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**An Exploration of the Factors Influencing Patient and
Family Initial Attendance at Memory Screening Clinics: An
Interpretative Phenomenological Analysis**

And Clinical Research Portfolio

Volume I

(Volume II bound separately)

Melanie Louise Young, MA Soc. Sci. (Hons.)

*Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology*

Institute of Health and Wellbeing
College of Medical, Veterinary and Life Sciences
University of Glasgow

March 2016

Declaration of Originality



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Chapter 1: Systematic Review

Patient and Family Dyad Experiences of Recognising and Adapting to Early Stage Dementia: A Meta-Ethnography

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Prepared in accordance with guidelines for submission to Dementia: The International Journal of Social Research and Practice (Appendix 1.1)

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Abstract

Objectives: This review aims to systematically examine and synthesise qualitative studies of patient and family recognition and experience of the pre-diagnostic stage of early dementia.

Method: A meta-ethnographic approach was employed. Systematic searches of Medline, Embase, PsychInfo, CINAHL and Web of Science were conducted. Hand searches of article reference lists, selected journals and Google Scholar were completed. Eight articles were identified for inclusion and appraised using a quality assessment framework. One article did not meet criteria and was removed.

Results: Five themes were identified: prior beliefs of ageing and dementia; loss of self; relational adjustment; maintaining social value; and concern for the future.

Conclusions: The meta-ethnography showed the role familial relationships can have on early recognition of dementia and their impact on living well with the onset of the disease. Clinicians should reflect on the relationships people operate within to consider how they are likely to respond and cope with future disease progression.

Keywords: Systematic review, Qualitative, Dementia, Patient and Family Dyad Experience.

Introduction

Dementia is a public health priority and a major cause of disability for older adults worldwide (The World Health Organisation, 2015). In the United Kingdom, it is estimated that 850,000 people will be living with the disease in 2015; this is expected to rise to one million by the year 2025 (Prince et al., 2014). The estimated financial cost to the United Kingdom is projected to be up to £26 billion per year (Prince et al., 2014). Dementia is an umbrella term used to describe a range of brain diseases characterised by progressive decline across intellectual and other mental functions. In the earliest stages symptoms may be mild and affect memory, but as the disease advances it progressively impacts upon a range of cognitive and functional abilities leading to disability and dependency on others (The World Health Organisation, 2015).

Despite there being no cure and limited treatments available to slow disease progression, an early and accurate diagnosis of dementia allows access to timely information, support, and care for patients and their families (Department of Health, 2009; The Scottish Government, 2013). This is reflected in the key aims of United Kingdom government policy; Living Well with Dementia: A National Dementia Strategy (Department of Health, 2009) and Scotland's National Dementia Strategy (The Scottish Government, 2013).

A significant challenge exists as the experience of symptom onset, recognition and the early stages of dementia differ from the linear pathway of other chronic and progressive diseases (Buntinx, et al., 2011). Despite people with dementia reporting early insight around symptom onset (Leung et al., 2011), retrospective Australian (Speechly, et al., 2008), British (Chrisp, et al., 2011), Canadian (Leung, et al., 2011), Dutch, (van Vliet et al., 2013) and American studies (Morhardt, et al., 2010) have demonstrated people delay contacting health services for between two and five years. Confirmed diagnoses have shown to take on average, three years from initial symptom awareness (Chrisp, et al., 2011; Speechly, et al., 2008).

Patient and family experiences of early stage dementia have been considered in the literature. Steeman, et al., (2006) synthesised 28 qualitative studies (total sample n=414, median sample n=12). Three transitional stages; pre-diagnosis, diagnosis and post-diagnosis, were outlined. Pre-diagnosis described experiences of gradual symptom onset, multiple emotions and the use of strategies to assume control. Diagnosis was triggered by arising needs or crisis points. People sought help to validate their understanding of the possible causes of impairment. A series of personal losses, feelings of irritation, frustration and uncertainty, and acts of self-maintenance and adjustment characterised post-diagnostic experiences (Steeman, et al., 2006).

A synthesis of 50 studies examining the lived experiences of patients diagnosed with early stage dementia delineated two central themes; *“impact”* and *“coping”* (de Boer, et al., 2007; of which 14 studies were included in Steeman et al., 2006). *“Impact”* was associated with quality of life, and defined by gradual functional losses, changes to significant relationships, and negotiating through feelings of fear, insecurity, confusion and disbelief. Individuals *“coped”* by adopting emotion-orientated (denial, avoidance, minimisation, normalisation and overcompensation) and problem-orientated strategies (facing and compensating, lowering aspirations, and maintaining control) (de Boer et al., 2007). Assessment and care were perceived as effective when interventions maximised individual autonomy (de Boer et al., 2007).

Subsequent reviews have considered the experiences of the diagnostic and post-diagnostic stages as defined by Steeman et al., (2006). Robinson et al. (2011) synthesised 62 qualitative and quantitative articles studying diagnostic experiences of dementia (patient and carers (n=35), professionals (n=24) and population surveys (n=3), total population n=7138, median n=30). A thematic review of 126 studies (total population n= 3095) reflected how people respond and adapt to a dementia diagnosis (Bunn et al., 2012). Both reviews demonstrated the significant challenge to overcome psychological, social and functional losses, but revealed active attempts by individuals to assimilate and accommodate the disease into their lives (Bunn et al., 2012; Robinson et al., 2011).

The socially embedded nature of the recognition and adaption to dementia has been appraised by two reviews (Ablitt, et al., 2009; Braun et al., 2009). Braun et al., (2009) summarised the literature concerning the relational aspects of dementia caregiving; premorbid attachment style and caregiver strain were negatively correlated to engagement in pleasurable activities and thus their interpersonal relationship. However, discrepant reports between people with dementia and their carers' were exposed as a limitation. Ablitt et al., (2009) reviewed 31 articles to study the influence relationship factors had on the experience of living with dementia. A theoretical framework was proposed whereby, "*prior relationship factors determine the form that the relationship will take in the context of dementia*" (Ablitt, et al., 2009, p.506). If the relationship quality declines, each individual's emotional well-being may reduce, leading to lower functioning and symptom exacerbation (Ablitt, et al., 2009). Both reviews reaffirmed the paucity of research directly involving people with dementia (Abitt et al., 2009; Braun et al., 2009). Furthermore, the use of dyad paradigms was proposed to facilitate a deeper understanding of the unique processes serving to enable individuals to live positively with early dementia (Braun et al., 2009).

Review Rationale

There is emerging evidence that symptom onset is characterised by varying awareness, symptom evaluation, and mixed emotions (Bunn et al., 2012; de Boer et al., 2007; Steeman et al., 2006). The existing literature illustrates experiences of diagnosis and post-diagnosis follow an individualised course but includes an

interaction between symptom recognition, biological, social and psychological changes, with help-seeking triggered when coping strategies fail or crisis points arise (Bunn et al., 2012; de Boer et al., 2007; and Robinson et al., 2011). Less evidence is available for the pre-diagnostic period. Furthermore the way symptoms emerge through social interactions is highlighted as potentially impacting on how individuals recognise and respond to dementia (Ablitt et al., 2009; Braun et al., 2009). Qualitative techniques offer in-depth exploration of experiences and provide richer personal accounts to inform the understanding of the phenomenon.

Due to the discrete processes noted in each transition (Steeman et al., 2006) further research was recommended. This was to refine and deepen current understanding of individual and family perceptions when facing dementia and to develop proactive care commencing at diagnosis (Bunn et al., 2012; de Boer et al., 2007; Steeman et al., 2006; Robinson et al., 2011). Consequently, this systematic review seeks to further existing understanding of the research area and explore the available qualitative research not previously included in the reviews by Steeman et al., (2006) and de Boer, et al., (2007). The review will specifically consider studies focusing on how spousal and familial dyads recognise and experience early stage dementia prior to diagnosis.

Research question

How do people with dementia and their families recognise and experience the pre-diagnostic stage of the disease?

Method

Search strategy

A systematic search of the following databases was conducted between March and April 2015 and updated on 30th July 2015; Medline (OVID), Embase (OVID), PsychInfo (EBSCO), CINAHL (EBSCO) and Web of Science. Searches of Google Scholar and selected journals; the Journal of Aging Studies and Dementia: The International Journal of Social Research and Practice were conducted. Subject heading and keyword searches used the terms outlined below. No date restrictions were applied. Boolean operators were used to combine search strings.

- 1. Dementia Terms:** Dementia / Alzheimer's disease (subject headings) OR dementia OR Alzheimer*AND mild OR moderate OR early OR diagnos* OR recogni* OR help-seeking,

AND

2. Patient/ Significant Other Dyad Terms: dyad (subject heading) OR dyad OR patient-carer OR caregiving OR carer-care recipient OR famil* OR spous* OR couple OR parent-child OR dyad* perspective OR relational perspective,

AND

3. Qualitative Research Terms: qualitative research OR qualitative studies (subject headings) OR qualitative OR experienc* OR narrat* OR focus group OR interview OR thematic OR phenomenolog* OR interpretative phenomenolog*.

Identified studies from the electronic searches were reviewed against the inclusion and exclusion criteria. The selected studies' reference lists were checked and "cited by" searches completed to identify additional articles not found in the electronic search.

Inclusion criteria

- Main research focus exploring the pre-diagnostic experience of symptom onset or early stage dementia,
- The patient is community dwelling, presents with early stage or mild dementia and is aged over 55 years,
- The patient has a spouse or family member who also participated,
- Qualitative methodological design,

- Written in English language,
- Original research in published peer reviewed journals.

Exclusion criteria

- Main research question on the diagnostic or post-diagnostic stages of dementia or other aspects of living with the disease,
- Samples that include only patients or only family members or people who reside in residential care or inpatient settings,
- Quantitative or mixed methodological designs,
- Articles included in the reviews by Steeman et al., (2006) or de Boer et al. (2007).

Quality rating strategy

Debate exists on the application of quality appraisal to qualitative research due to the multiple methodologies employed and the nature of the information that is obtained (Walsh and Downe, 2006). However, it is deemed necessary to mitigate poor quality research from distorting outcomes, leading to flawed conclusions being drawn, particularly for health care practice (Dixon-Woods, et al., 2004). It is reasoned quality appraisal may operate differently to quantitative appraisal checklists to account for the distinctive goals in qualitative research, while using the same broad concepts of validity and reliability (Mays and Pope, 2000). Walsh and Downe (2006) developed a 12 item checklist based on the synthesis of eight

quality assessment frameworks to appraise qualitative studies in the context of meta-syntheses. The checklist provides practical guidance to ensure a minimum level of quality assurance for health care practice and was used to quality appraise the selected articles in this review (Appendix 1.2).

Each checklist item was marked as being present or absent to determine a profile of strengths and weaknesses for each article. The process proved challenging as it led the author to consider the distinct qualitative methodologies to appraise each article. Furthermore the checklist does not determine the extent the category criteria need to be met. To increase appraisal reliability a second independent reviewer appraised the articles using the same criteria and was blind to the author's ratings. The level of agreement was 95% and the discrepancies were resolved through discussion.

Method of Synthesis

Effective methods have developed to interpret and synthesise qualitative research articles based on differing philosophical assumptions (Ring, et al., 2010). Meta-ethnography was selected for this review as it is considered a leading approach to synthesise healthcare research and preserves the original accounts' meanings (Atkins, et al., 2008; Ring et al., 2010). The seven step method, first proposed by Noblit and Hare (1988), produces a third order interpretation giving rise to new insights in the area (Table 1).

Table 1: Stages of Meta-Ethnography (Noblit and Hare, 1988)

Meta-Ethnography Stages	Description
1. Getting started	Determining the research question that could be informed by qualitative research.
2. Deciding what is relevant to the initial interest	Defining the scope of the synthesis, identifying relevant studies, confirming inclusion criteria and quality assessment.
3. Reading studies and extracting data	Becoming familiar with the content of the studies and commencing the process of extracting “metaphors” or emerging themes.
4. Determining how the studies are related	Creating a list of themes or metaphors, comparing them and determining how they are related. Reduce themes to relevant categories.
5. Translating studies	Arranging papers chronologically. Checking first and second order constructs and translating these from one study to another.
6. Synthesising translations	Moving from initial reciprocal translations towards a higher third order interpretation, “a line of argument synthesis.”
7. Expressing the Synthesis	Presentation of results.

Reflexivity

Prior to conducting the synthesis, the author had worked with people with dementia, and conducted research into the lived experiences of family dyads presenting to memory clinics. It is inescapable that such experiences informed and influenced the author’s approach to the synthesis. Due to the nature of qualitative methods, there may have been other ways to interpret the content of the studies.

Results

Systematic search results

The systematic search of electronic databases and other sources returned 3596 articles after duplicates were removed ($n = 2107$). The selected journal searches identified ten articles, all of which were present in the database search. The remaining articles were screened and 3560 articles were excluded. 36 full text articles were compared to the inclusion and exclusion criteria, leading to seven articles remaining for quality appraisal. Hand searches of the selected article reference lists and “cited by” searches, identified no additional studies. The updated electronic search yielded one more article. Figure 1 illustrates the search results.

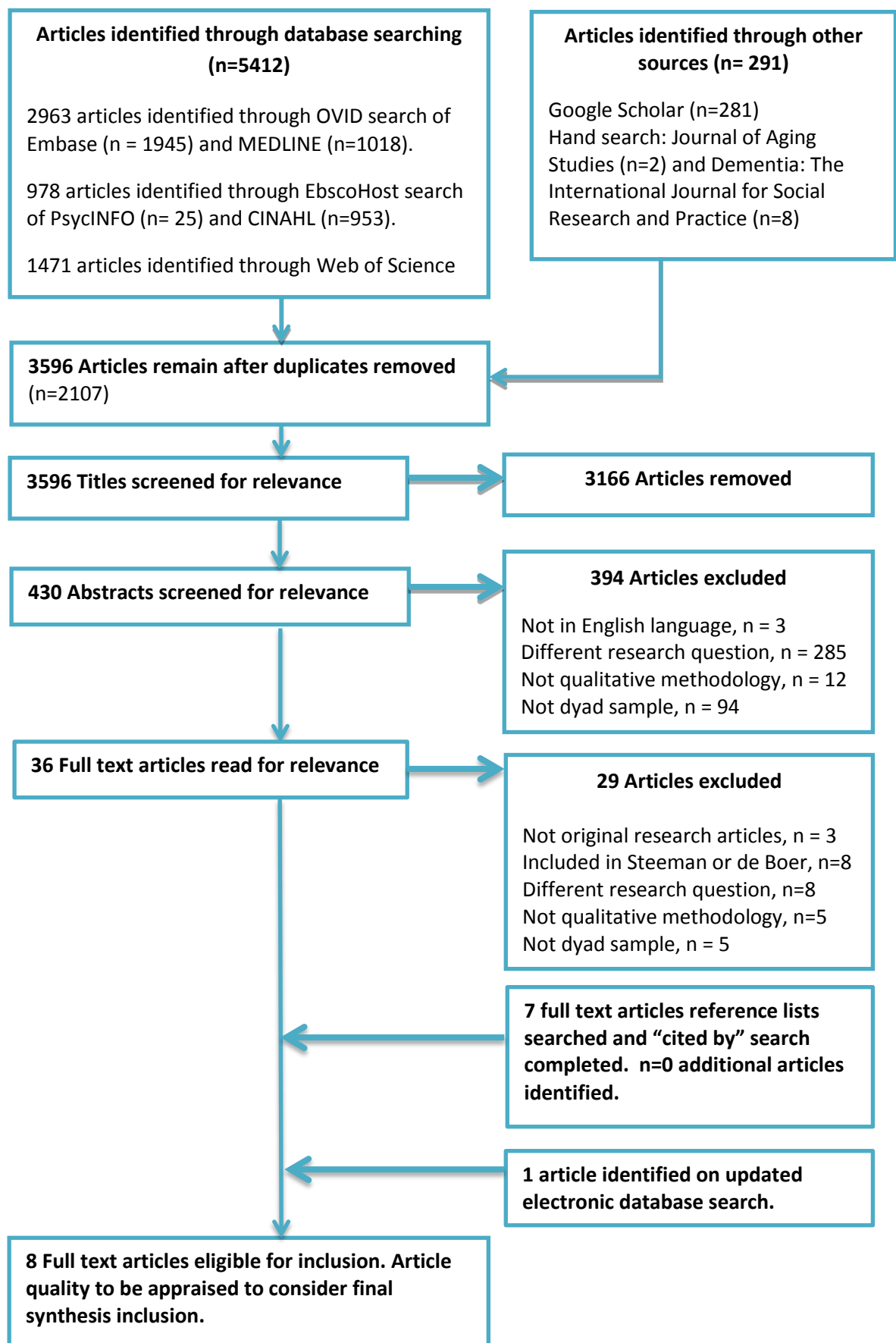


Figure 1: Flowchart of Systematic Search Strategy

Quality appraisal results

Eight articles were appraised using Walsh and Downe's (2006) framework (see Table 2). Three studies met all 12 criteria (Koehn, et al., 2012; Leung, et al., 2011; Steeman, et al., 2007) and four studies met 11 out of 12 criteria owing to not demonstrating researcher reflexivity (Beard, et al., 2012; Garcia, et al., 2014; McCleary, et al., 2012; Moniz-Cook, et al., 2006). The appraisal framework acknowledges many qualitative articles do not include such information due to publication word restrictions; therefore the decision was made to include these studies in the synthesis (Walsh and Downe, 2006). One study only met five criteria (Johnston and Terp, 2015). The study purpose, methodological design, and analytic approach were omitted. To prevent poor quality research distorting the synthesis, the study was excluded (Dixon-Woods et al., 2004). Seven studies remained for the meta-synthesis.

Table 2: Article Quality Appraisal Rating (Walsh and Downe, 2006)

Essential Criteria	Clear Rationale	Contextualised in literature	Method and Design Consistent with Research	Data Collection Appropriate	Sampling Strategy	Appropriate analytic approach	Context described	Clear Audit Trail	Data Supporting Interpretation	Researcher Reflexivity	Ethical Considerations	Relevance and Transferability Evident
Moniz-Cook et al., 2006	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	✓
Steeman et al., 2007	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Leung et al., 2011	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Beard et al., 2012	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	✓
Koehn et al., 2012	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
McCleary et al., 2012	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	✓
Garcia et al., 2014	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	✓
Johnston and Terp, 2015	x	✓	x	✓	✓	x	✓	x	x	x	✓	x

Meta-synthesis results

In accordance with meta-ethnography (Noblit and Hare, 1988), the identified studies were synthesised to generate a third order interpretation. Table 3 provides sample demographics, methodology, and original themes for each study. The seven studies represented 107 people with dementia and 110 family members (66 spouses and 54 family members). Five new super-ordinate themes relating to patient and family experiences of early stage dementia were produced; 1) prior beliefs of ageing and dementia, 2) loss of self, 3) relational adjustment, 4)

maintaining social value, and 5) concern for the future. Each theme will be discussed in turn. Quotations are presented in italics and used to illustrate each theme. Square brackets provide additional information.

Table 3: Included Articles (Characteristics and Themes)

Study, Year and Country	Method	Sample	Article Themes and Subthemes
Moniz- Cook et al., 2006, England	Interpretative Phenomenological Analysis	N=96, people with dementia (n= 48) and spouses (n=28), adult children (n=17), extended family (n=3)	<ol style="list-style-type: none"> 1. Loss of the Mind (self) 2. Loss Of Control <ul style="list-style-type: none"> • Function (Mobility & Continence) • Personality & Relationships 3. Inevitability of Future (Loss of Pleasure & Dependency) <ul style="list-style-type: none"> • Family Upset: “concern for relatives” (Patient) • Care Homes: “put away” (Patient) • Future: “deterioration & decline” (Spouses) • Care Homes: “concern for relatives” (Spouses)
Steeman et al., 2007, Belgium	Grounded Theory and Narrative Analysis	N= 40, people with dementia (n=20) and their spouses (n= 6), adult children (n=13) extended family (n=1)	<ol style="list-style-type: none"> 1. Positive Story of Being Valued <ul style="list-style-type: none"> • Minimising Memory Problems • Emphasising remaining competencies and self-value 2. Balancing Being of Value and Being Worthless 3. Struggling to Remain of Value

Study, Year and Country	Method	Sample	Article Themes and Subthemes
Leung et al., 2011, Canada	Inductive Thematic Analysis	N= 13, people with dementia (n=6) and their spouses (n=5) and children (n=2)	<ol style="list-style-type: none"> 1. Becoming Aware of Memory Problems 2. Attributing Meanings to Symptoms 3. Initiating Help-seeking 4. Acknowledging the Severity of Cognitive Changes 5. Obtaining a Definitive Diagnosis
Beard et al., 2012, USA	Grounded Theory Constant Comparative Analysis	N=20, people with dementia (n=10) and spouses (n=10)	<p>Couples described responding to dementia by:</p> <ol style="list-style-type: none"> 1. Retained Abilities - Manageable Disability 2. Support Persons Find Individual “Tricks” versus Group Support 3. Support Persons Promote Autonomy versus Admitting Discontent 4. Perceptions of Alzheimer’s Disease changing According to Diagnosis
Koehn et al., 2012, Canada	Critical Constructionist Approach	N=20, People with dementia (n=10) and their caregivers – spouses (n=9), child (n=1). Chinese Canadians	<p>The processes familial dyads go through to consider the presence of dementia include:</p> <ol style="list-style-type: none"> 1. Diverse and Varied Symptom Experience 2. Development of Hypotheses for Symptom Appraisal 3. Help-seeking; cultural understanding versus resource Accessibility 4. Contact with care providers: dismissal of symptoms and delays

Study, Year and Country	Method	Sample	Article Themes and Subthemes
McCleary et al., 2012, Canada	Qualitative Content Analysis	N=14, people with dementia (n=6) and their family; spouses (n=3) and adult children (n=5). South Asian Canadians	<ol style="list-style-type: none"> 1. Perception: perceiving and recognising the problem exists <ul style="list-style-type: none"> • Noticing early changes • Acknowledging the presence of a problem • Recognition after trauma • Ambivalence before problem acknowledgement 2. Action: How participant's coped 3. Affect: Emotions rousing help seeking behaviour
Garcia et al 2014, Canada	Qualitative Content Analysis	N= 14, people with dementia (n=7) and spouses(n=5) and children (n=2), French Canadians	<p>Participant dyads described the early stages of the disease as being associated with:</p> <ol style="list-style-type: none"> 1. Initial Symptom onset: lack of awareness & recognition 2. Accumulation of Subtle Changes, not one event 3. Support and advice gained from within the family 4. Professionals familiar with their personal history

Prior Beliefs of Ageing and Dementia

Every study described participants' prior beliefs surrounding ageing processes and knowledge of dementia. Initial symptom onset was often termed by patients and their families as within the confines of normal ageing (Beard et al., 2012; Koehn et al., 2012, Leung et al., 2011; McCleary et al., 2012 and Steeman et al., 2007). One patient reflected on her attributions around symptom onset:

"I did not think that I have the disease before, I would say I am getting old and forgetful. This is very natural ... So I think I am not unusual. Just a bit older ... Yes, especially think that my grandmother, mother, they all said that ... getting older would be clumsy, not clear in mind ..." (Koehn, et al., 2012 p.49)

Often individuals based their interpretations on symptom presence and to societal, familial, and cultural representations of aging:

"At this age, this is bound to happen' ...everyone said it... the doctor didn't say it. But acquaintances, friends, people at home are all saying that if you are advanced in age, then these things happen." (Person with dementia, McCleary, et al., 2012 p.776)

Patients and families described minimising symptoms, particularly if mild or had little influence on daily function:

“Because after all, when you get older, you get older. If you forget something, well it’s not a big thing.” (Female with dementia, Garcia et al., 2014 p. 971)

Attributing symptoms to normal ageing did not appear to be related to one culture or background. Consistent personal and societal representations were shown across British, Belgian, and Canadian samples (Moniz-Cook, et al., 2006; Leung et al., 2011; Steeman et al., 2007) and Chinese and South-Asian ethnic backgrounds (Koehn et al., 2012; McCleary et al., 2012). One study also highlighted how religious beliefs led to alternative interpretations. Here one patient reflects on his Hindu beliefs:

“I think, well first of all this is natural. You can’t help too much. This is, everything is, on a decline ... this Law of Shiva is working. Everything is deteriorating, getting back to the recycle process.” (Male with dementia, McCleary et al., 2012, p.776)

Patient experiences of symptom onset were also embedded within the context they occurred:

“We all have moments where you’ve misplaced something and you’re frustrated and maybe you’re rushing to do something...That could just be a bad day at the office.” (Male with dementia, Leung et al., 2011, p.375)

Prior to diagnosis, family members more often noticed episodes of memory loss compared to other aspects of the disease. Family members attributed symptoms to co-morbid physical illness or medication side effects (Garcia et al., 2014; Koehn et al., 2012; Leung et al., 2011):

“So, we were going through several different treatments ... trying to find something that could help that. And we blamed this on his medication.”
(Female, husband with dementia, Leung et al., 2011, p. 376)

Previous experiences of dementia led individuals to possess greater symptom knowledge and anticipate deterioration. However, rather than promoting recognition, awareness instilled apprehension and avoidance of the possibility the disease could have a personal impact:

“my father, he had it ... not the same person, didn’t know himself, thought I was his mother ... he became a different person, lost his mind, that’s why I don’t want to know about it ... dementia, because I don’t want to think what came of him.” (Female with dementia, Moniz-Cook et al., 2006, p.381)

Loss of Self

Participants in all studies expressed aspects of the individual that had been lost to dementia. The majority had clear insight and recognised the changes prior to, or simultaneously with, their family:

“[Alzheimer’s is] The loss of self as others know you, as others knew you.”
(Female, husband with dementia, Beard et al., 2012, p.7)

Memory lapses, reduced concentration and repetitive questioning were perceived by many as a minor aspect of change (Garcia et al., 2014; Koehn et al., 2012; Leung et al., 2011; Moniz-Cook et al., 2006; McCleary et al., 2012; Steeman et al., 2007):

“At least with the disease in the beginning, it was not that serious. Occasionally he forgot to turn off the water tap, or sometimes he forgot where things were kept. These have kept for 1 to 2 years with those [symptoms].” (Female, husband with dementia, Koehn et al., 2012, p.47)

More salient losses were socially contextualised and related to aspects of declining physical health, and participation in hobbies (Beard et al., 2012; Leung et al., 2011; Moniz-cook et al., 2006). Here, a patient described her realisation of losing skills:

“I’m telling you, I have forgotten how to do oils. And I cried. Tears have run down my face twice at art class because I can’t make the connection ... That hurts my soul.” (Female with dementia, Leung, et al., 2011, p.376)

The onset of disorientation was described by a patient’s spouse:

“He used to forget directions. When we drove anywhere, very familiar places, he would forget how to get there. And when he got there, he would forget how to get home.” (Female, Husband with cognitive decline, Beard et al., 2012, p.6).

Spouses reflected on their partner’s losses and how the changes related to them through altering their shared pleasure and experiences:

"If we can't go dancing...have holidays, enjoy together there is little left for me...maybe her too." (Male, wife with dementia, Moniz-Cook et al., 2006, p.383)

A challenging aspect appeared to relate to the social impact of losing means of communication had on spousal relationships (Koehn et al., 2012; Leung et al., 2011; McCleary et al., 2012; and Steeman et al., 2007):

"Dinners becoming too much now ... problem is the wife likes them...I feel noise in my head ... keeping track of conversations, that's difficult ... then they ask why I am quiet. Must give them up ... these dinners ... never been a social person, but my wife she likes them." (Male with dementia, Moniz-Cook, et al., 2006, p.380)

Furthermore a husband elucidates the gradual recognition of loss for both himself and his wife with dementia:

"It's not memory, conversations are not the same ... we liked debating ... it's like she's [wife referred to memory clinic] lost herself ... It's what I miss. She's the outgoing one, so now there is no one to talk to properly ... I can't

replace that ... her.” (Male, wife with dementia; Moniz-Cook et al., 2006, p.383)

Fragmented communication was described when an external relation expressed concern:

“And then we started noticing that even his brother with whom they talk, he will sort of, they’ll talk about something. The next time he speaks he will ask the same thing, or they will tell something and he’s asking again, or he’s forgotten completely.” (Female, husband with dementia, McCleary, et. al., 2012, p.778)

Rather than dementia being experienced as a series of cognitive losses, the interpersonal nature in which changes manifest is highlighted. The examples demonstrate that communication difficulties and reduced societal participation were disabling factors from the earliest stage of the disease.

Relational Adjustment

In all but one study (Leung et al., 2011) changes in relationship dynamics were described:

“...medical science has much to offer, but in the end it’s up to the person, ourselves to fight and manage ... no one can do this for you.” (Male, wife with dementia, Moniz-Cook, et al., 2006 p.385)

In spousal dyads the expectations of the affected partner were often reduced, while remaining capabilities were emphasised. Changes in marital functioning at the onset of decline were described:

“I do not want to focus on [Alzheimer’s]. I do not need to. So far, we are going along fine ... He thanks me for every meal. He washes all my dishes. He has done so for years. He does not do as many things around the house. But, he found an error in our statement that the bank had made that I overlooked. He watches the bank statements.” (Female, husband with dementia, Beard et al., 2012, p. 4)

Moreover, the subtle changes in the spouses’ interpersonal relationship are defined:

“When I am not clear about something, I just talk to [Husband] about it or figure it out myself. I mean it takes me a little longer, perhaps, than

somebody who did not have Alzheimer's, but you know, that's not a problem. You're just sometimes a little bit slower. Wouldn't you say?
[Asking husband, who concurs] *So, I mean, we sort of do things together."*
(Female with dementia, Beard et al., 2012, p.4)

Family members altered their interactions and the type of support they provided people with dementia. These adjustments appeared to evolve naturally to enable the person to maintain an active role within their relationship:

"I don't clean that much anymore. That's my maid [pointing to her son]. He does everything. Actually, I don't need to do anything anymore, if I don't want to. But I still try to keep busy, doing one thing or another. Not the heavy work, but I still try to do as much as possible." (Female with dementia, Steeman, et al., 2007, p.124)

Maintaining Social Value

All studies delineated instances where people with cognitive decline attempted to remain of value by focusing upon their continued areas of strength. One individual emphasised his remaining abilities while contemplating his possible future:

"I'm quite fit...feel in my 60s. Out every day in my garden, an hour walk, morning and evening, get out twice a week to the country, walking. Sometimes I fish. It's the everyday simple things that matter – fresh air, weather doesn't bother me ... If I can't walk... get out walking...there is little left to enjoy," (Male with dementia, Moniz-Cook et al., 2006, p.380)

His emphasis on physical ability demonstrates how hope can help to maintain an individual's functioning. Moreover, practical steps to facilitate engagement in purposeful activities and communication were emphasised:

"If you are just lazy and don't think about anything, you'll forget, I like to read. I like to study. I like to meet people and walk around. Keep my actions going." (Male with dementia, Beard et al., 2012, p, 7)

Attempting to remain of value, through masking and minimising decline, can enable individuals to stay engaged with others even when dementia progresses. In three studies (Beard et al., 2012; Moniz-Cook et al., 2006; Steeman et al., 2007) expressions of self-worth within relationships were stressed:

"We're a team, enjoy dancing once a week, eating with our friends ... my wife's a practical person, likes doing things ... cooking, eating out, dancing

but quite shy, she will be lost if my mind goes” (Male with dementia, Moniz-Cook, et al., 2006, p.381).

A grandmother responded to being unable to care for her grandchildren by pursuing value in her retained abilities:

“Oh I can accept it. If I were a poor soul and had to sit here and do nothing, then it would be worse. But I still do my work here and I drive the car. I don’t feel written off as a dead loss. It doesn’t bother me that I have to take that pill [acetylcholinesterase inhibitor].” (Female with dementia, Steeman et al., 2007, p126)

The studies explicitly described how people with dementia and families use concrete strategies to promote function and retain social value (Beard et al., 2012; Garcia et al., 2014; McCleary et al., 2012):

“I’ve always put notes around. I’ve tried to get [my husband] to do it but he wouldn’t do it. He wouldn’t put notes around. He was fine if you gave him a note and you left him a list.” (Female, husband with cognitive decline, Beard et al., 2012, p.6)

The use of coping strategies demonstrates the onset of dementia is not passively experienced. Overtly recording events and information limits individuals' succumbing to the disease and becoming marginalised from others (Beard et al., 2012; McCleary et al., 2012; Steeman et al., 2007). Despite the practical steps described here, the emotional burden on maintaining this stance was observed. In all but one study (Leung et al., 2011) families acknowledged feelings of fear, sadness, anxiety and frustration in continuing to uphold the person with dementia's functioning. In the following excerpt, a gentleman describes his struggle to maintain previous function:

"The challenge is the only thing driving part of it. Now I depend on public transport. Other than that, [in a broken voice] I lead a normal life." Which he later explained, *"I don't like to be shut in."* (Male with dementia, McCleary, et al., 2012, p.780)

Concern for the Future

Familial dyads described integrating the disease into their lives, with a diagnosis becoming a means for considering their current and future needs (Beard et al., 2012; Koehn et al., 2012; Leung et al., 2011; Moniz-Cook et al., 2006; Steeman et al., 2007). In some instances this instilled hope for a better quality of life:

“Once diagnosed, well I knew what to expect ... whereas now, what follows is a better quality of life for the time left. If there is no cure, we can at least give that [better quality of life]... Therefore people must know the, what and how of everything that is happening because it is on the rise [Alzheimer’s disease].” (Person with dementia, Garcia et al., 2014, p.968)

The following example characterises the transition spouses make from how they operate within a couple towards how they might cope with an alternative future:

“It’s a challenge. It’s a problem. You’ve got a problem, you do what you can and you do not give up and you adapt. It’s up to me to make myself happy, nobody else. I find things that give me what I need. Our life together is a challenge.” (Female, husband with cognitive decline, Beard, et al, 2012, p.8)

Personal experiences of the disease, attributions relating to medication and formal care provision influenced individuals’ emotional responses (Garcia et al., 2014; McCleary et al., 2012; Moniz-Cook et al., 2006):

“In the end it’s a home for me if I have it ... Alzheimer’s, Kath, my wife won’t cope, I know...I don’t blame her. You become a vegetable there ... no conversation, nothing to do, won’t get out for walks, no exercise. It’s a case

of if you don't use it you lose it. Now you see why I don't want to know about it...Kath must not know ... she won't cope." (Male with dementia, Moniz-Cook, et al., 2006, p.381)

Individuals expressed worry for how their family may respond to their declining health and contemplated ways they could limit the impact:

"Never liked drugs to control ... my mind ...will take them for him I suppose. After all if I get bad he will have to look after me. It will be too bad for him if I hadn't tried the mind drug." (Female with dementia, Moniz-Cook et al., 2006, p.385)

Whereas in this excerpt, the husband anticipates his endeavour to provide appropriate care for his wife with dementia:

"Her mother had it, senility ... lost her mind ...didn't use the toilet, know what she was doing ... toilet, dressing, baths, seeing to her ... Ann [wife] did that for her mother. If Ann needs seeing to, we have no children ... hope I can do for her." (Male, wife with dementia, Moniz –Cook, et al., 2006, p.382)

Discussion

Five super-ordinate themes were generated by synthesising seven qualitative studies considering patient and family experiences of the onset and early stages of dementia: 1) prior beliefs of ageing and dementia, 2) loss of self, 3) relational adjustment, 4) maintaining social value, and 5) concern for the future. This meta-ethnography is largely consistent with existing literature relating to experiences of dementia across the stages of decline (Bunn et al., 2012; de Boer, et al., 2007; Robinson et al., 2011; Steeman et al., 2006). This synthesis serves to highlight that the process of assimilation and adjustment between individuals and family members commences earlier than the point of diagnosis, often through subtle changes from symptom onset.

In the earliest stages individuals' symptom interpretations are constructed from pre-existing knowledge of dementia in addition to personal and societal expectations of older age. Ageing attributions characterised by anticipated physical, cognitive and social change are in agreement with the literature on ageing perceptions (Ayalon, 2015; Warmoth, et al., 2015). Consistent with previous research (Luszcz, et al, 2015; Warmoth et al., 2015), participants' understanding served to normalise symptoms and minimise functional decline, which as a consequence, limited alternative explanations and formal help being sought. This could in part explain help seeking delays of up to five years (Chrisp, et al., 2011; Morhardt, et al., 2010; Speechly, et al., 2008).

Three studies included participants from minority ethnic groups. Multiple barriers are recognised to influence help seeking in minority groups (Mukadam, et al., 2011). The factors include; normalising symptoms, attributing dementia to physical health, religious, social or psychological factors, and beliefs relating to the family responsibility for care provision, as well as community stigma and lack of knowledge of available treatments (Mukadam, et al., 2011). It is therefore acknowledged that these barriers may have been present in the synthesis sample and could have influenced the themes identified. Koehn et al., (2012) reflected that previous cultural explanations (Mukadam, et al., 2011) however may be insufficient to account for symptom recognition. Instead general social constructs relating to ageing beliefs and attributions related to functioning in older age may add to understanding of the distinct processes involved in dementia recognition (Ayalon, 2015; Koehn et al., 2012; Warmoth et al., 2015). The samples presented here were minority groups residing within a western country (Garcia et al., 2014; Koehn et al., 2012; McCleary et al., 2012) and this may also have served to impact on their experiences. The participants included in the seven articles resided in four western countries (Belgium, Canada, England and the United States of America). Each country has its' own distinct health and social care systems which range from state to insurance provision. Consequently the participants included in the review were operating within diverse health care system's which may have further influenced decision making to seek help. Limited access to health care through insurance provision has been shown to reduce the likelihood of help seeking behaviour (Blackwell et al., 2007). Further research is required to clarify the presence of

differential pathways for different ethnic groups and the impact different health and social care systems can have on help-seeking behaviour.

Consistent with previous reviews (Bunn et al., 2012; de Boer, et al., 2007; Steeman et al., 2006), the outcomes here demonstrate families work together and respond to decline by adopting strategies to maintain value and live positively with dementia. This appears to validate the theoretical framework proposed by Ablitt et al., (2009) whereby relationship quality serves to preserve emotional wellbeing, limit decline, and minimise symptom impact. The manner in which the interpersonal relationships adjust to cognitive decline can act as a key moderator to delay diagnosis seeking. This is consistent with other qualitative literature inferring informal family support is favoured in the early stages of disease (Werner, et al., 2014).

Most participants described a future with dementia as instilling fear and anxiety. The predictions provided insight into how individuals asserted what impact the disease may have on their personal and family's future. A review of lived diagnostic experiences indicated the expression of short term distress at diagnosis did not lead to long term mental health difficulties for patients (Robinson et al., 2011). Instead, negative emotional responses are shown to be based on an individual's social and personal experiences, with fear shifting an individual's attention to the present rather than future self (Kristiansen, et al., 2015). The ability to maintain their sense

of self appears to limit acknowledgement of progressive decline and lessen anticipation of the future (Bunn et al., 2012). This process was observed in a longitudinal study where individuals with early stage dementia reviewed their future and personal values and moved from, *"being valued for what you do,"* to *"being valued for who you are,"* (Steeman, et al., 2013, p.235). In this synthesis, participants' emotional responses and attributions may represent the start of this changing value base.

People with dementia have the right for their experiences to be included in research. However, it is acknowledged that the recruitment and consent procedures require substantial consideration due to the added complexity of working with this population (McKeown, et al., 2010). This review further demonstrates the value of including people with dementia in research.

By including the experiences of family dyads, this meta-ethnography adds to the wider evidence base on early stage dementia (Bunn et al., 2012; de Boer et al., 2007; Robinson et al., 2011) and family carers' experiences of the later stages of the disease (Gilles, 2011). The experiences reported here are consistent with the literature and highlight the social contexts in which symptoms of dementia emerge and are responded to. This review suggests in the early stages of dementia, the assignment of the care giving role in family dyads may be more appropriately represented as an altered form of relationship, with both individuals continuing to

contribute to maintain function and minimise disability. Together the experiences across the dementia timeline form an understanding of how services can provide appropriate support for patients and their families. However conceptualising the unique processes involved in the differential relationships of spouses and family members still requires development (Ablitt et al., 2009; Braun et al., 2009).

Excluded Articles

Eight studies were excluded during the systematic search of the literature as a result of being included in the reviews by Steeman et al., (2006) or de Boer et al., (2007). The decision to exclude the articles was based on the synthesis rationale to advance understanding from the existing published reviews. It is acknowledged that the excluded studies present consistent themes to those derived in this review. It is possible that inclusion of the articles may have contributed by providing supplementary accounts of the area under study. However the decision to exclude the studies is instead contextualised in the synthesis rationale to advance understanding of the phenomenon, rather than to include all published articles. Taken together, the reviews by Steeman et al., (2006) and de Boer et al., (2007) with this synthesis represent the experiences of those with early dementia before diagnostic confirmation.

The Johnston and Terp study (2015) was excluded to avoid flawed conclusions being drawn and decreasing the synthesis quality (Walsh and Downe, 2006). Of the

four themes Johnston and Terp (2015) generated, *“developing coping skills”* and *“anger”* could relate to the current theme, *“relational adjustment.”* However the paucity of quotes prevented interpretation of the extent the themes represented the participants’ experiences. Theoretical stance and analytic approach omissions further undermined the study validity. Therefore the decision maintained the synthesis integrity.

Limitations

Due to the range of the synthesis, the systematic search was restricted to published peer-reviewed journal articles. It is acknowledged that qualitative outcomes are often reported in unpublished and alternative sources. Therefore relevant studies, which may have influenced the outcomes, may have been omitted. Moreover, a sampling bias could exist as participants may have been more able and motivated to contribute to research. Those who did not participate may possess divergent experiences from those outlined here. This meta-ethnography concedes it may not represent all experiences of early stage dementia.

All but one of the studies (Moniz-Cook et al., 2006) used retrospective samples. The patients remained in the early stages of dementia, but had been diagnosed between three months and four years prior to participating. Emotional responses, symptom awareness and coping strategies have been shown to vary over time (Aminzadeh, et al., 2007; Bunn et al., 2012). Notably, individuals are shown to alter

their coping responses in the year post diagnosis (Clare, et al., 2005). Despite the studies focusing on the pre-diagnostic stage, the studies represent patients who are at different points in the assimilation process. Therefore their accounts of the period may have altered over time.

Furthermore, significant overlap exists in relation to the experience of living with the disease across the discrete early, middle and advanced stages of decline. Adjustment is observed to be a gradual idiosyncratic process (Bunn et al., 2012; de Boer et al., 2007; Robinson, et al., 2011; Steeman et al., 2006). Therefore, the review themes may extend beyond patients defined as in the early stages to community dwelling individuals who maintain their social identity. By excluding studies on earlier and later experiences, important concepts could have been omitted. However the review may have lost specificity to the original aim. Instead this review can be included with the literature on diagnostic (Robinson et al., 2011) and post diagnostic experiences (Bunn et al., 2012) to represent the early stage dementia pathway.

Heterogeneity existed across the familial samples, cultural background (Garcia et al., 2014; Koehn et al., 2012; McCleary et al., 2012) and environment (Beard et al., 2012) of the studies. These factors may have influenced each study author's interpretations. During the analysis phase of this meta-ethnography, the contextual aims of both the original studies and the current review were reflected

upon by the author. This ensured commitment to the review aim, but acknowledged the influence the different studies may have had on the themes generated.

Clinical Practice and Research Implications

The synthesis results may inform public health providers and memory clinic services of the information that may facilitate earlier insight and recognition of dementia by patients and their families. In line with government policy, this may assist targeting those who are contemplating seeking support more effectively in order to provide accurate information and timely diagnoses (The Scottish Government, 2013). Furthermore, the synthesis results may assist clinicians to review the role of families in supporting and enabling patients to maintain function. This may prompt the provision of support and care for individuals and their family even before a formal diagnosis has been made.

Conclusion

This meta-ethnography demonstrates individuals and their families experience marked cognitive and functional changes as well as, psychological and social adjustment commencing from symptom onset. Interpersonal strategies and relational adjustments can serve to maintain function and quality of life in the pre-diagnostic phase. Such experiences, predicated by ageing attributions, disease

awareness and concern for their future, are shown, in part, to account for help-seeking delays. This knowledge may inform services targeting information to patients and their families contemplating seeking a diagnosis, as well as informing how to appropriately support families facing the earliest stages of dementia.

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Chapter 2: Major Research Project

An Exploration of the Factors Influencing Patient and Family Initial Attendance at Memory Screening Clinics: An Interpretative Phenomenological Analysis

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Plain English Summary

Background

Formal diagnosis can help people with memory loss and intellectual changes associated with dementia access treatment and care. However, symptoms are often unrecognised and linked to normal ageing, physical illness, denial and avoidance. Help seeking can be delayed and only triggered when difficulties reach a “crisis point”. To help earlier recognition, dementia research has retrospectively explored patient and family experiences of the time before diagnosis. However, recall of symptoms and events can change after diagnostic confirmation. Little research has explored patient and family experiences before receiving a diagnosis.

Research Question

How do patients and their significant others (a person who knows them well) notice and make sense of the early symptoms? What are the triggers for them to attend memory services?

Method

Participants

Participants were English speaking patients aged over 65 years who had attended an initial memory clinic assessment. Patients were required to be able to

remember when the symptoms started and have presented with early stage cognitive changes associated with Alzheimer's disease or vascular dementia. Those with moderate to severe symptoms, or other types of dementia were excluded from the study. Patients presenting with mental health difficulties which affected their daily life and those with verbal communication problems were also excluded. Patients who did not have a significant other who could also participate in the interviews were not eligible to participate.

Recruitment

Participants were identified by clinic staff during their first memory clinic appointment and provided with written study information. A research appointment was arranged for those who expressed an interest in taking part, with the researcher. Each participant provided informed written consent.

Design

Ten separate in-depth interviews, lasting 45 minutes on average, were completed with five patient and significant other dyads. Interviews were recorded on a digital voice recorder, typed out exactly onto a computer and all identifying information removed. The project used Interpretative Phenomenological Analysis (IPA) to understand the common themes participants gave to their experiences.

Key Findings

Before seeking a diagnosis, patients and their significant others monitored symptoms for many years. Five main themes were identified:

1. The way people considered early symptoms were linked to their prior experiences and beliefs about ageing.
2. People became aware of problems through memory loss, disorientation and others raising concerns.
3. Families responded to symptoms by using a range of practical and social supports to maintain function.
4. The decision to tell others was linked to perceptions of their current and future needs and the anticipated benefit of diagnosis.
5. The start of cognitive changes triggered participants' view of their future to alter. They described fear of losses but hope for treatment and care.

Conclusion

The findings suggest improvements in public awareness of symptoms, diagnosis and supports may facilitate earlier help-seeking. Understanding dyad experiences may help clinicians and service providers provide accurate and timely support to families seeking help and undergoing assessment.

Abstract

Background: There is a national drive to provide early dementia diagnoses. Patient and family attributions at symptom onset contribute to significant help-seeking delays. Most qualitative studies have interpreted retrospective accounts of the pre-diagnostic period. However, experiential attributions are demonstrated to change over time. Few studies have sought patient and family dyad perspectives prior to diagnosis.

Aim: This qualitative study sought to explore patient and family experiences of early cognitive decline and help-seeking during the pre-diagnostic stage.

Method: Five patient and familial dyads were interviewed separately to explore their experiences of early stage cognitive decline and help-seeking decisions. Interpretative Phenomenological Analysis was employed to identify emerging themes.

Results: Five super-ordinate themes were identified: The inevitability of ageing; problem awareness; living with forgetting; disclosure to others; and how am I going to be today?

Conclusions: Patient and family dyads have early insight into symptom onset. Before diagnosis, attributions towards ageing, co-morbid illness and contextual factors limit concern. Help-seeking was precipitated by functional decline exposing the individual to potential risks. Health services were a source of reassurance, particularly when there was a lack of social supports available. Improvements in public awareness of symptoms, assessment and available care for dementia may encourage earlier help seeking.

Introduction

In the United Kingdom, 850,000 people are estimated to be living with dementia in 2015, however over half do not receive a formal diagnosis (Prince et al., 2014). The diagnostic pathway can be prolonged by difficulties recognising symptoms (Buntinx, et al., 2011). Retrospective studies indicate help-seeking delays from two to five years (Chrisp, et al., 2011; Leung, et al., 2011; Speechly, et al., 2008; van Vliet et al., 2013). In order to optimise health and wellbeing, an early diagnosis of dementia is crucial to provide timely support, care, and treatment for patients and their families (The Scottish Government, 2013).

Help-seeking delays have been explored within qualitative studies utilising retrospective patient and family accounts of early stage dementia. Symptom onset is characterised by declining ability across contexts, multiple emotions and interpersonal changes, with recognition following an idiosyncratic course (Bunn et al., 2012; Chrisp, et al., 2012; de Boer et al., 2007; Steeman, et al., 2006). Individuals use multiple practical and interpersonal strategies to minimise symptom impact and maintain their self-concept (de Boer et al., 2007; Leung et al., 2011; Innes, et al., 2014; Steeman et al., 2006).

Help-seeking can be delayed while individuals monitor the legitimacy of their concerns and is hindered by denial and resistance from family members (Bunn et

al., 2012; Chrisp et al., 2012; Innes et al., 2014). A systematic review of 48 studies suggests four impediments to help-seeking; socioeconomic barriers, increased disease severity, beliefs and, limited knowledge and experience of dementia (Werner, et al., 2014). Referrals to services for diagnosis were triggered by functional deterioration or “crisis points” when coping strategies failed (Bunn et al., 2012; Chrisp et al., 2012; Steeman et al., 2006).

Most qualitative studies examining the pre-diagnostic period have been conducted with retrospective samples, up to four years after diagnosis (Bunn et al., 2012; de Boer et al., 2007; Garcia et al., 2014; Innes et al., 2014; Koehn et al., 2012; Leung et al., 2011; McCleary et al., 2012; Steeman, et al., 2006). Retrospective accounts have been shown to change after confirmation of a dementia diagnosis, with individuals altering their coping strategies within the first year post diagnosis (Clare, Roth and Pratt, 2005). People experience varied emotions and symptom awareness while they begin to adjust their expectations and accommodate dementia into their lives (Aminzadeh, et al., 2007; Bunn et al., 2012). Furthermore, individuals’ attributions become focused on the present rather than future self to limit distress considering their future (Kristiansen, et al., 2015). Therefore, the retrospective accounts outlined in qualitative studies represent pre-diagnostic experiences of those who have had differential time to consider the disease. The accounts may deviate from participants’ lived experience as their recollections may have been reinterpreted to accommodate the dementia diagnosis.

Few studies have considered individual and family experiences of symptom onset and help-seeking concurrently with the assessment phase. The prospective studies differ from retrospective accounts, as the participants were interviewed to gather descriptions of their experiences prior to rather than after receiving confirmation of the diagnostic outcome. Robinson et al., (1997) interviewed eight patients undergoing assessment; while a quantitative case study reviewed 20 family carer's experiences (Chrisp, et al., 2012). The pre-diagnostic experiences of a British sample of 48 individuals and their family members were also assessed in a prospective qualitative study (Moniz-Cook, Manthorpe, Carr, Gibson and Vernooij-Dassen, 2006). Whilst the outcomes from the prospective studies were consistent with those from retrospective studies, the approach provides additional insights into the anticipatory emotional response and prediction of future diagnoses (Chrisp et al., 2012; Moniz-Cook, et al., 2006; Robinson et al., 1997). For patients and family members this presents as concern for future losses, anticipation of changes in activity and a shared apprehension for each other's future wellbeing (Chrisp et al., 2012; Moniz-Cook et al., 2006). This aspect of qualitative dementia research is particularly important to inform public health services. This is to enable them to deliver timely and appropriate information whilst minimising distress for individuals and families.

The experience of early cognitive decline and help-seeking has been demonstrated to be deeply embedded in complex social interactions between individuals and their family (Bunn et al., 2012; Chrisp et al., 2013; Garcia et al., 2014; Koehn et al.,

2012; McCleary et al., 2012). Relationship form is proposed to both delay and facilitate contact with health services, whilst providing support to preserve function (Ablitt, et al., 2009). Keady and Nolan (2003) suggest that before diagnosis, patients and families, “worked separately,” to consider symptom presence and legitimacy. “Working together,” was initiated when the individual and family together acknowledge symptoms and seek help. Chrisp et al., (2013) highlighted that the transition was dependent upon the carer accepting the carer role, placing the individual into the patient role. They argue the individual and family responses to this process delay help-seeking (Chrisp et al., 2013).

Study Rationale

Previous studies have focused on retrospective accounts of pre-diagnostic experiences of dementia. These accounts may have been influenced by changes in attributions following diagnosis. This study seeks to explore the experiences of symptom recognition prior to a diagnosis being confirmed. This study aims to advance the existing prospective studies (Chrisp et al., 2012; Moniz-Cook, et al., 2006; Robinson et al., 1997) by including both patients and significant others in a dyad paradigm. This approach will consider how the relationship between the patient and their significant other impacts on help-seeking behaviour. The current study therefore seeks to build upon existing literature as the relational aspect of help-seeking has not previously been considered.

Aims

This study aims to:

1. Explore the experiences of patients and their significant others as they become aware of the early stages of cognitive decline.
2. Explore the help-seeking process for patients and their significant others from initial symptom awareness to accessing the memory clinic.

Method

Design

This qualitative study utilised Interpretative Phenomenological Analysis (IPA) (Smith and Osborne, 2003). IPA has been used extensively to examine the experience of dementia (Bunn et al., 2012; de Boer et al., 2007; Steeman et al., 2006). It is theoretically underpinned by phenomenology, hermeneutics and idiography. IPA was identified for this study as it enables exploration of how individuals make sense of their personal and social world and the meanings they attach to experiences (Smith, Flowers and Larkin, 2013).

Sample

In order to derive a sufficiently detailed and multifaceted account, the recruitment of five patient and significant other dyads was proposed, yielding ten separate interviews. This adhered to sample recommendations for professional doctorates using IPA (Smith et al., 2013) and was similar to qualitative studies of dementia utilising dyad paradigms (Leung et al., 2011).

The inclusion and exclusion criteria were defined to achieve a homogenous sample required for IPA (Smith et al., 2013). Participants were English speaking patients aged over 65 years attending an NHS Greater Glasgow and Clyde Older People's Community Mental Health Team (OP-CMHT) memory clinic. The inclusion criteria defined significant others as: English speaking close family members, who knew the patient well, and had provided regular support throughout the pre-diagnostic period.

Patients presenting with symptoms characteristic of early stage Alzheimer's disease or Vascular dementia, and able to recollect symptom onset were included. People with young onset or more advanced dementia, and those with other dementia subtypes were excluded due to their distinct experiences (Moniz-Cook et al., 2006; Steeman et al., 2007; van Villet, et al., 2012). People with significant mental health difficulties, or verbal communication problems were excluded on the same basis.

Recruitment Procedure

As part of usual clinical practice, the OP-CMHT nurse who conducted the patient's initial memory clinic appointment, administered a cognitive screening examination (Adenbrooke's Cognitive Examination - III or Montreal Cognitive Assessment) and completed a clinical assessment interview. The OP-CMHT nurses were advised to consider the patient's presentation with respect to the study inclusion and exclusion criteria, cognitive examination score and the patients' ability to recall their experiences from symptom onset. Due the variability of functioning and clinical presentation of cognitive change, no clinical examination cut-off scores were used to exclude patients. Instead the OP-CMHT nurses' clinical judgement taking into account the aforementioned criteria was used to identify potential study participants. OP-CMHT nurses introduced the study and provided the information sheet (Appendix 2.3) to potential participants who attended their initial assessment appointment with a family member. Those who expressed an interest in participating then consented for their nurse to provide their contact details to the researcher. The researcher telephoned participants and arranged a research appointment.

Research Procedure

Before the interview, each participant provided written informed consent (Appendix 2.4 and 2.5), completed a brief demographic questionnaire (Appendix 2.6), and gave permission to notify the OP-CMHT of their involvement (Appendix

2.7). The researcher conducted a semi-structured interview with each participant in a private room at their local OP-CMHT, or in the participant's home. An interview schedule (Appendix 2.8), developed with reference to the existing literature, was employed and guided discussion. The researcher adopted a non-directive stance and used active listening, reflection and summaries to move from general to specific aspects of their experiences. The interviews were recorded on a digital voice recorder. Each interview concluded with a general conversation where participant questions were answered. In accordance with the study protocol, the patient's case manager was notified of disclosures of risk or health needs identified during the research procedure.

Data Analysis

Interviews were transcribed verbatim, with personal identifiers removed ensuring anonymity. Transcripts were checked for accuracy and completeness. The researcher followed the six stages of IPA (Appendix 2.15, Smith et al., 2013; see Appendix 2.16 for selected transcript extracts). To corroborate the process, a research log recorded key research decisions. Research supervisors independently reviewed five interview transcripts, and discussed all emergent themes.

Reflexivity

IPA involves a "double hermeneutic stance" (Smith and Osbourne, 2003) which acknowledges the researcher's prior assumptions and knowledge in their second

order interpretation of participant experiences. The researcher was a female Trainee Clinical Psychologist who previously worked in an OP-CMHT. The study coincided with her completing a meta-ethnography within the research area. A reflective diary and research supervision acknowledged these influences. The interviews could be interpreted differently with other background influences.

Ethical Approval

The West of Scotland Research Ethics Committee and NHS Greater Glasgow and Clyde Research and Development Department approved the study (See Appendices 2.9 and 2.10). In response to protracted recruitment, two substantial amendments were approved (See Appendices 2.11 - 2.14). The inclusion of home visits and six additional OP-CMHTs provided a wider population to sample from.

Results

Participants

Ten participants; five patient and significant other dyads, recruited from three OP-CMHTs, were interviewed. Patients were aged between 65 - 75 years old (average age 71 years) and significant others aged between 42 – 81 years old (average age 67 years). All, but one participant (Helen), were retired. Table 1 provides participant information. The interviews averaged 54 minutes with patients (range 45 – 73 minutes) and 37 minutes with significant others (range 29 – 61 minutes).

Themes

The analysis generated five superordinate themes: the inevitability of ageing; problem awareness; living with forgetting; disclosure to others; and how am I going to be today? Figure 1 delineates the sub-ordinate theme structure. Quotations illustrating the dyads' accounts are presented in italics and indented in the text (See Appendix 2.18 for dyad representation). Bold text denotes researcher comments and underlined names indicate significant others. Square brackets represent omitted text, or additional information, to improve extract relevance and clarity.

Table 1: Participant Demographic Information

	Patient Pseudonym	Significant Other Pseudonym	Relationship	Time from symptom awareness to Memory clinic (significant other awareness)	Patient Cognitive Examination Score	Memory Clinic Assessment Outcome
1	Claire	Alan	Spouse	1.5 years (1.5 years)	29/30 (MoCA)	Mild Cognitive Impairment and ongoing review
2	Beth	Thomas	Spouse	2 years (3 years)	29/30 (MocA)	Vascular impairment and ongoing review
3	Steven	Nancy	Spouse	5 years (1 year)	96 /100 (ACE-III)	No diagnosis received, ongoing review
4	Susan	Helen	Mother and daughter	6 months (6 months)	66/100 (ACE-III)	No diagnosis received, ongoing review
5	Colin	Sandra	Spouse	2 years (10 months)	82/100 (ACE-III)	Ongoing Assessment

MoCA: Montreal Cognitive Assessment

ACE-III: Adenbrooke's Cognitive Examination III

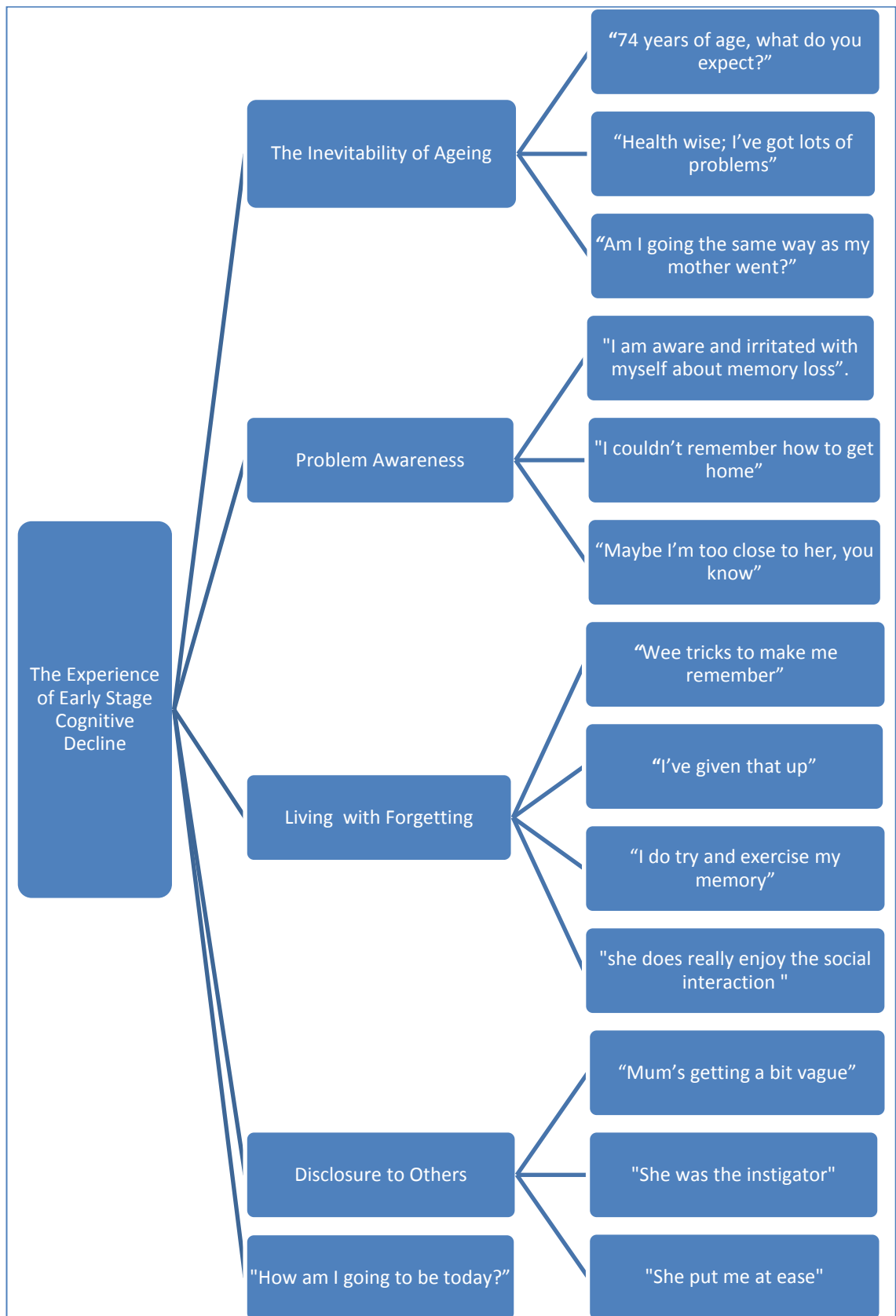


Figure 2: Super-ordinate and Sub-ordinate Themes

The Inevitability of Ageing

The transition to older age was important for patients and significant others. All participants anticipated cognitive change, while most associated ageing with co-morbid physical illness. Anticipation of cognitive change altered their psychological responses.

“74 years of age, what do you expect?” (Susan, p.34 Line 779)

Every participant used their age as a reference to functional expectations and ageing beliefs. This minimised concerns about cognitive decline. The following account infers personal and societal anticipation of decline related to ageing. It shows how the attributions prevent prioritising concerns:

“If I don’t remember I say, ‘What do you expect at my age?’ That’s my way to beat it, if you like, because I know eventually it will come, aye, and if it’s not going to come to me, well it’s not that important to me to be upset about it.” (Alan, p.1 Lines 22-25)

Furthermore, Claire’s recollection includes her doctor’s response:

“Och most people get like this when you get older, you know,” and they said eh, “I wouldn’t worry about it.” (Claire, p.3, Lines 60-62)

The colloquial remark alludes to attributing forgetting as a common experience. The remark attempts to minimise worry and links with Alan’s negligible concern. Authoritative figures’ responses are further highlighted by Susan:

“She [GP] just swept it under the counter ‘you are just an old woman like my mother is,’.” (Susan, p.24, Lines 536-538)

The stereotype infers cognitive decline to be an inevitable aspect of ageing and evoked no action. All participants’ expectations were normalised through peer comparisons. Beth reflected on her friendship:

“We’ve got a friend Mary, and we kid one another on and we’re kinda ages ‘gether and she’ll say, “oh, whit’s that word?” she’s worse than me for her words.” (Beth, p.25 Lines 680-682)

Functional comparisons reassure individuals that their difficulties are, “normal,” leading to denial of problem existence. This is shown by Claire’s peer comparisons:

"We're all 70, 80, we've got 90 year olds, you know what I mean? And we've all got people saying, "Ach do you know I was going to ask you something there, but I've forgotten what it was." We're quite used to these conversations, because we all have them you know, and eh well I thought, "Well I'm not old," not compared to a lot of them." (Claire p.17 Lines 475-479)

Claire's attempt to minimise ageing by remarking on her standing, *"Well I'm not old"* demonstrates her belief that symptoms are common.

"Health wise; I've got lots of problems" (Beth, p.11 line 296)

Physical illness co-morbidity presented as a primary concern to most participants and was related to misattributions of cognitive decline. The extract from Beth, above, and her spouse, Tommy, below, describe co-morbid illness:

"I mean, we're both crippled with arthritis, our legs, our knees, Beth's had a knee operation, she's waiting on another one, it keeps getting cancelled because of her diabetes. I've got bad knees and I broke an ankle a couple of year ago, which is giving me a lot of pain now. I imagine arthritis has set in on it." (Tommy, p4, Lines 108-113)

It appears that co-morbid illness may discount the presence of cognitive changes.

In this extract, Helen describes her mother's recovery from lung cancer:

"I probably brushed a lot of it off, because I just thought well, you know, she's tired, she's emotional, she's in pain, and obviously, you feel like your brain isn't probably functioning to its full capacity at the moment because her body is working so hard to try and heal itself." (Helen p.2, Lines 33-39)

By accounting for decline as a representation of physical illness it prevented further action. This view is shared by her mother:

"But eh, as I say, I don't know if it's that that's caused it, all that worry and stress, it certainly caused the cancer." (Susan, p.24, Lines 532-534)

An alternative explanation, considering the presence of sensory decline, was expressed only by significant others. Here Nancy and Tommy attribute repeated questioning to problems hearing:

"He gets a bit, a bit ratty about, having heard, having asking again about things, but to my mind that's the hearing." (Nancy, p.4, Lines 83-89)

"As I say, I really put it down to her deafness. I thought she wasn't hearing the whole story, you know." (Tommy, p.5 lines 128-129)

This suggests difficulty in receiving the information rather than the problem being related to cognitive decline. This is consistent with Helen's account relating her mother's vision and anxiety to reduced cognitive performance:

"My mum is also really short sighted and didn't have glasses all the way through primary school [...] she just thinks, "I can't do this, I can't do this," so I think that probably made the written things she had to do worse, 'cause I think she panicked before she even started, I mean you do panic, you do." (Helen, p.9 lines 203-209)

Together with co-morbid ill health, the examples demonstrate cognitive symptoms are rationalised in the context of physical health conditions.

"Am I going the same way as my mother went?" (Steven, p.16 line 434)

Most participants, with the exception of Tommy and Nancy, described experiences of a parent, family member or friend with dementia. These acted as comparators

to their cognitive changes. Steven who was the primary carer for his mother recalled his experiences:

“Well yes, well first of all I had discovered I had forgotten something and then of course obviously, my mother forgot things so the obvious logical thing to say is, “am I going the same way as my mother went?” (Steven, p.16 lines 430-434)

Steven’s insight was implicitly associated with his mother’s illness and contrasts with his spouse, Nancy:

“He was a bit eh [pause] he felt he was developing Alzheimer’s and I personally think that the both of them [Steven and his brother] think that because their mother had it and not totally because of things that are happening with them,” (Nancy, p.1 lines 11-15)

Nancy’s ambivalent comment allows receptiveness to alternative explanations.

Furthermore, Claire acknowledged the heredity risk association as she described nursing her mother who had Alzheimer's disease:

"I'm in that age group now where you come across it and having my mum being like that." (Claire, p.18 Lines 550-552).

"I don't have the history or the baggage or the history that she has with her mum." (Alan, p.7, Lines 183-184)

Alan's use of "*baggage*" and repetition of "*history*" emphasises prior experiences as a burden. This shows how differential experiences are used to interpret the same symptoms in the spouse. In distinct contrast to attributing cognitive decline to ageing or co-morbid illness, relating symptoms to dementia triggered strong emotions. Colin recalled his friend's diagnosis:

"She says James has been diagnosed with dementia." And I started to cry. And she says, "oh it's no too bad just now Colin," and I said, "it'll just get worse, so it will." (Colin, p.36, Lines 759-763)

His emotional response appears to be associated with a certainty of decline. This is mirrored by his wife's beliefs which evoke compassion in anticipation of future dependency:

"I mean when you think of it, it is like a second childhood isn't it. Going back the way." (Sandra, p.11, Lines 243-244)

Problem Awareness

Symptom awareness represented a progressive decline in ability and a shift from normal function to a concern requiring action. The realisation was embedded in intense psychological responses of frustration, shock, sadness and despair. The closeness of dyad relationship functioned to underline but also prevent awareness being brought to the fore.

"I am aware and irritated with myself about memory loss". (Steven, p.1, Line 15)

Despite every participant attributing forgetting and word finding difficulties to normal experiences, each patient noted their frustration at changes in their

communication skills. The impact of memory loss on the spousal relationship is shown here:

"I obviously repeat the thing and then I get a bit exasperated, which he gets annoyed at, eh you know I do find that, because you know, I'll say, "for goodness sake, we are going to," you know, [laughs]" (Nancy, p.13 Lines 266-268)

The utterance signifies awareness in the spouse's frustration and perhaps indicates Steven's embarrassment. Colin related his emotions to word finding difficulties:

"[...] Aye. I lose my temper very readily.

Can you tell me about that?

It comes from, now the words I want, [...], no getting the words to tell to Sandra, who I met, this all piles up and I get fed up" (Colin, p.10, Lines 196-202)

Successive instances therefore increase concern which triggers negative emotions. Becoming more frustrated with social interactions was also evident:

"She was definitely emm, had a shorter fuse and definitely was coming across as being more insecure about herself, so things that I would say just generally she was taking as an attack against her [...]" (Helen, p.22, Lines 218-222)

Her mother's defensive stance may be protective when it functions to limit other's awareness of her difficulties. These extracts imply symptom awareness emanates in part from changed emotional responses to situations. Every participant referred to the social consequences of word finding difficulties. Here, Claire describes her experience:

"[...] There was other times that I just have this blank, and I have to stop and think what was I going to say, which is very annoying, in the middle of a conversation" (Claire, p.3, Lines 73-75)

This is consistent with her husband's view of social situations:

"And it manifests itself in annoying, moments. When at home or outside, she's more concerned about outside." (Alan, p.5, Lines 136-137)

The accounts demonstrate word finding difficulties are more exposing in social situations when there is risk that problem awareness may extend to beyond the couple.

“I couldn’t remember how to get home” (Colin, p.4, Line 68)

Eight participants described events posing significant risk. These instances revealed previously unrecognised vulnerability and shocked dyads into realising something was wrong and warranted further attention. Helen illustrated this as she described her mother losing her bearings when dropping her off at the dentist:

“You know, is there, is there something wrong here? That was my first reaction, I, I felt sick in the pit of my stomach, emm when I saw the way she was walking about looking as if, “where am I going? What am I doing? Where am I?” And it did, it really shocked me, and I felt quite shook up for the rest of the day.” (Helen, p.37, Lines 890-894)

Helen’s bewilderment appears to draw parallel to her mother’s feelings. The series of questions implies a frantic search for answers to alleviate confusion. Furthermore, Alan described his wife becoming lost in an unfamiliar city:

"She went out one [door] and came in the wrong door. It completely and utterly bemused, and that knocked her right off, 360, she was there on her own, how she got back I'm not very sure." (Alan, p.10, Lines 290-292)

His description signifies distinct confusion, exemplified by "360" suggesting complete disorientation. The realisation appears to prompt significant others to consider different support needs for their loved one. Colin's wife describes increased awareness of his vulnerability:

"[...] I thought, "now that is worse" you know, cause if he goes out, he goes to the football and he was a wee bit later on Saturday and I thought, "I wonder where he is?" you know, if he is hanging about somewhere wondering eh, how to get home you know. So there is always that worry." (Sandra, p.3, Lines 59-63)

When compared to Colin's narrative of his experience of disorientation to that of his wife's, it highlights the different awareness of risk:

"I was so pleased. I didn't go seeking help from anyone else like you know; I managed to work it out myself like you know. However, when I told my GP this, about the, I says eh, "oh I came out of the chemist and I couldn't

remember how to get home,” and he says, “Oh Mr Smith that really concerns me.” (Colin, p.4, Lines 64-69)

These illustrate how disorientation can pose a significant risk to the individual but it is often significant others or clinicians who voice concern.

“Maybe I’m too close to her, you know” (Tommy, p.15, Line 431)

All dyads’ relationships had lasted more than four decades. The majority reflected on their relationship strength and cohesiveness while facing cognitive decline. Tommy reviewed his perception of Beth’s decline with respect to their relationship:

“I don’t think I could look back say, and say my god she’s a hundred times worse than you were this time last year, I don’t really see that. But then I don’t know, maybe I’m too close to her, you know.” (Tommy, p.15, Lines 428-431)

Tommy’s relational proximity masks his ability to perceive functional change in his wife. The subtlety of changes without a distinct incident is described in Alan’s account:

"I think we both knew. We more or less, we both realised about the same time, that something was subtly different in the relationship." (Alan, p.7, Lines 196-198)

Symptom awareness, although hard to quantify, presents as an important change between the couple. Physical proximity was noted by Sandra who had recently retired:

"I just cannae believe it has happened, just like that, you know, it's maybe been there all of the time but as I say if I am out all day I didn't notice it so much, but now..." (Sandra, p.5, Lines 45-49)

The contextual change led Sandra to review the onset and longitudinal presence of cognitive decline. Similarly, observations from those out with the dyad prompted recognition:

"Well, funnily enough, my brother [...] he's been up and around more and has eh, and has said to me, "what, how's Steven? Is he okay, because I've noticed he seems to be a bit confused about things." (Nancy, p.16, Lines 323 – 326)

These accounts imply that the relational and physical proximity to the patient can increase symptom awareness but reduce clarity of deterioration over time.

Living with Forgetting

Preceding diagnosis, dyads utilised a range of adaptive strategies to accommodate cognitive decline to live well occur in the context of functional losses.

“Wee tricks to make me remember” (Steven, p.8, Line 220).

Physical strategies and verbal prompts overcame cognitive difficulties and restored function. All participants voiced preferential strategies, with every patient using physical aids as a means of support. In the following extract, Susan defines her preparation to recall information:

“Write it down, before you go to bed at night, get your book out, your pen, and start writing, “I’m going so and so tomorrow at a certain time,” and it is helping amazingly, it is helping.” (Susan, p.39 Lines 884-887)

This is further exemplified through Steven's dialogue:

"Yes, that's the answer to everything, my diary.

So that is your ...

Yes, I refer to it as my memory actually." (Steven, p.5 Lines 127-130)

This suggests Steven externalises his recall to a concrete source to provide validation in the absence of a reliable memory. Spouses engaged in more verbal prompting particularly within social interactions. This was typically on a trial and error basis as Tommy highlights:

"I would try to say to her, was it this? Was it that? Was it the other? And you would hit on it and she would say oh that's what it was." (Tommy, p.3 Lines 75-76)

In a similar way, Alan describes his spousal communication:

*"She'll say, "I can't remember the name of that." I'll say, "It starts with a Y."
[Makes a popping noise] That's all I say, and it's there in a flash, so we use*

that and I'll say, "For goodness sake, don't talk to me of thingamajigs"

(Alan, p.6, Lines 153-157)

The expression, *"there in a flash"* instils an image of him enlightening her lost abilities.

"I've given that up" (Claire, p.8, Line 211)

Participants were shown to become selective in their choice of activities, preferring those that maintained function whilst protecting oneself from embarrassment or shame. In the following excerpt, Claire's central focus to retain control of her decisions is paramount:

"I'm still functioning and doing all the things I was doing before but I've given up, given up on a committee and I've given up on a treasurer-ship, because I just felt, no I don't want to take this on for another year. [...] I want to be able to do it under my own steam, so I've given that up." (Claire, p.8, Lines 205 - 211)

The repetition of “*given up*” emphasises the decision to withdraw from commitments at a point where she continues to function. The process of becoming selective alleviates unnecessary stress and minimises confusion:

“I only have one card, I had three, four cards and that confused me completely so the bank said they’d be as well to give me one card and then it is just one number.” (Susan, p.2, Lines 38-41)

Furthermore the following extracts demonstrate Beth’s difficulty retaining new information and her husband’s response by completing more household chores:

“I couldnae get it in there [points to head]” (Beth, p.5, Lines 131-135).

“I just, we just kid her on, and for if we were in company and she’ll pass a comment like, oh aye the washing, this that and the dishwasher. I’d say, “Aye if you went near it, it would bite you!” you know, [laughs]” (Tommy, p.8, Lines 222-225).

Tommy’s humour masked decline while enabling his spouse to maintain social interactions. Spousal companionship facilitated the alteration of shared activities

due to cognitive change. The following extract shows Sandra's acceptance of remaining closer to home:

"We used to go you know, to Edinburgh and things like that, but just local parks or round and about to the supermarket or something, but that is far enough." (Sandra, p.8, Lines 169-171)

"I do try and exercise my memory" (Helen, p.12, Line 288)

Every participant engaged in activities which retained their sense of self. This served to increase self-worth and attributions of hope. This was summed up by Helen:

"I just think your brain is a kind of a muscle and I suppose in a way you just have to keep using it to keep it healthy." (Helen, p.12, Lines 284-288)

This suggests belief that activity will improve subsequent cognitive function. Many participants described exercises to stimulate cognitive function. Claire substituted reading with Sudoku puzzles in response to diminished concentration:

"I said, "Hooray, I got it finished." And emmm, I feel quite happy when I get it done, and I feel I must try to do that." (Claire, p.11, Lines 288-289)

Her exclamation celebrates retained ability, suggesting value in continuing pursuits she can fulfil. This was reflected in every patient account. Beth's family response to her attaining further knowledge is described in the next excerpt:

"I went to a wee class to learn how to use tablet. Grandchildren, great-grandchildren hysterical, Gran Beth going to a class to learn how to use a tablet". (Beth, p.9, Lines 237-239)

Likewise, reading enables a sense of knowledge acquisition:

"[...] I read all of the time. I have so, I've learned new words, you learn about people and countries and everything you know." (Susan, p.18 Lines 427-429)

The process reflects her daughter Helen's assertion that activity can serve to keep the mind active.

“She does really enjoy the social interaction” (Helen, p.15, Line 355)

Social exchanges functioned to show retained value and a desire for social interactions. Despite forgetting, Steven emphasised his comprehension of others through his repetition of “*understand:*”

“I mean when people speak to me, eh I listen to them and I understand what they are saying to me, and I understand, I understand what you are saying to me and I understand what anybody says.” (Steven, p.17 Lines 474-477)

Communication strategies prevented withdrawal from others. For example, to overcome word finding difficulties, Colin described the environment or aspects of a situation:

“I’m not totally cut off, I’ve got other means of getting across where I mean and who I am talking about, “the dog”, or” the telephone kiosk,” like you know. I have other means of, to say what I am referring to like, you know.” (Colin, p.43, Lines 905- 908)

The continued ability to interact with others focuses attention toward living with, rather than, being disabled by decline. Helen values her mother's social interactions:

"She does really enjoy the social interaction and I do think that it's good for her, cause I know of other, you know, there's pensioners that live across the road that, they don't see someone from one week to the next and that, you know, I think that is terrible." (Helen, p.15, Lines 355-359)

Furthermore, social interactions allow patients to focus on their positive roles rather than their functional decline. Beth, listing her relationships demonstrates how she views her familial role:

"But I don't have family worries. Tommy is the best in the world. I've got a son and a daughter and their families and my daughter is a gran, so I'm a great-gran. I've got two, you know." (Beth, p.12, Lines 322-325)

Finally, being valued and useful to others is reflected by Susan describing her grandson's relationship and when Colin helped his daughter:

“Yes, so I’ll be teaching him to cook, making scrambled eggs now, does all of these things now, he’s nine.” (Susan, p.18, Lines 406-407)

“It got us out and we were doing something meaningful, we were cutting the grass for our daughter, like you know, and we tidied up all too, plus the fact neighbours would come out and pass the time of day with you, you know. I really, really enjoyed it so I did.” (Colin p.21, Lines 447-451)

Both extracts show individuals appraise their retained skills to demonstrate their value to others in ways other than conversations or recall.

Disclosure to Others

Disclosure to others signified a new stage towards acknowledging cognitive change. Dyads considered formal services, their future needs, and the anticipated benefit from raising concerns.

“Mum’s getting a bit vague” (Claire, p.16, Lines 439)

Despite increased recognition, every dyad resisted telling others. This prevented negative perceptions and limited personal shame. Beth avoided conversations to lessen the likelihood of embarrassment:

“[...] and I see people that I know. I think, “I cannae be bothered speaking to them.” And I stand outside the shelter, and kid on I don’t see them.”
(Beth, p.7, Lines 192-194)

Such avoidance was also described by Colin anticipating peer responses:

“No, I don’t want any sympathy at all like you know, it makes people think, “oh sorry for Colin” [imitates whiny voice] I don’t want any carry on. [...] I just leave it, I just leave it. I feel like I can deal with that way better you know, rather than telling them all.” (Colin, p.16, Lines 329-333)

Disclosure avoidance preserved self-concept. Steven outlined how he anticipated others to perceive his difficulties:

"There are other people who I haven't told em, and it is degrading to say that you are going off your rocker," (Steven, p.25, Lines 675-676)

It suggests telling others may lessen their view of him. The idiom, *"off your rocker,"* implies his behaviour as somewhat irrational. Claire and Beth discuss their suspicion of family awareness in the following extracts:

"But I thought, "maybe I better tell the family, that I'm not quite functioning. In case they're like, "mum's getting a bit vague" [laughs]. I think that's the thing, probably, I am more vague now." (Claire, p.16, Lines 438-440)

"Oh mum!" but he wouldnae let a word be said against me, you know, you know. I think the way he says "Oh mum!", he doesnae want to admit that mum's losing her brain box." (Beth, p.13, Lines 367-369)

Familial responses represent a more sympathetic stance compared to patient's anticipated reactions from others. However, significant others were also apprehensive of disclosure. Here, Nancy attempts to withhold her concerns:

"I haven't really, [pause] I suppose, I hide it from them [adult children] really." (Nancy, p.17, Line 344)

The decision to tell others was predicated by the perceived capacity the recipient had to support the patient:

"Sometimes you feel that you don't want to burden other people with it, that they've got a lot going on in their own lives as well, so maybe just generalised it to them." (Helen, p.33, Lines 797-799)

"Burden" elicits an impression of giving others a load to bear. Consideration appears to be based on the practical gains to be made by expressing concern. Here, the decision making process is based on the physical proximity of Alan's family to provide support:

"We're far enough away but near enough to be useful, but they are far enough away not to be able to help on a day-to-day basis, and I wouldn't want to trouble them with something until we have a clearer picture." (Alan, p.18, Lines 508-512)

This motivation to disclose is in contrast to the emotional concerns patients expressed which limiting those who were to be told.

“She was the instigator” (Alan, p.14, Line 399)

Seeking formal help for cognitive decline was characterised as a temporal marker for every participant. In every dyad, it was the patient who initiated contact with their general practitioner. The act appears to have distinct resonance as it suggests the beginning of something, with the locus of control remaining within the patient. The timing of help-seeking was significant in all cases, with the majority expressing surprise at disclosure:

“I didn’t actually see it coming I don’t think I saw it coming. [Pause] I didn’t think things had deteriorated, or I didn’t think that Claire thought things so badly that she wanted to take it one step further.” (Alan, p.2, Lines 45-48)

Alan’s hesitation infers a process of questioning his own attributions towards his spouse’s decline. This process is further emphasised in the admission from Helen’s mother:

"One day out of the blue my mum came up or I came over and she said, "I went to the doctor yesterday and I spoke to him about my fears about my memory," (Helen, p.8, Lines 182-184)

From the patient narratives, disclosure was spontaneous and not overtly planned:

"I don't think I went down to the doctor just to say, "doctor my memory is bad" you know, eh, but, when I went down with different things and, and I said about my memory." (Beth, p.22, Lines 592-595)

The process of combining one need with another is illustrated with illness co-morbidity. This is illuminated by Steven's account of telling his doctor:

"I went to see him about my athlete's foot, eh god knows what all I had wrong with me, [pauses and sighs] I have fungus on my toenail, very serious complaint, small stupid things like that, but primarily memory loss which I mean I don't give a damn about my toenail but but, but, my memory I, serious uhuh." (Steven, p.21, Lines 602-606)

Despite Steven's list of ailments, "*primary*" and "*serious*" suggest that his memory loss had become a priority. All patients reflected on telling their doctor at a point they perceived to be the "right time" for their circumstances. It suggests that avoidance of regret precipitates telling others:

"Whether you hang on and think, there's nothing wrong with me, no I'm fine and then they would maybe they would say, oh you should have come and seen us sooner when we could have done something for you. I don't know whether they can do anything for you anyway, but I thought well, this is my time to go and see him." (Claire, p.23, Lines 658-622)

Above all, the assertion, "*my time*," infers personal possession of disclosure and control of their health care decisions.

"She put me at ease" (Sandra, p.22, Lines 465)

In the absence of wider social support, all participants described the memory clinic as a source of reassurance and information. Every participant expressed gratitude, relief and future hope. Susan's description of her doctor highlights the supportive relational aspects which facilitated this process:

"My GP's are excellent, the ones I have now are absolutely great, they are lovely, they are sensitive, they are eh caring," (Susan, p.40, Lines 915-916)

The sentiments, *"sensitive"* and *"caring,"* are consistent with Helen describing the alleviation of concern as a significant factor:

"She's [memory clinic nurse] obviously used to dealing with people who are anxious and scared and don't know what, what's ahead of them and it did feel that she was fantastic she really did, she made me, and my mum feel at ease." (Helen, p.31, Lines 746-751)

It appears that the patient's relationship with her nurse provided the reassurance and support that she may have lacked through limited disclosure to her peers. The following extract implies how the clinicians alleviated family concern:

"I mean, it puts your mind at rest." (Tommy, p.15 Lines 424-425)

“How am I going to be today?”

All participants described anticipation of an altered future fluctuating between fear of losses and hope for potential treatments. Colin’s admission implies the notion that cognitive change is viewed as almost inescapable:

“It is the first thing that is on my mind when I wake up in the morning. I think, “How am I going to be today?” it really frightens me.” (Colin, p.41, lines, 870-872)

Furthermore, the progressive and enduring aspects of cognitive change are delineated by Steven’s comparison to prison incarceration:

“You get less than that for murder, as they say [laughs] you do.” (Steven, p.23, Line 667)

His comparison implies a belief that dementia is an unjust punishment. Participants described future uncertainty and fear of the loss of themselves to the disease. Colin identifies his fear as emanating from the reliance on others:

"I don't know what it could lead to and I'm frightened that I get the worst, you know. That you cannae cope and you are totally dependent on others to help you." (Colin, p.35, Lines 741-744)

Similarly Helen expressed the anticipation of future decline as an absence of the person she once knew:

"It must be heart-breaking, to walk in, and it's not, it's not your mum anymore. You know physically it is, but the essence that makes them, them, isn't there." (Helen, p.38, Lines 927-928)

The powerful description implies that the core aspects of an individual, "essence," are lost to cognitive change. This appears to be what generates greatest concern for the future for all participants.

Discussion

There is a national drive to increase the number of people receiving an early diagnosis of dementia in order to provide timely treatment, care and support (The Scottish Government, 2013). However diagnoses are often delayed due to limited symptom recognition and protracted help seeking. The findings here are similar to existing qualitative studies exploring patient and family accounts of early stage cognitive decline and dementia (Beard et al., 2011; Bunn et al., 2012; de Boer et al., 2007; Chrisp et al., 2012; Garcia et al., 2014; Innes, et al., 2014 Leung et al, 2011; McCleary et al., 2012; Steeman et al., 2006; Steeman et al., 2007). This study expands the evidence base by characterising pre-diagnostic experiences from both patient and significant others' perspectives. It highlights how interpersonal relationships can affect help-seeking behaviour. The Interpretative Phenomenological Analysis produced five themes; the inevitability of ageing, problem awareness, living with forgetting, disclosure to others, and how am I going to be today?

Participants anticipated older age to be characterised by co-morbid physical and sensory decline. Attributing cognitive change to normal ageing served to minimise anxiety and concerns, while evoking denial in all participants. This is consistent with the existing literature (Bunn et al., 2012, Chrisp et al., 2012; de Boer, et al., 2007; Steeman et al., 2006) and demonstrates that normalising symptoms delays help-seeking behaviour. The study also highlighted that patients received

normalising reactions from their GP on initial disclosure. The findings demonstrate individuals maintain function by prioritising their co-morbid illness and needs. It is possible that denying symptoms or attributing them to contextual factors may be protective in the early stages. It may allow individuals to avoid the potential stigma and negative perceptions associated with dementia and retain the belief that interventions may be available to aid their difficulties.

Consistent with existing research, the experiences illustrate patients monitor their abilities and behaviours for up to five years after symptom onset, often before those around them become aware of changes (Bunn et al., 2012; Chrisp et al., 2011; Modhardt, et al., 2010; Speechly et al., 2008; van Vliet et al., 2013). Within the current sample, the quality and duration of the relationship with the significant other influenced symptom recognition. Participant narratives were more integrated in dyads that spent more time together. Those in closest proximity may have had greater scope to support and monitor changes and therefore minimise risks. This is important as those who have more ability to manage and lessen risks, may defer requesting formal help. Prior experiences of caring for individuals with dementia elicited negative attributions and a range of emotions towards their future. This led to increased symptom monitoring by patients. The finding reflects existing literature and suggests increased dementia awareness can alter behavioural responses to the disease (Werner et al., 2014).

The experiences demonstrate participant dyads use adaptive strategies to overcome and manage cognitive change. In the earliest stages, families adapt and assimilate decline into their lives. This finding is consistent with retrospective qualitative literature considering later stages of dementia (Bunn et al., 2012; de Boer et al., 2007; Steeman et al., 2006). In the current study, adaptive strategies were largely used to preserve social identity and prevent embarrassment. The significant others' role intuitively minimised the impact of social difficulties and aided engagement with others. There may be less motivation to contact formal services if patients' needs are well supported by their interpersonal relationships. This may explain, in part, why only half of those with dementia are estimated to receive a diagnosis (The Scottish Government, 2012).

Although families refrained from peer disclosure, contact with clinicians provided reassurance and support. In the absence of a cure, disclosure to clinicians validated patients' experiences and enabled additional coping. In Scotland, the one year post-diagnostic support provision may facilitate this further and aid patient adaptation to living well with dementia for as long as possible (The Scottish Government, 2012). The experiences support the need to provide timely information and appropriate interventions to minimise risks to the patient and those who care for them.

This study was unique in its use of patient and significant other dyads to characterise early cognitive change prior to diagnosis. The process of conducting separate participant interviews revealed distinct interpretations and insights into the same events. Significant others more frequently attributed symptoms to normal ageing and denied the presence of dementia. Likewise, significant others expressed more attributions towards comorbid illness, personality and contextual factors. Despite both dyad members attending the memory clinic assessment, differential attributions continued to be made about symptoms origin. These attributions may account for the timing of the patient's help-seeking decision. The motivation to act on their concerns may relate the desire to approach services while they retain capacity and personal autonomy. This process fits with the model proposed by Keady and Nolan (2003) and may represent the participants' transition from "working separately" to "working together" to respond and manage their difficulties.

Service Implications

Despite information and support relating to dementia becoming more widely available, help-seeking delays continue. The current patient sample all continue to be undergoing review, with only tentative diagnoses being provided. This reflects the diagnostic challenge for dementia, as discrete markers to indicate disease presence are less evident and assessment is reliant on self-reports in the early stages. The first point of formal contact for dyads was the GP. However four of the dyads described their concerns being minimised by clinicians. Doctors may

prioritise concerns of potential risks or complex comorbidity and may not consider a dementia diagnosis based on beliefs about available treatments (Buntinx et al, 2011). Rather than minimise or deny symptom existence, patient disclosures should represent an opportunity for clinicians to provide appropriate information about the disease, and the support available. This may facilitate increased motivation to seek help earlier (The Scottish Government, 2013). All participants spoke positively about their assessment experiences. Rather than anticipated fear, hope was instilled through understanding the support available to maintain wellbeing and function for as long as possible.

Limitations

The study utilised IPA and therefore the inclusion criteria were purposefully selective. Despite seeking a homogenous sample, two relationship types, spouse and parent and child were recruited. The lived experiences of spouses and children of patients with cognitive changes may differ as a consequence of the relationship type, longevity and proximity. The inclusion of both relationships may have influenced the study findings as it may have comprised of differential accounts unique to spouses and to children. Furthermore, the sample included both male (n=2) and female (n=3) patients. Including both genders may have influenced the themes that were derived as aspects of the lived experiences that may be unique to the populations of male or female patients may have been included and combined. Care was taken to balance the impact each dyad had on the overall

themes and analysis. However the study concedes that the sample may not have been as homogenous as projected.

The participants were community dwelling and predominantly of white Scottish decent. While these outcomes may not represent those from minority groups, those who live alone, or those in inpatient or residential care settings, they strengthen the existing literature of experiences across different social (Bunn et al., 2012) and ethnic backgrounds (Koehn et al., 2012; McCleary et al., 2012). Further research into those who lack the social support from significant others by considering those who live alone, may represent an alternative experience to that represented here and in the current literature.

The recruitment period lasted over six months and it was necessary to extend the research to include six additional OP-CMHT and conduct home visits. This mirrors the lengthy recruitment period in a similar study conducted by Leung et al., (2011). Undergoing a dementia assessment places significant emotional strain on patients and their families. Participants in this study had actively sought help and were perhaps more motivated and informed at an earlier stage of change than research predicts. It is possible that those who engaged in the research may have been more resilient during such a difficult period of uncertainty.

The study recruitment was based on patients with early stage decline who had been referred onto specialist memory services. Despite an increase in individuals aged under 65 years attending the memory clinics, the exclusion criteria were defined to ensure sample homogeneity and acknowledged the distinct help-seeking pathway and experiences in this population (van Vliet et al., 2012). This is an area for future research. Moreover, those with significant disease progression were excluded thus limiting the population to recruit from. Anecdotal information from specialist services indicated that the majority of those referred were in the more advanced stages of dementia. The patients presented for assessment when previous coping strategies no longer maintained safety, or where family stress was observed. It is not known what proportion of patients who disclose concerns about cognitive changes are referred onto specialist services. Furthermore, the decision making process from primary care to memory clinics is unclear. The experiences here suggest that attributions related to ageing and treatment availability may influence help-seeking. Further consideration of these processes would be valuable areas for further research.

The inclusion and exclusion criteria led to a small potential participant sample of those attending clinics. A distinct proportion of those attending did not have a significant other to participate in the study. This factor accounted, in part, for the lengthy recruitment period. The participant experiences may be more representative of a subset population which, taken together with those aged under 65 years, those with more significant decline, or who present without a significant

other to support, represent the wider clinical population. It is acknowledged the current sample may not represent the whole profile of those accessing memory clinic services.

Conclusion

Early stage cognitive change was attributed by patient and significant other dyads to existing beliefs and prior experiences. Help-seeking was deeply embedded in social interactions and precipitated by functional decline exposing the individual to potential risks. Memory clinics were a source of reassurance, particularly when there was a lack of social supports available out with the patient and significant other dyad. Improvements in public awareness of symptoms, assessment and available care for dementia may reduce help seeking delays and motivate help-seeking. Further research into public health perceptions and general practitioner referral beliefs may add further insight into this area.

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Chapter 3: Advanced Clinical Practice I - Reflective Critical Account (Abstract Only)

Communicating Distress: Understanding the needs of those with dementia and the teams who care

The reflective account describes my experiences as an older adult aligned trainee clinical psychologist and my development in communicating psychological knowledge and interventions with health and social care colleagues. The reflective account draws upon my experiences during my core older adult placement and specialist placement within an acute dementia ward. I have drawn upon Gibb's Model of reflection (1988) to structure my reflection of my developmental progression through training. Within the reflective review of my learning, I have considered the Integrated Developmental Model (Stoltenberg, 1998) to consider the manner in which I seek support and guidance in supervision and how this can inform both my current and future practice. I found that the process of reflecting on my clinical practice has enabled me to view the manner I approach and respond to interactions with others in a different way. It has helped me to understand the situations in a new light and realise how the experiences may influence my future practice and development.

Chapter 4: Advanced Clinical Practice II - Reflective Critical Account (Abstract Only)

From Research Assistant to Scientist-Practitioner: Conducting Research within the National Health Service

The reflective account describes, from a developmental perspective, my experiences of conducting research within the National Health Service. The account draws upon my experiences, prior to commencing the clinical doctorate, when I was a research assistant, and while working as a trainee conducting both my service based evaluation and major research projects. I have utilised Gibb's Model of Reflection (1988) to structure my reflections and focused primarily on my implementation of research through the doctoral training. To consolidate and integrate the outcomes of my reflections, I have used The Integrated Developmental Model (Stoltenberg, 1998) to consider the manner in which I learn and develop from experiences and how this can inform my future practice. The review helped me to discover that many of the clinical skills I possess can be directly transferred to research approaches. I realise however that the level in which I utilise such skills may depend on the domain of work I am operating in. To aid my learning in the future, I believe it is crucial for me to seek out appropriate supervision and engage in reflective practice as a way of ensuring I maintain the Scientist Practitioner model in which practitioner psychologists are required to operate.

Appendices

Appendix 1.1: Guidelines for Submission to *Dementia*: International Journal of Social Research and Practice

Dementia publishes original research or original contributions to the existing literature on social research and dementia. The journal acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.

1. Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

2. Article types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia. *Dementia* also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 750-1500 words. The journal also publishes book reviews.

3. How to submit your manuscript

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned. *Dementia* is hosted on SAGE track a web based online submission and peer review system powered by ScholarOne[®] Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit <http://mc.manuscriptcentral.com/dementia> to login and submit your article online.

IMPORTANT: If you are a new user, you will first need to create an account. Submissions should be made by logging in and selecting the Author Center and the 'Click here to Submit a New Manuscript' option. Follow the instructions on each page, clicking the 'Next' button on each screen to save your work and advance to the next screen. If at any stage you have any questions or require the user guide, please use the '[Online Help](#)' button at the top right of every screen. All original papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

Innovative Practice papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Jo Moriarty jo.moriarty@kcl.ac.uk.

Books for review should be sent to: Book Review Editor ♦ *Dementia*, Heather Wilkinson, College of Humanities & Social Science, University of Edinburgh, 55-56 George Square, Edinburgh, EH8 9JU, UK. Email: hwilkins@staffmail.ed.ac.uk

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Appendix 1.2: Quality Appraisal Framework (Walsh and Downe, 2006)

Stages	Essential Criteria	Specific Prompts	Criteria Met? Yes/ Partially/ No
Scope and Purpose	Clear statement of and rationale for research question/ aims/purposes	Clarity of focus demonstrated Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing Link between research and existing knowledge demonstrated	
	Study thoroughly contextualised by existing literature	Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both	
Design	Method / design apparent and consistent with research intent	Rationale given for use of qualitative design Discussion of epistemological/ ontological grounding Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology) Discussion of why particular method chosen is most appropriate / sensitive/ relevant for research question /aims Setting appropriate	

Stages	Essential Criteria	Specific Prompts	Criteria Met? Yes/ Partially/ No
Design (cont)	Data collection strategy apparent and appropriate	<p>Were data collection methods appropriate for type of data required and for specific qualitative method?</p> <p>Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail?</p> <p>Was triangulation of data sources used if appropriate?</p>	
Sampling strategy	Sample and sampling method appropriate	<p>Selection criteria detailed, and description of how sampling was undertaken</p> <p>Justification for sampling strategy given</p> <p>Thickness of description likely to be achieved from sampling</p> <p>Any disparity between planned and actual sample explained</p>	
Analysis	Analytic approach appropriate	<p>Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory)</p> <p>Was it appropriate for the qualitative method chosen?</p> <p>Was data managed by software package or by hand and why?</p> <p>Discussion of how coding systems/conceptual frameworks evolved</p>	

Stages	Essential Criteria	Specific Prompts	Criteria Met? Yes/ Partially/ No
Analysis (Cont)		<p>How was context of data retained during analysis</p> <p>Evidence that the subjective meanings of participants were portrayed</p> <p>Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance</p> <p>Did research participants have any involvement in analysis (e.g. member checking)</p> <p>Evidence provided that data reached saturation or discussion/rationale if it did not</p> <p>Evidence that deviant data was sought, or discussion/ rationale if it was not</p>	
Interpretation	Context described and taken account of in interpretation	<p>Description of social/physical and interpersonal contexts of data collection</p> <p>Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena</p>	
	Clear audit trail given	Sufficient discussion of research processes such that others can follow 'decision trail'	
	Data used to support interpretation	<p>Extensive use of field notes entries/ verbatim interview quotes in discussion of findings</p> <p>Clear exposition of how interpretation led to conclusions</p>	

Stages	Essential Criteria	Specific Prompts	Criteria Met? Yes/ Partially/ No
Reflexivity	Researcher reflexivity demonstrated	<p>Discussion of relationship between researcher and participants during fieldwork</p> <p>Demonstration of researcher's influence on stages of research process</p> <p>Evidence of self-awareness/ insight</p> <p>Documentation of effects of the research on researcher</p> <p>Evidence of how problems/ complications met were dealt with</p>	
Ethical dimensions	Demonstration of sensitivity to ethical concerns	<p>Ethical committee approval granted</p> <p>Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants</p> <p>Evidence of fair dealing with all research participants</p> <p>Recording of dilemmas met and how resolved in relation to ethical issues</p> <p>Documentation of how autonomy, consent, confidentiality, anonymity were managed</p>	
Relevance and transferability	Relevance and transferability evident	Sufficient evidence for typicality specificity to be assessed	

Stages	Essential Criteria	Specific Prompts	Criteria Met? Yes/ Partially/ No
Relevance and transferability (cont)		<p>Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies</p> <p>Discussion of how explanatory propositions/emergent theory may fit other contexts</p> <p>Limitations/ weaknesses of study clearly outlined</p> <p>Clearly resonates with other knowledge and experience</p> <p>Results/ conclusions obviously supported by evidence</p> <p>Interpretation plausible and 'makes sense'</p> <p>Provides new insights and increases understanding</p> <p>Significance for current policy and practice outlined</p> <p>Assessment of value/empowerment for participants</p> <p>Outlines further directions for investigation</p> <p>Comment on whether aims/purposes of research were achieved</p>	

Appendix 2.1: Major Research Project Proposal

Exploring Patient and Carer Experiences of Early Cognitive Decline

Abstract

Background: The pathway towards a diagnosis of dementia has been shown to be hindered by difficulties in recognising initial symptoms and delays in help-seeking. **Aims:** Using qualitative methodology, the study will explore how people with symptoms (PWS) and their significant others perceive and make sense of the onset of early stage cognitive decline. **Methods:** Purposeful sampling will recruit people presenting with early stage symptoms characteristic of Alzheimer's disease or vascular dementia, at a NHS memory clinic. Separate semi-structured interviews lasting 30 - 45 minutes each will be conducted with up to five patient and significant other dyads. The interviews will be transcribed and analysed using Interpretative Phenomenological Analysis. **Applications:** This area of research may contribute to local service design to target information for raising awareness of early stage cognitive decline and to increase access to memory clinic services. **Word Count:** 139

Introduction

Receiving a diagnosis of dementia is often the initial access point to a range of treatments, care and support for the person with symptoms (PWS) and their family. In the United Kingdom, it is estimated that over half of people with dementia do not receive a formal diagnosis of the disease (Alzheimer's Society, 2013). For those who do receive formal identification, the pathway towards diagnosis remains prolonged through difficulties in

initial symptom recognition and delays in help-seeking (Buntinx, et al., 2011). Outcomes from Australian (Speechly, et al., 2008) and British (Chrisp, et al., 2011) caregiver samples recorded delays of 1.9 and 2.4 years, respectively, between initial symptom recognition and help-seeking, with confirmed diagnoses taking, on average, 3.1 years (Speechly, et al., 2008; Chrisp, et al., 2011). Qualitative reviews have considered PWS and caregiver experiences of the pre-diagnostic pathway of dementia (Steeman, et al., 2006; de Boer, et al., 2007), responses to initial symptoms, and receiving and adapting to a diagnosis (Bunn, et al., 2012).

Initial Symptom Recognition

A meta-synthesis of 28 qualitative studies (total sample N = 414, median sample N=12, Steeman, et al., 2006) and a systematic review of 50 qualitative studies (de Boer et al., 2007) reviewed the transitional experiences of early stage dementia and demonstrated pre-diagnostic symptom recognition follows a greatly individualised course. De Boer et al., (2007) delineated PWS experiences were characterised by losing skills and competence in usual activities, changes in significant relationships, and increased fear, insecurity and confusion. From the perspective of family caregivers, the first indicators of dementia were subtle difficulties with word finding, calculations and new tasks, reduced participation in usual activities, personality changes and problems driving (Cocoran, 2009; Innes, et al., 2012). Hayes, et al., (2010) reported spousal caregivers differentially detected symptoms; husbands were slower to notice symptom emergence in their spouses and relied on social prompts before engaging with services. Spousal wives delayed their husbands' diagnosis to conserve their own identity and role within the relationship (Hayes et al., 2010). Further, Leung et al., (2011) explored the pre-diagnostic pathway from both the PWS's and family perspectives. Early symptom recognition was experienced by all participants up to

four years prior to diagnosis; the PWS often had earlier insight into their cognitive decline. Despite earlier symptom awareness, the qualitative literature describes how PWS make efforts to cope and may attribute the symptoms to normal ageing or contextual stressors (Steeman, et al., 2006; de Boer et al., 2007; Leung et al., 2011; Innes et al., 2012). When symptom severity increases or a 'critical incident' occurs, PWS have been shown to begin attend to the symptoms as abnormal. PWS may deny or minimise symptoms or avoid discussions (de Boer et al., 2007; Leung et al., 2011; Innes et al., 2012), and form strategies to monitor deterioration, while maintaining their sense of self through increased vigilance and avoidance of their usual activities (Steeman et al., 2006).

Help-Seeking Triggers

Despite PWS and family's symptom awareness, the literature indicates people delay help-seeking by considering the legitimacy of their concerns, questioning symptom presence and validity, and rationalising the symptoms towards normal ageing or comorbid health related issues (Chrisp et al., 2012a; Innes et al., 2012). Help-seeking by family can be constrained by denial and resistance from the PWS and other family members, and concern for the PWS's reaction (Chrisp et al., 2012a). Further, a systematic review of minority ethnic groups reported caregiver help-seeking was also hindered by attributions towards the causes of dementia, stigma, shame and negative interactions with healthcare services (Mukadam, et al., 2011; Bunn et al., 2012).

Research examining help-seeking trigger events has shown that change in the PWS's functioning is a key facilitator for health service engagement. Leung et al., (2011) examined PWS's perspectives and described when individuals initiated contact with their

GP, prior to family involvement, the PWS was typically functioning within the expected range and no diagnoses were made. The qualitative literature from caregiver perspectives highlights, it is often the carer or family member who pursues of a formal diagnosis, often preceded by 'crisis points' (Hinton, et al., 2004; Chrisp et al., 2012a). Family caregivers reported noticing and raising concerns when the PWS's coping strategies began to fail, however they continued to monitor them until the need for an explanation became greater or the ability, from either party, to maintain normal function deteriorated (Steeman et al., 2006; Bunn et al., 2012; Innes et al., 2012). This followed when there were uncertainties about symptoms (Chrisp et al., 2012a), behavioural disturbances emerged (Eustace et al., 2007) cognitive decline became greater, predominantly memory difficulties and disorientation (Streams, et al., 2003), daily function became impaired or factors unrelated to the PWS, most commonly recommendations from other family or health care providers arose (Streams et al., 2003; Leung et al., 2011).

The Process of Symptom Recognition and Help-Seeking

Keady and Nolan (2003) proposed the pre-diagnostic phase is characterised by the PWS and their family member initially 'working separately' whereby both consider symptom presence and its legitimacy but will not communicate this with anyone. It is proposed this changes to the process of 'working together' when both the PWS and their family member recognise and acknowledge symptoms and seek help together. Chrisp, et al., (2012b) highlighted the transition towards 'working together' was dependent upon the carer becoming accepting of the carer role and placing the PWS into the sick role. Chrisp et al., (2012b) argued it was this process and the responses from the PWS and other family which delay the transition to help-seeking.

Rationale for the study

Qualitative research describes the onset of dementia as a transitional process for the PWS and caregivers, which follows a pathway characterised by gradual adjustment and accommodation (Steeman, et al., 2006; de Boer et al., 2007; Bunn et al., 2012; Chrisp et al., 2012a; Innes et al., 2012). The attributions people make in retrospective recall has been shown to change after a dementia diagnosis is confirmed (Clare, et al., 2005; Innes et al., 2012). The majority of qualitative studies have, however, reviewed PWS and caregiver experiences of the pre-diagnostic period, up to two years post diagnosis (Streams et al., 2003; Steeman, et al., 2006; Cocoran, 2009; Hayes et al., 2010; Leung et al., 2011; Innes et al., 2012; Bunn et al., 2012;) Therefore, alterations in the accounts of the pre-diagnostic period may have occurred. Few studies have considered the experience of the pre-diagnostic period for PWS (Robinson, et al., 1997, N=8) and family caregivers (Chrisp et al., 2012, N=20) during the memory clinic assessment process prior to receiving a formal diagnosis. In addition, the literature highlights the complex transitions and interactions between the PWS and their family in the pre-diagnostic period and how this impacts upon the decision to seek support from formal sources (Leung et al., 2011; Chrisp et al., 2012a). However to date, no studies have explored the experience of PWS and family caregiver dyads prior to a formal diagnosis being made. It is proposed to explore the experience of early stage cognitive decline in pre-diagnostic period and decisions to attend memory clinics, from the perspective of PWS and their significant other.

Aims and Research Questions

Aims

The present study proposes to consider the lived experience of early stage cognitive decline in the pre-diagnostic phase for the PWS and their significant others, before a formal diagnosis is made. Specifically, this will consider the timeline and decision making process from initial symptom experience to accessing memory clinic services.

Main Research Question

How do PWS and their significant others perceive and make sense of early stage cognitive decline?

Secondary Research Questions

Describe the key features of early stage cognitive decline as it is understood by the people attending memory clinic services.

To what extent does Keady and Nolan's (2003) proposal of families "working separately" and "working together," account for people initiating attendance at memory clinic services.

Plan of Investigation

Design

Qualitative research focuses upon the phenomenon under study from the insider's perspective; such approaches have been used extensively to examine the experience of dementia (Steeman et al., 2006; de Boer et al., 2007; Bunn et al., 2012). Specifically, Interpretative Phenomenological Analysis (IPA) explores how individuals make sense of their personal and social world in order to understand the meanings they attach to specific experiences (Smith and Osborn, 2003). The current study proposes to use IPA to interpret semi-structured interviews, designed to explore PWS's and their significant other's experiences of early symptom onset and accessing memory services.

Settings and Equipment

Previous qualitative research on dementia recruited participants through memory clinics (Steeman, et al., 2006; Leung et al., 2011; Bunn et al., 2012; Chrisp, et al., 2012). The NHS Greater Glasgow and Clyde memory clinics in West Dunbartonshire provide an assessment and diagnostic service for dementia. Patients are most often referred by their GP. At the initial appointment the clinician will meet with the PWS and their significant other, and assess them in relation to diagnostic criteria for dementia and complete a brief cognitive assessment (Addenbrookes Cognitive Examination –III edition (ACE-III), or Montreal Cognitive Assessment (MoCA), or equivalent). The clinician may arrange further psychiatric or psychological assessments or neuroimaging. The assessment results are delineated at a further appointment, typically four weeks later, after investigations are completed. Possible outcomes from the assessment can be a dementia diagnosis, watchful waiting, discharge, or, an alternative diagnosis. The present study will be conducted at PWS's usual

memory clinic within NHS Greater Glasgow and Clyde property. If participants are normally visited at home by the memory clinic team, the interviews will be conducted in the participant's home. Home visits will be conducted while working in accordance to the local memory clinic's risk assessment and NHS Greater Glasgow & Clyde and The University of Glasgow's Lone Working Policies.

Participants

In accordance with IPA, purposeful, homogenous and well defined sampling of participants for whom the research question is significant will be completed (Smith and Osborn, 2003). Such sampling allows the examination of the psychological variability within the sample and specific patterns of convergence and divergence (Smith, et al., 2009). Therefore, PWS who attend for an initial memory assessment with their significant other will be eligible to participate if they are;

- Aged over 65 years,
- English speaking, (due to interviewer and interpreter constraints)
- Presenting with symptoms characteristic of early stage Alzheimer's disease or vascular dementia,
- Able to recall the period of initial symptom onset and judged by the memory clinic clinician to be able to provide informed consent to participate.

PWS will be excluded from participation, who present with;

- Symptoms of moderate to severe dementia, fronto-temporal lobar degeneration or young onset dementia, (initial symptoms and triggers are shown to differ, van Villet, et al., (2012)),

- Significant co-morbid mental health difficulties which impact upon their functioning,
- Aphasia or verbal communication difficulties,
- Inability to recall the pre-diagnostic period or provide informed consent,
- No significant other to validate the pre-diagnostic period.

A significant other is implicitly defined as the person who attends the memory clinic appointment with the PWS, who knows the PWS well and, has had regular contact with them before, and since the onset of the symptoms.

Measures

The ACE-III (Hodges, 2012) is a brief assessment considering the cognitive domains of attention, memory, verbal fluency, language and visuo-spatial abilities. A score out of 100 is derived, with cut off scores of 82 and 88 indicating specificity and sensitivity for dementia, respectively. A score of 75 is noted in practice as indicating probable dementia. The MoCA (Nasreddine et al., 2005) is a brief cognitive assessment which considers the major cognitive domains and has discriminatory ability to distinguish mild cognitive impairment or mild Alzheimer's disease from normal controls. A score out of 30 is derived, with a cut of score of 26 noted in practice as indicating probable dementia. Administration of either of these measures takes up to 20 minutes and contributes to usual practice within NHS Greater Glasgow & Clyde Memory Clinics.

Recruitment Procedure

The NHS Greater Glasgow & Clyde Memory Clinic clinicians will be provided with the study information by the principal researcher (See Appendix 2.2). The clinicians will be advised to introduce the study to PWS attending their first appointment, with their significant other, who meet inclusion criteria to participate. The clinician will provide the participant dyads with an information sheet introducing the study (See Appendix 2.3). The dyad will be advised to contact the memory clinic, prior to their next appointment, to express interest in participating. The clinic staff will then provide the participant dyad's contact details to the principal researcher.

Research Procedure

The principal researcher will invite the participant dyad to attend their usual memory clinic for the research interviews. To enable individuals to make an informed decision to participate, the research interview will be scheduled at least 24 hours after the potential participants were provided with the information sheet and will be held between the memory clinics appointments which are typically scheduled three to four weeks apart. This will allow participants to have discussed their concerns with a health care professional, but to prior to the symptoms being formally attributed to a diagnosis of dementia. It is reasoned that this procedure will allow participants adequate time and information to consider whether to take part. Participation will not delay usual treatment. The PWS's capacity to participate will be informed by the memory clinician's and principal researcher's clinical judgement, as well as the cognitive assessment score. Informed written consent (See Appendices 2.4 and 2.5) from both of the participant dyad will be sought prior to participation.

A semi-structured interview, lasting up to 30 – 45 minutes each, will be conducted separately with the PWS and their significant other. Holding two separate interviews is proposed to allow analysis of the lived experience from two perspectives and will serve to validate and increase the reliability of the information. Breaks will be offered throughout the interviews, as required. A review of the dementia literature informed the interview schedule (Appendix 2.8). Pilot interviews with one participant dyad will be held to ensure that the schedule effectively elicits the topic of interest and can be completed in the estimated time. A de-brief discussion will be offered by the principal researcher at the end of each interview. Participants will be directed to memory clinic staff and relevant information if participating raises any distress or concerns. Participants can request a summary of the research outcomes. To characterise the research sample, the PWS's cognitive assessment score (ACE-III or MoCA or equivalent) and subsequent diagnosis will be requested from the memory clinic.

Justification of sample size

The sample size for IPA research is understood to be dependent on the degree of commitment to the case study level of analysis, the richness of the individual cases and the specific research constraints (Smith and Osborn, 2003). Qualitative studies considering dementia have used samples between one and 84 participants (Steeman et al., 2006; Cocoran, 2009; Leung et al, 2011; Chrisp, et al., 2012a; Innes et al., 2012). Professional doctorates are advised to conduct between four and ten interviews, and can use interviews to explore one phenomenon from multiple perspectives to develop a detailed and multifaceted account of the phenomenon (Smith et al., 2009). It is proposed to recruit four to five participant (PWS and significant other) dyads to the study. It is anticipated this will provide representative narratives to explore the phenomenon in adequate detail.

A recent audit of the service indicated 23 patients were referred to the memory clinic and seen over a four month period. Therefore recruitment of the sample size is expected to be feasible in the projected time.

Data Analysis

The interviews will be transcribed verbatim and anonymised, with patient identifying information removed. The transcriptions will be checked for accuracy and completeness and stored on an NHS password protected encrypted laptop. The recordings will then be deleted. In accordance with IPA protocols, the principal researcher will follow practical guidance of the stages involved in IPA (Smith et al., 2009). A secondary rater (academic supervisor) will independently rate a random selection to validate inter-rater reliability on the themes identified.

Health and Safety

The study will comply with standard University of Glasgow and NHS Greater Glasgow and Clyde research practice procedures to ensure the safety of the researcher and participants.

Ethics

Participants will not be coerced into the study and will have the option to withdraw at any time, with no impact or delay on their on-going treatment and care. Standardised written information will be provided. Confidentiality will be explained to the participants and there will be an opportunity to discuss any concerns. Written informed consent will be sought for each participant and on-going consent will be monitored throughout the

interviews through participant verbal and visual cues. Data will be handled and stored in accordance with the Data Protection Act (1998) and NHS policy. All identifying information will be removed prior to final analysis.

Finance

The project will cost £17.25 for stationary, recording and transcription equipment will be borrowed from the University Department.

Project Timetable

The project proposal will be submitted to the University of Glasgow on 15th April 2013. It is anticipated any amendments to the proposal will be completed by June 2013, and thereafter final approval for the project from the University of Glasgow will be obtained. Application for ethical approval for the project will be sought in November 2013, with final approval anticipated to be received within three months, by January 2014. Initial pilot interviews and recruitment to the project is anticipated to six months to be completed. Analysis of the project will take up to three months and the write up of the research will take up to two months. The final research paper will be submitted as part of the clinical research portfolio in November 2015.

Practical Applications

This area of research may contribute to local service design to target information for raising awareness of early stage cognitive decline at primary to tertiary levels of care. The outcomes may also increase the awareness of health professionals to the factors

influencing patient and carer decisions to seek access to memory clinic services. Increased knowledge of early stage experiences may help local services and health professionals encourage people with symptoms and their carers to seek GP and memory clinic consultation at an earlier stage in symptom onset. In turn this may allow for increased dementia recognition and diagnoses, earlier care planning and access to evidence based pharmacological and non-pharmacological interventions, in accordance with Scotland's National Dementia Strategy (The Scottish Government, 2010).

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Appendix 2.2: Staff Information Sheet



Staff Information Sheet

Title of Project: Exploring Patient and Carer Experiences of Early Cognitive Decline

Name of Researcher: Mrs Melanie Young, Trainee Clinical Psychologist

This information sheet has been given to NHS Greater Glasgow & Clyde Outpatient Memory Clinic Staff, on behalf of Melanie Young (Trainee Clinical Psychologist). I would like to ask you to take a few minutes of your time to read over this information sheet. My name is Melanie Young and I am a Trainee Clinical Psychologist with the University of Glasgow. As part of my Doctorate in Clinical Psychology I am undertaking a research project in partnership with your service. I am contacting you to ask you to support me in the completion of the research study.

This sheet is designed to give you all of the information that you will require to understand the study and identify patients who may want to participate. I have tried to answer any obvious questions that you may have, but if you would like to discuss any aspect of the study further, please do not hesitate to contact me.

Melanie Young

Trainee Clinical Psychologist

Mental Health and Wellbeing, The University of Glasgow,
Gartnavel Royal Hospital Academic Centre, 1055 Great Western Road, G12 0XH

Email: m.young.2@research.gla.ac.uk

Telephone: 01389 812 032

What is the study about?

The pathway from a patient's initial experience of memory problems to receiving a formal diagnosis of dementia has been shown to take up to three years. Research has identified that difficulties in recognising symptoms, attributions to normal aging, and co-morbid health problems can delay help seeking from patients and their family members. The decision to seek support from health care services is often dependent upon the interactions between the patient and their family and is frequently triggered only when a critical incident has occurred or previous strategies to cope begin to fail. Most qualitative research has focused on the retrospective accounts of patients and their carers post diagnosis, and often many years after initial symptom onset. However, the recall of events may have altered after the confirmation of a formal diagnosis. The current study is focused on exploring the pre-diagnostic period for people presenting with early stage cognitive decline, from the perspective of the patient and their significant other. In particular, I am interested in the experience of early symptom onset, how patients and those close to them cope with this, and exploring their decisions to seek help from health care services. As people's attributions change after receiving a diagnosis, I am interested in exploring their experiences before the patient has a diagnosis confirmed by the memory clinic staff.

What are participants being asked to do?

Each participant and their significant other (who knows them well and who attended the clinic) will be invited to take part in separate interviews, scheduled to occur between their initial memory clinic appointment and the follow up appointment to receive a formal diagnosis.

The interviews are expected to last for approximately 30 - 45 minutes each and will be recorded. The interviews will focus on the participant's experience of symptom onset, coping strategies and their decisions to seek help from health care services.

Who is eligible to take part?

Patients who attended for a memory assessment with their significant other, are being asked to take part. Participants who are eligible to participate will be;

- Aged over 65 years and English speaking,
- Presenting with symptoms characteristic of early stage Alzheimer's disease or vascular dementia,
- Able to recall the period of initial symptom onset and judged by the memory clinic clinician to be able to provide informed consent to participate.

Patients will be excluded from participation, who present with;

- Symptoms characteristic of moderate to severe dementia, fronto-temporal lobar degeneration, young onset dementia,
- Significant co-morbid mental health difficulties which impact upon their functioning,
- Aphasia or verbal communication difficulties,
- Inability to recall the period preceding diagnosis or provide informed consent to participate,
- No significant other to validate the pre-diagnostic period.

What do I need to do?

If you have assessed an individual who meets the criteria for the study, please provide the participant information sheet at the end of their initial appointment. If the patient and their significant other are interested in participating, please provide the memory clinic contact details for them to contact me (at the end of the participant sheet) or alternatively take their contact details and I can arrange to contact them to discuss the study.

If the participant is interested at the time of receiving the information sheet, please refer to the available interview times and provide the dyad with an appointment for a suitable date.



Alternatively I will arrange an appointment for the interviews at a time when the patient and their significant other can attend before their next memory clinic appointment. When we meet I will ask them to sign a consent form to show that they have read and understood the information provided to them and that they agree to take part in the study. I will ask their significant other to complete a consent form also.

Do patients have to take part?

No, patients and their significant other's do not have to take part and deciding not to take part will not affect their care in any way. Participants can withdraw from the study at any point without this affecting their care.

What information will be available to the service?

The service will be provided with a letter indicating the patient and their significant other have consented to take part in the study. I will contact the service after the participant's interview to obtain their cognitive assessment score (ACE-III, or MoCA, or equivalent), the outcome of their memory assessment and any arising diagnosis. The information from the interviews will be anonymised and therefore individual outcomes from the interviews will not be shared with the team. However, I will contact the service if any information arose from the interviews which led me to become concerned about the participant, their significant other or someone else who was at risk of harm.

What will happen to the participant information?

The interviews will be recorded. The recordings will be transcribed, anonymised then destroyed. The anonymous transcripts will be stored on an encrypted password protected computer. Only my supervisors (2 Psychologists working for the University and NHS Greater Glasgow and Clyde) and I will have access to the recordings. The information will be analysed and presented in the form of a report and submitted to the University of Glasgow in part fulfilment of Doctorate in Clinical Psychology and for publication in a scientific



journal. Within the report, anonymous quotes of what participants have said may be used. Participants will be provided with a summary of the results if they wish.

Are there any benefits to participants taking part?

There are no direct benefits to the participants if they take part in this study. However, the information that is provided may contribute to our understanding of how people experience memory problems, in particular how and when people decide to access memory clinic services. If this study is published in a scientific journal, it would contribute to the wider research literature and could contribute to developments in the psychological care of patients and their families.

Are there any down sides to participants taking part?

It is possible that the discussions may trigger upsetting thoughts or feelings that may be difficult for the participants to talk about. If this is the case, and the participant wishes to stop, they can end the interview at any time. If they need a break during the interview this is okay. If they wish to discuss any concerns raised with the Memory Clinic team, this can be arranged.

Who has reviewed the study?

The study has been approved by the University of Glasgow, the West of Scotland Research Ethics Committee 3 and the NHS Greater Glasgow and Clyde Research and Development Team.

Appendix 2.3: Participant Information Sheet



Participant Information Sheet

Title of Project: Exploring Patient and Carer Experiences of Early Cognitive Decline

This leaflet has been given to you by the Clinician at the Outpatient Memory Clinic, on behalf of Melanie Young. I would like to ask you to take a few minutes of your time to read over this information sheet. I am a Trainee Clinical Psychologist with the University of Glasgow. As part of my Doctorate in Clinical Psychology I am undertaking a research project in partnership with the Outpatient Memory Clinics in NHS Greater Glasgow & Clyde. I am contacting you to ask you to take part in a research study.

This sheet is designed to give you all of the information that you will require to make this decision. I have tried to answer any obvious questions that you may have, but if you would like to discuss any aspect of the study further, please do not hesitate to contact me.

Melanie Young
Trainee Clinical Psychologist
Mental Health and Wellbeing, The University of Glasgow,
Gartnavel Royal Hospital Academic Centre, Great Western Road, G12 0XH
Telephone: 01389 812 032, Email: m.young.2@research.gla.ac.uk

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Exploring Patient and Carer Experiences of Early Cognitive Decline; Participant Information Sheet Version 8 (09.07.2015)

**What is the study about?**

I am interested in hearing about patient and their family/ friend's experiences of memory problems. In particular, I am interested in the experience of early memory problems and how patients and their family cope with this.

Why are we being asked to take part?

You and your family or friend (a person who knows you well) are being asked to take part because you have reported having memory problems and have both attended the Outpatient Memory Clinic.

Do we have to take part?

No, you and your family / friend do not have to take part and deciding not to take part will not affect your care in any way. You can withdraw from the study at any point without this affecting your care.

What would we have to do?

You and your family / friend will be invited to take part in separate interviews at your local memory clinic with Melanie Young, who is conducting the research. If you are unable to attend the memory clinic, arrangements can

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Exploring Patient and Carer Experiences of Early Cognitive Decline; Participant Information Sheet Version 8 (09.07.2015)



also be made to visit you at home. The interviews are expected to last for approximately 30 - 45 minutes each. The interviews will be recorded. The information that you provide in the interview will not be shared your significant other. You will have the option to schedule the appointments consecutively on the same day. You may wait in the waiting area, while each other completes their interview. Refreshments will be provided. Participating in the research may take up to 2 hours, 20 minutes in total.

Who would know we were taking part?

The memory clinic would know that you were taking part in the study but the information that you provided would be anonymised so that no one would be able to identify you or your significant other. I would need to know your name and address to be able inform the team that you are taking part and to obtain the outcome of your memory assessment. I would only have to break this confidentiality if I became concerned that you, your family member or someone else was at risk of harm. In these circumstances, I would need to share my concerns but I would tell you before I did this.



What will happen to the information my family member and I provide?

The interviews will be recorded. The recordings will be transcribed, anonymised then destroyed. The anonymous transcripts will be stored on an encrypted password protected computer. Only my supervisors (two psychologists working for the University and NHS Greater Glasgow and Clyde) and I will have access to the recordings. The information will be analysed and presented in the form of a report and submitted to the University of Glasgow in part fulfilment of Doctorate in Clinical Psychology and for publication in a scientific journal. Within the report, anonymous quotes of what you have said may be used. All participants will be provided with a summary of the results if they wish.

Are there any benefits to taking part?

There are no direct benefits to you or your family member if you both take part in this study. However, the information that you provide will contribute to our understanding of how people experience memory problems, in particular how and when people decide to access memory clinic services. If this study is published in a scientific journal, it would contribute to the wider



research literature and could contribute to developments in the psychological care of patients and their families.

Are there any down sides to taking part?

It is possible that our discussion may trigger upsetting thoughts or feelings that may be difficult for you to talk about. If this is the case, and you wish to stop, you can end the interview at any time. If you need a break during the interview this is okay. If you wish to discuss any concerns raised with the Memory Clinic team, this can be arranged.

Who has reviewed the study?

The study has been approved by the University of Glasgow, the West of Scotland Research Ethics Committee 3 and the NHS Greater Glasgow and Clyde Research and Development Team.

What do I do now?

If you are interested in taking part in the study, please contact me directly or speak to the memory clinic staff who will pass on your contact details to me. If

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Exploring Patient and Carer Experiences of Early Cognitive Decline; Participant Information Sheet Version 8 (09.07.2015)



you would like to take part, it is important that you contact the memory clinic or myself before your next appointment. I will telephone you to answer any questions that you may have about the study and arrange an appointment for the interview at a time when you and your family member can attend that is planned before your next memory clinic appointment. When we meet I will ask you to sign a consent form to show that you have read and understood the information provided to you and that you agree to take part in the study. I will ask your family member to complete a consent form also.

If you have any further questions?

We will give you a copy of the information sheet and signed consent form to keep. If you would like more information about the study and wish to speak to someone not closely linked to the study, please contact Professor Tom McMillan, Professor of Clinical Neuropsychology, Institute of Health and Wellbeing, University of Glasgow. Telephone: 0141 211 0356.

If you would like to make a complaint about the study?

If you would like to make a complaint about any aspect of the study, please contact Melanie Young, Trainee Clinical Psychologist. The NHS Greater



Glasgow & Clyde Complaints Service is available for information and advice on procedures, Telephone 0141 201 4500, Email complaints@ggc.scot.nhs.uk

Thank you for taking the time to read this information sheet.

Appendix 2.4: Participant Consent Form (Patient)



Participant Consent Form

Title of Project: Exploring Patient and Carer Experiences of Early Cognitive

Decline

Name of Researcher: Mrs Melanie Young

Please initial each box:

I confirm that I have read and understood the participant information sheet (Version 8, 09.07.2015) for the above study, and I have had the opportunity to ask questions.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

☐

I understand that my interview will be recorded, transcribed and anonymised quotes may be used in the final report.

☐

I understand that it may be necessary for representatives from the University of Glasgow or NHS Greater Glasgow & Clyde to inspect my records to ensure the research is being conducted properly.

☐

I understand that my medical care or legal rights will not be affected by taking part.

☐

Please turn over



Participant Consent Form Continued

Please initial each box:

I understand that my memory assessment and any subsequent diagnosis or treatment will not be delayed by taking part in the study.

☐

I agree to take part in the above study.

☐

I would like to receive a summary of the outcomes of the study

☐

Name of participant

Date

Signature

Name of researcher

Date

Signature

1 copy to researcher, 1 to participant, 1 to hospital records.

Appendix 2.5: Participant Consent Form (Significant Other)



Participant Consent Form (Significant Other)

Title of Project: Exploring Patient and Carer Experiences of Early Cognitive

Decline

Name of Researcher: Mrs Melanie Young

Please initial each box:

I confirm that I have read and understood the participant information sheet (Version 8, 09.07.2015) for the above study and I have had the opportunity to ask questions.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

☐

I understand that my interview will be recorded, transcribed and anonymised quotes may be used in the final report.

☐

I understand that it may be necessary for representatives from the University of Glasgow or NHS Greater Glasgow & Clyde to inspect my records to ensure the research is being conducted properly.

☐

I understand that my medical care or legal rights will not be affected by taking part.

☐

Please turn over



Participant Consent Form Continued

Please initial each box:

I agree to take part in the above study.

☐

I would like to receive a summary of the outcomes of the study

☐

Name of participant

Date

Signature

Name of researcher

Date

Signature

1 copy to researcher, 1 to significant other, 1 to participant hospital records.

Appendix 2.6: Participant Questionnaire



Participant Questionnaire

Title of Project: Exploring Patient and Carer Experiences of Early Cognitive Decline

Name of Researcher: Mrs Melanie Young, Trainee Clinical Psychologist

Thank you for participating in this research project. To be able to describe participants in this study please complete the following questions. Your answers will remain anonymous.

Participant _____ Patient / Significant Other _____

Relationship to other Participant _____

Gender _____ Male / Female _____

Age _____

Occupation _____

To be completed by researcher (patient's only)

Memory Assessment Used _____ Score _____

Memory Clinic Assessment Outcome _____

Any resulting diagnosis _____

Appendix 2.7: Letter to Memory Clinic Team



Mental Health and Wellbeing,
The University of Glasgow,
Gartnavel Royal Hospital Academic Centre,
1055 Great Western Road,
Glasgow G12 0XH

Date

Memory Clinic Clinician
Cairnmhor Resource Centre,
Dumbarton Joint Hospital,
Cardross Road
Dumbarton

Dear Memory Clinic Clinician,

RE: Patient Name, Patient Address

The above named patient and their significant other, Name, have consented to participate in the research study "Exploring Patient and Carer Experiences of Early Cognitive Decline." The project is being conducted by Melanie Young Trainee Clinical Psychologist, in part fulfilment of the Doctorate in Clinical Psychology.

The patient and their significant other have now completed a qualitative interview as part of the research. The patient has consented to Melanie Young requesting the memory clinic assessment outcome from their memory clinic clinician. The patient's participation does not involve any on-going monitoring or research procedures.

If you require any further information in relation to the study, please do not hesitate to contact me,

Yours Sincerely,

Melanie Young
Trainee Clinical Psychologist

Appendix 2.8: Interview Schedule



Interview Schedule

Title of Project: Exploring Patient and Carer Experiences of Early Cognitive Decline

Name of Researcher: Mrs Melanie Young, Trainee Clinical Psychologist

1. Can you tell me about the **first experiences** of your/ your family member's memory problems?

Prompts

- *What symptoms did you notice first?*
 - *Forgetfulness*
 - *Word finding / calculation difficulties*
 - *Difficulty with new tasks*
 - *Difficulty with usual activities*
 - *Reduced participation with activities and with others*
 - *Personality changes*
 - *Changes in mood*
 - *Problems driving*
- *Was the onset gradual or occur suddenly?*
- *Were there any other symptoms?*
- *How did you react?*
- *How did it feel?*
- *What was the most difficult aspect of the symptoms?*
- *Did you speak to anyone / your family?*

2. What did you think your **first symptoms were related to?**

Prompts

- *What did you link / attribute your symptoms to?*
 - *Normal aging*
 - *Co-morbid physical or mental health problems*

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Exploring Patient and Carer Experiences of Early Cognitive Decline Interview Schedule Version 3 (08/10/2013)

- Contextual factors
- Dementia

- What did you think was happening?
- What was your understanding of the symptoms / memory problems?
- What **concerns**, did you have about the first symptoms?
- What were your main fears / worries?
- Where did get information and support from?

3. How did you **respond to / cope** with the symptoms?

Prompts

- Did you use any strategies to cope with or monitor the problems?
- Did you talk to anyone else?
- How long were the symptoms present before you talked to someone?

4. Can you tell me about your experience of **seeking help/ advice** from the health service?

(i) What **triggered** you to seek help?

Prompts

- What happened?
- What did you do?
- How did you feel?
- Did you seek formal help straight away? Did you delay?

(ii) What happened when you **contacted the service**?

Prompts

- What response did you receive from expressing your concerns?
- What was the process from attending GP to attending memory clinic?

5. What has been your experience of **accessing the memory clinic** service?

Prompts



- *Would you do anything differently?*
- *Have your views on your memory problems changed since attending the service?*
- *What advice would you give others in your situation?*

Appendix 2.9: Approval Letter WoSREC

WoSRES
West of Scotland Research Ethics Service



**AMENDED LETTER – THIS SUPERSEDES
LETTER ISSUED ON 15TH JANUARY 2014**

West of Scotland REC 3
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhs.gov.uk

Dr Alison Jackson
University Teacher / Academic Tutor (Mental
Health and Wellbeing)
The University Of Glasgow
Mental Health and Wellbeing
Gartnavel Royal Hospital Academic Centre
1055 Great Western Road
Glasgow
G12 0XH

Date 20th February 2014
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 1847
E-mail WOSREC3@ggc.scot.nhs.uk

Dear Dr Jackson

Study title:	An Exploration of the Factors Influencing Patient and Carer Attendance at Memory Screening Clinics
REC reference:	13/WS/0315
IRAS project ID:	136277

Thank you for your letter of 06 January 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Lead Reviewer.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Liz Jamieson, Liz.Jamieson@ggc.scot.nhs.uk.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on **applying for NHS permission for research** is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but **for non clinical trials this is not currently mandatory.**

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. **Guidance on where to register is provided within IRAS.**

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
GP/Consultant Information Sheets	3	19 August 2013
Interview Schedules/Topic Guides	3	08 October 2013
Investigator CV		27 November 2013
Letter of invitation to participant	2	20 November 2013
Letter to Memory Clinic Team	3	20 November 2013
Other: CV Student		27 November 2013
Other: Plain English Summary	2	04 January 2014
Participant Consent Form	5	04 January 2014
Participant Consent Form: Significant Other	5	04 January 2014
Participant Information Sheet	7	04 January 2014
Protocol	7	13 January 2014
Questionnaire	2	04 January 2014
REC application		26 November 2013
Referees or other scientific critique report		05 June 2013
Response to Request for Further Information		06 January 2014
Summary/Synopsis	2 Recruitment	27 November 2013
Summary/Synopsis	1 - Summary	13 April 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/WS/0315

Please quote this number on all correspondence

We are pleased to welcome **researchers and R & D staff at our NRES committee members'** training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



Liz Jamieson
Committee Co-ordinator
On behalf of Dr Adam Burnel, Chair

Enclosures: 'After Ethical Review – Guidance for Researchers'
Copy to: Emma Jane Gault, University of Glasgow
Dr Erica Packard, NHS Greater Glasgow and Clyde

Appendix 2.10: Approval Letter NHSGG&C Board R&D



Coordinator/Administrator: Dr Erica Packard/Mrs Elaine O'Neill
Telephone Number: 0141 211 9448
E-Mail: erica.packard@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

R&D Management Office
Western Infirmary
Tennent Institute
1st Floor 38 Church Street
Glasgow, G11 6NT,

24 February 2014

Dr Cerys MacGillivray
Consultant in Clinical Psychology
Cairnmhor Resource Centre
Dumbarton Joint Hospital
Cardross Road
Dumbarton G82 5JA

NHS GG&C Board Approval

Dear Dr MacGillivray,

Study Title:	An Exploration of the Factors Influencing Patient and Carer Attendance at Memory Screening Clinics
Principal Investigator:	Dr Cerys MacGillivray
GG&C HB site	Dumbarton Joint Hospital & Hardgate Clinic
Sponsor	NHS Greater Glasgow and Clyde
R&D reference:	GN13 CP557
REC reference:	13/WS/0315
Protocol no:	V7; 13.01.2014

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
 - a. During the life span of the study GGHB requires the following information relating to this site
 - i. Notification of any potential serious breaches.
 - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

2. **For all studies** the following information is required during their lifespan.
 - a. Recruitment Numbers on a monthly basis
 - b. Any change of staff named on the original SSI form
 - c. Any amendments – Substantial or Non Substantial
 - d. Notification of Trial/study end including final recruitment figures
 - e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,



Dr Erica Packard
Research Co-ordinator

Cc: Ms Melanie Young (University of Glasgow)
Dr Alison Young (University of Glasgow)

Appendix 2.11: Major Amendment 01: WOSREC Approval

WoSRES
West of Scotland Research Ethics Service



West of Scotland REC 3
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhs.gov.uk

Dr Alison Jackson
University Teacher / Academic Tutor (Mental
Health and Wellbeing)
The University Of Glasgow
Mental Health and Wellbeing
Gartnavel Royal Hospital Academic Centre
1055 Great Western Road
Glasgow
G12 0XH

Date 22nd May 2015
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 1847
E-mail WOSREC3@ggc.scot.nhs.uk

Dear Dr Jackson

Study title: An Exploration of the Factors Influencing Patient and Carer Attendance at Memory Screening Clinics
REC reference: 13/WS/0315
Amendment number: AM01
Amendment date: 12 May 2015
IRAS project ID: 136277

The above amendment was reviewed by the Sub-Committee in correspondence. The amendment covered the following:

Document	Version Number	Date	REC Changes Made
Project Proposal (MRP)	V8	07.05.2015	<input type="checkbox"/> Where ACE-III is noted, now replaced with, "ACE-III, or MoCA, or equivalent assessment", has been added. <ul style="list-style-type: none"> In Measures section, additional information on the MoCA has been added. <input type="checkbox"/> Appendices updated with MoCA Included
Staff Information Sheet	V4	07.05.2015	Where ACE-III is noted, now replaced with "their cognitive assessment score (ACE-III, or MoCA, or equivalent)",
Participant Questionnaire	V3	07.05.2015	"ACE-III Score" replaced with "Memory Assessment Used Score.....".
Recruitment Flow Diagram	V3	07.05.2015	Where ACE-III is noted, the recording of the "MoCA or equivalent assessment," has been added.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering letter on headed paper		08 May 2015
Notice of Substantial Amendment (non-CTIMP)	AM01	12 May 2015
Participant information sheet (PIS) [Staff]	4	07 May 2015
Research protocol or project proposal	8	07 May 2015
Summary, synopsis or diagram (flowchart) of protocol in non technical language	3	07 May 2015
Validated questionnaire	3	07 May 2015

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

13/WS/0315: Please quote this number on all correspondence

Yours sincerely



Liz Jamieson
REC Manager
On behalf of Eoin MacGillivray, Vice Chair

Enclosures: List of names and professions of members who took part in the review

Copy to: Dr Erica Packard, Research & Development Management Office, NHS Greater Glasgow & Clyde,

Appendix 2.12: Major Amendment 01: NHS GG&C Research & Development Approval

R&D Ref: GN13CP577 - SA01 - R&D Acknowledgement

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R&D Ref: GN13CP577 - SA01 - R&D Acknowledgement

Reid, Lorraine [Lorraine.Reid2@ggc.scot.nhs.uk]

Sent: 02 June 2015 16:57

To: MacGillivray, Cerys [Cerys.MacGillivray@ggc.scot.nhs.uk]

Cc: Emma-Jane Gault; Melanie Young; Alison Jackson

Dear Dr MacGillivray

R&D Ref: GN13CP577

Ethics Ref: 13/WS/0315

Chief Investigator: Dr Alison Jackson

Project Title: An Exploration of the Factors Influencing Patient and Carer Attendance at Memory Screening Clinics

Protocol Number: V8 dated 07/05/15

Amendment Ref: SA01 dated 07/05/15

Sponsor: NHS GG&C Health Board

I am pleased to inform you that R&D have reviewed the above study Amendment and can confirm that Management Approval is still valid for this study.

Reviewed Documents:	Version	Dated
Cover Letter	---	08/05/15
Notice of Amendment	V4.0	12/05/15
REC favourable opinion letter	---	22/05/15
Protocol	V8	07/05/15
Staff Information Sheet	V4	07/05/15
Participant Questionnaire	V3	07/05/15
Recruitment Flow Diagram	V3	07/05/15

I wish you every success with this research project.

Yours sincerely

Lorraine

Lorraine Reid
Senior Research Administrator
Research & Development
R&D Management Office
1st Floor, Tennent Institute
Western Infirmary
Glasgow
G11 6NT
Tel: 0141 211 1743
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Live in Scotland? Join SHARE and help us improve Scottish Health: <http://www.registerforshare.org/>

SHARE is an important initiative to establish a register of people interested in participating in health research across Scotland, and it is very important that we advertise it as much as possible. If you could also access the website and register your details it would be very helpful.

"Please note that from the 27th May 2013 R&D will be operating an electronic record system. Please submit your study documents via e-mail or IRAS from this date."

 www.nhsggc.org.uk/r&d

NHSGG&C Disclaimer

<https://mail.student.gla.ac.uk/owa/?ae=Item&t=IPM.Note&id=RgAAAADjX%2bQE...> 11/09/2015

Appendix 2.13: Major Amendment 02: WoSREC Approval

WoSRES
West of Scotland Research Ethics Service



West of Scotland REC 3
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhs.gov.uk

Dr Alison Jackson
University Teacher / Academic Tutor (Mental
Health and Wellbeing)
The University Of Glasgow
Gartnavel Royal Hospital
Academic Centre
1055 Great Western Road
Glasgow G12 0XH

Date 17th July 2015
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 1847
E-mail WOSREC3@ggc.scot.nhs.uk

Dear Dr Jackson

Study title:	An Exploration of the Factors Influencing Patient and Carer Attendance at Memory Screening Clinics
REC reference:	13/WS/0315
Amendment number:	AM02
Amendment date:	16 July 2015
IRAS project ID:	136277

Thank you for submitting the above amendment, which was received on 17 July 2015. I can confirm that this is a valid notice of a substantial amendment and will be reviewed by the Sub-Committee of the REC at its next meeting.

The amendment covers the following:

- 1) The project seeks authorisation to conduct the research interviews in the participant's home. This change is only applicable to those participants who have been seen at home by the memory clinic team as a result of the participant being unable to attend the memory clinic. This will allow potential participants who would otherwise meet the inclusion criteria, to participate in the research. The amendment does not alter the procedure of the study, and does not alter the participant's usual care. Sections A62, A13, A18 and A26 of the Application Form are affected.
- 2) The study also seeks to recruit participants from four additional memory clinic sites in NHS Greater Glasgow and Clyde. Individual SSI forms will be submitted to R&D to take account of this change. Sections A18 and Section C of the Application Form are affected.
- 3) In order to recruit the required number of participants, the project seeks to extend the REC authorisation to extend the project to 31st March 2016. Section A69-1 of the Application Form is affected. It is envisaged that these changes will enable the required number of participants to be recruited to the study.

Documents received/...

The documents to be reviewed are as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper		17 July 2015
Notice of Substantial Amendment (non-CTIMP)	AM02	16 July 2015
Participant consent form	6	09 July 2015
Participant consent form [Significant Other]	6	09 July 2015
Participant information sheet (PIS)	8	09 July 2015
Participant information sheet (PIS) [Staff]	5	09 July 2015
Research protocol or project proposal	9	09 July 2015

Notification of the Committee's decision

The Committee will issue an ethical opinion on the amendment within a maximum of 35 days from the date of receipt.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval for the research.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

13/WS/0315:	Please quote this number on all correspondence
-------------	-------------------------------------------------------

Yours sincerely



Liz Jamieson
REC Manager

Copy to: Ms Emma-Jane Gault, University of Glasgow
Melanie Young, Trainee Clinical Psychologist

Appendix 2.14: Major Amendment 02 NHS GG&C Research & Development Approval

RE: R&D Ref: GN13CP577 - SA02 - R&D Acknowledgement

Page 1 of 2

RE: R&D Ref: GN13CP577 - SA02 - R&D Acknowledgement

McGarry, Joanne [Joanne.McGarry@ggc.scot.nhs.uk]

Sent: 17 September 2015 11:20

To: Reid, Lorraine [Lorraine.Reid@ggc.scot.nhs.uk]; MacGillivray, Cerys [Cerys.MacGillivray@ggc.scot.nhs.uk]

Cc: Emma-Jane Gault; Melanie Young; Alison Jackson

Dear Dr MacGillivray,

R&D Ref: GN13CP577

Ethics Ref: 13/WS/0315

Chief Investigator: Dr Alison Jackson

Project Title: An Exploration of the Factors Influencing Patient and Carer Attendance at Memory Screening Clinics

Protocol Number: V9 dated 09/07/15

Amendment Ref: SA02 dated 09/07/2015

Sponsor: NHS GG&C Health Board

I am pleased to inform you that R&D have reviewed the above study Amendment and can confirm that Management Approval is still valid for this study.

Reviewed Documents:	Version	Dated
Cover Letter	---	17/07/15
Notice of Amendment	V4.0	09/07/15
REC favourable opinion letter	---	22/07/15
Protocol	V9	09/07/15
Staff Information Sheet	V5	09/07/15
Participant Consent Form	V6	09/07/15
Significant other Consent form	V6	09/07/15
SSI Form: Shawmill Mental Health Resource Centre	V4	17/07/15
SSI Form: Parkview Mental Health Resource Centre, Elderpark Clinic, Eastwood Mental Health Resource Centre	V4	31/08/15
Belmont Centre	V4	17/07/15

I wish you every success with this research project.

Yours sincerely

Joanne

Joanne McGarry
Academic Research Coordinator
Research and Development Directorate
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38 Church Street
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Please note my working hours are Tues - Fri 8am - 2pm

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Tel: +44 (0)141 211 2142

<https://mail.student.gla.ac.uk/owa/?ae=Item&t=IPM.Note&id=RgAAAADjX%2bQE...> 17/09/2015

Appendix 2.15: Interpretative Phenomenological Analysis, Analytic Procedure (Smith, Flowers and Larkin, 2013)

Stage	Process
1. Reading and re-reading	To ensure the participant becomes the focus of the analysis, the process begins by immersing oneself in the individual's account. Repeated reading of the account allows for active engagement with the data. The analysis may include noting of striking observations and understand the narratives that serve to bind the interview.
2. Initial Noting	The analyst remains open to the content of the transcript and engages in a process of recording exploratory comments by making descriptive, linguistic and conceptual comments throughout the entire transcript. Personal reflection is used to consider influences to the conceptual level of analysis.
3. Developing Emergent Themes	Using the exploratory comments to develop themes of the data. The themes reflect both the participant's words and the analyst's interpretation of the data.
4. Searching for Connections across Emergent Themes	The analyst charts or maps the themes to understand how they link together. This can include techniques of abstraction, subsumption, polarisation, contextualisation, numeration and function. The analyst may then use a graphic or table to represent the structure of emergent themes.
5. Moving to the Next Case	The analytic process is repeated, ensuring each account is treated on its own terms, sectioning off the emergent themes from the original transcript while working on the current account.
6. Looking for Patterns across Cases	The analyst moves across each set of emergent themes, looking for links and commonalities between them. The process may highlight higher order qualities as well as idiosyncratic instances. The final result of themes is presented in a graphic or table showing the connections for the group as a whole.

Appendix 2.16: Selected Transcript Extracts

Sample coded interview transcript; Patient - Steven

Emergent Themes	Original Transcript	Exploratory Comments
	347 Int: And how are you feeling about your memory changes?	
Changes in memory cause low mood and frustration	348 S: well eh a bit cheesed off [pause], should I use the word 349 depressed? Eh, I, I'm pretty cheesed off that I do forget things.	<i>"cheesed off" – repetition, emphasising frustration, forgetting causes significant impact on his mood</i>
Memory problems often most annoying part of life	350 The person that annoys me the most in this world is me, because 351 of that, and because, I've said that before, and I actually mean it.	Memory problems are the most annoying aspect of his life <u>Is this something that is repeatedly on his mind?</u>
Memory problems lead to worry about being viewed negatively by others	352 I get more irritated with my own feeling like that than eh, other 353 people forget things or annoy me in other ways and I just think, 354 "oh he's an idiot." That doesn't really bother me if he's an idiot, 355 but it does bother me if I'm an idiot.	Feels irritated. <i>"doesn't bother me,"</i> minimises concerns related to other's behaviour <u>Is personal concern related to other people viewing him negatively? Idiot – fear for the future?</u>
	356 I: Mmm uhuh. So it is bothering you at the moment?	
Memory problems are troublesome as there is nothing that can be done	357 S: Yes it bothers me that eh, it kind of lands me in the soup 358 occasionally and eh, you know as far as I understand there is 359 nothing that can be done about it.	<i>"lands me in the soup"- in trouble? In a bad situation?</i> Few interventions to help memory
Family history prompts symptom monitoring	359 The other relevant thing about it all was that my late mother had 360 the same condition, starting at approximately the same age.	Familial history of dementia. <u>Is his age a trigger for monitoring himself?</u>
	361 I: Right	
Family history triggers desire to avoid the same path	362 S: And she, she declined over a dozen years and eventually went 363 totally doolally. Which is a situation I certainly do not envy.	Disease progression was over many years. <i>"totally doolally" completely lost her mind</i> No desire to repeat mother's illness

Sample coded interview transcript; Significant Other - Helen

Emergent Themes	Original Transcript	Exploratory Comments
Memory problems trigger search for understanding	280 H:So, I probably did write a lot off to that, but then it gets to the 281 stage where you just think, you can't keep saying it, that her bad 282 memory is cause of that,	<i>"write a lot off to that" - disregards problem.</i> Considering whether poor memory is better attributed to other causes.
Declining memory is expected with normal ageing	282 and I know that your memory does get 283 worse, I mean I know my memory's is getting worse, and I'm only 284 42 and I do try and exercise my memory you know.	Description of ageing beliefs; <u>is she comparing her functioning to her mother's as a representation of what is abnormal?</u>
Memory and calculation exercises prevent cognitive decline	285 I even do things like, even exercise my brain in every way like at 286 work rather that use my calculator to count up all the money at 287 the end I try and use my mind to do it.	<i>"exercise my brain" – implies maintaining health.</i> Strategy to keep mind active: <u>Does she believe this will avoid future decline?</u>
Exercising memory prevents decline in older age	287 I just think your brain is a kind of a muscle and I suppose in a way 288 you just have to keep using it to keep it healthy and keep it 289 working and I try and do that and I know that obviously as you get 290 older your memory does get worse, especially and I don't think my 291 mum does exercise her memory or her brain.	<i>"Kind of a muscle" - brain requires stimulation to promote health.</i> Beliefs of normal ageing. Contrasts between her use of exercises and her mum's; <u>does she think lack of exercise contributed to her mother's decline?</u>
Reading keeps the brain active	292 She does read, she reads a lot, and I guess that's a way of, apart 293 from that she doesn't really, I don't think she really exercises her 294 brain very much, maybe that's caused the deterioration in 295 memory as well,	Mother exercises her brain through reading: <u>is this an overt decision to keep reading?</u> Absence of activity to stimulate her mother's memory: <u>is she seeking a specific cause?</u>
Forgetting causes increased concern for decline	295 emm but it was more the fact that I had just dropped my son and 296 the dog off and literally eight, nine hours later my mum's 297 expecting me home and I'd told her I wouldn't be home, that was 298 when I started to really, to really start to think about it and think 299 right, something is not quite right here.	Care arrangements for son a trigger for greater monitoring; <u>has the time between prompting become smaller?</u> <i>"really, to really start" emphasis on effort to consider changes.</i>

(Pink: patient themes; Purple: significant other's subordinate themes)

(Pink: patient themes; Purple: significant other's subordinate themes)



Appendix 2.18 Participant Representation across Themes

	Participant pseudonym	Inevitability of Ageing			Problem Awareness				Living with forgetting				Disclosure to Others		How am I going to be today?	
Dyad 1	Claire	2		1	1	1	1		1	1		1	1			10
	Alan	1		1	1			1				1	2			7
Dyad 2	Beth	1	1						1	1	1	2	1			8
	Tommy		2				1	1	1					1		6
Dyad 3	Steven			1	1			2		1		1	1		1	8
	Nancy		1	1	1		1					1	1			6
Dyad 4	Susan	2	1					1	1	1	1			1		8
	Helen		2		1	1			1	1		1	1	1	1	10
Dyad 5	Colin			1	1	1				1	1	1			2	8
	Sandra			1		1	1	1						1		5
Total Quotes		6	7	6	6	4	4	6	5	4	5	8	7	4	4	