It became clear that if a long term goal of this work could be to inform interventions to support people to continue to engage in activities, that an essential step at this stage would be to explore which activities mattered most to participants, and how and why they were being engaged with. Another unanticipated insight was the observation that there were not the repeated demonstrations of difficulties I had perhaps been anticipating – not that some participants were not significantly impaired, but that those who were, tended not to be repeatedly trying and failing at tasks with which they had great difficulty. In cases where participants were doing this, it seemed to signify that a task was of particular significance or importance, and therefore worth persevering with. If something was very problematic or difficult and not meaningful in some way, it was generally renegotiated or reallocated. While the dyadic interviews had developed understanding of the day-to-day stressors people with PCA experienced, and while a lot of those were related to ADLs, the home-based observations built on these findings by providing an opportunity to see what that meant for activity engagement in day-to-day life, as it was lived within participants’ everyday environments, and given these specific sets of difficulties and challenges faced. Related to this, prolonged immersion in the settings revealed that much of the day was ‘unallocated’ time – time which participants could choose what to do with, and observing this in real-time proved helpful as it revealed the weighted significance of
whichever activities those hours which fell either side of the more predictable ADLs were filled with. With these emergent questions, the results of this study add to the relatively small but growing qualitative literature on the meaning and experience of activity for PLWD – and specifically by exploring this for people with PCA for the first time. This small body of literature sits in contrast to the dominant activity-related literature in the dementia field which is focused around ADLs and studies of meaningful activity-based interventions, which are both often positioned within a deficit-model approach. The ADL literature conceptualises activities as a means of capturing functional decline, and the meaningful activity intervention literature often prioritises symptom reduction as an outcome, such as lower agitation and improvements in other behavioural and psychological symptoms of dementia (e.g. Phinney, Chaudhury and O’Connor, 2007; Sikkes et al., 2009; De Medeiros and Basting, 2014; Sikkes and Rotrou, 2014). Both of these bodies of literature are necessarily outcome focused – ADL scales ask about measurable functional outcomes such as efficacy (e.g. Eating – spills often) or frequency (e.g. Reading – reads less often) in the execution of activities, and there is a similar outcome focus in much of the research conducted around meaningful activity interventions. This is often conducted in residential care environments – settings where there are necessary pressures to meet important endpoints regarding quality of care, such as improving residents’ quality of life (e.g. Livingston et al., 2014; Testad et al., 2014). This dominant outcome-focused approach to activity can have practical implications too – Hammell (2004) for example has critiqued the focus put on productivity and purposeful action in occupational therapy theory. Hammell (2004) recommends a shift towards a more similarly weighted focus on the meaning and choice in occupation to that which is championed in existential philosophy and qualitative research (and was witnessed in this study), especially considering that one of the main aims of occupational therapy is enhancing QoL.

In line with this, the current study findings emphasise the importance of the consideration of the process and experience of activities, and not only their
outcomes. In this study of people at home in their everyday environments, there were many examples of people engaging with activities which could be said to have objectively ‘poor’ outcomes – for example tasks which took a long time to complete, activities being left unfinished, being executed incorrectly or otherwise inefficiently. However, despite the many challenges they faced, participants in this study continued to do things, they persevered or reallocated tasks and were motivated to find new ways to engage in activity where needed, highlighting the great value of activity to participants overall and also, the importance of how activities were experienced in determining their continued uptake. This arguably supports the novel application of theories of healthy ageing such as Atchley’s (1989) continuity theory to PLWD, as advocated by Menne, Kinney and Morhardt (2002), as it suggests that people living with at least the two types of dementia represented in this study, may allocate the same priority to continuity engaging in as much activity as possible, within the limits of their abilities, as healthily ageing older adults do.

The perseverance people showed despite any inefficiency or difficulty with activities fits with Phinney and Chesla’s (2003) findings that when PLWD begin to experience their usual skilled and habitual bodily actions as being disrupted, and start to have difficulties in holding thoughts and words in mind, that PLWD adjust the attention and effort they apply, taking extra care in order to continue to do those things which previously felt effortless and automatic. This also fits with findings from Phinney, Chaudhury and O’Connor’s (2007) study, that PLWD were motivated to continue engaging in household chores even when these became increasingly difficult, and Menne and colleagues’ (2012) unanticipated finding that PLWD are still motivated to engage in cognitively demanding activities such as reading and writing even though their condition is one of cognitive impairment. This prioritising of the process (despite the necessarily adjusted outcomes) of activities were also – like much else – a shared negotiation with carers in the current study, and this too is reflected in the literature. Merrick, Camic and O’Shaughnessy (2016) describe a
participant who continued to help scaffold her husband’s involvement in food and drink preparation even though this often resulted in a mess in the kitchen that she would need to spend time tidying up. Edvardsson et al.’s (2014) work also reflects the shared endeavour that continued engagement in activities can be with professional carers as well as family carers – he suggests that the focus of care tasks and activities should be oriented more towards the quality of the time spent together rather than achieving certain outcomes, and suggested a reconceptualization of care-task endpoints to meaningful moments between individuals. Similarly, when describing a couple’s collaborative baking activity, Majlesi and Ekström (2016) encouraged a reconceptualization of shared activities between PLWD and their family carers as activities being done with each other, rather than for the PLWD.

Zgola’s work (1987) also points to the role of practitioners as another set of stakeholders who have a role in interpreting and prioritising the outcomes of activities for PLWD. Using the example of perseverative behaviours such as those I observed Betty engaging with in the current study (e.g. ‘doing the dots’ of the tablecloth), Zgola encouraged a reframing of activities from being the result of a person’s impairment (and therefore inherently problematic) to recognising the process of the activity (providing it caused no harm) as representing a way for the person to be actively engaged in doing things and participating. The possibility for this kind of reframing has been demonstrated empirically too – in Majlesi and Ekström’s (2016) study of couple’s baking together in which they suggested that PLWD responding to caregiver instructions is more positively and helpfully framed as a collaborative and contributory act, rather than a sign of the PLWD’s incapacity and reliance. Similarly, they suggested that conceptualising PLWD’s reassurance-seeking as an indication of their motivation to avoid mistakes and an appropriate understanding of their potential to make them, rather than an as indication of their failings, offers a more enabling interpretation.
This perseverance in the face of challenges suggested that participants in this study did not simply want to engage with activities which made them feel positively, and that the potential meanings people can make when engaging with activities are much more complex, and this too resonates with both the existing theoretical and qualitative empirical literature. Deci and Ryan (2008a) propose a eudaimonic concept of wellbeing within their Self-Determination Theory of motivated action, some of the core components of which are feelings of purpose, meaning, contribution and importantly, not necessarily the seeking of positive affect or the avoidance of negative (e.g. Phinney, 2006; Ryff and Singer, 2008). Deci and Ryan (2008a) also suggest that eudaimonic wellbeing is better considered an approach to living than an ultimate goal, which is perhaps the ultimate example of process and experience being an important and worthwhile consideration over and above any resulting outcomes it leads to. Chung, Ellis-Hill and Coleman’s (2017) empirical work also supports this, in concluding that activity selection is often not driven by an end product or any specific successful outcomes, but by the opportunities they offer the PLWD for some continuation in their sense of agency, by connecting them to long-held interests or roles. The eudaimonic approach to activity motivation could explain how PLWD in the current study were motivated to continue their generative behaviours even when they faced challenges, and could also explain the frustrations or resistance of some when they felt activities were proposed as a passive way for them to pass the time (e.g to be entertained or distracted). This perhaps further supports the suggestion above that theories of development and motivation could be more applicable to and relevant for PLWD than traditionally considered. This could additionally contribute to a reorientation away from dominant discourses about what is lost for PLWD, towards one which maximises what is retained, or can still be gained or offered. Aligning with this, Nyman and Szymczynska (2016) demonstrated how psychological developmental theories could usefully be applied in the context of dementia in relation to meaningful activity, by showing how such activities went beyond pleasure-seeking to meet some fundamental needs of PLWD, including reflection over and connection with one’s life history, the fostering
of intergenerational relationships, and the opportunity to feel a sense of being in control. Øksnebjerg and colleagues (2018) have also suggested the applicability of positive psychological approaches to studies involving PLWD, especially those aiming to support people to live well with their condition.

The findings here and the literature they complement, when taken together, argue for a more nuanced approach to capturing the many facets and features of the concept of activity for PLWD. Hammell (2004) asserted that not all occupational activities can be neatly divided up into categories which suit researchers and their study protocols, and that some of the activities which are most meaningful to participants are those which are the least discrete and divisible. This perhaps is echoed in the extra depth and nuance in the understanding of participants’ activity engagement that was gleaned from the totally unstructured observational phase of this study, than in the possibly more constrained semi-structured dyadic interviews. One encouraging example of how this attempt to capture more nuance is being applied is in the empirical work of Giebel, Challis and Montaldi (2017), who divided ADL function into the initiation and performance of each task, and identified diagnosis-specific differences across different dementia subtypes. It seems intuitive that ways of measuring and conceptualising activity that more accurately represent the layered complexity of the real-world setting these are lived and experienced in, will help with the development of supportive interventions that are more aligned with and representative of PLWD’s true capabilities and motivations (e.g. Han et al., 2016). For example, Doyle, Rubinstein and Medeiros, (2015) highlight the discrepancies that can exist between a PLWD’s cognitive capacity and ADL function and their ability to contribute socially – a domain of activity shown in this and other studies to be of high importance for PLWD (e.g. Phinney, Chaudhury and O’Connor, 2007). In line with this, Hammell (2004) has also stressed how important it is that researchers acknowledge and make efforts to capture participant’s own priorities and preferences, to avoid reinforcing power imbalances by imposing their own hierarchical orders of meaning on participants’ occupations. This chimes with
emerging work which is beginning to question the traditional lines of enquiry into ADLs which focus on measuring dementia-related changes in function, and instead encourages a much needed shift towards more in-depth exploration of the everyday experiences and life histories which have shaped these individual preferences and priorities of PLWD (e.g. Nygård and Borell, 1998; Öhman and Nygård, 2005; Boyle, 2014; Missotten, Dupuis and Adam, 2016; Nyman and Szymczynska, 2016; Coulter, 2017).

This idiosyncrasy and variation was evident in the current study where – although there were common tendencies towards activities which helped others or promoted continuation of one’s sense of self and identity – there were also a wide range of other motivations for activity engagement including (but not limited to): activity for occupation, familiarity, entertainment, education, comfort and relaxation. This variation and breadth in outcomes of importance is captured in Øksnebjerg and colleagues’ (2018) work which looked at priority outcomes for PLWD from psychosocial interventions. These included: confidence, feeling good, feeling competent, having fun, feeling useful and feeling equal to others. Similarly social, and self-affirming outcomes have been shown to be the aims of self-chosen activities PLWD want to continue to be able to master. This potential idiosyncrasy within fairly universal constructs such as meaningful outcomes of activities was further supported by and compatible with Lindqvist et al.’s (2016) scoping review conclusions that the desired outcomes of such activities included conveying social values or independence, supporting significant roles, and encouraging wellbeing, all which the authors identify as being key dimensions of a meaningful life more broadly. The bigger argument for this kind of personalised approach to activity engagement is supported by findings that meaningful activities which can be tailored to individuals, have the greatest impact on wellbeing and other positive outcomes (e.g. Sauer et al., 2016; Lokon, Sauer and Li, 2019).

It is not only research into the outcomes of meaningful activities which this study’s results bear relevance to, but also the types of meaningful activities which are
researched. A wide range of activities were able to be observed being undertaken or attempted in the current study, because of the research setting being the complex and richly nuanced everyday environments and living situations of the participants. Traditional ADL scales (by definition) concentrate on an established set of activities which are considered to be universally applicable (e.g. dressing, eating), and as a result this means that activities which are naturally much more individually variable, are necessarily abstracted to a level that is applicable to everyone – specifically items relating to hobbies, leisure and social activities. It would not be practically viable for scales to dilute these categories of activities further without them becoming an unmanageable length (e.g. a single ‘Hobbies/Leisure’ item could multiply out to sports, film, arts, reading, crafts, music, to name but a few), further endorsing the value of an unstructured, qualitative approach, such as that used in the current study, for exploring the varied meanings and motivations attached to everyday activities for PLWD.

Further supporting the contribution this study has made in capturing the breadth of activities PLWD can assign meaning to, the other large body of activity-related literature in dementia research – that which measures the effects of meaningful activity-based interventions – can also be limited in the extent to which it can fully cover the broad range of activities people consider meaningful. It is widely acknowledged that the concept itself is not well defined and is difficult to operationalise (e.g. Phinney, Chaudhury and O’Connor, 2007; Øksnebjerg et al., 2018). As a result, what can often be seen in the literature are studies of meaningful activity in which valuable outcomes are measured (e.g. Harmer and Orrell, 2008; Nyman and Szymczynska, 2016), but in which no clear assessment of the actual ‘meaningfulness’ of the activity to particular individuals is made. Meaningful activity-based interventions are also often delivered to groups, and as such the individualisation of the activity itself or its delivery is often necessarily compromised or limited. This has in turn perhaps contributed to the often tautologous definitions of meaningful activity, as it would seem a difficult task to try to capture
in one definition, the range of activities that individuals within a large group would find meaningful. In addition, much of this research is completed in residential care home settings, with PLWD who are in the more advanced stages, and often with reduced capacity to organise their own activities. While that in itself is an encouraging endeavour, it has meant that very little is known about how activities are prioritised and supported in the naturalistic environment of people’s own homes, a gap the current study has hopefully made some contribution towards. Knowing more about how people intuitively cope and respond within their everyday environments and what they begin doing to support activity engagement in the earlier stages of the illness experience, at home, may be worthwhile for several reasons. Specifically, it may help towards developing understanding of how people demonstrate resilience, in acknowledging the creativity in the continual adaptation of people affected by dementias, It can provide insights which may inform the design of interventions to help others cope better and for longer at home, and it could contribute towards a divergence away from the dichotomising of people in the earlier and later stages of the condition (the manifold benefits of this in particular are discussed below in Theoretical Implications – section 5.7). Wilcock (1995) further encouraged similar approaches to these for studying everyday activities by critiquing the tendency to disregard them because of their apparent ordinariness, and stressing that this is problematic because it is exactly these sorts of activities which contribute towards the most essential and basic human psychological needs of us all.

This study therefore adds to the existing literature by maximising and explicating the variation and individual difference that can otherwise be unavoidably ‘averaged out’ in existing activity-related studies with PLWD. This approach allowed for the recognition of the full range of different formats of activities that participants embarked on, and the potential importance of this is reflected in the theoretical work of Baldwin (2008) and Boyle (2014), who consider all levels of daily practices, actions and everyday talk to have the potential to be personally meaningful, and a
vehicle for many of the motivations observed in this study – e.g. to express and constitute one’s sense of self and identity, and to offer something to others.

In line with this broad consideration of the form that meaningful activities can take, owing to the challenges they were facing, many of the participants in the current study engaged with activities of significance in necessarily modified ways. These modified modes of engagement were another example of the perseverance which highlighted people’s continuing motivation to be involved in activities, over and above achieving certain outcomes via them. Examples of these modified modes of engagement reflected in the empirical literature include: talking about previous meaningful activities or plans for future activity participation, holding or sharing objects or photographs associated with meaningful activities, enquiring as to others’ feelings about a given activity of importance and imagining or envisioning future activity engagement (e.g. Emirbayer et al., 1998; Boyle, 2014). Phinney, Chaudhury and O’Connor (2007) described a similar example of this modified engagement when a participant with dementia who was a professor of music vocalised his plans to oversee a small choir within the support group he was attending.

In summary, activity participation by PLWD is currently usually quantified in terms of how well/often things are done, or regarding the results of any activity engagement. Existing standardised scales and intervention studies can fail to capture the personal motivations and meanings of activities for PLWD, by pre-defining which activities will be studied and which outcomes are of importance. The current study hopefully adds to this an ecologically valid lens on: how activities are achieved (even when not perfectly), the shared and varied priority outcomes of them, and the meanings and motivations associated with them, in a relatively understudied population and setting, and in doing so, strengthens the argument for further unstructured observational work like this in naturalistic settings, to better understand the needs and experiences of PLWD.
5.6 Temporality

The findings of the current study were all shaped and framed by the continually changing temporal context within which they were observed, and temporality is also key in the interpretation of the findings in relation to other empirical and theoretical literature. Acknowledging the importance of timing seems inevitable and inherent in the study of any neurodegenerative diseases which are progressive by nature and indeed, ongoing symptom development and the need for responsive adaptation was evident in both phases of the current study, as coping strategies and activity engagement were increasingly modified over time, as is represented in the empirical literature (e.g. Nygård and Öhman, 2002).

5.6.1 The need for a stage-sensitive approach

Although the progressive natures of the conditions were common across both groups in this study, temporality was also key in underpinning some of the diagnostic differences that were observed in terms of primary symptoms (e.g. perceptual problems for the PCA groups and memory and language impairments in the tAD group). These in turn had implications for the changing nature of support provision over time – one key example of this in the current study was how the preservation of identity (via activities) gradually changed from being in collaboration with, to being on behalf of, some members of the tAD group. These changes in symptoms and strategies over time together strengthen the argument for the importance of research into different types of dementia which is stage-specific. The interview findings also stress the importance of the timing of the diagnosis and in the provision of disease-specific information and knowledge. This is echoed in the literature relating to other forms of dementia (e.g. Samsi et al., 2014; Lee et al., 2017), further emphasising the need for the development and dissemination of relevant training and resources to those affected by and working with people with lesser known kinds of dementia.
As discussed above, there can be a tendency to dichotomise research into the everyday experiences of people living with or caring for someone with dementia into the early and late stages (e.g. Clair, 1996; Kovach and Magliocco, 1998; Albinsson and Strang, 2003; Harman and Clare, 2006; Steeman et al., 2006; Burgener et al., 2008). One way that potential limitations of this distinction were highlighted within the current study findings was in terms of the suggested enduring expressions of agency and selfhood that can be made via embodied action (discussed further below – see section 5.7.2) which may not apply so readily to the trajectory of symptoms for people with a diagnosis of PCA (e.g. Chatterji, 1998; Davis, 2004; Phinney, Dahlke and Purves, 2013; Roland and Chappell, 2017). It is a possibility that other temporally significant trajectories identified across the general dementia illness experience will also not apply to those with PCA or other atypical presentations of dementia, and that taking a comprehensive multi-staged approach to this could help to delineate some of these variations further. Regarding activity engagement in particular, Regier, Hodgson and Gitlin's (2017) work supports this, in identifying variation in activity engagement in terms of the type of activities engaged with, the means of getting involved with them, and the preferred duration of activity engagement, according to disease-stage. Further endorsing this approach in future work, Phinney (2006) called for research questions to be posed across all stages of the disease process, and highlighted that despite the acknowledged need for continued engagement in activities across the whole span of the condition (as supported by the current findings), research has tended to overlook people in the mild to moderate stages in terms of activity engagement, especially PLWD who are living at home. In light of the current findings I would add to this that the home environment is also where there may be the greatest potential for complexity and variation in the environmental and psychosocial factors which can affect activity engagement and the broader stress process overall, making this potentially where there is most to be learned. Implicit in this acknowledgement of the importance of the progression of the condition is also a call for more longitudinal research, to assess the impact of the disease across stages. This is compatible with Keady and
Nolan’s (1994) proposal of a longitudinal model of dementia research in which they emphasised the significance of longitudinal approaches for PLWD under the age of 65 in particular, highlighting how the absence of specific knowledge about lesser known forms of dementia and how they develop over time, has significant implications for how care and support is delivered in the community. A more continuous, staged approach would help to increase understandings of the processes involved as PLWD move between the various phases of their condition and could be key to more fully understanding the illness experience as it lived across stages which are, like activities, rarely discretely divisible (Hammell, 2004; Aminzadeh et al., 2010).

5.6.2 Time and stage of life

The time of life at which the study participants were affected in this study was also key in terms of how the stress process was experienced overall and how engagement with different activities were impacted. The stress and other secondary impacts of the disruption to employment status and retirement plans which many participants experienced resonates with Hammell’s (2004) emphasis of the particular significance of engagement in meaningful occupation when one is facing any kind of biographical disruption (Bury, 1982), including a health crisis, which can compromise the long-held and taken-for-granted understandings of one’s body, sense of self, and time.

Employment was a particular temporally-relevant way that the PCA participants were impacted by the onset of their condition. While all participants had retired from full time work, for most of the PCA group this had been because of the onset of their PCA symptoms, whereas most of the tAD group had already retired from work by the time they had first noticed symptoms. Participants had mostly been used to experiencing high levels of competence having been at the peak of their careers, and suddenly found themselves having difficulties at a life stage which – according to Erikson’s psychosocial theory of development (1997) – should be
characterised by opportunities to make contributions to one’s relationships, communities and society more broadly. The findings here are in accordance with other published work which has demonstrated the impact of young onset dementia on one’s sense of competence because of the employment-related challenges and changes it can bring about (e.g. Svanberg, Spector and Stott, 2011; Roach and Drummond, 2014). The current findings about wanting to maintain generative engagement are also supportive of emerging work which encourages continued, appropriately supported employment opportunities for younger PLWD (e.g. Ritchie et al., 2015; Tolson et al., 2016).

The age-related changes observed in the adjustment to difficulties in engaging with activities were another temporal factor, and arguably strengthen the case for taking into account variables such as the contextual and mediating factors of the Stress Process Model such as age, employment status, previous experience and personality factors, when trying to understand the complex, layered and multifaceted experience of living with a dementia. Qualitative research and particularly ethnographic and case study approaches are considered well positioned to take account of such complexity (e.g. Baškarada, 2014; Abendstern et al., 2019), but I would also argue that the work of Giebel, Challis and Montaldi (2017) and others, in breaking down traditionally quantitatively measurable concepts into smaller component parts, and approaches which account for participant’s own subjective weightings of outcomes (e.g. PROMs and PREMs), also signify important steps towards the overall aim of capturing some of this complexity.

As described, for many of the participants, their time of life was also a factor in shaping their environment, which in turn had implications for their engagement with it and in activities within it, with many participants having recently moved or planning to down-size or to de-clutter. Drawing again on earlier points about the dichotomising of stages in dementia research and the focus on residential care settings, there is a paucity of research or theoretical acknowledgement of the significance of the physical environment of PLWD’s own homes, in influencing the
stress experience for both PLWD and their care partners, how PLWD and their families adapt these environments over time, how this is negotiated as an activity in its own right, but also what it means for activity participation more generally (e.g. De la Cuesta and Sandelowski, 2005; Aminzadeh et al., 2010). This extends to understandings of the use and meanings of objects too, and the current findings have expanded upon those of (e.g.) Stephens, Cheston and Gleeson (2013) regarding the value of transitional objects in the later stages of dementia, by illustrating how objects can be used to offer a reference point for the continued expression of selfhood for PLWD in the earlier stages, who are still living at home.

A final way that temporality was key throughout, was in the pervasive motivation to find continuity in the day-to-day, maintaining normality and familiarity in the environment, the preservation of identity over time, and continued engagement with activities of importance, despite the many challenges participants faced. This ultimate drive to maintain normality as far as possible and to find continuity is widely reported in other qualitative literature looking at the lived experience of dementia(s) (e.g. Phinney, Chaudhury and O’Connor, 2007; Edvardsson, Fetherstonhaugh and Nay, 2010; Edvardsson et al., 2014; Chung, Ellis-Hill and Coleman, 2017; Dröes et al., 2017), and perhaps further supports suggestions that developmental and positive physiological theories could be usefully applied in dementia research, and, in turn, that doing so may contribute to a more empowering research environment for PLWD, than one more centrally aligned with notions of decline and retrogenesis (e.g. Atchley, 1989; Erikson, 1997; Menne, Kinney and Morhardt, 2002; Nyman and Szymczynska, 2016).

5.7 Theoretical implications

The two phases of this study were predominantly framed by two theoretical approaches – the Stress Process Model which underpinned the dyadic interviews and a relational citizenship approach which largely framed the home-based observational study (Pearlin et al., 1990; Judge, Menne and Whitlatch, 2010;
Kontos, Miller and Kontos, 2017). Here I will discuss the findings in the context of both theories, in terms of where the theories can help with making sense of the findings but also where the findings may illuminate some limitations in the application of these theoretical approaches. Specifically, I will illustrate how the Stress Process Model and relational citizenship approaches helped me to understand some of my findings related to the stress and coping processes and the relational context within which PLWD were motivated to remain engaged and active, but I will also refer to some other – notably non-dementia specific – theoretical approaches which may be able to offer some additional understanding and sense-making of some elements of the current findings. Elements which perhaps do not relate so directly to the diagnosis and the symptoms of the conditions, but rather those richly layered and complex aspects of the ordinariness and minutiae of everyday life that I was privileged to witness over the course of the interviews and observations. These aspects of the findings in particular, related to the ordinary and the mundane, will be contextualised through a theory of everyday life, in section 5.8.1.

5.7.1 The Stress Process Model

The two variations of the Stress Process Model drawn on here (Pearlin et al., 1990; Judge, Menne and Whitlatch, 2010) provided a helpful framework for interpreting the findings, particularly because of their comprehensive acknowledgement of the wide range of diagnosis-related and contextual factors that could influence the stress process. Many of the contextual and mediating factors outlined such as age, occupational background, family situation, and knowledge of illness, were shown to be influential factors in how the participants in this study experienced stress. Interpreting the findings in the context of this model was also helpful for illuminating just how much the stress process is shaped by factors which are pre-existing, or not directly related to the disease or its symptom profile. The congruence of this with my experience of the home visits is clear in the lengthy conversations I had with participants and the range of activities undertaken in
which the diagnosis was not mentioned or referred to. While the diagnosis was by
definition the reason I was there, it appeared not to be centre stage for participants
every moment of every day. In this sense, the Stress Process Model was also
particularly well suited to the methods used here – the comprehensiveness of both
adaptations of the model was complementary to the in-depth interviews and to the
unstructured, qualitative observations which allowed access to the manifold
uncontrollable and interrelated variables characteristic of any naturalistic setting.

Slightly counter to how comprehensive the Stress Process Model is in
acknowledging varied contributory factors, in relation to the current study findings,
this could be considered as being perhaps too narrow in terms of the overall
conceptualisation of the illness experience as being one of predominant stress. The
varied stressors associated with the experience dominate, with coping taking up a
relatively small proportion of both versions of the model looked at here – it is one
of two mediating factors in the version for caregivers and not any further specified
than ‘coping’, and does not feature at all explicitly in the version accounting for the
stress process of PLWD, though is perhaps considered to be captured within the
internal mediating factors such as personality, hardiness and life orientation.

This weighting towards the stress of the process did not always feel compatible with
the interview and observational data. As is captured in the presentation of the
interview findings, even though I was there to ask about difficulties and symptoms,
it was very rare that participants would talk about a difficulty without automatically
continuing on to describe how they had attempted to deal with it. Even when these
strategies had not worked, in most cases they were an inevitable part of the illness
experience process. This sense that it was not only about stress was similar in the
home-based observations, so much so that my early reflexivity notes contained my
concerns that I was witnessing days which felt so much more positive than I had
anticipated, that I was concerned I was altering the research environment to such
an extent that it was no longer representative of participants’ typical day-to-day
experiences at all. This potentially unrepresentative focus on stress is also perhaps
what underlies the absence of cognitive reserve as a protective factor against stress within the model, which these study findings, particularly in regards to the PCA group, showed to be significant. The relatively well preserved insight, memory and language functions of the PCA group appeared to be of fundamental importance in their coping and in the mediation of stress, as couples worked together to problem solve, and as the aims of activity engagement were communicated and jointly negotiated. Acknowledging the possible variations in the constellations of cognitive functions could be a helpful and timely focus of the future development of the Stress Process Model, in terms of better capturing the nuances of atypical presentations of dementia but also more broadly, as the dementia research field as a whole continues to shift further away from a solely deficit-model approach. Pearlin et al. (1990) and Judge, Menne and Whitlatch (2010) all welcomed such developments to the model, considering it “something to be built upon rather than something to be followed or perpetuated” (Pearlin et al., 1990, p. 591).

Another way the empirical data here illuminated some potential limitations of the Stress Process Model was with regard to the impact of the physical environment on the stress process that individuals and their families experienced. The components of both the caregiver and PLWD iterations of the model are predominantly biological, psychological and social, and though they refer to many components which imply some involvement of the physical environment (e.g. PLWD dependence, functional status), the physical environment as an independent potential mediator of stress is not acknowledged in its own right, it is only implied as something the PLWD would be interacting with. The physical environment was shown to be a key factor for participants with PCA and tAD in terms of causing stress but also coping, and the model as it stands perhaps could be said to represent more person-related factors than adopting a truly contextualist perspective. As a result it fails to capture how the suitability or specific features of the physical environment can (and were shown to) support or hinder everyday engagement within the home environment, and this could be a particularly
worthwhile way the model could be further developed, not only for those with PCA and other atypical presentations of dementia but also for those with co-morbid physical health conditions, and perhaps those making the transition from the familiar physical environment of their own home to care home settings. The relative recency of Keady et al.’s (2013) proposed bio-psycho-social-physical model of dementia to fill this gap is testament to just how long the importance of the physical domain of the dementia experience has been under accounted for and underrepresented theoretically. Another theory which more explicitly accounts for how the physical environment plays a role, and interacts with both a person’s abilities, but also their subjective perceptions of those, is Gibson’s Affordance Theory (Gibson, 1977). For an extended discussion of how Gibson’s Affordance Theory may help to understand the findings from this study, see Appendix 17.

The acknowledgement of the significance of PLWD’s subjective experiences and interpretations within the Stress Process Model and Affordance Theory make both theoretical approaches seem very compatible with the empirical data observed here in terms of the prioritised outcomes of activities (Gibson, 1977; Pearlin et al., 1990; Judge, Menne and Whitlatch, 2010). The findings highlighted that subjective experiences of engagement and meaning-making via activities (e.g. in sustaining identity and fostering opportunities for social connection), were more significant as drivers of activity than many objectively measurable outcomes, such as efficiency or accuracy in activity completion. This relates to the engagement-over-efficiency idea suggested in the first theme, ‘The fun and the function’ above (see section 3.5.3.1.3) – the notion that participants did not just want to do things which were objectively effective but things which meant something to them. The methods used in this study were conducive to subjective experience being taken account of, but developing the Stress Process Model in terms of how those sorts of aspects of subjective experience could be captured on a larger scale, in order to further test and validate the model, would be a valuable contribution.
The importance of subjectivity in the illness experience is perhaps best captured by the fact that the two variations of the Stress Process Model referred to here – the one for PLWD and the one for caregivers – both acknowledge the importance of subjective strains within them (Pearlin et al., 1990; Judge, Menne and Whitlatch, 2010). This certainly fits with empirical findings in both of the current studies – that the illness experience is never just an isolated experience affecting only one individual. Further confirmation of this and the resulting importance of theoretical models which capture the multiple perspectives within any illness experience, come from discrepancies in the account of participants in the dyadic interviews, differing priorities for activity engagement identified in the observations, and different interpretations of the symptoms among dyads throughout both studies. While the two iterations of the model outlined here go some way towards acknowledging these differences in subjective experiences, they stop short of explaining how these multi-perspective illness experiences map on to each other, and how points of tension or conflict are reconciled or navigated in real-time in real-world settings, as seen happening empirically in the current studies. An example of this in theory, within the model, is where the impact that the diagnosis has on the relationship is positioned – for PLWD this is considered a secondary strain, whereas relational deprivation for caregivers is considered primary. Having witnessed such a team-based approach in the majority of cases in both of the current studies, it perhaps seems slightly incompatible that such a shared issue could feature so distinctly in the stress process for each member of the dyad. Perhaps this is reflective of the stage of disease at which the Stress Process Model is targeted, and while temporality is inherently acknowledged within it, by definition of it being a process model, there are perhaps some limitations in the applicability of this temporal-sensitivity in empirical settings (more on this below). Other examples of the difficulties in mapping the PLWD and caregiver versions of the model on to one another came from occasions when a coping strategy for a carer contributed towards stress (e.g. role captivity) for a PLWD. Extending the model’s abilities to capture how this is communicated, negotiated and resolved within a shared stress
process (i.e. a dyadic stress process), as it is lived in real-time could be invaluable in further determining how people affected by dementia may be best supported in a truly relational context.

Expanding on the inherent temporality of the Stress Process Model and its applicability, the model accounts for a range of factors that could have a varying ongoing influence on the stress experience, and as such seems to offer a dynamic model for taking almost a snapshot of how stress is experienced at any one point along the illness journey. However, given the future-oriented concerns reported particularly in the dyadic interviews, regarding how the condition would progress, how best to plan, caregivers’ concerns about their continued competence, and PLWD’s concerns about being or becoming a burden, it is not clear how adequately the model accounts for different temporal orientations such as these, i.e. concerns about the future which have a bearing on the stress experienced in the present. Further development of the model and its potential applicability over different time frames could be interesting to test empirically, and also a useful contribution to building an even more complete theoretical framework for understanding the whole dementia journey. In terms of timeframe, another way the model could be developed in light of the dyadic interview findings would be to redefine the period of time it considers the stress process over. It is of course by definition that the model is intended to be applied once someone has a diagnosis, but the interview findings demonstrated the significant and sometimes enduring stress which had resulted from that which had been experienced a long time prior to ever receiving one. This was time in which dyads and their wider families were without a clear understanding of those same symptoms which would later be accounted for by the Stress Process Model, but which in reality had begun to initiate a stress process far in advance of a diagnosis being made. Owing to the rarity of the condition, this period in the illness experience was extended for those whose symptoms would turn out to be owing to underlying PCA, and this further exemplifies the nuance and
variation that models of general dementia may need to account for if they are going to be applicable to the full range of presentations that can fall under that umbrella.

This connects to one particular element of the stress process that was identified as being of fundamental importance in the interviews and observations, in terms of both getting an accurate diagnosis but also the uncertainty about how best to support the PLWD to continue to engage with activities, and needing to take a somewhat trial-and-error approach. The key concept this relates to is knowledge of the illness, which does feature in the Stress Process Model, but only in the updated version for PLWD, and in both studies here this was seen empirically to be a very influential determinant of the stress experienced for both family members and the PLWD, at multiple stages of their dementia journey (Judge, Menne and Whitlatch, 2010). Expanding this as a contributory factor could be helpful in terms of better understanding and eventually specifying where and how knowledge most needs to be developed and delivered. For example, which professionals having knowledge would mean that the support network available in the background/context domain could be of optimal relevance and help for people, as and when they come to access it?

A final element of the Stress Process Model that the current study findings may help to develop concerns the direction of impact throughout the model. The model proposes that primary stressors can lead on to secondary strains in a unidirectional way, but the findings of the interview and observational studies here potentially suggest that these relationships could be more interactive and bidirectional than both adaptations of the model account for. One specific example of this in relation to PLWD was when people with PCA’s subjective appraisal of their ability would reduce their sense of mastery or self-efficacy in an activity, and this would feed back into their level of functional impairment in the activity, because of either their withdrawal from it or their loss of confidence and increased anxiety when completing it. An example of this which applied to caregivers was illustrated when their appraisal of their own competence could be seen to feed back into their
general feelings of overload, for example in Eleanor’s partner’s explanation that she was not best equipped for the emotional side of caregiving. These variations in the directionality of the stress process for PLWD and caregivers further endorses the potential applicability and importance of a dyadic iteration of the Stress Process Model, which more fully accounts for how the stress process is experienced, navigated and negotiated within the relational context in which it is lived.

5.7.2 Relational citizenship and Embodied Selfhood

Relational citizenship was the second overarching theoretical approach used to frame the current work and which the findings were interpreted in the context of (Kontos, Miller and Kontos, 2017). The findings from both the interviews and observational studies were compatible with the theory’s broad recognition of the dementia experience being best understood within, and shaped by, the relational context in which it happens. A central way this happened was in the way caregivers were both jointly affected throughout the process from pre-post diagnosis, and also essential in supporting the PLWD in engaging with their everyday environments. However, beyond this relational approach, which is not unique to Kontos and colleagues’ (2017) work, was the relevance of citizenship to the current study findings. As posited by the theory, PLWD showed an enduring motivation to make a contribution and to exercise choice and preference, and these too were inherently relational processes. Family members would support the upholding of PLWD’s choices and preferences, and PLWD would mostly want to be useful and helpful to others, or to make some contribution to them, whether that be by completing household chores or withdrawing from activities that may be a source of burden for their family member to support them in. As posited by the theory, this want to make a contribution and the relational nature of interactions, activities and expressions of self all went beyond care relationships or care activities – PLWD showed a desire to give as well as receive care. In shedding empirical light on these processes within the home environment, the findings of the current study have also allowed the consideration of the applicability of this theory to those in the earlier
stages of dementia, and in doing so have hopefully offered insights into how processes which are of relevance to those in the more advanced stages of dementia can have their roots and some relevance earlier on in the illness experience too. The current study findings arguably support and add weight to the theory’s proposition that there is a mutually motivated desire for the preservation and continuity of selfhood of PLWD, by showing both how early on in the disease course this begins, and the multiple stakeholders involved. This motivated continuity of self is also compatible with my earlier suggestion that whilst there is a diagnosis of dementia confirmed, this does not necessarily mean that other motivations and priorities suddenly fall by the wayside, and that a lot of the experiences with people in their naturalistic home environments in this study were centred around activities of interest and enjoyment and often (appeared at least), quite separate from concerns about their symptoms and the diagnosis. Observing these processes at play earlier on in the disease course, and not taking such a diagnosis-centric approach to exploring the everyday experiences of PLWD could potentially all help towards reducing the dichotomising of early and late stage dementia, which may perpetuate notions of PLWD being ‘other’, and serve to underplay the continuity in various processes relating to the selfhood of PLWD. This approach was endorsed and exemplified by Lindqvist et al.’s (2016) scoping review of mastery of meaningful activities, in which studies involving people with any kind of mild cognitive impairment were included, and as such this included people in the early stages of dementia along with those with cognitive impairment arising from brain injury, and so on. In doing so the authors arguably enact the client-centred approach they advocate for, by effectively categorising their sample more at the level of the challenges they are facing, rather than strictly according to the diagnosis they have been given, as is often the classification criteria for study samples. I would argue and hope that the more varied ways we find to classify and categorise participants, the further away we will move from such distinct dichotomies that are often seen in the dementia literature and in turn, the closer we will get towards an overriding appreciation for the commonalities in all of our experiences as people.
As another counter to the prevailing dichotomies, I would suggest the current study findings lend support for the future consideration of non-dementia-specific theoretical approaches to these populations – especially those in the earlier stages. Theories such as those concerned with process, like the Stress Process Model, but of ageing and development more generally, irrespective of diagnostic labels. Drawing on these theories could also contribute to efforts to shift away from a solely deficit model approach, in acknowledging the continued motivations, retained abilities and the usual life transitions which are still happening for PLWD alongside and around their diagnoses. As discussed above, Atchley’s (1993) Continuity Theory and Erikson’s (1997) Psychosocial Stages of Development, in particular the concept of Generativity, may offer some additional understanding of the contributory and other activities participants in this study were motivated to continue to engage with despite their diagnoses. Also, theories concerned with behavioural motivation more broadly (rather than just in the context of disease), such as Deci and Ryan’s (2002; 2008a) Self Determination Theory, which suggests that human behaviour is motivated to meet three psychological needs that are essential for wellbeing: autonomy, competence and relatedness, all of which seem compatible with elements of the current study findings. For an extended discussion of how these theories may help to understand the findings from this study, see Appendix 17.

It is also helpful to consider the applicability of the relational citizenship approach’s emphasis on embodied ways of being, doing and expressing one’s selfhood, in relation to the current study findings. The theory asserts that embodied action is an enduring way in which PLWD’s selfhood is constituted and can be expressed. Much of the existing empirical and theoretical work pertaining to this is conducted with people in the more advanced stages of dementia, when their verbal and other cognitive abilities can be most compromised (e.g. Chatterji, 1998; Boyle, 2014; Kaufmann and Engel, 2016). The current study findings however, perhaps offer a new lens from which to consider how these elements of the theory apply, and
potentially challenge the notion of embodied action as the ultimate, and eventually only, enduring means of expressing one’s personhood. The PCA group in the current study showed and reported marked difficulty with many embodied actions, owing to their disproportionately impaired visual and spatial processing. The profound psychosocial implications of these difficulties reported in the interviews, relating to loss of independence and threats to one’s identity, indeed support the assertion that embodied action is an important means by which selfhood is constituted and expressed. While Kontos, Miller and Kontos’ (2017) relational citizenship theory refers to the value of pre-reflective embodied action for those whose cognitive, rational and intellectual capacities may be severely impaired, the current findings perhaps extend these ideas, by suggesting that disrupted embodied action – even when reflective and rationalised – can pose similar threats to one’s sense of selfhood and agency, earlier on in the disease course. The findings may explicate our understanding of the varied ways that cognitive impairment can affect the effective expression of selfhood, and instead make the case for a more nuanced representation of the ways bodily agency can be enabled or challenged by different types of dementia. Keady et al.’s (2013) bio-psycho-social-physical model is one such model which offers a comprehensive account of the varying ways the physical body is impacted by (e.g. via physical treatment) and can impact (e.g. physical health and wellbeing) the experience of dementia. The PCA group in this study had relatively well preserved memory, intellect and rationality, and could all articulate to me actions which they remembered how to complete and were motivated to enact, but their profoundly impaired visuospatial and perceptual processing often prohibited this being actualised. This impaired perceptual functioning coupled with relatively well preserved insight meant the PCA group were able to mostly make appropriate appraisals of their own abilities, and as a result it was in fact their preserved cognitive capacities which were often responsible for inhibiting their embodied action.
What this means for the broader concept of agency is a central part of this discussion – agency is defined variesingly as one’s ability to exert control over, to influence or to make a mark on one’s environment (Kitwood and Bredin, 1992; Topo, Kotilainen and Eloniemi-Sulkava, 2012; Clemerson, Walsh and Isaac, 2014; Kaufmann and Engel, 2016; Chung, Ellis-Hill and Coleman, 2017). Topo, Kotilainen and Eloniemi-Sulkava, (2012) outline the necessary pre-conditions for agency as being perception and understanding of the world in which one wishes to act or exert influence, and while the rational or literal understanding of the world may be challenged in the later stages of more typical dementia, the intuitively more ‘elementary’ perceptual understanding of the world, is what is most compromised for people living with PCA. This further suggests the need for more nuanced conceptualisations of agency and to an extent this is supported in the literature. Agency can be conceptualised to refer to numerous dimensions of acting including: knowing how to do something, being able to do it and wanting to do it, (Topo, Kotilainen and Eloniemi-Sulkava, 2012); planned or intended versus actual action (Doyle, Rubinstein and Medeiros, 2015); and envisaged or imagined action (Emirbayer et al., 1998). In what Boyle (2014) describes as an over-theorised and under-empiricised area, more time spent in ecologically valid settings, with participants at a range of stages of a range of forms of dementia will be essential to developing an understanding of the different ways agency can be challenged, fostered and acknowledged for all PLWD.

5.8 Methodological reflections

Completing the dyadic interviews and observations within participants’ familiar physical environments facilitated their sharing of rich and reflective accounts, including unanticipated insights which were often prompted or cued by the environment or objects within it. Conducting the interviews and observations in the home setting also maximised accessibility for research participants, as they were within their own familiar settings and had the aid of familiar objects, daily routines
and practices to support their communication of their experiences, rather than having to solely rely on their abilities to recollect and articulate those experiences, as they might have to do during an interview within an unfamiliar clinical or lab setting (e.g. Öhman and Nygård, 2005; Nygård, 2006; Roach and Drummond, 2014; Ludwin and Capstick, 2017; Abendstern et al. 2019). The semi-structured qualitative interviews allowed participants’ voices to be centre stage and for them to steer the conversation in any directions important to them, and the unstructured observations built on this, in permitting and encouraging participants’ actions to drive and shape the day, and this participant-directed data collection contributed to the ecological validity and authenticity of the data overall (e.g. Askham et al., 2007; Ericsson, Hellström and Kjellström, 2011; Clemerson, Walsh and Isaac, 2014; Lloyd and Stirling, 2015; Baldwin and Greason, 2016; Kaufmann and Engel, 2016). Participants were free to direct me towards activities or objects of meaning, and this allowed concepts like meaningful activities to be opened up and explored fully, in terms of participant’s own individual experiences, rather than within any predetermined parameters of interest (e.g. Phinney, 2006; Dröes, 2007; Lloyd and Stirling, 2015). Considering the research context more broadly, there is arguably a pressing need for more research conducted in this way within the current sociocultural context of hyper-cognitivism, in which PLWD can be vulnerable to being marginalized or disempowered – even within research settings – because of their ongoing cognitive decline, despite their enduring agency and selfhood (e.g. Kitwood and Bredin, 1992; Czaja and Sharit, 2003; Davis, 2004; Brittain et al., 2010; Ladouce et al., 2017; Morrell, Camic and Genis, 2018).

The setting added a deeper understanding of the physical context in both phases of the study but particularly in the observational phase, as I naturally spent longer in different spaces within the home with participants, so gained a richer appreciation of how they were experiencing and using the space day-to-day, by experiencing this with them in real-time, than if they had simply explained this to me. This immersion in participants’ everyday worlds, particularly for the extended period of time of the
observations, allowed me to gain a more authentic sense and feel for their day-to-day lived experience. Additionally, even though the diagnosis was a defining element of why I was there, it was the extended periods of time spent in the field which allowed me to gain a more representative and balanced picture of how central (or not) the presence of the diagnosis appeared in terms of its impacts on day-to-day life, and revealed how notions of getting on with things and keeping going, regardless of the diagnosis, were the driving force of most households.

While the variation and complexity of individuals’ living situations in the community (physically and socially) was broad, conducting this study in people’s homes revealed helpful insights about how many of the processes of adjusting to the symptoms, one’s changing relationship with the physical environment, and of finding ways to continue activity engagement and enact one’s personhood, begin before PLWD are living in residential care settings – the environment in which some of these processes are often studied (e.g. Norman et al., 2004; Baldwin and Greason, 2016). Studying participants in their naturalistic settings also allowed acknowledgement of the holistic relational contexts that PLWD navigate challenges within, which is also key in building an ecologically valid evidence base (e.g. Phinney, 2006). Conducting dyadic interviews in phase I proved very helpful, as it offered insights into the relational context of the stress process, and illustrated some of the tensions and conflicts around the assessment, interpretation negotiation and implementation of coping strategies, which may not have been captured in separate individual interviews. The negotiation of interpretations that could happen at the micro-level within conversations, often spoke to more significant negotiations the dyads had had to make, which were revealed with further prompting. The dyadic interviews also permitted the reliable and efficient telling of the shared history and background context of the dyad, which could have proven difficult to do individually for some of the PCA participants who were experiencing some concurrent memory or language problems.
With regards to the observations, a common criticism of this kind of particular focus on the small-scale, mundane and context-specific detail is that it is at odds with some key notions of empirical science, such as large scale abstractions and laws which permit theory building. Stake (1995), Knoblauch (2005), Geertz (2008) and Simonds, Camic and Causey (2012) all discuss and reject this, with their assertions that a focus on the small scale, ordinary and context-specific can provide data which, while necessarily subjective and partial, in acknowledging its (inter)subjectivity, can in fact paint a truer picture of whichever aspect of reality the research is aiming to capture, and this certainly seemed the case here. They also argue that to dismiss what the mundane details can tell us about larger social issues is to (wrongly) devalue an ethnographic or case study approach. Specifically, that dismissing the everyday experiences of people as unstudiable because of their dependence on contexts which are rich in uncontrollable variables is circular and unhelpful, because these are central and irremovable features of the everyday environments that an understanding is sought of. Stake (1978) builds on this by querying the superiority afforded to high level explanatory theories over efforts to make the minutiae of other people’s experience understandable, especially in the social sciences, as real human understanding unavoidably relies on concepts such as intentionality and empathy, which are much more essential to human experience than broader scientific concepts of explanatory power, rules and prediction.

Indeed, many scholars working in this tradition dismiss traditional, statistical generalisability as an appropriate aim of work conducted in this way (e.g. Stake, 1978; Hammersley, 2008; Cruz and Higginbottom, 2013; Suryani, 2013; Baškarada, 2014; Yin, 2017). Suryani (2013), Stake (1978, 1995) and others write instead about naturalistic generalisations that can be made when context-specific, holistic interpretations are related to broader social contexts. Yin (1981, 2011, 2017) describes literal (within sample) and theoretical (beyond sample) replication – both strategies which seek to confirm some broader applicability of findings, and this kind of literal replication was of key importance when constantly comparing
individuals’ richly detailed data sets, in order to identify the more general themes and patterns.

The range of data collection tools and the triangulation during the observational phase facilitated the comprehensive capturing of this complexity, as it meant data of many modalities could be collated and integrated, to build as full a picture as possible of the experiential setting (e.g. Creswell and Miller, 2000; Askham et al., 2007). Given the atypical nature of the symptoms and their unusualness to both the participants experiencing them and their family members, having a multimodal data set (i.e. interview reports, neuropsychology scores, video data) also proved helpful in offering clarity about what was most likely underlying the difficulties that people were describing, and which I was observing and interpreting in the field. The case summaries and index cards in particular, and the qualitative comparative embedded multiple case study approach more broadly, was a helpful approach to use in tandem with focused ethnography, as they allowed me to capture, preserve and keep in mind the richly varied nuances and individual differences in the individual contexts, choices and meanings made around activity engagement across all the individual participants, when repeatedly moving between individual segments of data and the group-level analysis and broader pattern-seeking.

5.8.1 Trying to capture ‘a typical day’

Unstructured observations in participants' homes can naturally pose challenges, as data collection happens in a naturalistic setting with many complex and interacting variables, which cannot be controlled or manipulated by the researcher (e.g. Yin, 1981; Nygård, 2006; Ludwin and Capstick, 2017). As well as concerns about how much a researcher is able to take into account, there are also documented concerns about what cannot be observed (Briggs et al., 2003), and how this impacts validity. Briggs and colleagues (2003) have outlined a common criticism – that observations cannot be representative, as the very presence of a researcher will change any setting, and therefore the interactions and activities that happen within it. Briggs
and colleagues (2003) attest however that while observations may not generalise to a typical day for participants, that does not prevent them from offering unique and useful insights into those other, more typical days, and the wider practices and issues that extend beyond the observation period. Poignant examples of this in the current study included Oscar having saved up all his chores from the whole week for my visit. While it was not representative for him to do all the chores he did in that one day, it provided useful insights into how his PCA was affecting a wide range of familiar tasks. It also (when contextualised within the broader home visit) provided further evidence of the conscientiousness that seemed characteristic of Oscar — in the same way that he had described taking on the household chores as a means of contributing to family life since he had had to give up work, he also appeared a conscientious research participant, keen to make the most of the research visit as a means of contributing to the lives of others with the condition, by demonstrating as broad a range of how his day-to-day tasks were affected as possible. Another example came from the home visit with Lilian — when making arrangements for lunch it became clear that she and her husband usually went out to eat, but once they realised I would not be able to accompany them, Lilian seemed keener to stay at home. While at the time I was concerned about what this would mean for the representativeness and typicality of the day if they (unusually) stayed at home all day, on reflection this interaction provided useful supporting evidence for my emerging interpretations. I had begun to conclude that one of Lilian’s primary motivations for engaging with any activity was the opportunity it provided for social interaction, and their having lunch out would have interrupted the almost constant conversation we had been having over the course of the day so far, in which Lilian had been asking me many questions about my history and interests, and had shared much with me about hers. These examples reassured me that even if the day was not typical, that I could still learn meaningful things about typical days in an authentic way just by being in the setting, remaining reflective about my influence on it, and in not being afraid to address those concerns transparently with participants, e.g. by asking about how typical or usual various events were.
Although there are challenges relating to capturing a typical day, the authenticity and breadth of applicability of the findings here (particularly the three overarching themes) are testament to the significance of a typical day and the value in capturing the everyday, ordinary and mundane, in order to deepen understandings of lived experience. As such, as well as within the psychological theories already outlined, these findings can also be contextualised through a sociological theoretical lens of everyday life.

In his conceptual paper about the theorising of everyday life following acquired brain injury, Harvey (2018) attests to the value of studying and theorising everyday life so that an in-depth and contextualised understanding of people’s day-to-day experiences, which is free from societal assumptions and predetermined (mis)conceptions, can be gained. In the current study, this sort of challenge to common assumptions was evident in the finding that wanting to make a contribution underpinned much of the activity engagement PLWD were motivated towards, which sits counter to the dominant discourses of dementia which centre around deficits and losses of capabilities, and a unidirectional need to receive support and help rather than to provide it. At the core of the sociological approach to studying everyday life is a desire to understand, know, and particularly relevant to the context of disability or illness, a need to critique and/or dismantle any pre-existing judgements and assumptions (Scott, 2009; Harvey, 2018), something which became increasingly pertinent throughout the mixed methods triangulation of the current study data, when the focus shifted to the mechanisms and meanings of participants’ activity engagement, rather than the accuracy, efficiency or independence of their performance.

The studying and theorising of everyday life allows for a more sophisticated and nuanced understanding of experience, in which the meanings of micro-moments of interaction and small-scale behaviours can be elevated, and this in turn offers a way for the inclination to attend only to discretely divisible tasks and activities or significant life events to be resisted (Hammell, 2004; Hasselkus, 2006; Scott, 2009;
Attending to what can be considered trivial, mundane and unremarkable in this way can shed helpful light on broader and more complex social issues and phenomena (Scott, 2009). An example of where this attention to the minutiae of everyday life contributed to a broader overarching theme (‘The constitution and continuity of a changing self’) was in Sally’s by the by description of the time she spent sitting and looking out of the window at the hills, and how that offered some form of a stable anchor at a time during which she was experiencing inevitable and ongoing changes within herself. This was not a clearly divisible activity that neatly fell within a category, but it offered rich insights into how Sally’s everyday environment and her engagement with it offered a point of reference for her selfhood. This can be understood within Scott’s (2009) description of the home as a particular site of everyday life in which identities are performed, constructed and situated. Scott (2009) also describes the selection and use of everyday objects as being essential in this, which further resonates with the theme ‘The constitution and continuity of a changing self’, for example with Lilian’s attachment to the many ‘bits’ she had collected from her many years working in the chemist, which ‘us girls have’. Kalekin-Fishman (2013) and Pink (2012) further endorse the value of studying the material, in addition to the cognitive and affective, in order to gain a rich and textured understanding of everyday life.

Another quality of everyday life that Scott (2009) delineates which is relevant for contextualising the present findings is the habitual, routine, repetitive, and familiar, and how essential those features of everyday life are for establishing whatever it is that is considered normal, mundane and ordinary for each of us. And in turn, how it is through the disruption of this taken-for-granted, everydayness that significant and profound personal impacts reveal themselves and can be most fully understood (Scott, 2009). An example of the current study findings which can be understood through this explanation of Scott’s (2009) is the difficulty Lionel was beginning to have with remembering his granddaughter’s medication timings, which for his daughter was a change in routine which signified the progression of his condition.
Lionel’s situation was unique in a number of ways, and it is this variation, idiosyncrasy and messiness of everyday life which contributes to it being hard to define, and seemingly nebulous and ambiguous in terms of subject matter, but Hasselkus (2006), Scott (2009), Harvey (2018) and others all suggest that it is attending to this complexity and variation which prevents an illness experience being homogenised, which could otherwise marginalise those affected. This seems more broadly relevant to the current study findings in that patterns were identified within and across diagnostic groups, but also that there were exceptions and negative cases, as well as patterns revealed relating to factors other than the diagnosis (e.g. life stage, core values), highlighting once more the pervasive vastness of the ordinary of everyday life which extends in between and around any single extraordinary characteristic or event such as a diagnosis of a dementia.

5.8.2 Participants’ expectations of the researcher’s role

As with the feasibility and value of capturing a typical day, another well-documented concern when spending long periods of time in participants’ homes is that researchers may feel there are expectations on them to provide care, clinical advice, or counselling (for example), and navigating these expectations requires the researcher to reflect on their role and boundaries, in real-time whilst in the field (Batchelor and Briggs, 1994; Briggs et al., 2003). I certainly experienced this during the observations, with examples including participants asking for practical advice about how they should adapt their homes, clinical advice about medication and symptom progression, and expectations that I would take a role of supervising or safe-guarding the person with the diagnosis over the course of the day. This could also be particularly difficult in scenarios where there were discrepancies in the multiple accounts, for example, occasionally participants would invite me to offer some ‘expert’ advice to resolve disagreements they were having, about symptoms or strategies which might be helpful. In all cases, it was important I remained reflexive of my relationships with all participants involved in order to ensure I did
not allocate more credit to any one account or interpretation of events, and
transparent and consistent about the remit of my role as researcher.

5.8.3 Extended immersion in the setting

As illustrated in the two examples above, there are several ways that extended
periods of immersion in a naturalistic setting can contribute to the validity of
observational data. As Stake (1978, 1995) discusses, the aim is to thoroughly
describe specific cases in rich detail, and findings will demonstrate validity if they
reflect the realities and meanings people experience and construct in their everyday
settings. Briggs and colleagues (2003) describe how the length of the visit in their
study meant they had time to see how interactions and activities changed over the
course of the visit, and that this helped with their determining of what was genuine
and what might have been being censored. Rapport-building (discussed further in
section 5.9.1 below) is a key element of making participants feel comfortable
enough to relax and be their authentic selves as far as possible, and an extended
period of observation can help a researcher to judge if and when this has happened,
for example when efforts at self-presentation or acquiescence begin to relax (Roper
and Shapira, 2000; Briggs et al., 2003). Rather than threats to reliability, these
changes over the course of the day may instead be best considered as accurately
reflective of real-world interactional processes (Jorgensen, 2015). One example of
how the extended period of observation helped with the development of my
analytic interpretation in this study was with Maurice, who had many animated
conversations with me from the moment I arrived, about which I frantically
scribbled down field notes. It was only on reflection at the end of the visit that I was
able to identify that only some of the topics covered in these early conversations
seemed to correspond to genuine interests of Maurice’s which related to
meaningful activity (e.g. computer programming), as these had been further
verified by the information collated from other data sources over the course of the
day. Discussion about other topics (e.g. music), seemed more to be triggered by the
environment or a comment of mine, and seemed to serve more as a mechanism for
maintaining social interaction with me. On balance it seemed that in those cases it was this social interaction itself which constituted the meaningful activity for Maurice, rather than some of the specific topics we had discussed.

Overall, I would argue that despite the unique challenges associated with this kind of intensive and immersive observational work, it can provide uniquely rich insights, and go further than any single-modality data collection method in beginning to capture some of the complexity of the real-world lived experiences of PLWD. In reporting the trials and tribulations of my experience transparently, I hope to encourage other researchers to do the same, especially in the context of lesser known forms of dementia or other rare, chronic health conditions about which little is known, and in doing so to contribute more broadly to exciting methodological development in this area of ever-increasing importance.

5.9 Reflexivity

Reflexivity refers to the acknowledgement of role that the researcher plays in the research process, and is widely acknowledged to be a key consideration for ensuring the rigour and validity of qualitative research (e.g. Macbeth, 2001; Mauthner and Doucet, 2003; Dowling, 2006; Alvesson, and Sköldberg, 2017). It is based on the ontological idea that knowledge about the world – everything that can be known and communicated – has been through multiple stages of interpretation and because of this, something which is known cannot be separated from the person who knows (and is communicating) it (Alvesson and Sköldberg, 2017; Denzin, 2017). As part of my own reflexive practice I kept a reflexivity log and added to it after every home visit. Here I will outline some of the central issues that came up for me during the course of this PhD project.

5.9.1 The relationship with participants

Particularly relevant aspects of reflexivity for my work in both phases of this study were issues around building relationships with participants, which are important for
gaining and maintaining access to the setting (Briggs et al., 2003). Building rapport and trust is key, and spending time with people, getting to know them and making them feel comfortable are essential components of this (Charmaz, 2004; Nygård, 2006; Suryani, 2013). This involves elements of empathy, listening well and being non-judgemental, and an informal interviewing style and flexible or unstructured protocol can help with this (Roper and Shapira, 2000; Higginbottom, Pillay and Boadu, 2013; Pink and Morgan, 2013). Rapport-building felt particularly significant in relation to the observations, because of them being unstructured and for a long time period. Two illustrative examples of the different ways a rapport was built come from Mark and Richard. While they both seemed fairly quiet and apprehensive when I arrived, I took this to be for quite different reasons, as I tried to sensitively assess what was going on in, order to respond in a way that would put them both at ease. With Richard I sensed that his quietness was apprehension about whether his normal activities really were of interest, so in an effort to confirm that they were, I initially left him to reading his newspaper alone for the first couple of hours. By the time we went on a walk-around tour of the home he opened up about his current interests, which were politics, current affairs, and his research into his family history. In my initial conversations with Mark and his wife, it became clear that he was having some difficulty with talking about his diagnosis and – taking into account his body language and facial expressions during those early conversations – it seemed that he was uncomfortable with the idea of a day revolving around assessing or exposing his condition. As a result, our rapport-building was quite a different exercise – it was facilitated much more by very immediate and enthused conversations about Mark’s interests, which were a family member’s recent musical release and his reflections on his own career history. The literature endorses that if rapport building is successful, the researcher can establish what becomes a genuinely intimate connection with participants, which can also allow the researcher to relax and be more authentic, though some degree of reflective awareness of self is important to maintain throughout (e.g. Roper and Shapira, 2000; Briggs et al., 2003). There is also a balancing act of making
participants feel comfortable enough to be open and honest in directing the researcher towards what’s genuinely important to them, while remaining reflective about any behaviours or conversations the researcher may have more responsibility for eliciting or steering (Knoblauch, 2005; Angrosino, 2007). Finally, having built good rapport, disengaging from the setting can then be difficult, and Briggs and colleagues encourage advanced consideration and planning around disengagement, which I incorporated into my protocol and found very helpful.

5.9.2 Researcher biases and assumptions

Another key area requiring reflexivity is the researcher assessing how their prior knowledge, assumptions, theoretical positioning (etc.) may be impacting on the data collection and interpretation. Yin (2017) recommends that one way researchers moderate the effect of these on the data collection is by being aware of and open to the unexpected emerging. In the interviews of phase I, the fact that these had been conducted in combination with another researcher was very helpful, as we would debrief and challenge each other’s immediate responses and assumptions as we wrote field notes together shortly after the visit. During the observations this seemed more difficult, and I tried to prepare for this in advance by asking myself questions about what I expected to find when arriving at the home visit, based on any correspondence I had with participants up until then, and consciously testing myself to spot any evidence to the contrary of what I thought I was seeing, whenever I felt quite quickly very sure of my interpretations. Related to this, I found it especially important to note my reactions to the setting as soon after arrival as possible (but often in subtle, shorthand ways in case participants took a look at my notes), so that I could use this to inform my later interpretations of the interactions which had happened early on in the day. Otherwise I was concerned I would look back at the whole day through a lens based on my final, overarching impression of the space and participants. Researchers can also bring biases into play when collecting data in terms of what they choose to attend to, and Fabian (2010) points out that what different researchers will remember of an event between it
happening and being written up, will vary according to their personal experience, theoretical positioning, assumptions and prior knowledge, and will also have an impact on the final findings. Sometimes these sorts of reflexive issues cannot be resolved, but they should always be acknowledged and reported (Rioer and Shapira, 2000; Briggs et al., 2003; Knoblauch, 2005; Fetterman, 2009; Simonds, Camic and Causey, 2012; Suryani, 2013). I hope I managed to tackle some of the issues related to my assumptions when beginning the observations, that I would encounter participants demonstrating many difficulties, when debriefing with my supervisors and on reflecting on this in my reflexivity journal, as well as in my field notes and analytic memos.

5.9.3 Emotional impact

Another concern is the emotional burden this sort of immersive data collection can place on researchers, and how this can impact how data is collected and interpreted. Lofland (1995) notes that researchers become connected to individuals and events in a personal sense in a number of ways: being physically close to them in their environment for an extended amount of time, being permitted close access to their personal experience via what they share, and then later in closely and systematically poring through data about them. The importance of acknowledging the sort of impact that this kind of research – especially when about sensitive topics – can have on researchers, as well as participants is key, as is factoring in time and opportunity for supervision and thorough debriefing (Briggs et al., 2003; White, Drew and Hay, 2009), which we were careful to do. Empathy is a huge part of building rapport, and also a significant emotional investment, which in turn can colour a researcher’s interpretations (Pink and Morgan, 2013), and I think this was especially the case during some of the tAD observations, in which I was often required to respond numerous times to repeated stories and was conscious of each response being authentic. There were indeed participants I felt I had particular emotional connections to for all sorts of reasons, ranging from their professional
backgrounds, their family dynamics, where they lived, and particular jokes we shared or pieces of advice they shared with me.

Key for me in managing this emotional burden was in ensuring enough time between the scheduling of the interviews and home visits to not only input and upload all the data but also to have time to process the visit emotionally. The process of being reflexive can also be unnerving for researchers if they are working in a context that orients more towards a positivist approach, and if emotional engagement is typically dismissed or discouraged (Camic, Rhodes and Yardley, 2003; Simonds, Camic and Causey, 2012) (indeed, even writing this section with such openness feels like quite uncharted territory for me!). The research process itself (even beyond the participant relationships) can be daunting and emotionally fraught, especially given that these methods are underspecified and that so much relies on the researcher’s subjective, experientially-informed interpretations (Roper and Shapira, 2000). Roper and Shapira (2000) stress the importance of documenting these feelings and emotions separately to the data, in order that the researcher can explicitly assess how any emotional states may have influenced their interpretations.

Something which I found particularly preoccupying in the early visits was concern about data quality, which on reflection I hope was more a crisis of confidence about the inherent subjectivity of the method, and the authority my voice might be granted as the lead researcher collecting and interpreting this rich and complex data set. This seemed to be a concern which – once I had articulated and discussed in supervisions – gradually dissipated, both within the course of each home visit and over the course of them all.

I also felt intensely aware of the generous contribution participants were making in offering to be a part of the observational phase of the study which felt potentially quite intrusive and high in participant-burden, and which was novel to me and also within the field. This novelty alongside the unstructured nature of the study made
me feel conscious that there were unavoidably a lot of ‘unknowns’ for participants who committed to taking part. Additionally, given that they were also coping with a neurodegenerative condition, I felt extremely indebted to them and grateful for their trust, openness and time. In the early stages of the pilot visits, I reflected on how positive and generally enjoyable a time I had had with participants, and this slightly concerned me. I realised on reflection and in conversation with my supervisors that I had been anticipating having a difficult or negative time, as I had foreseen spending time watching people repeatedly struggling with simple day-to-day tasks, but that was not what seemed to be happening. I worried that in my gratitude I was trying to compensate for participants’ contributions, by going overboard to try to make sure they had as ‘nice’ a day with me as possible, and if so, that I might be missing or avoiding opportunities to ask about any very real and important difficulties. I held this in mind as I conducted the next few observations and realised that what was actually happening was that participants were simply not spending lots of time doing things ‘wrong’ – they were capitalising on the things they could do. I wondered if my assumptions had been influenced by the dominance of a deficit-model framework in the empirical literature on PCA and in the context of dementia research more broadly. This concept of ‘capitalising on capabilities’ that I realised I was observing went on to make a significant contribution to the overall findings of this study, highlighting a reflexive research methodology as not just a task to be ticked off but integral to revealing important insights.

5.10 Limitations: samples and snapshots

Although there are many ways in which conducting the interviews and observations within the home environment was a strength, there is also the possibility that it may also have contributed to some sampling bias. The home-based nature of the study may have deterred dyads who were not managing so well from taking part, for fear of this being exposed, or perhaps because of the pragmatic challenges of
organising participation. This seems to be corroborated by the largely good levels of QoL participants reported overall. As a result, it is possible therefore that the findings may not capture a full or representative range of the stressors and coping responses that people affected by PCA experience, or all the ways the full range of activities which are important to people are challenged and supported. While there is not necessarily a solution to this, and while there is some response bias inevitable in all self-selecting research samples, it is important that this is acknowledged and factored into the interpretation and implications of the findings. For example, if what I have heard and observed pertains to the coping strategies and enduring engagement of PLWD who are uncharacteristically well-supported and fulfilled, these findings could still make a valid and useful contribution, for example to intervention design and the development of support provision, from which those who perhaps are not coping so well may be able to benefit. 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. In accordance with the Stress Process Model, all of these factors could shape how the stress process is experienced and as such, future work with more broadly representative and hard to reach groups will be needed. In meeting this aim, there may be some initial work to be done in order to develop understanding about why this disproportionate representation can happen, and whether this is also reflected in clinical as well as research contexts. Determining to what extent this sample is representative of general coping and activity engagement would require larger numbers, but would be a worthwhile avenue of exploration for future work.

Another possible sample bias perhaps accounts for some differences in the two groups in the observational phase of this work. The slightly higher average MMSE score of the tAD group indicates that this group were marginally less impaired overall. My sense during recruitment was that the more severely impaired the potential AD participants were, the more their family member was concerned they
may become suspicious or restless with an unfamiliar visitor in the home for such a long period. In contrast, those with PCA who were more severely impaired were not so likely to be considered potentially suspicious or confused about my role and attendance, and further contributing to this slight difference in disease severity, I may have been less likely to identify people with very early stage PCA to approach in the first place because of their documented difficulties and delays in getting an accurate diagnosis of their condition.

Having used methods which acknowledge the researcher as the data collection instrument, my background, assumptions, preconceived ideas, theoretical orientation and more will have no doubt influenced and shaped my observations and interpretation of the data throughout. While it is not possible to conduct interpretive, subjective research without any bias or prior knowledge, I hope I have addressed this limitation as far as is possible by keeping a detailed reflexivity journal throughout all stages of data collection (during, after and between home visits) and analysis, and by openly discussing my influences on data collection and my interpretations with my supervisors and colleagues throughout, and by reporting on them here.

Another limitation relates to the complexity of hearing reports of and observing such varied symptom profiles in real-world settings, with only a limited neuropsychological assessment to inform my interpretations. The lack of ability to control or manipulate the environment meant that it was not possible for me to conclude with certainty exactly which symptom was a manifestation of which underlying aspect of cognitive impairment, and as a result this has limited how much I have been able to conclude about exactly which features of the PCA and tAD profiles contribute to different difficulties day-to-day. However, I have attempted to deal with this necessary uncertainty appropriately in my cautious interpretations, and in fact my being exposed to these sometimes ambiguous symptom manifestations offered some valuable insights into the day-to-day experiences of people living with these conditions, as they try to understand and compensate for
unpredictable and inconsistent difficulties themselves. This served to further illustrate the importance of the development of tools and resources which will help professionals and families to better understand and navigate the complex sets of symptoms they are faced with.

A small sample size was used here because of the intensity of data collection. In exploring the rich complexities of individual cases, the extent to which these findings can be generalised to others in these diagnostic groups is limited. However, this is not necessarily a limitation of this PhD project, as this is in keeping with the epistemology of the research questions and methodology I have adopted – that there is not one version of truth or reality that will be endorsed by or applicable to everyone. The fact that there were some general themes constructed, which applied not only within but across diagnostic categories, demonstrates that some naturalistic generalisation was possible (within rather than beyond the sample) which is also within the remit of the methodological approaches used (e.g. White, Drew and Hay, 2009; Yilmaz, 2013; Baškarada, 2014). The 40 homes I visited overall represented a wide range in terms of factors like geographical location, size, layout, inhabitants and décor which I considered important in order to reflect some of the complexity and variation of people’s individual living situations. While finding patterns within this complexity may not allow us to start theorising about others living with these conditions, they may provide some promising possibilities for ideas to be further explored and tested for validity more robustly, in larger and more diverse samples in the future.

Finally, given the key importance of the changing temporal context in the findings of both phases of this PhD work, the findings from the interviews and observations are necessarily limited by their being conducted at a single time point. The findings may only provide a snapshot of participants’ experiences, however, it is worth noting that all participants referred to a range of temporal timeframes during their interviews and informal conversations, and so some sense of the progression but also of the past, and anticipations regarding the future, were captured.
5.11 Implications

Implications of these findings for theory have been discussed throughout this section, particularly regarding the stage-sensitivity in the applicability of theories of embodied selfhood, and the potential relevance of developmental and positive psychology-derived theories, as well as sociological theories of everyday life, to PLWD (Menne, Kinney and Morhardt, 2002; Chapman, 2005). Here I will outline some implications for future research and practice in this area, considering the current study findings.

5.11.1 Implications for research

Questions remain about the course of PCA progression beyond the mild-moderate stages as were observed here, and this would be a worthwhile focus of future work, especially relating to the suitability of residential care settings for people with PCA, where the environment may be naturally less adaptable, given what the current study findings have revealed about the significance of the physical environment for this population. While there is a significant body of existing literature about how the physical environment in residential care settings can support activity engagement for people with dementia (e.g. Marshall and Hutchinson, 2001; Marquardt, Bueter and Motzek, 2014; Chaudhury et al., 2017; Woodbridge et al., 2018), this is usually involving older participants with more typical, memory-led presentations. Future empirical work theoretically informed by a comprehensive model which acknowledges the many and varied ways the physical environment can contribute to the experience of living with dementia, such as the bio-psycho-social-physical model developed by Keady and colleagues (2013), could make a worthwhile contextually sensitive contribution to the field. While these findings have demonstrated the profound day-to-day impacts of predominant visual symptoms, further work is also needed to better understand how people with other forms of dementia experience and are impacted by the secondary visual and perceptual symptoms they may experience later on in their conditions (e.g. Passini et al., 2000;
Paxton et al., 2007). More ecologically valid work such as that called for by Czaja and Sharit (2003), and that recently published by Samra et al., (2019) is much needed, and specifically that which explores the potential of adaptation of the physical environment for people with PCA, given their profound impairments in interacting with it, as asserted by Weill-Chounlamountry, Alves and Pradat-Diehl (2016). Related to this, future research which considers more explicitly the impacts of the secondary symptoms people with PCA can experience, such as the concurrent memory and language difficulties seen in subgroups of the sample here, would also be helpful. Explicating and illustrating the complexity of the PCA syndrome and the varying impacts it can have, would be an encouraging example of a truly person-centred approach, which is widely acknowledged as the gold standard in dementia care and treatment (e.g. Dewing, 2008; Edvardsson, Fetherstonhaugh and Nay, 2010; Kaufmann and Engel, 2016).

An essential component in future studies of PCA would also be a longitudinal element where possible, given how strikingly the temporal context was shown to frame people’s overall experience of the stress process throughout the illness journey, but also their day-to-day coping with the condition. This would be an important and valuable contribution alongside research which has delineated how the pathology and symptom profile associated with the condition progresses over time (e.g. Firth et al., 2019). Further supporting this, two participants in the interview phase of this study also took part in the home-based observations, and although it was not within the scope of this work, I could not help but reflect on some of the ways their coping strategies and their dyadic dynamic had changed since I had last seen them, and am sure that this would be a very interesting, revealing, and relevant approach to take in future work.

Implications for future research also include the continued need for further work exploring the lived experiences of PCA as well as other rarer forms of dementia, in ways that are sensitive to stage of disease, but without dichotomising so distinctly between (e.g.) the early and advanced stages and home and residential care.
settings (e.g. Marshall and Hutchinson, 2001; Phinney, 2006). Further qualitative work and observational work in particular, may help to contribute towards the continued repositioning of PLWD, via the acknowledgement of the value of their voices in research and in increasing accessibility in the ways this can be enabled. Observational work in naturalistic settings, case study approaches, and qualitative work more broadly, to capture the complexities of these conditions in the everyday contexts in which they are lived, may be especially important to expose the unique strengths and capabilities of those with PCA (and other atypical presentations of dementia), which can facilitate their coping (e.g. Marshall and Hutchinson, 2001; Hellström, Nolan and Lundh, 2007). This is supported by the recent work of McParland, Kelly and Innes (2017), which questions the utility of another common dichotomy in discourses around dementia – that of living well with dementia versus the tragedy of it, and McParland et al. (2017) assert the need for a more fluid and nuanced approach to the study of dementia, in order to more accurately capture the sometimes paradoxical complexity that is experienced by those affected.

5.11.2 Implications for practice

These findings highlight a pressing need for health and social care professionals to have improved awareness of PCA, disease-specific knowledge, and the ability to provide tailored information and care to the families affected by it. Information, support, and interventions which acknowledge the particular challenges of dementia-related visual impairment and the relative strengths that people with PCA can demonstrate, particularly in the early stages, may assist practitioners and families to support ongoing adjustment and engagement for people with PCA. Considering how this training may be best developed or delivered, McIntyre et al.’s (2018) study of 61 health and social care professionals from a range of disciplines (including social workers, occupational therapists, care home staff, rehabilitation officers for visual impairment and Admiral nurses) captured how reflective discussion and critical analysis of video clips fostered opportunities for practitioners to expand their understanding of visual impairment related difficulties - both in the
clips as well as in their own existing caseloads. This study also highlighted the specific need for this quality of information and training within a diagnostic context, to reduce the stress of convoluted referral and assessment processes for people with atypical presentations of dementia such as PCA. Considering that people who eventually get a diagnosis of PCA or any form of dementia first experience symptoms in their own home or work contexts, and first express these concerns to their GP in their own words on the basis of that experience, more research conducted in these settings, and which captures participants own descriptions of their symptoms, could make a particularly beneficial contribution to those professionals who may come across PLWD in diagnostic settings. The dominant difficulties that people with PCA 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 more broadly, while their relatively well-preserved insight, memory and language functions may indicate that psychosocial interventions could compensate in instances where this is not possible. In contrast to the findings of Häusler et al. (2016), which suggest that dyadic coping only mediates stress and QoL for carers, and not PLWD, the current study findings suggest that for people with PCA, psychosocial interventions targeted at the marital or family unit as a whole may hold particular promise, owing to these relative cognitive strengths, and the broader relational context of the illness experience.

The findings reported on here also have implications for how decisions are made regarding how activities are targeted by interventions for PLWD more generally, particularly for community-based practitioners supporting people in their own homes, and specifically in terms of which activities are prioritised, which outcomes are prioritised, and for who. This study has also illustrated the importance of acknowledging both the relational (e.g. Merrick, Camic and O’Shaughnessy, 2016; Wadham et al., 2016) and environmental elements of activity engagement, and hopefully provides useful examples of the sorts of modified ways PLWD can be encouraged or facilitated to continue to engage with activities of meaning and
importance, and the objects and spaces associated with them. The importance of doing this is captured in Raber, Teitelman, Watts and Kielhofner’s (2010) study of volition, with eight people in the moderate stages of dementia in an assisted living unit, in which they concluded that carers sometimes had difficulty in navigating the different dimensions of activity, for example when residents expressed a keenness to talk about an activity but a hesitancy in participating in it. Providing psychosocial interventions to support engagement with activities that promote one’s sense of self and identity and also those which offer the possibility of generativity (e.g. Doyle, Rubinstein and Medeiros, 2015) may be especially helpful, and one way both these needs could potentially be met is in offering opportunities for a legacy component within interventions, something which Johnston and Narayanasamy (2016) suggested is an important but often-missed opportunity in the current delivery of psychosocial interventions.

Reorienting the focus of the delivery of care towards an appreciation of what PLWD are still able and motivated to do could have significant implications, given that a lack of functional independence is associated with a range of negative outcomes (e.g. Woods, 1999; Mokhtari et al., 2012; Black et al., 2013). Acknowledging people’s retained capabilities is just one aspect of looking beyond the label of dementia, something which the current study findings suggest is both important and compatible with the approach PLWD and their families take in their everyday lives. In the current study, although there were broad symptomatic distinctions across the two diagnostic groups, there were also three major overarching themes which applied across both groups, and a lot of variation within groups. This highlights the many other determining factors in people’s situations that need to be acknowledged, for example, age, stage and living situation, in order to really respond to the impacts of these varied sets of symptoms on people’s everyday lives, in a holistic way.

The insights that the triangulation of the mixed methods data provided in this
study, for example the distinction between ADL function, ADL engagement and QoL in relation to ADL subtypes, arguably makes the case for further exploration of the different dimensions of activity engagement and other key constructs such as stress and coping in future studies. This could contribute towards capturing more of the complexity of lived experience in ways that can inform how practitioners and services can best align and tailor any support provided with the needs and preferences of the families affected. As well as providing useful insights for shaping analytic outcomes, the observed discrepancies between cognitive, functional and experiential outcomes illustrated here also raise questions for research and practice. Considering the significant role cognitive measures can play in the diagnostic process and in tracking disease progression, which in turn can determine (e.g.) access to services and support, trial participation, and pharmacological interventions, these discrepancies present a conundrum in terms of how they are interpreted and reconciled (including whether they need to be). This further demonstrates the need for future work which explores how mixed methods data can be integrated, what different data sources can reveal in one other, and ultimately how the outputs of this can be applied.

5.12 Conclusions

This PhD study has provided new insights into the stress process for individuals and families affected by a rare form of dementia with a distinct symptom profile (PCA), from the convoluted and prolonged search for an accurate diagnosis, through to the daily challenges of perceiving and interacting with the physical environment and the objects within it. The findings point to a pressing need for the increased availability and accessibility of relevant and specific information about PCA, its early symptoms, and how it progresses, for both healthcare professionals and affected families, to aid timely diagnosis and minimise the ongoing stress and uncertainty that families face. This study has also highlighted how these dominant difficulties with visual and spatial processing differentially affect the way everyday activities are impacted, and
how this is responded to, for and by people with PCA, compared to those with tAD, expanding understanding of the lived experience of atypical presentations of dementia which have been to date, mostly investigated from a deficit-based, biomedical perspective.

This study has highlighted how these outlined disease-related differences in symptoms and strategies make themselves known and are experienced and responded to in everyday life, is contingent on and situated within people’s preferences, personhood, contexts and histories. In that sense the study has explicated some of the complexity and idiosyncrasy in how activity engagement is both affected and enduring for people living with different kinds of dementia. The relational context within which this happens has been shown to be of critical significance in determining how and why activity engagement continues (or does not), with the influences of PLWD’s and family carers’ varied perceptions, priorities and preferences all to be negotiated, and in an ever-changing temporal context.

Methodologically, in studying PLWD in their own homes and using multiple data sources over an extended period of immersive observation permitted a lens of authenticity and ecological validity not yet directed towards the subjective experiences of people living with a diagnosis of PCA or tAD in the community. These extended and unstructured periods of data collection allowed observation of the resourcefulness and responsiveness families demonstrated in their day-to-day processes of coping and adjustment, and in doing so, also allowed witnessing of the ordinariness and minutiae of everyday life – that which began long before and continues on within and around the daily negotiations of a diagnosis of a dementia.

Theoretically, these enriched understandings of diagnosis-specific differences alongside the unifying complexities of different contexts, motivations and meanings, offered possibilities for the extended application of a number of existing theoretical approaches which are more commonly applied in healthy adults, through to those in the more advanced stages of dementia. Specifically, those
which acknowledge enduringly important aspects of life such as home, self and social connectedness, which were shown to be significant throughout the stages of dementia observed here, and which had been prior to diagnosis too, and which disregarded diagnosis-related dichotomies. Specifically, this work has illustrated unifying characteristics of engagement in activity, including the capacities it offers for reciprocity and constitution of self, and important insights into why these differential challenges are ever overcome, which points ultimately to the commonalities in experiences all of us who share a common humanity and motivation to engage with our environments can relate to and identify with.

These findings may be helpful to PLWD, their families, healthcare professionals and practitioners in supporting ongoing activity engagement in meaningful everyday activities and in turn, foster continuity in PLWD’s senses of identity and of making an active and agentic contribution to and impact on the world around them.
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Berkshire UK: NFER-Nelson.


Appendices

APPENDIX 1: Participant information sheets, consent forms, pre/post visit assessment forms

1.a Phase I Interviews – PLWD
PARTICIPANT INFORMATION SHEET

Neuropsychological Investigation of visuo perceptual, visuospatial and literacy skills in posterior cortical atrophy

You are being invited to take part in a research study. This study is funded by Alzheimer’s Research UK/Economic and Social Research Council/National Institute for Health Research and is based at University College London (UCL) with involvement from UCL and Brunel University researchers. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?
   To examine the range, type and impact of visual problems experienced by individuals with Posterior Cortical Atrophy. The purpose of the study is find out how much of a link there is between difficulties with everyday activities such as reading, writing and finding a way around a room and being able to see things clearly and judge distances. Observing a link between these different abilities will then allow us to better understand how our reading, writing, navigation and other skills are affected by dementia and under what conditions any problems can be minimised (e.g. what size and type of written words are most easy to read; what lighting is optimal to navigate a room).

2. Why have I been chosen?
   We are seeking the help of up to 150 people with a diagnosis of Posterior Cortical Atrophy, 150 people with probable Alzheimer’s disease who have prominent memory problems, and 200 people who do not have a neurological disease. We are approaching people attending the Specialist Cognitive Disorders clinics at the National Hospital, people being cared for within Brighton and Sussex University Hospitals NHS Trust, people who have taken part in research before, and carers of those with a diagnosis of Posterior Cortical Atrophy or Alzheimer’s disease.

3. Do I have to take part?
   It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your current or future medical care.
4. What will be involved if I decide to take part?
Taking part will require a series of testing sessions lasting up to two hours. The number and timing of the sessions would be arranged by agreement between you and the researcher. A maximum of 10 sessions might be involved though in many cases fewer sessions would be needed. You may want to consider attending multiple testing sessions on the same or different days depending on what is most convenient for you. You will also be asked to have yearly follow-up assessments. In addition, if you are not already having regular brain scans as part of another project here at the Dementia Research Centre, you will also be asked to have a scan once at the beginning of the study and then again at your yearly follow-up assessment. You will also be asked to have a neurological examination by a trained physician and to answer questions about any symptoms you/someone you know may experience.

The research will take place either at the National Hospital for Neurology and Neurosurgery, or at the UCL Pedestrian Accessibility Movement Environment Laboratory (PAMELA). Some visits may take place at your home if this is more convenient for you. The study involves answering spoken and written questions, completing paper-and-pencil and computerized tests and navigating a simulated environment. If you are happy to take part in visits taking place in the home, you may be asked to keep a sensor device which monitors your physical activity. We will record only your answers to the test questions, your eye movements, your balance/navigation ability, your physical activity and some basic personal information (name, age, gender, years of education, main profession). We will record the audio responses to some questions on a digital voice recorder so we can make anonymised transcripts to assist researchers to analyse data after the research visit. A subset of people will also be asked to undergo video telemetry while carrying out an everyday task; the purpose of this recording is simply to enable the researcher to make detailed notes after the visit about how people with dementia and carers carry out such daily activities. The recording will only be seen by the research team and will not be used for any purposes other than analysis as part of research. We will give you the opportunity in the Consent Form to opt out of this should you not wish to provide video data. We would also like to consult your medical notes for other information which may be relevant to the study. Where participating in the project will involve visits to the hospital which you would not otherwise be making, reasonable travel expenses will be reimbursed.

On one occasion we will ask 3 individuals with a diagnosis of posterior cortical atrophy to take part in an additional testing session lasting approximately 2 hours, to be assessed by an optometrist, ophthalmologist and neurologist. Each assessment will last approximately 20 minutes and be followed by a 10 minute debrief to gather feedback. The purpose is to better understand the best methods to test visual impairment in posterior cortical atrophy. The testing sessions and debrief interviews will be video recorded for use at a subsequent consensus meeting of experts to set priorities and debate the value of different assessments, and form part of training packages designed for specific professional audiences (such as members of the College of Optometrists).

5. What do I have to do?
You will be asked to view and make judgements about a variety of shapes, colours, objects and words. You will also be asked to complete a short set of standard tests of general abilities such as memory and language. You will be asked to move around in a simulated environment (PAMELA) and to undergo tests of your balance (UCL Sensorimotor laboratory). You will also be asked to provide a verbal description of any unusual visual experiences you/someone you know may have had, such as washes of colour or double vision, these descriptions may be recorded and listened to be researchers. You may also be asked to carry out an everyday task with someone you know and this process may be video recorded and analysed by researchers. You may be asked to keep a device which records your physical activity. You may also be asked to have a brain scan and neurological examination once per year.

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6. What is the procedure that is being tested?
We are trying to establish how important different visual problems affect one another, how they develop, their impact on everyday activities, and how damage to the brain can result in unusual visual experiences.

7. What are the possible disadvantages and risks of taking part?
There are no risks involved in the psychology tests. No experimental treatment will be given. You will be assessed to see whether you can have a brain scan safely. Anybody who is not suitable for a brain scan (e.g., those with pacemakers) will not be asked to take part in that section of the study. The brain scans we perform are designed for research rather than clinical examination. However, if an unexpected finding is seen on your scan, your GP will be informed and the finding will be discussed with you.

8. What are the possible benefits of taking part?
The benefits, we hope, will be in the future in helping to understand the brain and to develop aids and strategies which help one to better cope with problems reading or navigating a room. However, it will not help directly with any problems you may have.

9. What if something goes wrong?
If you are unhappy with your treatment at any point during the research study, you are entitled to complain through the University College London Hospitals Trust complaints procedure.

10. Will my taking part in this study be kept confidential?
All information which is collected about you during the course of the research will be managed in accordance with the Data Protection Act. Your GP will be informed of your participation in the study. Audio and video recordings made during the assessment and information on physical activity will be kept on a secure computer system at UCL or Brunel University and only accessed by research staff involved specifically on this project. Video recordings will be uploaded immediately on an encrypted laptop and stored securely on this system. Any information about you which leaves the research unit will have your name and address removed so that you cannot be recognised from it. Information about you and your involvement in the study will be handled by the lead researchers (Dr Sebastian Churc at University College London, Professor Nick Tyler of University College London and Professor Mary Gilhooly of Brunel University) and their team members. This information, including audio/video recordings and transcripts, will be held for at least 10 years so that further ethically approved research may be conducted in the future.

11. What will happen to the results of the research study?
The results will be presented to the scientific and medical community to improve further research. You will be very welcome to request a copy of any resulting publications, and if you would like you may receive a copy of the Dementia Research Centre newsletter which describes this and other work taking part in this department.

12. Who is organising and funding the research?
This study is being organised and funded by the Alzheimer’s Research UK, Economic and Social Research Council and National Institute for Health Research.

13. Who has reviewed the study?
This study has been reviewed by the London-Queen Square Research Ethics Committee.

14. Contact for Further Information
You may contact [Redacted]

Thank you for considering taking part in this study. You will be given a copy of the information sheet and a signed consent form to keep.
CONSENT FORM

Title of project: Neuropsychological investigation of visuoperceptual, visuospatial and literacy skills in posterior cortical atrophy.

Name of Principal investigator: Professor Sebastian Crutch

1. I confirm that I have read and understood the information sheet dated 25-January-2016 (Version 9) for the above study and have had the opportunity to ask questions.

2. I confirm that I have had sufficient time to consider whether or not want to be included in the study.

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

4. I understand that sections of any of my medical notes may be looked at by responsible individuals from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.

5. I understand an audio recording will be made in order to measure the speed of my responses and/or be reviewed by research staff investigating how to live with dementia-related visual impairment. I understand that my name and any other identifiable details will be removed from the recording.

6. I consent to undergoing video telemetry in order to provide video data only to be viewed by the research team. If you do not wish to undergo video telemetry please circle ‘No’. This will mean that you will not take part in tasks requiring the observation of everyday activities, but you will be able to take part in other experimental tasks.

7. I agree to take part in the above study.

Name of patient __________________________ Date ____________ Signature __________________________
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<th>Name of Person taking consent</th>
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<tr>
<td>Prof Sebastian Crutch</td>
<td>[Redacted]</td>
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**Researcher (to be contacted if there are any problems)**

**Comments or concerns during the study**

If you have any comments or concerns you may discuss these with the investigator. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, UCL hospitals. Please quote the UCLH project number at the top this consent form.
1.b Phase I Interviews – Carers

**CARER INFORMATION SHEET**

**Neuropsychological investigation of visuoperceptual, visuospatial and literacy skills in posterior cortical atrophy**

You are being invited to take part in a research study. This study is funded by Alzheimer’s Research UK, Economic and Social Research Council/National Institute for Health Research and is based at University College London (UCL) with involvement from UCL and Brunel University researchers. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

1. **What is the purpose of the study?**
   To examine the range, type and impact of visual problems experienced by individuals with Posterior Cortical Atrophy. The purpose of the study is to find out how much of a link there is between difficulties with everyday activities such as reading, writing and finding a way around a room and being able to see things clearly and judge distances. Observing a link between these different abilities will then allow us to better understand how our reading, writing, navigation and other skills are affected by dementia and under what conditions any problems can be minimised (e.g. what size and type of written words are most easy to read; what lighting is optimal to navigate a room).

2. **Why have I been chosen?**
   We are seeking the help of up to 100 people who care for or have experience of assisting people with a diagnosis of Posterior Cortical Atrophy or probable Alzheimer’s disease. We are approaching the carers of people attending the Specialist Cognitive Disorders clinics at the National Hospital, people being cared for within Brighton and Sussex University Hospitals NHS Trust, people working within a professional care setting, and people who have taken part in research before. Other parts of the study may involve patients with Posterior Cortical Atrophy or Alzheimer’s disease whom you care for or who are known to you.

3. **Do I have to take part?**
   It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your current or future medical care.
4. **What will I be involved if I decide to take part?**

Taking part will involve completion of a series of questionnaires, rating scales, and interviews (with or without the person you care for, as appropriate). You may also be asked to participate in small group discussions about your experience of caring for someone with dementia. These assessments will require a series of sessions each lasting no longer than 2 hours. The number and timing of the sessions would be arranged by agreement between you and the researcher. A maximum of 3 sessions might be involved though in many cases fewer sessions would be needed. You may want to consider attending multiple testing sessions on the same or different days depending on what is most convenient for you. You will also be asked to participate in yearly follow-up assessments either in person or by post/phone.

The research will take place either at the National Hospital for Neurology and Neurosurgery. Some visits may take place at your home or in a professional care setting if this is more convenient for you. We will record only your answers to the test questions, and some basic personal information (e.g. name, age, gender). We will record the audio responses to some questions on a digital voice recorder so we can make anonymised transcripts to assist researchers to analyse data after the research visit. A subset of people will also be asked to undergo video telemetry while carrying out an everyday task: the purpose of this recording is simply to enable the researcher to make detailed notes after the visit about how people with dementia and carers carry out such daily activities. The recording will only be seen by the research team and will not be used for any purposes other than analysis as part of research. We will give you the opportunity in the Consent Form to opt out of this should you not wish to provide video data. Where participating in the project will involve visits to the hospital which you would not otherwise be making, reasonable travel expenses will be reimbursed.

5. **What is the procedure that is being tested?**

We are trying to establish how visual problems and related symptoms impact upon the everyday abilities and quality of life of people with dementia and their carers.

6. **What are the possible disadvantages and risks of taking part?**

There are no risks involved in the assessments and interviews. No experimental treatment will be given.

7. **What are the possible benefits of taking part?**

The benefits, we hope, will be in the future in helping to understand the brain and to develop aids and strategies which help one to better cope with problems reading or navigating a room. However, it will not help directly with any problems someone you care for may have.

8. **What if something goes wrong?**

If you are unhappy with your treatment at any point during the research study, you are entitled to complain through the University College London Hospitals Trust complaints procedure.

9. **Will my taking part in this study be kept confidential?**

All information which is collected during the course of the research will be managed in accordance with the Data Protection Act. Your GP will be informed of your participation. Audio and video recordings made during the assessment will be kept on a secure computer system at UCL or Brunel University, and only accessed by research staff involved specifically on this project. Video recordings will be uploaded immediately onto an encrypted laptop and stored securely on this system. Any information about you which leaves the research unit will have your name and address removed so that you cannot be recognised from it. Information about you and your involvement in the study will be handled by the lead researchers (Dr Sebastian Crutch at University College London, Professor Nick Tyler of University College London and Professor Mary Gilbody of Brunel University) and their team members. This information, including audio/video recordings and transcripts, will be held for at least 10 years so that further ethically approved research may be conducted in the future.
10. **What will happen to the results of the research study?**
The results will be presented to the scientific and medical community to improve further research. You will be very welcome to request a copy of any resulting publications, and if you would like you may receive a copy of the Dementia Research Centre newsletter which describes this and other work taking part in this department.

11. **Who is organising and funding the research?**
This study is being organised and funded by the Alzheimer’s Research UK, Economic and Social Research Council and National Institute for Health Research.

12. **Who has reviewed the study?**
This study has been reviewed by the London-Queen Square Research Ethics Committee.

13. **Contact for Further Information**
You may contact [Redacted]

Thank you for considering taking part in this study. You will be given a copy of the information sheet and a signed consent form to keep.
CARER CONSENT FORM

Title of project: Neuropsychological investigation of visuo- perceptual, visuospatial and literacy skills in posterior cortical atrophy

Name of Principal investigator: Professor Sebastian Crutch

1. I confirm that I have read and understood the information sheet dated 14 August 2015 (Version 2) for the above study and have had the opportunity to ask questions. [ ]

2. I confirm that I have had sufficient time to consider whether or not want to be included in the study. [ ]

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. [ ]

4. I understand that an audio recording will be made and reviewed by research staff, investigating how to live with dementia-related visual impairment. I understand that my name and any other identifiable details will be removed from the recording. [ ]

5. I consent to undergoing video telemetry in order to provide video data only to be viewed by the research team. If you do not wish to undergo video telemetry, please circle 'No'. This will mean that you will not take part in tasks requiring the observation of everyday activities, but you will be able to take part in other experimental tasks. Yes/No

6. I agree to take part in the above study. [ ]

Name of carer  Date  Signature

Name of Person taking consent  Date  Signature

[Redacted]

PCA Study Carer Consent Form  Version 2 (14 August 2015)
Comments or concerns during the study

If you have any comments or concerns you may discuss these with the investigator. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, UCL hospitals. Please quote the UCLH project number at the top this consent form.
1.c Phase II Home-based observations – PLWD
PARTICIPANT INFORMATION SHEET

Principal Study: “Neuropsychological investigation of visuospatial, visuospatial and literacy skills in posterior cortical atrophy”

You are being invited to take part in a research study. This study is funded by Alzheimer’s Research UK/ Economic and Social Research Council/ National Institute for Health Research/ Alzheimer’s Society and is based at University College London (UCL) with involvement from UCL and Brunel University researchers. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?
To examine the range, type and impact of visual problems experienced by individuals with Posterior Cortical Atrophy. The purpose of the study is to find out how much of a link there is between difficulties with everyday activities such as reading, writing and finding a way around a room and being able to see things clearly and judge distances. Observing a link between these different abilities will then allow us to better understand how our reading, writing, navigation and other skills are affected by dementia and under what conditions any problems can be minimised (e.g. what size and type of written words are most easy to read, what lighting is optimal to navigate a room).

2. Why have I been asked to participate in this study?
We are seeking the help of up to 200 people with a diagnosis of Posterior Cortical Atrophy, 200 people with typical sporadic Alzheimer’s disease who have prominent memory problems, and 200 people who do not have a neurological disease. We are approaching people attending the Specialist Cognitive Disorders clinics at the National Hospital, people being cared for within Brighton and Sussex University Hospitals NHS Trust, people who have taken part in research before, and carers of those with a diagnosis of Posterior Cortical Atrophy or Alzheimer’s disease.

3. Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you
are still free to withdraw at any time and without giving a reason. A decision to withdraw at any
time, or a decision not to take part, will not affect your current or future medical care.

4. What will be involved if I decide to take part?
Taking part will require a series of testing sessions lasting up to two hours. The number and timing of
the sessions would be arranged by agreement between you and the researcher. A maximum of 10
sessions might be involved though in many cases fewer sessions would be needed. You may want to
consider attending multiple testing sessions on the same or different days depending on what is
most convenient for you. You will also be asked to have yearly follow-up assessments. In addition, if
you are not already having regular brain scans as part of another project here at the Dementia
Research Centre, you will also be asked to have a scan once at the beginning of the study and then
again at your yearly follow-up assessment. You will also be asked to have a neurological examination
by a trained physician and to answer questions about any symptoms you/ someone you know may
experience.

The research will take place at the National Hospital for Neurology and Neurosurgery. Some visits
may take place at your home if this is more convenient for you. The study involves answering spoken
and written questions, completing paper-and-pencil and computerized tasks. We will record only
your answers to the test questions, your eye movements, your brain scan and some basic personal
information (name, age, gender, years of education, main profession). We will record the audio
responses to some questions on a digital voice recorder so we can make anonymised transcripts to
assist researchers to analyse data after the research visit. We would also like to consult your medical
notes for other information which may be relevant to the study. Where participating in the project
will involve visits to the hospital which you would not otherwise be making, reasonable travel
expenses will be reimbursed.

Should you be unable to travel to London for the annual visit but remain willing to be involved in the
study, we would conduct clinical interviews by telephone at a time convenient to you.

5. What do I have to do?
You will be asked to complete a short set of standard psychology tests of general abilities such as
memory and language, and visual tasks including viewing and making judgements about a variety of
shapes, colours, objects and words. You will also be asked to provide a verbal description of.
and complete questionnaires about, any unusual visual experiences you/ someone you know may have
had, such as washes of colour or double vision; these descriptions may be recorded and listened to
by researchers. You may also be asked to have a brain scan and neurological examination once per
year. In addition to the annual psychology tests, questionnaires and brain scan, you may also be
asked to participate in one or more sub-studies involving further examination of reading, navigation,
the impact of visual problems on everyday life, vision testing, everyday tasks, or balance. As with the
principal study, participation in each of these sub-studies is entirely voluntary; if you do decide to
take part in these additional studies, information about your psychology tests, questionnaires and
brain scans gathered in this study will be re-used so that you don’t have to complete these assessments again.

6. What is the procedure that is being tested?
We are trying to establish how important different visual problems affect one another, how they develop, their impact on everyday activities, and how damage to the brain can result in unusual visual experiences.

7. What are the possible disadvantages and risks of taking part?
There are no risks involved in the psychology tests. No experimental treatment will be given. You will be assessed to see whether you can have a brain scan safely. Anybody who is not suitable for a brain scan (e.g. those with pacemakers) will not be asked to take part in that section of the study. You may feel claustrophobic or uncomfortable lying in the scanner. You will hear loud knocking noises but we will provide you with earplugs to wear during the MRI. You can ask to stop the MRI at any time if it becomes too uncomfortable. The brain scans we perform are designed for research rather than clinical examination. However, if an unexpected finding is seen on your scan, your GP will be informed and the finding will be discussed with you.

8. What are the possible benefits of taking part?
The benefits will be helping to understand the brain and to develop aids and strategies which help one to better cope with problems reading or navigating a room. However, it will not help directly with any problems you may have.

9. What if there is a problem?
If you, your relatives or your informant have any concerns about the research study you can speak to a member of the research team who will do their best to answer any questions. Contact details are at the end of this information sheet.

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this. You, your relatives or your informant can also contact the UCLH Patient Advice and Liaison Service at the following address; PALS, Box 25, National Hospital for Neurology and Neurosurgery, Queen Square, London WC1N 3BG or you can email PALS@uclh.nhs.uk.

In the unlikely event that you are harmed by taking part in this study, compensation may be available. If you suspect that the harm is the result of the Sponsor’s (University College London) or the hospital’s negligence, then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to Professor Sebastian Crutch who is the Principal Investigator for the research and is based at The Dementia Research Centre, Box 10, The National Hospital for Neurology and Neurosurgery, London WC1N 3BG. The Chief Investigator will then pass
the claim to the Sponsor’s Insurers, via the Sponsor’s office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

10. Will my taking part in this study be kept confidential?
All information which is collected about you during the course of the research will be managed in accordance with the Data Protection Act. Your GP will be informed of your participation in the study. Any recordings made during the assessment and information on physical activity will be kept on a secure computer system at UCL or Brunel University and only accessed by research staff involved specifically on this project. Any information about which leaves the research unit will have your name and address removed so that you cannot be recognised from it. Information about you and your involvement in the study will be handled by the lead researchers (Professor Sebastian Crutch at University College London, Professor Nick Tyler of University College London and Professor Mary Gilhooley of Brunel University) and their team members. This information, including audio recordings and transcripts, will be held for at least 10 years so that further ethically approved research may be conducted in the future.

11. What will happen to the results of the research study?
The results will be presented to the scientific and medical community to improve further research. You will be very welcome to request a copy of any resulting publications, however, it will not be possible for you to know individual test results. If you would like you may receive a copy of the Dementia Research Centre newsletter which describes this and other work taking part in this department.

12. Involvement of your General Practitioner (GP)
With your consent, we will notify your GP by letter that you are taking part in this study, and will contact your GP for a health update in the event we lose touch with you during the course of the study. Whilst you will not receive individual results of the different assessments, if your test results are unusual the Chief Investigator of this study (Sebastian Crutch) will discuss with you the implications of your results, and any need to inform your GP. Your GP will only be notified with your consent.

13. Identifying a consultee
If you are participating in this study as a person living with dementia, we will ask you to choose someone (either a close relative/friend or carer if applicable) to act as a personal consultee. The person you nominate would act in your best interests and decide whether or not you should continue in the study if you were finding it difficult to make a decision about taking part in this study in the future. They would only be asked to take on this role if we are unsure in the future as to whether you are able to continue to understand what taking part in the project would involve.

If we need to appoint your consultee to act on your behalf (a ‘nominated consultee’) to decide whether or not you were able to continue taking part in the study, two things might happen:
1. If your nominated consultee agrees for you to continue taking part in the study, you would be able to continue being a participant in this study. We would keep consulting your consultee and checking that they continue to agree for you to take part in ongoing sessions.

2. If your nominated consultee does not agree that you should take part, or continue to take part in the study, then you would be withdrawn from the study. Any data collected as part of the project up to that point with your consent would be retained by us. We would not collect further data or undertake any other research procedures with you going forward.

14. Who is organising and funding the research?
This study is being organised and funded by the Alzheimer’s Research UK, Economic and Social Research Council and National Institute for Health Research.

15. Who has reviewed the study?
This study has been reviewed by the London Queen Square Research Ethics Committee.

16. Contact for further information
You may contact [Redacted]

Thank you for considering taking part in this study. You will be given a copy of the information sheet and a signed consent form to keep.
**CONSENT FORM**

**Principal Study:** “Neuropsychological investigation of visuoperceptual, visuospatial and literacy skills in posterior cortical atrophy”

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<td>1.</td>
<td>I confirm that I have read and understood the information sheet dated 21 December 2016 (Version 10.0) for the above study and have had the opportunity to ask questions.</td>
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<td>2.</td>
<td>I confirm that I have had sufficient time to consider whether or not I want to be included in the study.</td>
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<td>3.</td>
<td>I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.</td>
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<td>4.</td>
<td>I understand that sections of any of my medical notes may be looked at by responsible individuals from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.</td>
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<tr>
<td>5.</td>
<td>I understand that an audio recording will be made in order to measure the speed of my responses and/or be reviewed by the research staff investigating how to live with dementia-related visual impairment. I understand that my name and any other identifiable details will be removed from the recording.</td>
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<td>6.</td>
<td>I agree to my General Practitioner (GP) being informed of my participation in the study and consent for the study team to contact my GP for an update on my health in the event of them being unable to contact me, or if any unusual medical results are found as a result of this study.</td>
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<td>7.</td>
<td>I give permission to be contacted by a member of the research team to conduct annual clinical interviews by telephone should I be unable to travel to London for...</td>
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the annual visit. I understand that I would not be contacted should I have expressed my desire to withdraw from the study.

8. I nominate the person named below as my personal consultee and understand that they will share information about my medical details with the research team.
   Name of Personal Consultee: ____________________________

9. I agree to take part in the above study.

This consent has been obtained using verbal modality (audio-recorded):

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<tr>
<th>Name of Participant</th>
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<tr>
<th>Name of Researcher</th>
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Name of Chief Investigator:
Professor Sebastian Crutch
Email: [Redacted]
Tel:

Name of Researcher to be contacted if there are any problems
(if different to the Chief Investigator):

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PARTICIPANT INFORMATION SHEET

“Neuropsychological investigation of visuoperceptual, visuospatial and literacy skills in posterior cortical atrophy”

PCA Sub-study 5: Home-based observations of everyday activities

You are being invited to take part in a research study. This is a subsidiary study to the “Neuropsychological investigation of visuoperceptual, visuospatial and literacy skills in posterior cortical atrophy” study in which you have already participated. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

1. Why have I been asked to participate in this study?
You are being asked to consider taking part in this subsidiary study about carrying out everyday tasks because you took part in the principal posterior cortical atrophy study.

2. Do I have to take part?
It is up to you to decide whether or not to take part. You are under no obligation, and deciding not to take part or withdrawing will not affect your participation in the main study or your current or future medical care.

3. What is the purpose of this subsidiary study?
This sub-study aims to complement our lab-based assessments (psychology tests, questionnaires and brain scan) with more real-world (so-called ‘ecologically valid’) tests of everyday abilities and to understand any factors (e.g. reasonable changes in lighting levels, decors, signs, etc.) which predict the ease, comfort and accuracy with which you carry out these activities.

4. What will be involved if I decide to take part?
(i) Sensor data collection: We would like to measure aspects of your physical activity at home through a combination of wearable and non-wearable sensors. Wearable sensors (for example, the Fitbit® or EmpaticaE4) calculate users’ motion temperature, heart rate and electrodermal activity. We would like you to wear these devices as you go about your daily activities. If they become uncomfortable or
if you feel they seem intrusive or unnecessary (e.g. when bathing) please feel free to remove them. Non-wearable sensors (for example, MobileRF) estimate users’ location using radio signal. We would provide you with all sensors and would ask you to keep sensors for up to eight weeks. We may collect information on physical characteristics of the home environment, for example, measuring the dimensions of a room or the levels of lighting. The data collected will not retain any identifiable information and will only be interpretable once transferred to the UCL network for subsequent analysis.

(ii) Video data collection: We would like to use video recording to observe you interacting physically with your home environment, including any outdoor spaces belonging to your home if applicable (e.g. garden). Specifically we would like to observe you completing everyday tasks. Examples of such everyday tasks may include using cutlery to eat a meal, navigating through your home, using the stairs, house cleaning, using the TV remote. This data will be collected through a hand-held camcorder and/or a wearable clip-on camera. We will not collect video data of activities which you feel are intrusive (e.g. dressing/undressing, toileting). Before any video data is collected, we will ask you to indicate the areas of your home where you would like us to avoid capturing video footage. We will stop recording at any point should you feel uncomfortable.

We will visit you for up to three sessions over the course of one month, during which we will capture your activities across the morning, afternoon and evening. The timings of these slots will be agreed upon to suit you. Our aim will be to capture a total of approximately 16 hours of observational data during our visits. When scheduling the home visits with you, the researcher will ask you to make any planned visits aware that filming and data recording will be taking place within your home on the particular day(s); visitors should attend your home on the understanding that there is a possibility that they will be included in the recordings. If any children are present at the time of the observation, the researcher will not direct any video or audio recording towards them. However, it is possible that video footage of children present in the home may be captured via wearable body cameras. The researcher will use their discretion to ensure that any sensitive, intrusive and/or inappropriate video footage is deleted. Observational notes may be taken on interactions you have with anyone else present in the home during the research visit; all information that might reveal their identity will be excluded from these notes.

You will be able to request the deletion of some or all data at any point during the visit, or up to one week after the visit. Our researcher will contact you after one week as a final check that you are happy for the remaining data to be used in our research.

All video data will be uploaded onto an encrypted computer system which will be password protected. Video data will only be watched by research staff for the purposes of coding participants’ responses to the environment. Names and personal information will be anonymised when coding this data. You will be given the opportunity in the Consent Form to opt out of this should you not wish to provide video data.
We would also ask for your consent to use select video footage captured during the visit(s) for select future teaching purposes, for example educational presentations. You will be given the opportunity in the Consent Form to opt out of this should you not wish to consent to video footage being used for this purpose.

(iii) Interview participation: During our visits we may ask you some interview-style questions relating to your daily activities and home environment. These conversations may be captured in the video footage as outlined above, or via audio recordings. We may also ask you to respond to items from standardised questionnaires, measures or scales. Information gathered will be reviewed by research staff to create anonymised transcripts, which will assist them to analyse data after the research visit. You will be given the opportunity in the Consent Form to opt out of this should you not wish to provide interview data.

(iv) Photographic information collection: We would like to take selective photographs of parts of your home which you may have adapted or modified to aid you in your daily activities. We would like to use the photographs to identify stresses and coping mechanisms within home surroundings. Examples of such mechanisms include particular furniture arrangements, and wayfinding lighting attached to stair bannisters.

Every effort will be made to anonymise photos as much as possible. You will be able to view and request the deletion of any photographs taken at any point during the visit, or up to one week after the visit. Our researcher will contact you after one week as a final check that you are happy for the photographs to be used in our research.

The photographs would be used for research as well as for select teaching purposes, for example educational presentations. You will be given the opportunity in the Consent Form to opt out of this should you not wish to consent to photograph data.

5. Are there any risks, disadvantages or benefits of taking part in this sub-study which are different to the main study in which I have already participated? No.

6. Does the same information about confidentiality, and the outcomes, funders and reviewers of the research apply to this sub-study as to the principal study? Yes.

7. Who should I contact for further information? [Redacted]

[Redacted]

Thank you for considering taking part in this study. You will be given a copy of the information sheet and a signed consent form to keep.
CONSENT FORM

“Neuropsychological Investigation of visuo perceptual, visuospatial and literacy skills in posterior cortical atrophy”

PCA Sub-study 5: Home-based observations of everyday activities

1. I confirm I understand that I am already participating in the “Neuropsychological investigation of visuo perceptual, visuospatial and literacy skills in posterior cortical atrophy” study and have been given an opportunity to re-read the principal study information sheet dated 21-December-2016 (Version 10.0).

2. I confirm that I have read and understood the information sheet dated 21-December-2016 (Version 10.5) for this PCA sub-study and have had the opportunity to ask questions.

3. I confirm that I have had sufficient time to consider whether or not I want to be included in the study.

4. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my participation in the main study or my medical care or legal rights being affected.

5. I understand that information gathered about me during the principal PCA study will be used by researchers in conjunction with information gathered during this sub-study.

6. I consent to participating in the following activities within my home in order to provide data to be viewed only by the research team. (If you do not wish to participate in any of the following tasks please circle ‘No’. This will mean that you will not take part in these activities but you will be able to take part in other experimental tasks):
   i) Sensor recordings
   ii) Video recording

Yes / No

Yes / No
<p>| | | |</p>
<table>
<thead>
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<tbody>
<tr>
<td>iii) Wearing a clip-on camera</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>iv) Audio-recording interviews about my daily activities and home environment</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>v) Photographs being taken of parts of my home</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>I consent to the following data information, video recordings and photographs collected during this study to be used for future research, teaching and educational purposes. I understand that some people may be able to recognise or identify me from this data.</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>i) Video recording</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ii) Photographs of parts of my home</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

8. I agree to take part in the above study.

This consent has been obtained using verbal modality (audio-recorded):

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

Name of Chief Investigator:

Professor Sebastian Crutch

Email: [Redacted]

Tel:

Name of Researcher to be contacted if there are any problems

*(if different to the Chief Investigator)*

Email: __________________________

Tel: __________________________
1.d Pre and post visit assessment forms for home-based observations

**Seeing What They See observational home visits**

**Pre-assessment form:**

<table>
<thead>
<tr>
<th>Visit number:</th>
<th>Visit arranged by (researcher):</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

Date of visit:

<table>
<thead>
<tr>
<th>Visit start time:</th>
<th>Visit end time:</th>
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</thead>
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</tr>
</tbody>
</table>

Participants' contact name(s):

Participants' contact number(s):

Participants' home address:

---

Travel arrangements:

---

Plan for the day:

---

Any causes for concern/possible risks and actions required:

---

Agreed contact:

- [ ] EH to contact by text once per 2 hour period
- [ ] Senior staff member/PI to make contact in the event of missed contact from EH

Signed:

<table>
<thead>
<tr>
<th>Researcher:</th>
<th>Senior staff member/PI:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tbody>
</table>

Print name: ________________  ________________

Sign: ________________  ________________

Date: ________________  ________________
Post-visit form:

Visit number:

Visit conducted by (researcher):

Date of visit: Participant code:

Any causes for concern/possible risk-related issues:

Actions taken:

Further actions required: Date due: Done?

Risk reporting:

☐ Reported to and discussed with senior member of staff/PI

Signed:

Researcher: Senior staff member/PI:

Print name: ____________________ ____________________

Sign: ____________________ ____________________

Date: ____________________ ____________________
APPENDIX 2: Interview schedules and topic guides

2.a Interview schedule for phase I Interviews and walk around tours

**Patient and Carer Interview Schedule**

Using a narrative approach, the semi-structured interviews will take place, as much as possible, in the patient’s home environment. The visits will be conducted by two researchers to enable the patient and the carer interview to be conducted concurrently following the dyad interview:

1. Introduction and consent (15 minutes)
   - re-consent patient participant into PCA longitudinal study
   - consent carer participant into prep study 3
2. Walk through the home (30 minutes)
   - to be completed virtually or through real tour of home
3. Short break
4. Dyad interview (60 minutes)
5. Short break
6. Patient interview and carer interview (60 minutes)
   - complete and discuss questionnaires
   - break after 60 minutes to re-coordinate timing of individual interviewers
7. Debrief, invitation for RW follow up study and thank you (10 minutes)

**Walk Through**

1. Talk me through a typical day together from when you get up to going to bed at night.
   
   *Probe: daily activities, problems faced (and feelings about them), coping strategies, Meal times*

2. Thinking about your home environment and the rooms in the house do they support your daily lives?
Probe: changes since diagnosis, future changes, belonging and attachment to home, potential future and existing interventions

3. Have you modified your home in any way since [individual with dementia] got diagnosed?
Probe: at what point was this needed/why did you implement it? Perceived success and ‘lifespan’ of intervention, future interventions and needs

**Dyad Interview**

1. Shared and personal narrative.
Probe: tell me about yourself /ves (where brought up, school, work, employment/retirement, hobbies), shared history (marriage, children etc.), recent history (diagnosis, diagnosis journey - e.g. why did they seek help? What help have they had since?)

2. Has this routine changed since [individual with dementia] got diagnosed?
Probe: impact of visual/cognitive impairments, daily activities, problems faced, coping strategies, relationship

3. How do you perceive your daily lives in the future?
Probe: short and long term coping strategies, relationship, problems

**PLWD Interview**

1. Earlier you and [IWD/carer] talked about [situation] can you talk to me a bit more about this?
Probe: coping, changes since diagnosis and future changes

Interview is then facilitated by using the following scales:

3. QoL-AD questionnaire (Logsdon et al., 1999)
Probe: changes over time and impact (e.g. job, social interests), strategies to mediate problems/stresses/losses, anticipated problems/stresses/losses, positive views of situation/plans/future, meanings associated with situation overall

4. Dyadic Relationship Scale (Sebern and Whitlatch, 2007)
Probe: impact of illness on relationships, quality of relationships now versus in the past, new relationships, strategies to maintain relationships

Carer Interview
1. Earlier you and [IWD/carer] talked about [situation] can you talk to me a bit more about this?
   Probe: coping, changes since diagnosis and future changes

Interview is then facilitated by using the following scales:
2. The ADL Questionnaire (Johnson et al., 2004)
   Completed by carer
   Probe: challenges, coping mechanisms, impact on daily life

3. QoL-AD questionnaire (Logsdon et al., 1999)
   Completed by carer
   Probe: changes over time and impact (e.g. job, social interests), strategies to mediate problems/stresses/losses, anticipated problems/stresses/losses, positive views of situation/plans/future, meanings associated with situation overall

4. Dyadic Relationship Scale (Sebern and Whitlatch, 2007)
   Probe: impact of illness on relationships, quality of relationships now versus in the past, new relationships, strategies to maintain relationships

5. Zarit Burden Interview (Zarit, Reever and Bach-Peterson, 1980)
   Probe: Thoughts on caring, commitment, stresses, coping, anticipated future, meanings associated with caring role and situation overall
2.b Visit schedule for phase II Home-based observations

The interview data has been instrumental in beginning to explore how the physical environment in the natural setting may or may not mediate the stress associated with living with dementia and highlighting the complex intersection and interactions between the physical and psychosocial environments. This complexity is exemplified by some of the following:

- Individual and relationship factors (both previous to and since diagnosis) among people with dementia and family members have been shown to be of importance when considering social interactions within the physical environment. For example, an individual's desire to maintain independence may impact on how readily they will ask for and accept help. In the other direction, family members vary in their ability, availability and inclination to provide help including assisting with implementation of aids and assistive technologies.

- The personal attachments to the physical space and objects within it. Two examples are: a selection of hand creams which were important for maintenance of identity; landmark objects that were used as signposts to navigate to the bathroom. Both of these might be considered ‘clutter’ – something our work in PAMELA has shown to impair task performance.

- Participants consistently mentioned the way their environments (physical and psychosocial) were changing over time – both in the short term (morning to evening) and longer term (good days and bad days, a gradual decline).

The observational study will further describe and continue to develop our understanding of the ways in which the physical and psychosocial environments interact and intersect to mediate stress and coping for individuals and families living with dementia related visual impairment. The use of observational methods will permit exploration of the environments as they occur in real time, offering an ecological lens on the interview.
findings. The use of selective video recordings and informal interviews will also permit us to capture micro-behaviours (e.g. hand-holding, eye contact) and micro-communications (e.g. reflecting feelings, verbal prompts). The following research questions have been defined to guide our data collection:

1. Subjective assessment of the quality of the morning, afternoon and evening
   - Rate and explain
   - Completed at end of observation period

2. Guiding selective visual and/or audio-recording
   When does the spouse/carer assist with an activity – ADL or social engagement? Who initiates?
   How does the spouse/carer assist during this time (e.g. verbal and/or physical cues, planned versus spontaneous).
   Are there others that do the same?
   How does person with dementia react/respond to the offers of assistance?
   Are the offers of assistance more focused on ADL function (problem-based) rather than emotional need or hobby (for fun), for example?
   Does the person with dementia express wanting to do something that they cannot do on their own?
   Who else comes and goes in the home and how does this affect the environment overall?
   During the course of the day how much time is the person with dementia alone and what does s/he do during this time?
   How many activities are solitary versus with someone?
   What is the physical proximity between the person with dementia and their spouse/carer and how does this change throughout the day?
   Are pre-morbid interests maintained in any way, either individual or couple?
   Can the person with dementia engage in activities outside the home?
   How does the person with dementia interact with objects/spaces in the home?
   Specifically, how does the person interact with technology or other assistive aids which they/family members have introduced or come up with?
   Does the person with dementia have any particular attachments to objects/spaces within the home?
   Are there things in the environment that the person with dementia finds stressful?
   To what extent are there examples of independence versus interdependence versus dependence?
   How is now explained in the context of the past?
   Are there ways that the person with dementia interacts differently with the environment over the course of the day?
Are there any particular strategies that the person with dementia and/or spouse/carer have come up with, origin and are these effective or not?

In addition to the above, the use of wearable sensors will add a true biopsychosocial angle to be taken and in particular will permit greater understanding of participants’ general activity levels and changing physiological states within these intersecting environments (including heart rate and galvanic skin response). The use of a wearable body camera will allow us to ‘see’ the world from the perspective of our participants as they carry out activities and participate in their social and physical environments. Various physical features of the environment will also be measured including luminance levels across rooms and times of day and dimensions of rooms.

As part of one of the PhD projects attached to the study (EH), a sub-sample of participants (N=6) will be invited to take part in a Q sort exercise exploring measurement and meaning in dementia (described in full below).

**Observational schedule and visit summary –**

*In advance:*
- Enter on to spreadsheet
- Make contact and confirm interest
- Send information and consent forms x 4 (main; sub-study 5)
- Remind re: warning potential visitors about filming
- Answer any questions
- If happy to proceed, schedule visit
- Complete pre-assessment form
- Get signed off
- Collect demographics/scale data (ADL, QoL, mobility, NPI) in advance (where poss)

*On the day:*
- **Arrival, hello, questions, confirm consent (PWD only):**
  - Explain the session: Forms / neuropsych / measurements of home / tech + cameras + SYNC / normal day (some informal interview questions throughout)
  - timings… [3 x sessions, morning, afternoon + evening]
- Answer any questions, reconfirm consent
  - Reaffirm re: any areas/behaviors not to be filmed/observed and right to request deletion of any data during the day or at 1 week follow up
- Explain that participants should continue with their day as usual while researcher observes and takes some notes, but that the researcher may stop them to ask questions or video from another angle at points if either may help us to better understanding of difficulties and coping strategies in the home environment
Structured observations:
- neuropsych: pen and paper tests
- Questionnaires/scales
- Luminance (1, 2, 3) and dimensions measurements
- Researcher to keep log of main activities at 15 minute intervals
- Sensor data and body camera footage
- Good day/bad day rating on a scale of 1-10

Unstructured observations:
- Researcher to take brief key notes throughout
- Selective photo-taking, video and audio recording (including informal interviews/questions) as appropriate to answer the research questions above
- Qualitative explanations of good day/bad day ratings

Observation sessions checklist:

START —

| Participant code: |  |
| Session date: |  |
| Info / Qs / Consent: |  |

Demographics: | PWID | Family member |
---|---|---|

Scales: ADL | Mobility | NPI | QoL |
---|---|---|---|
Neuropsych (if needed): | MMSE | SRRT (w) | Naming | Digit span |
---|---|---|---|---|
Vis. Acuity | Figure-ground | Dot count | Frag letters | Sp. speech |
---|---|---|---|---|
Luminance measures: |  |
Fit tech + cameras = tag: |  |
Note start time: |  |
Room dimensions:

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Floor plan (sketch):
### Luminance measures

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</table>

**BREAKS—**

- Remove cameras and tech:
- Charge as needed:
- Transfer data as needed:
- Confirm time to resume:
<table>
<thead>
<tr>
<th>Start of session:</th>
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<td>Room</td>
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**BREAKS**

- Remove cameras and tech:
- Change as needed:
- Transfer does needed:
- Confirm time to resume:
Luminance measures III: ____________________________________________

<table>
<thead>
<tr>
<th>Start of session:</th>
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<tr>
<td>Room</td>
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<table>
<thead>
<tr>
<th>Breaks:</th>
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<tbody>
<tr>
<td>Remove cameras and tech:</td>
</tr>
<tr>
<td>Charge as needed:</td>
</tr>
<tr>
<td>Transfer data as needed:</td>
</tr>
<tr>
<td>Confirm time to resume:</td>
</tr>
<tr>
<td>Structured observation – (fill in actual times below)</td>
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<td>-----------------------------------------------------</td>
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</table>

Observation notes: ___________________________ (tag code) ___________________________ (session/time)
<table>
<thead>
<tr>
<th>Structured observation – (fill in actual times below)</th>
<th>Details</th>
<th>Yes / No / Tag</th>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Structured observation - (fill in actual times below)</th>
<th>Details</th>
<th>Yes / Not / Tag</th>
</tr>
</thead>
</table>

Total survey hours: ________________
On a scale of 1-10 how much had this been a typical good/bad day? [0-bad]

Can you say why? [audio-record]

END –

<table>
<thead>
<tr>
<th>Cameras off + remove tech:</th>
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<tbody>
<tr>
<td>Debrief and thank you:</td>
</tr>
<tr>
<td>Any requests for data deletion:</td>
</tr>
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</table>

IN THE OFFICE –

<table>
<thead>
<tr>
<th>Dictate detailed field notes (10 mins):</th>
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<tbody>
<tr>
<td>Upload/File/clean data/scoring:</td>
</tr>
<tr>
<td>Complete post-visit form:</td>
</tr>
<tr>
<td>Set reminder for 1 week follow up call re: data deletion.</td>
</tr>
</tbody>
</table>
Field notes.
APPENDIX 3: Demographic questionnaires

3.a PLWD – Phase I interviews

Version 3: 21/10/2014

<table>
<thead>
<tr>
<th>Patient Demographic Form</th>
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<tbody>
<tr>
<td>From case notes</td>
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<tr>
<td>From case notes</td>
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</table>

<table>
<thead>
<tr>
<th>Patient Code</th>
<th>Gender</th>
<th>Age</th>
<th>DOB</th>
<th>1st Language</th>
<th>Neuropsych Assessment Date</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
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<table>
<thead>
<tr>
<th>Dementia Diagnosis</th>
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<tbody>
<tr>
<td>PCA</td>
</tr>
<tr>
<td>Young onset Typical AD</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Year of Diagnosis</th>
<th>Length of Illness</th>
<th>Carer code</th>
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<tr>
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</tbody>
</table>

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Clinical Information

1. Subjective age of dementia onset
   - Patient
   - Caregiver

10. Do you have any other chronic health issues?
   - Yes
   - No
   If yes, please specify:
      - Diabetes
      - Emphysema / COPD
      - Heart disease Specify type: __________________________
      - Arthritis or other rheumatic disease Specify type: __________________________
      - Cancer Specify type: __________________________
      - Stroke
      - Mental health Specify type: __________________________
      - Other Specify type: __________________________

11. Do you take any medication specifically for Dementia?
   - Yes
   - No
   If yes, please specify
      __________________________

12. Do you take any other medication?
   - Yes
   - No
   If yes, please specify
      __________________________
      __________________________
Socio-economic status

1. What is your postcode?

2. What is your highest education level?
   - Left school before age 16
   - GCSE or equivalent
   - Trade/technical/vocational training
   - A Level or equivalent
   - Undergraduate degree
   - Master's Degree
   - PhD
   - Other (please specify)

3. Which of the following best describes your situation?
   - Full time paid employment
   - Part time paid employment
   - Volunteer work
   - Primary homemaker
   - Long-term sick
   - Unemployed
   - Retired

4. What is your current or most recent job / occupation title?

5. What was your last year of paid employment?

6. What is the reason for leaving employment?
   - N/A still employed
   - Dementia onset (include if retired on ill health for dementia)
   - Other health related problems (include if retired on ill health other)
   - Family / care commitments
   - Retirement
   - Other (please specify)


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13. Where do you live at the moment?
   - Own home
   - Sheltered accommodation

14. Is your home ...?
   - Owner-occupied
   - Rented

15. If you live in your own home please tell us ...
   How many bedrooms do you have ___________________________
   How many bathrooms do you have ___________________________
   Do you have a garden yes ☐ yes ☐ no ☐
   Do you have a staircase yes ☐ no ☐

16. In years how long have you lived in your current residence? ___________________________

17. Who do you live with at the moment?
   - Living alone
   - Living with partner
   - Living with family (partner + children)
   - Living with children / relatives
   - Living in a hostel / care home
   - Other (please specify) ___________________________

18. Do you live with your primary carer?
   - Yes
   - No
   - N/A lives in residential / care home

19. Do you live with any dependent children?
   - Yes
   - No

20. If yes, how many?
    ___________________________
### Family

21. What is your relationship status?
   - Single
   - Long term partner
   - Married / Civil partnership
   - Separated
   - Divorced
   - Widowed

22. If applicable, how long have you been in this relationship? ____________________________

23. Do you have any children
   - yes [ ]
   - no [ ]

24. If applicable, how many children do you have? ____________________________

### Carers and Service utilisation

25. What is the relationship between you and your primary carer?
   - Partner
   - Parent/Child
   - Other family member
   - Friend
   - Professional carer

26. What is the relationship between you and your secondary carer?
   - Partner
   - Parent/Child
   - Other family member
   - Friend
   - Professional carer
   - N/A no secondary carer

27. Do you use professional carers?
   - yes [ ]
   - no [ ]

If yes, what type of care:
   - Home carer during the day
   - Home carer during the night
   - Day centre
   - Respite care
   - Other:

If yes, how often do you use this care?

<table>
<thead>
<tr>
<th>Hours</th>
<th>Days per month (out of 28 days)</th>
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</table>
3.b Carer – Phase I Interviews

Version 2 21/10/2014

<table>
<thead>
<tr>
<th>Carer Demographic Form</th>
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<tbody>
<tr>
<td><strong>From case notes</strong></td>
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<tr>
<td><strong>Carer Code</strong></td>
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<tr>
<td><strong>Gender</strong></td>
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<td>Female ☐</td>
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<td>Male ☐</td>
</tr>
<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>-----------------------</td>
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<tr>
<td><strong>DOB</strong></td>
</tr>
</tbody>
</table>

**Patient code**

Relationship between patient and carer

- ☐ Partner
- ☐ Parent/Child
- ☐ Other family member
- ☐ Friend

---

457
**Socio-economic status**

1. What is your postcode? ________________________________

2. What is your highest education level?
   - [ ] Left school before age 16
   - [ ] GCSE or equivalent
   - [ ] Trade/technical/vocational training
   - [ ] A Level or equivalent
   - [ ] Undergraduate degree
   - [ ] Master's Degree
   - [ ] PhD
   - [ ] Other (please specify)

3. Which of the following best describes your situation?
   - [ ] Full time paid employment
   - [ ] Part time paid employment
   - [ ] Volunteer work
   - [ ] Primary homemaker
   - [ ] Long-term sick
   - [ ] Unemployed
   - [ ] Retired

4. Have you taken time off work to care for the person with dementia?
   - [ ] Yes
   - [ ] No

5. If yes, approximately how many days per month?

6. What is your current or most recent job / occupation title?

7. When was your last year of paid employment? ________________________

8. What is the reason for leaving employment?
   - [ ] N/A still employed
   - [ ] Caring commitments for individual with dementia
   - [ ] Health related problems related to caring for individual with dementia
   - [ ] Other health related problems
   - [ ] Family commitments
   - [ ] Retirement
   - [ ] Other (please specify) ____________________________
### Health

7. Do you have any health issues that affect your ability to care for...?  

- [ ] Yes  
- [ ] No

If yes, please specify:

- [ ] Diabetes  
- [ ] Emphysema / COPD  
- [ ] Heart disease Specify type:  
- [ ] Arthritis or other rheumatic disease Specify type:  
- [ ] Cancer Specify type:  
- [ ] Stroke  
- [ ] Mental health Specify type:  
- [ ] Other Specify type:  

8. Do you take any medication?  

- [ ] Yes  
- [ ] No

If yes, please specify:

9. Does caring for... have an impact on your health or general well-being?  

- [ ] Yes  
- [ ] No

If yes, which areas are affected?

- [ ] Sleep / Tiredness  
- [ ] Stress  
- [ ] Anxiety / Worry  
- [ ] Depression  
- [ ] Physical health Specify type:  
- [ ] Other aspects of mental health Specify type:  


Living Situation

10. Is your home ...?
   □ Owner-occupied
   □ Rented

11. In years how long have you lived in your current residence? ____________________________

12. Who do you live with at the moment?
   □ Living alone
   □ Living with partner
   □ Living with family (partner + children)
   □ Living with children / relatives
   □ Living in a hostel
   □ Other (please specify) ____________________________

13. Do you live with the individual with dementia?
   □ Yes
   □ No

14. Do you live with any dependent children?
   □ Yes
   □ No

25. If yes, how many? ____________________________

Family and caring

16. What is your relationship status?
   □ Single
   □ Long term partner
   □ Married / Civil partnership
   □ Separated
   □ Divorced
   □ Widowed

17. If applicable, how long have you been in this relationship? ____________________________

18. Do you have any children yes □ no □

19. If applicable, how many children do you have? ____________________________
3.c PLWD – Phase II Home-based observations

Version 2: 21/10/2014

**Patient Demographic Form**

<table>
<thead>
<tr>
<th>Patient Code</th>
</tr>
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<table>
<thead>
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</thead>
</table>

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<table>
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<tr>
<th>Dementia Diagnosis</th>
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<tbody>
<tr>
<td>☐ PCA</td>
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<tr>
<td>☐ Young onset Typical AD</td>
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<th>Year of Diagnosis</th>
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</table>
Clinical Information

1. Subjective age of dementia onset
   Patient __________________________
   Carer __________________________

10. Do you have any other chronic health issues?
    □ Yes
    □ No
    If yes, please specify:
    □ Diabetes
    □ Emphysema / COPD
    □ Heart disease Specify type:
    □ Arthritis or other rheumatic disease Specify type:
    □ Cancer Specify type:
    □ Stroke
    □ Mental health Specify type:
    □ Other Specify type:

11. Do you take any medication specifically for Dementia?
    □ Yes
    □ No
    If yes, please specify
    ___________________________________________________

12. Do you take any other medication?
    □ Yes
    □ No
    If yes, please specify
    ___________________________________________________
    ___________________________________________________
Social-economic status

1. What is your postcode? ____________________________

2. What is your highest education level?
   - Left school before age 16
   - GCSE or equivalent
   - Trade/technical/vocational training
   - A Level or equivalent
   - Undergraduate degree
   - Master's Degree
   - PhD
   - Other (please specify) ____________________________

3. Which of the following best describes your situation?
   - Full time paid employment
   - Part time paid employment
   - Volunteer work
   - Primary homemaker
   - Long term sick
   - Unemployed
   - Retired

4. What is your current or most recent job / occupation title?
   ____________________________

5. What was your last year of paid employment?
   ____________________________

6. What is the reason for leaving employment?
   - N/A still employed
   - Dementia onset (include if retired on ill health for dementia)
   - Other health related problems (include if retired on ill health other)
   - Family / care commitments
   - Retirement
   - Other (please specify) ____________________________
13. Where do you live at the moment?
   - Own home
   - Sheltered accommodation

14. Is your home ...?
   - Owner-occupied
   - Rented

15. If you live in your own home please tell us ...
   How many bedrooms do you have
   How many bathrooms do you have
   Do you have a garden ...
   Do you have a staircase ...

16. In years how long have you lived in your current residence...

17. Who do you live with at the moment?
   - Living alone
   - Living with partner
   - Living with family (partner + children)
   - Living with children / relatives
   - Living in a hostel / care home
   - Other (please specify)

18. Do you live with your primary carer?
   - Yes
   - No
   - N/A (lives in residential / care home)

19. Do you live with any dependent children?
   - Yes
   - No

20. If yes, how many?
## Family

21. What is your relationship status?
- Single
- Long term partner
- Married / Civil partnership
- Separated
- Divorced
- Widowed

22. If applicable, how long have you been in this relationship?  

23. Do you have any children  
   - yes ☐  
   - no ☐

24. If applicable, how many children do you have?  

## Carers and Service utilisation

25. What is the relationship between you and your primary carer?
- Partner
- Parent/Child
- Other family member
- Friend
- Professional carer

26. What is the relationship between you and your secondary carer?
- Partner
- Parent/Child
- Other family member
- Friend
- Professional carer
- N/A no secondary carer

27. Do you use professional carers?  
   - yes ☐  
   - no ☐

If yes, what type of care:
- Home carer during the day
- Home carer during the night
- Day centre
- Respite care
- Other:

If yes, how often do you use this care?

<table>
<thead>
<tr>
<th>Hours</th>
<th>Days per month (out of 28 days)</th>
</tr>
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<tbody>
<tr>
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Carer Demographic Form

From case notes

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<td>[ ]</td>
<td>Male</td>
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<tr>
<th>DOB</th>
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<tr>
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</tbody>
</table>

Patient code: _______________________

Relationship between patient and carer:

- [ ] Partner
- [ ] Parent/Child
- [ ] Other family member
- [ ] Friend
Socio-economic status

1. What is your postcode?  

2. What is your highest education level?
   - Left school before age 16
   - GCSE or equivalent
   - Trade/technical/vocational training
   - A Level or equivalent
   - Undergraduate degree
   - Master’s Degree
   - PhD
   - Other (please specify)  

3. Which of the following best describes your situation?
   - Full time paid employment
   - Part time paid employment
   - Volunteer work
   - Primary homemaker
   - Long-term sick
   - Unemployed
   - Retired

4. Have you taken time off work to care for the person with dementia?
   - Yes
   - No

5. If yes, approximately how many days per month?

6. What is your current or most recent job / occupation title?

7. When was your last year of paid employment?

8. What is the reason for leaving employment?
   - N/A still employed
   - Caring commitments for individual with dementia
   - Health related problems related to caring for individual with dementia
   - Other health related problems
   - Family commitments
   - Retirement
   - Other (please specify)
7. Do you have any health issues that affect your ability to care for...?

☐ Yes
☐ No

If yes, please specify:

☐ Diabetes
☐ Emphysema / COPD
☐ Heart disease Specify type: ____________________________
☐ Arthritis or other rheumatic disease Specify type: ____________________________
☐ Cancer Specify type: ____________________________
☐ Stroke
☐ Mental health Specify type: ____________________________
☐ Other Specify type: ____________________________

8. Do you take any medication?

☐ Yes
☐ No

If yes, please specify ____________________________
### Living Situation

10. Is your home...
   - [ ] Owner-occupied
   - [ ] Rented

11. In years how long have you lived in your current residence? __________________________

12. Who do you live with at the moment?
   - [ ] Living alone
   - [ ] Living with partner
   - [ ] Living with family (partner + children)
   - [ ] Living with children / relatives
   - [ ] Living in a hostel
   - [ ] Other (please specify) __________________________

13. Do you live with the individual with dementia?
   - [ ] Yes
   - [ ] No

14. Do you live with any dependent children?
   - [ ] Yes
   - [ ] No

15. If yes, how many? __________________________

### Family and caring

16. What is your relationship status?
   - [ ] Single
   - [ ] Long term partner
   - [ ] Married / Civil partnership
   - [ ] Separated
   - [ ] Divorced
   - [ ] Widowed

17. If applicable, how long have you been in this relationship? __________________________

18. Do you have any children:  
   - yes [ ]  
   - no [ ]  

19. If applicable, how many children do you have? __________________________
3.4 Carers – Phase II Home-based observations

APPENDIX 4: Examples of scales (full scales where permitted)

4.a ADL Scale (Johnson et al., 2004)
# Activities of Daily Living Questionnaire

**Johnson et al. (2004)**

**Instructions:** For each item please circle the appropriate response according to your spouse's current level of ability relative to his/her typical performance before the onset of dementia symptoms.

<table>
<thead>
<tr>
<th>Self-Care Activities</th>
<th>Eating</th>
<th>Elimination</th>
<th>Taking pills or medicine</th>
<th>Interest in personal appearance</th>
<th>Household care</th>
<th>Home maintenance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No problem</td>
<td>Goes to the bathroom independently</td>
<td>Remembers without help</td>
<td>Same as always</td>
<td>Plans and prepares meals without difficulty</td>
<td>Does all tasks usual for him/her</td>
</tr>
<tr>
<td></td>
<td>Independent, but slow or some spills</td>
<td>Goes to the bathroom when reminded: some accidents</td>
<td>Remembers if dose is kept in a special place</td>
<td>Interested if going out but not at home</td>
<td>Some cooking, but less than usual, or less variety</td>
<td>Does at least half of usual tasks</td>
</tr>
<tr>
<td></td>
<td>Needs help to cut or pour; spills often</td>
<td>Needs assistance for elimination</td>
<td>Needs spoken or written reminders</td>
<td>Allows self to be groomed, or does so on request only</td>
<td>Gate food only if it has already been prepared</td>
<td>Occasionally rakes or some other minor job</td>
</tr>
<tr>
<td></td>
<td>Must be fed most foods</td>
<td>Has no control over either bowel or bladder</td>
<td>Must be given medicine by others</td>
<td>Resists efforts of caretaker to clean and groom</td>
<td>Does nothing to prepare meals</td>
<td>No longer does any maintenance</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>Don’t know</td>
<td>Does not take regular pills or medicine OR Don’t know</td>
<td>Don’t know</td>
<td>Never did this activity OR Don’t know</td>
<td>Never did this activity OR Don’t know</td>
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<tr>
<td>Setting the table</td>
<td>Home repairs</td>
<td>Laundry</td>
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<tr>
<td>---------------------------</td>
<td>-----------------------</td>
<td>-----------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No problem</td>
<td>Does all the usual repairs</td>
<td>Does laundry as usual (same schedule, routine)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent, but slow or clumsy</td>
<td>Does at least half of usual repairs</td>
<td>Does laundry less frequently</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forgets items or puts them in the wrong place</td>
<td>Occasionally does minor repairs</td>
<td>Does laundry only if reminded; leaves out detergent or steps</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No longer does this activity</td>
<td>No longer does any repairs</td>
<td>No longer does laundry</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never did this activity OR Don't know</td>
<td>Never did this activity OR Don't know</td>
<td>No longer did laundry</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Housekeeping</td>
<td></td>
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</tr>
<tr>
<td>Keeps house as usual</td>
<td></td>
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</tr>
<tr>
<td>Does at least half of his/her job</td>
<td></td>
<td></td>
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<tr>
<td>Occasional dusting or small jobs</td>
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<td>No longer keeps house</td>
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</tr>
<tr>
<td>Employment and recreation</td>
<td></td>
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</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
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<tr>
<td>Continues to work as usual</td>
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<tr>
<td>Some mild problems with routine responsibilities</td>
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<tr>
<td>Works at an easier job or part-time; threatened with loss of job</td>
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</tr>
<tr>
<td>No longer works</td>
<td></td>
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<tr>
<td>Never worked OR retired before illness OR Don't know</td>
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<td>Organisation -s</td>
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<td>Attends meetings, takes responsibilities as usual</td>
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<td>Attends less frequently</td>
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<td>Attends occasionally; has no major responsibilities</td>
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<tr>
<td></td>
<td>No longer attends</td>
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<td></td>
<td>Never participated in organisations OR Don't know</td>
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<tr>
<td>Recreation</td>
<td></td>
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<tr>
<td>Same as usual</td>
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<td></td>
</tr>
<tr>
<td>Engages in recreational activities less frequently</td>
<td></td>
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<tr>
<td>Has lost some skills necessary for recreational activities (e.g. bridge, golfing); needs coaxing to participate</td>
<td></td>
<td></td>
<td></td>
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<td>No longer pursues recreational activities</td>
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<tr>
<td>Same as usual</td>
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<tr>
<td>Gets out if someone else drives</td>
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<tr>
<td>Gets out in wheelchair</td>
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<td>Shopping and money</td>
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<tr>
<td>Food Shopping</td>
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</tr>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Forgets items or buys unnecessary items</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Needs to be accompanied while shopping</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>No longer does the shopping</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never had responsibility in this activity OR Don't know</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Managing finances</td>
<td></td>
<td></td>
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<tr>
<td>No problem paying bills, banking</td>
<td></td>
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<tr>
<td>Pays bills late; some trouble writing checks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forgets to pay bills; has trouble balancing check books; needs help from others</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>No longer manages finances</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never had responsibility in this activity OR Don't know</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
| Handling cash | No problem
| Has difficulty paying proper amount, counting
| Loses or misplaces money
| No longer handles money
| Never had responsibility for this activity OR Don’t know |

<table>
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<tr>
<th>Travel</th>
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</thead>
<tbody>
<tr>
<td>Public transportation</td>
</tr>
<tr>
<td>Uses public transportation as usual</td>
</tr>
<tr>
<td>Uses public transportation less frequently</td>
</tr>
<tr>
<td>Has gotten lost using public transportation</td>
</tr>
<tr>
<td>No longer uses public transportation</td>
</tr>
<tr>
<td>Never used public transportation regularly OR Don’t know</td>
</tr>
<tr>
<td>Mobility around the neighbourhood</td>
</tr>
<tr>
<td>Same as usual</td>
</tr>
<tr>
<td>Goes out less frequently</td>
</tr>
<tr>
<td>Has gotten lost in the immediate neighborhood</td>
</tr>
<tr>
<td>No longer goes out unaccompanied</td>
</tr>
<tr>
<td>This activity has been restricted in the past OR Don’t know</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Driving</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drives as usual</td>
</tr>
<tr>
<td>Drives more cautiously</td>
</tr>
<tr>
<td>Drives less carefully; has gotten lost while driving</td>
</tr>
<tr>
<td>No longer drives</td>
</tr>
<tr>
<td>Never drove OR Don’t know</td>
</tr>
<tr>
<td>Travel outside familiar environment</td>
</tr>
<tr>
<td>Same as usual</td>
</tr>
<tr>
<td>Occasionally gets disoriented in strange surroundings</td>
</tr>
<tr>
<td>Gets very disoriented but is able to manage if accompanied</td>
</tr>
<tr>
<td>No longer able to travel</td>
</tr>
<tr>
<td>Never did this activity OR Don’t know</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Using the telephone</td>
</tr>
<tr>
<td>Same as usual</td>
</tr>
<tr>
<td>Calls a few familiar numbers</td>
</tr>
<tr>
<td>Will only answer telephone (won’t make calls)</td>
</tr>
<tr>
<td>Does not use the telephone at all</td>
</tr>
<tr>
<td>Never had a telephone OR Don’t know</td>
</tr>
<tr>
<td>Understanding</td>
</tr>
<tr>
<td>Understands everything that is said as usual</td>
</tr>
<tr>
<td>Asks for repetition</td>
</tr>
<tr>
<td>Has trouble understanding conversations or specific words occasionally</td>
</tr>
<tr>
<td>Does not understand what people are saying most of the time</td>
</tr>
<tr>
<td>Don’t know</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Talking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Same as usual</td>
</tr>
<tr>
<td>Less talkative; has trouble thinking of words or names</td>
</tr>
<tr>
<td>Makes occasional errors in speech</td>
</tr>
<tr>
<td>Speech is almost unintelligible</td>
</tr>
<tr>
<td>Don’t know</td>
</tr>
<tr>
<td>Reading</td>
</tr>
<tr>
<td>Same as usual</td>
</tr>
<tr>
<td>Reads less frequently</td>
</tr>
<tr>
<td>Has trouble understanding or remembering what he/she has read</td>
</tr>
<tr>
<td>Has given up reading</td>
</tr>
<tr>
<td>Never read much OR Don’t know</td>
</tr>
<tr>
<td>Writing</td>
</tr>
<tr>
<td>--------------------</td>
</tr>
<tr>
<td>Same as usual</td>
</tr>
<tr>
<td>Writes less often; makes occasional spelling errors</td>
</tr>
<tr>
<td>Signs name but no other writing</td>
</tr>
<tr>
<td>Never writes</td>
</tr>
<tr>
<td>Never wrote much OR Don't know</td>
</tr>
</tbody>
</table>

**Additional comments:**
4.b QoL-AD (Logsdon et al., 1999)
Instructions for Interviewers

The QOL-AD is administered in interview format to individuals with dementia, following the instructions below. The interview is carried out with the subject and/or an informant. The subject should be interviewed alone.

Hand the form to the participant, so that he or she may look at it as you give the following instructions (instructions should closely follow the wording given in bold type):

I want to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: poor, fair, good, or excellent.

Point to each word (poor, fair, good, and excellent) on the form as you say it.

When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of those areas. We want to find out how you feel about your current situation in each area.

If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.

It is usually apparent whether an individual understands the questions, and most individuals who are able to communicate and respond to simple questions can understand the measure. If the participant answers all questions the same, or says something that indicates a lack of understanding, the interviewer is encouraged to clarify the question. However, under no circumstances should the interviewer suggest a specific response. Each of the four possible responses should be presented, and the participant should pick one of the four.

If a participant is unable to choose a response to a particular item or items, this should be noted in the comments. If the participant is unable to comprehend and/or respond to two or more items, the testing may be discontinued, and this should be noted in the comments.

As you read the items listed below, ask the participant to circle her/his response. If the participant has difficulty circling the word, you may ask her/him to point to the word or say the word, and you may circle it for him or her. You should let the participant hold his or her own copy of the measure, and follow along as you read each item.

1. First of all, how do you feel about your physical health? Would you say it's poor, fair, good, or excellent? Circle whichever word you think best describes your physical health right now.

2. How do you feel about your energy level? Do you think it is poor, fair, good, or excellent? If the participant says that some days are better than others, ask him or her to rate how she/he has been feeling most of the time lately.

3. How has your mood been lately? Have your spirits been good, or have you been feeling down? Would you rate your mood as poor, fair, good, or excellent?

4. How about your living situation? How do you feel about the place you live now? Would you say it's poor, fair, good, or excellent?

5. How about your memory? Would you say it is poor, fair, good, or excellent?

6. How about your family and your relationship with family members? Would you describe it as poor, fair, good, or excellent? If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.

7. How do you feel about your marriage? How is your relationship with [spouse's name]? Do you feel it's poor, fair, good, or excellent? Some participants will be single, widowed, or divorced. When this is the case, ask how they feel about the person with whom they have the closest relationship, whether it's a family member or friend. If there is a family caregiver, ask about their relationship with this person. If there is no one appropriate, or the participant is unsure, score the item as missing.
8. How would you describe your current relationship with your friends? Would you say it’s poor, fair, good, or excellent? If the respondent answers that they have no friends, or all their friends have died, probe further. Do you have anyone you enjoy being with besides your family? Would you call that person a friend? If the respondent still says they have no friends, ask how do you feel about having no friends—poor, fair, good, or excellent?

9. How do you feel about yourself—when you think of your whole self, and all the different things about you, would you say it’s poor, fair, good, or excellent?

10. How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it’s poor, fair, good, or excellent?

11. How about your ability to do things for fun, that you enjoy? Would you say it’s poor, fair, good, or excellent?

12. How do you feel about your current situation with money, your financial situation? Do you feel it’s poor, fair, good, or excellent? If the respondent hesitates, explain that you don’t want to know what their situation is (as in amount of money), just how they feel about it.

13. How would you describe your life as a whole. When you think about your life as a whole, everything together, how do you feel about your life? Would you say it’s poor, fair, good, or excellent?

Scoring instructions for QOL-AD:
Points are assigned to each item as follows: poor = 1, fair = 2, good = 3, excellent = 4.
The total score is the sum of all 13 items.
### Quality of Life in Alzheimer’s Disease (QOL-AD) Form

**UWMCADPR/QL**
Aging and Dementia: Quality of Life in AD
Quality of Life: AD
(Family Version)

<table>
<thead>
<tr>
<th>ID Number</th>
<th>Assessment Number</th>
<th>Interview Date</th>
<th>Score for clinician’s use only</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Instructions:** Please rate your relative’s current situation as you see it. Circle your responses.

1. Physical health | Poor | Fair | Good | Excellent |
2. Energy | Poor | Fair | Good | Excellent |
3. Mood | Poor | Fair | Good | Excellent |
4. Living situation | Poor | Fair | Good | Excellent |
5. Memory | Poor | Fair | Good | Excellent |
6. Family | Poor | Fair | Good | Excellent |
7. Marriage | Poor | Fair | Good | Excellent |
8. Friends | Poor | Fair | Good | Excellent |
9. Self as a whole | Poor | Fair | Good | Excellent |
10. Ability to do chores around the house | Poor | Fair | Good | Excellent |
11. Ability to do things for fun | Poor | Fair | Good | Excellent |
12. Money | Poor | Fair | Good | Excellent |
13. Life as a whole | Poor | Fair | Good | Excellent |

Comments: ____________________________________________________________

Total
### Quality of Life in Alzheimer’s Disease cont’d

**QOL-AD**

**UWMCIADPR/QOL**  
Aging and Dementia: Quality of Life in AD  
**Quality of Life: AD**  
(Respondent Version)

<table>
<thead>
<tr>
<th>ID Number</th>
<th>Assessment Number</th>
<th>Interview Date</th>
<th>Score (for clinician's use only)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Instructions:** Interviewer administer according to standard instructions. Circle your responses.

1. **Physical health**  
   - Poor  
   - Fair  
   - Good  
   - Excellent

2. **Energy**  
   - Poor  
   - Fair  
   - Good  
   - Excellent

3. **Mood**  
   - Poor  
   - Fair  
   - Good  
   - Excellent

4. **Living situation**  
   - Poor  
   - Fair  
   - Good  
   - Excellent

5. **Memory**  
   - Poor  
   - Fair  
   - Good  
   - Excellent

6. **Family**  
   - Poor  
   - Fair  
   - Good  
   - Excellent

7. **Marriage**  
   - Poor  
   - Fair  
   - Good  
   - Excellent

8. **Friends**  
   - Poor  
   - Fair  
   - Good  
   - Excellent

9. **Self as a whole**  
   - Poor  
   - Fair  
   - Good  
   - Excellent

10. **Ability to do chores around the house**  
    - Poor  
    - Fair  
    - Good  
    - Excellent

11. **Ability to do things for fun**  
    - Poor  
    - Fair  
    - Good  
    - Excellent

12. **Money**  
    - Poor  
    - Fair  
    - Good  
    - Excellent

13. **Life as a whole**  
    - Poor  
    - Fair  
    - Good  
    - Excellent

**Comments:**

_______________________________________________________

_______________________________________________________

**Total**

### Quality of Life in Alzheimer’s Disease cont’d

**QOL-AD**

**Score Summary Sheet**

Informant’s score of subject’s QOL  
☐ (maximum 52)

Subject’s own QOL rating  
☐ (maximum 52)
4.c Dyadic Relationship Scale (Sebern and Whitlatch, 2007) – example items

(1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree)

Because of helping my family member / 'Because of my health condition...

...I felt angry toward her/him

...I felt closer to her/him than I have in a while

...Communication between us has improved

4.d Zarit Burden Interview (Zarit, Reever and Bach-Peterson, 1980) – example items

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite frequently</th>
<th>Nearly always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you feel that your relative asks for more help than he/she needs?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Do you feel embarrassed over your relative’s behavior?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Do you feel angry when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
4.e Bristol ADL scale (Bucks et al., 1996) – mobility and transfers items

This questionnaire is designed to reveal the everyday ability of people who have memory difficulties of one form or another. For each activity (No. 1 - 20), statements a - e refer to a different level of ability. Thinking of the last 2 weeks, tick the box that represents your relative’s/friend’s AVERAGE ability. (If in doubt about which box to tick, choose the level of ability which represents their average performance over the last 2 Weeks. Tick ‘Not applicable’ if your relative never did that activity when they were well).

10. TRANSFERS
a. Can get in/out of chair unaided
b. Can get into a chair but needs help to get out
c. Needs help getting in and out of a chair
d. Totally dependent on being put into and lifted from chair
e. Not applicable

11. MOBILITY
a. Walks independently
b. Walks with assistance, i.e. furniture, arm for support
c. Uses aids to mobilize, i.e. frame, sticks etc.
d. Unable to walk
e. Not applicable

4.f npiTEST – Neuropsychiatric Inventory (NPI) Questionnaire (Kaufer et al., 2000)
The Neuropsychiatric Inventory Questionnaire: 
Background and Administration

By Jeffrey L. Cummings, MD
The Neuropsychiatric Inventory—Questionnaire: Background and Administration

The Neuropsychiatric Inventory—Questionnaire (NPI-Q) was developed and cross-validated with the standard NPI to provide a brief assessment of neuropsychiatric symptomatology in routine clinical practice settings (Kaufe et al, J Neuropsychiatry Clin Neurosci 2000; 12:233-239). The NPI-Q is adapted from the NPI (Cummings et al, Neurology 1994; 44:2308-2314), a validated informant-based interview that assesses neuropsychiatric symptoms over the previous month. The original NPI included 10 neuropsychiatric domains; two others, Nighttime Behavioral Disturbances and Appetite/Eating Changes, have subsequently been added. Another recent modification of the original NPI is the addition of a Caregiver Distress Scale for evaluating the psychological impact of neuropsychiatric symptoms reported to be present (Kaufe et al, JAGS, 1998;46:210-215). The NPI-Q includes both of these additions.

The NPI-Q is designed to be a self-administered questionnaire completed by informants about patients for whom they care. Each of the 12 NPI-Q domains contains a survey question that reflects cardinal symptoms of that domain. Initial responses to each domain question are "Yes" (present) or "No" (absent). If the response to the domain question is "No", the informant goes to the next question. If "Yes", the informant then rates both the Severity of the symptoms present within the last month on a 3-point scale and the associated impact of the symptom manifestations on them (i.e. Caregiver Distress) using a 5-point scale. The NPI-Q provides symptom Severity and Distress ratings for each symptom reported, and total Severity and Distress scores reflecting the sum of individual domain scores.

Most informants will be able to complete the NPI-Q in 5 minutes or less. It is recommended that responses to the NPI-Q be reviewed for completeness by a clinician and for clarifying uncertainties after each administration. The first time an informant completes the NPI-Q, it may be useful to verbally review the instructions. In some instances, it may be necessary to conduct the NPI-Q in part or entirely as an interview.

The NPI and NPI-Q are both copyright-protected by Jeffrey L. Cummings, MD. The NPI-Q was developed by Daniel Kaufe, MD with permission. Use of the NPI or NPI-Q in investigational studies sponsored in whole or part by for-profit entities is prohibited without express written consent.

For inquiries regarding the NPI-Q, contact:

Jeffrey L. Cummings, MD
Mary S. Easton Center for Alzheimer’s Disease Research
10911 Weyburn Ave; #200
Los Angeles, CA 90065
jcummings@mednet.ucla.edu

The NPI-Q can be found at:
www.NPItest.net
Please answer the following questions based on changes that have occurred since the patient first began to experience memory problems.

Circle "Yes" only if the symptom(s) has been present in the last month. Otherwise, circle "No". For each item marked "Yes":

a) Rate the SEVERITY of the symptom (how it affects the patient):
   1 = Mild (noticeable, but not a significant change)
   2 = Moderate (significant, but not a dramatic change)
   3 = Severe (very marked or prominent, a dramatic change)

b) Rate the DISTRESS you experience due to that symptom (how it affects you):
   0 = Not distressing at all
   1 = Minimal (slightly distressing, not a problem to cope with)
   2 = Mild (not very distressing, generally easy to cope with)
   3 = Moderate (fairly distressing, not always easy to cope with)
   4 = Severe (very distressing, difficult to cope with)
   5 = Extreme or Very Severe (extremely distressing, unable to cope with)

Please answer each question carefully. Ask for assistance if you have any questions.

**Delusions**

Does the patient have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her in some way?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>SEVERITY: 1 2 3</td>
<td>DISTRESS: 0 1 2 3 4 5</td>
</tr>
</tbody>
</table>

**Hallucinations**

Does the patient have hallucinations such as false visions or voices? Does he or she seem to hear or see things that are not present?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>SEVERITY: 1 2 3</td>
<td>DISTRESS: 0 1 2 3 4 5</td>
</tr>
</tbody>
</table>

**Agitation/Aggression**

Is the patient resistive to help from others at times, or hard to handle?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>SEVERITY: 1 2 3</td>
<td>DISTRESS: 0 1 2 3 4 5</td>
</tr>
<tr>
<td><strong>Depression/Dysphoria</strong></td>
<td>Does the patient seem sad or say that he/she is depressed?</td>
</tr>
<tr>
<td>--------------------------</td>
<td>------------------------------------------------------------</td>
</tr>
<tr>
<td>Yes No</td>
<td>SEVERITY: 1 2 3   DISTRESS: 0 1 2 3 4 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Anxiety</strong></th>
<th>Does the patient become upset when separated from you? Does he/she have any other signs of nervousness such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes No</td>
<td>SEVERITY: 1 2 3   DISTRESS: 0 1 2 3 4 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Elation/Euphoria</strong></th>
<th>Does the patient appear to feel too good or act excessively happy?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes No</td>
<td>SEVERITY: 1 2 3   DISTRESS: 0 1 2 3 4 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Apathy/Indifference</strong></th>
<th>Does the patient seem less interested in his/her usual activities or in the activities and plans of others?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes No</td>
<td>SEVERITY: 1 2 3   DISTRESS: 0 1 2 3 4 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Disinhibition</strong></th>
<th>Does the patient seem to act impulsively, for example, talking to strangers as if he/she knows them, or saying things that may hurt people’s feelings?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes No</td>
<td>SEVERITY: 1 2 3   DISTRESS: 0 1 2 3 4 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Irritability/Lability</strong></th>
<th>Is the patient impatient and cranky? Does he/she have difficulty coping with delays or waiting for planned activities?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes No</td>
<td>SEVERITY: 1 2 3   DISTRESS: 0 1 2 3 4 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Motor Disturbance</strong></th>
<th>Does the patient engage in repetitive activities such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes No</td>
<td>SEVERITY: 1 2 3   DISTRESS: 0 1 2 3 4 5</td>
</tr>
</tbody>
</table>
**Nighttime Behaviors**  Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

| SEVERITY: | 1 | 2 | 3 | DISTRESS: | 0 | 1 | 2 | 3 | 4 | 5 |

**Appetite/Eating**  Has the patient lost or gained weight, or had a change in the type of food he/she likes?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

<p>| SEVERITY: | 1 | 2 | 3 | DISTRESS: | 0 | 1 | 2 | 3 | 4 | 5 |</p>
<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Severity</th>
<th>Caregiver Distress</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Delusions</strong></td>
<td>0</td>
<td>1 2 3</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td><strong>Hallucinations</strong></td>
<td>0</td>
<td>1 2 3</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td><strong>Agitation/Aggression</strong></td>
<td>0</td>
<td>1 2 3</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td><strong>Dysphoria/Depression</strong></td>
<td>0</td>
<td>1 2 3</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
<td>0</td>
<td>1 2 3</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td><strong>Euphoria/Elation</strong></td>
<td>0</td>
<td>1 2 3</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td><strong>Apathy/Indifference</strong></td>
<td>0</td>
<td>1 2 3</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td><strong>Disinhibition</strong></td>
<td>0</td>
<td>1 2 3</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td><strong>Irritability/Lability</strong></td>
<td>0</td>
<td>1 2 3</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td><strong>Aberrant Motor</strong></td>
<td>0</td>
<td>1 2 3</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td><strong>Nighttime Behavior</strong></td>
<td>0</td>
<td>1 2 3</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td><strong>Appetite/Eating</strong></td>
<td>0</td>
<td>1 2 3</td>
<td>0 1 2 3 4 5</td>
</tr>
</tbody>
</table>

**TOTAL**
APPENDIX 5: Example stimuli from neuropsychological tests of cortical visual function

5.a Incomplete letters – VOSP (Warrington and James, 1991)
5.b Dot counting – VOSP (Warrington and James, 1991)
5.c Figure-ground discrimination – VOSP (Warrington and James, 1991)

APPENDIX 6: Example of digitised time log, end of day field notes, reflexivity notes and layout notes/sketches

Maurice observation notes:
<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.45-10</td>
<td>[wife] “Maurice would usually doze off in his chair at this time” Briefing on days plans, might hoover when [wife] out/wait til gets back Breakfast (verbal description or actual?) Difficulty with taking apron off [wife] -&gt; hairdressers</td>
</tr>
<tr>
<td>10-10.15</td>
<td>Me and Maurice chatting re: job, music, personal history Word-finding difficulties (patient – he was patient with it/asking me to be patient?)</td>
</tr>
<tr>
<td>10.15-30</td>
<td>Chatting re: job and music Word-finding problems Asking me if I want to chat Responsibility to entertain/interest me?</td>
</tr>
<tr>
<td>10.30-45</td>
<td>“my fingers don’t belong to me” Talking about friend at Singing for the Brain (him being ‘worse’ than Maurice but Maurice keen to establish a way to communicate) Model engineering [wife] back Maurice forgot to take medication</td>
</tr>
<tr>
<td>10.45-11</td>
<td>Coffee and biscuits and chatting Talking about local support services</td>
</tr>
<tr>
<td>11-11.15</td>
<td>Chatting re: family Stresses and strains (relationships) Chatting re: holiday</td>
</tr>
<tr>
<td>11.15-30</td>
<td>Chatting re: holiday planning Having coffee Chatting about eating and mealtimes Hand-eye drifting problems; glasses lens cover (demoed) “I’m not looking where I think I should be looking”</td>
</tr>
<tr>
<td>11.30-45</td>
<td>Glasses lens cover Large magnifier Chatting re: sourcing adaptations and assistive tech (incl. telling time, bowls, magnification) Problems with things designed for people with solely eye-related visual problems (dexterity, spatial)</td>
</tr>
<tr>
<td>11.45-12.40</td>
<td>Neuropsychology</td>
</tr>
<tr>
<td>12.40-1.10</td>
<td>Maurice giving directions Chatting in kitchen Emma to Tesco for lunch</td>
</tr>
<tr>
<td>1.10-2</td>
<td>Lunch</td>
</tr>
<tr>
<td>Time</td>
<td>Event</td>
</tr>
<tr>
<td>-------</td>
<td>-------</td>
</tr>
</tbody>
</table>
| 2-2.30 | QoL-AD questionnaire | - spoke about computer magazines during and how he’d like to donate them to a group who could make use of them but that’s the sort of thing he can’t independently initiate any more. 
- Maurice asking [wife] for a drink; she runs through options (water, tea, orange, coke) he replies to each (‘no, no, no, yes’). |
| 2.30-3 | Walkaround with [wife] (for luminance measurements?) | - Lighting path -> loo at night |
| 3-3.15 | [wife] showed me photos on computer of lathe, model engineering, etc. | - Maurice asleep when we returned to lounge |
| 3.15-45 | Quiz and clues – [wife] reads questions and gives clues if Maurice struggling | - Maurice says “wait a minute” while he tries to say answer 
- Hoovering suggested? 
- Cup of tea 
- Maurice is tired |
| 3.45-4 | [wife] explains Maurice not v mobile atm otherwise could’ve seen Maurice in and out of the patio doors and up/down the step to the garden | - Maurice questions re: what the research is for 
- Stairs (for all) 
- The old house (Maurice misses it) 
- Chatting re: their history |
| 4-4.15 | Chatting re: research and tech | - Maurice checking whether [wife] got his photos to show me 
- Chatting re: day centre |
| 4.15-5 | Emma went to do luminance measures and sorting out tech | - Maurice to loo 
- Emma chatting with [wife] re: career, their daughter (passed away) |
| 5-6 | Emma chatting with [wife] re: the course of the day, timings, a typical day? | - [wife] off upstairs to do jobs (meter readings etc.) 
- Maurice mostly asleep, some reading of computer magazine |
| 6.05-6.25 | Maurice awake with computer magazine | - “I need a new head” 
- [wife] puts Eggheads on television 
- Chatting w Maurice re: model engineering, magazines |
Maurice definitely tiring throughout course of the day

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.25-7.30</td>
<td>Dinner; chatting re: family, neighbours, travels, etc.</td>
</tr>
<tr>
<td>7.30-end</td>
<td>Chocolates</td>
</tr>
<tr>
<td></td>
<td>Debrief and thank you</td>
</tr>
<tr>
<td></td>
<td>Emma and [wife] to do 3rd luminance measures</td>
</tr>
<tr>
<td></td>
<td>Maurice picking up fluff from floor and pacing/looking for bin while we did that</td>
</tr>
</tbody>
</table>

Miscellaneous extras:

Didn’t want to do exercises that [wife] suggested (or hoovering) but did take mug out each time and pick fluff up off the floor (i.e. exertion in other ways)

Verbal reminders and prompts were not always successful (e.g. medication and handwashing) and [wife] knows he forgets

(in conversation with Mary Pat) Think about the demands on carer’s time – i.e. should she let him sleep and get on w chores versus find activities to stimulate?

Finding that balance...

Maurice has a pendant alarm for when [wife] is out but could he locate the button properly? Have they tested this? Or is it just thee to serve another indirect purpose e.g. to increase his confidence or reduce her worry

Appears to get a lot of enjoyment from talking about things even if he can’t participate in them any more

Lighting: Changed lighting in hallway and downstairs loo to LED

Lighting makes a big difference

Some sensor lights and hallways lights left on upstairs and bathroom mirror lights to light way to loo in the night

Sensor lights stay on for 1 min

10am lighting walkaround – [wife] mentioned Maurice uses upstairs loo because forgets to lift seat in downstairs one

Reflexivity:
Maybe I’m obsessing too much about validity and thoroughness and consistency and I shouldn’t be; maybe the way they are going to be as open as poss is by feeling comfy with me and so that is my validity/rigour tool?

Think about who/what video and audio is for (all came about bc 360 overheated and turned itself off and I hadn’t realised and then panicked)

[wife] said ‘thank you for being you’ when I thanked them at the end of the day

How to interpret that which we only see later in footage e.g. picking up fluff when me and [wife] doing luminance

My sensitivities re: drawing attention to failings – can you actually read the words in the magazine? Oh I suppose not now you ask

Already knew them – progression and familiarity (comfortable quickly but signs of decline upsetting)

My previous awareness of [wife] burden and previous caring role

End of visit field notes:

! pick your feet up
! put glasses on
! you’re hopeless
[wife] tries to let him get on with things as far as poss
He’ll ask for help when he needs it e.g. coke

He seems concerned re: her level of burden/not wanting to be a burden to her e.g. encouraging her to go to Hatfield House without him

He demonstrated frustration at his symptoms but always patient and good-humoured to me about them and great social skills with me (what shall we talk about now then?)

Seems v happy go lucky on the surface but acknowledged there are bigger underlying issues

Discrepancies in how they view sleeping:

Maurice: bc of boredom, sad, a waste
[wife]: fondly teasing as though it’s an indulgence
Discrepancies in how they talk about his magazine collection:

Maurice: want to do something useful with them; would like to find someone to give them too but can’t do that independently

[wife]: need to get rid of/taking up space

Profound physical difficulties; gets around with some aids, some caregiver assistance, some withdrawal from activities

Psychosocial impacts seem to be of huge significance

Feels worthwhile for helping with research (and would like to know outputs!)

Humour – intact and appears to be hugely important for coping

He sits and sleeps a lot (out of boredom – misses being busy with work)

Ongoing jokes throughout the say like strawberries and cream (me being naughty for getting the cream even though was Maurice’s suggestion; ‘I never forget chocolates’ after dinner)

Still connection psychosocially/relationally e.g. via quiz, [wife] provides clues but was quite equalising of them in that context; a shared activity that he can excel at/feels competent at;

? music show/creative quiz/ Eggheads

[wife] experience with caring for daughter and finding it draining and needing respite

Maurice’s gratitude and looking out for [wife]

OBJECTS:

magazine (still looks at them although can’t read them anymore – wasn’t necessarily sure about that until I asked?)

model engineering, lathe (and photos – keen to show friend at Singing for the Brain and me and he followed up about this)

apron – required for spillages but hard to get a masculine one (who’s that important for?)

Stage of life and untimeliness (he’d love to still be working, was so busy and never stopped on the floor of the print line he worked on)

“I need a new head”
“My hands aren’t mine”
“Wait a minute” (talking to self during word finding difficulties)
Wanting to know more about his friend at Singing for the Brain who has similar/worse speech problems
V socially motivated and astute (huge discrepancy between that and ability to act)
Family: v proud of grandchildren; ‘dysfunctional’ in places; [wife]’s sibling(s) provided help when [wife] broke her shoulder
Went to loo upstairs even though further away and arguably/objectively more complicated to get to but does so because has trouble with the loo seat down in the downstairs loo (i.e. it’s not just about distance/efficiency/navigational challenges)
Also inconsistency between finding taps in upstairs bathroom and downstairs kitchen even though pretty much same taps (chrome) – perhaps coffee in sink in kitchen was visually confusing
Wanting to be useful – always took mug out; picking up fluff from carpet at the end of the day, is that in an effort to be useful or out of agitation?

Layout:
Sketch in field notes of main room layouts and lighting pathway to loo they use at night
He sits mostly in a chair opposite the patio doors at far end of the living room (closest to
TV)

1 page time log:
9:30: Arrived
9:45: Handshakes and chatting
10:30: Setting up
Coffee + chatting
11:15: Demonstrating eye-hand drift + avoidance aid / adaptation
11:45: Neuropsychology tests.
1:10: Lunch
2: Caregiver questionnaire
2:30: Caregiver workshop, OH + Moff + doing
guests
3:15: 8 am cup of tea
chatting
4:15: + fauna chatting
5: Uptown for church
6: Dinner + magazine (Mediterranean)
6:30: Dinner
7:10: Shopping + photos
7:30: Picking up friends
8:30: Departs
9:30: Return
APPENDIX 7: Example Atlas.ti (7) outputs

7.a Coding framework – Phase I Interviews

* Family & marital history
* marital and family history
* Visual (quickfind)
* Family and marital history
? vision related (quick find)
  1. Stressors
    1.1 Participation
    1.1.a Hobbies
    1.1.a.i Reading (e.g. novels, the paper)
    1.1.a.i Sports
    1.1.b Useful
    1.1.b.i Writing
    1.1.b.i Reading (e.g. labels, instructions)
    1.1.b.ii Driving
    1.1.b.iii DIY
    1.1.b.iv Employment
    1.1.c Boredom
  1.10 Relationships
    1.10.a Marital
    1.10.a.i Clinginess
    1.10.a.ii Lack of privacy
    1.10.a.iii Mothering (e.g. monitoring)
    1.10.b Family
    1.10.b.i Family strain
    1.10.b.ii Child/parent responsibilities (e.g. teenage children/elderly parents)
    1.10.b.iii Lack of support/understanding from family
    1.10.c Friends
    1.10.c.i Avoidance (them avoiding patient)
    1.10.c.ii Practical difficulties in visiting them
    1.10.c.iii Lack of support/understanding from friends
    1.11 Wider/broader social environments/contexts
    1.11.a Communication
    1.11.a.i Dysphasia/aphasia (expressive or receptive, difficulties generating or understanding speech/language)
    1.11.b Social comparisons

1.11.c Fear of judgement
1.11.d Roles
1.11.d.i Existing role(s)
1.11.d.ii Lost role(s)
1.11.d.iii New role(s)
1.11.d.iv Power shift/swapping roles
1.2 Home environment
1.2.a General home environment
1.2.a.i Stairs
1.2.a.ii Clutter
1.2.a.iii Orientation
1.2.b Technology
1.2.b.i Phone
1.2.b.ii TV/Radio
1.2.b.iii Appliances
1.2.c Self care
1.2.c.i Eating
1.2.c.ii Preparing food/drinks
1.2.c.iii Washing
1.2.c.iv Dressing
1.2.c.v Toileting
1.3 Wider physical environment (i.e. not at home)
1.3.a Public transport
1.3.a.i Crowds
1.3.a.ii Speed
1.3.a.iii Escalators
1.3.b Roads
1.3.c Public toilets
1.3.d Navigation
1.4 Broader physical environment (i.e. factors that apply across environments)
1.4.a Reflective surfaces
1.4.a.i Mirrors
1.4.a.ii Glassware
1.4.b Light levels
1.4.b.1 Darkness
1.4.b.2 Shadows
1.4.b.iii Slire
1.4.c Patient safety
1.4.c.i Patient coming to harm
1.4.d.i Patient being left alone
1.4.d Unfamiliarity
1.4.d.i Unfamiliar places
1.4.d.ii Unfamiliar objects
1.5 The disease
1.5.a The nature of it
1.5.a.i The nature of it (e.g. progressive)
1.5.a.ii The nature of it (e.g. progressive)
1.5.a.iii Inconsistent profile
1.5.a.iiii Rarity
1.5.a.iii ‘Invisability’ (i.e. others may not immediately know something’s wrong)
1.5.b Healthcare
1.5.b.i Attending appointments
1.5.b.ii Testing/scanning (MMSE, MRI etc.)
1.5.c Professionals
1.5.d Physiological symptoms
1.5.d.i Balance
1.5.d.ii Headaches
1.5.d.iii Medication side effects
1.5.d.iv Sleep
1.5.d.v Tired/Irritated eyes (etc.)
1.6 Intrapersona/the self
1.6.a Personality factors
1.6.a.i Impatience
1.6.a.ii Sociable
1.6.b Mood/emotion
1.6.b.i Anxiety/worry
1.6.b.ii Depression
1.6.c Identity
1.6.c.i Loss of confidence
1.6.c.ii Loss of independence
1.6.d Feeling a sense of burden
1.6.d.i Concern about caregiving abilities
1.7 Cognitive symptoms
1.7.a Memory
1.7.b Insight
1.7.b.i Preserved
1.7.b.ii Lossing
1.7.c Language
1.7.c.i Dysphasia/aphasia (expressive or receptive; difficulties generating or understanding speech/language)
1.8 What’s ahead
1.8.a Fear of the future
1.8.a.i Uncertainty
1.8.a.ii Hopelessness
1.8.b Making changes
1.8.b.i Ongoing adjustment
1.8.b.ii Significant changes (e.g. moving bedroom)
1.9 Resources
1.9.a Support services
1.9.a.i National
1.9.a.ii Local
1.9.a.iii Online
1.9.a.iv Support groups
1.9.a.v Linkage
1.9.b Money
1.9.b.i Own financial situation
1.9.b.ii Financial support
1.9.c Time
2. Coping strategies
2.1 Physical assistance
2.1.a Physical aids (homemade)
2.1.a.i Visual markers (e.g. stickers, labelling)
2.1.a.ii Memo board/calendar/diary
2.1.b Assistive technologies
2.1.b.i Audio books
2.1.b.ii Talking watch/clock
2.1.b.iii Sensor-controlled lighting
2.1.b.iv Pendant alarm
2.1.b.v Coloured items (e.g. crockery, loo seat)
2.1.b.vi Grab rails
2.1.b.vii Symbol care
2.1.c Physical support from carer
2.1.c.i Carer helping with tasks
2.1.c.ii Carer doing tasks
2.1.d Prompts/reminders
2.1.d.i Food
2.1.d.ii Drink
2.1.e Marital
2.1.e.i Letting patient persevere
2.1.e.ii Working as a team
2.1.e.iii Mothering/monitoring
2.1.b Family support
2.1.c Friends
2.1.c.i Old
2.1.c.ii New
2.1.d Support from neighbours
2.11 Wider/broader social environment/contexts
2.11.a Help-seeking
2.11.a.i Seeking reassurance
2.11.a.ii Asking for assistance
2.11.a.iii Talking it through
2.11.b Keeping socially busy
2.11.c Avoidant techniques
2.11.c.i Having ‘me’ time
2.11.c.ii Social withdrawal
2.11.c.iii Hiding difficulties
2.11.d Social comparisons
2.11.e Roles
2.11.e.i Existing role(s)
2.11.e.ii Lost role(s)
2.11.e.iii New role(s)
2.11.e.iv Power shift/swapping roles
2.2 Physical activity
2.2.a Increasing physical activity
2.2.a.i Walking
2.2.a.ii Maintaining physical activity levels
2.2.b.i Walking
2.2.c Reducing physical activity
2.2.d Physical avoidance (of certain places/objects)
2.3 Wider/broader physical environment (i.e. across multiple environments)
2.3.a Trips out
2.3.a.i Adjusting mode of transport
2.3.a.ii Adjusting route
2.3.a.iii Using disabled toilets
2.3.b Familiarity (inc. keeping things in the same place)
2.3.c Simplifying the environment
2.3.d Lighting
2.4 The disease
2.4.a Research participation
2.4.b Healthcare
2.4.b.i Medication
2.4.b.ii Attending appointments
2.4.c The nature of it
2.4.c.i ‘Invisibility’ (i.e. others wouldn’t immediately know something is wrong)
2.4.c.ii Rarity (e.g. feeling like a ‘celebrity’ patient)
2.5 Cognitive skills
2.5.a Concentrating
2.5.b Memory (PCA mainly)
2.6 Intrapersonal/the self
2.6.a Personality factors
2.6.a.i Stubborn
2.6.a.ii Adaptive
2.6.a.iii Being proactive
2.6.b Previous life experience/events
2.6.b.i Illness
2.6.b.ii Loss of a loved one
2.6.b.iii Preserving identity
2.7 Attitudinal/existential approach
2.7.a Positive
2.7.a.i Focusing on positives
2.7.a.ii Humour
2.7.b Confronting the diagnosis
2.7.b.i Getting on with it
2.7.b.ii Acceptance/coming to terms
2.7.b.iii Resignation
2.7.c Avoiding the diagnosis
2.7.c.i Denial
2.7.c.ii Detachment (e.g. from the diagnosis; from the patient – ‘make sure he’s fed and watered’)
2.7.c.iii Blaming the disease
2.7.c.iv Protection/collusion
2.7.c.v Normalising (e.g. ‘I think most people our age would struggle with that though’)
2.8 What’s ahead
2.8.a Planning
2.8.a.i Planning ahead
2.8.a.ii Living day to day
2.8.b Continuity/change
2.8.b.i Ongoing adjustment
2.8.b.ii Significant changes (e.g. moving bedroom downstairs)
2.8.b.iii Maintaining normality
2.9 Resources
2.9.a Support services
2.9.a.i National
2.9.a.ii Local
2.9.a.iii Online
2.9.a.iv Support groups
2.9.a.v Linkage
2.9.b Money
2.9.b.i Own
2.9.b.ii Financial support
2.9.c Time
2.9.d Information
2.9.d.i Having a diagnosis
2.9.d.ii Information provided by professionals
2.9 d. iii Self-driven information seeking
3. Information
3.2. a. Quality
3.2. a. i. Good
3.2. a. ii. Poor
3.2. b. Amount provided (by professionals)
3.2. b. i. Lots
3.2. b. ii. Little
3.2. d. Accessibility of self-sought info
3.2. d. i. Easy to find
3.2. d. ii. Hard to find
3.3. Professionals
3.3. a. Type
3.3. a. i. GP
3.3. a. ii. Optician/optometrist
3.3. a. iii. Neurologist
3.3. a. iv. Psychologist
3.3. b. Knowledge
3.3. b. i. Well-informed about condition
3.3. b. ii. Lack of knowledge about condition
3.3. c. Bedside manner/phrasing
3.3. c. i. Sensitive and helpful
3.3. c. ii. Insensitive and unhelpful
3.3. d. Communication with other professionals
3.4. Accuracy
3.4. a. Misdiagnosis
3.4. a. i. Stroke
3.4. a. ii. Eye condition
3.4. b. Level of certainty/confidence
3.4. c. Co-existing problems
3.4. c. i. Eye-related
3.4. c. ii. Balance related
3.5. First noticed
3.5. a. Problem type
3.5. a. i. Memory
3.5. a. ii. Visual problems
3.5. b. Who noticed by
3.5. b. i. Patient
3.5. b. ii. Carer
3.5. b. iii. Family
3.5. b. iv. Friends/neighbours
3.5. b. v. Colleagues
3.6. Time taken
3.6. a. Time taken
3.6. a. i. Less than 6 months
3.6. a. ii. 6-12 months
3.6. a. iii. More than 12 months
3.6. b. Acceptability
3.6. b. i. Unacceptably long process
3.6. b. ii. Efficient process
7.b Coding framework – Phase II Home-based observations

Code-Filter: All

HU: Home-based observations DRC 240818
File: [C:\Users\harding\Documents\Scientific Software..\Home-based observations DRC 240818.hpr7]
Edited by: Super
Date/Time: 2019-11-25 10:33:31

Acceptance (of diagnosis; of no longer being able to do things; of needing help from others; etc.)
Aids, adaptations, assistive tech, (off-the-shelf, specialised, home-made; etc.)
Anxiety
Apathy
Awareness/attribute/explanation/insight into/knowledge of symptoms/difficulties (PWD or carer’s)
Being alone (PWD)
Burden (PWD feeling like one; carer burden; carer competence concerns; etc.)
Carer giving verbal assistance/guidance/instruction
Carer physically helping (i.e. hands on doing things; getting things; demonstrating things; etc.)
CHECK BACK THROUGH 1-7 Simplifying
Clutter
Co-morbidities (e.g. eye-health problems; mobility issues; etc.)
Compensating/finding ways around things
Confidence DO QUERY
Conflict/tension/discrepancies
Context and background factors: career/employment status/missing work/ etc.
Context and background factors: personality type/style/traits
Context and background factors: previous interests/experience/life events
Context and background factors: previous/existing relationship quality
Depression DO QUERY for 1-13
Diagnostic journey/healthcare/first symptoms
Disorientation/getting lost/way-finding/navigating
Doing new things since diagnosis (e.g. piano playing)
Dressing
Driving
Eating/drinking/food preparation/etc.
Engaging with support services (age-appropriateness; pros and cons; etc.)
EXPAND NAME? preservation/protection of dignity/identity/independence/personhood
Facing the future DO QUERY for 1-13
Family
Finances/money/handling cash/bills/etc.
Finding things to do/boredom
Finding/using things
Friends
Frustration/anger/irritation
Gardening
Glass
Having to stop doing tasks
Home improvements (e.g. reorganising, stair-lift; down-sizing, etc.)
Household chores (e.g. hoovering, washing up, making beds, laundry)
Humour
Interest/in/ability to/motivation to socially connect with others (e.g. engaged in conversation)
Jigsaws/puzzles/crosswords
Keeping things the same/familiarity
Lighting
Meaningful objects
Medication
Mirrors
Music
NEEDS MAJOR UNPACKING & LIT REVIEW Meaningful/useful/purposeful activity
NEEDS RE-WORKING & REVIEWING PWD asking for help
NEEDS REWORKING Getting on with it/maintaining normality/keeping going/keeping trying
Neighbours
News; current affairs
normalising/making comparisons/feeling lucky
organising
Other self-care (e.g. handwashing, grooming, toileting)
PCA symptoms (all/other)
PCA symptoms: memory
PCA symptoms: motor/propriorceptive/...
PCA symptoms: speech/language problems
PCA symptoms: visuo perceptual or visuopatral
people distancing/not understanding/fear of judgement/stigma
phone
Photos
Public places/external environments - challenging (e.g. geographical location, supermarket, etc.)
Public places/external environments - supportive (e.g. neighbourhood, library)
PWD expressing concern about me (MERGE WITH REFLEXIVITY?)
PWD having caring responsibilities for others MERGE W DURDEN?
Reaching/grasping/holding objects
Reading/books/magazines
Reflexivity: me as participant/my involvement
Reminders/prompts
RENAME AND UNPACK Time: inconsistent/unpredictable/always changing/ongoing
adjustment/seasons/change across day/progression
Repetitive questions/comments
Research participation/motivation/conscientiousness
REVIEW - DOES THIS NEED TO BE EXPLICIT STATEMENT OR CAN BE MY INFERENCE?INTERPRETATION?
MERGE WITH FINDING THINGS TO DO?BOREDOM?Keeping busy/stimulated
REVIEW & CONSIDER HOW FITS W TIME + DO QUERIES?"A typical day", good days and bad days;
unpredictability, etc.
Safety (risk, concerns, etc.)
Sequencing/forgetting steps/axtypical order
Shopping
Speed/slowness/effortful processing/trying harder/taking time/etc.
Sports/leisure
Stress DO QUERY
tAD symptoms (all/other)
tAD symptoms: (potential) perceptual problem
tAD symptoms: confusion
tAD symptoms: language/speech problems
tAD symptoms: memory
tAD symptoms: motor symptoms
Tech/gadgets
The physical home environment (e.g. doors, design, etc.)
Time: age of onset/time of life/socio-cultural or historical context
Time: altered perception of it
Tiredness/sleep
Transport/travel QUERY FOR CYCLING (e.g. public transport, holidays, etc.)
TV/film
Visual cues/aids (e.g. labelling, colour contrast)
Walking
Working as a team
Writing
7.c Initial coding example – Phase I Interviews

Camilla: I can answer the phone okay, but I still can’t really...

Jack: see, you’ve got a receiver in the hallway there which amplifies, and I’ve got a pad there with nine numbers on which... but even that, Camilla, does struggle to interpret. All she’ll do is pick up the receiver and press the button, press a number, and you get the... and you get your call through to... And you do it sometimes, but then she hit a blank.

Camilla: Well, yes, but I still think that I don’t use it enough, because you’re always around. So if the phone rings I say, I’ll do it, I’ll get it. Well, I’ll grab it and then she’ll come and say, you know, ‘Oh, yes, sorry Camilla, thank you, I don’t... Not that I want to, don’t get me wrong, but certain things I do... I’d like to do it regularly, I’m sure I could, but I don’t know, do it. And then you don’t want to be caught up not knowing what to do when you thought you knew how to do it because it would be a pain, wouldn’t it, because I wouldn’t be right. I might do something wrong.

00:45:40

IV. Yes.

Camilla: So that’s what I think, I think... I do things in the house, don’t I? I do certain things are my jobs.

Jack: Yes, you. Obviously, now, mainly when I’m around, and so you do things. Yes, it... You know, Camilla used to... I used to go off... I only play golf once a week, but I used to go off and have tea in the Hawes, but then they went through the war as a couple of times, didn’t you, so I thought I can’t really leave that because it’s... You know, even though she can do the hoovering...

Camilla: I used to love doing ‘hoovering’ [00:46:19] all sorts.

Jack: The actual doing [?], what we can see, you know, she’ll run across the bed, and that was a taboo, you know, sort of... And so...

Camilla: That’s it, he said, you are not having it again.

Jack: Stopped doing that, you know.

00:46:95

Camilla: I couldn’t even do the hoovering. And the hoovering, well, the hoover’s a drag, you know, isn’t it? It frightens me to death, the hoover, I mean, I’ve just done a bit, what, three pairs or four pairs...?

Jack: What, headscarf?

Camilla: Headscarf, because I’m determined I’m not going to get... No I’ll do the headscarf. You know, I can do them because they’re flat and all of them, you know. I’ve just done the morning the bedroom, whereas he does all the morning and everything now. And I say, oh, that’s my job.

IV. That’s your thing, yes.

Camilla: I’m determined. I’m not going...
7.d Initial coding example – Phase II Home-based observations
APPENDIX 8: Key case summary index cards
APPENDIX 9: Case summaries (four questions about activities)

9.a Alan

Alan was a 64 year old retired sound system installer who had been diagnosed with PCA two years previously, having first noticed symptoms 10 years before that. He lived at home with his wife and according to his MMSE score of 5, was the most severely cognitively impaired participant in the study. He showed impaired performance on the neuropsychological tests of naming and on the figure ground discrimination and fragmented letter tests of visual perception. He declined the remaining tests. Alan was severely impaired on ADL functions overall and on each individual subscale except for self-care which he showed moderate impairment in. Alan and his wife rated his QoL as excellent and good respectively.

What activities did people do? What activities were they motivated toward/interested in?

Alan had some significant difficulties engaging both verbally and physically but despite that, initiated two separate rounds of a relatively new-found pastime of leaf-clearing in the front and back gardens - this involved Alan walking around the garden and collecting up the dried leaves from the floor to put in the garden waste. He also was clearly very engaged by and motivated to participate in conversations about numerous topics including tales of their travels abroad, Christmas and his previous love of driving and cars. Apart from this, and necessary ADL functions like eating lunch and handwashing, the only other thing Alan independently initiated or engaged with throughout the day was when he got up to adjust the volume levels on the sound system while watching the news towards the end of the day. He also spoke keenly about a regular film club he and [Alan’s wife] had with another couple of whom the husband had a diagnosis of PCA.

2) How was engagement in those things/activities challenged?
Alan was no longer able to drive because of his compromised visual processing. He was still able to travel with [Alan’s wife] but wasn’t able to contribute to the practical or physical organisation of such trips in any way. The leaf-clearing was challenged by Alan’s visual processing problems and as such he would miss whole sections or odd leaves depending on where he was attending to. He also found it difficult in the back garden where there were also weeds and plants growing, to tell these apart from the dead leaves he was trying to clear. The most evident challenge to Alan’s engagement throughout the day – and something he agreed with [Alan’s wife] was his ‘biggest challenge’ – was his extremely effortful speech and significant word-finding difficulties. He also had quite evident anxiety and some motor symptoms including tremors, jerks and proprioceptive difficulties which affected things like his ability to hold his yoghurt pot and stir it at the same time and his ability to interlace his fingers properly when hand washing.

3) How was engagement in those things/activities supported?

Although he’d been forced to withdraw from driving himself, Alan’s ongoing engagement with his love of driving was cued (and therefore arguably engaged) by the environment, e.g. when leaf-picking around the car he stopped and reflected on how much he missed it and how important it had been to him and engaged me in a conversation about it. One way Alan continued his ongoing engagement in his and [Alan’s wife]’s holidays and other travel plans was in his volunteering of suggestions and his opinions on possible location choices (both past and future).

Leaf-picking was something Alan initiated and completed largely independently, with [Alan’s wife] supporting him to get his shoes and jacket on and then with hand washing afterwards. [Alan’s wife] did this mostly with physical demonstrations of what he needed to do but also verbal prompts and descriptions and sometimes more hands on helping. Alan dealt with his missing of some of the leaves by persevering and doing multiple rounds of the garden/driveway until they were all cleared. Alan employed a similar approach when it came to his word-finding –
accepting and being open to [Alan’s wife]’s (and my) help, while employing a determined perseverance. This took the form of a guessing game which we played several times throughout the course of the day, with Alan attempting to show [Alan’s wife] and I by physical gesture, pointing at relevant objects, making a similar sound to the object and continually trying again to pronounce the word, until one of us got it (which Alan would acknowledge with a cheer or clap).

4) WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

Driving and engaging with the sound system were both very clear examples of long standing interests of Alan’s that he was attempting to maintain engagement in, albeit in a different way since his diagnosis. His motivation for and the meaning of the film club seemed to be in the importance he placed on supporting others (rather than say entertainment or occupation), as he explained he liked to think he could provide some comfort and help to the other person with PCA who had now become a friend. This motivation and meaning-making chimed with what he had said he found rewarding about his career in sound system installations – that he got great satisfaction from the feeling of having arriving to a tangled mess of wires and a flustered customer and then doing the practical, hands-on problem solving needed to untangle and rewire/reorganise the system, and to be able to leave the customer feeling relieved that things were sorted and working. This sense of satisfaction from hands on problem solving seemed to be what motivated the leaf-picking too – an entirely new activity he had taken up because of the space in the day left by the things he could no longer do (working and driving). During leaf-picking Alan explained emphatically that he enjoyed it because it was ‘doing something’ and gestured with his hands to imply that it was the hands on nature of the task that he found fulfilling. He also made reference to wanting to offer to do the neighbours’ gardens too, which seemed another nod to it being the ‘helpful’ nature of tasks which was a key motivator for Alan. This vital social component to activity also seemed to underlie Alan’s effortful but enduring perseverance with
speaking despite his profound difficulties with it – throughout the entire visit he made repeated efforts to share stories with me and check in with me that I was OK and comfortable (e.g. that I wasn’t getting cold when we were outside leaf-picking), in a way that could only suggest that looking out for, being hospitable to or just generally socially connecting with others was important enough to persevere with despite the described difficulties.

9.b Anita

Anita was a retired special educational needs teacher and at 88 years old at the time of the visit, one of the oldest participants in the study. Anita lived in a large home in the suburbs of London with her husband of more than 60 years who had been registered blind 30 years previously. Anita had been diagnosed with AD at the age of 86 after first experiencing symptoms at 84. Anita had an MMSE score of 27 indicating normal cognitive functioning and only demonstrated impaired performance on two of the neuropsychology tests – naming and dot counting. Anita had minimal impairment of functioning in 3 of the ADL subscales (self-care, travel and transport and communication) and showed no impairment in household care, employment and recreation or shopping and money. Anita and her husband rated her QoL as good and excellent respectively.

What activities did people do? What activities were they motivated toward/interested in?

The activities Anita seemed most engaged in over the course of the day were preparing lunch for the three of us and later in the afternoon playing the piano to us both, then enjoying wine and crisps with [Anita’s husband] as they waited for dinner to cook while I was packing up to leave. Anita was also very engaged and enthused throughout the day when telling stories about her interesting international family history and when telling me about a book she was enjoying reading for a second time and which she thought I might enjoy too.
2) How was engagement in those things/activities challenged?

Anita was very highly functioning and had very little observable difficulty throughout the day, but I noted that when making coffee in the morning she seemed confused by the label on the front of the jar, spending longer than you might expect looking at it. Regarding the book she had enjoyed more than once, Anita explained that she couldn’t remember what it had been about, but that she knew she’d definitely enjoyed reading it nonetheless, and she also had difficulty recalling some of the details of her family history. These memory difficulties were also exemplified in Anita’s repeated questions to me, most notably when asking if I would care to join them for a glass of wine at the end of the visit. Anita showed very little difficulty in her piano playing which she did by ear, but AUDGA made reference to the fact that she didn’t cite-read music any more, but there had been such a large gap between Anita’s previously piano playing in her teens to now that it was difficult to know how much this was attributable to her AD symptoms rather than other factors. Anita didn’t appear to have any difficulties when preparing lunch and recalled the preferences of [Anita’s husband] and me regarding our filling choices.

3) How was engagement in those things/activities supported?

Anita asked [Anita’s husband] for help with recalling the details of her family history and regarding whether she was doing the right thing with the coffee jar that she’d seemed confused about. It was also [Anita’s husband] who let Anita know that she had already asked certain questions (e.g. if I wanted a glass of wine), and this was pointed out playfully and chuckled about between the three of us. Most of the support provided by [Anita’s husband] for Anita was verbal, (rather than physical), and it seems important to take note of the context here and how it determined the use of support strategies, as AUDGA was registered blind himself, so a lot of physical assistance and support was delivered by Anita to him, as opposed to the other way around.
Anita’s memory difficulties with reading weren’t ‘supported’ in any concrete way, and Anita didn’t seem to be seeking any support with that – despite her difficulty recalling the narrative of the book she continued to read it (and recommend it) on the basis of how the book made her feel (and perhaps it was the forgetting of the narrative which encouraged her re-reading and resulted in this repeated enjoyment).

4) WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

Anita was clearly very fond of and proud of her family history and their previous overcoming of various hardships which seemed to underlie her joy in recounting those stories to me. Reading seemed to provide a lasting sense of enjoyment for Anita even if the factual content of the narrative wasn’t retained beyond the time of reading, and it also offered a means of social connection as Anita recommended the book to me and enthused about how much she thought I’d enjoy it. Interestingly, though two seemingly quite disparate activities, the lunch preparation and piano playing seemed to share a common purpose or meaning in that they both offered Anita opportunities to demonstrate her care and affection for [Anita’s husband]. She checked all his preferences for his sandwiches and during her piano playing repeatedly asked him if there was anything else he would like to hear her play. [Anita’s husband] noted that she’d only recently resumed playing since stopping in her teens so despite their having been married for over 60 years, he was now hearing her play for the first time. They mentioned she’d previously cite-read music but that now was playing by ear and I wondered if like with reading, Anita’s diagnosis or symptoms may have fostered a new approach to her engagement with the feeling and intention of the activity (i.e. as a gesture of care towards [Anita’s husband]) more so than the following of a particular set structure or pattern as dictated by sheet music (as with the book’s narrative contents). I took this to be a prioritisation of quality of experience and feeling over efficacy or accuracy of activity execution and felt this was mirrored and further captured in Anita and
[Anita’s husband]’s consumption of wine and crisps towards the end of the home visit. More specifically, AUDGA tipped the crisps into a bowl and largely missed, leaving crisps scattered across the table, but rather than drawing attention to this or tidying them up, Anita proceeded to just pick them up from where they were. This activity also seemed to serve an additional socially connective purpose above and beyond a purely functional one of curbing hunger and hydration as the two sat very closely together and affectionately swapped stories and jokes while I packed up around them.

9.c Betty

At 88 Betty was one of the oldest participants in the study – she’d been diagnosed with AD five years previously and lived with her partner of 20 years in a large home in the suburbs. Betty had mobility issues after a double hip replacement some years earlier and walked using a frame. She had previously been a model. Her MMSE score was 15 indicating moderate impairment and she showed impaired performance on the sRMT(w) and naming. Betty was rated as exhibiting delusions and aberrant motor behaviours on the NPI. She was maximally impaired in ADLs overall, and on all of the subscales except for self-care (moderate impairment) and communication (mild impairment). Betty and her partner rated her QoL as excellent and good respectively.

What activities did people do? What activities were they motivated toward/interested in?

Betty’s mobility was very impaired, so we spent the majority of the day sitting and chatting in the conservatory. Betty mentioned that had I not been there she would probably have been looking at her art books, and towards the end of the visit she got very engaged in a conversation with [Betty’s partner] about some artworks they were having valued. During our conversations Betty was particularly engaged in topics including her nearby family particularly her grandsons, the flowers she had recently been gifted which were on display throughout the house, the garden and
her planned works for it (e.g. building a small swimming pool and repainting the
gate) and in offering to help [Betty’s partner] tidy up after lunch and sharing her
thoughts on the ingredients and where they should be stored. Betty did very little
physical activity during the course of the day, but of what she did do the things she
seemed particularly motivated towards or engaged in included (what seemed to be)
pushing her cuticles down, ‘playing’ with the remaining peas after lunch (using a
spoon to push them all into a circle) and repetitively wiping the spotted tablecloth
after lunch.

How was engagement in those things/activities challenged?

Betty’s main means of engaging with topics on the day was verbally and it seemed
the biggest challenges to her physically engaging with any activities were her
mobility issues but also possibly a lack of motivation. She reflected on this at several
points, remarking that she was ‘lazy now’ and contrasted this with her having been
very active and involved in lots of activities when she was young. She said this in a
way that was very light-hearted and cheerful, almost self-mocking, which [Betty’s
partner] joined in with and gently teased her about.

It was difficult to disentangle how much some of Betty’s physical engagements with
the environment were exacerbated by (or could entirely be conceptualised as)
aberrant motor behaviours. Betty’s ‘cuticle pushing’ seemed to go on for longer
than might be typical and was in fact ineffective because her nails were already
painted. Similarly with the playing with the peas, it’s difficult to say just from
observing whether this was intentional goal-directed or perseverative action. Betty
eventually ate some spoonfuls of the peas once she’d finished organising them into
a pile, and again it’s difficult to say whether this was an active intention or
potentially a utilisation behaviour. Additionally, with the joining up of the dots on
the tablecloth, it was hard to distinguish at which points this changed between
being more functional wiping of the crumbs from the table to perseverative or
aberrant joining up of the dots. It seemed the latter wasn’t entirely passive and

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without reflection or awareness though, as Betty commented she would help with tidying when she had finished ‘doing the dots’.

How was engagement in those things/activities supported?

Betty’s lack of independent initiation of activities was largely supported by [Betty’s partner]’s taking on of all the physical tasks, but it was notable that he made efforts to ensure Betty didn’t feel guilty about this imbalance. The two had a fond and affectionate running joke throughout the day relating to Betty’s plans or what she was going to ‘do’, and something repeatedly joked about as a top priority of hers was ‘solving the crisis in outer Mongolia’. Similarly, when Betty repeatedly offered to help with clearing up after lunch (despite it being quite apparent that she’d have difficulty carrying anything to put it away because of her needing the frame when mobilising), [Betty’s partner] went along with her intention to help, rather than disputing whether or not she could, or even telling her not to worry, he acknowledged and endorsed her concerns about him doing it all and it not being fair and said that perhaps she could clear up the wine. [Betty’s partner] placed the wine in front of Betty for a while, which seemed to reduce Betty’s concerns about not helping as she began to talk about other topics again. [Betty’s partner] then eventually cleared the wine away himself but it appeared he intentionally waited enough time that Betty would have forgotten that that was a job that had been allocated to her.

This difficulty with engaging physically with activities seemed overall to be dealt with using humour and a prioritisation of verbal communication and engagement throughout the day. Betty and [Betty’s partner] had almost constant fond and affectionate banter throughout the home visit and, similarly to the after lunch helping (and [Betty’s partner]’s verbal endorsement of Betty’s attempts at helping even if these couldn’t be executed physically), with lunch preparations, though Betty couldn’t help physically she was consulted by [Betty’s partner] on her
preferences and choices and she too volunteered lots of thoughts and opinions about how various ingredients should be stored and tidied away.

Along with [Betty’s partner]’s prompting, objects in the environment also seemed to cue Betty’s engagement in topics and activities. For example the spots on the tablecloth and the remaining peas after lunch (in fact it seemed that even conversations about her long standing interests could be triggered by environmental cues - for example seeing the flowers or looking out to the garden).

WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

Some topics or activities Betty most engaged in (even if only verbally) were things of long standing importance to her like her family, her interest in gardening and arguably her cuticle pushing as she had previously been a model and very invested in her appearance (which was clearly still maintained by others on her behalf as her nails were painted beautifully and she was extremely well presented).

It also seems important to acknowledge that these activities must have served a purpose for [Betty’s partner] too, that there was something to be gained for him - whether directly or by proxy - in his orchestration of opportunities for Betty to make her opinions/ preferences/ intentions known or to otherwise participate or contribute. In doing so he enabled Betty’s continuing engagement and involvement in what seemed like a very fond and affectionate dialogue throughout the day. The overarching motivation for and purpose of activities they engaged in or spoke about seemed to be for them to socially connect and to generally have a nice time together. It may not have been particularly balanced in terms of productivity but this didn’t seem to be an issue for either party (as I had seen this be for others) and there was a general sense that they were having fun and enjoying passing time together. Perhaps given their age and time of life, other health conditions and previous experiences ([Betty’s partner] had raised his children largely alone around
his military career) any challenges to Betty’s previous means of engagement were easier to adjust to and accept.

9.d Brian

[Demographics and quant measures and general description of day/house?]

Brian was a 75 year old retired accountant who had been diagnosed with AD four years previously. He lived at home with his wife and had an MMSE of 30 indicating normal cognitive functioning. His performance on all other neuropsychological tests was in the normal range but he had mild impairment on ADL function overall (specifically he was performing as usual on the household care and shopping and money subscales, was mildly impaired on the self-care and employment and recreation and communication subscales and moderately so on the travel and transport subscale). Brian was reported as displaying a number of neuropsychiatric symptoms but he and his wife both rated his QoL as good.

What activities did people do? What activities were they motivated toward/interested in?

During the course of the day Brian was most engaged in doing crosswords, helping his wife with problems she was having with the computer’s connection to the printer and with the thermostat and looking up where Singapore was on the globe (after we had been discussing his travels). He spoke about enjoying ‘throwing himself into research projects’ and various community groups for older people that he was part of, a running club and also how he enjoyed spending time reading and watching different television series. He made cups of coffee for the two of us throughout the day and made himself a crumpet between meals.

2) How was engagement in those things/activities challenged?

Brian described having noticed problems with his memory and mentioned specifically having difficulty with remembering characters in books or on TV series
and their relationships to each other. When preparing the coffees and crumpet he also appeared to have some difficulties with finding things (looking in multiple cupboards for some things) and potentially with sequencing, for example he placed the kettle back on the surface rather than on its stand initially and then went back to it after getting the coffee. He also mentioned having recently slowed down at running.

Brian had some word finding difficulties throughout the day which is how the search for Singapore on the globe came about – when recounting stories from his travels he had trouble remembering the word ‘Singapore’ and then repeatedly tried to bring it to mind throughout the day, as what appeared to be a sort of test to himself. He also had some difficulty with some of the answers to the crossword puzzles he was working through.

3) How was engagement in those things/activities supported?

To remind himself of characters in books Brian kept notes about them inside the cover so that he could refer to them when needed. When having trouble finding things or with sequencing during hot drink and food preparation he persevered rather than asking for help and managed eventually to find all the things he needed and to return them to where they needed to go.

Similarly with trying to remember the word ‘Singapore’, Brian kept trying and was keen that neither me nor his wife jump in to help and was visibly pleased when he eventually managed to recall it without any assistance.

One instance in which Brian’s engagement in activities was supported by others was in his running group, where he mentioned that other runners had slowed down in order to run with him. He seemed quite touched as he spoke about this and went on to describe how he had noticed a marked change in his sociability since the onset of his AD and the associated difficulties.
When struggling with crossword puzzle answers Brian initially involved me, asking me if I knew some of the answers, though this didn’t seem wholly representative of his usual approach as he eventually continued alone with this when I began filling in some paperwork i.e. he didn’t ask his wife to assist.

Brian’s fond recollections of his tales of travelling seemed to be supported by cues from the physical environment, for example, souvenir objects or photos playing in a loop on the computer screen appeared to act as prompts for his revisiting and retelling of those experiences.

4) WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

Brian was open about his concerns about his cognitive function and vigilant about noticing any decline (e.g. he tried to check his scores with me and then against his own recollections during the neuropsychological testing) and it seemed his main motivation for the activities he was very engaged in was to keep his brain stimulated and engaged – similarly to how he looked after his physical health. This seemed to explain the purpose of activities such as doing crosswords as well as engaging with books and television series with complex character profiles and plotlines. He didn’t avoid the issue of cognitive decline as some others who had expressed their concerns about it had done – if anything he confronted it very openly e.g. via his regular research participation and challenging himself to recall the word ‘Singapore’ so frequently throughout the day. It seemed he had long prioritised his intellectual capabilities and physical fitness, but his throwing himself into social activities was a relatively new approach. It’s possible Brian was becoming more socially oriented owing to his - so far very subtle- gradually increasing dependence, or perhaps his own awareness that this would happen. Counter to this confrontation of his current health status, Brian’s recounting stories of his previous travels seemed to offer a connection to perhaps happier or more carefree times in his life.
Brian assisting his wife with technology (i.e. the printer and thermostat) seemed to be meaningful for a few reasons. He’d always been very techie and those things had always been his allocated jobs so it seemed to offer him some continuation of his role, identity/sense of self. He’d also mentioned with some sense of pride that even though he was slowing down physically in his sports clubs he was still the one who managed the group communications because no one else could figure out the technology. Linked to this maintenance of identity it seemed it was also important for him to maintain his independence and one of the contributory reasons for this seemed to be his not wanting to be a burden on his wife, which he spoke about candidly when she popped to the shops. He explained she’d always taken responsibility for the organising of things and he was wary of her having to take on any more. This too seemed fitting with the support strategies he relied on (e.g. perseverance and self reliance).

9.e Eleanor

Eleanor was a 74-year-old retired nurse who had been diagnosed eight years previously after first noticing symptoms four years prior to that. Eleanor lived with her partner [Eleanor’s partner] in a county they’d relatively recently relocated to in order to be near their close friends. Eleanor’s MMSE score was 20 indicating moderate impairment, and while she performed in the normal range on the digit span test of working memory and the naming test, she showed impaired performance on the dot counting task and was untestable on the remaining tests. Eleanor was maximally impaired on ALDs overall and on all subscales except the Communication one which she was rated as moderately impaired on. Eleanor rated her QoL as Good and her partner rated it as Fair.

What activities did people do? What activities were they motivated toward/interested in?

As I arrived Eleanor and [Eleanor’s partner] were disagreeing about whether Eleanor’s t shirt and vest were supposed to be tucked in or not, and [Eleanor’s
partner] mentioned to me later that choosing outfits and dressing was an important activity for Eleanor and something she took care and pride in. However, Eleanor did very little else physically during the day and spent most of it watching quiz shows on the television. Aside from that Eleanor was mostly interacting with me and [Eleanor’s partner] and that’s certainly what she seemed most engaged in – conversation. Eleanor told me about her career as a nurse which she missed dearly, her wonderful friends living close-by who they’d relocated to be near and how much she enjoyed her research participation.

How was engagement in those things/activities challenged?

Eleanor’s mobility and coordination was significantly challenged and when moving between her TV chair and the dining table and the bathroom she did a lot of ‘furniture-walking’. Eleanor’s reaching and fine motor skills were also quite challenged (she would frequently put things down in an unstable position or wide-reach for objects or grasp them inaccurately) and this impacted her engagement with television watching as she struggled to use even the simplified and specially adapted remote control which had minimal buttons all brightly coloured. Eleanor seemed to be having difficulty placing her thumb on the button she was intending to, despite a lot of effort and concentration and her good articulation of what she was attempting as she was attempting it.

[Eleanor’s partner] described the difficulties Eleanor had with dressing when we did our walk-around tour, particularly how much trouble she had with finding the particular individual items she had in mind for a given outfit.

Eleanor’s involvement in the activities she found most engaging such as research participation, her career and meeting up with various friends were all challenged by her cognitive impairment as she couldn’t independently initiate, organise or transport herself in order to be involved in these sorts of activities.

How was engagement in those things/activities supported?
Eleanor relied heavily on her partner [Eleanor’s partner] to coordinate her activities and for a lot of physical hands on assistance and had had to withdraw from a range of activities or accept doing less of them because of her difficulties. [Eleanor’s partner] showed me what they called the ‘gadget corner’ which contained a range of assistive technologies designed to increase Eleanor’s independence, including the simplified remote control and various lighting options, but they both described how these things had become redundant and no longer helped Eleanor because of the spatial and other cognitive impairments accompanying her visual processing problems.

Similarly, strategies [Eleanor’s partner] had put in place for labelling bedroom cupboards and drawers with coloured labels to signify which items of which colour could be found where, were no longer useful (only for EARSI). [Eleanor’s partner] now supported Eleanor with dressing by tidying up the numerous discarded items Eleanor had tried on and decided against during her morning dressing routine.

Despite her mobility difficulties and visuospatial processing problems Eleanor persevered with moving around the home when there was something she was curious to see, e.g. whether [Eleanor’s partner]’s car was on the drive, and if the sunlight was causing a glare on my notes and if I needed the blind closed. Eleanor also preserved with the remote control and self-talked as she concentrated on pressing the right button.

WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

SOCIAL CONNECTION

It seemed that one of the most overarching motivators for the activities Eleanor engaged in (in conversation mostly) was that of social connection. Her previous career very was socially-oriented – she described the privilege she’d had as nurse to hear other people’s stories and accompany them in such vulnerable times and
expressed her enviousness of me currently being on the side of the table I was on and how much she’d like to trade places.

Eleanor she was also very socially attuned as demonstrated by her detection of my discomfort at her and EARSI’s conflict about the vest/top tucking in when I arrived (‘don’t worry we’ve always been this abrasive’) and also socially conscientious, as she described her concerns about the burden it would place on [Eleanor’s partner] if they were to try to make it to the London PCA support group meetings where she’d be able to fulfil her motivations to connect with others on a similar journey. In that sense, perhaps Eleanor’s solitary and seemingly quite passive television watching could be conceptualised as a gesture of care towards [Eleanor’s partner] in that it was an activity [Eleanor’s partner] didn’t have to assist with and therefore not burdensome ([Eleanor’s partner] used the time Eleanor spent watching television to do household chores).

As well as her concerns about others Eleanor was also clearly very motivated towards her own self-presentation. This was observed from the importance and investment she made in her dressing activities through to how readily and regularly she voiced her opinions and preferences throughout the day - she said herself that she was ‘difficult, and long may I be!’. This active engagement socially or intellectually perhaps was extra important to Eleanor given the difficulties she was now having interacting with the physical environment. It seemed fitting with this and the above that her preference for television watching was quiz shows - something which she could interact and actively engage with and which provided an opportunity for her to demonstrate her knowledge and intellectual capabilities.

Eleanor’s keen involvement in medical research perhaps offered some sense of continuation and familiarity with her previous career (which was very important to her) and new means of engaging in activities she considered to be socially worthwhile and purposeful.
9.f Helena

Helena was 75 years old and had been diagnosed with AD 6 years previously. She lived in a three storey townhouse in London with her husband, daughter, son-in-law and two grandchildren. Helena and [Helena’s husband] had spent most of their married life in Italy and had returned to the UK in the last couple of years for proximity to their family due to Helena’s progressing condition. Helena had the lowest MMSE score of all the AD participants (10/30) and declined the majority of the neuropsychological assessment, asking if we could say ‘basta’ which means ‘stop/enough’ in Italian (Helena moved between the two languages throughout the day). Helena was moderately impaired in ADL functioning overall – severely on the recreation and employment, shopping and money and travel and transport subscales; moderately on the communication and household chores subscales and mildly on the self-care subscale. Both Helena and [Helena’s husband] rated her QoL as good.

What activities did people do? What activities were they motivated toward/interested in?

Helena completed a number of household chores throughout the visit, including making her and [Helena’s husband]’s and her daughter and son-in-law’s beds, hanging, folding and sorting laundry and setting the table, all of which she did alone. She also loaded and unloaded the dishwasher and ran errands in town with [Helena’s husband]. Although Helena didn’t initiate the activities, she appeared engaged throughout them, as demonstrated by her questioning where a certain cushion she wanted to put on the bed was, and making repeated efforts to wind the iron cable up correctly. I also noted that she seemed particularly motivated towards making sure I was comfortable and OK throughout – whether that was reiterating that it was fine for me to be observing, insisting I find somewhere comfortable to sit or reassuring me that there was no rush for us to get through the visit protocol.

2) How was engagement in those things/activities challenged?

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Perhaps the biggest challenge to Helena’s completion of these activities was the ability to independently initiate them. There also seemed to be some issues during the completion of various chores which seemed to represent difficulties with sequencing, remembering where things were stored and seeing/perceiving objects accurately, although the exact nature of the difficulties was at times difficult to discern/ambiguous. I was also unsure whether Helena’s insight into her own difficulties would be sufficient for me to prompt and ask about this for clarification. With sequencing, Helena appeared to have difficulty knowing which clothes were dry, which were damp, which had already been pegged up to dry and which still needed to be, when she did the laundry. In terms of remembering where things were stored, Helena had difficulty knowing where to put the Tupperware when unloading the dishwasher (though it’s also difficult to say whether this was a problem with recognising the object or memory for its home in the kitchen). I had wondered if an impairment in visual processing and seeing/recognising objects accurately was a possibility because of Helena’s difficulties with: locating a cushion she was looking for to place on the made bed, handling and placing down of a set of stacked drinking glasses she was given by [Helena’s husband] to set out for lunch, and knowing if the coat and shoes [Helena’s husband] had handed her to put on for their trip into town were hers.

Helena also demonstrated some restlessness and anxiety throughout the day, particularly in relation to the home visit schedule.

3) How was engagement in those things/activities supported?

Helena’s impressive productivity despite her lack of initiation of activities was possible owing to [Helena’s husband]’s verbal prompting, and once engaged in an activity Helena would persevere with it even when faced with difficulties e.g. with the iron cord, or finding the cushion, Helena would keep trying. It was less clear if Helena was aware of the sequencing difficulties with the laundry and with that [Helena’s husband] did seem to do some subtle checking. A strategy Helena
employed a number of times was to ask for help from me (e.g. with where the cushion would be and where the Tupperware should be put away to), which was perhaps further evidence of her memory impairment but also evidence that she was happy to ask for help when having difficulties. As well as help, Helena also asked for reassurance from [Helena’s husband] about the plan for the day (though interestingly she did this away from me, and to me would insist that I didn’t need to rush and that she was happy to proceed).

Helena’s engagement in activities was also perhaps supported by cues from the environment, as seemed to be the case when a spoon fell from its rest as [Helena’s husband] was cooking lunch and Helena was the first to respond to catch it. It was also perhaps what supported Helena’s continued engagement in the household chores through to completion despite the fact that she hadn’t independently initiated them.

4) WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

It seemed familiarity and routine were important elements of the activities Helena undertook – when I asked if she enjoyed the bed-making she replied that she was ‘used to it’ with a smile. The engagement in activities did also seem to serve as a means by which Helena could be occupied and her anxiety/restlessness reduced, though her involvement of activities was mostly orchestrated by [Helena’s husband], illustrating the importance of relationality in this context, and acknowledging that the meanings of activities can in fact be shared, or even constructed by one person on behalf of another. To make the context wider still, in living in an intergenerational household with two school aged children and two adults in full-time employment, there was also what seemed a very practical purpose of Helena’s continued engagement in these household in that they were essential for the efficient running of the household for all of those sharing it.
9.g Lionel

Lionel was a 76 year old retired dentist who had only recently been diagnosed with AD despite first noticing symptoms 5 years previously. He lived in a 4 bedroom flat in an apartment complex on the outskirts of London and the family owned a second flat in the same block which he was shortly planning to relocate to. He lived with one of his two daughters and a granddaughter with complex health needs and two of her full-time carers. His wife had died 20 years previously. His MMSE score was 22 indicating moderate levels of impairment and his daughter rated him as having a number of neuropsychiatric symptoms. His neuropsychological profile showed impairments on the tests of naming and figure ground discrimination. In terms of ADL impairment, Lionel could do self-care tasks as usual but showed mild impairment on the travel and transport and communication subscales and moderate impairment on the household chores, employment and recreation and shopping and money subscales. Both he and his daughter rated his QoL as good.

What activities did people do? What activities were they motivated toward/interested in?

The activities Lionel was most engaged in and motivated towards on the day was preparation of two meals (lunch and dinner) and preparing his granddaughter’s medication. He also went to spend time with his granddaughter several times throughout the day. Several other household chores and administrative tasks were discussed as important to Lionel by both himself and his daughters and those included: laundry, ironing, handling post, taking phone messages, diary planning, filing and organising the move to the flat downstairs. In terms of activities outside of the house, Lionel described his driving one of his ex-patients who also has a diagnosis of dementia to a support group they both attended as giving him a sense of satisfaction.

2) How was engagement in those things/activities challenged?
Lionel showed some difficulty knowing where to find or put different lunchtime ingredients – his daughter mentioned it was harder with things like condiments (of which some go in the fridge and some in the cupboard) than things like salad which more universally belong in the fridge. His daughter also described how several times he’d mistimed the laundry airing and had too hastily put it away when it was still slightly damp and this had turned out to be very dangerous for his granddaughter because of her respiratory issues. Lionel was also having some difficulty with locating things like various sets of keys and with recalling and relaying phone messages accurately and selecting the right diary to write his scheduled activities in. His daughter also described him purchasing lots of excess stationary. While he was still very motivated to prepare his granddaughter’s medication his daughter described this as one of the only remaining activities he completed totally independently and that it had recently become challenged somewhat by Lionel’s disorientation to time as when they were out he would become worried and anxious many hours before it was due that they wouldn’t be home in time for him to prepare it.

3) How was engagement in those things/activities supported?

Lionel rarely seemed to ask for help proactively, rather his daughter(s) would notice that something was becoming problematic and then implement a strategy to deal with that (e.g. him appearing confused looking in the fridge for a long time was prompted with ‘Are you OK dad? What are you looking for?’). His daughter would also offer verbal reassurance when he worried about being home in time for his granddaughter’s medication. There were many physical adaptations too but these would always be sensitively introduced and discussed with Lionel and the family were quite open throughout the day about the psychosocial implications of some of these strategies. An example of this sensitivity was that Lionel’s daughter would periodically quietly offer the excess stationary to her daughter’s carers rather than confront Lionel about there being too much of it. His daughter had also set up a separate phone line and labelled their diaries very clearly to remind him which was
which. They had agreed in conversation to reallocate the responsibility for doing the laundry to Lionel’s daughter because of the risks but it had become necessary to put a reminder sign on the washing machine about this, which Lionel described finding stigmatising and embarrassing to have on display when they hosted a birthday party for his granddaughter (it was temporarily taken down). The planned move for Lionel to the flat downstairs was considered an exercise in simplifying his living situation to increase his ability to manage his daily activities independently but his daughter was worried that any stress caused by the change and unfamiliarity could counteract this.

4) WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

Lionel seemed to want to continue the care-taking, household-running role he had taken within the family for many years, especially since his wife had passed away (more than 20 years ago). Even though he admitted to enjoying some household chores like ironing, which he found ‘very therapeutic’, his predominant motivation seemed to be to help - this was captured well by his daughter’s remark that he ‘sometimes just comes up to me, salutes and says ‘it’s me your humble servant – what can I do to help?’’. The care-taking aspect in his contribution to the running of the household was also evidenced to me in Lionel’s very apparent keenness to accommodate me and be hospitable - he repeatedly asked me about my preferences around certain ingredients when preparing lunch and his reiterated many times that he hoped everything tasted OK. Lionel also obviously had a great fondness for his granddaughter who he had previously shared the 24 hour caring responsibilities for. Many of the activities he really engaged with seemed to offer a continuation of existing roles of his – specifically relating to family caring and his role in the community as a respected and involved dentist who knew his patients well. It seemed there was a strong social component to this helpful role-taking in terms of the importance he placed on others’ perceptions of him, arguably demonstrated by his great pride in his sustained good relationships with previous
patients and reinforced by his hesitance to have the reminder note about him no longer doing the washing visible to guests at his granddaughter’s birthday party.

9. Lilian

Lilian was a 70 year old woman who had been a retail assistant in a chemist before retiring due to the onset of her symptoms at age 62, before she was diagnosed with PCA at 64. Her MMSE score was 14 indicating moderate impairment and she performed in the normal range on the forward digit span but showed impaired performance on the sRMT(w) and naming, and declined all the visual tasks. Lilian was maximally impaired on ADLs overall and on all subscales apart from self-care which she was moderately impaired on. Lilian and her husband both rated her QoL as Good.

1) What activities did people do? What activities were they motivated toward/interested in?

Lilian was particularly motivated towards getting ready for the day – she was in the bathroom grooming for a long time and commented that there was no rush these days so she could take her time. She then spent a while looking for a particular white jumper that she wanted to wear. She was also very motivated towards engaging with other people – she mentioned that this was one of the things she missed most about being able to get herself into town independently and spoke at length about the surprising and very satisfying close friendship she had developed with her professional carer. She also showed great interest in and concern for friends who called on the phone throughout the day and for me, and in conversations about her sons. Lilian was also very enthusiastic when talking about the interior design and décor of the house during our walk-around tour. She also made efforts to do some pottering and tidying of the kitchen surfaces, and spent long periods of the day watching television (which, in contrast to the other activities mentioned, she didn’t seem very engaged in).
2) How was engagement in those things/activities challenged?

Lilian’s independence was greatly limited by her visual processing problems and she could do very little alone with any confidence or accuracy. She had difficulty turning the television on and had long been unable to use the phone to contact friends or to travel outside of the home independently. She had difficulty with finding the jumper she was looking for and her shoes when changing out of her slippers to go for lunch. She also had difficulty replacing the lids on the tubes and tubs of cosmetics and toiletries she’d been using in the bathroom, and also with seeing or accurately grasping or placing down the glasses and other items on the draining board.

3) How was engagement in those things/activities supported?

[Lilian’s husband] supported Lilian by turning the television on when she was struggling with that and by giving her verbal instructions towards the handbag and slippers she couldn’t find before eventually helping physically. Lilian’s professional carer supported her in venturing out into town by providing her arm and organising the trips. Lilian just persevered with her grooming routine as far as I could tell – she spent a long time in the bathroom and clearly continued to use the tubes and tubs of cosmetics even though many didn’t have their lids or at all or properly and though she wouldn’t have been able to read their labels. Lilian also persevered with her pottering and clearing items from the draining board – as she did this she also had a look at the mince that [Lilian’s husband] was defrosting and commented that she would have done it differently, and even when she had trouble picking up the glass accurately, she remained motivated to be involved in what was going on in the kitchen.

Lilian also had had to withdraw from many activities like home décor, cooking and phoning friends because these weren’t possible for her to initiate independently anymore and because she was quite concerned about being reliant on people or a burden.
4) WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

It seemed very clear throughout the day and in a number of different discussed contexts that Lilian was an inherently social person who was most motivated to continue engaging in activities that offered her a chance to connect with others. She was very caring and considerate towards me throughout the day and about those phoning and towards her professional carer, but was very limited in how she could demonstrate those gestures of care because of her symptoms. She could ask [Lilian’s husband] after the welfare of the people who called, but couldn’t initiate a call to them herself – [Lilian’s husband] acted as the gatekeeper of this information which was meaningful for Lilian, and he didn’t seem to prioritise or be very motivated towards Lilian’s fulfilment of these acts of care as he withheld information and brushed aside her concerns (despite her repeatedly asking).

As well as social connections it seemed clear that Lilian had also valued aesthetics and both her and the household’s presentation or appearance. This was demonstrated in her lengthy grooming, particularity regarding which jumper she wanted to wear and in her disclosing how difficult she found it no longer being able to be involved in the home décor. [Lilian’s husband] clearly shared Lilian’s prioritisation of her personal grooming and appearance as they both described the active role he took in taking her shopping and describing colours and patterns to her so that she could select outfits. This seemed in stark contrast to the sense of importance he attached to activities of social connection for Lilian. One of her most meaningful social connections seemed to be with her professional carer, and it seemed particularly to be the reciprocity of the relationship that Lilian found meaningful. She described how the carer accompanied her into town and helped her to navigate but that in turn Lilian had introduced the carer to some areas in town that she hadn’t known of before which she’d really appreciated.
Despite the difficulties, Lilian’s attempted perseverance with engaging in activities which aligned with her long standing interests, preferences and values seemed to contribute towards an attempt to maintain her identity and sense of self. In support of this interpretation, Lilian was quite self-referential throughout the visit, commenting for example that she had always been ‘a sparkles girl’ when it came to her fashion choices.

9.i Mandy

[Demographics and quant measures and general description of day/house?]

Mandy was a 72-year-old retired medical secretary who continued to work part-time in her local garden centre. She lived with her long term partner in a quiet residential area they had just relocated back to for proximity to her family. Mandy was diagnosed with AD two years previously, shortly after noticing symptoms. She had an MMSE score of 19 indicating moderate impairment but of the neuropsychological tests administered she only showed impaired performance on the backwards digit span. Her ADL function was mildly impaired overall – specifically she showed mild impairment on the household chores, travel and transport and communication subscales but performance as usual on the others. Mandy and her partner rated her QoL as excellent and good respectively.

What activities did people do? What activities were they motivated toward/interested in?

We spent the bulk of the home visit watching the Winter Olympics on the television and Mandy seemed engaged throughout, frequently commenting on what was happening and asking me and her partner questions and for our thoughts. During our walk-around tour Mandy mentioned that sorting and organising the house (to which they were having a lot of work done) was a real priority of hers, and she seemed anxious to be making progress with that whenever we came across any stacks of piled up boxes. Mandy also described an exercise class she regularly
attends and thoroughly enjoys, as well as her part-time work at the local garden centre. She also expressed several times how much she wanted to continue to be involved in research participation and that one of her fears when they recently relocated was that she’d no longer be eligible to remain on our research register.

How was engagement in those things/activities challenged?

Mandy’s main observable symptom was her memory impairment and this was made clear by her consistent repetitive questioning throughout the home visit. She repeatedly directed a small number of questions to me and her partner about which Winter Olympic sport we would be best at, and whether we’d be as good as the athletes we were watching, and this was all in good humour. She also seemed to have some difficulty using the control to turn the television on.

Mandy’s memory problems also seemed to be challenging her progress with the household sorting, as even though she’d described several times its importance to her, it seemed that she wasn’t able to hold that pressing need to complete that task, but rather would be reminded of it as she came across boxes on her walk through various parts of the home.

How was engagement in those things/activities supported?

Generally, Mandy and her partner seemed to take a normalising approach to her difficulties – from the completion of the NPI during which Mandy’s partner acknowledged that she exhibited some of the symptoms but ‘no more than anyone else would’ and ‘not in a way that needs to be written down on a questionnaire’. This approach was also applied when Mandy had difficulties with the remote – she made a few light hearted comments (again all in good humour) about it being the remote that was the problem rather than her, and that she was having ‘a funny moment’ but which she and her partner agreed everybody has sometimes, before he took over with the remote. In response to her repeated questions during the television watching, her partner and I both responded each time as if it was the first
time we’d been asked the question, i.e. not drawing attention to Mandy’s repetition.

As mentioned, the household sorting seemed to be ‘supported’ by cues in the environment – it was upon coming across boxes that Mandy would begin talking about the importance of doing this again. However, the task wasn’t supported beyond this point of Mandy’s being reminded of it (which in turn went on to cause further repeated worry and motivation to resolve it, but again, only fleetingly).

WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

The range of activities which were important to Mandy or which she seemed motivated to engage in (television viewing, part-time work at the garden centre, exercise classes, research participation and the sorting out of the house) seemed not to be linked by any particular common interest but more so by the fact that these were all means by which Mandy could stay occupied and engaged. She had no affiliation or connection to winter sports (exemplified by her repeated mentions that she could never do something like that) but happily passed several hours engaged in watching these. Similarly regarding her research participation, I had struggled to make sense of Mandy’s motivation to continue participating and to reconcile that with her and her partner’s seemingly shared denial of her difficulties. Indeed Mandy even commented at one point that she believed she was actually improving and getting better now, but the keenness to keep participating could perhaps best be understood as another way for Mandy to keep busy, which would be compatible with her reported enjoyment of participation in studies which required a lot of commitment in terms of time and travelling, often involving a stay overnight and a full couple of days of scheduled activities and tasks.

Mandy’s sense that she was getting better and her continued participation in research and exercise classes could also be understood together as being motivated by or serving the purpose of Mandy retaining health. She described the exercise...
class as being good for her, and also implied that her ‘getting better’ could make her a helpful research participant. Wanting to help others at this macro level perhaps chimes with the micro level social connections that Mandy was clearly motivated to make with her repeated questions and good humoured comments to me and her partner throughout the television viewing. The social connectivity her exercise class and work at the garden centre permitted also seemed to be an important purpose these activities served as Mandy mentioned the other people she got to catch up with when she discussed both.

Finally the house sorting seemed to be of necessary importance to Mandy for more pragmatic reasons - the sorting of boxes and decluttering was an inherent part of the process of down-sizing which they had recently initiated because of her condition.

9.j Mark

[Demographics and quant measures and general description of day/house?]

Mark was a 68 year old retired paediatric neurologist living with his wife and their dog in a large house in a small market town. Mark had been diagnosed with AD two years previously and first noticed symptoms two years prior to that. His MMSE score was 21 indicating mild impairment and he performed in the normal range throughout the neuropsychological assessment except for on the sRMT(w). Mark exhibited a number of neuropsychiatric symptoms and mild impairment in the self-care, shopping and money and communication subscales of the ADL measure and moderate impairment in the household care, employment and recreation and travel and transport subscales. He and his wife [Mark’s wife] both rated his QoL as good.

What activities did people do? What activities were they motivated toward/interested in?

Mark was regularly engaged in care-taking of the dog and the lighting of the fire throughout the day. He also cleared leaves in the garden and checked the firewood
store with [Mark’s wife] and they took the dog for a walk together during the morning. Mark also became very animated and enthusiastic telling stories about his previous jobs (bar work during medical school through to paediatric neurology) and tales of his family’s impressive musical history. We also spent some time listening to an album of his nephew’s and Mark remained very animated throughout. Later in the visit when I was completing questionnaires with [Mark’s wife] Mark spent some time playing the double bass in a separate music room.

2) How was engagement in those things/activities challenged?

Mark’s memory impairment was evident through his repeated story-telling and occasional repetitive questioning about the tasks his wife had asked him to do (e.g. clearing leaves from the garden). Some emotional lability also seemed evident during Mark’s animated story-telling, and he became very excitable and also very tearful (very quickly) on a couple of occasions. He had some difficulty in using the controls to get the sound system to work when trying to play the CD of his nephew and appeared slightly restless and anxious when I was about to begin questionnaires with [Mark’s wife] as to what he should do during that time.

3) How was engagement in those things/activities supported?

[Mark’s wife] provided repeated verbal reminders of the task Mark had forgotten he had been asked to do (leave clearing). She disclosed her concerns that this wasn’t the best approach as her instructions were not always understood by Mark, for reasons [Mark’s wife] couldn’t work out, and as such she would then rely on demonstration of or accompaniment during the activities. [Mark’s wife] also provided prompting suggestions for what Mark could do while we completed questionnaires (bass playing, which he did). It didn’t appear that Mark had very much difficulty with or needed support with the care-taking of the dog or tending to the fire – at one point he noticed the fire had gone out (sooner than I did) and he soon addressed it. It’s possible that cues in the environment were what repeatedly drew his attention to these activities and ensured they were regularly engaged with.
and responded to – for example the dog would make it known if anything was needed by pining for attention, and the fire provided continually changing and eye-catching visual stimulus and warmth when it was working, so that when it went out this pretty immediately obvious in the environment, which seemed to be what spurred Mark into action to relight it (i.e. he didn’t need to rely on his working memory for top-down reminders like you might need to if you were holding in mind a relative to call, or that you needed to hoover at some point on a given day). When struggling with the controls for the CD player, Mark persisted and used self-talk until he eventually got the machine working. It’s difficult to say how his story-telling was supported despite his emotional lability as it could be considered that the lability is almost what motivated the story-telling - the strong emotional resonance he felt with the tales - but it was certainly the case that he persisted with that too (whether it was despite or because of the emotional lability).

4) WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

It seemed that taking care of the dog and the fire offered Mark the opportunity for ownership of some tasks and a sense of responsibility – he referred to them both throughout the day as his ‘jobs’. This want to do something contributory and helpful was in keeping with his repeatedly asking if there was anything else at all he could help me with as he accompanied me on my walk-around tour of the house.

Listening to his nephew’s music was clearly very enjoyable for Mark but it seemed the reason he was motivated towards the activity was not solely for the continuation of a longstanding enjoyable pastime of his but also because of his sense of enduring pride in his family’s musical achievements. This is supported by both his repeated retellings of his mother’s and other family members’ musical accomplishments throughout the day but also in how he engaged me in his appreciation of it. For example, in asking me engaging, prompting questions e.g. ‘can you believe where this is going!’ which seemed to be an attempt to encourage
me to join him in his recognition of the admirable unpredictability of the pieces (it being a jazz album) and letting me know when there was a particularly impressive section coming up. There were numerous socially motivated elements to this exchange I felt – the music was simultaneously a way for Mark to connect to his own family and history and also to share this proud family history with me, an outsider. This proposed interpretation of the purpose/meaning of this activity is perhaps further supported by the fact that Mark’s solo playing of the bass was something initiated by his wife [Mark’s wife], i.e. engaging with music was not such a priority of his when it was a solo activity serving the purpose of occupying, engaging or distracting Mark, as opposed to a shared social musical encounter.

These driving motivations – connection with one’s past, connection with others, having responsibilities and playing a contributory or helping role were further supported by, compatible with and captured by Mark’s fond recollections of varied jobs and hobbies over the previous years (namely bar work, paediatric neurology and rugby playing) all of which he described having previously enjoyed so much because of the team-playing element that was common to them all. He brought these references up to date by relating them to his current situation with an equally fond description of marriage as being ‘the only team there is now’.

9.k Mike

[Demographics and quant measures and general description of day/house?]

Mike was a 73 year old living in London with his wife and a lodger in a 3 storey house. He had been diagnosed with AD that year after noticing symptoms three years previously and his MMSE score was 21 indicating mild impairment in cognitive function. Consistent with that, he showed impaired performance on the sRMT(w) but performed in the normal range on the other neuropsychological tests administered. Mike was rated as mildly impaired in overall ADL functioning, and on the self-care, household care, shopping and money and communication subscales, and moderately impaired on the employment and recreation and travel and
transport subscales. He was experiencing a number of neuropsychiatric symptoms including agitation, aggression and disinhibition but he and his wife rated his QoL as good and excellent respectively.

What activities did people do? What activities were they motivated toward/interested in?

During the day of the home visit Mike seemed most engaged in and spent most of his time reading and discussing his adjustment to his diagnosis. He and [Mike’s wife] described how he also enjoyed gardening and going for walks and bike rides. He showed around me his two guitar-making workshops - where he had previously spent the majority of his time - during our walk-around tour of the home and paused briefly to play one of the guitars.

2) How was engagement in those things/activities challenged?

Mike described his guitar-making having stalled or slowed and explained that he had orders he was behind on completing, but it was difficult to disentangle in which ways his symptoms may have been contributing to that. In the accounts he gave, it seemed as though he had some difficulty prioritising jobs accordingly and with his time management. [Mike’s wife], when talking about Mike’s continued enjoyment of walking and cycling, mentioned that new or unfamiliar routes could be challenging and Mike did also seem to demonstrate some disorientation at one point when he appeared of unsure which of the 3 landings he was on. It also became apparent that Mike had had some difficult conversations with customers of his and bank staff previously, in which he explained he had been accused of being very angry and uncooperative. Mike didn’t consider these to be reasonable assessments but (taken alongside reports from his wife) it seems likely that this may have been a function of the disinhibition he was experiencing.

3) How was engagement in those things/activities supported?
[Mike’s wife] mentioned that familiarity was helpful in allowing Mike to continue engaging in activities independently, e.g. familiar routes when cycling/walking, and how much easier it was to achieve familiarity at home than in the external environment. In terms of other activities, it seemed that Mike was withdrawing from those proving difficult (e.g. guitar-making) and instead was spending more time on those he had fewer difficulties with (e.g. reading), and could manage alone. I didn’t see Mike proactively ask for any help with anything during the course of the visit and had the sense that this may have been because previous communication about the provision and acceptance of assistance had been quite confrontational or difficult to navigate, perhaps again related to Mike’s disinhibition. It also seemed a possibility that this in turn may have been related to Mike’s apparent difficulty adjusting to or accepting the diagnosis and its impact.

4) WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

It seemed that the activities Mike most engaged with were those which he had previously enjoyed and which therefore allowed him to continue engaging with longstanding interests of his, and largely those which he was still able to do independently, perhaps to preserve a sense of independence and identity and to minimise the acknowledgement of his condition and the associated difficulties. This interpretation would also be compatible with his avoidance of other activities which were also very much based on longstanding interests of his (e.g. guitar-making) but which were proving difficult because of his symptoms and/or could not be continued independently via some familiarisation or simplification strategy (as opposed to seeking hands on assistance from someone else). In that sense, it seemed that the activities Mike continued to be motivated towards allowed him to continue to engage with the things he was interested in while also allowing him to continue to present himself as the highly functioning, articulate person he had always presented as.
9.1 Maurice

Maurice was a 79-year-old retired print floor manager who has been diagnosed with PCA three years previously after first noticing symptoms three years prior to that. He lived with his wife [Maurice’s wife]. Maurice’s MMSE score was 17 indicating moderate cognitive impairment and he performed in the normal range on the test of working memory (forward and backward digit span) and naming, but showed impaired performance on the figure ground discrimination task and was untestable on the remaining visual tasks. Maurice was rated at severely impaired on ADLs overall and on all subscales except for self-care, for which he was rated as moderately impaired. He and his wife rated his QoL as Good and Fair respectively.

What activities did people do? What activities were they motivated toward/interested in?

Maurice was very engaged socially and verbally although wasn’t able to do very much physically. He engaged in conversations about his previous career (he greatly missed being as busy as he had been), his local dementia singing group, how much he’d loved using computers, using his lathe and model engineering. He engaged in watching quiz shows on the television and doing a quiz with [Maurice’s wife]. The activities he physically engaged in were taking his mug out to the sink after each hot drink, flicking through computer magazines and picking up bits of fluff from the carpet and putting them in the waste paper basket.

How was engagement in those things/activities challenged?

Maurice was only able to engage in many of his preferred activities by talking about them because he had profound difficulties with seeing what and where things were and also sensing where he was in relation to things and even where parts of his body were in relation to others (‘my hands aren’t my own’). Maurice demonstrated difficulties finding and transferring into the seat of the armchair and dining chair, finding the bin when he’d been picking up bits of fluff from the carpet and using the
kitchen taps to wash his hands and spent most of the day sitting and chatting and dozing. He also exhibited word finding difficulties throughout the day and these were particularly evident when taking part in the quiz. He could no longer use the computer himself and when asked about the magazine he was flicking through he explained that he wasn’t in fact reading the text. He could no longer operate his lathe or do model engineering because of his difficulties with dexterity and coordination.

How was engagement in those things/activities supported?

Maurice largely had to withdraw from the activities he’d most engaged with prior to his diagnosis but he did find ways to maintain engagement with the subjects of those activities – for example he wanted to show me photographs of his model engineering accomplishments and lathe, and still looked through the computer magazines even though he couldn’t read the text any more. [Maurice’s wife] adjusted the quiz she was reading out from a quiz book for Maurice and provided tiered clues when he had difficulty remembering an answer or finding a word. Maurice also managed to stay engaged even when faced with word finding difficulties by asking [Maurice’s wife] and I to ‘wait a minute’ for him to find his words. Maurice’s PCA symptoms and the common but counterintuitive phenomenon that smaller things can be easier to see than larger seemed to support him in picking up bits of fluff from the carpet.

WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

Most of the things Maurice was engaged in were things which had been long standing interests of his and as such continued involvement with them seemed to provide some sense of continuity of interest, although it seemed significant that his mode of engaging with these things had changed somewhat. Beforehand, Maurice’s engagement with computing, model engineering, his lathe, his career had perhaps centred on accomplishment and productivity. and this was illustrated in his and
Maurice’s wife’s very different appraisals of his dozing in the afternoon – he thought this wasteful whereas Maurice’s wife thought it was almost a luxury. Maurice’s changing means of engaging with those topics seemed to be driven by a motivation for social connection these days. For example, he could no longer work or use the lathe or computer but wanted to make me aware of his previous achievements in those areas – so there was some motivation towards connecting with another person about those interests, and the purpose of that seemed to be for some continuation of Maurice’s sense of self and identity. This socially-connective motivation seemed to fit with the good humour Maurice displayed throughout the day. However, there were also a couple of modes of engagement that seemed to be predominantly motivated by purely pro-social purposes (beyond social connection as a means of expressing Maurice’s sense of identity), for example Maurice described wanting to donate his computer magazines to some sort of school or community-based computer group who could make use of them, and he also described the most meaningful thing about his singing group being his meeting someone with the same diagnosis as him and with even more profound word-finding difficulties who Maurice was slowly encouraging to come out of his shell and who he really wanted to learn more about.

This ultimate prioritising of social connectivity over accomplishment or productivity seemed to be well exemplified in Maurice’s differential engagement with the two different formats of quizzes he embarked on during the day. He was much more animated, invested and motivated towards that which Maurice’s wife adapted and read out to him than when watching the quiz show on television.

The pro-social motivations for Maurice’s behaviour were further demonstrated in his regular taking out of his mug to the kitchen after finishing a hot drink – this wasn’t an easy task for Maurice as it relied on him locating, reaching for and grasping the mug accurately (all things he had difficulty with) before navigating to the kitchen and placing it in the sink (something else he had difficulty with). This was one of the only hands on tasks Maurice did throughout the day and it seems
notable that this was something which was helpful and partly eased the load for [Maurice’s wife]. This also seems fitting with the concerns about being a burden on [Maurice’s wife] which Maurice voiced on a few occasions, particularly in relation to stopping her doing things she enjoyed. It was more difficult to work out the motivation or purpose of Maurice’s picking up of the bits of fluff, and whether this was another attempt at being helpful or whether this was less purposeful and unintentional and more environmentally cued and perseverative.

9.m Oscar

Oscar was a 56 year old teacher who had taken early retirement because of the development of PCA. He had been diagnosed two years previously but had first noticed symptoms five years before that. Oscar lived at home with his wife and one daughter and another daughter who was living away at university during term time. Oscar’s MMSE score was 19 and he demonstrated impaired performance on all of the neuropsychological tests administered apart from the dot counting. He was mildly impaired in ADL function overall and on the self-care and household care subscales and was rated as moderately impaired on all other subscales. Oscar and his wife rated his QoL as good and excellent respectively.

1) What activities did people do? What activities were they motivated toward/interested in?

Oscar did a number of household chores throughout the day and was very motivated towards and engaged in these – he explained he had saved some of them up from the previous day which he joked he had found difficult to do. These included washing up, loading and unloading the dishwasher, taking the bins out, making beds for guests, hanging, folding and putting away laundry, hoovering, lighting the fire and helping towards preparing lunch and dinner. Aside from chores, Oscar was also very engaged in using (and demonstrating the use of) his iPad and iPhone to watch programs and contact friends via FaceTime. This enthusiastic demonstration of how he used technology and his patient postponing of chores
until the research visit both seemed to be examples of how highly he valued and was engaged in the research participation too.

Outside of the home, Oscar still enjoyed cycling and walking.

2) How was engagement in those things/activities challenged?

There were several examples of Oscar struggling with activities during the day and it was not always easy to work out exactly which symptom (or combination of symptoms) was underlying the difficulty (complicated further by the fact that many of these seemed to fluctuate or show inconsistencies in their presentations). For example at one point he seemed to struggle to locate the microwave which was hidden behind cupboard doors, and opened several sets of them in his attempts but during this also seemed to have forgotten which task he and [Oscar’s wife] had agreed he would start first. He seemed to have some sequencing difficulties later when preparing lunch with his daughter and left a few laundry items hanging on the line which he later came back to. He also had difficulty fitting a new bin bag into the bin and with locating some objects throughout the day – he mentioned this was a particular challenge when others had completed chores on his behalf. It was often unclear whether these were underpinned by memory difficulties, visual processing problems, something else entirely or a combination of factors. Word-finding difficulties were demonstrated throughout the day as were memory problems by repetition of story-telling or certain phrases.

Oscar had also previously struggled with getting lost when out cycling and with using the interface on his iPad.

3) How was engagement in those things/activities supported?

Oscar dealt partly with his difficulties with locating objects and completing household chores by maximising on familiarity and the way he did this was by taking on all these tasks himself – so that he could be sure how things had been
done and where things had been put. He used a number of strategies for reminding him of things, e.g. writing a list of tasks with [Oscar’s wife] and using the notes section on his iPhone to store key information about him and his diagnosis. He’d made good use of the accessibility features on his iPad and iPhone, making the text and icons appear larger. Most of these strategies seemed to follow a pattern of being largely self-manageable after an initial assisted set up with help from family members. This was true also of the Life 360 GPS tracking app the whole family had started using to allow Oscar to continue cycling (and to know when to put the kettle on for [Oscar’s wife] as she approached home). When Oscar did require in the moment on hand support, this was primarily with simultaneous verbal guidance and hands on support but notably delivered in a very tactful way by both his wife and daughters in which it appeared they were working as a team to solve a shared problem. Examples of this on the day included fitting the bin in the bag and deciding on the order of steps to be taken in preparing lunch.

4) WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

Oscar had clearly found it very difficult leaving work prematurely, and described how his completion of the household chores (a new sole responsibility of his) was the way he now contributed to the household. This seemed to permit some continuation of the role he saw for himself in the household although the means by which he was contributing had changed. Linking to this idea of activity as a means by which one’s longstanding sense of purpose can be continued, it seems worth noting that Oscar’s career had involved making a contribution to the development and education of the next generation and it appeared that some of these broader pro-social underlying motivations and goals for engagement in activities were now being fulfilled via Oscar’s keen participation in research.
The nature of activities – that they were largely household chores and contained within the home environment also seemed to serve the purpose of maximising Oscar’s contribution and independence.

Oscar had also clearly always thrived on being very busy, active, engaged and occupied generally and the family were clearly used to being very busy and active, so activity as a means of occupation and engagement seemed fitting with Oscar’s personality and previous experience and preferences more broadly.

9.n Paul

[Demographics and quant measures and general description of day/house?]

Paul was a 79 year old man who had been diagnosed with PCA three years previously, having first noticed symptoms three years prior to that. He was a retired electronics engineer who had also been a mature student late into his career and who had toured with a professional band for most of his working life. His MMSE score was 14 indicating moderately severe cognitive impairment and he demonstrated impaired performance on the digit span (backwards), naming, figure ground discrimination and dot counting tasks. He performed in the normal range on the digit span (forwards) and was untestable on the sRMT(w) and fragmented letters. Paul was severely impaired overall in ADL function and on all the individual subscales apart from household care for which his score indicated moderate impairment. He was demonstrating almost all of the neuropsychiatric symptoms covered by the NPI but he and his wife both rated his QoL as good.

1) What activities did people do? What activities were they motivated toward/interested in?

Aside from talking with me and eating lunch and dinner (all of which he was very engaged in) the only other activity Paul engaged in throughout the home visit was listening to and playing music. Specifically, he played a keyboard, and listened to recordings of him and his previous bandmates playing together.
Paul was also very motivated in the research participation itself, which he demonstrated via repeated questions about how useful it was going to be and also with his suggestions for other possible research project ideas, based on the strategies he’d developed for coping with his PCA-related balance problems.

2) How was engagement in those things/activities challenged?

Paul got very visibly upset during the listening of the recording of him and his friend who had since passed away. Without enquiring too much at risk of upsetting Paul further it was difficult to tell whether this was an example of his emotional lability or a more reasonable and warranted response to being reminded of his and his friend’s history of playing together and the subsequent loss of this friend.

As mentioned, Paul had some significant difficulties with balance and mobility - he claimed he had developed his own strategy for managing this but his assertion was tempered by his wife privately to me. The repetitiveness of these assertions and what seemed to be Paul’s inaccurate recollection of the efficacy of his strategies seemed to be examples of his memory problems. His difficulties mobilising around the home were perhaps exacerbated by his disorientation within the home – Paul and his wife had only recently relocated when I visited them at and Paul several times demonstrated that he was confused about whereabouts he was in the home or how he would get to a designated room (e.g. bedroom, bathroom).

Paul’s visual processing problems were apparent in his inability to read sheet music any longer or to make out the highlighted key words in [Paul’s wife]’s simplified filing system of his sheet music.

Fitting with Paul’s also quite global neuropsychological profile of impairment he also had some word finding difficulties, for example when he was peckish before lunch he struggled to find the word for raisins and had to describe them in a fairly convoluted way until [Paul’s wife] grasped what he was referring to.
3) How was engagement in those things/activities supported?

As mentioned, [Paul’s wife] attempted to improve Paul’s ability to select sheet music and use his musical equipment independently by highlighting and simplifying the labelling of keys, sheet music and operational buttons. This had apparently been a graded response, initially with simplified track names and numbers assigned but this had progressed to highlighting with corresponding colours but was now at a stage where – as most things were – these activities had to be supported by hands on assistance from [Paul’s wife]. This was also the case for Paul mobilising and finding his way around - he needed a lot of physical assistance. [Paul’s wife] had tried to use the labelling strategy on the toilet seat to help Paul to know if it was up or down but this too didn’t seem to be working consistently.

4) WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

A lot of the activities Paul was supported and encouraged to engage in represented long standing interests of his and things he had been expert in – the elements of the research programme he was especially motivated towards involved the kind of technologies he had been very familiar with as an electronics engineer and his music playing and listening had been an important constant personal and professional interest throughout his life. Paul confirmed the significance of music to him when talking through the difficulty he was having in confronting the fact that he may not be able to play for much longer.

This continuation of Paul’s interests and previous roles seemed to offer some sense of continuity of his identity and self - he and Paul both reflected throughout the day to the sort of person he’d always been, and on his interests as these sorts of continuous threads running through each phase and stage of his life so far. It seemed that an additional, perhaps over-arching motivator for Paul was his want to socially connect with others. His wife endorsed this, and it was notable that he was perhaps more enthusiastic in talking to me about those previous interests of his. 
than he was in actually initiating the activity of playing or listening to music. Similarly, when Paul recounted his time as a mature student and in his band, what he reflected on was not the content or the subjects so much as the relationships he developed with his fellow students/musicians and the sense that gave him of being part of a team or collective.

9.0 Rhian

Rhian was 55 years old and living at home with her husband and one daughter (one other daughter was living away at university) at the time of the visit. Rhian had previously worked in childcare but had been diagnosed with PCA at 53 after noticing symptoms a year beforehand. Rhian had an MMSE score of 15 indicating moderate impairment, and demonstrated impairment on all of the neuropsychological tests administered. Rhian was maximally impaired on ADL function overall and on all individual subscales except self-care (moderate impairment). Rhian and her husband rated her QoL as good and fair respectively.

1) What activities did people do? What activities were they motivated toward/interested in?

Rhian engaged in a number of household chores throughout the course of the day including food and drink preparation, loading and unloading the dishwasher and hanging up laundry. She also watched television with her husband and daughter, played games on an iPad and spent some time looking through photo books with her husband and daughter. In terms of activities outside of the home, Rhian mentioned how much she missed swimming and generally visiting and being visited by friends. In terms of social connection within the home, Rhian was good humoured in her interactions with her husband and daughter throughout the visit and to me directly.

2) How was engagement in those things/activities challenged?
Rhian was quite tearful when talking about swimming and visits with friends as these were no longer possible because of her difficulty in organising and transporting herself independently. It seemed as though the stopping of these activities had also potentially been exacerbated by others’ distancing from Rhian because of a lack of understanding of her diagnosis and how she may need to be supported. The household chores were arguably challenged by Rhian’s lacking motivation towards them, as she didn’t initiate any of these tasks independently. The chores were also significantly challenged by Rhian’s profound visual processing difficulties and motor symptoms (tremors and jerks), she made several attempts to find the button to turn the kettle on, mistaking it a couple of times for the button to lift the lid and several other times picking the whole kettle up off the stand again to look around it for the button. She also had difficulty putting mugs and glasses away when unloading the dishwasher and I had to intervene a couple of times as she attempted to push them onto a shelf that was already full, causing others further along the shelf to fall out. When hanging laundry, Rhian seemed to have difficulty seeing the whole rack, as she began concentrating her efforts in one lower corner of the rack, piling items on top of others. When preparing lunch, Rhian seemed to have a similar difficulty with perceiving the whole of the slice of bread as she concentrated the butter-sprreading in one spot. All these pronounced visual processing problems were exacerbated by the myoclonic jerks Rhian was experiencing, and this made many activities not only inefficient but also unsafe.

When playing the iPad word game Rhian had some difficulty selecting the word she needed on the screen and moving it to the right location to move the game along.

Rhian also had difficulties with word-finding and sentence construction and would sometimes hesitate for some time before attempting to say something. This challenged her interactions with her daughter and husband in that they would often answer on her behalf and seemed to underestimate her understanding at times (on several occasions Rhian would explain something to me separately once we were alone).
3) How was engagement in those things/activities supported?

Rhian wasn’t supported to carry out the majority of the household chores apart from being prompted to initiate them by her husband. On the day I intervened when I saw that something was going to be dangerous but it appeared that usually Rhian was left to complete these tasks alone as there was evidence of broken glass on the surfaces and her husband and daughter made references to glasses that had been broken previously. Rhian’s own strategy seemed to be one of perseverance rather than asking for help. Rhian’s husband stood alongside her and prompted her verbally when she was preparing lunch, eventually taking over by hand.

Rhian also attempted to persevere with the iPAD game but her daughter eventually came and sat with her to help, checking with Rhian which word she wanted moved where before doing the physical movement for her.

4) WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

It seemed that relatively little of what Rhian was doing seemed especially important to her, and this seems fitting with the fact it was Rhian’s husband who prompted and encouraged her participation in these activities. These activities arguably served a particular purpose for him, as he explained he was hoping to increase Rhian’s independence at home so that he could return to work after a yearlong sabbatical. While those activities didn’t seem to particularly engage Rhian, that’s not to say that nothing did – it appeared that social connection was of the utmost importance to her and it was unfortunately those sorts of activities (meeting friends, having visitors, sharing jokes with her family) which were significantly challenged by not only her PCA symptoms but also others’ perceptions of them.

The iPAD games and television watching seemed to serve the purpose of passing time and entertaining Rhian, but it was notable that she still attempted to use these activities as an opportunity for social connection with others (e.g. by making
conversation about the subject matter of the program, receiving help from her daughter with the iPad games).

9. Richard

[Demographics and quant measures and general description of day/house?] Richard was a 77-year-old retired IT management consultant who’d been diagnosed with AD 7 years ago after first noticing symptoms 5 years previously. His MMSE score was 16 indicating moderate impairment, and he showed impaired performance on the sRMT(w), naming and the figure ground discrimination and fragmented letters tests. Richard was moderately impaired in ADL function overall and specifically on the self-care, communication and employment and recreation subscales, and was rated as maximally impaired on the remaining household care, shopping and money and travel and transport subscales. Richard and his wife both rated his QoL as good.

What activities did people do? What activities were they motivated toward/interested in?

Richard spent a lot of time during the day watching the news on television, reading the paper and helping with household chores including setting the table, folding and hanging up laundry and loading the dishwasher. He also became particularly animated and enthused during the walk-around when we came across photos of him involved in a political protest from many years ago and also when we came to photos of his family members in the hallway, and he described various iterations of his intention to create some kind of a family tree or log of his ancestry. He also regularly attended gym and exercise classes with his wife and/or their close friend and neighbour.

How was engagement in those things/activities challenged?
Richard’s wife mentioned that he had become much more placid and laid back in his responses to political situations and events than he had been prior to his diagnosis but that he remained just as engaged and interested in the subject on the whole. She also described his attempts to keep stacks of copies of old newspapers in a way that he hadn’t before.

Corroborating his performance on the neuropsychological assessment, RCLO did seem to have some difficulty seeing what and where things were, for example he appeared to have trouble orienting the plates to the racks in the dishwasher, and his wife mentioned that he had difficulty seeing individual items (e.g. of shopping) when surrounded by lots of other items (though Richard disagreed or didn’t appear to remember having had trouble with this). He also had some difficulties which could have been underpinned by a visual processing problem but also memory or executive function impairments in sequencing – for example when setting the table Richard had some trouble with putting the cutlery in the right places. Difficulties which seemed more obviously a problem with sequencing or orientation included Richard’s confusion about how to hang up or take down the smaller laundry items from their drying rack and his putting some dirty mugs from the sink onto the drying rack or away into the cupboards rather than into the dishwasher. Richard also seemed to demonstrate what may have been utilisation behaviours in that he repeatedly washed his hands under the running water that had been turned on for him to rinse the mugs under before placing them in the dishwasher.

Richard had some difficulty with telling the ages and recalling the names of some of the family members he was hoping to create an ancestry log about when asked by [Richard’s wife] during the walk-around tour.

How was engagement in those things/activities supported?

Richard’s wife was instrumental in his continuing to engage with activities, but Richard himself also showed keen motivation to help even when he wasn’t entirely sure how to complete a task, he was motivated to contribute and happy to ask for
assistance. With the smaller items of laundry hanging on a mobile rack, he asked [Richard’s wife] to show him what he needed to do, and following her demonstration he then proceeded to do the rest on his own upstairs and appeared to have little difficulty. [Richard’s wife] also did a lot ‘behind the scenes’ to support Richard’s continued engagement with tasks and this seemed to be centred around not highlighting his difficulties to him. When he placed the cutlery in the wrong places, [Richard’s wife] mentioned that their daughter had previously discouraged her from pointing this out to Richard because it didn’t really matter. Similarly, when Richard mistakenly put the dirty mugs onto the draining rack or away into the cupboards, [Richard’s wife] explained that she had stopped trying to say anything to reorient him to the task but instead now waits until he is focused on another task and then she will replace things to where they should be. [Richard’s wife] also avoided letting Richard know that she was removing several newspapers a day from his sizable pile of them to the recycling so as not to cause him any worry or upset (but to also keep the pile of them to a manageable size).

Richard’s regular gym and sports club attendance was facilitated by accompaniment of either [Richard’s wife] or their close family friend and neighbour.

WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

Richard’s engagement with politics was a longstanding interest of his which continued and was evident in a number of the different activities or objects he seemed especially engaged with throughout the visit (i.e. watching the news, reading the paper, and retelling the story of his involvement with political protests many years earlier).

Richard’s interest in documenting his family ancestry and history seemed to be something that had become meaningful for him in only recent years because of the reflective time of life he was entering into.
His keenness to help with chores seemed to be a general desire to help and to contribute to the household as he offered his help to [Richard’s wife] and then relied on her to allocate tasks to him, all of which he agreed to, even those which (when it came to it) he struggled to recall the required steps for.

Given how instrumental [Richard’s wife] was in supporting Richard’s continued engagement with all these activities it also has to be acknowledged that they had a meaning and purpose for her too, and that seemed to be that they were efforts towards maintaining Richard’s sense of self and identity as far as possible, in making sure that he continued to engage with the subjects he’d always found interesting and that opportunities for him to act on the intentions that were typical of his character (e.g. to be helpful) were maintained even though his ability to execute those tasks was at times compromised. [Richard’s wife] described the discrepancy that her ‘behind the scenes’ efforts illuminated to her - in her taking responsibility for minimising the appearance of Richard’s difficulties to him (and potentially others), she herself seemed quite confronted by them and reflected tearfully several times on what an independently capable man he been previously.

9.q Simon

Simon was a 62-year-old retired IT consultant diagnosed with PCA two years previously shortly after noticing symptoms. He lived at home with his wife and had an MMSE score of 28 indicating normal cognitive functioning, and performed in the normal range on most of the neuropsychological tests apart from two tests of visual processing (fragmented letters and dot counting). Simon was mildly impaired in ADL function overall and on all subscales apart from household care on which he showed no impairment.

What activities did people do? What activities were they motivated toward/interested in?
Simon spent most of the day on the computer which he said was typical, in particular he was doing the family finances and researching his upcoming trip to Australia with his son. Other activities Simon mentioned engaging in included watching series on the television and joining walks with a local history group. Simon also cleared away the lunch things after we’d all eaten.

How was engagement in those things/activities challenged?

Simon described a number of challenges he had with perceiving the visual information on his computer screen and he also seemed to misperceive some of the items left over from lunch when clearing away (either missing them completely or mistaking things for other items). He also had slowed speech throughout and described the difficulties he had with getting words in the right order and needing to run things through in his head before speaking them aloud. Needing to process things (particularly speech) quickly was very difficult. He described this particularly in relation to watching television and that subtitles were sometimes helpful, however there were also issues with the lighting when watching the television, and making sure that he and [Simon’s wife] both had satisfactory levels of lighting from their respective viewing points. On a social level, Simon’s engaged with the local historical walking group was challenged by his perception that they had not been as accommodating or patient and understanding as he might have hoped and so he didn’t feel as comfortable as he would have liked to in participating with them.

How was engagement in those things/activities supported?

Simon reduced his involvement in the walks but for all physical challenges he found his own work-arounds that he was able to implement independently. These were a combination of inbuilt accessibility features within his computer’s operating system like the magnifier, existing off the shelf adaptations like a desk lamp with a very wide-reaching and even spread of light and his own creative strategies like saving two versions of important numbers or passwords on his desktop for easy access, a different version using different dividers between characters (spaces versus slashes)
according to whether he needed to read it out or copy and paste it into a web form. The lighting when watching television was negotiated between Simon and [Simon’s wife] and the arrangement of the furniture adjusted accordingly. In terms of his slowed processing speed and difficulty ordering his words and formulating sentences, Simon took his time and engaged in more conscious effortful processing in order to share his input throughout the day.

WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

Simon had always spend a lot of time with computers, both at work and at home, so they offered a familiar mode of engagement for him and continuation of his long standing role within the family (researching and finances) despite his having to withdraw from them at work. Simon had hoped to engage with a local community group to make connections and be involved in and occupied with local community life but this hadn’t worked out as planned and was perhaps an unmet need of Simon’s. His withdrawal from that activity perhaps relates to wider concerns he and [Simon’s wife] mentioned several times throughout the course of the day around stigma and others’ judgements and assumptions about his capabilities now that he had a diagnosis of a dementia. This desire to avoid the judgement of and stigmatisation by others perhaps speaks further to Simon’s continued solo use of computers in his own home and for his own needs despite having had to give up working with them. It also perhaps links to his not wanting to be videoed for fear of it feeling intrusive. Instead he’d suggested that he let me know if there were any difficulties as and when they came up and that I could film then, but in the end he didn’t let me know of any. Perhaps all at once Simon’s continued but adapted engagement in working on the computer offered him a continuation of his identity in a way that capitalised on his problem solving skills without exposing his difficulties and leaving them open to the judgement of others. The tasks he did on the computers seemed meaningful as a means of connecting with or contributing to his family, as he had always done. In looking after the family finances he was taking
responsibility for some of the household admin and again continuing a role that had long been his. The holiday destination he was researching was somewhere he was taking his son, and he had started taking big trips with his adult children since his diagnosis of PCA, as an opportunity to connect with them in the knowledge that he may not have as long to do that as he may have anticipated. He and [Simon’s wife] both expressed their sadness and injustice at this several times throughout the visit, and it was clearly articulated as a strong motivator for Simon’s engagement in such long haul trips (and therefore the researching of them too). It also was apparent that Simon would require the accompaniment of someone during the trip because of the difficulties he was having but this wasn’t how he and [Simon’s wife] framed the ultimate meaning of the activity.

9.r Sally

Sally was a 64 year old retired civil servant in computer engineering who had first noticed symptoms 9 years previously and who had been diagnosed with PCA 6 years after that. She lived with her husband in a detached house in the countryside. Sally’s MMSE score was 19 indicating moderate impairment and she performed in the normal range on the digit span test of working memory and on the naming task, but showed impaired performance on the sRMT(w) and declined the visual tasks. Sally was moderately impaired in ADL function overall and on the communication subscale; she was mildly impaired on the self-care subscale and maximally on all other subscales (household care, employment and recreation, shopping and money and travel and transport). Both Sally and her husband rated her QoL as Excellent.

1) What activities did people do? What activities were they motivated toward/interested in?

Throughout the day Sally was particularly physically engaged in listening to music and in gardening (shredding and pruning). She also described with great enthusiasm her joy in watching sunsets out of the window, and looking at the landscape generally. She described greatly missing reading and she and [Sally’s husband] both
commented several times on their current ‘project’ which was general organising and decluttering but specifically – what seemed to be top priority – organising photos of their travels to be scanned in and made into a slideshow format.

2) How was engagement in those things/activities challenged?

Sally was unable to read anymore at all due to her visual processing problems. Gardening was challenged by both her memory and visual difficulties. Sally initially struggled to locate her gardening clothes and tools. She also struggled to get changed into her gardening clothes and to locate the sticks for shredding as well as the hole in the shredder to feed them in through. When pruning, Sally had difficulty telling the stems from her fingers and also with seeing all her tools in her bucket (which she also misperceived the colour of) when packing up to come inside. While giving me a tour of the garden Sally had some trouble with going down the steps and with remembering the name of one of the plants she was showing me. Sally described having some difficulties getting the words in the right order in her requests directed to the Amazon Echo to play music at times (though she showed good memory for the activation word and her and [Sally’s husband]’s strategy to avoid accidentally turning it on when referring to it throughout the visit).

3) How was engagement in those things/activities supported?

[Sally’s husband] provided hands on assistance in some cases – he helped with finding Sally’s gardening kit and with setting up the Amazon Echo to play a certain album for Sally later in the afternoon. Sally had many of her own strategies though too – with the garden plant name she couldn’t find, she talked me through the steps of a mnemonic she’d created in order to recall it when we got back around to it on our tour and it hadn’t come back to her by then. Sally employed other strategies which relied on her own conscious self-talking – she counted the steps when going up and downstairs in order to know when she had reached the top/bottom because the visual information was too difficult to process. When pruning, Sally described and demonstrated how she used her sense of touch and
concentration to feel which her fingers were and which were stems before she pruned. This was similar to the strategy she employed when trying to find a chair – feeling with her hands and patting the seat to confirm it’s placement and her orientation to it. Reading sadly could not be supported for Sally – she didn’t find audio books the same and so gave away many of her books. Sally’s sunset viewing was actually supported by her PCA symptoms arguably, and she described how she was now spending more time watching them and the landscape generally because of how beautiful and vivid the colours had become.

4) WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

Many of the activities Sally was very engaged in were long standing passions of hers. Music, reading, gardening and enjoying the landscape and views around the cottage were all things Sally had dedicated a lot of time to especially since retiring. Sally and [Sally’s husband] stood out in the sense that they both mentioned they’d never been very social and that that hadn’t changed. It certainly fit with the fact that most of the activities Sally most engaged with were solitary, and that she developed many independent support strategies in order to maintain her involvement in those things. It seemed that in embarking on these activities Sally was aiming not only to entertain or occupy herself but to maintain her skills and continue her active involvement and engagement in things which brought her joy and satisfaction (it was notable she had handed over the household chores to a professional many years earlier because she didn’t get any sense of satisfaction or pleasure from those). Despite both admitting to being relatively non sociable, Sally and [Sally’s husband] did seem connected to each other in their approach to everyday life with the diagnosis – they both maintained they operated predominantly at the level of wanting to scientifically understand the disease, which seemed very fitting with their general matter-of-fact and pragmatic/direct style in how they went about choosing and preserving with activities, however I was somewhat surprised when Sally described how the sunset viewing which she had
been spending more and more time doing of late, was actually serving the purpose of helping her existential adjustment to the diagnosis and what it meant on an ever-changing basis day to day. [Sally’s husband] (similarly surprisingly) fleetingly admitted that he couldn’t start thinking about or talking about what was ahead and how things would change because it was too difficult to process. In that sense it seemed activities for both of them were a way of practically engaging with the world perhaps partially to avoid or distract from the gravity of the emotional implications of the progression of Sally’s PCA. This was nodded to however in their prioritisation of collating their holiday photos into some sort of slideshow as the purpose of this was to hopefully remind Sally of some of the nicer times and adventures they had had, at a time when her memory becomes more affected.

9.s Wendy

[Demographics and quant measures and general description of day/house?]

Wendy was a 75-year-old retired lab technician diagnosed with AD 6 years previously. She lived in a large house spread over 4 floors with her husband [Wendy’s husband] and their two Burmese cats. Wendy had an MMSE score of 20 and showed impaired performance on the sRMT(w) but performed in the normal range on the other tests administered. Wendy was reported as displaying a number of neuropsychiatric symptoms including agitation, irritability, anxiety and aberrant motor behaviours. She was maximally impaired on the shopping and money and travel and transport subscales of ADL functioning, moderately on household care (and overall) and only mildly so on the self-care, employment and recreation and communication subscales. Wendy and [Wendy’s husband] both rated her QoL as good.

What activities did people do? What activities were they motivated toward/interested in?
Wendy was engaged in a range of activities throughout the day including grooming and other care-taking activities related to the cats, gardening, cross-stitching, completing a jigsaw puzzle with her granddaughter and in conversations about the history of the household, its current organisation, the local area she’d grown up in as well as consulting on dinner preparations and enquiring about the wellbeing of various friends, family members and neighbours.

How was engagement in those things/activities challenged?

Although she engaged in a lot of activities throughout the day Wendy notably didn’t independently initiate the crafting activities, cat grooming or gardening (even though these were things she clearly engaged in once they’d been initiated). [Wendy’s husband] mentioned his concerns about how best to manage Wendy’s motivation levels to ensure she still engages ongoing in the things she enjoys. Wendy was demonstrably anxious about the cats and their whereabouts (they were indoor cats) and she occasionally abandoned activities having forgotten where she last saw them and checked several times with me whether they had perhaps been let out by mistake.

Memory problems were evident in Wendy’s forgetting that she’d advised on the dinner preparations the day before and also when the cats had last been brushed and had their claws trimmed. Also in relation to her concern for family members and others, Wendy several times demonstrated that she had forgotten the latest updates which [Wendy’s husband] had already shared with her a number of times. Wendy struggled with knowing how to operate the Amazon Echo to turn the radio to off so after some hesitation opted initially to switch off the multi-socket plug it was plugged into at the wall and [Wendy’s husband] had described how she had previously demonstrated difficulties with operating the washing machine too.

How was engagement in those things/activities supported?
[Wendy’s husband] took on responsibility for getting Wendy involved in hobby and leisure activities, and would prompt and remind and encourage her verbally about the things she or they could do. To reduce her anxiety about the cats’ whereabouts Wendy asked [Wendy’s husband] and I for reassurance about where they were – there was also a boldly written reminder to check they were somewhere safe before opening the front door on a piece of fluorescent card. Similar written reminders were placed on the washing machine, and [Wendy’s husband] explained those had originally been on white card but that Wendy had stopped noticing them. There was another fluorescent reminder about how to use the Amazon Echo which Wendy initially struggled with (opting instead to switch everything off at the wall) but she did then return to this and persevere with it while self-talking her way through how to operate it. When Wendy asked about the plans for dinner and it became clear she had forgotten that she had previously been consulted on them, [Wendy’s husband] explained that they had had the same conversation the night before which Wendy then asked him to repeat back to her which he did. When the timings [Wendy’s husband] gave then tallied with what Wendy had been suggesting in the moment, Wendy was reassured. Wendy also asked for the forgotten details of the wellbeing of friends, family members and others when [Wendy’s husband] mentioned them in conversation.

WHY were those things important to that person? What purpose did they serve? What was the meaning of them?

Wendy had clearly been a keen crafter for many years as was demonstrated by her extremely busy but well organised craft room and though she didn’t independently initiate these activities on the day, in his initiation of them it was apparent that [Wendy’s husband] considered these important and meaningful activities on Wendy’s behalf. He discussed how important he felt it was that Wendy continued to do things she’d always enjoyed but also described his discomfort in having to be the one to orchestrate this as it made him feel ‘bossy’. It seemed rather than solely wanting Wendy to be distracted or occupied, that the activity

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served a more significant purpose for [Wendy’s husband] of keeping Wendy engaged with things she had a strong personal connection to, and this championing of her history, interests, previous roles and ultimately identity seemed fitting alongside his deference to her expertise and choice when deciding what to do with the piece of garden furniture they were restoring and when consulting with her about the plans for dinner. And although she didn’t initiate them, these long-standing interests of Wendy’s did actively engage her once she was immersed in them - joking with her granddaughter about the jigsaw they were completing, talking me through the story of the treehouse as she took me on a tour around it in the garden, and explaining where she was up to and what steps she still had to complete in her latest crafting activity. She was similarly enthused during conversations about her life history, as demonstrated by the thorough and detailed accounts she gave of the house and its various iterations of housemates as we did a walk-around tour. This was echoed in the lengthy conversations we had later about the local area where Wendy grew up and how it had changed, which she also related to me and my hometown, encouraging me to revisit a certain area we had in common and to report back to her with what I thought about it. Some of the only activities that WHIR independently initiated her own engagement in were with her expressing her concerns about the cats’ whereabouts (and looking for them) and for those family members, friends and neighbours she repeatedly enquired about. These appeared to be motivated and meaningful gestures of connection and care-taking.
APPENDIX 10: Example thematic diagrams
3) Home school are constituted in the persons special objects via the routines.
They are engaged in a motivated team, e.g.

- Sally
- Lionel
- Paul
- Wendy
- Betty

ii) Each when activity engagement in and by objects in the environment in important features.

- Betty, Richard, Helena

iii) Caring engagement articulated in a manner with a scale of self

- Martin, Richard
- etc.

We may gather interests @

Contingent on: factors and parts/relationships dynamic

- Martin

→ including e.g. motivation to uphold/extend this or extend or plot

- Richard, Oscar
- Martin

- Betty, Martin

- etc.

- Martin

- etc.

- Martin

- etc.
Attracting "Men"/
the fun and the function

type & meaning of activity / i.e., doesn't
process or well & outcome / matter if not
controlled or helped (b) self-presentation, engagement, distraction, mindset to end
what "matters"
pure vs. fun tastes

Reception of care
acts of care (b) me!

past (+ care) not wanting past to be burden
bi-directional
pre-existing caring responsibilities
wanting to help (as well as be helped) biographical disturbance
for those - care taking & care for maintenance of identity/money (b)

Constitution & continuity of a changing self
beets + attitude as representative/representations of self
maintenance of identity, period, career etc.

perceived
what "matters"
changing: symptoms and

? distinct
? coherent
? comprehensible

Agenda
- 9th & 10th
- No meeting cell
- review - research &
- case summary - make sense
- "men" - stimulating
- detailed plan - see self
- main goal & skill making esp pp
- e. c. data

Need: more before detailed plan.
The fun + the further

- physician?
- does like “fun”
- formation of engagement
  - lecture as well as practical
  - process as well as outcome
  - gel or intimidate to keep person for pad
  - what makes it prioritised
  - meaningful activity in care home vs bed
  - the practices that
  - ways of remaining

- meaningful activity in care home & bed
- the practices that
- ways of remaining

- conceptual of care
- how activity of achieving personal development & care
- power of helping
- also that activities are meaningful and how/why they happen
- broader narrative of dementia care being due to people (10% of agency)
- concern for leader / time, emotion / value
- social?
- existing relationships, quality; existing care, responsibility

- contribution + continuity of a changing soul
- relational activity
- within our homes / deaths / activities are shared materials
- people are motivated to continue the expression of that

- organisation changing be of diverse progression (1 common factor)
- shift Things needed: shift. Shift. Dem... - threat to identity vs community
- change
- identity
- history, influence career interests, presented, social?
- child shift
- shift of being intentionally good in self presentation
<table>
<thead>
<tr>
<th>Alan</th>
<th>Paul</th>
<th>Oscar</th>
<th>Simon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Martin</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rhian</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maurice</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eleanor</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Richard</td>
<td>Mandy</td>
<td>Anita</td>
<td></td>
</tr>
<tr>
<td>Betty</td>
<td>Lionel</td>
<td>Brian</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mike</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helena</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Wendy</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The level of impairment:

- [x] 0%
- 0%
- 0%
- 0%
- [x]

Who did a lot while I was there (It doesn't mean they always do, you can consider reading/motivation/means)
APPENDIX 12: Example visualisation of qualitative and quantitative data for individual participants

Figure 12.1: An initial draft attempt at bringing together multiple data sources relating to individual moments of significance for individual participants – here, using Alan’s leave-cleaning as an example, I have combined his % ADL function, the time spent on ADLs during the home visit, the ascribed meaning of ADLs extracted from field notes and stills from the video data into one schematic representation.

APPENDIX 13: Diagrammatic representation of interdisciplinary data session
Figure 13.1: Diagrammatic representation of interdisciplinary data session

Connections and tensions between both approaches with regard to reliability, representativeness, variability, influences on/of the research process such as being observed, tester’s/teachers/observer consistency, consistency of experience, etc.

Connections in terms of extraneous factors (e.g., participant anxiety, previous experiences), limitations (e.g., sample size, selection bias)

Quantitative

Qualitative

Neuropsychology
- e.g., memory/vision
- e.g., cognitive vs. individual tests

Self-report scales
- e.g., QoL-AD/ADL scales
- e.g., questionnaire/individual items/scales

Natural science

Social science

Group means, trends, differences

Assumptions, expectations, interests informed by discipline, existing theoretical or empirical literature (e.g.):
- Pronounced impairment of everyday skills
  (Graham et al., 2015)
- Vision better predictor than memory of poor everyday function (Perry & Hodges, 2000)

Assumptions, expectations, interests informed by discipline, existing theoretical or empirical literature (e.g.):
- Depression and relationship quality
  (caregiver O. Hiltz et al., 2016)
- Impact of young onset dementia on socialization (Maris & Kees, 2009)

Comparisons to make/ questions to ask could arise from any data type and be directed towards any data type, e.g.:
- Neuropsychology -> Self-report scales: did participants with greater memory impairment need more help with ADLs?
- Neuropsychology -> Interviews: did participants with impaired perceptual function describe not seeing objects right in front of them?
- Self-report scales -> Observations: did participants rated as most impaired in their ADL functioning undertake any household chores?
- Observations -> Neuropsychology: did participants who seemed to miss reach for objects show impaired visuospatial functioning.
APPENDIX 14: Publications arising from this work

14.a Harding et al., 2018

‘Because my brain isn’t as active as it should be, my eyes don’t always see’: a qualitative exploration of the stress process for those living with posterior cortical atrophy.
‘Because my brain isn’t as active as it should be, my eyes don’t always see’: a qualitative exploration of the stress process for those living with posterior cortical atrophy

Emma Harding,1 Mary Pat Sullivan,1,2 Rachel Woodbridge,2 Keir X X Yong,3 Anne Mcintyre,2 Mary L Gilhooley,2 Kenneth J Gilhooley,3 Sebastian J Crutch1

ABSTRACT

Objectives To explore the stress process for individuals living with posterior cortical atrophy (PCA) and their families.

Design A qualitative study using in-depth semi-structured dyadic and individual interviews with people living with a diagnosis in PCA and a family caregiver. Interview transcripts were thematically analysed.

Setting Participants’ homes.

Participants 20 individuals in the mild to moderate stages of PCA and 20 family caregivers.

Findings Three major themes were identified: (1) the diagnostic journey: mostly an unsettling and complicated process, owing to the early onset of visual, receptive and auditory symptoms; (2) emotional reactions to the social and psychological environment: profound difficulties with functional and leisure activities were usually compensated for with adaptations maintaining familiar or simplistic; (3) implications within the psychological environment: symptoms impacted individuals’ sense of independence and identity and required modifications of roles and responsibilities. Ongoing uncertainties and the progressive nature of PCA caused most dyads to take a ‘one day at a time’ approach to coping. Relatively well-preserved insight and memory were a benefit and burden, as interviewees shared the illness experience with family members and also compared their current situation to pre-diagnosis. The experience was formed by background and contextual factors and understood within an ever-changing temporal context.

Conclusion The stress process in PCA is characterised by uncertainty and unpredictability from diagnosis through to ongoing management. The provision of tailored information about cortical visual problems and associated functional difficulties, supported by meaningful environmental adaptations to help those with PCA to identify what and where things are and psychological interventions for the caregivers might assist. The diagnostic journey (1) stress and coping in the earlier stages of PCA, and (2) the nature and impact of visual impairment(s) in typical Alzheimer’s disease would be worthwhile.

Strengths and limitations of this study

As the first qualitative study of those living with posterior cortical atrophy (PCA), this paper provides original, in-depth insights into the subjective experiences of those with dementia-related visual impairment.

Conducting both individual and dyadic interviews within participants’ homes permitted both the multiple perspectives of people with the diagnosis and their family members to emerge and a richer understanding of the physical and psychological context within which daily difficulties and visual processing problems were experienced.

As well as providing empirical description of the stress experience, using a conceptual framework for the Stress Process Model, this study also makes a contribution to social science and the field of dementia research.

Interviews were conducted over time, but owing to the progressive nature of the disease, future longitudinal research would be valuable to develop the current study findings.

The interview method relies on participants’ abilities to accurately recall the experiences of themselves and those with PCA, especially in the earlier stages, can have initially well-preserved memory, disease severity varied across the current sample, and a subgroup of those interviewed were demonstrating some memory impairment during interview.

BACKGROUND

There are an estimated 850,000 people currently living with dementia in the UK, and it is estimated that 5% of these (approximately 42,500) are cases of young-onset dementias, with symptoms beginning before the age of 65 years. Posterior cortical atrophy (PCA), originally called Benson’s disease, is a rare form of dementia that is typically early in onset with symptoms usually...
beginning between the ages of 50 years and 65 years. The underlying pathology in the majority of individuals is Alzheimer’s disease (AD), although a small number of cases attributable to Levy body disease and corticobasal degeneration have been reported. The prevalence is unknown. PCA is characterised by initial neurodegeneration towards the back of the brain, specifically in the parietal, occipital and occipitotemporal regions. Correspondingly, the initial symptoms predominantly relate to cortical visual impairment, particularly deficits in visuospatial and visuoperceptual processing. Other characteristic symptoms relate to impairments associated with posterior functions, including literacy, spelling and numeracy. While current clinical criteria cite visual processing impairments with proportionally less impaired memory as core diagnostic features of PCA, patients may in fact exhibit memory impairments at initial presentation. When compared with other dementias, PCA is relatively under-researched. The majority of research into PCA is concentrated around establishing the neuro-psychological, cognitive and imaging profile(s) of those with the diagnosis. 

Aneurdoal and laboratory-based evidence suggests ways in which PCA might impact on people’s daily lives, including problems with reading, driving and localising objects in space, but there is a paucity of research focusing on the everyday impact of living with the diagnosis for individuals and families.

One recent paper investigated the impact of PCA on activities of daily living, documenting difficulties with performance of everyday skills for people with PCA (including operation of appliances, writing and handling money) and self-care (including dressing, feeding and bathing) compared with predominant deficits in memory, motivation and orientation of people with typical, amnestic presentations of AD (AD). In another recent paper, Suárez-González et al. investigated the neuropsychiatric profile of people with PCA. They found similar increases in depression, apathy, irritability and anxiety for those with PCA to participants with TAD.

In the absence of disease-modifying therapies for AD and other forms of dementia, environmental and psychosocial interventions to improve the quality of life and wellbeing of those living with it hold particular significance. Better understanding the needs of those with different rates and/or young-onset dementias will be an important step in developing effective environmental or psychosocial interventions. A second generation of literature is beginning to delineate the particular experiences of those with less common forms of dementia such as young-onset dementias and those with atypical symptom profiles like behavioral variant frontotemporal dementia. Developing a greater understanding of the day-to-day impact of dementia in relation to visual problems will be a timely addition to this, not least because those with TAD may also go on to have cortical visual impairment, likely later on in their diagnosis and as such at a time when they may not be so able to articulate their experiences of the symptoms.

These varied everyday impacts of dementias that pose challenges for quality of life and well-being are often considered within a broad conceptual category of stressors, defined as demands that are considered to exceed a person’s available resources. Cognitive, emotional and/or behavioral attempts to manage these demands are often approached and studied as coping strategies. Much attention has consistently been given over the past few decades to understanding what contributes to informal caregiver stress and what facilitates coping, given the huge societal contribution informal carers make by continuing to care for loved ones with dementia at home.

The stress-coping approach is widely acknowledged as dominant within this literature, and its popularity is exemplified by the numerous reviews into stress and coping in dementia noted by Gillhoosy et al. There are multiplications of studies looking at the chronic and particular psychological, socioemotional and practical stressors and strains faced by carers of people with dementia, and also the nature and efficacy of the many practical, emotional, psychological and social coping strategies employed to mediate this.

The current study sought to maximise on the relative abilities of those with PCA to reflect on and communicate their experiences. Using the Stress Process Model as a conceptual framework, we present findings from a qualitative exploration of the stressors associated with moderate to severe stage PCA and responses to these over time. The Stress Process Model outlines primary stressors that result directly from the disease itself, secondary stressors that may follow and both internal and external factors that radiate both of these in shaping outcomes. Having been developed to conceptualise informal caregivers’ experiences, it has since been adapted for individuals with dementia, and in doing so acknowledges the multiple perspectives to be taken into account when understanding the dementia experience. More specifically, the study aimed to explore the potential of the physical environment to contribute to and/or mediate the stress process owing to the prominent visuospatial and visuoperceptual symptoms.

METHODS

Design/sampling

A qualitative design was deemed appropriate in order to gain rich detailed accounts and for possibly unanticipated insights to emerge. This was considered important because of both the paucity of knowledge about the impact of PCA on individuals’ subjective experiences and also the distinctiveness of the symptom profile. In-depth semi-structured interviews were chosen owing to the abilities of those with PCA to recount their experiences and, again, to facilitate the collection of data of sufficient richness and depth. Participants were recruited via the Specialist Cognitive Disorders Clinic at the National Hospital for Neurology and Neurosurgery, University College London Hospitals NHS Foundation Trust. Inclusion criteria were a
### Table 1: Five verification strategies for attaining reliability and validity in qualitative research

<table>
<thead>
<tr>
<th>Verification strategy</th>
<th>Explanation</th>
<th>How or where demonstrated in the current study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Methodological coherence</td>
<td>Ensuring congruence between research question and methods</td>
<td>Background (Stress Process Model)</td>
</tr>
<tr>
<td>Methodological coherence</td>
<td></td>
<td>Methods (design/sampling, i.e., community-based sample; data collection, i.e., individual and dyadic interviews in order to gain both shared and individual perspectives; data analysis, i.e., qualitative approach for study of life-known topic)</td>
</tr>
<tr>
<td>Appropriate sampling</td>
<td>Participants who best represent or have knowledge of the research topic</td>
<td>Methods (design/sampling, i.e., community-based sample; data collection, i.e., individual and dyadic interviews in order to gain both shared and individual perspectives; breadth range of disease severity)</td>
</tr>
<tr>
<td>Collecting and analysing data concurrently</td>
<td>Establishing an iterative interaction between what is known and what one needs to know</td>
<td>Methods: moving between data collection and data analysis, including: memo-writing (keeping an ongoing log of analytical thoughts and ideas); amendments to interview schedule (adding questions/prompts to further explore emerging areas of interest, e.g., role changes); field notes (written together by the two interviewing authors—MPS and RW or RW and EH—immediately after the interview to document initial responses and reflections on the data collected)</td>
</tr>
<tr>
<td>Thinking theoretically</td>
<td>Constant, cyclical process of checking that emerging ideas are recontextualized in new data</td>
<td>Methods: moving between data collection and data analysis, including: memo-writing (keeping an ongoing log of analytical thoughts and ideas); amendments to interview schedule (adding questions/prompts to further explore emerging areas of interest, e.g., role changes); field notes (written together by the two interviewing authors—MPS and RW or RW and EH—immediately after the interview to document initial responses and reflections on the data collected)</td>
</tr>
<tr>
<td>Theory development</td>
<td>Moving between microperspective to macroconceptual/theoretical understanding</td>
<td>Results (major and subthemes, supporting quotes and explanatory commentary); Discussion (compatibility with existing literature, e.g., empirical—relationship impact and theoretical—utility of the Stress Process Model; research and clinical practice implications; suggestions for future work, e.g., other rare dementia populations)</td>
</tr>
</tbody>
</table>

confirmed diagnosis of PCA and an accompanying family member or familiar other also willing to participate.

Twenty individuals with PCA (12 female; 8 male) took part in the interviews, and the mean age was 68 years (7.66 SD). Scores on the Mini Mental State Examination ranged from 16 to 29 (mean=20.05; SD=5.84), indicating mild to moderate dementia. Twenty spouses/family carers took part (10 female; 10 male), in 18 cases, this was a spouse, in one case the dyadic relationship was mother/daughter and in the other case it was aunt/niece. One spouse (female) opted not to take part in an individual interview but did participate in the dyadic one. Only one participant lived alone. The number of years since diagnosis ranged from 0 to 12 (mean=3.31; SD=2.75), and the number of years since subjective onset ranged from 2 to 14 (mean=8.39; SD=5.26).

A comparative sample of people living with TAD (n=17) and their family carers (n=17) were also interviewed and findings from the subsequent analysis of that data will be reported in another paper.

**Ethical approval**

Informed consent was obtained from all participants. After the interviews, the researchers conducted a short debrief providing further information and contact details in case of any issues or causes for concern related to the study.

**Data collection**

Individual and dyadic interviews were conducted at participants’ homes (by EH and RW or MPS and RW). Dyads were interviewed together and then separately in order to capture the dyad’s shared experience, to allow the family carer to supplement the person with PCA’s account in the case of additional, secondary memory impairment and to provide the opportunity for individuals to provide information they might not feel comfortable to disclose in the presence of their family member. The interview schedule covered contextual factors (personal, marital and occupational history and current family situation), the diagnostic journey and daily difficulties and coping strategies within the home environment. In total, interviews lasted between 3 hours and 4 hours per dyad. The home visit also involved a walk-around of areas of the home posing particular challenges to participants or where they had implemented adaptive strategies.

Audio-recorded interview files were transcribed, and a random portion was checked for quality. All names and place names were changed.
Data analysis

Interview transcripts were uploaded into Atlas.ti qualitative data analysis software (v.7). The data were analysed using thematic analysis, which was selected owing to its flexibility and accessibility. These were considered important factors given that this is the first qualitative exploration of the experiences of individuals with PCA and also the wide range of health professionals who may find relevance in the findings. Two members of the research team (EH and MPS) were responsible for the analysis. They first familiarised themselves with the data with multiple read-throughs of transcripts before creating an initial coding framework based on existing literature on stress and coping in dementia, the study research questions and the initial familiarisation process. This coding framework was flexible, and new codes were added as required, following discussion and agreement. Each dyad's set of three interviews (person with PCA, family carer and joint interview) constituted one case for analysis, and the cases were divided among the authors EH and MPS. Once all 60 transcripts had been analysed and assigned initial codes, the codes were sorted into broader themes. Some codes were organised into major themes, some into subthemes and others became theme headings themselves. Themes and coded extracts within them were then reviewed in terms of their relevance, distinction from each other and coherence, and codes were reclassified or reorganised where required. Themes were then defined and named in such a way that they offered a coherent and consistent account of the data.

Quality assurance

Ongoing discussions acknowledged the complexity but necessity of ensuring the quality of qualitative research. We drew on a notion of rigour in qualitative research suggested by Morse et al. Morse et al. identified five verification strategies for attaining reliability and validity in qualitative research that require consideration by the researchers throughout the research process, as opposed to criteria for reliability and validity that are determined post hoc and only by readers. Table 1 outlines these five verification strategies and where or how they are or were addressed in the design, conductance and write up of this study.

Member checking

Member checking is the process of presenting qualitative research findings to respondents or participants and inviting their feedback and/or checking for resonance of the findings with their own experiences. The advantages and disadvantages of member checking are much contested, and details of the debate are beyond the scope of this paper, but several issues bear particular relevance here. First, there is a concern that participants may inaccurately recall their original account, and this is perhaps more likely in the case of progressive cognitive decline. Second, developments since the participants gave their original accounts may have changed their perceptions or how they may now choose to respond to the same questions and this too may be of increased likelihood for those living with a progressive condition. For these potentially confounding reasons, we sought external validation of the current findings via two regional PCA support groups, made up of people with a diagnosis of PCA and their family carers (as in the study sample). Study findings were presented to both groups and comments invited, and there was a general consensus across both groups that the themes elicited here were compatible with support group members’ own experiences. Many support group members went on to share their experiences by way of demonstrating the overlaps and coherence with the results of the current study.

To further establish the quality of the current research project, the project was conducted in accordance with the Consolidated criteria for REporting Qualitative research criteria (see online supplementary appendix 1).

Findings

Neuropsychological assessment

All participants with a diagnosis of PCA had previously (within 6 months) completed a selection of neuropsychological tests of memory, language and visual processing skills (visuospatial and visuoperceptual). Descriptive data relative to normative data sets appropriate for the
mean age of the group are presented in Table 2. Mean participant scores on the Short Recognition Memory Test (words), fragmented letters (visuo-perceptual) and dot counting (visuospatial) tasks were below the 5th percentile, with mean scores on the concrete synonyms test falling within a normal range. About half of participants’ individual scores on the tests of memory (Short Recognition Memory Test for words) and language (concrete synonyms test) fell below the 5th percentile (n=11 and n=9, respectively), whereas almost all participants’ individual scores on the tests of visuo-perceptual (fragmented letters) and visuo-spatial (dot counting) processing skills fell below the 5th percentile (n=19 and n=18, respectively).

Qualitative interviews
Participants described a range of ways in which the diagnosis of PCA and the associated symptoms contributed to stress over time and various strategies they and close others employed in response. The findings comprise three central themes that highlight some of the diagnosis-specific characteristics of PCA: the journey to diagnosis; interacting with the physical environment; and the importance of maintaining independence and the adoption of one day at a time approach to coping. Within these key themes, there were associated temporal variations due to transitions associated with stage of life and others more representative of living with a neurodegenerative illness. The illness experience was framed by numerous contextual and background factors (eg, existing relationship quality, personality factors etc, being a caregiver/caretaker/going person) and life stage transitions.

The journey to diagnosis
Initial symptoms were often described as incongruous or hard to pinpoint but nevertheless an indication that something was wrong. Often, struggles with very familiar activities were first noticed:

Everything was hard for about a year, and [I was] beginning to feel there’s something not right here, because I couldn’t work out sort of basic things. (Participant with PCA)

It was not uncommon for individuals to describe a problem that arose in their workplace, for example, reading financial accounts, or difficulties judging distance while driving. These challenges were often attributed to the health of their eyes and presented in stark contrast to the typical short-term memory problems first noticed in cases of CJD.

With the everyday nature of tasks becoming difficult, this was inherently unsettling and a primary source of stress in and of itself. The majority (n=19) of individuals consulted eye health professionals (eg, ophthalmologists) in the first instance and underwent various inconclusive eye health tests despite the cortical nature of their visual impairment. With hindsight, couples reflected on how the stress had been exacerbated and drawn out because of the lack of knowledge of the illness among the healthcare professionals they were consulting. For some (n=19), this was complicated by concurrent eye health issues, further delaying diagnosis. Experiences with general practitioners (GPs) (n=17) were similarly reported to be frustrating because of a lack of answers or appropriate and timely referrals. For some, even a referral to a neurologist did not guarantee a diagnosis.

That would have saved me a lot of trouble if I’d believed myself. And it took ages, we went through about five or six neurologists... Nothing. It was just dreadful because I kept thinking if I tell them what’s wrong, what’s happening and the symptoms, they’re bound to know... And nobody knew. (Participant with PCA)

A minority of participants (n=5) reported a timely and efficient diagnostic process, and this was mostly attributed to their own efforts towards information seeking but for one male was attributed to the ‘luck’ of his GP’s professional connections. The remaining patients (n=17) described stress caused by having to persist in their search for a diagnosis for what they considered to be an unacceptable long period of time. This is consistent with existing literature that describes the benefits of and need to prioritise the early diagnosis of dementia for individuals, families and society; however, this study highlights the particular barriers those with PCA face in receiving a timely diagnosis, owing to the rarity of the condition, associated lack of professional awareness and atypical symptom profile that lead them to expiring an eye health route. Consistent with this idea of the importance of having knowledge of the illness, many participants explicitly stated the relief they experienced when the diagnosis was provided (n=11).

Following diagnosis, there was a widely reported lack of accessible information. This has previously been reported by those adjusting to a diagnosis of Dementia and young-onset dementia specifically, and the current findings therefore add to knowledge about the varied types of dementia for which advice and information are needed. The rarity of PCA had the potential to be an ongoing source of stress over time in that those living with the diagnosis repeatedly found themselves better informed on the condition than healthcare professionals they came into contact with, often having to re-explain the syndrome and their symptoms on multiple occasions.

Interacting with the physical environment
The nature of the symptoms (ie, predominantly visual) meant effectively interacting with the physical environment was the predominant issue. This included interactions within and outside the home environment and with activities both functional and fun.

Every participant described complications with completing self-care tasks, most prominently dressing and cooking. Difficulties with dressing included finding
or selecting clothes or shoes, orienting them and using fastenings:

I do struggle a bit sometimes in working out which were round shirts go... If it’s all in a big heap, which it generally is, it’s just a question of I will perhaps turn it round, sort of, two or three times before I work out where the collar is. (Participant with PCA)

Dressing problems were exacerbated by distinguishing clean versus soiled clothes, seeing the closet and bedrooms being a shared space. Dressing assistance was frequently obtained from a family member or by dedicating, organizing and simplifying the bedroom environment. In contrast to those with tAD, where problems with dressing may be attributable to problems with sequential task performance and attention, most of those with PCA exhibited described clear visuospatial and visuo-spatial processing problems underpinning their difficulties. Those with PCA were able to similarly articulate about their choices and preferences around clothing and remained motivated to initiate dressing activities, which may be in contrast to those with tAD whose dressing may more commonly be disrupted by temporal disorientation and lack of motivation.

With cooking, typical problems were with locating ingredients/equipment in the kitchen, reading labels, following recipes, using appliances or confidently and safely handling hot materials. For cooking or other household tasks, some individuals attempted to use visually salient strategies such as labelling cupboards or putting a red dot on the start button of an appliance. The effectiveness of these strategies varied and more typically individuals retreated from these activities. As with dressing, when these difficulties are reported in the literature on tAD, they are usually attributable to declining executive function skills.

Of particular importance to participants were difficulties they had in engaging with a wide range of hobbies and interests including reading, DIY, sports and arts activities. The impact of this seemed heightened by the typically young age of onset that saw all participants either approaching retirement age, having recently retired or reducing their working hours, and therefore allocating and looking forward to increasing time related to leisure activities.

I think we thought we’d be going out to theatre and travelling, and things more, whereas I’m planning in 2015 to make it the year I’m going to go on the matrix, try that. But, travelling has virtually stopped. We were going to take John’s mother to the Christmas market, thinking well, with her help, I can probably get John on and off the train, but it... with her breaking her hip, that’s another thing, another holiday went because of that, and so we thought, this is the time, this will be the time in our life that we need to travel, and this is the time in life, for one reason or another, we can’t... Yes, I think we thought this would be the golden years. (Family carer)

The stress at having to retreat from or renegotiate hobbies is consistent with a study that looked at aspects that are important for quality of life but challenged by dementia.52 However, the barriers here were largely due to the specific visuospatial and visuo-spatial processing deficits, which is in contrast to a study by Giebel et al53 in which carers described those with tAD having difficulties with the initiation rather than performance of such activities.

Beyond the home environment, all participants had difficulties navigating the external environment either on foot, by car or on public transport. Particular challenges were wayfinding through crowds, reading signs or maps, general orientation and using stairs/escalators.

I’m usually quite okay here but the minute I step outside the door it all goes mad... Life goes a bit strange, yes... even inside the village can be a bit strange but definitely when I go catching buses and dealing with... interacting with people, in general, no, it’s not great, not great... I don’t know what happens but it goes mad, yes. Not all the time and not every time but I’m much less comfortable and avoid, now, going unless I really need to go into town. (Participant with PCA)

Participants commonly stated they relied on routine responses to the environment and cues within it (eg, using the same underground line or bus) or environmental cues (eg, recognizing a street by a particular shop or church), but naturally the external environment is not a stable one. In the case of (for example) a delay in public transportation or a busy blocking the view of an environmental cue, problems arose such as the person with PCA getting lost or disoriented. It is important to note that, for most, this was not due to forgetfulness, distractibility or other executive function deficits as might be expected in cases of tAD61-63 but because of problems accurately perceiving visual information about the environment that would help individuals to work out where they were in relation to their target destination.

The difficulties that participants described in interacting with their physical environments are compatible with the sorts of neuropsychological deficits documented in people with PCA in the literature. Deficits like visual crowding, simultagnosia, spatial navigational problems and apraxia43-45 corroborate with the issues people described with locating and manipulating objects, reading and dressing in this study.

As described above, the tendency towards simplification and familiarity meant withdrawing from certain activities. In addition though, almost all participants described ongoing uncertainty and unpredictability associated with the disease profile, commenting that the difficulties were not reliably ever-present (n=16). This uncertainty was once again exacerbated by a reported lack of disease-specific provision and guidance. A minority of participants opted for off-the-shelf adaptations for those with eye health problems, for example, a symbol cane (n=3), or had been in touch with the
Royal National Institute for the Blind regarding visual aids (n=5) but most took a self-initiated, largely trial-and-error approach owing to the unusual, unpredictable and continually changing nature of the symptoms. This process was rife with uncertainty regarding if things would work, why they might not and over time, how long they would continue to work.

Camilla can still read, so if it’s just one word it’s okay… but we’ve done different colour coding (on shampoo/conditioner bottles) and this sort of stuff but then she forgets which colour’s which. So it’s not, you know, it seems to be simple… but then there’ll be some other obstacle along the way. (Family carer)

This family carer provides an example of the complexity of progressive cognitive decline where strategies to compensate for the dominant visual symptoms may rely on other cognitive capacities (eg. memory) that may also be affected to an extent. This was in contrast to those without memory impairment at the time of interview (n=6) who frequently relied on the familiarity of their environment to help them find their way or something they needed, often closing their eyes or feeling their way to minimise any confusing visual information.

Allen et al. recently described a similar trial-and-error approach to environmental adaptations being employed by community-dwelling people with TAD and their carers, but these were more often triggered by—and designed to ameliorate—difficulties associated with dominant memory problems (eg. using labels as reminders).

Acknowledging the temporal context, the participant above like many others referred to what his wife could ‘still do’—appearing to demonstrate an anticipation of continuing decline over time. This is something commonly reported throughout the dementia literature in general. In the case of PCA though, this was coupled with a relative paucity of accessible knowledge or professional guidance as to how the particular course of disease would progress.

Implications within the psychosocial environment

Overall, there were broader psychosocial ramifications arising from these day-to-day difficulties such as maintaining independence and contemplating an uncertain short- and long-term future.

The symptoms themselves and resulting difficulties in interactions within the physical environment naturally impacted individuals’ ability to perform daily activities independently.

I think that is the worst thing I can do nothing for myself all the time you’ve got to ask somebody. (Participant with PCA)

Psychosocial strategies used to mediate the stress associated with performance of these daily activities were largely the provision of physical assistance and reallocation of responsibilities within the dyad or family. Over time, this often resulted in increasing feelings of dependence.

One of my biggest problems is frustration that I can’t do things I want to do. I don’t need to do them but because I’ve always been able to do them it really irks me to have to phone my son up and say come and put this together for me. (Participant with PCA)

This example illustrates a common phenomenon reported in the interviews—the way this perceived dependency resulted in changing roles and responsibilities within families. The extent to which this caused secondary strain for individuals seemed to be mediated by contextual factors including the age of onset, personality factors and previous relationship quality. Interestingly, the one couple who were recently married (<5 years) described their biggest challenges as being with each other. They were able to emotionally support each other well. This was perhaps owing to their less well-established household roles and responsibilities but their relatively recently established and continuing affection for each other.

With age of onset, individuals had often been at the peak of their careers and/or in a critical position within the family system (eg. looking after both children and elderly parents). Such activities and the roles they represented were often defining in terms of individuals’ sense of self and identity:

... he does all the ironing and everything now. And I say no, that’s my job… I’d always done it, you know. (He) was always sorting and I had the children and everything, and just did it… And I must admit, I sit here now and I think, I can’t do anything. (Participant with PCA)

The threat that dementia and the associated decline in functioning can pose for a person’s sense of identity and independence is well documented throughout the existing literature, even when functional capacity is disrupted by memory problems rather than predominant cortical visual deficits as seen here.

Family carers (n=15) also described concerns they had about their family’s capabilities in taking on the new role of caregiver and reported the strain of uncertainties in knowing how and when to provide help. Many noted trying to strike a balance between getting things done, preventing family member’s distress or frustration and encouraging or facilitating their ongoing independence.

Any stress and strain for participants who had a diagnosis of PCA regarding the impact on identity, role and independence were arguably emphasised by their relatively intact long-term memory functions and abilities and inclination to reflect on and compare their previous experiences with their current situations. One way this caused stress was that the person with PCA could reflect on themselves and their declining abilities, and in doing so, most (n=15) were concerned that they were becoming a burden to their partner or wider family. However, these relatively intact capacities were also able to contribute to relieving stress for the majority of couples who took
an interdependent or ‘teamwork’ (n=16) approach to managing the difficulties via continued collaboration and joint problem solving. Those dyads who did not adopt such a team-based approach (n=4) appeared not to be affected by either factors relating to their previous relationship quality (eg, living fairly independent lives), personality (eg, pride and stubbornness), or the cognitive decline of the person with PCA (eg, poor memory for shared events). The dominant ‘teamwork’ approach or sense of ‘being on the same page’ and navigating the illness experience together was made evident in shared storytelling during the joint interviews and in the corresponding and complimentary accounts given in the individual interviews. However, there were also some instances of discrepancies in the accounts of the person with PCA and their family carer. Sometimes differing recollections of events (eg, a family occasion, first symptom onset) would seem to be easily explained by the person with PCA’s concurrent memory impairment, but in other cases, the discrepancies were harder to unpack. Several dyads offered differing accounts of the person with PCA’s functional ability. In one case, a daughter attested that her mother was trying to not let us, the researchers, know how impaired she was by insisting she was still doing household chores and that the discrepancy could be explained as an exercise in self-presentation. In another case, a man with PCA and his wife disagreed over whether he could safely go for a walk unattended—she considered his walking abilities to be too compromised and be considered him to be too closely monitoring him and disproportionately concerned. Day-to-day difficulties were also attributed to different underlying symptoms, for example, one man with PCA put his problem with navigating the stairs as a relative’s house down to the area being ‘dim’ and ‘dark’, whereas his wife put this down to him not remembering where he was correctly:

...you still get lost on that landing...So it’s a square area with four closed doors where does he go? And he never knows...like where is it, where on earth is it? So he can’t retain the information...this is like every single time...he is walking down those stairs for the first time. (Family carer)

These discrepancies—though not the common pattern in the current study—clearly highlight the importance of acknowledging potential differences in perspectives and the challenges these could pose in the day-to-day understanding of and responses to the symptom profile and its impact. Despite these occasional discrepancies, many individuals with PCA (n=11) expressed extensive gratitude or feeling ‘lucky’ for their spouse/family carer while also normalising any symptom-specific dependency as one of many ways in which they and their family member worked together to manage life’s challenges:

If you get married, sickness and in health, you have to keep to these things... I’m old-fashioned enough to think...you know, if it were me, he would look after me. I have no doubt...So, you know, what I think, and this is what I say to him, we’re married, we’re two parts of a whole, so in many ways it affects me, because then when you are supposed to be as one, as a whole...then you have to look after the other half of you, and, you know, by keeping one half healthy, helps the other half. (Family carer)

There was a suggestion that a relatively preserved insight and ability to plan in people with PCA prompted a continuation of closeness and collaboration between dyads, potentially contrasting with previous studies involving participants with younger but memory-impacted dementia. Bullock reported a loss of joint decision making in marital relationships, while separateness made up part of an overarching theme in a study by O’Shaughnessy et al about the impact of dementia on the marital relationship. Similarly, Weight described how a lack of awareness contributed to discrepancies in the accounts of people with dementia and their spouses regarding their experiences of tension within the relationship and also an overall reduction in shared meanings made about the illness experience. However, there are also reports of couples living with memory-impacted dementia taking a continued teamwork approach and sustained reciprocity in consideration of the others’ needs, both of which serve as a useful reminder of our need to interpret with caution. An example of this within our own study was one of the male participants who demonstrated concurrent memory problems along with his dominant visual processing deficits, whose wife commented:

Everything’s more flat, yes. And he’s got no sense of time, so whereas before...he would go...oh yes...this is the year that she said was our silver wedding anniversary...now he’s got to rely on the children to say...we’d better do something about it...I found it painful. (Family carer)

Two points seem salient here. First, the dementia progress in different ways for different people, and second, given the variation, states of separateness or connectedness, or teamwork versus independence, do not apply discretely and exclusively to a group of people with one diagnosis and not to another. The participants with PCA interviewed here will likely progress to have more memory challenges over time, potentially posing additional challenges to shared meaning-making, and those in the early stages of more typical dementia are increasingly shown to be able to reflect reliably and accurately on their own experiences and abilities, something essential for joint problem solving and shared decision making. Another factor to consider is the sociocultural context within which research questions are framed and studies are carried out. As the value put on quality of life surpasses that of quantity and as curbs for dementia remain elusive, attention has shifted to ideas of preserving personhood of...
those with dementia and more recently still, the couplehood of dyads living with a diagnosis. Acknowledging the person and not just their disease has also meant a shift in focus from seeking to document deficits, loss and failings and attempts to capture the whole breadth of experience as attempted here: the positives, strengths, closeness and resilience.

One day at a time

Beyond diagnosis and in terms of longer term ongoing coping with the diagnosis, uncertainty and a lack of knowledge persisted, this time with regards to what to expect and how the disease would progress.

There’s little point in thinking about the future because, in that sense, one would have to have a model of what the future may hold and therein lies part of the difficulty, that I can’t map that future and make any choices. (Participant with PCA)

This impacted how able many dyads felt to effectively plan for the future and many described taking a conscious decision to not think about it, given that there seemed to be little purpose or pleasure in doing so because of the incurable and progressive nature of the diagnosis.

Every now and again I get down, mainly because if I think too much about what the future holds then... it’s counter-productive... It’s going to happen. There’s nothing you can do about it. You know, it’s like one of those things. It’s nothing... it’s all... you can give a problem a lot of thought if there’s an answer... right, do we do this or do we do that? Right, think about it a long time, perhaps worry about it for a couple of days. Right, let’s do that. With this, there isn’t... What’s Plan B? You haven’t got a Plan B. And that’s this situation. There isn’t a Plan B. (Participant with PCA)

In shifting the focus away from an uncertain future, many described their approach as being centred around ideas of ‘keeping going’ and ‘living with things’, with almost all dyads describing efforts to maintain normality as far as possible (n=17):

When she [my wife] got her head around what she had, she said, there’s nothing I can do about it, we’ve just got to get on with it. And we just carried on as normal... When it crops up, I deal with it, but 99% of the time, we just carry on as normal... I mean, obviously you gradually get worse and worse, but, you know. (Family carer)

This family carer’s comment clearly demonstrates the complexity and significance of temporality in describing the simultaneous day-by-day approach that can exist in combination with broader acknowledgement and anticipation of ongoing decline over the long term.

There were several reports of professionals endorsing or echoing this approach of living in the moment:

She [doctor] just looked at him and... put her hands on his legs and said, just live your life... just go on and live your life, that’s all you can do. (Family carer)

This comment also seemed to address the inevitability of the progression of the disease and the absence of a cure, in describing continuing to ‘go on’ and ‘live your life’ as the only options open to participants in facing the diagnosis. Perhaps it also hints at the lack of published guidance and knowledge about progression of the disease and what to expect that may have enabled or assisted longer term care planning and management.

This is corroborated by a recent paper that identified the challenges families and practitioners face in finding tailored, disease-specific information and practical advice about PCA that is evidence based.

Taking a day-by-day approach was preferred and required due to the ever-changing nature of the symptom profile as the disease progressed. Individuals and families were continually responsive, and the majority described being attuned to the necessary ongoing adjustments and adaptations required by the continual change that is characteristic of the disease profile (n=10):

Yes, as I say, if I let my mind go there [the future], I will probably collapse in a heap, so I find it’s best just to deal with things as they present, and just try and think one step ahead, and not too far, because, as I keep being told, each individual with the disease is different, and they can make no... they’ve got no crystal balls to see into the future: about exactly how it’s going to pan [out] for any... one person. (Family carer)

The sense of needing to balance the maintenance of normality in the face of diagnosis-related changes that require ongoing adjustment is also commonly reported throughout the qualitative literature on dementia.

A decision to focus on the ‘here and now’ is also widely reported, owing to the uncertainty or discomfort associated with thoughts about the future, in line with what was reported here. These similarities with existing literature perhaps highlight the progressive nature that is common to all variations of AD and dementia more broadly.

**DISCUSSION**

This study has illustrated some of the diagnosis-specific stresses associated with PCA and the various ways individuals and families attempt to mediate these. The characteristic visually dominated symptom profile led to primary difficulties in interacting with the physical environment. These were situated within a complex psychosocial environment involving a range of roles and responsibilities requiring reallocation and various individuals’ longstanding preferences regarding independence versus asking for, accepting and providing help.

The rarity of the condition meant a lack of knowledge and accessible information about the symptoms, disease
course and provision of support for those living with PCA and healthcare professionals, all of which contributed to stress. The temporal context was of particular significance in shaping the stress process in terms of the time of life (e.g., employment, retirement status and position in the family), previous levels of performance and engagement in activities of daily living, awareness of and concern about the future, and the time-limited efficacy of support strategies.

This study offers an original contribution in looking at the day-to-day impacts of progressive visual impairment related to dementia rather than the more typically dominant memory loss. Also, the inductive, qualitative methodology used here offers unique insights to complement the existing PCA literature that is largely laboratory-based and concentrated on specifying the cognitive profile and underlying pathology of the disease. This study has gleaned insights firmly grounded in participants’ day-to-day experiences, within their home environments and recounted in their own words. This has allowed the full range of experience to be reported and documented. For example, families were able to share the problematic nature of symptoms and ongoing decline and also their resilience in their collaborative and creative approaches to developing coping strategies and in continually adapting to the diagnosis-related changes.

Although this is the first qualitative study of PCA, the findings here bear relevance to existing literature in several ways. The stress caused by the uncertainty and atypical nature of the diagnosis and the impact of lacking disease-specific support and guidance echoes that which other authors have described in relation to other rare diseases. The findings here may also bear relevance for those living with or seeking diagnoses of other rarer types of dementias, into which research is rightfully ever-increasing (e.g., behavioural variant frontotemporal dementia and the primary progressive aphasia).

Overall, we need to remain critical of the questions we ask and sensitive to the individual differences in disease profile across and within diagnostic groups, especially in terms of what this means in terms of psychosocial impact for the individual and family. Perhaps the most significant contribution of this paper is in outlining the different mechanisms (e.g., visual vs memory problems) that can underpin difficulties with daily activities, even if the psychosocial ramifications of such difficulties are similar or overlapping. Understanding the ways in which the experiences of those with different diagnoses and at different stages of their disease overlap and diverge will be essential if we are to build a knowledge base in which all the complex stories of living with the dementia are told.

A strength of the study is that those with a diagnosis of PCA and a family member were interviewed together and separately, ensuring that multiple perspectives were represented in the data set. In this case, and in contrast to some existing literature on spousal couples living with tAD, the relatively well-preserved insight of those with PCA resulted in largely congruent accounts of both parties in terms of levels of abilities and shared understandings of the illness experience. However, the discrepancies discussed above—and the varying plausible reasons for them—highlight the importance of interviewing in such a way that rich data from a range of perspectives can be gleaned and also the sensitivities and ethics around the assigning of credit to and/or interpretation of such data. That interviews were conducted in the home environment enriched the data in permitting researchers an in-depth understanding of the everyday physical environment in which difficulties emerged and were responded to and often acted as a useful prompt for participants when discussing challenges and strategies. Working within a process model encouraged consideration of related underlying mechanisms, resulting in new stressors and responsive coping strategies. The study also makes a broader contribution in highlighting a potential limitation of the Stress Process Model in not taking account of the physical environment as a potential source or mediator of stress, despite suggestions that this may play a particularly significant role for people with PCA and dementia in general. A possible limitation of the study is that the home-based nature of the interviews may have deterred dyads who were not managing well or taking part and, as such, the findings may not capture the full range of coping responses to the stress process. The interviews took place at one time point, and the emergent importance of the temporal context may make this another limitation of the study.

In light of these findings, implications for clinicians centre around the need for increased knowledge and provision of information—particularly in a diagnostic context—which is particular to the challenges associated with dementia-related visual impairment and sensitive to the psychosocial ramifications of these difficulties. In addition, dominant difficulties interacting with the physical world may make those with PCA particularly suitable for psychosocial interventions targeted at the marital or family unit as a whole, owing to the relative cognitive strengths of those with PCA (e.g., insight, memory and language). Unanswered questions remain about how PCA progresses beyond the moderate stages and also how visual problems may affect people with more typical, memory-limited forms of dementia, perhaps at a later stage when they are less easily communicated. Equally, future focused work that factors in the impacts of secondary impairments such as the concurrent memory and language impairments seen in subgroups of our sample here would be helpful to further unpick and illustrate the complexity of the PCA syndrome and the varying impacts it can have. Future research that looks at this both over time and taking account of the multiple perspectives inherent in any dementia journey would constitute valuable and original contributions to knowledge.
CONCLUSION
This study provides new insights into the stress process for individuals and families living with PCA, from the search for a diagnosis through to the daily challenges of living with dementia-related visual impairment. Increased availability and accessibility of information about PCA, its early symptoms and progression for both healthcare professionals and affected families would be beneficial in aiding timely diagnosis and minimizing ongoing stress and uncertainty. Key considerations in the design of supportive interventions for those with PCA would be timeliness and sensitivity to the complexities of the surrounding psychosocial environment within which they must be adapted and adapted to over time.

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Contributions: EJC contributed to study protocol development, data collection, analysis and interpretation, and manuscript preparation (writing and incorporation of comments/endorsements); MRS contributed to study protocol development; data collection, analysis and interpretation, and provided comments on draft manuscript. SKF contributed to study protocol development, data collection, analysis and interpretation, and provided comments on draft manuscript. COY contributed to study protocol development, data collection, analysis and interpretation, and provided comments on draft manuscript. ANC contributed to study protocol development, data collection, analysis and interpretation, and provided comments on draft manuscript. MKM contributed to study protocol development, data collection, analysis and interpretation, and provided comments on draft manuscript. JAM contributed to study protocol development, data collection, analysis and interpretation, and provided comments on draft manuscript. NGK contributed to study protocol development, data collection, analysis and interpretation, and provided comments on draft manuscript. JAM contributed to study protocol development, data collection, analysis and interpretation, and provided comments on draft manuscript. ANC contributed to study protocol development, data collection, analysis and interpretation, and provided comments on draft manuscript. MKM contributed to study protocol development, data collection, analysis and interpretation, and provided comments on draft manuscript. JAM contributed to study protocol development, data collection, analysis and interpretation, and provided comments on draft manuscript.

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Compelling interests: None declared.

Patient consent: Detail has been removed from this case description to ensure anonymity. The editors and reviewers have seen the original information and are satisfied that the information backs up the case the authors are making.

Ethics approval: The study was approved by the National Research Ethics Service Committee – London Queen Street.

Provenance and peer review: Not commissioned; externally peer reviewed.

Data sharing statement: Data will be made available in accordance with funder guidelines after the completion of the project (March 2019).

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REFERENCES
14.b Invited book chapter (in revision)

I have been invited to contribute to a chapter to the 2nd edition of ‘Qualitative Research in Psychology: Expanding Perspectives in Methodology & Design’ due for publication in 2020. The chapter is titled ‘Into the ordinary – lessons learned from a mixed methods study in the homes of people living with dementia’ and is currently in revision with my co-authors (Professor Sebastian J. Crutch and Dr Keir X. X. Yong at the Dementia Research Centre, UCL and Professor Mary Pat Sullivan at Nipissing University, Ontario, CA).
APPENDIX 15: Example of public engagement outputs arising from this work

15.a BakeTell tarts workshops

BakeTell tarts: telling stories about the dementias through the universal language of baking

- Bloomsbury Festival – London (2016)
- NCCPE Engage Conference – Bristol (2016)
- Norwich Theatre Royal – Norwich (2019)
Eye opening!
Never knew Alzheimer's affected people's vision/eyesight!
Now I know what my granpa felt.

What a trickier our brain is...
Interesting to learn about dementia & visual problems.

The quotes from people with dementia about their experiences is very thought provoking and the vast range of different problems they as a result of visual disturbances is fascinating.

Very eye opening - another view in the brain to understand.
APPENDIX 16: COREQ Checklists (Tong, Sainsbury and Craig, 2007)

Phase I Interviews

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Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.
Phase II Home-based observations

### COREQ (Consolidated criteria for Reporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

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### Topic: Analysis and Findings

#### Data Analysis

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APPENDIX 17: Extended discussion of additional theoretical approaches which could offer further understanding of the study findings

**Affordance Theory**

Gibson’s (1977) affordance theory relates to how individuals interact with their environments – it suggests that objects within the environment and physical spaces themselves offer possibilities for action, but that these are interpreted by individuals, and that this then determines action. As such the theory is relational – affordances are constructed on the basis of these interpretations, therefore different objects and spaces offer different possibilities for action for different people (Gibson, 1977; Topo, Kotilainen and Eloniemi-Sulkava, 2012). In relation to the populations under study here, it could be expected that people with different diagnostic profiles would have different possibilities for interactions within the same environment. Environments and objects come to represent opportunities for action based on these interpretations, highlighting a dynamic and interpretive relationship between perception and action, contingent on an individual’s appraisal based on the information available in the situation (Greeno, 1994). This too has relevance for the groups in the current study, as this highlights, compatibly with the two versions of the Stress Process Model, the importance of the individual’s subjective interpretation of their abilities and difficulties, and their accurate perception of the environment – all things which were differentially affected in the two groups here, in ways that were indeed seen to be determining in how participants interacted with their environments. For example, participants with PCA would often talk themselves through an activity they were not receiving reliable visual information about, and Betty provided good examples of a potential lack of insight into her own abilities to interact with the environment when she persisted with offering to help with tidying things away after lunch, and when she spoke at length about her plans for redesigning the garden. These examples are both
compatible with the theory’s acknowledgement that affordances can also be falsely perceived, when there is a perceptual impairment reducing the accuracy of the information being interpreted by the potential actor (Gibson, 1977; Topo, Kotilainen and Eloniemi-Sulkava, 2012). Affordances are also suggested to not be fixed, they are said to be continually changing as the environment is continually reinterpreted and reassessed, and not all possible affordances will be conceived of or considered (Gibson, 1977; Topo, Kotilainen and Eloniemi-Sulkava, 2012). This too would be compatible both with the variation which was seen over the course of the observational home visits as participants’ energy levels and cognitive abilities fluctuated, but was also captured over the longer term in the verbal accounts given during the interview phase, in which participants described the gradual progression of difficulties alongside the day-to-day fluctuations and unpredictability. As well as on the perceptions of the actor, according to the theory, affordances also rely on the actor’s motivation and attention, and these can be prerequisites for action but also inaction – they may encourage or constrain a person’s activity within a given environment (Topo, Kotilainen and Eloniemi-Sulkava, 2012) – and this was something evident in both groups during the home-based observations. This is compatible with Majlesi, Ekström and Hydén’s (2019) findings that it is via attentional and perceptual processes that the spatial organisation of different objects can vary the order in which PLWD complete the various activities associated with them. A number of the tAD group’s data was compatible with this – Richard, Betty and others appeared to have activities environmentally-cued when their attention landed on various objects in the environment, highlighting how important attention was in the process of determining action, and there were also a number of tAD participant whose lacking motivation (i.e. apathy) inhibited their action, to the extent that their family members would coordinate and encourage their participation in activities.

Lastly, the theory posits that the process of interpretation and perception involved in determining action relates to one’s own ability, as well as to features of the
environment – the environment is not appraised independently but in relation to the observer and their own perceptions and beliefs about their abilities (Gibson, 1977; Greeno, 1994). Both versions of the Stress Process Model and the empirical data from both phases of this study endorse this as being key at both ends of the spectrum – with PCA participants commonly withdrawing from their traditional means of engaging with activities because of their insight into how their abilities had changed, and with tAD participants’ perhaps overestimating their capabilities and making plans for activities accordingly (e.g. Betty with garden landscaping, Richard with family ancestry book plans, Mandy with generally sensing improvement in her condition). The continued but adapted use of the same objects and spaces associated with meaningful activities in particular – such as Alan gesturing to the car that he had previously considered to be his ‘existence’, and Betty talking through her plans for landscaping the garden when she noticed some chipped paint on the gate – seem to also be compatible with Gibson’s Affordance Theory (1977). In acknowledging the individual’s key role in assessment of the environment, rather than the objective possibilities of it, the theory allows for interpretations like Betty’s regardless of whether they represent any objective measure of ability (e.g. Betty would not have been physically or cognitively able to oversee the actual landscaping of the garden, but her ability to perceive the garden afforded her the possibility of making plans for it).

**Self-Determination Theory**

One such example of a theory about how behaviour and action is motivated in healthy populations is self-determination theory, a theory of human development concerned with an individual’s internal motivation for growth (Deci and Ryan, 2002; Deci and Ryan, 2008a). According to the theory, human behaviour is motivated to meet three underlying psychological needs, and the meeting of these needs results in psychological wellbeing. The needs are: autonomy, competence and relatedness (Deci and Ryan, 2002, 2008a). Autonomy is having a sense of agency and control over one’s behaviour. It is a sense of ownership of one’s behaviour and choices, and
that these are coherent with one’s sense of self and values. A key distinction to make for the purposes of how this theory might fit with the findings of this study, is that autonomy is not considered to be synonymous with independence – a person can depend on others very willingly and still have their need for autonomy met, providing reliance on their helping is congruent with a person’s values (Ryan, Huta and Deci, 2008). This was in keeping with the current study findings, with many dyads adopting the same team-work approach to managing the diagnosis-related difficulties which had always characterised their relationship, and with others retreating somewhat from those activities which they could not orchestrate themselves. It could be argued that the theory can only be considered to apply to the PCA group however, where motivation for engagement with specific activities of interest was expressed by all participants, whereas in the tAD group, a subsection of family caregivers were more likely to take on the responsibility of ensuring the PLWD was engaged in activities which were in line with their prior values on their behalf. Competence refers to a sense of confidence in one’s abilities to interact effectively with the environment, and to have opportunities within the environment to demonstrate and enact one’s capabilities (Deci and Ryan, 2002, 2008a). Appropriate activity selection is of significant importance therefore, as meeting this need means seeking out challenges which are appropriately pitched for a person’s level of functioning. This seemed to apply for both groups – in the PCA group this was compatible with their modified modes of engaging with the environment and activities in accordance with their diagnosis-related reduced capabilities. In the tAD group this was often orchestrated by family carers who would organise activities and support them in such a way that they knew their partner would be able to execute them. Relatedness refers to feeling a sense of belonging and connectedness to others, whether in personal relationships, wider social circles or the community or society as a whole (Deci and Ryan, 2002, 2008a; Ryan, Huta and Deci, 2008). The multiple levels at which reciprocity was observed in the current study, from shared problem solving to the negotiation of activities, the motivations underlying them, the meanings associated with them, and the enduring nature of
this as a motivating force for activity engagement, is compatible with this idea of relatedness as a core and fundamental psychological need. Central to the concept, rather than any explicit concrete goals, is an ongoing sense of needing to feel cared for and to care for others (Deci and Ryan, 2002, 2008a). Social connection was a significant motivator for much of the activity undertaken or that which was greatly missed by participants in both the interviews and the observations in the current study, but this particularly resonates with the many examples participants in both groups demonstrated of opting for activities which could be of some benefit to others in some way. This seemed to be a key enduring motivator for activities, despite the difficulties people were experiencing, and this is compatible with recent findings that impaired ability to engage with socially-related daily activities has particular implications for wellbeing (Giebel, Challis and Montaldi, 2016).

The theory takes a eudaimonic approach to wellbeing which – at odds with the traditional and often still-dominant hedonic view – conceptualizes wellbeing as a process of self-realisation, a sense of fulfilling one’s potential in meaningful ways (Deci and Ryan, 2008b; Ryan, Huta and Deci, 2008; Ryff and Singer, 2008). It considers wellbeing to be more a process in the sense that it is a way of living life in accordance with one’s values and capabilities, rather than a desired end state of pleasure and joy. This is compatible with Kitwood’s interpretation of wellbeing for PLWD – one of the observational indicators of wellbeing he described was the ability to experience and express both positive and negative emotions (Kitwood and Bredin, 1992; Kitwood, 1997a, 1997b), and is fitting with many of the observational findings here, whereby PLWD would persist with activities which were difficult, or with things which perhaps were not just for fun but which served a bigger purpose (e.g. by contributing to the running of the household, or easing what they perceived as the burden on their family carer).

Ryff (1989) proposed a six-dimensional model of eudaimonic psychological wellbeing, and two pertinent elements of the model for the findings of this study are environmental mastery and autonomy (discussed above).
Environmental mastery refers to an individual’s ability to select or build environments which are suited to one’s needs and abilities, and to be able to adjust and adapt these as needed. The ability to create environments one can thrive in is the foundation for the meaningful, contributory and otherwise complex interaction with and navigation of that environment a person will need to embark on, if they are going to fulfil their potential. The ongoing adaptation and responsiveness that the PCA group and their family members reported and showed – these being the participants whose environmental mastery was most challenged by their symptom profile – is supportive of this motivation. Perhaps the fact that these participants were largely able to do this, or at least had the resources and energy to try to (even when adaptations were not effective, or worked only for a short period of time) could explain the generally positive experiences had with participants during most of the observations. Perhaps those struggling to adapt their environments, and whose sense of wellbeing was suffering as a result, were the portion of the population who were under-represented in the current study (see discussion of possible sampling bias in ‘Limitations’ – section 5.10 – below).

Self-Determination Theory is dialectic in that it is primarily concerned with the individual who it considers an agentic solo organism, but it also accounts for the social contexts which surround and influence the individual’s attempts at meeting their goals via their motivated actions (Deci and Ryan, 2002; Deci and Ryan, 2008a). This is compatible with the essential role carers were seen to play in supporting activity engagement in the current study. The fact that participants themselves also demonstrated a determined perseverance to continue to engage with activities of meaning supports the potential applicability of Self-Determination Theory in PLWD, as it is compatible with the notions of mastery and autonomy as key influencing forces on one’s actions. A theory of motivation and personal development like Self-Determination Theory perhaps runs counter to the dominant discourse of decline and loss of self that has already been discussed, but the enduring agency observed in both groups (though it may have taken different forms and been enacted in
different ways) is suggestive that the concept of autonomy is indeed a fundamental psychological need in this population, as much as any. The theory has a strong empirical base and has been applied in a range of contexts, but not explicitly in the dementia research field (though it has in other areas of healthcare) (e.g. Johnson, 2007; Ntoumanis, Edmunds and Duda, 2009; Zubialde, Mold and Eubank, 2009), though the compatibility of some of the findings observed in the current studies with the tenets of the theory suggests this could be a potentially useful endeavour.

**Activity and Continuity Theories**

Another theory targeted at healthy populations which I would suggest could be worth considering within this context, despite the diagnostic status of these populations is Activity Theory – a theory of successful ageing developed by Havighurst (1961). It posits that maintaining engagement in as much activity as is possible for as long as is possible is key for successful ageing. The end of employment is highlighted as an age at which there is significant change in activity levels, and therefore a time when engagement in other activities becomes particularly important for maintaining wellbeing (Havighurst, 1961; Nimrod and Kleiber, 2007). This is compatible with reports and observations in this study, of the time of life as a key factor in shaping how participants responded to the challenges of their diagnoses, particularly in terms of the disruption and/or reprioritising of one’s roles, responsibilities and activities relating to employment, existing caregiving responsibilities and opportunities for making a contribution. Activity Theory was further developed by Atchley (1993) into Continuity Theory, which aimed to account for the empirical findings that while people show a desire to maintain activity as they age, there are unavoidable changes that come with ageing, which can place necessary limits on a person’s activity engagement as time goes on (Atchley, 1989, 1993, 1999; Nimrod and Kleiber, 2007). This perhaps increases the applicability of the theory to PLWD, given the progressive challenges associated with the diagnoses which were observed here, and which activity engagement was adapted in accordance with. Atchley’s (1993) continuity theory instead focuses on
how continuity (where possible) can help in adapting to necessary and inevitable changes that come with ageing. Continuity in activities in particular – a type of embodied, action-based, external continuity, which occurs outwardly in the observable physical and social environments – is said to be able to contribute to the continuity of one’s sense of self and identity (which are examples of internal continuity) (Atchley, 1989, 1993, 1999). This is particularly fitting with the third theme of the observational study findings, ‘The constitution and continuity of a changing self’, which suggests that ongoing (even if modified) activity engagement is a means by which PLWD can constitute and make reference to their enduring selves. Continuity can be especially helpful following negative life events, with familiar activities which allow someone to express their personhood helping to re-establish meaning and direction, which may have been disrupted by such events (Atchley, 1989, 1993, 1999; Nimrod and Kleiber, 2007). This also seems very fitting with such a disruptive event as a diagnosis of dementia – particularly one which is rare, atypical and onsets early, such as PCA. Atchley (1989, 1993, 1999) suggested that specific activities may need to be adapted, but that often there will usually, ideally, be some continuity in an area of interest or skill set, which connects the selected activities of later life to previous roles and leisure or occupational activities. This was also observed in the current study, via PLWD’s various modified modes of engagement with activities of personal importance over time. Although Atchley (1989, 1993, 1999) makes reference to negative life events which are most common in older age, the continued iterations and developments of the theory are generally applied to well populations, and assume the possibility of successful and active ageing. Application of the theories for PLWD has remained relatively unexplored, but has been encouraged (e.g. Menne, Kinney and Morhardt, 2002).

Psychosocial developmental theory – The Stage of Generativity

The final theoretical idea which comes from a developmental approach but which perhaps provides a useful context within which to consider some of the current study findings, is Erikson’s psychosocial stages of development – specifically the
seventh stage of generativity (versus stagnation) (1997). Erikson proposed eight developmental stages which present as crises, and which must be resolved in order for an individual to continue developing beyond that stage (Erikson, 1997). The seventh stage usually occurs in middle adulthood, ages 40-59 (but can also be triggered by a sudden health or employment related crisis – as experienced by many of the PCA group in this study), and is the point at which individuals become concerned with being generative – giving and contributing for the benefit of others (Erikson and Erikson, 1981; Erikson, 1997; Slater, 2003). These others can be one’s own family, people with whom one has personal relationships (e.g. spouse, friends), networks of colleagues, or the wider community and society (e.g. the younger generation) (Slater, 2003). This generativity includes notions of productivity and proactivity, and requires investment in acts of giving that feel important and worthwhile (Erikson and Erikson, 1981; Bradley, 1997; Erikson, 1997; Slater, 2003). Generative acts can take the form of guiding others, creating for them, caring about others and feeling a sense of responsibility for them (Erikson, 1997; Slater, 2003). Generativity has been said to be in operation in any situation when one shows concern and care for another, and serves the fundamental need that people have to be needed (Erikson, 1997; Slater, 2003). The findings from the home-based observation study here provide examples of PLWD in both groups showing motivation to complete what could be considered generative acts, in line with the outlined variations and definitions of what constitute those above.

This further illustrates the potential for theories which, like the Stress Process Model, have an inherent temporal sensitivity, but one which is not solely modelled around inevitable decline (Pearlin et al., 1990; Judge, Menne and Whitlatch, 2010) to be applied to the experiences of PLWD. Theories which instead highlight the manifold ways people continue to develop during ageing, which could offer useful insights and fitting contexts within which to better understand the experiences of people with and without a diagnosis of dementia. I would endorse the suggestions of others that these sorts of theories can be helpfully applied for PLWD, and further
to this would hope that doing so could reduce some of the (even when unintended) ‘otherness’, which may arise when employing only dementia-specific theoretical lenses to the study of PLWD.