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Young Onset Dementia as Experienced by Family Members

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

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Table of Contents

Chapter 1: Systematic Review	4
<i>The Experiences and Needs of Children and Young Adults with a Parent with Young Onset Dementia: A Systematic Review</i>	
Abstract.....	5
Introduction.....	7
Method.....	9
Figure 1 Search Process.....	11
Results.....	13
Table 1 Study Characteristics and Themes.....	14
Figure 2 Overarching Analytical Themes Derived from Data Synthesis.....	17
Discussion	24
References	34
Chapter 2: Major Research Project	38
<i>Partners' Experiences of the Pre-Diagnostic Phase of Young Onset Dementia</i>	
Plain English Summary	39
Abstract.....	41
Introduction.....	43
Method.....	45
Table 1 Sample Characteristics	47
Results.....	49
Table 2 Superordinate and Subthemes	50
Discussion	59
References	68
Appendices	74
Appendix 1: Manuscript Submission Guidelines	74
Appendix 2: Search Strategy	82
Appendix 3: CASP Qualitative Checklist	85
Appendix 4: Quality Ratings with CASP Qualitative Checklist	91
Appendix 5: Ethical Approval Documents.....	92
Appendix 6: Participant Information Sheet	99
Appendix 7: Participant Consent Form	103
Appendix 8: Interview Schedule.....	105
Appendix 9: Sample Transcript.....	107
Appendix 10: Sample Theme and Exemplar	108
Appendix 11: Research Proposal	110

Chapter 1: Systematic Review

The Experience and Needs of Children and Young Adults with a Parent
with Young Onset Dementia: A Systematic Review.

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Abstract

Introduction

Young onset dementia (YOD) occurs before the age of 65. A growing body of literature suggests that YOD can lead to emotional and psychological issues for the children of those affected. This review synthesises the qualitative research in relation to the lived experiences of the children of those diagnosed with YOD.

Method

A systemic search of Embase, Medline, CINAHL, PsycINFO and hand searching of reference lists was conducted, to identify relevant qualitative studies. Following this, 2392 records were screened for eligibility and 8 studies were identified for the review. Findings were extracted and synthesised using thematic synthesis.

Results

Three central interrelated themes were identified: *'psychological impact and coping: challenges and positives'*, *'transformation of family relationships'* and *'interactions with the wider support system'*

Conclusions

The studies synthesised provide a rich account of the psychosocial experiences of the children of a parent with YOD. Findings are generally consistent with existing research around other dementia types and young carers, whilst also highlighting contrasting findings which emphasise the unique nuances of the experiences of this group. The children of those with YOD face a combination of complex and interacting challenges including an increased 'parental role' for their parent combined with decreased social

support and high levels of societal stigma. The review highlights directions for future research and implications for service delivery, including service provision that is tailored to the needs of the whole family.

Introduction

Young onset dementia (YOD) is defined as dementia occurring before the age of 65 (WHO, 2012), estimated to form around 5% of all dementia diagnoses (Prince et al., 2014). YOD has been characterised by more neuropsychiatric symptoms, such as changes in social-emotional behaviour and insight, than late onset dementia (LOD) (Mendez, 2006). This helps explain why time taken to diagnosis in YOD can be lengthy and initial misdiagnosis common (Van Vliet et al., 2013). Those with YOD are often employed and caring for young children, therefore disease timing and the long route to diagnosis can have a significant impact on family functioning. Studies have highlighted tension among family members and increased marital separation (Van Vliet et al., 2011).

Most of the research related to the impact of YOD has focused on the person with YOD or their partner or carer (Spreadbury & Kipps, 2019). Despite this, a small, growing body of research suggests YOD can lead to emotional and psychological issues for the children of those affected (Hutchinson et al., 2016). The current literature on children of those with YOD encompasses a wide range of ages from 6 years old (Sikes & Hall, 2017) to adult children up to 37 (Barca et al., 2014), with studies including both adult and younger children in their samples (Gelman & Rhames, 2018; Millenaar et al., 2014; Allen et al., 2009). There is no clear consensus of when a child becomes an adult and it has been argued that the current social context, where young people more commonly live at home with parents up until their 30s, challenges traditional ideas around transition to adulthood (Pollock, 2008).

For the children of those with YOD, studies have highlighted increased stress within the family and negative emotions including anger, confusion and sadness (Rosenthal

et al., 2011). YOD can significantly affect transition to adulthood with a role reversal between parent and child that results in the young person prematurely taking on significant responsibility and caring duties (Johannessen et al., 2015). This can impact on educational attainment (Sikes & Hall, 2018) and adult children's lives are often significantly affected by assuming a caring role for their parent earlier than anticipated (Barca et al., 2014).

Services have traditionally been diagnosis-led and condition-specific, as opposed to encompassing the needs of the whole family (Denny et al., 2012). Millenaar et al. (2014) interviewed 15 children with a parent with YOD, describing the impact of YOD on daily life, coping with the disease and the need for care and support. Children described reluctance to seek professional support; however, particularly in the later stages of the disease, support from a professional knowledgeable about YOD was valued.

Qualitative evidence synthesis can inform service provision through exploring how people experience illness and interventions, as well as barriers and facilitators of accessing services (Booth et al., 2016). A small number of systematic reviews have synthesised experiences of those with YOD and their wider family (Cabote et al., 2015; Erskine, 2019). However, no systematic review was found specifically concerning the children of those with YOD. This group experience unique challenges compared to other family members and given the detrimental impact of YOD on children in terms of their wellbeing and educational attainment; synthesising qualitative research on experiences of children of those with YOD will help to deepen understanding and inform policy and service provision.

Aims

To synthesise qualitative research on the lived experiences of children of those diagnosed with YOD. Specifically, this review aimed to explore the psychosocial impact of a diagnosis of parental YOD on children.

Method

Search Strategy

During initial scoping, no existing reviews specific to experiences of children with a parent with YOD were found. Psychinfo, Medline, Embase and CINAHL were systematically searched up to 2nd December 2019. A university librarian was consulted on the development of the search strategy, which used the following search terms:

1. ("young* onset" OR "early onset" OR "early age" OR "working age" OR presenile) n3 (dementia OR alzheimer* OR frontotemporal)
OR
2. dementia OR alzheimer*
AND
3. parent* OR father* OR mother* OR family*
AND
4. child* OR son* OR daughter* OR adolescent* OR teenager* OR "young* people" OR "young* Person" OR "adult child*" OR carer* OR caregiver*
AND
5. experience* OR perspective* OR "lived experience*" OR view* OR qualitative OR "life experience*"
6. 1 OR 2 AND 3 AND 4 AND 5

Further details are noted in Appendix 2.

Eligibility

Inclusion Criteria

- Peer reviewed journal articles focusing on the experiences of those with a parent with YOD, including studies that included experiences of mixed family members, providing the experiences of children could be clearly distinguished and extracted.
- Written in English.
- Peer reviewed journal articles.
- Qualitative or mixed-methods research containing original qualitative data.

Exclusion Criteria

- Studies that include parents with late onset dementia.
- Articles that focus on parents with a cognitive impairment not related to dementia.

Procedure

Titles and abstracts were screened for relevance with duplicates removed. Full text articles were screened against inclusion and exclusion criteria. A hand search was carried out of the references of all included articles. Overall, eight papers were identified for inclusion. An overview is provided in Figure 1.

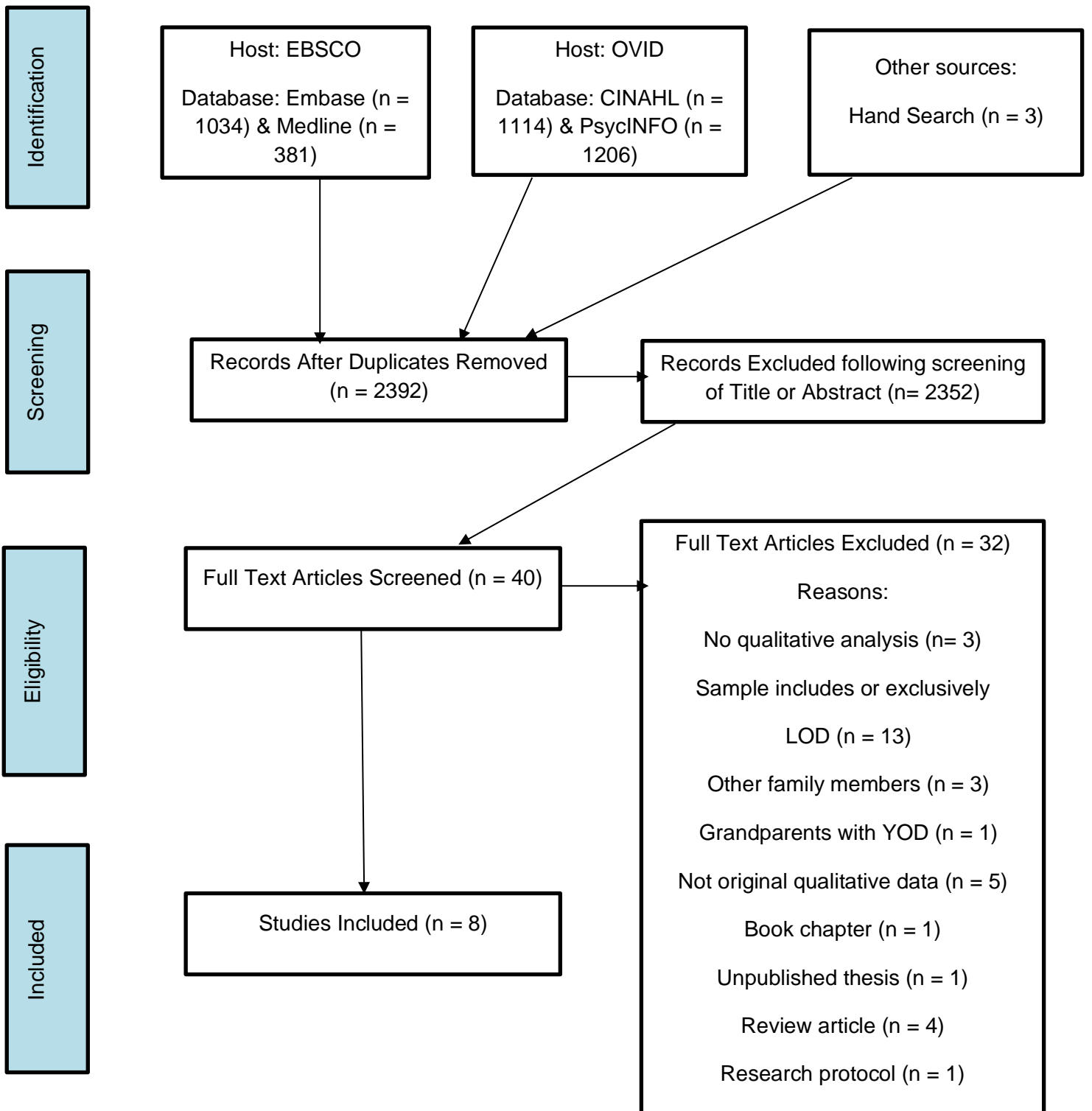


Figure 1. Search Process

Quality Appraisal of Included Studies

There is no consensus on evaluating quality of studies for qualitative synthesis (Sandelowski, 2015). Majid & Vanstone (2018) identified over 100 tools developed to appraise qualitative research. Their guidelines were used to select the Critical Appraisal Skills Programme (CASP) Qualitative Checklist (2018), chosen as appropriate for novice researchers and reportedly the most commonly used appraisal tool in qualitative evidence synthesis. An independent reviewer (trainee clinical psychologist) rated a sample of studies ($n = 3$); initial agreement was 90%. Discrepancies in ratings were discussed and resolved resulting in full agreement. Quality appraisal was not used to exclude studies based on a threshold but to interpret the possible impact of study quality on findings (Thomas & Harden, 2008).

Researcher Reflexivity

Thematic synthesis involves interpretation by the researcher and is influenced by the researcher's prior experiences and conceptions. The author was a trainee clinical psychologist, who had experience of assessing a patient with YOD with teenage children. The author was also conducting research exploring partners' experiences of the pre-diagnostic phase of YOD and this may have impacted on the interpretation of findings. A reflective diary and supervision were used to reduce bias through increasing awareness of reactions and reflections evoked during analysis.

Data Synthesis

Although the epistemological underpinnings of synthesis approaches are a contentious field, Barnett-Page and Thomas (2009) argue that approaches including thematic synthesis are more directly relevant to inform policy and practice because

results are reproducible and correspond to a shared reality. Therefore, it was decided that thematic synthesis would fit best with the review aims of integrating information to inform policy and practice. The three stages of thematic synthesis outlined by Thomas and Harden (2008) were followed. All text labelled as 'results' or 'findings' were coded line by line. Similarities and differences were identified across codes, in order to group them into descriptive themes. The final stage involved returning to the original research aims, in order to generate analytical themes from the descriptive themes and develop a deeper understanding.

Results

Study Characteristics

Table 1 summarises the eight papers included. Overall, the experiences of 108 children of parents with YOD were synthesised. The term 'children' referred to anyone with a parent with YOD regardless of age, therefore the sample included a wide age range from 6-37 years old. In the studies that included younger children, most participants were in late adolescence or adulthood (Hutchison et al., 2016; Sikes & Hall, 2017). Living circumstances varied, with some participants living with parents and others living separately. Studies were carried out in 5 countries. They included both sons and daughters of mothers and fathers with YOD. Parents had a variety of YOD subtypes, most commonly Alzheimer's. In all studies, data were collected via individual participant interviews. The studies employed a range of analytic methods including thematic analysis, grounded theory and inductive content analysis.

Table 1. Study Characteristics and Themes

Study Citation & Country	Method of Analysis	Participants	Characteristics of Parent with YOD	Main Themes
Allen et al., 2009 UK	Grounded Theory	N=12 from 7 families 13-24yo (M=19) 7 females (58%): 5 males (42%)	7 fathers: <ul style="list-style-type: none"> • 4 Alzheimer's Disease • 2 Fronto-temporal Dementia • 1 Vascular Dementia 	<ol style="list-style-type: none"> 1. Damage of dementia 2. Reconfiguration of relationships 3. Strain 4. Caring 5. Coping
Svanberg et al., 2010 UK	Constructivist Grounded Theory	N=12 from 9 families 11-17yo (M=15) 6 females (50%): 6 males (50%)	7 fathers and 2 mothers: <ul style="list-style-type: none"> • 5 probable Alzheimer's Disease • 2 Pick's Disease • 1 Vascular Dementia • 1 suspected Pick's Disease 	<ol style="list-style-type: none"> 1. Discovering dementia 2. Developing a new relationship 3. Learning to live with it 4. Going through it together
Barca et al., 2014 Norway	Modified version of Grounded Theory	N=14 from 14 families 20-37yo (M=22) 10 females (83%): 2 males (17%)	12 mothers and 2 fathers: <ul style="list-style-type: none"> • 6 Alzheimer's Disease • 4 Fronto-temporal Dementia • 1 Mixed Dementia • 3 Dementia as consequence of brain damage or tumour 	<ol style="list-style-type: none"> 1. Experiences in social relationships 2. Experiences and needs related to services
Millenaar et al., 2014 The Netherlands	Inductive Content Analysis	N=14 from 11 families 15-27 yo (M=21) 8 females (57%): 6 males (43%)	8 fathers and 3 mothers: <ul style="list-style-type: none"> • 5 Alzheimer's Disease • 4 Fronto-temporal Dementia • 1 Vascular Dementia • 1 Dementia type not specified 	<ol style="list-style-type: none"> 1. Impact of dementia on daily life 2. Coping with the disease 3. Need for care and support
Johannessen et al., 2015 Norway	Stegers 3 Step Metaphor Analysis	N=14 from 14 families 18-30 (M=24) 9 females (64%): 5 males (36%)	9 fathers and 5 mothers: <ul style="list-style-type: none"> • Dementia type not specified 	<ol style="list-style-type: none"> 1. My parent is sliding away 2. Emotional chaos 3. Becoming a parent to my parent 4. A Battle

Hutchinson et al., 2016 Australia	Thematic Analysis	N=12 unclear if any participants drawn from same family 10-33 (M=24) 11 females (92%): 1 male (8%)	7 participants with a mother and 5 with a father with YOD. Unclear if these overlap, e.g. siblings: <ul style="list-style-type: none"> • Dementia type not specified 	<ol style="list-style-type: none"> 1. Emotional toll of caring 2. Keeping the family together 3. Grief and loss 4. Psychological distress
Sikes & Hall, 2017 UK	Narrative Life History	N=22 from 19 families 6-31 (M=21) 18 females (82%): 4 males (18%)	11 fathers and 8 mothers: <ul style="list-style-type: none"> • 8 Fronto-temporal Dementia • 7 Alzheimer's Disease • 1 Dementia with Lewy Bodies • 1 Posterior Cortical Atrophy • 2 Vascular Dementia 	<ol style="list-style-type: none"> 1. Diagnosis 2. Ongoing loss 3. Life on hold 4. Missing landmark events 5. Envy 6. Coping or not
Gelman & Rhames, 2018 USA	Thematic Narrative Analysis	N=8 from 4 families 13-20 (M=18) 5 females (62%): 3 males (38%)	4 fathers: <ul style="list-style-type: none"> • 1 Fronto-temporal Dementia • 3 unspecified 	<ol style="list-style-type: none"> 1. Abrupt interruption/disruption of child's developmental course 2. Adaptation, coping and growth 3. Lack of YOD information and relevant services

Quality Appraisal

Studies were evaluated using the CASP Qualitative Checklist (2018); see Appendix 4. All studies described the scope and purpose of their research and all but one gave a clear statement of aims. Sikes and Hall's (2017) statement of aims was more vague, having to be related to previous text for context. Qualitative methodology was justified and study design was apparent and appropriate to address the research aims in all studies. The recruitment strategy was appropriate for all studies except Sikes and Hall (2017) who accepted participants outside of their initial defined sample. In this study, it was also not clear if the authors collected data in a way that addressed the research aims as they provided insufficient information regarding the interview process. There was no mention of data saturation or other basis for ceasing data collection in four studies (Barca et al., 2014; Gelman & Rhames, 2018; Hutchinson et al., 2016; Johannessen et al., 2015).

Only two studies adequately discussed the relationship between the researcher and the participants, (Allen et al., 2009; Sikes & Hall, 2017). Ethical issues were considered in varying detail. Millenaar et al. (2014) did not mention whether they had sought or received ethical approval. Four studies did not adequately explain how their studies were explained to participants (Gelman & Rhames, 2018; Millenaar et al., 2014; Hutchinson et al., 2016; Sikes & Hall, 2017) and in four studies the researchers did not mention how or if they handled the effects of the research on participants (Allen et al., 2009; Barca et al., 2014; Johannessen et al., 2015; Millenaar et al., 2014).

The rigorousness of data analysis varied across studies and reported reflexivity was limited. Two studies reported little or no deviant case analysis (Gelman & Rhames, 2018; Hutchinson et al., 2016). Most studies gave a clear statement of findings that

could be applied locally. However, Gelman and Rhames (2018) and Johannessen et al. (2018) provided little critical appraisal. The findings of Sikes and Hall (2017) were less applicable due to the methodological limitations within their study. Overall, the quality of studies was generally good apart from Sikes and Hall (2017).

Thematic Synthesis

Three analytic themes derived from thematic synthesis are presented in Figure 2. Analytic themes were interrelated across studies and participants' accounts.

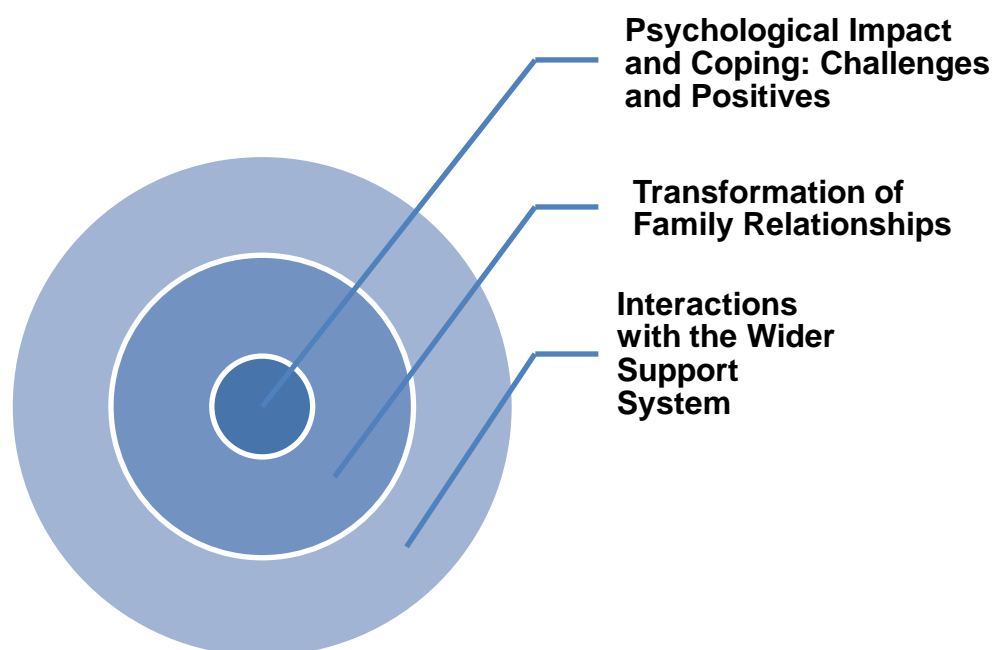


Figure 2. Overarching Analytical Themes Derived from Data Synthesis

Psychological Impact and Coping: Challenges and Positives

In all studies, the emotional impact of having a parent with YOD was discussed. Participants were described as experiencing negative emotions around caring and their situation including fear, sadness, shame, anger and guilt. For many this was described as a constant burden in their lives.

“Like carrying a stone on my shoulders every day” (Johannessen et al., 2015)

In four studies, the impact of negative emotions and the burden of caring was related to negative school performance, with participants describing school absences, lower attainment, reduced ability to concentrate and disruption to future career prospects.

As one participant put it:

“This spin occupied my head, destroyed my concentration and my interest in school” (Johannessen et al., 2015)

In five studies, there was a focus on the negative impact of stigma related to YOD. Some participants described shame around their parent’s YOD which was compounded by the wider societal perspective. Hutchison et al. (2016) highlighted a participant’s experience of having a parent dying from cancer whilst the other parent was diagnosed with YOD. They described there being a societal acceptance of the cancer as opposed to the YOD, which further compounded their own isolation and shame.

“It’s so different having a parent sick with something physical like cancer to a parent sick with something like Alzheimer’s...there’s this real shame around Alzheimer’s. No one wants to talk about it. No one wants to acknowledge it. Everyone wants to say she’s fine, there’s such denial. Where with dad it’s much more, how’s your dad and how’s chemo and oh you poor things”
(Hutchison et al., 2014)

Societal stigma appeared linked to increased social isolation and active concealment of the YOD diagnosis, due to experiences being difficult to communicate to others.

“A taboo, no one shall know about it” and *“You cover it up”* (Johannessen et al., 2015)

In a few studies, participants recounted receiving specific mental health diagnoses including depression; it was also emphasised that participants were sometimes only aware in hindsight of their mental health difficulties (Hutchison et al., 2016). All studies referred to coping strategies. Participants described being unsure how to cope with the magnitude of their situation, engaging in strategies including avoidance, emotional detachment and compartmentalisation of their caring role. Several studies discussed young people removing themselves from the home either permanently or for shorter periods. This was generally perceived as helpful; however, at times this strategy also placed them in unsafe situations, with one participant describing homelessness as a result (Hutchinson et al., 2016). Some young people also described engaging in maladaptive coping strategies including self-harm (Hutchinson et al., 2016).

Several studies described a process of adjustment and adaptation where participants were more able to cope over time. However, in contrast to this, some participants anticipated being less able to cope in the future as their parent’s dementia progressed (Millenaar et al., 2014). Several studies highlighted personal growth through caring, for example increased faith, improved relationships, improved school performance and a desire to help others. Some participants found ways of coping which they viewed positively including spending time with friends and trying to make the most of their situation through *“looking on the bright side”* (Svanberg et al., 2010).

Overall, a range of factors were highlighted as affecting participants’ abilities to cope, including the level of care provided by them (Hutchison et al., 2016), levels of family collaboration in caring (Barca et al., 2014) and whether the participant lived at home

with their parent with YOD (Johannessen et al., 2015). It is possible that these factors contributed to resilience and growth rather than solely increased psychological burden.

Transformation of Family Relationships

Seven studies discussed role reversal in the relationship between the parent with YOD and the participant.

“That feels like I’m a grown up and [Dad]’s my kid but, he’s not”

(Svanberg et al., 2010)

Participants described a change from being a recipient of parental care to becoming a carer for their parent. Parents were described as *“becoming like a child in behaviour”* (Johannessen et al., 2015). Tasks carried out included ensuring the safety of their parent, as well as household tasks. Intimate care was a particularly challenging aspect of this role reversal that disrupted normative development (Gelman & Rhames, 2018). The impact of increased caring impacted on young people’s ability to engage with friends and in their education. Role transitions evoked mixed emotions including responsibility to take over the parental role to support the family (Allen et al., 2009), whereas others struggled to adjust, with one participant stating *“I hate the role of being daddy to my daddy”* (Johannessen et al., 2015).

Within all studies, loss was an integral component of the changing relationship with the parent with YOD. Allen et al. (2009) highlighted present loss and grief was often complicated by fluctuations in parental abilities that were not consistent, for example, the parent with YOD recollecting family on some days but not others. Several studies

discussed the complicated nature of experiencing loss for a parent still physically there in body and how this could compound loss for the parent they once knew.

“The person is physically there but there’s also grief of losing someone... That person is not here anymore. But they are. But I can’t reach them. But they’re right there... is hard emotional circumstance for anyone to deal with”

(Hutchinson et al., 2016)

A changing relationship with the non-YOD parent was described in seven studies, with increased worries for the emotional wellbeing of the non-YOD parent, in some cases due to the impact a deterioration in their wellbeing would have on family functioning. Relational role reversals were described with the young person providing emotional support in a manner that had previously been carried out by the parent with YOD.

“I try to comfort and to support my mother when my father is being difficult. He used to be the one comforting her but now he does not see when she needs him, therefore it is my job now” (Millenaar et al., 2014)

Whilst providing increased emotional support for the non-YOD parent, decreased reciprocal support was common. Some studies emphasised participants actively withholding their emotions, due to perceiving that this would further burden their parent.

Studies also highlighted an overall change in family functioning, with YOD placing increased stress on the whole family. In two studies, changing relationships with extended family were discussed, with extended family described as not understanding

and becoming increasingly removed from immediate family (Allen et al., 2009; Barca et al., 2014). In contrast to the distancing from extended family, in some studies, immediate family bonds were strengthened with increased closeness (Millenaar et al., 2014).

Interactions with the Wider Support System

In all studies, participants described their interactions with the wider support system, including health services and friends. Some participants found talking to friends helpful, whereas some described sharing information on a 'need to know basis' (Millenaar et al., 2014). In contrast, not all participants found sharing information with friends beneficial due to perceiving that others did not understand and could not relate, compounding feelings of isolation.

“So many times I feel so, so alone, and it’s easy for me to tell someone about it and then feel sorry [I did because]...they really don’t understand unless...they are actually witnessing everything that’s happening and are going through the same thing as me” (Gelman & Rhames, 2018)

In two studies, peer support groups with those in a similar situation were discussed. Adult children expressed a desire for groups with others at a similar life stage, for support and to share experience. General carers groups and groups with other family members were not perceived as useful due to differing experiences (Barca et al., 2014). Another younger participant described being introduced to families in a similar situation later in the disease progression, by which point they felt it was less useful (Gelman & Rhames, 2018).

Six studies focused on interactions with health and social care support services. Support was often perceived as difficult to obtain and “*a battle*” (Johannessen et al., 2015). Participants relayed not feeling recognised or included by services and described communication as difficult. Some participants acknowledged feeling unable to assert their needs, perhaps linked to difficulty recognising their needs in the first place (Hutchison et al., 2016). One participant highlighted their perception that support should be offered routinely, as opposed to on request, because they did not feel they had the status or resources to seek help.

*“There is a need for it [support], but you should not have to ask for it yourself.
It should be offered, because I would never have asked for it by myself.”*

(Barca et al., 2014)

In contrast, the timing of support was also considered important, with one study highlighting that support offered too soon was sometimes perceived as unnecessary; however, as time progressed, support needs became more apparent (Millenaar et al., 2014).

Access to information was highlighted, with participants describing not receiving adequate information at the point of diagnosis. This was perceived as important for understanding and processing the diagnosis. Two studies highlighted the need for specific practical information on managing a parent’s behaviour.

Discussion

This review aimed to synthesise the experiences of the children of those with YOD; specifically, to describe the psychosocial impact of a diagnosis of parental YOD and to explore factors that affect outcomes for this group. The process of thematic synthesis resulted in the construction of three interrelated analytic themes: *'psychological impact and coping: challenges and positives'*, *'transformation of family relationships'* and *'interactions with the wider support system'*.

Psychological Impact and Coping: Challenges and Positives

In all studies, the emotional impact of having a parent with YOD was emphasised. In some instances, participants described developing mental health difficulties including depression. Research indicates that up to 38% of young carers may have a mental health problem (Sempik & Becker, 2013), with McAndrew et al. (2011) arguing the juxtaposition of young carers providing emotional support to significant others, whilst social and familial barriers prevent their emotional needs being met, leave them vulnerable to mental health difficulties.

Some studies linked negative emotions to school performance and attendance. Considering wider young carers research, there is evidence of disruption to future trajectories with a 20% likelihood of young carers aged 16-18 being not in education or employment, as opposed to 10% for the overall age group (Audit Commission, 2010). These findings highlight the importance of holistic, multi-agency support for the children of those with YOD to meet their potential, incorporating education, social work and healthcare services.

Five studies emphasised the psychological impact of stigma related to YOD, which has been emphasised in wider YOD literature. Werner et al. (2020) looked at spousal caregivers' experiences surrounding YOD, identifying three types of stigma: public stigma, whereby the person with YOD was subject to discrimination and social exclusion; courtesy stigma, whereby they experienced negative reactions due to their association with the person with YOD; and discrimination from service providers, termed structural stigma. Feelings of shame leading to active concealment of the diagnosis and increased social isolation were present, also apparent within this synthesis. This is important in considering support of those with a parent with YOD because it may affect engagement and interactions with services.

One interesting finding was that stigma surrounding YOD was felt greater than for a parent with a physical illness such as cancer. This has been reported elsewhere in the dementia literature. Woo and Mehta (2016) measured Chinese Americans' perceptions of diabetes and dementia, finding higher stigma related to dementia. This is not unique to the children of parents with YOD; Rose and Cohen (2010) reported that young carers of relatives with drug and alcohol, mental health difficulties or a learning disability also faced greater stigma than those caring for someone with cancer.

Participants were often unsure how to cope and adopted a range of strategies including avoidance and compartmentalisation. Factors linked to coping ability included the level of care provided, levels of family support and living situation. Some studies described adjustment over time, where participants became more able to cope. However, this was not always the case and some participants envisioned being less able to cope as YOD progressed. Pakenham et al. (2007) used a stress/coping model of adjustment to predict how young carers adjusted over time. Better adjustment

was linked to higher social support, as well as lower stress and less avoidant coping over time. This is interesting when considering the children of those with YOD because often social support is low, in part linked to the high levels of stigma which could help explain why better coping over time was not always apparent.

This synthesis found evidence of growth through caring, in line with wider research on young carers (Pakenham et al., 2007). Services engaging the children of those with YOD should remain sensitive to the complex nature of their situation, which is not always perceived negatively.

Transformation of Family Relationships

Role reversal with the parent with YOD was described in most studies, with a dynamic where participants felt they had become a parent to their parent. Thomas et al. (2003) looked at the experiences of 27 young carers, finding contrasting results. Most of the children and young people did not see themselves in a parenting role whilst caring. Only two participants reported this role reversal; one with a parent suffering from a degenerative condition that had resulted in cognitive impairment and one parent recovering from substance abuse. This indicates that parental role reversal is not universal for all young carers, occurring more in instances where a parent may be cognitively impaired, including YOD.

Loss was central to the transformation of the relationship with the parent with YOD. In one model of grief, Walter (1996) argues that to process the grief of a loved one, people talk with others who knew this person, creating a biographical story that places the dead within their lives. It is hypothesised that through this process, people develop an understanding of how the deceased person shaped their life and contributed to the formation of their identity. For some children of parents with YOD, beginning to create

this biography whilst their parent is still alive could be beneficial, due to the nature of YOD where often the parent is experienced as gone prior to death. Particularly, it may benefit adolescents who developmentally are at an important stage in identity formation that is already in part shaped through making meaning from narrative and memories (McLean, 2005). However, participants often felt that others did not understand their experience of loss; therefore, finding ways to support the children of those with YOD to be able to create and share their biographical story may be required.

Participants also described relational changes and role reversal with their non-YOD parent. They highlighted increased worries regarding the emotional wellbeing of their non-YOD parent, congruent with existing literature on the impact of YOD on the whole family system including spouses (Roach & Keady, 2008). This synthesis highlighted that whilst supporting their non-YOD parent, participants began actively withholding their emotions due to not wanting to burden their non-YOD parent and as a result received decreased reciprocal support. Wider research into young carers of parents with mental illness highlights that the availability of one or more supportive adults is a key protective factor (Cowling, 1999). Therefore, emotional withdrawal of a key adult in the lives of those with a parent with YOD is a pertinent factor to consider in emotional wellbeing.

Interactions with the Wider Support System

Experiences were mixed regarding benefits of seeking support from friends, with some participants emphasising others not understanding their experiences (Gelman & Rhames, 2018). Isolation within friendships has been described elsewhere in the young carers research, not specific to YOD (Thomas et al., 2003). Friends not

understanding may be linked to the wider societal stigma previously discussed, as well as the general lack of knowledge in the population.

Support from health and social care services was depicted as being difficult to obtain and participants described inadequate communication and exclusion by services. Participants often struggled to identify their own support needs (Barca et al., 2014; Hutchison et al., 2016), highlighting the need for professionals to take a proactive approach in offering routine support. Despite this, Millenaar et al. (2014) highlighted support may not be sought initially but perceptions around this may change as YOD progresses. Therefore, it is important that services continue to assess the need for family support over time.

In some instances, peer support groups with those with similar experiences were perceived as helpful. As this was only discussed in two of the studies, further research is needed to understand potential benefits of peer group interventions. Furthermore, participants often felt that services did not provide adequate information around YOD, including practical information about responding to parental behaviour. Given YOD has a psychosocial impact on the whole family, with similar needs such as for information, this synthesis evidences the importance of services tailoring support for families.

Limitations

Studies incorporated wide heterogeneity in children's age, dementia subtype and living circumstances, including both sons and daughters of mothers and fathers with YOD. These details were not always clearly distinguishable and therefore it was difficult to determine their influence on findings. Furthermore, in one study, adult children

recounted experiences from their youth with participants reflecting on experiences from many years ago, affecting their narratives (Johannessen et al., 2015). The synthesis is also likely to have been influenced by studies being carried out in five countries. Different countries utilise distinct education, health and social care systems, influencing participants' experiences. For example, perspectives on the healthcare system may differ between public funded and private systems.

Efforts were made to enhance rigour, including discussing developing analytic themes through academic supervision and a second rater for quality appraisal. The purpose of quality appraisal was to highlight limitations in study quality, as opposed to excluding low quality studies, as this remains contentious (Thomas & Harden, 2008). Methodologically flawed studies may have influenced findings; however, themes derived from methodologically weaker studies were comparable to the stronger papers.

A final limitation is that Poole and Patterson (2020) recently published a systematic review relating to the experiences and needs of children who have a parent with YOD. This therefore limits the novel contribution of this review; however, highlights a review in the field was warranted.

Implications for Future Research and Clinical Practice

The findings have important implications for services encountering the children of those with YOD. The children of those with YOD often felt disempowered by a lack of recognition, support and appropriate communication. Young people highlighted a lack of information from services and the need for practical support responding to their parent with YOD. Research indicates that often professionals have limited knowledge regarding YOD (Werner et al., 2020). Research has begun to consider the

perspectives of clinicians (Giebel et al.,2020); however, to date, no studies were found to have explored the experiences of clinicians working with children of a parent with YOD, and this may aid the development of more positive interactions with services. In some instances, peer groups were perceived as helpful, particularly when they were tailored to include those with similar experiences, such as solely adult or younger children. Future research could explore the possible benefits of group interventions and psychoeducation groups.

Dementia research suggests that caregiving is experienced differently by male and female carers (Morris et al., 1991) and it would be interesting to compare experiences of male and female children of those with YOD. Research has included very broad samples containing both adult and younger children. The literature around experiences of children under the age of 18 is particularly limited. This is important because the healthcare services and wider systems, including education, are different to adult services and systems. For some participants, YOD appeared to present key challenges in engaging in age-appropriate activities including school and spending time with friends. Research has highlighted that between the ages of 9 and 15, spending time with friends becomes increasingly important in individuation from parents (Larson & Richards, 1991). Further research with under 18s specifically is therefore required to understand in more depth how the developmental trajectory of children and young people with a parent with YOD influences experiences, needs and service provision.

Conclusions

This synthesis provides an insight into experiences of the children of those diagnosed with YOD. The review outlines the social and psychological impact

through three interrelated themes: *'psychological impact and coping: challenges and positives'*, *'transformation of family relationships'* and *'interactions with the wider support system'*. Findings were broadly consistent with wider literature relating to dementia and young carers; however, the unique nuances of the experiences of those with a parent with YOD were also highlighted. The review provides implications for service delivery and future research.

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Chapter 2: Major Research Project

Partners' Experiences of the Pre-Diagnostic Phase of Young Onset Dementia

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Plain English Summary

Title

Partners' Experiences of the Pre-Diagnostic Phase of Young Onset Dementia.

Background

Young onset dementia (YOD) is thought to make up around 5% of all dementia diagnoses (Prince et al., 2014). Getting a diagnosis can be complicated, with no clear route through the healthcare system (Williams et al., 2001). Partners of those with YOD are often involved in this process; however, little is known about their experience from when they start to notice symptoms to when they seek support for their loved one.

Aims

To explore how partners of those with YOD make sense of the period from observing initial symptoms to seeking healthcare support, as well as what it is like for them to seek help from healthcare services.

Method

Seven individuals living with a partner diagnosed with YOD were interviewed about their experiences. These were audio recorded and analysed to explore themes.

Results

Three main themes were focused on in the findings. '*Changing relationship with partner*' showed that partners started to experience conflict and withdrawal in their relationships, as well as feelings of loss for their relationship and partner.

'*Challenging relationship with healthcare services*' highlighted feelings of exclusion,

isolation and powerlessness experienced by partners in their interactions with healthcare services. They also described unmet needs in relation to the support offered and barriers to accessing this. '*Conflicted relationship with the diagnosis*' explored participants' mixed emotions about their partner's diagnosis. The diagnosis was experienced as 'needed yet unwanted'. Betrayal was felt when accessing help as well as regret at not doing so sooner. Partners avoided the reality of possible YOD, as well as struggling to be believed by others.

Conclusions

This study adds to the limited research about how the partners of those with YOD experience the phase from noticing symptoms to their partner receiving a diagnosis. These themes offer healthcare services some useful ideas to consider. Importantly, partners of those with YOD need to be included in the diagnostic process, as well as having their own support needs met.

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Abstract

Background

Young onset dementia (YOD) is estimated to make up around 5% of dementia diagnoses (Prince et al., 2014). Obtaining a diagnosis can be complex, with multiple diagnostic pathways. Partners of those with YOD are often involved; however, little is known about their experience of the pre-diagnostic phase from initial symptom recognition to diagnosis seeking.

Aims

To explore partners' experiences of the pre-diagnostic phase of YOD. Specifically, the study aimed to analyse how partners make sense of being involved in the process of seeking help from healthcare services.

Method

The study utilised a retrospective qualitative design. Seven partners of individuals diagnosed with YOD within the last three years, were recruited from a community Young Onset Dementia Service within NHS Greater Glasgow & Clyde. Semi-structured interviews were transcribed verbatim and analysed using interpretative phenomenological analysis.

Results

Three superordinate themes were identified from partners' experiences: '*changing relationship with partner*', '*challenging relationship with healthcare services*' and '*conflicted relationship with the diagnosis*'.

Conclusions

The findings provide valuable insights into partners' experiences of the pre-diagnostic phase of YOD. Themes discussed offer healthcare providers factors to consider when designing and providing services for those with YOD and their partners. Further research exploring experiences of partners with different characteristics would be helpful in generating further knowledge to inform service development.

Introduction

Dementia is typically thought of as affecting only older people; however, it occurs in younger people, with dementia before the age of 65 referred to as young onset dementia (YOD). YOD is estimated to make up around 5% of all dementia diagnoses (Prince et al., 2014) and this is reflected within a Scottish context, with the NHS National Services Scotland's Information Services Division (NSS ISD, 2016) predicting 648 YOD diagnoses in Scotland in 2020.

Individuals with YOD are often economically and socially active at onset; for example, employed and caring for younger children. It can have a profound impact on sense of identity (Harris & Keady, 2009) and quality of life (Baptista et al., 2016). YOD often affects family functioning (Svanberg et al., 2011) and can result in psychological distress for partners who find themselves suddenly in a caring role (Kaiser & Panegyres, 2007).

Accessing a Diagnosis of Young Onset Dementia

Timely dementia diagnosis continues to be a key theme in the Scottish Government's third dementia strategy (Scottish Government, 2017). Despite the detrimental economic and social impact of delayed diagnosis, challenges remain worldwide in diagnosing YOD (Carter et al., 2018). Those with YOD, compared to late onset dementia (LOD), may exhibit changes in mood or personality, as opposed to memory difficulties typically characteristic of LOD (Kelley et al., 2009). Draper et al (2016) found it took an average of 4.7 years for those with YOD to receive their final diagnosis. Furthermore, 49% had received another psychiatric diagnosis prior to YOD. Spreadbury and Kipps (2018) explored views on care from the perspective of healthcare professionals. Staff acknowledged the importance of recognising early

symptoms; however, they also highlighted the challenges of diagnostic uncertainty. This reflects the findings of Williams et al. (2001) who found that for 132 YOD patients, 38 different pathways of care were identified in reaching a diagnosis.

Experiences of Carers and Family Members

Interactions with healthcare services during this period have been experienced negatively by carers, who reported being passed between medical consultants and not receiving enough practical help and support (Spreadbury & Kipps, 2019). Carers described not 'fitting in' to existing systems and often received confusing and contradictory information (Lockeridge & Simpson, 2012).

To obtain a diagnosis, a person, carer or family member must identify that there is something wrong and attend their GP. There is a paucity of research into the ways in which family members of those with YOD experience the diagnostic pathway from initial symptom recognition to diagnosis seeking. Van Vliet et al. (2011) explored the pre-diagnostic period, carrying out interviews with 82 carers, predominately partners but also siblings and children. Key themes included disrupted family life, initial misattribution of symptoms and non-responsiveness of GPs.

The Current Study

Research highlights differences in the experiences of spouses or romantic partners in a caregiving role compared to other carers. Partners have been found to be more at risk of experiencing loneliness (Luscombe et al., 1998) as well as changes to sexual and intimate relations impacting on relationship quality (Holdsworth & McCabe, 2018).

Given these differences, further exploration is needed to understand how partners living with individuals with YOD come to recognise a problem and attend healthcare

services. A greater understanding could inform service development, aid understanding of the barriers to diagnosis and best support those with YOD and their partners.

Aims

To explore retrospectively partners' lived experiences of the pre-diagnostic phase of YOD. Specifically, the study aimed to analyse how partners make sense of being involved in the process of seeking help from healthcare services.

Method

Design

A qualitative design employing Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) was used. IPA has theoretical foundations in phenomenology. Underpinnings also include a focus on understanding an individual's unique perspective (idiography), as well as the researcher's role in making sense of the individual's sense of their own experiences (double hermeneutic). IPA was chosen due to its emphasis on in-depth exploration of lived experience.

Ethics

Approval was sought and obtained from the West of Scotland Research Ethics Committee (19/WS/0094) and NHS Greater Glasgow and Clyde (GG&C) Research and Development Department (GN19MH183; Appendix 5).

Recruitment Procedure

Individuals living with a partner diagnosed with YOD within the last 3 years, were recruited from the Young Onset Dementia Service within NHS GG&C. The term

partner refers to someone in a marriage or committed relationship. Participants able to reflect on pre-diagnostic experiences were eligible. Individuals were excluded if they did not speak English, were unable to give informed consent, or if their partner had a secondary dementia diagnosis. Primary dementias are those in which dementia itself is the major sign of organic brain disease. Secondary dementias are those caused by, or closely related to, another disease such Huntington's disease; research has shown experiences of those with primary and secondary dementias may differ (Bunn et al., 2014).

Clinical staff approached eligible participants and provided them with a participant information sheet (Appendix 6), seeking verbal consent for the researcher to contact them directly.

Sample Characteristics

Participants were recruited between September and November 2019. Purposive sampling was used to select participants who could provide a rich, reflective account of their experiences. To enhance homogeneity, those with a partner with young onset Alzheimer's Disease were selected.

The study sought to recruit approximately 4-10 participants, in line with recommendations for similar doctoral research studies using IPA (Smith et al., 2009). Eleven partners were invited to participate. Nine agreed to be contacted by the researcher and two declined; reasons were not given for declining. Of the nine contacted, one declined to participate and another cancelled their interview. Reasons were not given. The final sample of seven participants, along with details of their partners, are summarised in Table 1. Pseudonyms were assigned to maintain

anonymity. From the data, it was evident all participants in the sample had been in a relationship or married to their partner for a significant period.

Table 1. Sample Characteristics

Participant Pseudonym and Gender	Participant Age	Pseudonym of Partner and Gender	Partner Age	Time Since Diagnosis
Mark (M)	65	Anna (F)	64	2 y 4 mo
Nina (F)	60	Paul (M)	60	1 y
Frank (M)	59	Mary (F)	58	2 y 9 mo
Josh (M)	63	Jane (F)	62	2 y 9 mo
Karen (F)	57	Neil (M)	58	9 mo
Natalie (F)	66	Alex (M)	65	9 mo
Daniel (M)	65	Rebecca (F)	60	1 y 10 mo

Key: M = male F = female y = year mo = month

Research Procedure

Interviews were conducted in NHS premises (n=3) or the participant's own home (n=4), dependent on participant preference. Written informed consent was obtained prior to interviews. Interviews were conducted by the researcher using a semi-structured interview schedule (Appendix 8); to facilitate access to aspects of experience most pertinent to participants rather than researcher assumptions (Larkin et al., 2006). The schedule was developed in line with existing literature and consultation with a group who had experience of having a partner with YOD, accessed through the Scottish Neuroprogressive and Dementia Network.

Interviews were conducted flexibly and participants reminded they could stop the interview at any point. They were advised if they required further support following the interview, they could contact the Young Onset Dementia Service within NHS GG&C. Audio recorded interviews (M = 52 minutes) were transcribed verbatim, with identifiable data anonymised.

Researcher Reflexivity

IPA acknowledges that how the researcher makes sense of a participant's account will be influenced by their prior conceptions, as well as the interaction between researcher and participant (Brocki & Wearden, 2006). The researcher conducting the interview was a trainee clinical psychologist who had prior experience assessing a patient with YOD and therefore pre-existing ideas around the challenges encountered by partners with services during the pre-diagnostic period, including a lack of appropriate service provision. A reflective diary was kept and research supervision was used to discuss reflections and interpretations and increase awareness of researcher assumptions and bias. For example, the researcher's own knowledge and experience around the pre-diagnostic phase of YOD influenced their understanding of participants' interpretation of their experiences around service provision in the development of the subtheme 'unmet needs'. However, the researcher's pre-existing ideas also needed to be bracketed to maintain a commitment to exploring individual experience, for example, where participants felt their needs had been met adequately by services.

Data Analysis

Concurrent data analysis was carried out to inform the appropriate point to end recruitment. After interviews six and seven, it was apparent that similar themes were being constructed from the data and data saturation may have been met. However,

according to Saunders et al. (2017), there are often inconsistencies in the definition and application of data 'saturation' and the decision was made to also consider other measures of data 'sufficiency'. According to Vasileiou et al. (2018), the richness and volume of data is one measure considered in research in justifying sample size sufficiency. In this study, this was felt particularly important to consider in maintaining IPA's commitment to idiography, which could theoretically be compromised by over-recruiting. Therefore, the decision was made to stop recruitment after interview seven and sufficiently rich data were obtained to address the research aims.

Transcripts were analysed using IPA as outlined by Smith et al. (2009). The researcher became immersed in the data by listening to the interviews and familiarisation with the transcripts. Initial line-by-line comments were noted and these were used to develop initial emergent themes. A sample of an analysed transcript is included in Appendix 9. Following this, overarching superordinate and subordinate themes were constructed across all transcripts by identifying shared higher-order qualities, whilst also considering the unique idiosyncratic instances within the data. A document/table recorded excerpts related to each theme and a sample is included in Appendix 10. Developing themes were scrutinised and discussed in regular academic supervision.

Results

Three superordinate themes and eight associated subthemes which represent partners' experiences of the pre-diagnostic phase of YOD are summarised below in table 2. Divergent experiences are discussed in cases where subthemes applied differently to a participant's account.

Table 2. Superordinate and Subthemes

Superordinate Themes	Sub Themes
Changing Relationship with Partner	<p>"A sort of battle": The Battle</p> <p>Loss: "Coming to an end"</p>
Challenging Relationship with Healthcare Services	<p>Exclusion: "Sitting on the outside"</p> <p>Powerlessness: "In a fog"</p> <p>Unmet Needs: "Need to have support"</p>
Conflicted Relationship with the Diagnosis	<p>Needed but Unwanted To "deal with it" - yet "some comfort" in not knowing</p> <p>Betrayal and Regret "like stabbing my wife in the back" - yet "a mistake [was] no' going earlier"</p> <p>Own and Others' Disbelief "don't want to acknowledge [this] serious problem" - yet "nobody believes me"</p>

Changing Relationship with Partner

The first theme encapsulates participants' changing relationship with their partners, which can be understood in two subthemes: 'the battle' and 'loss'.

The Battle

Six participants conveyed the changing relationship with their partner as a battle with an inherent sense of struggle within their relationship. For some, this struggle was apparent externally, with direct conflict and arguments. For other participants, the battle was an internal one, as a result of increased distancing and withdrawal from their partner.

“We stopped doing anything in the house. Everything was a battle of negotiation, to get a room painted... something repaired... these were tiny little insidious incremental changes that suddenly I - from somebody that was really easy going and good fun...everything became a sort of battle” (Karen, pg 1)

Karen highlights twice how *‘everything became a battle’*, emphasising the pervasive nature which was even over trivial things that would not normally have precipitated conflict. Her description of stopping carrying out household tasks due to the *‘battle of negotiation’* illustrates the change in her behaviour and the breakdown of effective partnership.

For several participants, ‘keeping the peace’ and avoiding conflict was a factor linked to delays in accessing healthcare services. Mark described being concerned by his wife’s behaviour, but she did not want to attend the GP and he avoided pursuing this to prevent disagreement.

*“I didnae push her... sometimes you just want the easy life that you’re thinking, ‘Oh f**k that’ll upset her, don’t bother.’”* (Mark, pg 9)

Daniel portrayed his confusion at the changes in his partner’s behaviour as he tried to make sense of it. He described a decline in communication and meaningful interaction. At this stage, he was not aware this was linked to YOD and, therefore, began to feel not listened to and ‘invisible’. This led to an internal struggle where he felt isolated and invalidated within his relationship.

“Well I couldnae make sense of it. I thought it was just total un-, she was no’ interested...she’s no’ listening...just generally thinking that, it doesnae matter what I say” (Daniel, pg 3)

One participant, Frank, did not describe a battle within the marital dynamic prior to diagnosis; however, his experience differed in that he reported not noticing changes in his partner prior to these being pointed out by her colleagues. Frank focused instead on the impending post-diagnosis battle relating to the deterioration of his wife’s health and their relationship.

Loss

A sense of loss at the changing relational dynamic was evident across all participants’ accounts.

“It was awful because we were married...36, 37 years married [inhales]...everything seemed to be going really well in life, touch wood. And then all of a sudden - what I thought - ‘was our marriage coming to an end after all that time?’ So...it was really upsetting.” (Josh, pg 2)

Josh emphasised the emotional impact of his changing marital dynamic and he was one of four participants who began questioning whether their relationship was breaking down. His loss was heightened by the long duration of his relationship. Indeed, the length of partnership was emphasised by four participants as deepening their sense of loss. Mark also expressed his anticipatory grief during the pre-diagnostic period at the realisation that the changes occurring in his wife meant loss of the life they had hoped for.

“She’d retired for about 8 years and I’d just retired and thinking, ‘oh we’ll do this, or oh we’ll do that’ but it didnae happen - just didnae happen” (Mark, pg 14)

Challenging Relationship with Healthcare Services

A second superordinate theme characterises the challenging relationship that participants experienced with healthcare services, as they attempted to gain a medical explanation for their partners’ behaviour. This was apparent within three interrelated subthemes: *‘exclusion’*, *‘powerlessness’* and *‘support needs’*.

Exclusion

“I didn’t feel part of any of that. I felt like I was sitting on the outside...I’d been brought in to give them my knowledge of how my wife had been over the last year or so and then I was put back out again - until we came for a diagnosis” (Josh, pg 14)

Josh’s account of *‘sitting on the outside’* illustrates the perceived exclusion by services, which amplified his existing feelings of isolation within his marriage. In four accounts, feeling excluded during the healthcare process increased feelings of worry and frustration, due to concerns that partners were unable or unwilling to accurately portray their difficulties, as highlighted by Natalie.

“I did speak to the GP and he said to me, ‘yeah but Alex has said such and such’, and I said to him ‘yeah but he’ll no’ tell you anything. If Alex thinks you want him to say your hair’s green, then Alex’ll say to you your hair’s green”
(Natalie, pg 5)

Natalie also described attempting to find out information regarding her partner's care but facing barriers linked to confidentiality. Her sense of exclusion was heightened by the fact that she was providing a significant amount of care at home, therefore, felt a need to be included in order to provide appropriate support.

Powerlessness

Another subtheme characterising interactions with healthcare services was the feeling of powerlessness. Frank recalled phoning the local adult mental health team for his wife's test results. The family were told she did not have YOD but were phoned several days later and told they had been given the wrong person's results.

"You're told it's alright - and then all of a sudden [clicks fingers] - somebody grabbing it away from you. That's no' alright" (Frank, pg 11)

Frank's account emphasises the power dynamic in healthcare services, where they have the perceived 'power' to give the relief of good news or, just as suddenly, to snatch this away with the devastation of a diagnosis. Being given reassurance only to have this revoked left Frank feeling disempowered and angry at the unfairness.

"It was as if you were in a fog...and you were getting pulled-, or you, you were getting blown by this big wind machine that was saying [blowing noise] 'go there' and then sucking you back and pushing you somewhere else. Em, felt as if I didn't have any control over anything" (Natalie, pg 11)

When recounting her experience with healthcare services, Natalie conveyed being pushed and pulled by a 'big wind machine' that left her at the mercy of the elements. This emphasises the impersonal nature of her experience and conveys her sense of powerlessness and lack of control, as she and her husband were passed between

services. Her description of being '*in a fog*' emphasises her difficulty seeing where the process was heading. Furthermore, her account of not having '*any control over anything*' highlights the pervasiveness of powerlessness, which was both in relation to the disease but also compounded by her lack of control in the process of obtaining a diagnosis.

Unmet Needs

The final subtheme related to the challenges of support needs being met.

"...if you're giving somebody a diagnosis that is really devastating and there's no cure for, you need to have support there pretty much right away...he should have been organising support for the two of us right away to be able to explain the impact of that diagnosis, if he wasn't able to do it himself" (Nina, pg 19)

Nina highlights the incurable nature of YOD and her struggle to understand the implications of it, to emphasise the need for timely support being offered at the point of diagnosis.

"I will always feel the help was there, I just needed to ask for it" (Daniel, pg 12)

On the other hand, two participants - Mark and Daniel - both reflected that, although they felt help was always available, they themselves did not feel in a place to be receptive to this support at the point of diagnosis, due to the magnitude of trying to comprehend this. This suggests barriers to getting support needs met adequately could include services' lack of available, timely support but also partners' difficulty asking for or accessing it initially.

“There was nobody giving me any support...the doctor wouldn’t speak to me unless I was there with Alex. The doctor wasnae asking me how I was feeling”
(Natalie, pg 18)

Furthermore, several participants highlighted they felt as if there was no emotional support available to them as individuals. Natalie perceived that, during the pre-diagnostic process, health professionals were not interested in how she was coping. She reflected that if she had been unable to cope or support her husband, this would have had a detrimental effect on his wellbeing and access to healthcare.

Conflicted Relationship with the Diagnosis

Participants’ narratives conveyed both the positive and negative aspects of obtaining the diagnosis and of being involved in this process. Three subthemes are discussed: ‘*needed but unwanted*’, ‘*betrayal and regret*’ and ‘*own and others’ disbelief*’.

Needed but Unwanted

The tension between wanting answers versus grasping on to hope for another outcome is reflected in quotations from Natalie and Nina.

“Some folk say they don’t want to know but if, if you know what the diagnosis is then you can deal with it - it’s the 3 or 4 years of something else happening and nothing, nothing, nothing coming. Does that make sense? So, you’re worrying, ‘is it this, is it this, is it this, is it this?’” (Natalie, pg 5)

“Even once Paul got into the system and as I say it took ages for a diagnosis. That was some comfort that - I was saying to the doctors, ‘Is this dementia?’ And they were saying, ‘oh it’s too early to say...we don’t know what it is’ and that was some comfort, you know?” (Nina, pg 8)

For Natalie, although the diagnosis was not a welcome one, she reflects a sense of relief in comparison to the prolonged period of unknown, which had heightened worry around the diagnostic outcome. Her comment '*then you can deal with it*' suggests the pivotal role the diagnosis played in knowing how to respond or manage the situation. This was echoed by several participants who described their partners' diagnosis as enabling them to seek further support from health and social care. Conversely, Nina's account portrays a sense of comfort where not having a diagnosis allowed her to hold on to hope for a better outcome. Here, the competing desires for maintaining hope and avoiding bad news contrast with the desire to know in order to respond appropriately and resolve the worry of uncertainty.

Betrayal and Regret

The second subtheme '*betrayal and regret*' characterises the conflicting position participants faced in relation to seeking the diagnosis. On the one hand, it was felt important to raise concerns in order to seek healthcare support. However, no course of action led to a desirable outcome, with betrayal felt for raising concerns and regret experienced as a result of not doing so sooner.

"I would never ever think about telling anyone something my wife can't do or how bad she might be or, not that she is. But I would never ever...I said to the doctor, 'I feel as if I'm stabbing my wife in the back'" (Josh, pg 17)

"If there was a mistake made, it was me no' going earlier or no' trying to push it earlier. [Inhales] As I say, the easy life." (Mark, pg 14)

Josh's feelings of guilt appeared to centre around disclosing his concerns about his wife to the doctor. His use of the phrase '*stabbing my wife in the back*' depicts the

deep sense of betrayal felt. Despite recognising the importance of raising concerns, he did not want to speak negatively of his wife, as this was perceived as a breach of their longstanding commitment and partnership.

Similarly, for Mark there was a sense of a double bind. He had experienced a relatively straight-forward route through the pre-diagnostic pathway, whereby concerns around his wife's dementia had been initially raised by healthcare services, following treatment for an unrelated physical health problem. His account depicts the regret felt for his perceived failure to question the changes earlier and access services sooner. He reflects on how his behaviour at the time was linked to maintaining '*the easy life*' and avoiding difficulties within the relationship.

Own and Others' Disbelief

The third subtheme encapsulates a dynamic whereby participants described a denial and avoidance of the possible impending diagnosis, contrasted with a frustration over not having their initial concerns taken seriously.

"You don't want to acknowledge that there's some sort of potentially serious problem there" (Nina, pg 7)

"There was this wee voice in the back of my mind thinking 'he's getting worse all the time but nobody believes me'" (Karen, pg 5)

Nina acknowledged her avoidance regarding her husband's difficulties and the possibility that these could be linked to YOD. From her account, it appeared that her pre-existing knowledge regarding dementia may have been contributing to this sense of avoidance. As a result, she described '*covering it up from family*', possibly due to a fear that they could raise concerns and force her to confront her avoidance.

Conversely, Karen noticed changes in her husband which she perceived as not being immediately obvious to others. In contrast to Nina, she described frustration at her perception that others did not believe her account of her husband's deterioration. This compounded feeling isolated within her friendships and wider family relationships.

Discussion

This study explored partners' lived experiences of the pre-diagnostic phase of YOD. The study aimed to analyse how partners make sense of being involved in the process of seeking help from healthcare services. Partners' accounts were analysed using IPA leading to the construction of three superordinate themes. '*Changing relationship with partner*' highlighted changing relational dynamics experienced as a 'battle' and a loss of their partner. '*Challenging relationship with healthcare services*' emphasised partners' interactions with the healthcare system and the feelings of exclusion, and powerlessness linked to unmet needs. Finally, '*Conflicted relationship with the diagnosis*' recognised the ambivalence surrounding obtaining the diagnosis.

Changing Relationship with Partner

Participants described a changing relationship with their partner during the pre-diagnostic phase, creating an inherent sense of struggle. This presented in varying ways including direct conflict and arguments, distancing and withdrawal. Changing dynamics often precipitated avoidance of tasks or conversations that could lead to conflict. At times, this desire to 'keep the peace' contributed to delays in accessing healthcare services, including avoiding encouraging their partner to attend the GP. This is significant due to the crucial role that partners and carers play in help-seeking and differs from Lockeridge and Simpson (2012) whose participants described a prolonged period encouraging their partner to attend the GP for investigations. One

possibility for this difference could be how changes were initially perceived by partners. In the current study, some participants initially attributed changes to a possible relationship breakdown, whereas Lockeridge and Simpson (2012) described spouses attributing changes as internal to their partner, such as a physical condition or stress, where it would be normative to encourage a partner to attend the GP.

Partners and families often only seek initial help from the GP after a significant life event or change in routine, such as a holiday (Van Vliet et al., 2011; Williams et al., 2001). It is not fully clear why this is the case; however, in this study, changing relational dynamics shifted gradually over time and appeared to contribute to difficult dynamics being perceived as a 'new normal' within the relationship. It may be that a significant change acts as a facilitator for difficulties being attributed to something outside the relationship. This would be interesting to explore in future research.

In the current study, loss related to partnerships and anticipatory loss for the future were described. Anticipatory loss in adult and spousal caregivers was echoed in a systematic review by Cabote et al. (2015), although not specific to the pre-diagnostic period. Ducharme et al. (2013) noted that diagnosis often marked the moment when spouses began experiencing loss for their spouse and the future; however, in this study, partners appeared to begin experiencing loss prior to having a diagnostic explanation for the changes occurring. Participants' perceptions of their relationships deteriorating prior to diagnosis may account for this difference.

Challenging Relationship with Healthcare Services

Difficulties in interactions with healthcare services whilst seeking a YOD diagnosis have been well documented (Erskine, 2019; Flynn & Mulcahy, 2013). This study builds

upon existing findings highlighting the range and complexity of the negative emotional experiences of partners when interacting with healthcare services.

Partners described powerlessness, echoing the findings of Van Vliet et al. (2011) who described carers, including partners, perceiving they were not being taken seriously by their GPs and were passed 'from pillar to post'. Johannessen et al. (2017) discussed exclusion experienced by spouses who felt that GPs became annoyed with their involvement, perceiving this as 'interfering'. They highlighted negative interactions being related to a lack of professional knowledge and understanding around YOD, which was also highlighted as a contributory factor in the current study. Increased knowledge of YOD within clinical settings is therefore important in promoting positive and less challenging interactions between partners and healthcare services.

Professionals have highlighted the need for more information around YOD. Werner et al. (2020) explored experiences of family members and professionals involved in the development and provision of YOD services, with a focus on stigma. Families highlighted lack of knowledge from professionals and inappropriate treatment, whereas professionals highlighted the need for more information around YOD. Professionals' misconceptions about YOD were reported, with negative emotions when interacting with people with the condition and wider stigma within systems. Such challenges and stigma could be further contributing factors for the negative interactions described by participants in the current study.

Spreadbury and Kipps (2018) interviewed healthcare professionals in YOD care, presenting a paradigm for holistic YOD care including eight different themes spanning pre-diagnosis to post-diagnosis. Again, increased knowledge of healthcare

professionals was highlighted; however, clinicians felt that GPs may encounter few YOD patients and increased awareness may have limited practical impact.

Their paradigm emphasised working closely with caregivers beyond simple assessment and patient monitoring, for example, through empathic concern, validation, emotional support and providing a sense of security for caregivers. They also noted the importance of helping caregivers feel supported in their decision-making and of service user confidence. These findings are interesting because they highlight important aspects of care that were generally not felt to be provided by participants in the present study and this lack may have contributed to challenging interactions with healthcare services. Future research could explore the impact of implementing Spreadbury and Kipp's (2018) model on interactions with partners and families.

Conflicted Relationship with the Diagnosis

Partners described the competing desire for maintaining hope and avoiding the reality of an incurable disease, in contrast to the desire to have a diagnosis in order to resolve the worry of uncertainty. Prior research has found a similar sense of reassurance related to the diagnosis (Van Vliet et al., 2013) versus denial (Flynn & Mulcahy, 2013). One theory that may help to understand these different ways of processing information around the diagnosis is the idea of monitor-blunter coping styles (Miller, 1987). This contrasts whether people seek or avoid information (high versus low monitors) and whether they distract or do not distract themselves (high versus low blunters). In previous research, health messages have been successfully matched to monitor-blunter coping styles in order to encourage engagement in health screening processes (Williams-Piehota, 2005). In the current study, it appeared that when the diagnosis

was unwanted and partners were in disbelief and grasping on to hope for another outcome, they were more likely to cope through low monitoring. In contrast, when they wanted answers and for others to believe them, they engaged in high monitoring. It seems that when partners were high monitors/low blunterners, they were most likely to experience betrayal and regret because they were engaging with the information without distraction. Considering the monitor/blunter coping style of partners could have important clinical implications and help services to facilitate appropriate levels of information and support at the right time for partners.

Alongside consideration of individual coping styles, there are other models which view coping as a phase-based adjustment over time. In one such model, Kubler-Ross (1969) suggested that those coping with loss and grief go through a series of five non-linear stages: denial, anger, bargaining, depression and acceptance that result in different behaviours at each stage. When considering this model, it is possible that participants' accounts of avoiding the reality of the diagnosis were characteristic of a 'denial' phase of transition, whereas those who were exploring their options by more actively seeking a diagnosis were describing a phase of growing 'acceptance'.

The Social-Cognitive Transition Model of Adjustment (Brennan, 2001) is a further phase-based model that specifically addresses cognitive processes in a way not addressed by Kubler-Ross (1969). This model posits that the cognitive models an individual hold determines their assumptions and expectations about the world and these are either confirmed or disconfirmed by experience. If models are disconfirmed, individuals are required to alter their mental models which can be stressful and create resistance. It is possible in this study that those participants who were avoiding the diagnosis were in part resisting having to alter their mental model of their current circumstances.

Wawrziczny et al.'s (2016) analysis of couples' experiences with early onset Alzheimer's disease similarly highlighted a conflicted relationship with the diagnosis, describing a 'need to know more' prior to diagnosis versus a 'need to know less' following diagnosis. Their findings indicate a conflicted relationship with the diagnosis does not just occur during the pre-diagnostic period but carries on throughout the course of the disease progression. They emphasised several ways that couples coped with diagnostic information including accepting and seeking knowledge, minimising and resisting knowledge and blaming themselves for waiting too long before seeking help. These were all evidenced within the current findings.

Strengths and Limitations

This study provides a valuable contribution to the evidence base in an emerging field and the relative homogeneity with respect to specific YOD diagnosis (Alzheimer's) and to the type of relationship (spouse/partner) adds to the depth of analysis and transferability of the findings to those with these characteristics.

In accordance with the principles of IPA, these findings are a construction of the experiences of a small sample of partners who chose to participate. As is typical with YOD, participants all had different journeys through the pre-diagnostic process and healthcare system. The time passed since the participants' partners diagnosis of YOD varied from nine months to two years, nine months. The criteria that participants had to be living with a partner diagnosed with YOD in the last three years was applied to seek a balance between enabling adequate recruitment and preserving the integrity of accounts. However, some participants described the pre-diagnostic period as spanning many years prior to diagnosis and therefore accounts may have been subject to retrospective biases, including current stressors and caregiver burden.

Purposive sampling was used to select participants who could give a rich reflective account of their experiences; however, it was not clear how clinicians deemed participants as able to give a rich reflective account and therefore included them in the pool of participants eligible for the study. There may have been biases in clinician judgment that affected who was approached to participate in the study. For example, clinicians may not have approached those who they felt were experiencing high levels of stress in their life.

Although Alzheimer's disease was purposefully sampled due to being the most common dementia subtype, female partners were not purposefully sampled despite being the more common and more empirically affected gender, due to the higher rate of YOD in males (Shinagawa et al., 2007). Furthermore, all couples were heterosexual; therefore, the experiences of homosexual partners were not represented. This was due to the relatively small number of cases open to the YOD Service during the recruitment window and the purposeful sampling of participants who could provide a rich reflective account.

Implications for Clinical Practice

These findings are relevant to clinicians in many fields due to the many care pathways that families experience in YOD. However, findings may be most relevant to GPs, mental health services and neurology. It is crucial for services to be aware of and better understand YOD, as well as partners' experiences during the pre-diagnostic phase and how partners play a crucial role in recognising and facilitating the process of seeking help. Increased information about the experiences of partners could help services recognise and respond better to their needs.

This study highlighted negative relational changes that occur between the person with YOD and their partner during the pre-diagnostic phase. Larochette et al. (2019) assessed experiences of a personalised programme for spouses of those with YOD, with modules focusing on skill development to support role transition, acceptance processes and couple dynamics preservation. They found this to be beneficial for spouses' well-being, coping strategies and communication with their partner. Services could consider providing such educational modules for partners who are struggling in the above areas at the point of diagnosis, given the high caregiver burden they go on to face (Lim et al., 2018).

Future Research

It would be helpful to investigate partners' experiences during the pre-diagnostic period among samples with different characteristics, such as sexual orientation and dementia subtype. To increase homogeneity, we sampled partners of those with Alzheimer's Disease. Evidence that burden and distress is higher in caregivers of those with frontotemporal dementia (De Vugt et al., 2006) warrants further research.

Conclusions

This study explored partners' experiences of the pre-diagnostic phase of YOD. It highlighted relational changes in the pre-diagnostic phase, which influenced participants' perceptions of the dementia-related difficulties, therefore affecting the stage at which they sought help. Once engaged with healthcare services, dynamics were challenging, with negative emotional experiences and interactions. A conflicted relationship with the diagnosis influenced partners' experiences. These themes offer healthcare services and clinicians some useful reflections to consider when designing and providing streamlined and person-centred services for those with YOD and their

partners. Importantly, partners of those with YOD need to be included in the diagnostic process, as well as having their own support needs met. Further research exploring experiences of partners with different characteristics could help inform service development.

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Appendix 1: Manuscript Submission Guidelines for the Journal ‘Dementia’

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Dementia, please ensure you have read the [Aims & Scope](#).

1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

The journal also publishes book reviews. We send out a list of books to review twice a year in September and March.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on [how to get published](#), plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: [How to Help Readers Find Your Article Online](#).

[Back to top](#)

2. Editorial policies

2.1 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.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the

manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission,
- The reviewer should not have recently collaborated with any of the authors,
- Reviewer nominees from the same institution as any of the authors are not permitted.

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

2.4 Funding

Dementia requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the [Funding Acknowledgements](#) page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of Dementia to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations [here](#).

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the [World Medical Association Declaration of Helsinki](#).

Submitted manuscripts should conform to the [ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals](#), and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record. The confirmatory letter may be uploaded with your submission as a separate file.

Please also refer to the [ICMJE Recommendations for the Protection of Research Participants](#).

At SAGE we are committed to facilitating openness, transparency and reproducibility of research. Where relevant, The Journal encourages authors to share their research data in a suitable public repository subject to ethical considerations and where data is included, to add a data accessibility statement in their manuscript file. Authors should also follow data citation principles. For more information please visit the [SAGE Author Gateway](#), which includes information about SAGE's partnership with the data repository Figshare.

[Back to top](#)

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' [International Standards for Authors](#) and view the Publication Ethics page on the [SAGE Author Gateway](#).

3.1.1 Plagiarism

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If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the [SAGE Author Gateway](#) or if in doubt, contact the Editor at the address given below.

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3.3 Open access and author archiving

Dementia offers optional open access publishing via the SAGE Choice programme. For more information please visit the [SAGE Choice website](#). For information on funding body compliance, and depositing your article in repositories, please visit [SAGE Publishing Policies](#) on our Journal Author Gateway.

[Back to top](#)

4. Preparing your manuscript for submission

Dementia requires authors to submit a short author biography. You will be asked to upload this as a separate file.

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the [Manuscript Submission Guidelines](#) page of our Author Gateway.

Dementia requires authors to submit a short author biography. You will be asked to upload this as a separate file.

4.2 Language

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. demented). Language that might be deemed sexist or racist should not be used. All submissions should avoid the use of insensitive or demeaning language. In particular, authors should use 'dementia-friendly' language in positioning people living with dementia in their article and avoid using pejorative terms such as 'demented' or 'suffering from dementia'.

Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage, please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

Useful websites to refer to for guidance

We recommend that authors refer to the [Dementia Engagement and Empowerment Project \(DEEP\) guidance](#) which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information.

Alternatively, Alzheimer's Australia sets out [guidelines for dementia-friendly language](#), as do the [Alzheimer Society of Canada](#), both of which are useful for guidance.

4.3 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

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This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our [guidelines on submitting supplementary files](#).

4.5 Reference style

Dementia adheres to the APA reference style. View the [APA](#) guidelines to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit [SAGE Language Services](#) on our Journal Author Gateway for further information.

[Back to top](#)

5. Submitting your manuscript

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Book reviews must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Sarah Campbell Sarah.Campbell@MMU.ac.uk

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You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. The affiliation listed in the manuscript should be the institution where the research was conducted. If an author has moved to a new institution since completing the research, the new affiliation can be included in a manuscript note at the end of the paper. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

Dementia requires authors to submit a short author biography. You will be asked to upload this as a separate file.

5.3 Permissions

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[Back to top](#)

6. On acceptance and publication

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Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be made available to the corresponding author via our editing portal SAGE Edit or by email, and corrections should be made directly or notified to us promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

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[Back to top](#)

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Dementia editorial office as follows:

dem.pra@sagepub.com

Appendix 2: Search Strategy

Below is a summary of search terms for each database. Search terms were adapted to map onto subject headings where appropriate. Boolean operators were used to combine search terms and truncation and proximity codes were adapted for individual databases.

Database	Search Terms
Embase	<ol style="list-style-type: none"> 1. Dementia (subject heading) 2. ("young* onset" or "early onset" or "early age" or "working age" or presenile) adj3 (dementia or alzheimer* or frontotemporal) 3. 1 or 2 4. Subject heading parent 5. Subject heading family 6. Subject heading family relation 7. (parent* or father* or mother* or family*) 8. 4 or 5 or 6 or 7 9. Subject heading caregiver 10. Subject heading child development 11. Subject heading adult child 12. (child* or son* or daughter* or adolescent* or teenager* or "young* people" or "young* person" or "adult child*" or carer* or caregiver*) 13. 9 or 10 or 11 or 12 14. Subject heading qualitative research 15. Subject heading life event 16. (experience* or perspective* or "lived experience*" or "life experience*" or view* or qualitative) 17. 14 or 15 or 16 18. 3 and 8 and 13 and 17
CINAHL	<ol style="list-style-type: none"> 1. Dementia (subject heading) 2. ("young* onset" or "early onset" or "early age" or "working age" or presenile) n3 (dementia or alzheimer* or frontotemporal) 3. 1 or 2 4. Subject heading parents 5. Subject heading family 6. Subject heading family relations 7. (parent* or father* or mother* or family*) title or abstract 8. 4 or 5 or 6 or 7 9. Subject heading caregivers 10. Subject heading adult children 11. Subject heading child development

	<p>12. (child* or son* or daughter* or adolescent* or teenager* or "young* people" or "young* person" or "adult child*" or carer* or caregiver*)</p> <p>13. 9 or 10 or 11 or 12</p> <p>14. Subject heading qualitative studies</p> <p>15. Subject heading life experiences</p> <p>16. (experience* or perspective* or "lived experience*" or "life experience*" or view* or qualitative)</p> <p>17. 14 or 15 or 16</p> <p>18. 3 and 8 and 13 and 17</p>
Medline	<p>1. Dementia (subject heading)</p> <p>2. ("young* onset" or "early onset" or "early age" or "working age" or presenile) adj3 (dementia or alzheimer* or frontotemporal)</p> <p>3. 1 or 2</p> <p>4. Subject heading parents</p> <p>5. Subject heading family</p> <p>6. Subject heading family relations</p> <p>7. (parent* or father* or mother* or family*)</p> <p>8. 4 or 5 or 6 or 7</p> <p>9. Subject heading caregivers</p> <p>10. Subject heading child development</p> <p>11. Subject heading adult children</p> <p>12. (child* or son* or daughter* or adolescent* or teenager* or "young* people" or "young* person" or "adult child*" or carer* or caregiver*)</p> <p>13. 9 or 10 or 11 or 12</p> <p>14. Subject heading qualitative research</p> <p>15. Subject heading life change events</p> <p>16. (experience* or perspective* or "lived experience*" or "life experience*" or view* or qualitative)</p> <p>17. 14 or 15 or 16</p> <p>18. 3 and 8 and 3 and 17</p>
PsychINFO	<p>1. Dementia (subject heading)</p> <p>2. ("young* onset" or "early onset" or "early age" or "working age" or presenile) n3 (dementia or alzheimer* or frontotemporal)</p> <p>3. 1 or 2</p> <p>4. Subject heading parents</p> <p>5. Subject heading family</p> <p>6. Subject heading family relations</p> <p>7. (parent* or father* or mother* or family*) title or abstract</p> <p>8. 4 or 5 or 6 or 7</p> <p>9. Subject heading caregivers</p> <p>10. Subject heading childhood development</p> <p>11. Subject heading adult offspring</p>

	<p>12. (child* or son* or daughter* or adolescent* or teenager* or “young* people” or “young* person” or “adult child*” or carer* or caregiver*) [title or abstract]</p> <p>13. 9 or 10 or 11 or 12</p> <p>14. Subject heading qualitative methods</p> <p>15. Subject heading life experiences</p> <p>16. (experience* or perspective* or “lived experience” or “life experience” or view* or qualitative)</p> <p>17. 14 or 15 or 16</p> <p>18. 3 ad 8 and 13 and 17</p>
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Appendix 3: CASP Qualitative Checklist



CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- ▶ Are the results of the study valid? (Section A)
- ▶ What are the results? (Section B)
- ▶ Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA ‘Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

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Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

4. Was the recruitment strategy appropriate to the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- If the researcher has explained how the participants were selected
 - If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
 - if there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- If the setting for the data collection was justified
 - If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
 - If the researcher has justified the methods chosen
 - If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
 - If methods were modified during the study. If so, has the researcher explained how and why
 - If the form of data is clear (e.g. tape recordings, video material, notes etc.)
 - If the researcher has discussed saturation of data

Comments:

6. Has the relationship between researcher and participants been adequately considered?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

8. Was the data analysis sufficiently rigorous?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used, if so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
 - To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix 4: Quality Ratings with CASP Qualitative Checklist

CASP Criteria	Allen et al. (2009)	Svanberg et al. (2010)	Barca et al. (2014)	Millenaar et al. (2014)	Johannes sen et al. (2015)	Hutchison et al. (2016)	Sikes & Hall (2017)	Gelman & Rhames (2018)
Clear statement of aims?	✓	✓	✓	✓	✓	✓	✓	✓
Is qualitative methodology appropriate?	✓	✓	✓	✓	✓	✓	✓	✓
Was the research design appropriate to address research aims?	✓	✓	✓	✓	✓	✓	✓	✓
Was the recruitment strategy appropriate to research aims?	✓	✓	✓	✓	✓	✓	X	✓
Was the data collected in a way that addresses the research issue?	✓	✓	✓	✓	✓	✓	X	✓
Has the relationship between researcher and participants been adequately considered?	✓	X	X	X	X	X	✓	X
Have ethical issues been taken into consideration?	✓	✓	✓	X	✓	✓	✓	✓
Was the data analysis sufficiently rigorous?	✓	✓	✓	✓	X	✓	X	X
Is there a clear statement of findings?	✓	✓	✓	✓	✓	✓	X	X
Will the results help locally?	✓	✓	✓	✓	✓	✓	X	✓

Appendix 5: Ethical Approval Documents



Administrator: Mrs Elaine O'Neill
Telephone Number: 0141 314 4001
E-Mail: elaine.o'neill2@ggc.scot.nhs.uk
Website: <https://www.nhsggc.org.uk/about-us/professional-support-sites/research-development/>

Clinical Research & Development
Dykebar Hospital, Ward 11
Grahamston Road
Paisley, PA2 7DE
Scotland, UK

21/06/2019

Daryl Regan
NHS GG&C

NHS GG&C Board Approval

Dear Ms D Regan,

Study Title: Young onset dementia: Partners experiences of the pre-diagnostic phase.
Principal Investigator: Ms Daryl Regan
GG&C HB site Gartnavel General Hospital, GP practices and Community Mental Health
Sponsor NHS Greater Glasgow and Clyde
R&D reference: GN19MH183
REC reference: 19/WS/0094
Protocol no: V2; 12/04/19
(including version and date)

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. First study participant should be recruited within 30 days of approval date.
 - b. Recruitment Numbers on a monthly basis
 - c. Any change to local research team staff should be notified to R&D team
 - d. Any amendments – Substantial or Non Substantial



- e. Notification of Trial/study end including final recruitment figures
- f. 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,

Mrs Elaine O'Neill
Senior Research Administrator

Cc: Miss Emma-Jane Gault (Glasgow University)



Dr Naomi White
Clinical Psychologist
The University of Glasgow
University of Glasgow, 1st Floor, Admin
Building
Gartnavel Royal Hospital
1055 Great Western Road, Glasgow
G12 0XH

West of Scotland REC 1
West of Scotland Research Ethics Service
Ward 11
Dykebar Hospital
Grahamston Road
Paisley PA2 7DE
www.nhsqgc.org.uk
Date 03 July 2019
Direct line 0141-314-0212
e-mail WosRec1@ggc.scot.nhs.uk

Dear Dr White

Study title: Young onset dementia: Partners experiences of the pre-diagnostic phase.
REC reference: 19/WS/0094
Protocol number: Not Applicable
IRAS project ID: 260766

The Research Ethics Committee reviewed the above application at the meeting held on 02 July 2019. Thank you to MS Daryl Regan for attending to discuss the application.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

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

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

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 management permissions from host organisations.

Registration of Clinical Trials

It is a condition of the REC favourable opinion that all clinical trials are registered on a publicly accessible database. For this purpose, clinical trials are defined as the first four project categories in IRAS project filter question 2. For clinical trials of investigational medicinal products (CTIMPs), other than adult phase I trials, registration is a legal requirement.

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>

You should notify the REC of the registration details. We routinely audit applications for compliance with these conditions.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: <https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/>

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).

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, including early termination of the study
- Final report

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

NHS/HSC Sites

The favourable opinion applies to all NHS/HSC sites taking part in the study taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [University Study Approval Letter]	Version 1	16 January 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Clinical Trials Revised Letter]		06 June 2019
Interview schedules or topic guides for participants [YOD interview schedule]	Version 4	11 April 2019
IRAS Application Form [IRAS_Form_10062019]		10 June 2019
Participant consent form [Consent Form]	Version 3	12 April 2019
Participant information sheet (PIS) [Participant Information Sheet]	Version 3	12 April 2019
Research protocol or project proposal [Daryl Regan Study Protocol]	Version 2	12 April 2019
Summary CV for Chief Investigator (CI) [N White Research CV]	Version 1	04 February 2019
Summary CV for student [Daryl Regan Research CV]	Version 1	04 February 2019

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

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.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: <https://www.hra.nhs.uk/planning-and-improving-research/learning/>

19/WS/0094	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely

On behalf of
Dr Malcolm Booth
Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: Ms Emma Jane Gault
Lead Nation

West of Scotland REC 1

Attendance at Committee meeting on 02 July 2019

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Gazala Akram	Lecturer and Advanced Psychiatric Pharmacist	Yes	
Dr Malcolm Booth	Consultant in Anaesthesia and Intensive Care (Chair)	Yes	Chair of Meeting
Dr Katriona Brooksbank	Clinical Trial Manager	No	
Dr Anne Marie Coleman	Psychotherapist	No	
Dr Ross Fairgrieve	Consultant in Paediatric Anaesthesia and Pain Management	Yes	
Dr Natasha Fullerton	Consultant Neuroradiologist	No	
Mrs Elspeth Fulton	Retired Senior Clinical Research Associate (CRA)	No	
Miss Linda Galbraith	Former Management Consultant	No	
Mrs Lynda Hamilton	Retired Manager	Yes	
Dr Peter Hutchison	GP (Vice Chair)	Yes	
Dr Derek Manson-Smith	Information Research Consultant (Retired)	Yes	
Dr John D McClure	Statistician	Yes	
Dr Colin Petrie	Physician and Cardiologist	No	
Mr Elliot Porter	General Teaching Assistant-Philosophy	Yes	
Mrs Laura Rooney	CRUK Lead Research Nurse	No	
Dr Patricia Roxburgh	Medical Oncologist	No	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Ms Veronika Burgess	Assistant Coordinator
Mrs Kirsty Burt	Senior Co-ordinator

Appendix 6: Participant Information Sheet



University
of Glasgow

PARTICIPANT INFORMATION SHEET

Young onset dementia: Partners' experiences of the journey to diagnosis

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear, or if you would like more information.

What is the purpose of the study?

The study is a collaboration between the University of Glasgow and NHS GG&C. The aim of the study is to gain a better understanding of partners' experiences during the pre-diagnostic stage of young onset dementia.

Who is organising and funding the research?

NHS GG&C is the sponsor for this study. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. NHS GG&C will keep identifiable information about you (for 10 years after the study has finished until 2029).

Why have I been asked to take part?

You have been asked to participate because you are the partner of an individual supported by the NHS GG&C Young Onset Dementia Service.

Do I have to take part?

No, you do not need to take part. If you do decide to take part, you will be given this information sheet to keep and your contact details will be passed on to the researcher carrying out the study.

If you decide to take part, you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your legal rights or the care of you or your partner.

What will happen to me if I take part?

If you do decide to take part, you will be invited to an interview in NHS premises near where you live. A home interview can also be arranged, where it is not possible to attend NHS premises. It is possible to claim travel expenses within NHS GG&C to the research interview, by providing the researcher with receipts for your travel to the interview. You will be asked to sign a consent form. The interview is expected to last between 60 and 90 minutes. The interview will be recorded.

Following the interview, if required, we can also discuss possible sources of support that may be available to you.

Will my taking part in this study be kept confidential?

All of the information gathered will be kept confidential in compliance with the General Data Protection Regulation (2018). You will be asked to provide some personal details such as your name and age, as well as some other demographic details. All paper documentation will be stored in a locked filing cabinet within the NHS GG&C Young Onset Dementia Service. The recordings from the interview will be transcribed and then made anonymous. The anonymous transcripts will be stored on an encrypted password protected University of Glasgow computer. They will be destroyed once the study is complete. No personally identifiable information will be included in the publication of this research. Direct quotes may be used but these will be fully anonymised. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

NHS GG&C will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from NHS GG&C and regulatory organisations may look at your research records to check the accuracy of the research study. The YOD Dementia Service will pass these details to NHS GG&C along with the information collected from you. The only people in NHS GG&C who will have access to information that identifies you will be people who need to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. NHS GG&C will keep identifiable information about you from this study for 10 years after the study has finished until 2029.

If you share information that makes the researcher concerned for your safety or the safety of other people, they may be required to tell others (e.g. your General Practitioner). They will always endeavour to discuss this with you beforehand and to explain why.

What will happen to the results of the research study?

The results of the study will form part of the principal researchers' qualification of Doctorate in Clinical Psychology. They will be published on the University of Glasgow website as part of an academic thesis. It is anticipated that the results of the study will also be published in an online academic journal. In any publication, information will be provided in such a way that neither you nor your relative can be identified. Prior to taking part in the study, you will be given the option to receive a summary of the study findings once the study is complete.

Who has reviewed the study?

The study has been reviewed by the University of Glasgow and the West of Scotland Research Ethics Committee to ensure that it meets standards of ethical conduct. Approval has been granted by NHS GG&C Research and Development department.

Are there any benefits to taking part?

There are no direct benefits to you for taking part in this study. However, the information that you provide will help our understanding of how partners experience the pre-diagnostic phase of young onset dementia. It will help us to work out how best to support individuals within this context and develop better psychological care and support for patients and their families.

Are there any down sides to taking part?

It is possible that the research interview 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 become upset or distressed as a result of your participation in the research, you will be signposted to appropriate supports.

What if I withdraw from this research study?

You can withdraw from the study at any time. You do not have to provide a reason and if you withdraw this will have no effect on the care of your family member.

What will happen if I have a problem or complaint?

If you have any concerns about the study or the way it is conducted or if you want to complain about any aspect of this study, please contact Professor Tom McMillan, Mental Health and Wellbeing, Gartnavel Royal Hospital, 1st Floor, Admin Building, University of Glasgow, Glasgow G12 0XH. The normal NHS complaint mechanisms will also be available to you.

What do I do now?

If you are interested in taking part in the study, please discuss this with a member of the staff team in the Young Onset Dementia Service. Your contact details will then be passed on to the principal researcher. Alternatively you can contact the principal researcher directly using the contact details below. Following this, you will then be contacted to answer any questions that you may have about the study and to arrange an appointment for the interview if you decide to participate.

Contact Details

Chief Investigator:

Dr Naomi White

Dept of Psychological Medicine,

Administration Building,

Gartnavel Hospital,

1055 Great Western Road,

Glasgow

G12 0XH

Tel: 0141 211 3920

Principal Investigator:

Daryl Regan

Trainee Clinical Psychologist

Administration Building,

Gartnavel Hospital,

1055 Great Western Road,

Glasgow

G12 0XH

Email:

Tel: 0141 211 3920

Field Supervisor and NHS Contact

Dr Marie Prince

Consultant Clinical Psychologist and Team Lead

Young Onset Dementia Service

West House, Room 6.08

Gartnavel Royal Hospital

1055 Great Western Road,

Glasgow

G12 0XH

Tel: 0141 201 4805

Independent Research Contact

Professor Tom McMillan

1055 Great Western Road

Glasgow

G12 0XH

Tel: 0141 211 3920

Thank you very much for reading this and for any involvement you may have with the study.

Appendix 7: Participant Consent Form



University
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CONSENT FORM

Title of Project: Young onset dementia: Partners' experiences of the pre-diagnostic phase

Name of Researcher: Daryl Regan

Please initial box

1. I confirm that I have read and understand the participant information sheet Version 3 dated 12/04/19 for the above study and have had the opportunity to ask questions, and I am satisfied with the answers I received.

2. I understand that my participation is voluntary and that I am free to withdraw at any time. Should I wish to withdraw, I understand that I can do so without giving reason, without my legal rights being affected and without my or my family members' care being affected.

3. I understand that all my personally identifiable information will be kept confidential and securely in line with data protection policies/regulations, and that only the researcher, her supervisors and regulators whose job it is to check the work of researchers will have access to that information.

4. I agree that my name, contact details and data described in the information sheet will be kept for the purposes of this research project.

5. I understand that if I withdraw from the study, my data collected up to that point will be retained and used for the remainder of the study.

6. I agree to my interview being audio recorded and transcribed.

7. I agree that fully anonymised quotations may be used in the study write up, publications and other materials arising from the study, but that these will be fully anonymised and it will not be possible to identify myself or my family member as an individual.

8. I confirm that I agree to the way my data will be collected and processed and that data will be stored for up to 10 years in University or NHS archiving facilities in accordance with the General Data Protection Regulation (2018).

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

If, when the study is finished, you would like to receive a summary of the study findings, please write your postal address or email address below.

Name of Participant

Date

Signature

Researcher

Date

Signature

(1 copy for participant; 1 copy for researcher)

Appendix 8: Interview Schedule



University
of Glasgow

Young onset dementia: Partners' experiences of the pre-diagnostic phase

Interview Schedule

Initial Changes

1. Can you tell me about when you first noticed a change in your partner?
 - 1.a What else did you notice?
2. At first, how did you try to make sense of the changes you'd observed?

Impact on Carer

3. How did the changes in your partner affect you?
 - 3.a How did you feel about that?

Experience of Getting a Diagnosis

4. Can you tell me how your partner came to receive their diagnosis of young onset dementia?
5. How did the process affect you?
 - 5.a How did that make you feel?

Experience of Services

6. Can you tell me which services you had contact with during the process of your partner receiving their diagnosis?

6.a What did you find helpful about your experiences with services?

6.b What did you find unhelpful about your experiences with services?

Appendix 9: Sample Transcript

702 and can't really be spoken to on their own and given those set of
 703 instructions. If you're running a Neurology clinic in a hospital, you
 704 can't have people at the front desk who are offhand and are not
 705 communicating properly. You know, you need, you even need, you
 706 could do with an escort, you know, not just round there and (makes
 707 dismissive noise).

708 R: So something maybe around, it sounds like the professionals, not
 709 the doctors but everyone else

710 P: Yeah everyone else, the nurses, everybody, you know everybody
 711 really needs to have an understanding or an appreciation, if
 712 somebody's ill in Neurology, they're there because they are sick.)
 713 they may look fine but they're not. You know and they need time,
 714 they need space, they need explanation and the person with them
 715 also needs explanation. You know...it's (sighs) and the (laughs) some
 716 of the medical letters that have come back, results of scans and
 717 stuff...even looking them up on the internet to try and decipher what
 718 they're about, you can't, you can't. You know (laughs).

719 R: So it's quite confusing at times? *disbelief*

720 P: It's impenetrable, you know, em but I think as well if you think
 721 about that very first meeting with the GP where he was giving us the
 722 results, sorry there's an increased white matter, what does that
 723 mean? I don't know what that means! You know and then he has to
 724 look up Cadasil, you know. That's (laughs) that's not good. You know
 725 where your doctor is googling stuff, you know.

726 R: So it sounds as if that initial communication *frustration*

727 P: Yeah it's, you know, it's (sighs) it's not really good enough. It's not
 728 really good enough from Health Professionals. I wouldn't have
 729 behaved like that in my professional life. Your paid...a salary to to
 730 have the knowledge and the communication skills and it's not really
 731 good enough, to to behave like that. I think it's not helpful in a very
 732 stressful situation. The (name) the girl from Alzheimer's Scotland, she
 733 was saying that one of her colleagues had had a diagnosis of cancer
 734 and when she was given the diagnosis, she was taken into a room,
 735 the doctor was there and she was there and there was a nurse there
 736 to help support. So she was given the diagnosis, I'm really sorry,
 737 you've got cancer and then she was given time with the nurse who
 738 said, ok this is what's gonna happen now, don't panic, this is the
 739 treatment you're going to get. These are the people you need to be
 740 talking to, these are the support services and all the rest of it. For
 741 your doctor to say to you, you've got increased white matter, I'm
 742 sorry...out you go. That's it. That is, I mean you

Whole staff approach

physical presentation masking illness

system impenetrable

Communication causing stress

YoD treatment leading to physical illness

Communicate to patient

wants to have a wider role and that to be acknowledged

- Holistic approach.

All staff being trained not just medic

inclusion of all

All staff need to keep patient's needs at forefront

perception that you cannot see illness person is treated as being unwell

des and simple explanation

implies impossible to break a navigate disbelief

disbelief at GPs behaviour

If GP doesn't know who to refer to?

- confidence in system & repetition series emphasis from

Communication and behaviour not good enough

Awareness that this impacts negatively on her stress

Thinking about difference in treatment with physical health e.g. cancer

Huge contrast in participants own experience versus their awareness of the experience of others with illnesses such as cancer.

Appendix 10: Sample Theme and Exemplar

Superordinate Theme	Subtheme	Exemplar	Representation
Changing Relationship with Partner	The Battle	<p><i>"I didnae [didn't] push her... sometimes you just want the easy life that you're thinking, 'Oh f**k that'll upset her, don't bother'"</i> (Mark)</p> <p><i>"So, we went from having this very calm relationship to having a very sort of niggly one. Or rather, me having a go at him all the time"</i> (Nina)</p> <p><i>"Well I couldnae [couldn't] make sense of it. I thought it was just total un-, she was no' interested...she's no' listening...just generally thinking that, it doesnae [doesn't] matter what I say"</i> (Daniel)</p> <p><i>"I really thought my wife was fed up living with me...I could never ever give her an answer that suits, that seemed to suit her"</i> (Josh)</p> <p><i>"We stopped doing anything in the house. Everything was a battle of negotiation, to get a room painted... something repaired... these were tiny little insidious incremental changes that suddenly I - from somebody that was really easy going and good fun...everything became a sort of battle"</i> (Karen)</p> <p><i>"And then you know, he was getting so aggressive".</i> (Natalie)</p>	<p>Mark Nina Daniel Josh Karen Natalie</p>
	Loss	<p><i>"She'd retired for about 8 years and I'd just retired and thinking, 'oh we'll do this, or</i></p>	<p>Mark Nina Daniel</p>

	Loss	<p><i>oh we'll do that' but it didnae happen - just didnae happen"</i> (Mark)</p> <p><i>"You still see the sick person, I still see Paul as you know, I look at him and I see my husband there (becomes tearful)"</i> (Nina)</p> <p><i>"Oh you're hurt, you're cut because for 30 years we've, we don't do anything separate... we're always together, you see one you see the other that's it"</i> (Daniel)</p> <p><i>"It was awful because we were married...36, 37 years married [inhales]...everything seemed to be going really well in life, touch wood. And then all of a sudden - what I thought - 'was our marriage coming to an end after all that time?' So...it was really upsetting"</i> (Josh)</p> <p><i>"We're not a married couple anymore. We've got no, there's no meeting of minds"</i> (Karen)</p> <p><i>"It wasn't the man that I married or that I'd been married to for over 40 years"</i> (Natalie)</p> <p><i>"That's the way I feel because we've been, my best pal, you know what I mean, she's my best friend and...I'm no gonnae break down because aye, I've done all that but it's, it's a horrible horrible disease"</i> (Frank)</p>	Josh Karen Natalie Frank
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Appendix 11: Research Proposal



Doctorate in Clinical Psychology

The University of Glasgow / NHS (Scotland)

Major Research Project Proposal

Young onset dementia: Partners' experiences of the pre-diagnostic phase

Exam Number:

Date of Submission: 8th December 2018

Version Number: Version 4

Maximum Word Count: 3000

Actual Word Count: 3155

Abstract

Background

It is estimated that in 2019 there will be 640 people diagnosed with a young onset dementia (YOD) in Scotland. Obtaining a diagnosis of YOD can be complex, with multiple diagnostic pathways. Partners of those with YOD are often involved in this process; however, little is known about how they experience the pre-diagnostic phase from initial symptom recognition to formal diagnosis seeking.

Aims

This study aims to examine how partners make sense of the period from observing initial symptoms to seeking healthcare support, as well as what it is like for them to be involved in the process of seeking help from health and social care services for the patients' YOD.

Methods

Participants will be partners of those who have a diagnosis of YOD, living within Greater Glasgow and Clyde. Semi-structured interviews will be audio recorded then transcribed verbatim and analysed using IPA.

Application

Findings will contribute to a better understanding of the experiences of partners in the pre-diagnostic stage of YOD. It is hoped that findings can aid service development around timely diagnosis, as well as helping to inform clear, well co-ordinated care pathways.

Introduction

Dementia is often thought of as a disease that affects only older people; however, it can also occur in younger people, with dementia occurring before the age of 65 being referred to as young onset dementia (YOD). YOD makes up a notable number of dementia diagnoses worldwide (Mendez, 2006) and this is reflected within a Scottish context, with the NHS National Services Scotland's Information Services Division (NSS ISD, 2016) predicting that there will be 640 YOD diagnoses in Scotland in 2019. Of these, it is estimated that 135 will be within Greater Glasgow and Clyde.

As YOD occurs at a younger age, individuals are often economically productive and socially active, for example, employed and caring for young children. Therefore, YOD can have a profound impact on an individual's sense of identity (Harris & Keady, 2009) and quality of life (Baptista et al, 2016). Alongside this, the diagnosis often has a major impact on family functioning (Svanberg, Spector & Stott, 2011) and can result in psychological distress for partners who find themselves suddenly in a caring role (Kaiser & Panegyres, 2007).

Timely dementia diagnosis continues to be a key theme in the Scottish Government's third dementia strategy (Scottish Government, 2017). Despite the detrimental economic and social impact of delayed diagnosis, there remain challenges worldwide in diagnosing YOD (Carter, Oydbode & Koopmans, 2018; Chrisp, Thomas, Goddard & Owens, 2011). Those with a YOD, compared to late onset dementia (LOD), may present with neuropsychiatric symptoms such as changes in mood or personality, as opposed to the memory difficulties typically characteristic of LOD (Kelley, Boeve & Josephs, 2009). This difference, in combination with the relatively low prevalence rate,

can mean that YOD is frequently misdiagnosed in the initial pre-diagnostic stage (Werner, Stein-Shvachman & Korczyn, 2009). As well as this, behavioural and personality changes resulting in a loss of insight have been shown to reduce help seeking behaviours for individuals with YOD (Van Vliet et al, 2011).

Draper et al (2016) found that it took an average of 4.7 years for those with YOD to receive their final diagnosis. Furthermore, 49% of those who received a diagnosis of YOD had received another psychiatric diagnosis during this process. In a recent qualitative study exploring views on care from the perspective of YOD healthcare professionals, staff acknowledged the importance of recognising early symptoms. However, they also highlighted the challenges of diagnostic uncertainty (Spreadbury & Kipps, 2018).

This reflects the findings of Williams, Dearden and Cameron (2001) who found that for 132 YOD patients, 38 different pathways of care were identified in reaching a diagnosis. Furthermore, at a more local level, a 2015 audit within NHS Greater Glasgow and Clyde (GG&C) found complex diagnostic pathways in the assessment and diagnosis of those with YOD. Overall, across 26 cases, it was found that there were 20 different care pathways to reaching a diagnosis.

Interactions with health services during this period have been described in the literature as being experienced negatively by carers, who reported being passed between different medical consultants and not receiving enough practical help, support or counselling (Spreadbury & Kipps, 2017). Carers also described feeling that they did not 'fit in' to existing services or systems and often receive incorrect, confusing and contradictory information (Lockeridge & Simpson, 2012).

As well as the potential impact of inconsistent pathways, for a diagnosis to occur, a person, carer or family member must first identify that there is something wrong and decide to attend their GP. There is a paucity of research into the ways in which family members of those with YOD experience the diagnostic pathway from the point of initial symptom recognition to formal diagnosis seeking. In one of the few qualitative studies exploring the pre-diagnostic period, Van Vliet et al (2011) carried out interviews with 82 YOD caregivers and analysed these using grounded theory. Caregivers included spouses, siblings and children of those with YOD. Key themes emerged including the carers' initial misattribution of symptoms, inadequate service provision, as well as serious disruption to the marital relationship for those carers who were spouses.

A number of studies have highlighted differences in the experiences of spouses or romantic partners in a caregiving role as opposed to other forms of carers such as a child, sibling or other relative. Partners have been found to be more at risk of experiencing loneliness (Luscombe, Brodaty & Freeth, 1998) as well as changes to sexual and intimate relations impacting on relationship quality (Holdsworth & McCabe, 2018).

Given that the nature of the experience for a partner is therefore different to another form of carer, further exploration is needed to understand how intimate partners living with individuals with YOD come to recognise a problem and attend health services. It is well documented that the route that patients take through services to reach a diagnosis, often referred to as the diagnostic pathway, can be complex; however, little is known about how partners of those with YOD experience these pathways along with the initial pre-diagnostic phase. A greater understanding could be used to inform service development, aid understanding of the barriers to YOD diagnosis and to best support those with YOD as well as their partners.

Aims

The aim of this study will be to retrospectively explore partners' lived experiences of the pre-diagnostic phase of YOD. Specifically, the study will aim to analyse how partners make sense of what it is like for them to be involved in the process of seeking help from health services.

Plan of Investigation

Participants

Participants will be the partners of those who have received a diagnosis of YOD, living within GG&C. Purposive sampling will be used to select participants on the basis that they can provide a rich, reflective account of their experiences.

Inclusion Criteria

Individuals who are living with a partner who was diagnosed with YOD within the last 3 years will be invited to participate. The term partner refers to someone in a marriage or romantic relationship. Participants must be able to recall and reflect on the period from when they noticed symptoms to when their partner received their diagnosis.

Exclusion Criteria

Individuals will be excluded if they do not speak English fluently as the use of interpreters is out with the financial scope of the study. They will also be excluded if their partner has a secondary dementia diagnosis as opposed to a primary dementia diagnosis. Primary dementias are those in which the dementia itself is the major sign of an organic brain disease. Secondary dementias are those caused by, or closely

related to another disease such as HIV, Parkinson's disease or Huntington's disease. Research has shown that experiences may be different for those where dementia is secondary to a primary comorbid diagnosis (Bunn et al, 2014). Partners who are unable to give informed consent will also be excluded.

Recruitment Procedures

Participants will be recruited from the YOD Service within NHS GG&C. Staff in the YOD Service will identify suitable participants. They will give those interested a participant information sheet and will also gain verbal consent, for the researcher to be given their contact details. Participants will be contacted by the lead researcher to answer any further questions and to confirm their interest in participating.

Design

The study will be qualitative, employing Interpretative Phenomenological Analysis (IPA). IPA aims to explore in great depth an important aspect of the participant's life and how they make sense of their personal and social world. IPA acknowledges that how the researcher makes sense of a participant's experiences will be influenced by their own prior conceptions, as well as the interaction between the researcher and the participant (Brocki & Wearden, 2006). Key quality criteria in qualitative research outlined by Tracy (2010) including credibility and sincerity will be used to inform the development of the study. The Consolidated Criteria for Reporting Qualitative Research (COREQ), a 32 item checklist for comprehensive reporting of qualitative studies (Tong, Sainsbury & Craig, 2007), will be adhered to.

Measures

A semi-structured interview schedule will be used. This will allow participants to explore aspects of their experience which are most pertinent to them, as opposed to being determined by researcher assumptions and questions (Larkin, Watts & Clifton, 2006). The interview schedule will be informed by existing literature on the experiences of those living with a partner diagnosed with YOD and developed by the lead researcher in consultation with the researcher's Academic and Field Supervisors. Questions will be open and prompts used judiciously to facilitate access to experience and meaning.

In line with NHS National Institute for Health Research (2014) recommendations, the researcher will consult with a service user group, to shape the development of the interview schedule. Where possible this will be through accessing an existing service user group, such as by contacting Alzheimer Scotland Policy and Research Department. If it is not possible to access an existing service user group, the invitation will be extended to carers from the YOD Service, who do not meet inclusion criteria.

Research Procedures

Written consent will be sought prior to participation and one to one interviews will take place in either local NHS premises, or at the participant's home in exceptional circumstances. Research has shown that the burden of care in the YOD population can be particularly high (Van Vliet, de Vugt, Bakker & Koopmans, 2010) and as YOD is not a common diagnosis in NHS GG&C, a home visit may be considered in exceptional circumstances to facilitate inclusion.

Prior to the interview, participants will be asked if they have any further questions regarding the study and will be reminded that they can withdraw from the study at any point. Each interview is expected to last approximately 60-90 minutes. Interviews will be recorded on two digital recording devices and will be transcribed verbatim.

Data Analysis

Data will be analysed using IPA (Smith, Flowers & Larkin, 2009). Computer assisted qualitative data analysis software such as QDA Miner will be used to help organise and code data. A close line by line analysis of each participant's experiential claims and understandings will be employed. Following this, emergent themes will be explored firstly within then between cases. Following the identification of themes, the research supervisor will take a subset of the data to check validity and relevance. Themes will also be reviewed by the service reference group. A dialogue will be developed between the researcher, their research supervisor, the coded data and their combined psychological knowledge about what it might mean for participants, to form a more interpretative account. Finally, relationships between key themes will be represented diagrammatically.

Justification of Sample Size

Within IPA, the aim is to gain a rich depth of understanding of participant experience. For this reason, purposive sampling will be used to select a homogeneous sample of participants who are able to provide a rich account of experience. Based on Smith, Flowers & Larkin (2009), it is estimated that the study will recruit approximately 4-10 participants. Concurrent data analysis will be used to inform the appropriate point to end recruitment, once data saturation has been met.

Health and Safety Issues

Researcher safety issues

If a home visit is required, the 'Home Visits and Research Guidance' in the Glasgow University Doctorate Handbook and the NHS GG&C Lone Working Policy will be adhered to. Home visits will be carried out in working hours and will only be considered if a recent comprehensive risk assessment has been carried out by NHS staff.

Participant safety issues

There are measures in place to protect participant safety. Participants will be briefed prior to participation. They will be reminded that they can withdraw at any point and will be debriefed. The researcher is a Trainee Clinical Psychologist and has training in undertaking interviews sensitively and engaging with those in distress. If a participant becomes distressed, steps will be taken to offer support. Participants will be reminded that they can seek support from the NHS YOD team. They may be signposted towards their GP, or other relevant 3rd sector support.

Ethical Issues

Ethical approval will be sought from the appropriate body, either the University of Glasgow or NHS ethics. Further advice will be sought on the type of ethical approval required for the study. Digital recording devices will be transported in a password protected NHS briefcase. They will be stored in a locked NHS filing cabinet, then audio data will be deleted once transcribed and anonymised. Transcriptions will be stored on a password protected laptop and encrypted USB drive.

Following the study, transcribed data will be stored securely for a period of ten years, within the University of Glasgow. An end of study declaration form will be completed,

along with a plan for how and when the data is eventually destroyed, for example by staff in the Health and Wellbeing department. This is in accordance with Glasgow University Data Retention Policy (University of Glasgow, 2016) as well as the General Data Protection Regulation (2018).

Financial Issues

See Appendix 2

Timetable

See Appendix 3

Practical Applications

The study is expected to contribute to a better understanding of the experiences of partners in the pre-diagnostic stage of YOD. It is hoped that the findings can aid service development in Scotland around timely diagnosis in YOD, as well as helping to inform clear and well co-ordinated pathways that suit the needs of those with YOD and their partners. This is in line with Scotland's National Dementia Strategy (2017).

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Appendices

APPENDIX 1: HEALTH & SAFETY FORM HEALTH AND SAFETY FOR RESEARCHER

Title of Project: Young onset dementia: Partners' experiences of the pre-diagnostic phase

Participants: (age, group or subgroup, pre- or post-treatment, etc): Participants are the partners of clients with YOD who have been diagnosed in the past 3 years.

Procedures to be applied (eg, questionnaire, interview, etc): Individual interviews.

Setting (where will procedures be carried out?) i) General ii) Are home visits involved Y/N: The setting will be NHS clinic space, the Alzheimer Scotland Dementia Café and possibly participants homes.

Potential Risk Factors Identified see chart: The main risk factor identified is home visits under exceptional circumstances.

Actions to minimise risk: Where possible, participants will be seen within NHS clinic space or at the Alzheimer Scotland Dementia Cafe. If it is not possible to meet with them in this setting, a home visit will be considered to facilitate participation. As cases are all known to the YOD service or Alzheimer Scotland, staff within these teams will be able to advise if there are any known risk factors and a home visit will only be carried out, if a recent risk assessment has been completed. If home visits are conducted, the researcher will follow NHS Glasgow's Lone Working policy and the 'Home Visits and Research Guidance' in the Glasgow University Doctorate Handbook. This includes measures to minimise risk such as letting another staff member know when the home visit has been completed and only carrying it out within working hours.

APPENDIX 2: RESEARCH COSTS & EQUIPMENT RESEARCH EQUIPMENT, CONSUMABLES AND EXPENSES

Year of Course: First Year

Intake Year: 2017

Please refer to latest stationary costs list (available from student support team)

Item	Details and Amount Required	Cost or Specify if to Request to Borrow from Department
Stationary	Paper for participant information packs	£2
Postage	Stamps for sending information to participants if required	£10
Photocopying and Laser Printing	Printing participant information sheets	£10
Equipment and Software	<ul style="list-style-type: none"> • 2 Digital recording devices • Laptop • Transcription foot pedal 	These will be borrowed from the University of Glasgow.
Measures		
Miscellaneous	Participant travel expenses	£50
Total		£50

Appendix 3: Timetable

Task	To Be Completed By
Proposal Submitted	September 2018
Awaiting Confirmation to proceed to ethics	October – December 2018
Writing and Submitting Ethics Application	December 2018 – January 2019
Recruitment Data Collection Transcribing	April – July 2019
Data Analysis and Write Up	August 2019 – January 2020
Submission of Thesis	February 2020
Viva	April 2020