Validation of the Multidimensional Scale of Perceived Social Support (MSPSS) for family carers of people with dementia

Anna Cartwright

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Thesis Declaration Form

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

Signature 

Name: Anna Cartwright

Date: 17/06/2020

Overview

There are approximately 850,000 people with dementia in the UK, many of whom are cared for by family members. The protective effects of social support is an incredibly important area of research for family caregivers. However, it is unclear whether measures of social support retain their psychometric properties when used with this population.

Part 1 comprises a systematic review of qualitative studies investigating the lived experiences of children of people with young onset dementia (YOD). Fifteen articles were appraised and included in a thematic synthesis. Findings indicated significant variation in experiences and highlighted the lack of knowledge and understanding of YOD and the scarcity of appropriate support. The findings have clinical implications for professionals working with families affected by YOD, in particular with regards to service design and delivery.

Part 2 comprises an empirical study, the primary aim of which was to conduct an in-depth psychometric analysis of the Multidimensional Scale of Perceived Social Support (MSPSS) in a sample of family caregivers of people with dementia. This was a joint study conducted with Rich Pione (Trainee Clinical Psychologist), who sought to determine the psychometric properties of the Positive Psychology Outcome Measure (PPOM). Findings indicated that the MSPSS has robust psychometric properties and is suitable for use with caregivers of people with dementia.

Part 3 is a critical appraisal, the aim of which was to reflect on the process of the research, consider conceptual issues and key decisions that arose during the project and discuss implications and recommendations for further research.

Impact Statement

There are hundreds of thousands of individuals in the UK providing care for a family member with dementia. Around 5% of those with dementia have young onset dementia (YOD), defined as dementia diagnosed before the age of 65 years. People with dementia are often cared for by their families, including their children.

Caring for a family member with dementia has been associated with poorer mental and physical health. However, the impacts of caregiving vary widely and factors such as social support have been associated with improved wellbeing. Prior to the current project, there was no gold standard measure of social support for family caregivers of people with dementia, as the psychometric properties of available measures, when applied to this population, had not been rigorously assessed.

The review paper was the first to critically appraise and synthesise recently published qualitative literature regarding the lived experiences of those affected by parental YOD. The paper has been submitted for peer-review to the journal 'Dementia: The international journal of social research and practice'. It is hoped that dissemination of the findings within academia will lead to further research into the experiences of those caring for a parent with YOD, an area of research that is currently in its infancy.

Raising awareness of these findings amongst clinicians and commissioners involved in service design and delivery will hopefully lead to improvements in the support available to this population, such that the needs of individuals with YOD and their families are better met. It is hoped that increasing knowledge and awareness of YOD amongst the general public will also reduce the stigma associated with caring for a parent with YOD and improve quality of life for family caregivers.

The empirical study was the first to conduct an in-depth psychometric analysis of a measure of social support, when used with family caregivers of people with dementia. The findings indicate that the Multidimensional Scale of Perceived

Social Support (MSPSS) may be recommended for use with family caregivers of people with dementia due to its robust psychometric properties. This paper has been submitted for peer-review to the journal 'Aging and Mental Health'.

It is hoped that the dissemination of these findings will lead to greater consistency in the use of social support outcome measures in research and clinical practice. The MSPSS has been used internationally and translated into a number of different languages and is freely available online. More widespread use of the MSPSS will enable greater comparability across studies and thus more rigorous research regarding the role of perceived functional social support, for example using meta-analysis. It is also hoped that further research will establish the responsiveness of the MSPSS to enable its use in determining clinically important change following intervention.

Finally, the paper highlights the importance of social support as a predictor of greater quality of life and lower levels of depressive symptoms. This has important implications with regards to public health and wellbeing, particularly for family caregivers.

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Part 1: Literature Review

The experiences of those affected by parental young onset dementia: A qualitative systematic literature review

Abstract

Aim: To develop understanding of the lived experiences of children of people with young onset dementia (YOD), defined as individuals both under and over the age of 18 years whose parent was diagnosed with dementia before the age of 65 years.

Method: A critical appraisal and thematic synthesis of the available qualitative literature regarding the lived experience of individuals whose parent has a diagnosis of YOD. A three-stage approach for conducing thematic synthesis was followed.

Results: Fifteen articles were included in the review. Four analytical themes and eleven subthemes were found. The analytical themes were: 'making sense of dementia', 'impact of dementia', 'coping' and 'support'.

Conclusions: The experiences of those affected by parental YOD vary widely. There is a lack of knowledge and understanding of YOD by professionals and the public, and a scarcity of appropriate support. This has clinical implications for professionals working with families affected by YOD, in particular with regards to service design and delivery.

Introduction

Dementia and Young Onset Dementia (YOD)

Dementia is an umbrella term used to describe a set of symptoms in which there is a deterioration in cognitive function, beyond what might be expected from normal ageing. Symptoms may include memory loss, mood changes and difficulties communicating and reasoning. YOD is defined as the presentation and diagnosis of dementia before the age of 65 years. This is a widely used but arbitrary and socially determined cut-off point with no biological significance, possibly originating from retirement age (Rossor et al., 2010). There has been inconsistency in terminology used within the literature, with 'young onset', 'early onset' (Johannessen & Moller, 2013), 'working age' (Rudman et al., 2011) and 'presenile' used interchangeably. Recently, the term YOD has become the most frequently used and will therefore be used within this paper (Koopmans & Rosness, 2014).

There are approximately 42000 people in the UK with a diagnosis of YOD, representing around 5% of the total number of people with dementia (Dementia U.K., 2014). The most common causes of dementia in both older and younger people are Alzheimer's disease (AD), vascular dementia (VD), frontotemporal degeneration (FTD) and dementia with Lewy Bodies (Rossor et al., 2010).

Differences Associated with YOD

There are clinical and psychosocial differences associated with YOD, which differentiate it from dementia diagnosed in later life. For example, people with YOD are more likely to have dementias other than AD, such as frontotemporal degeneration, characterised by changes in personality, behavioural disturbances and reduced empathy and motivation (Jefferies & Agrawal, 2018). In addition, the younger the onset, the more likely it is that dementia is caused by a genetic or metabolic disease (Sampson et al., 2004). YOD is therefore more likely to be hereditary.

Differences in the presentation of YOD also complicate the diagnostic process and often lead to misdiagnosis. For example, approximately one third of people with young-onset sporadic AD have non-amnesic deficits, compared to only 5% of those with later-onset variants (Koedam et al., 2010). Neuropsychiatric symptoms, such as aggression, agitation, depression, anxiety, hallucinations, delusions, disinhibition and apathy are also more common (Mendez, 2006). There are more varied differential diagnoses, many of which are infections, toxic-metabolic or inheritable conditions. Difficulties obtaining a timely and accurate diagnosis are therefore more common for people with YOD, as symptoms are often attributed to other causes. One study reported the average time between onset of symptoms and diagnosis as 4.4 years for YOD, compared to 2.8 years for people with later onset dementia (van Vliet et al., 2013).

Impact of YOD

Adults diagnosed with YOD commonly have a range of important roles and responsibilities, including employment, parenting, caring for elderly family members and significant financial commitments. They tend to be more physically fit at the time of diagnosis, with fewer comorbid health problems compared to those diagnosed in later life. As dementia is commonly perceived as an illness of old age, people with YOD often report the diagnosis as a shock, with many experiencing adjustment difficulties (Sansoni et al., 2016).

Common issues raised by people with YOD in the early stages include difficulties being taken seriously by doctors and obtaining a diagnosis (Johannessen & Moller, 2013). In the post-diagnostic period, there are often significant changes to the person's lifestyle, including withdrawal from activities such as working, driving, hobbies and socialising (Spreadbury & Kipps, 2019). These changes can lead to strain on relationships, social isolation and feelings of marginalisation, increased financial pressure, poor self-esteem, and reduced sense of purpose (Harris, 2004; Roach & Drummond, 2014). Dementia can have a significant impact on a person's

identity as a worker, partner and parent and has been described as a 'threat to identity' (Clemerson et al., 2014). The experience of dementia can also have a positive impact, for example some people with YOD experience the relationship with their caregiver as 'closer' or 'strengthened' (Harris, 2004; Johannessen & Moller, 2013).

Caring for People with YOD

The majority of people with dementia are cared for at home by a relative or friend (Newbronner et al., 2013). Spouses and adult children are typically the main sources of informal care (Wawrziczny et al., 2016). Caring responsibilities may include emotional support, practical support with tasks such as cooking and cleaning, help with personal care, such as washing and toileting and support with finances and medication.

Spouses report difficulties managing the behavioural and psychological symptoms of dementia, experiencing grief associated with the 'loss' of their spouse and finding it hard to balance the caring role with other responsibilities such as employment and parenting (Sansoni et al., 2016). There may also be a decline in intimacy and emotional closeness and increase in conflict, impacting the spouse-caregiver relationship (Nogueira et al., 2015; van Vliet et al., 2011).

The responses to caregiving are thought to differ for children and young people, suggesting that findings from studies with spouses and other family members may not apply to this population. For example, Spreadbury and Kipps (2019) reported that adolescent and young adult caregivers may be more susceptible to mental health problems as a result of caregiving, including self-harm and suicidal ideation. They were also reported to use different coping strategies, including withdrawal from the caregiving environment, emotional detachment, denial, masking feelings and trying to maintain a sense of normality. The positive effects of caring for young people may include learning new skills, feeling useful and feeling a sense of closeness to the family (Joseph et al., 2012).

Professional Support

Typically, people presenting with YOD are referred to dementia services set-up for older adults and receive their diagnosis and care from old age psychiatrists (The Royal College of Psychiatrists, 2018). However, staff in these services may be less well-equipped to provide specialist support and advice catering to the particular needs of people with YOD and their families (Sansoni et al., 2016). Richardson et al. (2016) emphasised the need for the development of interventions that benefit people with YOD and their carers. Reviews have highlighted the lack of clear diagnostic pathways, poor availability of relevant information, lack of appropriate referrals to support services and paucity of age-appropriate services (Sansoni et al., 2016; Spreadbury & Kipps, 2019). A report by the Royal College of Psychiatrists suggests that "the needs of patients with YOD in the care of mental health trusts are best met by a dedicated specialist service which actively links with the wider clinical and social network of specialties and services" (The Royal College of Psychiatrists, 2018, p. 6).

For young carers in the UK, there is legislation to ensure that their needs are met. Under the Children and Families Act 2014, local authorities are required to take reasonable steps to proactively identify young carers (often defined as people under the age of 25 who provide regular and ongoing care and emotional support). Carers under the age of 18 also have the right to an assessment, based on the appearance of need, covering topics such as their needs for support and the impact of caring on their education, wellbeing and development. The Department of Health's Care and Support Statutory Guidance (2014) states that: 'Children should not undertake inappropriate or excessive caring roles that may have an impact on their development. A young carer becomes vulnerable when their caring role risks impacting upon their emotional or physical wellbeing and their prospects in education and life.'

Rationale and Aims of the Current Review

In this review, the term 'children' is used to refer to offspring, including those both under and over the age of 18 years, or stepchildren. There are a small number of reviews that have included studies reporting the experiences of children of people with YOD (Cabote et al., 2015; Millenaar et al., 2016; Sansoni et al., 2016; Spreadbury & Kipps, 2019; Svanberg et al., 2011; Van Vliet et al., 2010). However, none of these have focused exclusively on the children. This is likely due to the large gap in research into their needs and experiences, which has been previously highlighted in the literature (Richardson et al., 2016). Over the past few years, there has been an increase in the number of studies published in this field but there has not been a recent systematic review of the literature specifically exploring the experiences of individuals whose parent has a diagnosis of YOD.

The aim of the present review was to critically appraise and synthesise the qualitative literature investigating the lived experiences of those affected by parental YOD. Specifically, it aims to answer the research question: What are the lived experiences of individuals whose parent has been diagnosed with YOD? This question was kept broad to allow for the inclusion of studies focussing on different aspects of lived experience for both children under the age of 18 years and adult children. These findings will lead to a greater understanding of the children's experiences, which can be used to inform service development, ensuring needs of families affected by YOD are better met.

Methods

Search Strategy

Four electronic databases were searched on 13th September 2019: PsycINFO, Ovid (MEDLINE), Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Embase. An example search strategy is included (Table 1). For each database, equivalent database-controlled terms were entered, with the search terms categorised into 4 groups: (1) Time of onset (2) Condition (3)

Population and (4) Experience/qualitative approach. Search terms were combined using AND/OR linking operations. Search strategies consisted of Medical Subject Heading (MeSH) terms and key words. Due to the relative scarcity of research, no date or age restrictions were imposed to ensure inclusion of all relevant articles.

Table 1.

Example electronic search strategy conducted in PsychInfo

Search Concept	Search Terms
1. Time of onset	'working age*' OR 'young* people' OR 'earl* onset' OR 'under 65*' OR ' young* onset' OR presenile
2. Condition	dement* OR alzheimer* OR *exp Presenile Dementia/* OR *exp Dementia/* OR *exp Alzheimer's Disease/*
3. Population	relative* OR child* OR family OR families OR son* OR daughter* OR care* OR *caregivers/*
4. Experience	experience* OR perception* OR perspective* OR impact* OR interview* OR qualitative*

Note. Medical Subject Heading (MeSH) terms used are reported in italics.

Study Selection

Search results were imported into EndNote reference management software. After removing duplicates, titles and abstracts were screened independently against the following criteria.

Inclusion Criteria

1. Published in English in a peer-reviewed journal.
2. Study population consisted primarily of the children (including those both under and over the age of 18 years and stepchildren) of a person with YOD (defined as dementia diagnosed before the age of 65), or the data from children could be separated from that of other participants.

3. Stated aim of the study concerned individual experiences, caring experiences or implications of caring on the children.
4. Qualitative or mixed methods, primary research.

Exclusion Criteria

1. Published in non-peer reviewed journals, grey literature or were unpublished theses.
2. Not an empirical paper (e.g. was a review, conference abstract, protocol)
3. Solely quantitative data collected.

Full texts were sought for all articles thought to potentially meet the above criteria and screened against these criteria. Those considered borderline were discussed with Aimee Spector (supervisor) in order to reach agreement as to whether to include them. Supplementary searches were conducted, including searching reference lists of included papers, reference searching relevant systematic reviews and searching Google Scholar. Although some qualitative reviews only include as many papers required for conceptual saturation, there is no established method for reaching this point of saturation. Therefore, all studies meeting criteria were included.

Data Extraction

A standardised data extraction form was developed, and data extracted independently from all studies under the following headings: study and country, research question/aim, sample, age of participants at time of interview, data collection and approach to analysis. When these data were not reported, authors were contacted for further information.

Quality Appraisal

Quality appraisal was conducted independently using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist (Critical Appraisal Skills Programme (CASP) UK, 2018). This outlines 10 questions to help the reviewer appraise qualitative studies with regards to their validity, findings and value. Most questions

require a ‘yes’, ‘no’ or ‘can’t tell’ response. CASP was chosen, as it is reported to be the most commonly used tool in the quality appraisal process of qualitative evidence syntheses (Majid & Vanstone, 2018). Only studies considered methodologically ‘flawed’ were excluded (Dixon-Woods et al., 2004).

Data Synthesis

A three-stage thematic synthesis approach was used, adopting methods described by Thomas and Harden (2008). This approach was chosen as it addresses review questions, with the aim of informing clinical practice. Other qualitative synthesis methods, such as meta-ethnography, are more suitable for developing new theories or models (Noblit & Hare, 1988).

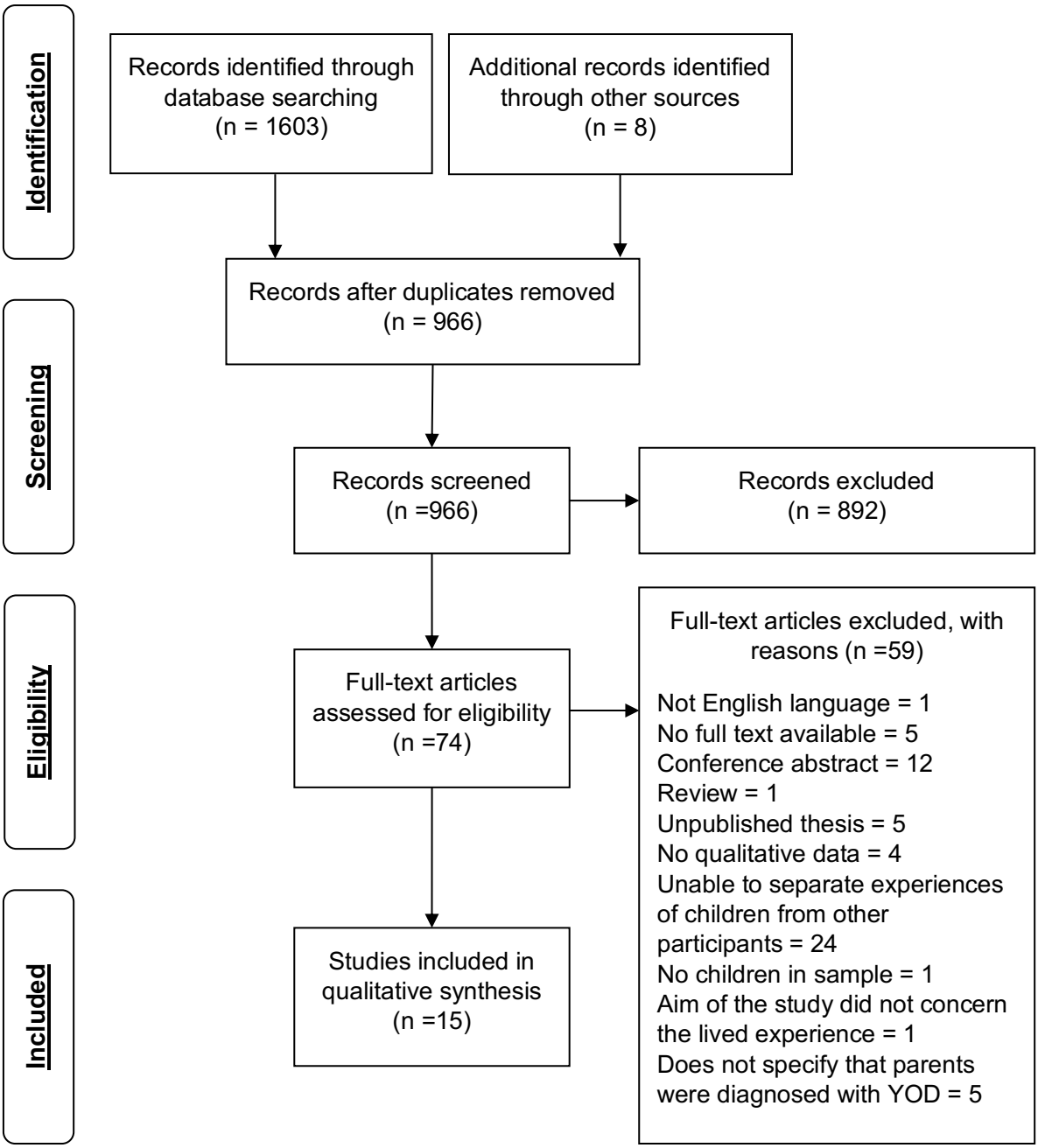
The findings from each paper were entered into NVivo software and text was coded ‘line-by-line’ according to its meaning and content, enabling the translation of concepts from one study to another in an iterative fashion. The second stage involved examining similarities and differences between initial codes, grouping them into a hierarchical structure and assigning descriptive codes to capture the meaning of these groups. This stage was conducted independently by Rich Pione (Trainee Clinical Psychologist) and Anna Cartwright and discussed, to decide upon a final hierarchical structure. The final stage of synthesis involved using descriptive codes to develop analytical themes, going beyond the content of the original studies to answer the review questions and inform clinical practice.

Results

The initial search identified 1603 studies. Fifteen papers were included in the final review, after removing duplicates and those not meeting criteria. Figure 1 shows the number of papers excluded at each stage. If a paper failed to meet multiple criteria, the primary reason for exclusion was noted. The fifteen papers represented findings from 10 unique studies, as some papers reported findings from the same research projects.

Figure 1.

PRISMA (Moher et al., 2009) flow diagram showing the screening process.



**Note.* YOD = young-onset dementia

Quality Appraisal

No studies were considered significantly methodologically flawed and all were considered to have met the majority of criteria on the CASP checklist. All studies were thus considered to be of satisfactory quality to be included. A summary of the information extracted using the CASP checklist is presented in Table 2.

Table 2.

Quality appraisal using CASP qualitative checklist

Study	Aim	Method	Design	Recruitment	Data Collection	Relationships	Ethical issues	Analysis	Findings	Value
Allen and Oyebode (2009)	✓	✓	✓	✓	✓	-	✓	✓	✓	✓
Svanberg et al. (2010)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Nichols et al. (2013)	✓	✓	✓	✓	-	-	-	✓	✓	✓
Barca et al. (2014)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Millenaar et al. (2014)	✓	✓	✓	✓	✓	×	-	✓	✓	✓
Johannessen et al. (2015)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Hutchinson, Roberts, Daly, et al. (2016)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓

Study	Aim	Method	Design	Recruitment	Data Collection	Relationships	Ethical issues	Analysis	Findings	Value
Hutchinson, Roberts, Kurrle, et al. (2016)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Johannessen et al. (2016)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Hall and Sikes (2017)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Sikes and Hall (2017)	✓	✓	✓	✓	✓	✓	✓	-	✓	✓
Gelman and Rhames (2018)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Hall and Sikes (2018)	✓	✓	✓	✓	✓	×	✓	×	✓	✓
Sikes and Hall (2018)	✓	✓	✓	✓	✓	✓	✓	-	✓	-
Aslett et al. (2019)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓

Note. ✓ = criteria met. - = cannot tell or criteria partly met. × = criteria not met

All studies stated their aims and used appropriate methodology, research design, and recruitment strategy. Most used semi-structured interviews, collecting data in a way that addressed the research question and included sufficient justification and detail as to how these were conducted. Nichols et al. (2013) did not provide enough information regarding methods of data collection to enable rating of this item.

No studies stated their epistemological position and very few considered the relationship between researcher and participants, apart from Sikes and Hall (2017, 2018), who discussed possible influences of personal experience. Most studies included sufficient detail regarding ethical considerations. Millenaar et al. (2014) and Nichols et al. (2013) provided limited information regarding this, stating that consent was sought, but did not discuss other issues, such as ethical approval or debrief.

All studies stated using a qualitative method of analysis. Hall and Sikes (2018) did not provide in-depth description of the analytic process, and some studies provided minimal description regarding how the analysis was conducted (Sikes & Hall, 2017, 2018). All studies used quotes to illustrate key findings and themes and discussed findings in relation to the research question. Due to overlap in findings and implications between the studies by Sikes and Hall (2017, 2018), the 'value of research' criterion of the later study was considered 'party met'.

Selected Studies

Table 3 provides a summary of included studies. All studies included by Sikes and Hall reported on findings from the same project, with three additional participants recruited between the start and end of the project. The two studies by Johannessen and colleagues and those by Hutchinson and colleagues also reported on findings from the same participants. The decision was made to include all papers, as the focus of the papers and therefore the findings from these papers differed.

Table 3.

Details of included studies.

Study and Country	Research question/aim	Sample (M: F)	Age at interview (years)	Data collection and approach to analysis
Allen and Oyebode (2009), UK	To explore the impact on young people's wellbeing of having a parent with YOD.	12 children (5:7) of men with YOD, from 7 families	11-24	Interviews, grounded theory
Svanberg et al. (2010), UK	To discover the experiences of the children of younger people with dementia and explore the impact of the diagnosis.	12 children (6:6) of people with YOD, from 9 families	11-18	Semi-structured interviews, grounded theory
Nichols et al. (2013), US and Canada	To learn about the experiences of children of people with FTD, what they had needed at various points in the patient's diagnostic process and course of illness.	14 young people (4:10) caring for family member (8 fathers, 2 mothers, 2 stepfathers, 2 grandfathers) with FTD (defined as having onset before age 65)	11-18	2 focus groups using semi-structured interview schedule, thematic analysis
Barca et al. (2014), Norway	To explore how adult children of a parent with YOD have experienced the development of their parents' dementia and what needs for assistance they have.	14 children (2:12) of Pw YOD	20-37	Semi-structured interviews, Corbin and Strauss' (2008) reformulated grounded theory
Millenaar et al. (2014), Netherlands	To explore the experiences of children living with a young parent with dementia with a specific focus on the children's needs.	14 children (6:8) of people with YOD, from 11 families	15-27	Semi-structured interviews, Inductive content analysis

Study and Country	Research question/aim	Sample (M: F)	Age at interview (years)	Data collection and approach to analysis
Johannessen et al. (2015), Norway	To explore how adult children of persons with YOD describe their experiences in everyday life with metaphors, and how these metaphors might be understood.	14 children (5:9) of people with YOD	18-30	Semi-structured interviews, Steger's (2007) three-step metaphor analysis
Hutchinson, Roberts, Daly, et al. (2016), Australia	To explore the lived experiences of young people having a parent with YOD from the perspective of the social model of disability and to explore influencing factors that could enable these young people to be included and supported within their community.	12 children (1:11) of people with YOD	10-33	Semi-structured interviews, Thematic analysis using framework analysis
Hutchinson, Roberts, Kurrle, et al. (2016), Australia	To explore the lived experience of young people living with a parent with YOD from the perspective of the social model of disability.	12 children (1:11) of people with YOD	10-33	Semi-structured interviews, Thematic analysis using framework analysis
Johannessen et al. (2016) Norway	To explore how adult children experienced the influence of their parents' dementia on their own development during adolescence.	14 children (5:9) of people with YOD	18-30	Semi-structured interviews, Corbin and Strauss' (2008) reformulated grounded theory
Hall and Sikes (2017), UK	To give 'voice to silenced lives' and explore social and cultural experiences of having a parent with dementia.	22 children of people with dementia (all but 1 diagnosed before age 65)	6-31	Invited participants to 'tell me your story', thematic analysis

Study and Country	Research question/aim	Sample (M: F)	Age at interview (years)	Data collection and approach to analysis
Sikes and Hall (2017), UK	To address the gap in research and literature around living with dementia by focusing on the perceptions and experiences of children and young people who have a parent with YOD.	22 children of people with dementia (all but 1 diagnosed before age 65)	6-31	Invited participants to 'tell me your story', thematic analysis
Gelman and Rhames (2018), USA	To ask children and well-parents about the impact of living at home with a parent with YOD in order to better understand their experience and more effectively respond to their unique needs.	8 children (3:5) of people with YOD. Sample also included 4 of their mothers	15-20	semi-structured interview, thematic analysis
Hall and Sikes (2018), UK	To gain a sense of how individuals with different biographies go through similar social and cultural experiences: in this case, being a young person with a parent who has dementia.	20 children (4:16) of people with dementia (all but 1 diagnosed before age 65)	7-31	Interviews, thematic approach
Sikes and Hall (2018), UK	To collect in-depth, personal stories of children and young people who have or have had a parent with dementia.	19 children (3:16) of people with dementia (all but 1 diagnosed before age 65)	8-31	Invited participants to 'tell me your story', auto/biographical, life history approach
Aslett et al. (2019), UK	To explore the personal meaning attached to having a parent with YOD; to consider how this impacts on relationships with other family members; and to consider positive as well as negative impact of having a parent diagnosed with YOD.	5 children (2:3) of people with YOD	23-36	Semi-structured interviews, interpretative phenomenological analysis (IPA)

Thematic Synthesis

From the synthesis of included studies, 4 analytic themes and 11 sub-themes were identified (Table 4).

Table 4.

Summary of analytic themes and subthemes.

Analytic Theme	Subtheme
Making sense of dementia	Change over time Comparisons to other illnesses
Impact of dementia	Emotional impact Caring responsibilities Roles and relationships
Coping	Difficulties coping Distancing Resilience
Support	Informal support Professional support Suggestions

Making Sense of Dementia. People spoke about their journey with dementia requiring constant adaptation and throughout their narratives, often drew comparisons to other illness.

Change over time. Participants recalled noticing changes in their parent's memory, mood, personality and behaviour. However, these were rarely attributed to the possibility of dementia but instead to stress, variations in mood, fatigue, menopause, distraction, or different personality traits that the children were noticing as they matured (Millenaar et al., 2014; Sikes & Hall, 2018).

As changes became more apparent, medical attention was sought. Misdiagnosis and delays in accurate diagnosis led to uncertainty and confusion. The diagnosis, often communicated via their other parent, was described as overwhelming, horrific, a shock and by some, a relief. It was important for children to

know the diagnosis in order to understand their parents' behaviour and attribute changes to illness (Nichols et al., 2013). One participant commented: "You have to be honest to kids, I think, they have a right to know, 'cause if we don't…we'll pick it up anyway" (Svanberg et al., 2010, p. 742).

Participants discussed ongoing changes in their parent, including memory and communication difficulties and behavioural and personality changes, including withdrawal, disinhibition, aggression and changed interests and parenting practices. People found it particularly challenging if their parent was incontinent, aggressive or had forgotten who they were. They were constantly adapting to accommodate these changes, both practically and emotionally (Svanberg et al., 2010). "The need to keep 'getting used to a new normal' did not get easier" (Sikes & Hall, 2017, p. 332).

However, despite a theme of disruption and distress, there was also a narrative of growth and coping (Gelman & Rhames, 2018). The terminal nature of dementia was difficult to understand and accept. Eight papers mentioned the parent going into residential care or concern about this happening and the mixed emotions associated with this, including relief, sadness, worry and guilt. "The young people in these families seemed torn between relief at the easing of their care burden and sorrow that they had not been able to care for the fathers themselves" (Allen & Oyebode, 2009, p. 471).

Comparisons to other illnesses. Dementia was often compared to other conditions, particularly cancer. There was a perception that it would be easier for their parent to have a condition that others understood, could empathise with, was curable and which did not affect cognition. One participant commented: "Whereas sometimes with other things, you've always got that little bit of hope but with Alzheimer's that's it" (Hall & Sikes, 2017, p. 1208). Some also spoke of the inequalities in research funding and support services for dementia compared to cancer (Hall & Sikes, 2017; Hutchinson, Roberts, Kurrle, et al., 2016).

Impact of Dementia.

Emotional Impact. Having a parent with dementia was experienced as incredibly sad, stressful and worrying. Participants described resentment (Allen & Oyebode, 2009), embarrassment of their parent (Hall & Sikes, 2017), envy of other children (Sikes & Hall, 2017) and anger and frustration regarding their situation (Johannessen et al., 2016), their parent's behaviour (Millenaar et al., 2014) and the lack of acceptance by others (Hutchinson, Roberts, Kurrle, et al., 2016). Feelings of shame, often resulting from discrimination, marginalisation and stigma were common. For one participant, "having a mother labelled in this way excluded her from friendships and as a consequence, she faced discrimination and marginalisation in the community" (Hutchinson, Roberts, Daly, et al., 2016, p. 661). Participants were distressed by rumours amongst peers (Nichols et al., 2013) and judgements of the public, which could lead to shame and secrecy (Hutchinson, Roberts, Daly, et al., 2016).

Participants expressed guilt and self-blame, particularly when their patience wore thin (Nichols et al., 2013), and tried to avoid feeling guilty. One participant described their predicament as follows: "Sometimes I choose not to visit her, because then my whole day is spoiled. But then you have to go, or the feeling of guilt is even worse" (Johannessen et al., 2016, p. 7).

They expressed sadness at their parent missing landmark events, such as winning awards, graduating, weddings and having children. People experienced loss and grief as their parent deteriorated, and confusion about losing their 'real parent': "It's almost like an in tandem place to be, you're not bereaved, but you're not *not* bereaved. You have a Dad but you haven't got a Dad" (Hall & Sikes, 2017, p. 1205). However, participants reported that their emotional wellbeing and life situations improved over time, since dementia onset (Johannessen et al., 2016). Five papers also discussed the positive impact, such as "pride in reciprocating care

and supporting the family" (Svanberg et al., 2010, p. 743) and feeling good about being able to help (Nichols et al., 2013).

Caring Responsibilities. Children often prioritised their parents' needs over their own. Responsibilities varied with age, but often included practical tasks such as cooking, supervising their parent, administering medication and communicating with professionals. Particularly challenging was supporting personal care. Many provided emotional support, supporting their parent's self-esteem, cheering them up and maintaining their sense of being a valued member of society (Hutchinson, Roberts, Kurrle, et al., 2016; Johannessen et al., 2016; Millenaar et al., 2014). One participant "felt anger towards everyone because of his or her lack of acceptance of her father with dementia and as a result was ready to fight for him to ensure he was not affected negatively by the discrimination she witnessed" (Hutchinson, Roberts, Kurrle, et al., 2016, p. 619). Participants also expressed concern for their other parent, noticing the increased responsibilities, stress and sadness and wanted to comfort and protect them, as well as other family members, such as younger siblings.

The impact of caring responsibilities varied; some missed school or dropped out of college/university, however others excelled and delved into academic and extracurricular activities (Gelman & Rhames, 2018). Some were less able to see friends, becoming socially isolated. Caring responsibilities impacted participants' perceptions of the future, often changing their plans and decisions, including whether to go to university, career choices, relationships, starting a family and where to live. Uncertainty about the progression of dementia was difficult and some felt "a sense of "waiting" for their parent's inevitable death, over an unknown period of time" (Hall & Sikes, 2017, p. 1207) or feeling like life was on hold. Others avoided thinking about the future, instead taking each day as it comes (Allen & Oyebode, 2009). Despite these responsibilities, many did not view themselves as a young carer, minimising the significance of their caring role.

***Roles and Relationships*.** Dementia impacted the whole family. Many spoke of tension and conflict amongst family members and the importance of working together. Changes in family roles included the parent with dementia stopping work and the other parent working more for financial reasons or working less to provide care (Allen & Oyebode, 2009). Some described the parent with dementia feeling more like a friend or developing a stronger relationship with them as a result of the shared caring experience (Nichols et al., 2013; Svanberg et al., 2010). Others emphasised the importance of them maintaining a parental role or criticised their other parent for "leaving the most responsible child to take on the caregiving work" (Barca et al., 2014, p. 1939). Extended family members were often perceived as unable to cope (Allen & Oyebode, 2009), not understanding (Gelman & Rhames, 2018) or neglecting (Hutchinson, Roberts, Daly, et al., 2016).

Some felt that their parent without dementia had become disinterested and remote, leaving them feeling ignored and forgotten, losing their parent's support in their own development (Barca et al., 2014; Johannessen et al., 2016; Svanberg et al., 2010). They often missed their old relationship (Hall & Sikes, 2017), feeling the need to "form a new relationship and accept the loss of the parent they knew before" (Svanberg et al., 2010, p. 742). Participants described a role reversal, whereby they were cast into a parental role. One participant, when talking about their parent, summed this up by saying: "she is my child, she really is" (Johannessen et al., 2015, p. 250).

It often appeared helpful for participants to distinguish between dementia and their parent in order to cope with the changes. However, this was not always the case, and some used language that did not distinguish between the person and the illness. For example, one participant commented: "It makes someone who was a lovely character really easy to dislike and you have to fight to not hate your own parent" (Hall & Sikes, 2017, p. 1206).

Coping. There were variations in participants' coping and adjustment, including strategies employed.

Difficulties Coping. Many spoke of how difficult it was to cope. Denial of reality was sometimes used as a way of coping (Allen & Oyebode, 2009). Some described struggles with depression, self-harm and thoughts of not wanting to be alive or of ending their life (Hall & Sikes, 2017). A combination of stressors, including bullying, moving to university, financial worries, their parent moving into residential care and lack of support from family and professionals contributed in making coping particularly difficult (Hall & Sikes, 2017; Hutchinson, Roberts, Daly, et al., 2016). Concerns about burdening others led some to hide their difficulties, portraying that they were coping (Hutchinson, Roberts, Kurrle, et al., 2016). For example, Kevin commented: "There was lots of different things that I didn't, I didn't really want to burden [Mum] with, that I'd bottle up" (Svanberg et al., 2010, p. 744).

Other emotion-focused and avoidant coping strategies included using alcohol, drugs and smoking (Allen & Oyebode, 2009). Many found it difficult to speak about dementia (Hall & Sikes, 2017), sometimes due to believing that this would make them feel worse or would be overwhelming (Johannessen et al., 2015; Millenaar et al., 2014). Others felt they had no one to speak to (Sikes & Hall, 2017).

Distancing. Participants often distanced themselves from their parent or the situation, needing to spend time away from the family home. This often led to improvement in the relationship with their parent and improvement in their own emotional wellbeing (Johannessen et al., 2016). For some, this physical escape could be extreme, as commented by 13-year old Trudy: "I have memories of spending two nights in the elevator…because it was the warmest place in the winter." (Hutchinson, Roberts, Kurrle, et al., 2016, p. 617).

Some were forced to become more self-sufficient as their parents became more focussed on the dementia. Coping sometimes required participants to detach

emotionally or depersonalise their caregiving (Hutchinson, Roberts, Kurrle, et al., 2016), which often had a negative impact on their emotional wellbeing.

Distancing by distraction or taking part in other activities (e.g. sport, choir, volunteering) was also common (Nichols et al., 2013). Many valued education and spending time with friends, enabling them to maintain a sense of normality. Some commented on how helpful it was that their friends were not going through the same thing (Hutchinson, Roberts, Daly, et al., 2016).

Resilience. Over time, participants developed increasingly helpful coping strategies (Johannessen et al., 2016). Many reflected on the positive changes, such as becoming 'more of a leader', stronger, more mature, or experiencing greater life satisfaction (Gelman & Rhames, 2018; Johannessen et al., 2016). One participant commented: "This happening to my father has inspired me in my academic life to excel…[and] to want to be a doctor…to help people like my Dad" (Gelman & Rhames, 2018, p. 348).

Some people found it helpful to try to continue life as normal, watching TV, having family meals, going shopping or on holidays (Allen & Oyebode, 2009; Nichols et al., 2013). For younger participants, school could provide stability and a purpose, which was experienced as important and protective of their wellbeing (Hutchinson, Roberts, Daly, et al., 2016). One 19-year old participant commented: "You try to continue with your life as normal as possible without things influencing you" (Millenaar et al., 2014, p. 2005). However, some found it unfair that others expected life to continue as normal, failing to appreciate the impact of dementia (Sikes & Hall, 2017).

Spending time with their parent reminiscing about old memories could be helpful (Nichols et al., 2013), however, some found this upsetting (Johannessen et al., 2016). Many spoke of the importance of maintaining a positive but realistic attitude (Millenaar et al., 2014; Nichols et al., 2013), making the most of their situation, using humour and looking for positives (Svanberg et al., 2010). One

participant gave the following advice: “My best advice to all those new to this situation is: use a lot of humour! You have much to gain!” (Johannessen et al., 2016, p. 8). For others, turning to their faith was helpful.

Support.

Informal Support. Isolation and loneliness were common; participants reported that others either did not understand or had distanced themselves. Younger participants identified their parent without dementia as a main source of information and support (Nichols et al., 2013) and some were grateful to have a sibling to confide in (Allen & Oyebode, 2009; Hutchinson, Roberts, Daly, et al., 2016). However, others felt neglected by family members, who failed to notice their distress (Hutchinson, Roberts, Kurrle, et al., 2016) and experienced others as dismissive and invalidating.

Some participants sought support from friends, valuing having someone outside the family to talk to (Millenaar et al., 2014; Svanberg et al., 2010). However, others reported feeling that their peers were unsympathetic, ill-informed or did not want to deal with their difficulties, leading to reluctance in seeking their support (Gelman & Rhames, 2018; Hutchinson, Roberts, Daly, et al., 2016). Older participants valued emotional and practical support from their partner (Barca et al., 2014).

Professional Support. Some people received professional support through memory clinics (Millenaar et al., 2014), school, social services (Allen & Oyebode, 2009) or private arrangements. However, discussions often focussed on the lack of adequate and appropriate services. People felt unsure of where to get support (Hutchinson, Roberts, Daly, et al., 2016), as dementia services were often aimed at older adults (Hutchinson, Roberts, Kurrle, et al., 2016).

There was a dearth of resources and services designed for families of those with YOD, lack of information (Gelman & Rhames, 2018), absence of guidelines and recommendations (Barca et al., 2014; Nichols et al., 2013) and lack of

understanding from professionals (Svanberg et al., 2010). As the child of the person with dementia, they were often not consulted by professionals or invited to express their needs (Barca et al., 2014), resulting in them searching for information independently. Some had managed to find information online, which was helpful (Gelman & Rhames, 2018), however others found the information overwhelming and not specific to their parents' diagnosis (Millenaar et al., 2014).

Where services were available, families often had difficulties accessing this and had to actively seek it, describing this as a 'battle' and a 'fight' (Hall & Sikes, 2017; Johannessen et al., 2015), requiring them to 'jump through hoops' (Hutchinson, Roberts, Kurrle, et al., 2016). Others did not feel able or know how to ask for support (Barca et al., 2014), sometimes due to stigma surrounding dementia and young carers (Hutchinson, Roberts, Kurrle, et al., 2016). For those who were offered help, this either came too soon and was experienced as unnecessary, or was too late (Johannessen et al., 2015; Millenaar et al., 2014). One participant commented: "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, p. 1940).

Those who attended support groups generally reported finding this helpful (Barca et al., 2014; Gelman & Rhames, 2018; Hutchinson, Roberts, Daly, et al., 2016), feeling less alone and more understood (Johannessen et al., 2016). However, many described difficulties finding support groups or found them too inclusive, for example they could be the only young person in the group (Barca et al., 2014). In one study, many commented that they did not feel in need of professional help, but some imagined needing this in future (Millenaar et al., 2014).

Suggestions. Many participants made suggestions of what could be helpful for others caring for a parent with YOD. Many highlighted the need for education, including the importance of public knowledge and understanding. Some felt that information in school would be helpful, so teachers could facilitate children to access

relevant support (Barca et al., 2014). People spoke of the importance of having someone to talk to who knew their parent and was familiar with their situation (Barca et al., 2014). They also had ideas to relieve burden, such as respite or befriending (Svanberg et al., 2010) and others suggested providing practical guidance on how to handle specific behaviours, such as stubbornness (Millenaar et al., 2014).

Support groups were often considered an important source of support (Gelman & Rhames, 2018; Svanberg et al., 2010), however people highlighted the importance for these to be small and stratified by age (Nichols et al., 2013). Participants preferred face-to-face support but agreed that support via technology could be acceptable, and some (particularly teenagers) expressed interest in joining online forums (Barca et al., 2014; Nichols et al., 2013).

Discussion

The aim of the current review was to systematically search, critically appraise and synthesise the qualitative literature regarding the lived experiences of those affected by parental YOD. Data from fifteen studies meeting criteria were appraised using the CASP qualitative checklist. Thomas and Harden's (2008) three-stage approach for conducing thematic synthesis was followed, resulting in the organisation of data into four analytic themes and eleven subthemes.

All fifteen studies meeting criteria were appraised and considered to be of adequate quality. Overall quality varied. All studies used an appropriate research methodology, although detail regarding data analytic methods was mixed. Some provided a less detailed description of the ethical considerations (Millenaar et al., 2014; Nichols et al., 2013) and only two studies considered the relationship between researchers and participants (Sikes & Hall, 2017, 2018).

The four analytic themes captured the variety in people's experiences of having a parent with YOD, with regards to 'making sense of dementia', the 'impact of dementia' on different aspects of their life, 'coping' and experiences of 'support'.

In making sense of dementia, participants spoke about 'change over time' and the constant need to adapt to changing circumstances. Although they noticed change in their parent, dementia was generally not considered as a possible explanation. Participants described the long and confusing diagnostic process (Johannessen & Moller, 2013) and diagnosis as a shock. Change over time continued as their parent's health deteriorated, with many speaking about residential care and the difficult emotions associated with this. Within the narratives, comparisons were drawn to other illnesses, especially those that are more common, less stigmatised or can be 'cured', such as cancer. There was a sense that other illnesses would not have been as bad as dementia.

The impact of dementia varied, highlighting the need for a person-centered approach. Participants reported mixed emotions, although shock, sadness and grief were common. Many also mentioned positive emotions associated with caring, including pride. Caring responsibilities differed with age and circumstances and the impact of these responsibilities also varied. For example, some became increasingly isolated or dropped out of education, whereas others excelled. Uncertainty for the future made it difficult for participants to plan ahead. Another subtheme, which has previously been reported by spouse caregivers was changes in family roles and relationships (Sansoni et al., 2016). Many described the loss of their old relationship with the parent with dementia or role reversal, as well as changes in the relationship with their other parent.

The Transactional model of Stress and Coping (TSC; Lazarus & Folkman, 1984) defines coping with stress as a process of 'constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands…appraised as taxing or exceeding [personal] resources' (p.141). The participants in these studies often experienced stress and found coping difficult. Some unhelpful emotion-focused strategies were employed, such as denial and avoidance. However, these strategies could also be experienced as adaptive and protective ways of coping. Other

strategies, such as distancing and distraction were mostly experienced as helpful. Those struggling to cope often experienced a combination of stressors. Many participants reflected on the positive effects of caring and showed resilience, finding it helpful to attempt to continue life as normal or use humour to cope.

The main source of informal support was from immediate family and in particular, the parent without dementia and siblings. However, some felt isolated, dismissed or invalidated. The amount of support received from friends also varied. Although some participants reported receiving professional support, this was often experienced as inadequate or inappropriate and many found that as the child of the person with dementia, support was not routinely offered. It may thus be suggested that guidance regarding the protection of younger carers and identification of those providing regular and ongoing care/support is not consistently implemented or monitored. Participants suggested that more information and support for children caring for a parent with dementia, such as small, age-specific support groups or access to online forums would be helpful.

Limitations

In order to ensure adequate quality of included studies, papers published in non-peer reviewed journals, grey literature and unpublished theses were excluded from this review. Therefore, it is possible that the review does not include all relevant research regarding the lived experiences of children of people with YOD.

Secondly, the CASP checklist was used to identify any issues with quality when selecting studies to include. All fifteen studies meeting inclusion criteria were considered to be of acceptable quality and provided valuable contribution to the research question. However, the process of quality appraisal is a subjective process, which is open to bias and interpretation. Although the CASP checklist is popular with qualitative researchers (Majid & Vanstone, 2018), it has been criticised for favouring papers that are sound with regards to compliance with expectations of research practice but make weaker contributions to the conceptual development of the field

(Dixon-Woods et al., 2007). CASP has also been found to be less sensitive to aspects of validity than some other tools (Hannes et al., 2010).

The availability of qualitative studies looking specifically at the experiences of children under the age of 18 years was scarce. It is acknowledged that many of the studies grouped children under the age of 18 with adult children and in most papers, the age range varied considerably, with some studies focussing exclusively on the experiences of adult children (e.g. Johannessen et al., 2015). Although it is likely that experiences vary by age, unfortunately it was not possible to report on these differences. This lack of specificity thus limits the conclusions that can be drawn.

Eight of the fifteen articles reported on the findings from the same three projects in the UK (Hall & Sikes, 2017, 2018; Sikes & Hall, 2017, 2018), Norway (Johannessen et al., 2015, 2016) and Australia (Hutchinson, Roberts, Daly, et al., 2016; Hutchinson, Roberts, Kurrle, et al., 2016). The decision was made to include all papers, as the focus of the papers differed. An attempt was made to ensure that quotes were chosen from different sources, however, it is possible that findings from these projects are over-represented in the current review.

Finally, although the included studies represented people from six different countries (USA, Canada, UK, Norway, Netherlands, Australia), these were all Western, high-income countries. It may be hypothesised that the experiences of children affected by YOD would vary considerably depending on factors such as stigma, beliefs about dementia, and cultural norms and expectations. Caution must therefore be applied when interpreting the findings of this review, as they are the experiences of a specific subset of the population.

Clinical Implications

The findings indicate a scarcity of appropriate support services to meet the needs of children of people with YOD and lack of information available regarding the diagnosis. In the first instance, it is crucial to raise awareness of YOD amongst the

public and professionals so that families feel more understood, more supported and less stigmatised.

The findings also present the wide variations in individual experiences, highlighting the need for a person-centred approach. Clinically, the findings suggest that having a parent with YOD can have a significant emotional impact on children and that interventions focusing, for example, on shame, low mood and coping strategies, could be beneficial. Changes are also required in order to improve the diagnostic pathway and post-diagnostic support for people with YOD and their families, possibly through the introduction of more specialist age-appropriate services.

Further Research

There was a relative lack of research focussing on the experiences of those affected by parental YOD, with a substantial proportion coming from the same research projects. Further research in this field is therefore required. It would also be helpful to distinguish between the experiences of younger children (e.g. under 18 years old) and those of adult children.

This review highlights the paucity of public knowledge surrounding YOD and appropriate interventions and support in place. Further research is required in order to broaden our understanding of YOD and how best to support those affected. Finally, the included studies were conducted within a range of different countries. It would be interesting to determine whether there are differences between countries with regards to children's experiences, as it is possible that experiences vary depending on the structure of the health service and availability of relevant services.

Conclusions

The current thematic synthesis presents the varied experiences of individuals affected by parental YOD. There is evidently a lack of knowledge and understanding of YOD by professionals and the public, and a scarcity of appropriate support. This, in combination with the stigma surrounding dementia and for some, of being a young

carer, can lead people to hide their difficulties. These findings have important clinical implications for professionals working with families affected by YOD and in particular those involved in service design and delivery. As the number of people being diagnosed with dementia is increasing and many of those with YOD are cared for by their children, it is important that further research is conducted to enable better understanding of and support for these individuals.

References

Allen, J., & Oyebode, J. R. (2009). Having a father with young onset dementia: The impact on well-being of young people. *Dementia (14713012), 8*(4), 455-480. https://doi.org/10.1177/1471301209349106

Aslett, H. J., Huws, J. C., Woods, R. T., & Kelly-Rhind, J. (2019). 'This is killing me inside': The impact of having a parent with young-onset dementia. *Dementia, 18*(3), 1089-1107. https://doi.org/10.1177/1471301217702977

Barca, M. L., Thorsen, K., Engedal, K., Haugen, P. K., & Johannessen, A. (2014). Nobody asked me how I felt: Experiences of adult children of persons with young-onset dementia. *International Psychogeriatrics, 26*(12), 1935-1944. https://doi.org/10.1017/S1041610213002639

Cabote, C. J., Bramble, M., & McCann, D. (2015). Family caregivers' experiences of caring for a relative with younger onset dementia: A qualitative systematic review. *Journal of Family Nursing, 21*(3), 443-468. https://doi.org/10.1177/1074840715573870

Clemerson, G., Walsh, S., & Isaac, C. (2014). Towards living well with young onset dementia: An exploration of coping from the perspective of those diagnosed. *Dementia, 13*(4), 451-466. https://doi.org/10.1177/1471301212474149

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Sage.

Critical Appraisal Skills Programme (CASP) UK. (2018). *CASP qualitative research checklist*.

Dementia U.K. (2014). *Dementia UK: update*. https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf

Dixon-Woods, M., Shaw, R. L., Agarwal, S., & Smith, J. A. (2004). The problem of appraising qualitative research. *Quality and Safety in Health Care, 13*(3), 223. https://doi.org/10.1136/qshc.2003.008714

Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., Bonas, S., Booth, A., & Jones, D. (2007). Appraising qualitative research for inclusion in systematic reviews: A quantitative and qualitative comparison of three methods. *Journal of Health Services Research and Policy, 12*(1), 42-47. https://doi.org/10.1258/135581907779497486

Gelman, C. R., & Rhames, K. (2018). In their own words: The experience and needs of children in younger-onset Alzheimer's disease and other dementias families. *Dementia, 17*(3), 337-358. https://doi.org/10.1177/1471301216647097

Hall, M., & Sikes, P. (2017). "It would be easier if she'd died": Young people with parents with dementia articulating inadmissible stories. *Qualitative Health Research, 27*(8), 1203-1214. https://doi.org/10.1177/1049732317697079

Hall, M., & Sikes, P. (2018). From "what the hell is going on?" to the "mushy middle ground" to "getting used to a new normal": Young people's biographical narratives around navigating parental dementia. *Illness, Crisis & Loss, 26*(2), 124-144. https://doi.org/10.1177/1054137316651384

Hannes, K., Lockwood, C., & Pearson, A. (2010). A comparative analysis of three online appraisal instruments' ability to assess validity in qualitative research. *Qualitative Health Research, 20*(12), 1736-1743. https://doi.org/10.1177/1049732310378656

Harris, P. B. (2004). The perspective of younger people with dementia: Still an overlooked population. *Social Work in Mental Health, 2*(4), 17-36. https://doi.org/10.1300/J200v02n04_02

Hutchinson, K., Roberts, C., Daly, M., Bulsara, C., & Kurrle, S. (2016). Empowerment of young people who have a parent living with dementia: A social model perspective. *International Psychogeriatrics, 28*(4), 657-668. https://doi.org/10.1017/S1041610215001714

Hutchinson, K., Roberts, C., Kurrle, S., & Daly, M. (2016). The emotional well-being of young people having a parent with younger onset dementia. *Dementia, 15*(4), 609-628. https://doi.org/10.1177/1471301214532111

Jefferies, K., & Agrawal, N. (2018). Early-onset dementia. *Advances in Psychiatric Treatment, 15*(5), 380-388. https://doi.org/10.1192/apt.bp.107.004572

Johannessen, A., Engedal, K., & Thorsen, K. (2015). Adult children of parents with young-onset dementia narrate the experiences of their youth through metaphors. *Journal of multidisciplinary healthcare, 8*, 245-254. https://doi.org/10.2147/JMDH.S84069

Johannessen, A., Engedal, K., & Thorsen, K. (2016). Coping efforts and resilience among adult children who grew up with a parent with young-onset dementia: A qualitative follow-up study. *International Journal of Qualitative Studies on Health and Well-being, 11*, 30535. https://doi.org/10.3402/qhw.v11.30535

Johannessen, A., & Moller, A. (2013). Experiences of persons with early-onset dementia in everyday life: a qualitative study. *Dementia (London), 12*(4), 410-424. https://doi.org/10.1177/1471301211430647

Joseph, S., Becker, F., & Becker, S. (2012). *Manual for Measures of Caring Activities and Outcomes for Children and Young People*. Carers Trust.

Koedam, E. L., Lauffer, V., van der Vlies, A. E., van der Flier, W. M., Scheltens, P., & Pijnenburg, Y. A. (2010). Early-versus late-onset Alzheimer's disease: more than age alone. *Journal of Alzheimer's Disease, 19*(4), 1401-1408. https://doi.org/10.3233/jad-2010-1337

Koopmans, R., & Rosness, T. (2014). Young onset dementia-what does the name imply? *International Psychogeriatrics, 26*(12), 1931-1933. https://doi.org/10.1017/s1041610214001574

Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal and Coping*. Springer

Majid, U., & Vanstone, M. (2018). Appraising qualitative research for evidence syntheses: A compendium of quality appraisal tools. *Qualitative Health Research, 28*(13), 2115-2131. https://doi.org/10.1177/1049732318785358

Mendez, M. F. (2006). The accurate diagnosis of early-onset dementia. *International Journal of Psychiatry in Medicine, 36*(4), 401-412. https://doi.org/10.2190/q6j4-r143-p630-kw41

Millenaar, J. K., Bakker, C., Koopmans, R. T., Verhey, F. R., Kurz, A., & de Vugt, M. E. (2016). The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: A systematic review. *International Journal of Geriatric Psychiatry, 31*(12), 1261-1276. https://doi.org/10.1002/gps.4502

Millenaar, J. K., van Vliet, D., Bakker, C., Vernooij-Dassen, M. J., Koopmans, R. T., Verhey, F. R., & de Vugt, M. E. (2014). The experiences and needs of children living with a parent with young onset dementia: Results from the NeedYD study. *International Psychogeriatrics, 26*(12), 2001-2010. https://doi.org/10.1017/S1041610213001890

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ, 339*, b2535. https://doi.org/10.1136/bmj.b2535

Newbronner, L., Chamberlain, R., Borthwick, R., Baxter, M., & Glendinning, C. (2013). *A road less rocky: supporting carers of people with dementia*. C. Trust.

Nichols, K. R., Fam, D., Cook, C., Pearce, M., Elliot, G., Baago, S., Rockwood, K., & Chow, T. W. (2013). When dementia is in the house: Needs assessment survey for young caregivers. *Canadian Journal of Neurological Sciences, 40*(1), 21-28. https://doi.org/10.1017/s0317167100012907

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies*. Sage.

Nogueira, M. M., Neto, J. P., Sousa, M. F., Santos, R. L., Rosa, R. D., Belfort, T., Torres, B., & Dourado, M. C. (2015). Spouse-caregivers' quality of life in Alzheimer's disease. *International Psychogeriatrics, 27*(5), 837-845. https://doi.org/10.1017/s1041610214002646

Richardson, A., Pedley, G., Pelone, F., Akhtar, F., Chang, J., Muleya, W., & Greenwood, N. (2016). Psychosocial interventions for people with young onset dementia and their carers: A systematic review. *International Psychogeriatrics, 28*(9), 1441-1454. https://doi.org/10.1017/S1041610216000132

Roach, P., & Drummond, N. (2014). 'It's nice to have something to do': Early-onset dementia and maintaining purposeful activity. *Journal of Psychiatric and Mental Health Nursing, 21*(10), 889-895. https://doi.org/10.1111/jpm.12154

Rossor, M. N., Fox, N. C., Mummery, C. J., Schott, J. M., & Warren, J. D. (2010). The diagnosis of young-onset dementia. *Lancet Neurology, 9*(8), 793-806. https://doi.org/10.1016/s1474-4422(10)70159-9

Rudman, N., Oyebode, J. R., Jones, C. A., & Bentham, P. (2011). An investigation into the validity of effort tests in a working age dementia population. *Aging & Mental Health, 15*(1), 47-57. https://doi.org/10.1080/13607863.2010.508770

Sampson, E. L., Warren, J. D., & Rossor, M. N. (2004). Young onset dementia. *Postgraduate Medical Journal, 80*(941), 125-139. https://doi.org/10.1136/pgmj.2003.011171

Sansoni, J., Duncan, C., Grootemaat, P., Capell, J., Samsa, P., & Westera, A. (2016). Younger onset dementia: A review of the literature to inform service development. *American Journal of Alzheimer's Disease and Other Dementias, 31*(8), 693-705. https://doi.org/10.1177/1533317515619481

Sikes, P., & Hall, M. (2017). ‘Every time I see him he’s the worst he’s ever been and the best he’ll ever be’: Grief and sadness in children and young people who

have a parent with dementia. *Mortality, 22*(4), 324-338. https://doi.org/10.1080/13576275.2016.1274297

Sikes, P., & Hall, M. (2018). “It was then that I thought ‘whaat? This is not my Dad”: The implications of the ‘still the same person’ narrative for children and young people who have a parent with dementia. *Dementia (14713012), 17*(2), 180-198. https://doi.org/10.1177/1471301216637204

Spreadbury, J. H., & Kipps, C. M. (2019). Measuring younger onset dementia: What the qualitative literature reveals about the ‘lived experience’ for patients and caregivers. *Dementia, 18(2)*, 579-598. https://doi.org/10.1177/1471301216684401

Steger, T. (2007). The stories metaphors tell: Metaphors as a tool to decipher tacit aspects in narratives. *Field Methods, 19*(1), 3-23. https://doi.org/10.1177/1525822X06292788

Svanberg, E., Spector, A., & Stott, J. (2011). The impact of young onset dementia on the family: A literature review. *International Psychogeriatrics, 23*(3), 356-371. https://doi.org/10.1017/S1041610210001353

Svanberg, E., Stott, J., & Spector, A. (2010). 'Just helping': Children living with a parent with young onset dementia. *Aging & Mental Health, 14*(6), 740-751. https://doi.org/10.1080/13607861003713174

The Royal College of Psychiatrists. (2018). *Young-onset dementia in mental health services: Recommendations for service provision* (CR217). https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr217.pdf?sfvrsn=31e04d9f_2

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology, 8*, 45. https://doi.org/10.1186/1471-2288-8-45

van Vliet, D., de Vugt, M. E., Bakker, C., Koopmans, R. T., Pijnenburg, Y. A., Vernooij-Dassen, M. J., & Verhey, F. R. (2011). Caregivers' perspectives on

the pre-diagnostic period in early onset dementia: A long and winding road. *International Psychogeriatrics, 23*(9), 1393-1404. https://doi.org/10.1017/S1041610211001013

Van Vliet, D., De Vugt, M. E., Bakker, C., Koopmans, R. T. C. M., & Verhey, F. R. J. (2010). Impact of early onset dementia on caregivers: A review. *International Journal of Geriatric Psychiatry, 25*(11), 1091-1100. https://doi.org/10.1002/gps.2439

van Vliet, D., de Vugt, M. E., Bakker, C., Pijnenburg, Y. A., Vernooij-Dassen, M. J., Koopmans, R. T., & Verhey, F. R. (2013). Time to diagnosis in young-onset dementia as compared with late-onset dementia. *Psychological Medicine, 43*(2), 423-432. https://doi.org/10.1017/S0033291712001122

Wawrziczny, E., Antoine, P., Ducharme, F., Kergoat, M. J., & Pasquier, F. (2016). Couples' experiences with early-onset dementia: An interpretative phenomenological analysis of dyadic dynamics. *Dementia, 15*(5), 1082-1099. https://doi.org/10.1177/1471301214554720

Part 2: Empirical Paper

Validation of the Multidimensional Scale of Perceived Social Support (MSPSS) for family caregivers of people with dementia

Abstract

Aims: The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988) is a measure of the perceived adequacy of social support. Whilst this is an incredibly important area of research for family caregivers of people with dementia, it is not clear whether the MSPSS retains its psychometric properties when used with this population. The primary aim was to conduct an in-depth psychometric analysis of the MSPSS in a sample of family caregivers.

Method: A validation study, looking at reliability and validity of the MSPSS. Participants completed measures electronically using a self-complete procedure. Properties assessed were internal consistency, floor and ceiling effects, test-retest reliability, convergent validity and factor structure.

Results: 270 participants completed the study and 58 comprised the test-retest sample. Internal consistency was excellent for the total score (α = 0.92) and three subscales (α = 0.92-0.94). Significant correlations were observed in the expected directions with depression (r = -.48, p < .001) and mental (*r* = 0.32, *p*<.001) and physical (*r* = 0.17, *p*=.003) health-related quality of life. Test re-test reliability over a 4-week period was excellent for the total score (ICC = 0.90 95%CI = 0.84, 0.94) and subscale scores (ICC = 0.84-0.89). Confirmatory factor analysis indicated acceptable fit indices for the three-factor solution.

Conclusions: The MSPSS has robust psychometric properties and is suitable for use with family caregivers of people with dementia. The MSPSS may therefore be recommended for use with this population. Further research is required to establish responsiveness and determine cross-cultural validity.

Introduction

There are approximately 850,000 people with dementia living in the UK, many of whom are cared for by family members (Alzheimer's Research UK, 2017). An ageing population and growing emphasis on early diagnosis means that this number is rapidly increasing and has been predicted to approximately double every 20 years (Abbott, 2011).

Many people with dementia are primarily cared for by family members (Moore et al., 2001). There are approximately 700,000 friends and family members caring for a person with dementia in the UK (Alzheimer's Research UK, 2017). Rising public health care costs, a focus on enhancing care in the community and the impact of austerity measures on public services mean that the number of family caregivers of people with dementia is likely to increase.

Caring has been associated with poorer mental health, including elevated levels of depression and anxiety (Schulz et al., 1995). It has also been reported that caregivers are less likely to engage in preventative health behaviors (Schulz et al., 1997), show greater cardiovascular reactivity (King et al., 1994) and slower wound healing (Kiecolt-Glaser et al.,1991), thus also experiencing poorer physical health.

However, there are large individual differences with regard to the health impacts of caregiving and many factors have been hypothesised to moderate and/or mediate these associations. According to the stress/health model (Schulz & Martire, 2004), caregivers experience stress when they perceive caring demands as threatening and their coping resources as inadequate. Interventions focused on enhancing coping resources aim to alter these appraisals and thus reduce stress. One such resource is social support (Haley et al., 1996).

Social Support

Social support has been defined as ‘the social resources that persons perceive to be available or that are actually provided to them by nonprofessionals in the context of both formal support groups and informal helping relationships’ (Cohen

et al., 2010, p. 4). However, social support has been defined, conceptualised and measured in a number of different ways.

Scales measuring social support fall approximately into three main categories with regards to what exactly they measure: structure of a person's social network (e.g. number of people in the social network); perceived availability of support in the future; or past experiences of having received support (Smerglia et al., 2007). Measures of structure have been criticised, as the size of an individual's network may not indicate the extent to which the support is functional (Cohen & Wills, 1985). The majority of studies therefore measure the perceived availability of support and/or past experience of receiving support. These are typically defined in terms of instrumental/tangible support (e.g. financial and practical support) and/or socio-emotional support (e.g. companionship and empathy).

To the researchers' knowledge, the psychometric properties of the currently available measures, when applied to caregivers of people with dementia, have not been rigorously assessed (hereafter referred to as 'validation'). There is consequently a lack of 'gold standard' outcome measure of social support for this population. The lack of consistency is problematic. For example, a review synthesising findings of social support interventions for caregivers of people with dementia highlighted how the heterogeneity of outcome measures prevented pooling of data into a meta-analysis (Dam et al., 2016). Measures of social support thus need to be validated for caregivers of people with dementia to enable a more homogeneous use of measures. This will allow comparability across studies and more rigorous research regarding the role of social support and the causal mechanisms of change in interventions.

There are a variety of social support measures that have been used in research with caregivers of people with dementia and have been reported to have good psychometric properties when used with other populations (Gottlieb & Bergen, 2010). However, the psychometric properties of these scales, when used with

caregivers of people with dementia have not been rigorously assessed. The Social Provisions Scale (SPS; Cutrona & Russel, 1987), when used with carers of people with symptoms of dementia, has been found to have relatively poor internal consistency, with a Cronbach's alpha of 0.5, 0.55, 0.55 and 0.74 for the attachment, nurturance, social integration and reassurance of worth subscales, respectively (Stensletten, et al., 2016).

Another widely used measure is the Inventory of Socially Supportive Behaviours (Barrera et al., 1981), a 40-item measure of how often respondents received different forms of assistance within the past month. As some items on this scale refer to amounts of money in US dollars, it was considered inappropriate for this UK study. Furthermore, there is inconsistency in how this scale has been used with family caregivers of people with dementia. For example, some studies have used just 11 items (Gallagher-Thompson et al., 2003), or have combined items from this scale with other items (Rabinowitz et al., 2006).

A further measure of social support that has previously been used with caregivers of people with dementia is the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988), a measure of the perceived adequacy of support from family, friends and a significant other. Out of the currently available measures, the MSPSS was considered to be most appropriate for the present study, as it has been found to be psychometrically sound when used with a range of other populations (Hardan-Khalil & Mayo, 2015), is freely available online, is a relatively brief and thus practical measure, the items are easy to understand, thus enabling online administration and it is easy to administer, score and interpret.

The Multidimensional Scale of Perceived Social Support

In the original study, the MSPSS was administered to 275 university undergraduates (Zimet et al., 1988). Using confirmatory factor analysis, the three proposed subscales were identified and found to have strong factorial validity: family, friends and significant other. Coefficient alphas for the subscales and whole

scale ranged from .85 to .91, indicating good internal reliability. Test-retest values ranged from .72 to .85. Adequate construct validity was demonstrated in significant correlations between the MSPSS subscales and measures of anxiety and depression. The authors extended these findings, demonstrating good internal reliability and factorial validity in a sample of pregnant women, adolescents and paediatric residents (Zimet et al., 1990).

Since its development, the MSPSS has been validated amongst different populations, including psychiatric outpatients (Cecil et al., 1995), older adults (Stanley et al., 1998), and adolescents (Canty-Mitchell & Zimet, 2000). It has also been adapted and translated into over 20 different languages (Dambi et al., 2018). However, despite its widespread use, the MSPSS has not yet been validated with caregivers of people with dementia.

Although it has not been validated with caregivers of people with dementia, the MSPSS has been used in research with this population (Charlesworth et al., 2008). Orgeta and colleagues administered a paper version of the MSPSS to 170 caregivers of people with dementia and reported a Cronbach's alpha of 0.82, thus demonstrating good internal consistency of the MSPSS when used with this population (Orgeea et al., 2013). However, the authors only reported internal consistency and no other measures of reliability and validity. Further analysis is therefore required, to determine the measure's full psychometric properties when used with caregivers of people with dementia.

Rationale

It is important to establish the psychometric properties of the MSPSS specifically in this population, as there are important differences between family caregivers of people with dementia and family caregivers of people with other health problems. For example, caregivers of people with dementia have been found to spend significantly more hours per week providing care and have reported greater impact of care in terms of employment complications, caregiver strain, mental and

physical health problems, time from leisure and other family members, and increased levels of family conflict compared to 'non-dementia' family carers (Ory et al., 1999).

Furthermore, the health and social impacts of caring for a person with dementia appear to be related to factors specific to dementia. Carers UK found that 57% of carers lose touch with family or friends as a result of their caring responsibilities, leading to increased isolation and emotional distress (Carers UK, 2014). Importantly, the stigma surrounding dementia was one reason why some people did not want to keep in contact with their relative with dementia. Caregivers also expressed concern and anxiety about the future, due to the unpredictable nature of disease progression. Finally, caregivers reported an additional sense of loss of the person they once knew, which contributed to feelings of social isolation. These factors make caring for someone with dementia particularly challenging and unique. It may thus be suggested that findings from studies with caregivers of people with other health conditions may not generalise to this population. Therefore, it is important to establish the psychometric properties of the MSPSS specifically within this population.

Although the MSPSS has been previously used with caregivers of people with dementia (Charlesworth et al. 2008), changes in health care policy and practice mean that it would not be appropriate to use this existing data for the purpose of validation. Dementia has become a national priority in the UK, as is evidenced by the publication of The Prime Minister's 2020 Challenge on Dementia (Department of Health, 2016). A retrospective cohort study aiming to explore the potential impact of policy changes on dementia care found that the proportion of people diagnosed with dementia in the UK doubled from 0.42% in 2005 to 0.82% in 2015 (Donegan et al., 2017). In addition, the prescription of antidementia drugs more than doubled and the prescription of potentially hazardous antipsychotics halved after the introduction of national dementia strategies. These new policies, changes in dementia care, the

impact of austerity on health and social care, and increased rates of dementia diagnosis are likely to have had a significant impact on family caregivers of people with dementia, thus supporting the collection of new data for the purpose of validation.

Aims and Hypotheses

The primary aim of the current study was to validate the MSPSS in a sample of family caregivers of people with dementia, hopefully enabling its wider use for both clinical and research purposes, such as when evaluating interventions for caregivers and assessing caregivers' needs. The current study is also novel, in that it will be testing the psychometric properties of the MSPSS, when used as an online tool. It was hypothesised that MSPSS scores would remain relatively stable at retest, with a good level of reliability and internal consistency. With regards to convergent validity, the MSPSS was hypothesised to correlate negatively with depression (Ng et al., 2015) and positively with health-related quality of life (Zhang et al., 2014). Finally, it was hypothesised that the three-factor structure previously reported (Zimet et al., 1988) would be replicated in the present sample.

The second aim was to determine whether the perceived adequacy of social support differs depending on demographic characteristics, specifically age and gender. In line with previous research, it was hypothesised that the correlation between age and social support would not be significant (Wang et al., 2017). There were no specific hypotheses regarding gender differences in social support, as previous findings have been mixed, with some reporting higher levels of perceived social support in women (Ross & Mirowsky,1989; Turner & Lloyd, 1999) and others reporting higher levels in males (Soman et al., 2016).

The final aim was to investigate the relationships between social support, hope and depression in caregivers of people with dementia. Research with patients with central nervous system tumours found a significant negative relationship

between the amount of social support and depressive symptoms, with much of this relationship explained by hope (Bao et al., 2019). The current study therefore aimed to determine whether hope mediates the relationship between social support and depressive symptoms in the present sample.

Methods

Participants and Recruitment

The researchers emailed invitations, including a link to take part in the study, to individuals who had identified themselves as a caregiver of someone with dementia on Join Dementia Research Network, an online service which helps match people to dementia-related research studies. A link to the study was also included in an electronic advert (Appendix 1), which was emailed to UK charities and organisations including Age UK and Alzheimer's Society, who recruited participants through their own internal adverts. The study was also advertised via social media. Inclusion criteria for participants were:

- Age 18 years or over.
- Currently living in the UK.
- Unpaid family caregiver of a person who has a diagnosis of a primary progressive dementia.
- Ability to provide informed consent (see below).
- Able to read and write in English.
- Able to access questionnaires online.

Design

Data for the current study was collected as part of a larger study conducted jointly with another trainee clinical psychologist (Pione, 2020), who assessed the psychometric properties of the Positive Psychology Outcome Measure (PPOM; Stoner et al., 2018). Individual contributions are outlined in Appendix 2. All measures were administered using an online self-complete procedure on Qualtrics.

Ethics

Ethical approval was sought from the UCL Research Ethics Committee (REC; approval: 15139/001; Appendix 3). Upon clicking the link to the study, potential participants were presented with the information sheet (Appendix 4) and consent form (Appendix 5), which they were also able to download and save. Potential participants were given the opportunity to email the researchers before consenting to take part. Participants were required to read through each item on the consent form and select either 'yes' or 'no' to each item. Only those who answered 'yes' to every item on the consent form, confirming that they understood and consented to each aspect of the form were eligible to take part in the study.

Measures

Upon completion of the consent form, participants were first required to provide demographic and clinical information, including age, gender, ethnicity, marital status, work status, education level, relation to the person with dementia, whether they were living with the person for whom they cared, whether they were the primary caregiver and the duration for which they had been caring for the person with dementia. The following measures were then counterbalanced to control for order effects. Some measures are presented in Appendix 6, although those subject to copyright have been removed.

The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988). The MSPSS is a 12-item self-report measure of social support, designed to measure the perceived adequacy of social support. Respondents rate each item on a 7-point scale, from 1 (very strongly disagree) to 7 (very strongly agree). The total score is calculated by summing all responses. Possible scores range from 12 to 84, with higher scores indicating a greater level of perceived social support. There are three subscales, with four items per subscale: family (e.g. item 3: My family really tries to help me), friends (e.g. item 7: I can count on my friends when things go wrong) and a significant other (e.g. item 2: There is a special person

with whom I can share my joys and sorrows). Subscale scores range from 4 to 28. The MSPSS was initially developed in a group of undergraduate students (Zimet et al., 1988). It has shown good internal reliability in other populations including pregnant women, adolescents and paediatric residents (α = .84 - .92, Zimet et al., 1990).

Positive Psychology Outcome Measure (PPOM; Stoner et al., 2018). The PPOM is a 16-item self-report measure of the degree of a person's hope and resilience. It was initially developed for people with dementia but its validity for family caregivers was being tested as part of this study by another trainee (Pione, 2020). Items are measured on a 5-point scale from 0 (not true at all) to 4 (true nearly all the time) using a 1-month time frame. Scores are summed to produce a total score with higher scores indicating greater levels of hope and resilience. The scale can also be divided into two subscales, with 8 items measuring hope (e.g. Item 7: I believe that each day has potential) and 8 items measuring resilience (e.g. Item 13: I can bounce back). The PPOM has good psychometric properties, including a high level of internal consistency (α = 0.94, Stoner et al., 2018) and acceptable test retest reliability (ICC=0.69).

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). The HADS is a 14-item self-report questionnaire, with 7 questions measuring anxiety (e.g. I feel tense or wound up) and 7 measuring depression (e.g. I have lost interest in my appearance). A recent study assessing the validity and usefulness of the HADS in caregivers of people with dementia concluded that the depression scale can be used with this population but suggested that the HADS does not accurately measure distress or anxiety (Stott et al., 2017). Therefore, only the questions forming the depression subscale were used in the present study. Each item is rated from 0 to 3, with different verbal descriptors, depending on the question. Possible scores range from 0 to 21, with higher scores indicating higher levels of depression. The HADS has been recommended by the European

consensus guidelines for carers of people with dementia (Moniz-Cook et al., 2008) and is used widely in both research and clinical practice. The HADS depression subscale (HADS-D) has good internal consistency (α = 0.85) and high levels of concurrent validity when used with caregivers of people with dementia (Stott et al., 2017).

Short Form-12 Health Survey (SF-12; Ware et al., 1996). The SF-12 is a 12-item self-report questionnaire measuring health-related quality of life. Response options vary, for example some items require a yes/no response, some are rated on a 5-point likert scale (e.g. Item 1: In general, would you say your health is: excellent, very good, good, fair, poor) and some are rated on 6-point likert scale (e.g. Item 10: How much of the time during the past 4 weeks did you have a lot of energy? All of the time, most of the time, some of the time, a little of the time, none of the time). The SF-12 was scored using the 4-step procedure recommended by the developers (Ware et al., 1995) to produce two summary scores: the mental component score (MCS) and physical component score (PCS). First, four items were reverse scored such that higher scores indicated better health. The second step involved creating indicator variables for all but one of the response choice categories for each item. Thirdly, each indicator variable was multiplied by their respective regression weight before aggregating the scores for the MCS and PCS. The final step involved transforming the two scale scores to have a mean of 50 and standard deviation of 10 by adding a constant. The two component scores have been shown to have good psychometric properties with test retest reliability coefficients of 0.86 and 0.77 for the PCS and MCS subscores, respectively (Ware et al., 1996).

Procedure

During completion, a response was required for all questions in order to continue to the next question. The battery was initially piloted with three caregivers to check acceptability and completion time. A further pilot analysis was conducted

after 30 participants had completed the battery to check for design problems (Browne, 1995).

The study consisted of one baseline assessment during which all measures were administered and one retest assessment for a subsample of participants, during which only the PPOM and MSPSS were re-administered, the order of which was counterbalanced to control for order effects. For the retest, participants were emailed an invitation to complete the MSPSS and PPOM again four weeks after the date of first completion, until at least 50 participants had taken part. This time frame was chosen to minimise the likelihood of practice effects, whilst also reducing the chances of significant life events occurring between completion dates.

Sample Size and Power Calculation

There are no widely agreed guidelines as to how many participants to include in outcome measure validation studies. However, power calculations can be computed for correlation designs, used to measure convergent validity. One study using the HADS, MSPSS and a quality of life questionnaire found significant negative correlations (p<.001) between the HADS depression subscale and MSPSS subscales, ranging from -0.35 to -0.41 and significant positive correlations between quality of life and the MSPSS ranging from 0.31 to.0.36 (Aaronson et al., 1993). Due to variations in effect sizes found within the literature and differences in populations and measures used, a more conservative estimate using Cohen's convention for the size of a small/medium effect (r = .2) was adopted for the present study. An a priori power analysis carried out using G*Power3 (Faul et al., 2007) gave an estimated sample size of 193 to provide 80% power with an alpha level of 0.05 for a bivariate correlation design. This was thus considered a minimum sample size for the present study.

Analysis

Descriptive Statistics. The range of scores on the MSPSS were plotted to determine possible skew and kurtosis. Floor and ceiling effects were assessed by

examining the number of participants achieving lowest and maximum possible scores, respectively. If more than 15% of respondents achieved these sores, the floor and ceiling effects would be considered significant (Terwee et al., 2007).

Reliability. Internal consistency was measured using Cronbach's alpha, which has an excellent range of 0.95> α ≥0.9 and a good range of 0.9> α ≥0.8 (George & Mallery, 2003). Test re-test reliability for the subsample who completed the MSPSS at both time points was measured using an Intraclass Correlation Coefficient (ICC). Magnitude guidelines were adopted, with a 'good' ranging from 0.75> ICC >0.9 and 'excellent' ICC considered as ≥0.9 (Portney & Watkins, 2000). It was hypothesised that measures would remain relatively stable at retest, with a good level of reliability.

Validity. Convergent validity, a subtype of construct validity, was measured using a Pearson Product-Moment Correlation Coefficient (Pearson's *r*). It was hypothesised that there would be a negative correlation between HADS-D and the MSPSS (Ng et al., 2015). A positive correlation was expected between the SF-12 PCS and MCS and the MSPSS, as a positive correlation has previously been reported between social support and health-related quality of life in family caregivers of people with dementia (Zhang et al., 2014).

Binary logistic regression was used as a further measure of convergent validity. A series of categorical variables were created using the median scores to categorise participants into high and low scorers on the MSPSS, HADS-D and SF-12 PCS and MCS scales. It was hypothesised that being a low scorer on the HADS-D would significantly predict being a high scorer on the MSPSS and that being a high scorer on the SF-12 would significantly predict being a high scorer on the MSPSS.

Confirmatory Factor Analysis (CFA) was used to measure construct validity and investigate whether the three-factor structure could be replicated in the present sample. Analysis was performed using SPSS Amos version 25. The chi-squared

statistic was used to determine whether the data was a good fit for the three-factor model, whereby a significant chi-squared differences test indicates a bad fit. However, this test is heavily sensitive to sample size, such that a large sample can lead to a significant chi-squared statistic even with trivial differences between the sample and fitted covariance matrices. Other fit indices were therefore reported. The Comparative Fit Index (CFI) was considered acceptable if >0.95 and Standardised Root Mean Square Residual (SRMR) if <0.08. The Root Mean Square Error of Approximation (RMSEA) was considered to indicate a good model if <0.06 and considered an acceptable fit if between 0.06 and 0.08. Guidelines reported by Hu and Bentler (1999) were used for the current study, although alternatives have been suggested (e.g. Schumacker, 2015).

Relationships Between Social Support and Participant Characteristics. A combination of Pearson's *r* and t-tests were used to assess the relationships between social support and demographic characteristics, specifically age and gender.

Relationships Between Social Support, Hope and Depression. As suggested by Baron and Kenny (1986), four criteria had to be met in order to conclude that hope mediates the relationship between social support and depressive symptoms:

1. A significant association between social support (independent variable) and depressive symptoms (dependent variable).
2. A significant association between social support and hope (mediator).
3. A significant association between hope and depressive symptoms.
4. With both social support and hope in a regression model, the effect of social support on depressive symptoms is no longer significant (full mediation) or is of a smaller magnitude (partial mediation).

Pearson's *r* was used to examine the associations between social support, hope and depressive symptoms (criteria 1-3). Using depressive symptoms as the

outcome variable, a hierarchical multiple regression analysis was then performed to determine the extent to which hope mediated the relationship between social support and depressive symptoms (criterion 4). The regression analysis was performed in two steps, with social support included in block 1 and hope added to the model in block 2. Bootstrapping was then performed using the PROCESS macro in SPSS to test the statistical significance of the mediation effect.

Results

Participant Characteristics

A total of 293 participants consented to take part in the survey, of which 270 completed all required measures. A subsample of 58 participants completed the MSPSS at time 2. The total sample consisted of 93 men and 177 women, with a mean age of 60.5 years (Table 1). They were predominantly married (69.6%) and either retired (47.8%) or in full-time (21.1%) or part-time (14.1%) employment and were mostly well-educated, with 57.4% holding an undergraduate degree or over. The vast majority of participants were white British (92.2%).

The most commonly cited relationship with the person with dementia was daughter (40.7%; Table 2), followed by husband (21.9%) and approximately half of participants were living with the person with dementia (49.6%). Most relatives with dementia had been diagnosed with Alzheimer's disease (48.1%) or mixed dementia (22.6%). The demographics and clinical characteristics appeared similar for the total sample and test-retest subsample.

The majority of participants (87.4%) heard about the research via Join Dementia Research Network. Other recruitment sources reported included Age UK (1.9%), social media (2.6%), a friend or family member (1.9%) and 'other' (6.3%).

Table 1.

Participant demographics

	Total Sample (n=270)	**Test-retest subsample (n=58)**
Gender *n (%)*		
Male	93 (34.4)	19 (32.8)
Female	177 (65.6)	39 (67.2)
Age *M(SD)*	60.5 (14.40)	62.9 (10.6)
Range	20-92	41-91
Ethnicity *n (%)*		
White (British)	249 (92.2)	54 (93.1)
White (other)	13 (4.8)	2 (3.4)
Black	2 (0.7)	1 (1.7)
Asian	2 (0.7)	0 (0.0)
Mixed	3 (1.1)	0 (0.0)
Other	1 (0.4)	1 (1.7)
Marital Status *n (%)*		
Single	33 (12.2)	5 (8.6)
In a relationship	30 (11.1)	2 (3.4)
Married	188 (69.6)	44 (75.9)
Divorced	10 (3.7)	3 (5.2)
Widowed	3 (1.1)	1 (1.7)
Separated	3 (1.1)	1 (1.7)
Other	3 (1.1)	2 (3.4)
Employment Status *n (%)*		
Full-time employment	57 (21.1)	9 (15.5)
Part-time employment	38 (14.1)	15 (25.9)
Self-employed	16 (5.9)	2 (3.4)
Unemployed	13 (4.8)	3 (5.2)
Homemaker	15 (5.6)	5 (8.6)
Student	2 (0.7)	0 (0.0)
Retired	129 (47.8)	24 (41.4)
Education *n (%)*		
Postgraduate degree (or equivalent)	73 (27.0)	14 (24.1)
University degree (or equivalent)	82 (30.4)	18 (31.0)
Higher education (or equivalent)	44 (16.3)	11 (19.0)
A level (or equivalent)	27 (10.0)	3 (5.2)
GCSE grades A*-C (or equivalent)	24 (8.9)	7 (12.1)
Other qualifications	9 (3.3)	3 (5.2)
No qualifications	11 (4.1)	2 (3.4)

Table 2.

Characteristics relating to person with dementia

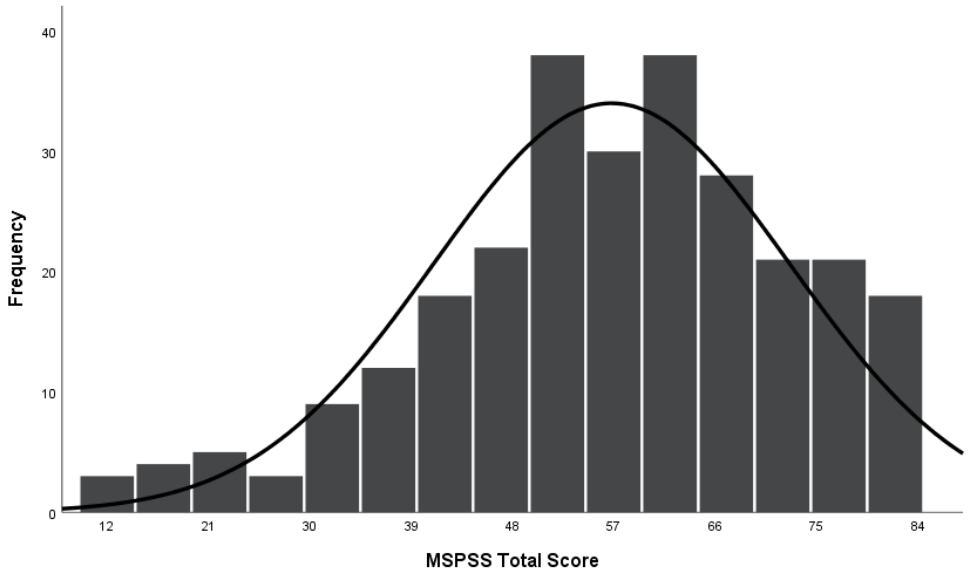
	Total Sample (n=270)	**Test-retest subsample (n= 58)**
Relationship to person with dementia *n (%)*		
Husband	59 (21.9)	12 (20.7)
Wife	43 (15.9)	9 (15.5)
Son	26 (9.6)	7 (12.1)
Daughter	110 (40.7)	24 (41.4)
Son-in-law	5 (1.9)	0 (0.0)
Daughter-in-law	5 (1.9)	2 (3.4)
Granddaughter	10 (3.7)	0 (0.0)
Grandson	1 (0.4)	0 (0.0)
Other	11 (4.1)	4 (6.9)
Living with person with dementia *n (%)*		
Yes	134 (49.6)	27 (46.6)
No	136 (50.4)	31 (53.4)
Primary caregiver *n (%)*		
Yes	174 (64.4)	37 (63.8)
No	86 (31.9)	2 (3.4)
Joint Primary	10 (3.7)	19 (32.8)
Diagnosis of person with dementia *n (%)*		
Alzheimer's disease	130 (48.1)	32 (55.2)
Vascular dementia	33 (12.2)	3 (5.2)
Dementia with lewy bodies	6 (2.2)	1 (1.7)
Parkinson's dementia	5 (1.9)	3 (5.2)
Frontotemporal dementia	13 (4.8)	3 (5.2)
Mixed dementia	61 (22.6)	12 (20.7)
Dementia (subtype unknown)	13 4.8)	1 (1.7)
Other	9 (3.3)	0 (0.0)
Time since diagnosis *n (%)*		
0-1 year	40 (14.8)	11 (19.0)
1-2 years	55 (20.4)	7 (12.1)
3-4 years	80 (29.6)	19 (32.8)
5-8 years	71 (26.3)	13 (22.4)
9 years +	23 (8.5)	7 (12.1)
Missing	1 (0.4)	1 (1.7)
Time caring *n (%)*		
0-1 year	16 (5.9)	6 (10.3)
1-2 years	40 (14.8)	4 (6.9)
3-4 years	86 (31.9)	21 (36.2)
5-8 years	76 (28.1)	13 (22.4)
9 years +	52 (19.3)	14 (24.1)

Descriptive Statistics

The full possible range of scores from 12 to 84 was observed (*M* = 56.80, *SD* =15.84). Inspection of a histogram suggested that the MSPSS total score followed a relatively normal distribution (Figure 1), however statistically, the total score was significantly negatively skewed (-0.52). The kurtosis value was 0.08. However, given the robustness of parametric tests and the expected approximate normal distribution of the data in the population, parametric tests were considered appropriate. Three participants (1.1%) scored the lowest possible score of 12 and nine (3.3%) scored the maximum possible score of 84. Therefore, neither floor nor ceiling effects were observed.

Figure 1.

Distribution of the MSPSS



The ‘significant other’ subscale was significantly negatively skewed (-0.60) and the kurtosis value was -0.55. Only 5.2% of participants scored the lowest possible score of 4, however, 16.7% scored the highest score of 28. This is above the 15% recommended by Terwee et al. (2007), thus indicating a ceiling effect for the ‘significant other’ subscale.

Both the 'family' and 'friends' subscales were significantly negatively skewed (-0.79 and -0.69, respectively) with kurtosis values of -0.30 and 0.08, respectively. The lowest possible score was reported by 7.8% of participants for the 'family' subscale and 3.3% for the 'friends' subscale. No participants scored the maximum possible score for the 'family' subscale and only 5.9% achieved the maximum possible score on the 'friends' subscale. Neither the floor nor ceiling effects were therefore problematic for the 'family' and 'friends' subscales.

Internal Consistency

Internal consistency was excellent with $\alpha = 0.92$ and not indicative of multicollinearity ($\alpha \geq 0.95$). No items were identified as improving the internal consistency if deleted. Internal consistency was excellent for the 'significant other', 'family' and 'friends' subscales, with $\alpha = 0.93$, $\alpha = 0.94$ and $\alpha = 0.92$, respectively. Again, no items were identified as improving the internal consistency if deleted. These values are similar to those reported in the original development study (Zimet et al., 1988): $\alpha = 0.88$ for the total scale and $\alpha = 0.91$, $\alpha = 0.87$ and $\alpha = 0.85$ for the 'significant other', 'family' and 'friends' subscales, respectively.

Test-retest Reliability

The number of days between the test and retest for the subsample of 58 participants ranged from 28 to 42.5 (*Mdn* = 28.52), with 69% of participants completing the retest questionnaire on the 28th day. An 'excellent' degree of consistency was found between MSPSS scores at time 1 and time 2 (ICC = 0.90, 95%CI = 0.84, 0.94). Consistency was 'good' for the 'significant other' subscale (ICC = 0.89, 95%CI = 0.82, 0.93); the 'family' subscale (ICC = 0.86, 95%CI = 0.77, 0.91); and the 'friends' subscale (ICC = 0.84, 95%CI = 0.74, 0.90).

Convergent Validity

Pearson's *r* correlations were conducted, using a Bonferroni adjusted alpha level of 0.004 per test (.05/12) such that $p < .004$ were considered significant. Non-

parametric tests were performed for comparison; however, parametric tests are reported as these are more robust and differences were negligible. Binary logistic regression analyses were performed as additional tests of convergent validity.

The HADS-D score was significantly negatively correlated with the total MSPSS score (r = -0.48, p < .001), as well as 'significant other' (r = -0.34, p < .001), 'family' (r = -0.33, p < .001) and 'friends' (r = -0.45, p < .001) subscales, with medium effect sizes. There were two potential outliers identified on the HADS-D, however as excluding these and re-running analyses made only a negligible difference, they were retained. The total MSPSS score was significantly positively correlated with the SF-12 PCS (r = 0.17, p = .003) and MCS (r = 0.32, p < .001), with small and medium effect sizes, respectively. The 'significant other' subscale score was significantly positively correlated with the MCS (r = 0.20, p = .001) with a small effect size, but not with the PCS (r = 0.13, p = .018). The 'family' subscale score was significantly positively correlated with the MCS (r = 0.26, p < .001) with a small effect size, but not with the PCS (r = 0.09, p = .064). The 'friends' subscale score was significantly positively correlated with both the MCS (r = 0.27, p < .001) and PCS (r = 0.19, p = .001) with small effect sizes.

Categorical variables were created using the median score for each variable in order to identify participants as high or low scorers on the MSPSS, HADS-D, MCS and PCS. The median score on the MSPSS was 58. Those scoring 58 or less were categorised as low scorers (n = 137) and those scoring above 58 were categorised as high scorers (n = 133). The median for the HADS-D was 6, with 143 participants classified as low scorers and 127 as high scorers. The PCS had a median score of 50.65, with 135 participants were classified as low scorers and 135 as high scorers. The median score for the MCS was 38.91, with 135 classified as low scorers and 135 as high scorers.

A series of three separate binary logistic regression analyses were performed, with either the HADS-D, MCS or PCS as the predictor variable and

MSPSS as the dependent variable. HADS-D was a significant predictor of MSPSS (χ^2 = 23.10, df = 1, p < .001; Wald = 22.07, p < .001), with an odds ratio of 0.3 (95%CI 0.18 – 0.5). This model explained 10.9% of the variability in MSPSS score and correctly predicted 64.4% of cases.

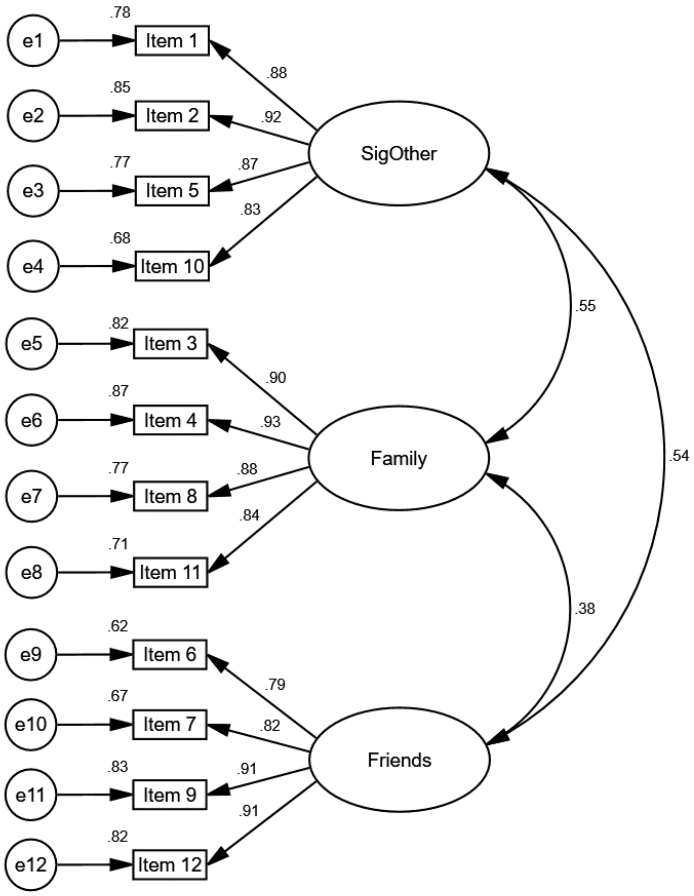
PCS was not a significant predictor of MSPSS (χ^2 = 3.34, df = 1, p = .068), accounting for only 1.6% of the variance in MSPSS scores and correctly predicting 55.6% of cases. However, MCS was a significant predictor of MSPSS (χ^2 = 7.88, df = 1, p = .005; Wald = 7.76, p = .005), with an odds ratio of 1.99 (95%CI 1.23 – 3.23). This model explained 3.8% of the variance in MSPSS scores and correctly predicted 58.5% of cases.

Factor Structure

In the CFA, although the chi-squared analysis was significant, χ^2 (51, *N* = 270) = 144.829, *p* < .001, fit indices were suggestive of an acceptable model fit (CFI = 0.97, SRMR = 0.04, RMSEA = 0.08). All 12 items significantly loaded onto their respective factor. Standardised factor loadings ranged from 0.79 to 0.93 (Figure 2). These are similar to the factor loadings reported in the original development paper for a three-factor solution reported by Zimet et al. (1988), in which loadings ranged from 0.74 to 0.92.

Figure 2.

Factor structure of the MSPSS



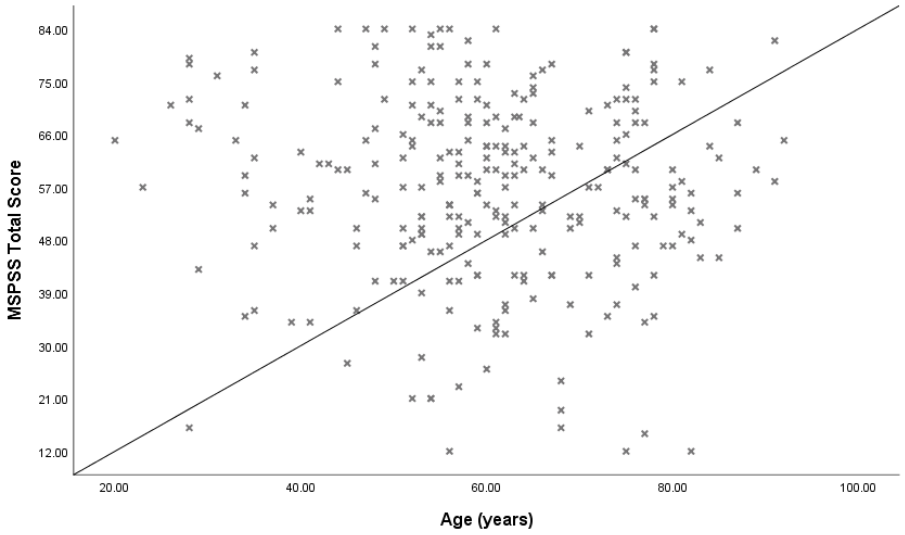
Relationships Between Social Support and Demographic Characteristics

A combination of Pearson's *r* and t-tests were used to assess the relationships between social support and demographic characteristics.

Age. Visual inspection of a scatter plot (figure 3) indicated no evidence of a linear relationship between age and MSPSS score. This was supported by a Pearson's *r* correlation coefficient between age and MSPSS which was not statistically significant (p = .432). There was, however, a significant negative correlation between age and scores on the 'significant other' subscale (r = -0.20, p = .001) and a positive correlation between age and the 'family' subscale (r = 0.12, p = .048).

Figure 3.

Scatter plot of the relationship between age and total scores on the MSPSS



It was hypothesised that the relationship between age and scores on the 'significant other' and 'family' subscales may be due to the different relationships between participants and the person for whom they were caring, such that older participants were more likely to be caring for their significant other and thus receive less support *from* their significant other, but as a result, potentially more support from other family members (e.g. adult children). In support of this hypothesis, descriptive statistics show that those caring for a spouse were, on average, older than those caring for a parent (table 3).

Table 3.

Mean age of participants grouped by their relationship to the person with dementia

	N	*M* (years)	*SD* (years)
Husband	59	75.69	8.15
Wife	43	66.12	11.06
Son	26	55.65	8.21
Daughter	110	53.83	10.67
Son-in-law	5	64.2	18.43
Daughter-in-law	5	54	11.22
Granddaughter	10	32.6	11.59
Grandson	1	48	-
Other	11	62.55	9.25

Gender. Independent samples t-tests were conducted using Bonferroni adjusted alpha levels of 0.013 per test (.05/4). There was no significant difference in the mean total MSPSS score for males and females (p = .249). There was also no significant difference in scores on the 'family' (p = .059) and 'significant other' (p = .031) subscales between males and females. However, females scored higher on the 'friends' subscale (M = 20.00, SD = 5.36) compared to males (M = 17.69, SD = 6.46), $t(159.71) = -2.96$, p = .004, d = 0.39, the effect size of which was small.

Relationships Between Social Support, Hope and Depression

Pearson's r correlations indicated that MSPSS total score was significantly negatively correlated with HADS-D (r = -0.48, p < .001) and significantly positively correlated with PPOM hope (r = 0.45, p < .001) and that hope was significantly negatively correlated with HADS-D scores (r = -0.69, p < .001), thus satisfying Baron and Kenny's (1986) first three criteria.

A hierarchical multiple regression analysis was performed to determine whether hope mediated the relationship between social support and depression.

Social support was added as a predictor in the first step and hope as an additional predictor in the second step (table 4). In the first step, social support significantly predicted depressive symptoms (*b* = -0.13, 95% CI [-0.15, -0.10], *ß* = -0.48, *t* = -8.85, *p* < .001; figure 4 c path). In the second model, with both hope and social support added into the model, social support remained a significant predictor of depressive symptoms, although predictability was reduced (*b* = -0.05, 95% CI [-0.08, -0.03], *ß* = -0.21, *t* = -4.23, *p* < .001; figure 4 c' path). Finally, hope predicted depressive symptoms when controlling for social support (*b* = -0.44, 95% CI [-0.51, -0.37], *ß* = -060., *t* = -12.45, *p* < .001; figure 4 b path). A separate simple linear regression analysis showed that social support significantly predicted hope (*b* = 0.16, 95% CI [0.12, 0.20], *ß* = 0.45, *t* = 8.28, *p* < .001; figure 4 a path).

Table 4.

Predictors for depressive symptoms with stress as a mediator

	b	*SE b*	*ß*
Step 1			
Constant	13.63	0.83	
Social Support	-0.13	0.01	0.48***
Step 2			
Constant	19.17	0.80	
Social Support	-0.05	0.01	-0.21***
Hope	-0.44	0.04	-0.60***

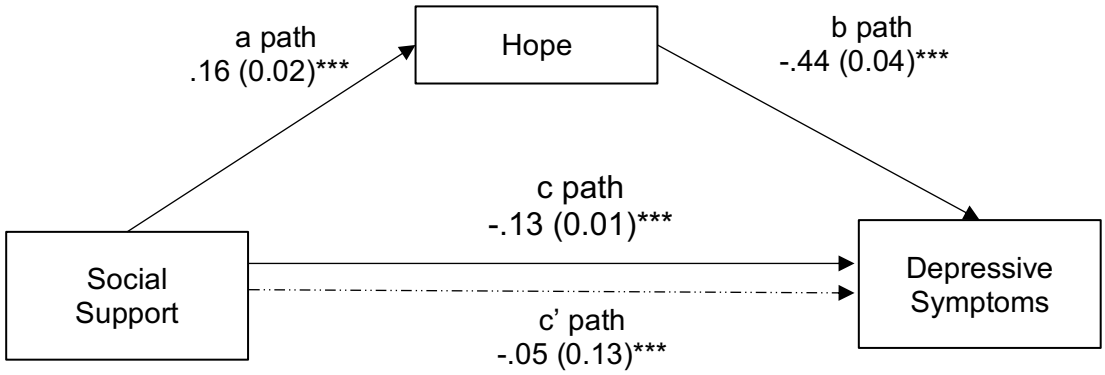
Note. R^2 = 0.23 for Step 1. ΔR^2 = 0.28 (*ps* < .001). *** *p* < .001.

A bootstrapping method, using the PROCESS tool in SPSS indicated that there was a significant indirect effect of social support on depressive symptoms through hope, *b* = -0.07, BCa CI [-0.09, -0.05], which accounted for 27% of the total

effect of social support on depressive symptoms, thus supporting the hypothesis that the relationship between social support and depressive symptoms may be partly accounted for by hope (figure 4).

Figure 4.

Standardised regression coefficients for the relationship between social support and depressive symptoms as partially mediated by hope.



Note. Standard error of regression coefficients are in parentheses. *** = $p < .001$.

Discussion

This study presents strong evidence that the MSPSS maintains good psychometric properties when used with family caregivers of people with dementia, thus supporting its use in research and clinical practice. According to criteria (Terwee et al., 2007), neither floor nor ceiling effects for the total score were observed. As hypothesised, internal consistency was very good and test-retest reliability was excellent.

Correlations with the MSPSS total score and measures of convergent validity were significant and in the expected directions. As hypothesised, there was a negative correlation between the MSPSS total score and HADS-D and a positive correlation between the MSPSS total score and both SF-12 component scores.

However, the size of the correlation between PCS and MSPSS, although significant, was relatively small. Binary logistic regression analyses largely supported these findings, as HADS-D scores and SF-12 MCS scores significantly predicted high/low classification on the MSPSS. However, SF-12 PCS scores did not significantly predict MSPSS high/low MSPSS classification.

A CFA showed that all items significantly loaded onto their respective factors ('significant other', 'family' and 'friends'), with fit indices suggestive of an acceptable model fit for the hypothesised three-factor model (Hu & Bentler, 1999). These findings were comparable with previous findings of the factor structure of the MSPSS (Zimet et al., 1988).

In line with previous research (Wang et al., 2017), there was no significant relationship between age and social support, as measured using the MSPSS total score. However, older age was associated with lower scores on the 'significant other' subscale and higher scores on the 'family' subscale. Descriptive statistics indicated that participants who were caring for a spouse with dementia were, on average, older than those caring for other family members, providing a possible explanation for the significant relationship between age and MSPSS scores for the 'significant other' subscale. It may be further hypothesised that family members (e.g. adult children or grandchildren) provided additional support to older participants who were caring for a spouse, therefore offering a possible explanation for the association between older age and higher scores on the 'family' subscale, although this hypothesis requires further research.

With regards to gender differences, no significant differences in MSPSS total scores, 'significant other' or 'family' subscale scores were found between males and females. However, females scored significantly higher on the 'friends' subscale score than males.

Finally, as hypothesised, there was a significant negative relationship between the perceived adequacy of social support and depressive symptoms.

Furthermore, in line with previous research (Bao et al., 2019), the findings are in support of the hypothesis that the relationship between social support and depressive symptoms was partially mediated by hope, with hope accounting for 27% of the total effect of social support on depressive symptoms. However, caution must be applied when interpreting these findings due to the limitations of cross-sectional data in determining mediation.

Implications

This is the first paper to rigorously assess the psychometric properties of a widely used measure of social support, when used with family caregivers of people with dementia. The findings indicate that the MSPSS is a suitable and psychometrically sound measure of social support for family caregivers of people with dementia.

This finding has important implications for research as there is currently a plethora of measures of social support used within the literature. The wide range of currently used measures makes it difficult to compare and synthesise research findings, making it difficult to draw conclusions regarding the role of social support. Furthermore, some of the other currently used measures have been found to have relatively poor reliability when used with caregivers of people with dementia (Stensletten et al., 2016) or have been used inconsistently across studies (Gallagher-Thompson et al., 2003; Rabinowitz et al., 2006). It may thus be suggested that the MSPSS can be used to measure social support in future research with caregivers of people with dementia. A more homogeneous use of measures will allow comparability across studies and enable more rigorous research regarding the role of social support. Clinically, the MSPSS could be used to identify caregivers who are struggling, enabling services to intervene appropriately and in a timely manner.

Findings regarding the relationships between social support, hope and depressive symptoms suggest that hope may partially mediate the relationship

between social support and depressive symptoms, such that caregivers reporting higher levels of social support have more hope and, as a result, experience fewer symptoms of depression. These findings are in line with the Stress/Health Model (Schulz & Martire, 2004), which posits that those who perceive the caring demands as unthreatening and their coping resources as adequate are less likely to experience stress. These findings suggest that interventions aimed at increasing social support and/or increasing caregivers' hope may help to improve psychological wellbeing of caregivers and possibly prevent depressive symptoms.

Future Research

An important aspect of psychometric evaluation and a criterion upon which outcome measures are evaluated, is responsiveness (Terwee et al., 2007), or the ability of a questionnaire to detect clinically important changes over time, for example as the result of an intervention. It was not possible to establish the responsiveness of the MSPSS in the current study as no intervention was administered. Further research is therefore required to determine whether the MSPSS is able to pick up change in the perceived adequacy of social support following an intervention, in order to determine whether it can be used reliably as a clinical outcome measure. Once responsiveness of the MSPSS has been established for family caregivers, the measure could also be used to evaluate the efficacy of clinical interventions aimed at improving levels of perceived social support.

Limitations

The main limitation of this study was the lack of diversity in the sample, particularly with regards to ethnicity. There were very few participants who were from Black, Asian and Minority Ethnic (BAME) groups, with the vast majority of participants being white British. Participants were also generally well-educated, with a large proportion of participants having a university degree or higher. In addition, the majority of participants were recruited via Join Dementia Research Network. It

may therefore be suggested that the current sample was not representative of the wider population of family caregivers.

In addition, assessing convergent validity using Pearson's *r* correlation coefficients indicated that the relationship between social support and quality of life, as measured using the PCS of the SF-12, was small albeit statistically significant. Further analysis using binary logistic regression suggested that PCS score did not significantly predict whether someone was a high or low scorer on the MSPSS. In addition, clinical significance was not determined in the current study. It is therefore possible that there are concepts other than quality of life that are more closely linked to social support for this population, which warrants further research.

Previous research suggests that the depression scale of the HADS can be used with carers of people with dementia but that the HADS anxiety scale is not useful for this population (Stott et al., 2017). In order to reduce completion time of the battery and given that only the HADS-D was required for analysis, only the items from the depression subscale were administered in the battery. However, it is possible that using the HADS-D alone may have compromised the validity of this scale. Other measures of depression, such as the Patient Health Questionnaire-9 (Kroenke et al., 2001), may thus have been more appropriate.

Conclusions

The MSPSS has good psychometric properties when used with family caregivers of people with dementia. It is hoped that this will enable greater consistency in the choice of outcome measure used in research evaluating social support in this population. The MSPSS was significantly correlated with depression and health-related quality of life, suggesting that the perceived adequacy of social support has important implications for family caregivers' psychological wellbeing. Further research is required in order to determine the responsiveness of this measure following an intervention and asses cross-cultural validity.

References

Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., Filiberti, A., Flechtner, H., Fleishman, S. B., De Hes, J. C. J. M., Kaasa, S., Klee, M., Osoba, D., Razavi, D., Rofe, P. B., Schraub, S., Sneeuw, K., Sullivan, M., Takeda, F. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: A Quality-of-Life Instrument for Use in International Clinical Trials in Oncology. *JNCI: Journal of the National Cancer Institute, 85*(5), 365-376. https://doi.org/10.1093/jnci/85.5.365

Abbott, A. (2011). Dementia: A problem for our age. *Nature, 475*(7355), S2-S4. https://doi.org/10.1038/475S2a

Alzheimer's Research UK. (2017). *Dementia in the Family: The impact on carers*.

Bao, Y., Li, L., Guan, Y., Liu, Y., Wang, W., Zhao, D., Tao, S., Ling, Y., Want, Y., Bi, B., Wu, A., Cao, L. (2019). Is the relationship between social support and depressive symptoms mediated by hope among Chinese central nervous system tumor patients? *Supportive Care in Cancer, 27*(1), 257-263. https://doi.org/10.1007/s00520-018-4321-z

Baron, R. M., & Kenny, D. A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*(6), 1173-1182. https://doi.org/10.1037/0022-3514.51.6.1173

Barrera. M., Sandler, I. N., & Ramsay, T. B. (1981). Preliminary development of a scale of social support: Studies on college students. *American Journal of Community Psychology, 9*(4), 435-447. https://doi.org/10.1007/bf00918174

Browne, R. H. (1995). On the use of a pilot sample for sample size determination. *Statistics in Medicine, 14*(17), 1933-1940. https://doi.org/10.1002/sim.4780141709

Canty-Mitchell, J., & Zimet, G. D. (2000). Psychometric properties of the Multidimensional Scale of Perceived Social Support in urban adolescents.

American Journal of Community Psychology, 28(3), 391-400. https://doi.org/10.1023/A:1005109522457

Carers UK. (2014). *State of Caring Survey 2014*: Carers UK.

Cecil, H., Stanley, M. A., Carrion, P. G., & Swann, A. (1995). Psychometric properties of the MSPSS and NOS in psychiatric outpatients. *Journal of Clinical Psychology, 51*(5), 593-602. https://doi.org/10.1023/A:1005109522457

Charlesworth, G., Shepstone, L., Wilson, E., Reynolds, S., Mugford, M., Price, D., Harvey, I., & Poland, F. (2008). Befriending carers of people with dementia: randomised controlled trial. *BMJ, 336*(7656), 1295-1297. https://doi.org/10.1136/bmj.39549.548831.AE

Cohen, S., Gottlieb, B., & Underwood, L. (2000). *Social relationships and health: challenges for measurement and intervention.* New York: Oxford University Press.

Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*(2), 310-357. https://doi.org/10.1037/0033-2909.98.2.310

Cutrona, C. E., & Russell, D. W. (1987). The provisions of social relationships and adaptation to stress. In W.H. Jones & D. Perlman (Eds., *Advances in Personal Relationships.* Greenwich, CT: JAI Press

Dam, A. E., de Vugt, M. E., Klinkenberg, I. P., Verhey, F. R., & van Boxtel, M. P. (2016). A systematic review of social support interventions for caregivers of people with dementia: Are they doing what they promise? *Maturitas, 85*, 117-130. https://doi.org/10.1016/j.maturitas.2015.12.008

Dambi, J. M., Corten, L., Chiwaridzo, M., Jack, H., Mlambo, T., & Jelsma, J. (2018). A systematic review of the psychometric properties of the cross-cultural translations and adaptations of the Multidimensional Perceived Social

Support Scale (MSPSS). *Health and quality of life outcomes, 16*(1), 80-80. https://doi.org/10.1186/s12955-018-0912-0

Department of Health (2016). *Prime Minister's Challenge on Dementia 2020.* Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf

Donegan, K., Fox, N., Black, N., Livingston, G., Banerjee, S., & Burns, A. (2017). Trends in diagnosis and treatment for people with dementia in the UK from 2005 to 2015: a longitudinal retrospective cohort study. *Lancet Public Health, 2*(3), e149-e156. https://doi.org/10.1016/s2468-2667(17)30031-2

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*(2), 175-191. https://doi.org/10.3758/BF03193146

Gallagher-Thompson, D., Coon, D. W., Solano, N., Ambler, C., Rabinowitz, Y., & Thompson, L. W. (2003). Change in indices of distress among Latino and Anglo female caregivers of elderly relatives with dementia: site-specific results from the REACH national collaborative study. *Gerontologist, 43*(4), 580-591. https://doi.org/10.1093/geront/43.4.580

George, D., & Mallery, P. (2003). *SPSS for Windows step by step: A simple guide and reference. 11.0 update* (4th ed. ed.). Boston: Allyn & Bacon.

Gottlieb, B. H., & Bergen, A. E. (2010). Social support concepts and measures. *Journal of Psychosomatic Research, 69*(5), 511-520. https://doi.org/10.1016/j.jpsychores.2009.10.001

Haley, W. E., Roth, D. L., Coleton, M. I., Ford, G. R., West, C. A., Collins, R. P., & Isobe, T. L. (1996). Appraisal, coping, and social support as mediators of well-being in black and white family caregivers of patients with Alzheimer's

disease. *Journal of Consulting and Clinical Psychology, 64*(1), 121-129. https://doi.org/10.1037//0022-006x.64.1.121

Hardan-Khalil, K., & Mayo, A. M. (2015). Psychometric Properties of the Multidimensional Scale of Perceived Social Support. *Clinical Nurse Specialist, 29*(5), 258-261. https://doi.org/10.1097/nur.0000000000000148

Hu, L., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling: A Multidisciplinary Journal, 6*(1), 1-55. https://doi.org/10.1080/10705519909540118

Kiecolt-Glaser, J. K., Dura, J. R., Speicher, C. E., Trask, O. J., & Glaser, R. (1991). Spousal caregivers of dementia victims: longitudinal changes in immunity and health. *Psychosomatic Medicine, 53*(4), 345-362. https://doi.org/10.1097/00006842-199107000-00001

King, A. C., Oka, R. K., & Young, D. R. (1994). Ambulatory blood pressure and heart rate responses to the stress of work and caregiving in older women. *Journal of Gerontology, 49*(6), M239-245. https://doi.org/10.1093/geronj/49.6.m239

Kroenke, K., Spitzer, R. L., & Williams, J.B., (2001). The PHQ-9: Validity of a Brief Depression Severity Measure. *Journal of General Internal Medicine, 16(9),* 606- 613. https://doi.org.uk/10.1046/j.1525-1497.2001.016009606.x

Moniz-Cook, E., Vernooij-Dassen, M., Woods, R., Verhey, F., Chattat, R., De Vugt, M., Mountain, G., O'connell, M., Harrison, J., Vasse, E., Dröes, R. M., & Orrell, M. (2008). A European consensus on outcome measures for psychosocial intervention research in dementia care. *Aging & Mental Health, 12*(1), 14-29. https://doi.org/10.1080/13607860801919850

Moore, M. J., Zhu, C. W., & Clipp, E. C. (2001). Informal costs of dementia care: estimates from the National Longitudinal Caregiver Study. *Journals of*

Gerontology. Series B: Psychological Sciences and Social Sciences, 56(4), S219-228. https://doi.org/10.1093/geronb/56.4.s219

Ng, C. G., Mohamed, S., See, M. H., Harun, F., Dahlui, M., Sulaiman, A. H., Zainal, N. Z., & Taib, N. A. (2015). Anxiety, depression, perceived social support and quality of life in Malaysian breast cancer patients: a 1-year prospective study. *Health Qual Life Outcomes, 13*, 205. https://doi.org/10.1186/s12955-015-0401-7

Orgeta, V., Sterzo, E. L., & Orrell, M. (2013). Assessing mental well-being in family carers of people with dementia using the Warwick–Edinburgh Mental Well-Being Scale. *International Psychogeriatrics, 25*(9), 1443-1451. https://doi.org/10.1017/S1041610213000835

Ory, M. G., Hoffman, R. R., Yee, J. L., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *Gerontologist, 39*(2), 177-185. https://doi.org/10.1093/geront/39.2.177

Pione, R. D. (2020). *The development of the PPOM-C for family carers of people with dementia: Psychometric properties and factor structure.* Unpublished clinical psychology doctoral thesis, Department of Clinical, Educational, and Health Psychology, University College London.

Portney, L. G., & Watkins, M. P. (2000). *Foundations of Clinical Research: Applications to Practice*. Upper Saddle River, NJ: Prentice Hall.

Rabinowitz, Y. G., Mausbach, B. T., Coon, D. W., Depp, C., Thompson, L. W., & Gallagher-Thompson, D. (2006). The Moderating Effect of Self-Efficacy on Intervention Response in Women Family Caregivers of Older Adults With Dementia. *The American Journal of Geriatric Psychiatry, 14*(8), 642-649. https://doi.org/10.1097/01.JGP.0000192496.73673.e5

Ross, C. E., & Mirowsky, J. (1989). Explaining the social patterns of depression: Control and problem solving: or Support and talking? *Journal of Health and Social Behavior, 30*(2), 206–219. https://doi.org/10.2307/2137014

Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry, 12*(3), 240-249. https://doi.org/10.1097/00019442-200405000-00002

Schulz, R., Newsom, J., Mittelmark, M., Burton, L., Hirsch, C., & Jackson, S. (1997). Health effects of caregiving: the caregiver health effects study: an ancillary study of the Cardiovascular Health Study. *Annals of Behavioral Medicine, 19*(2), 110-116. https://doi.org/10.1007/bf02883327

Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *Gerontologist, 35*(6), 771-791. https://doi.org/10.1093/geront/35.6.771

Schumacker, R. E. (2015). *Using R with Multivariate Statistics*. Thousand Oaks, CA: Sage Publications.

Smerglia, V. L., Miller, N. B., Sotnak, D. L., & Geiss, C. A. (2007). Social support and adjustment to caring for elder family members: A multi-study analysis. *Aging & Mental Health, 11*(2), 205-217. https://doi.org/10.1080/13607860600844515

Soman, S., Bhat, S. M., Latha, K. S., Praharaj, S. K. (2016). Gender differences in perceived social support and stressful life events in depressed patients. *East Asian Archives of Psychiatry, 26(1),* 22-29.

Stanley, M. A., Beck, J. G., & Zebb, B. J. (1998). Psychometric properties of the MSPSS in older adults. *Aging & Mental Health, 2*(3), 186-193. https://doi.org/10.1080/13607869856669

Stensletten, K., Bruvik, F., Espehaug, B., & Drageset, J. (2016). Burden of care, social support, and sense of coherence in elderly caregivers living with individuals with symptoms of dementia. *Dementia, 15*(6), 1422-1435. https://doi.org/10.1177/1471301214563319

Stoner, C. R., Orrell, M., & Spector, A. (2018). The Positive Psychology Outcome Measure (PPOM) for people with dementia: Psychometric properties and factor structure. *Archives of Gerontology and Geriatrics, 76*, 182-187. https://doi.org/10.1016/j.archger.2018.03.001

Stott, J., Orrell, M., & Charlesworth, G. (2017). Validity and Usefulness of the Hospital Anxiety and Depression Scale in Carers of People with Dementia: Evidence from Confirmatory Factor Analysis, Concurrent Validity, and Measurement Invariance in a Large Sample. *American Journal of Geriatric Psychiatry, 25*(11), 1270-1280. https://doi.org/10.1016/j.jagp.2017.05.017

Terwee, C. B., Bot, S. D., de Boer, M. R., van der Windt, D. A., Knol, D. L., Dekker, J., Bouter, L. M., & de Vet, H. C. (2007). Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of Clinical Epidemiology, 60*(1), 34-42. https://doi.org/10.1016/j.jclinepi.2006.03.012

Turner, J. & Lloyd, D. A. (1999). The stress process and social distribution of depression. *Journal of Health and Social Behavior, 40(4),* 374-404. https://doi.org/10.2307/2676332

Wang, Y., Wan, Q., Huang, Z., Huang, L., & Kong, F. (2017). Psychometric Properties of Multi-Dimensional Scale of Perceived Social Support in Chinese Parents of Children with Cerebral Palsy. *Frontiers in Psychology, 8*, 2020. https://doi.org/10.3389/fpsyg.2017.02020

Ware, J., Jr., Kosinski, M., & Keller, S. D. (1996). A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Medical Care, 34*(3), 220-233. https://doi.org/10.1097/00005650-199603000-00003

Ware, J. E., Kosinski, M., & Keller, S. D. (1995). *SF-12: How to Score the SF-12 Physical and Mental Health Summary Scales* (Second Edition ed.). Boston, MA: The Health Institute, New England Medical Center.

Zhang, S., Zhang, S., Edwards, H., Yates, P., Li, C., & Guo, Q. (2014). Self-Efficacy Partially Mediates between Social Support and Health-Related Quality of Life in Family Caregivers for Dementia Patients in Shanghai. *Dementia and Geriatric Cognitive Disorders, 37*(1-2), 34-44. https://doi.org/10.1159/000351865

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica, 67*(6), 361-370. https://doi.org/10.1111/j.1600-0447.1983.tb09716.x

Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment, 52*(1), 30-41. https://doi.org/10.1207/s15327752jpa5201_2

Zimet, G. D., Powell, S. S., Farley, G. K., Werkman, S., & Berkoff, K. A. (1990). Psychometric characteristics of the Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment, 55*(3-4), 610-617. https://doi.org/10.1080/00223891.1990.9674095

Part 3: Critical Appraisal

Introduction

The intention of this critical appraisal is to reflect on the process of the research, consider conceptual issues and key decisions that arose during the project, discuss the implications of the two papers and make recommendations for further research. Four key issues will be discussed:

1. Defining and measuring social support
2. Key joint decisions in designing the study
3. Reflections on the process of recruitment
4. Implications and further research

Defining and Measuring Social Support

The review paper highlighted the scarcity of appropriate support services to meet the needs of children (including those both under and over the age of 18 years and stepchildren) of people with young onset dementia. Participants often spoke of feelings of shame (Hutchinson, Roberts, Daly, et al., 2016) and embarrassment (Hall & Sikes, 2017) and described not seeking support from their peers due to discrimination and stigma (Hutchinson, Roberts, Daly, et al., 2016). They would also hide their own difficulties due to concerns about burdening others (Hutchinson, Roberts, Kurrle, et al., 2016). Some found their peers unsympathetic and ill-informed and were therefore reluctant to seek support (Gelman & Rhames, 2018; Hutchinson, Roberts, Daly, et al., 2016). As a result, isolation and loneliness were common, with many participants finding it difficult to cope.

However, some did seek support from friends and valued having someone outside the family to talk to (Millenaar et al., 2014; Svanberg et al., 2010). Participants also sought support from their parent without dementia and siblings, and older participants valued emotional and practical support from their partner (Barca et al., 2014). Those who were able to attend support groups largely found these useful, although emphasised the importance of them being stratified by age. The review therefore suggests that receiving social support from others is often

experienced as beneficial. It is also suggested that those who experience their peers and family members as unavailable or unsympathetic are more likely to find it difficult to cope.

However, despite the benefits of social support for family carers of people with dementia, the psychometric properties of widely used measures of social support, when applied to caregivers of people with dementia, have not been rigorously assessed. Thus, the aim of the empirical paper was to validate a measure of social support, the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988), in a sample of family carers.

The term social support is often used within the psychosocial literature, however there are variety of ways that social support has been defined and operationalised. It is widely understood that social support is a multifaceted construct, but there are also numerous ways of defining and measuring the different aspects of social support. A full review of the social support literature was beyond the scope of the empirical paper. However, before selecting the most appropriate tool, it was first necessary to understand the different ways in which social support has been defined in the literature thus far.

The concept of social support incorporates both structural and functional aspects. Structural aspects include, for example, the size of the person's social network and the frequency of contact with this network. Measures of structure might include questions about the number of contacts that a person has with members of their social network over a given amount of time, the number of close relationships as opposed to more distant acquaintances, marital status, membership of certain groups and geographic proximity to members of the social network. However, measures of structure have been criticised, as they may not indicate the extent to which the support is functional (Cohen & Wills, 1985).

Functional support, on the other hand, has been defined as the support that the social network provides. Functional support can come in different forms and

theorists have differentiated between different subtypes (Lett et al., 2009). For example, emotional support refers to the care and concern that someone shows to another person through their verbal and nonverbal communication (Hogan et al., 2002). Instrumental or tangible support refers to concrete support (e.g. in doing tasks) in order to meet material demands. Other types of functional support may include financial support, informational support, and appraisal (i.e. help evaluating a situation).

The above subtypes can be used to describe received functional support, i.e. the support that is actually received, and perceived functional support, i.e. the person's satisfaction with the support and perception of the extent to which support would be available in future, should they need it (Smerglia et al., 2007). A further differentiation of the concept of social support is who the support comes from. For example, Zimet et al. (1988) divided it into three dimensions: family support, support from friends and support from a significant other.

Measures of received functional support often correlate with need or physical illness (Lett et al., 2009). Questions relating to received support may thus fail to measure the extent to which support *could* be available, should it be required, particularly for individuals who do not often access this support. Therefore, it is more common to measure perceived as opposed to received functional support, particularly when determining the relationship between social support and psychological concepts. Perceived functional support was therefore selected as the most appropriate type of social support to focus on for the present study.

As well as there being a multitude of different types of social support, there are also a large number of tools purporting to measure the same types of social support. One of the initial challenges was therefore to select the most appropriate measure of perceived functional support. We aimed to select a measure that was appropriate for use with a sample of UK carers of people with dementia, had shown to have robust psychometric properties when used with other populations, was

relatively brief and easy to administer and score, had been previously used as an outcome measure in intervention studies and was freely available online. The hope was that this measure, once validated for use with carers of people with dementia, could be used more widely in research and clinical practice and lead to greater consistency within the social support literature. This greater consistency would enable researchers to draw comparisons between studies, combine findings from numerous studies and thus develop a better understanding of the role of social support for carers of people with dementia.

After reviewing different outcome measures that have been used in studies with carers of people with dementia, the Multidimensional Scale of Perceived Social Support (MSPSS) was chosen as the most appropriate measure. The MSPSS is a measure of perceived social support from family, friends and a significant other. Although not explicitly grouped into different subtypes of functional support outlined above, it is suggested that the items cover emotional support (e.g. Item 2 'there is a special person with whom I can share my joys and sorrows), instrumental/tangible support (e.g. Item 3 'my family really tries to help me') and appraisal (e.g. Item 11 'my family is willing to help me make decisions). However, some of the items may be classified into multiple subtypes, for example item 3 'my family really tries to help me' could be interpreted as either instrumental/tangible support or emotional support, depending on the participants interpretation of 'help'.

Key Joint Decisions

After deciding upon which social support measure was most appropriate, the next key decision was to select two measures to use to assess convergent validity of the MSPSS. This was a joint project with another trainee clinical psychologist, who aimed to validate the Positive Psychology Outcome Measure (PPOM; Stoner et al., 2018) in the same sample of carers of people with dementia (Pione, 2020). We felt that it was important to keep the length of the survey to a minimum, whilst using measures that were detailed enough to capture the full concepts being measured, in

order to ensure that participants remained engaged and motivated throughout the survey and to reduce attrition. We thus aimed to find two measures that could be used in the validation of both the PPOM and MSPSS.

It was clear, following exploration of the positive psychology and social support literature, that depression was consistently negatively correlated with hope (Cheavens, 2000), resilience (Dias et al., 2015) and social support (Ng et al., 2015) and that quality of life was positively correlated with hope (Duggleby et al., 2011), resilience (Pessotti et al., 2018) and social support (Zhang et al., 2014).

Having researched which measures had good psychometric properties, were appropriate to use with carers of people with dementia and had previously been found to correlate with both social support and hope and resilience, it was decided that the Hospital Anxiety and Depression Scale – Depression (HADS-D) and Short Form-12 Health Survey (SF-12) would be most appropriate. Both measures are freely available online, relatively brief and easy to administer. The HADS-D is easy to score and interpret and the SF-12 has clear guidelines on how to score and interpret the measure, although it became evident that the scoring algorithm is more complex. The original SF-12 was chosen, as it has been widely used and there are clear guidelines produced by the authors of the measure as to how to score it.

The results presented in the empirical paper indicated that the correlation between social support and quality of life, as measured by the physical component score of the SF-12, was small. Furthermore, a binary logistic regression analysis suggested that the physical component score of the SF-12 did not significantly predict whether someone was a high or low scorer on the MSPSS. It is therefore possible that the SF-12 was not an optimal measure of convergent validity for the MSPSS and that an alternative measure of quality of life or alternative concept would have been more appropriate.

A final key decision when creating the battery of measures was whether or not to give participants the opportunity to add qualitative feedback or additional

comments following completion of the quantitative measures. Qualitative feedback was not required in order to satisfy the aims of the project and we were not planning on analysing qualitative data as part of the project. However, following a discussion with supervisors who had previous experience in conducting research with carers of people with dementia, it was decided that adding a comments box at the end of the survey would be important to provide participants with the opportunity to be heard: to contribute further comments, ideas or information that was important to them.

We decided to add a final question, which simply invited participants to add any further comments should they wish. Although this information was not included in analysis, receiving these comments was incredibly valuable to the research process. Participants used the comments box to add further detail and clarifications to their responses. For example, some spoke about how their circumstances had changed over time: “My answers would have been very different a year ago when I was caring alone for my father”. Others added further information of the impact of caring for a family member with dementia: “I don’t feel the joy I used to – I am too preoccupied, too tired, depleted of my usual energy”. Some participants used the space to thank us for conducting the research: “Hope this helps. Thank you for caring enough to do the research.”

As a researcher conducting an online study and therefore not meeting participants, reading the comments helped me to feel more connected to the participants who were taking part in the project and encouraged me to reflect on the importance of social support to carers. For example, one participant commented on the functional support they received from other family members, highlighting how helpful it was to have the support of others: “I share caring for my father with 2 of my siblings (sometimes 3) which is a real help, rather than to have to do this all alone”. Another participant commented on the emotional support that they received from their wife, who was also the person for whom they were caring: “The special person

in my life who I share my thoughts and emotions with is still my wife even with Alzheimer's dementia".

Some of the comments provided by participants also related to their concerns about seeking support from family members. For example, one participant commented: "although you know you can talk to your family I tend not to as I don't want to worry them or drag them down." These comments were often similar to those reported in the review paper by children caring for a parent with YOD, who often spoke of not wanting burden others.

These additional comments brought a more human perspective to the data, rather than purely quantitative information and some participants commented on the need for a more mixed-methods approach. For example, as one participant eloquently stated: "life is a bit more than being able to tick boxes". As a result of these comments, I would be inclined to collect more qualitative data in future research, ask additional open-ended questions and include this data into the analysis.

Recruitment

Prior to starting the project, I was not aware of Join Dementia Research Network (JDR). However, JDR was incredibly helpful during recruitment and has led me to think further about the process of recruitment in research more generally.

JDR was set up by the National Institute for Health Research (NIHR) in partnership with Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society in order to help researchers to recruit participants into projects and to enable those who are interested in taking part in research to be matched to relevant studies.

During the initial stages of recruitment, we contacted JDR and met with one of their delivery officers via video conference, who assisted us in setting up a page to advertise the study. It was an incredibly easy and efficient process. The study was then advertised via the JDR website and we were provided with access to basic

demographic information and contact details of thousands of carers who had expressed an interest in taking part in dementia-related research. We were then able to email potential participants directly with further information about the study. Recruiting via JDR enabled us to meet our recruitment target quickly, as the majority of participants were recruited in this way.

To my knowledge, JDR is quite unique in the way it advertises studies and helps match potential participants to appropriate projects. However, the efficiency of this resource for researchers and participants interested in taking part in research has encouraged me to consider whether this model could be used to support recruitment for other groups of participants and the value that this would bring to research, particularly for populations who are harder to reach. Having a hub or single point of access into research studies for particular groups could help streamline the recruitment process for researchers and help participants find out about studies that are most relevant to them, thus saving time and effort for both parties.

One of the limitations of the current study was the lack of diversity within the sample. It was possible via JDR to filter potential participants, for example by age and ethnicity. Using these filters, an attempt was made to recruit participants of varying ages and ethnicities, by specifically emailing those who fell into more under-represented groups in the sample. However, despite our effort to recruit participants of a range of ethnicities, the vast majority of participants in our study were white British. The sample were also highly educated: over 50% of participants had an undergraduate degree or higher. On reflection, we may have been able to achieve a more diverse sample by recruiting from a wider range of sources. I wonder whether websites such as JDR are likely to attract people who are particularly interested in research or have experience of doing research themselves and therefore possibly more likely to have a university degree. It may have been possible to achieve a sample that was more representative of family carers by recruiting through different

avenues, such as online via social media, websites or through NHS services. This also raises a question as to how sites such as JDR can recruit volunteers who are more representative of the general population.

Implications and Further Research

Young Onset Dementia

The review paper highlights the lack of information available regarding YOD and the scarcity of appropriate support services. It is crucial to raise awareness of YOD amongst the public, clinical professionals and the research community. Raising awareness may be one way of reducing stigma so that families affected by YOD feel more able to reach out for support.

There is also limited research into the experiences of people whose parent has YOD. Many of the studies included in the review were published within the last 10 years and there were multiple papers published by the same research groups. This suggests that although it may be a growing area of research, further research is required in order to develop our understanding of the experiences of those affected by parental YOD. Using mixed methods in this research will enable participants to provide clarifications and additional information where needed, which will ensure that findings are grounded in experience.

Clinically, changes are required to improve the diagnostic pathway and post-diagnostic support for people with YOD and their families. In the UK, services are often specific to particular age groups. For example, there are often separate services for children, adults and older adults and people with YOD are often cared for by psychogeriatricians, who are highly trained in working with older adults. However, these clinicians may be less equipped to work with people with YOD. Similarly, professionals working in child and adolescent or family services may not have sufficient knowledge of YOD to provide adequate support for clients whose parent has been diagnosed with YOD. It is therefore important that those working in dementia services receive adequate training in order to identify and diagnose YOD

in a timely manner and can provide appropriate information and support to those affected by YOD, including the children of people with YOD. YOD affects the whole family and thus it is important to provide support for children as well as other family carers.

Participants often spoke of the usefulness of attending support groups but wanted these to be specifically for people of a similar age to them and for those caring for someone with YOD. Specialist services may make this possible and help clients feel less alone. New services could be specifically set up for people diagnosed with YOD and their families, enabling staff to develop more specialist knowledge and gain more specialist experience.

Social Support

The empirical paper was the first paper to rigorously assess the psychometric properties of a widely used measure of social support, when used with family caregivers of people with dementia. Importantly, the findings indicate that the MSPSS is a suitable and psychometrically sound measure of social support for family caregivers of people with dementia. It is therefore suggested that this measure be used in future research.

Clinically, the MSPSS could be used to identify caregivers who are struggling. For example, the MSPSS may be used to identify individuals who are receiving minimal social support and who may also be experiencing symptoms of depression and/or reduced quality of life. Identifying these individuals would then enable services to intervene appropriately and in a timely manner.

Over time, it may also be appropriate to use the MSPSS as an outcome measure following interventions aiming to increase perceived functional social support. However, before the MSPSS is used as an outcome measure with carers of people with dementia, it would first be important to measure the responsiveness of the scale, or the ability of the scale to distinguish clinically important changes as the result of intervention. Given the above discussion regarding the

multidimensional nature of social support, it would be important for researchers to carefully consider how social support is defined in the intervention and therefore which measure may be most appropriate to capture the mechanism of change.

Conclusion

The issues considered here demonstrate the importance of social support for family carers of people with dementia, including the children of people with YOD and other family caregivers. Social support is a multidimensional construct and it is important that careful consideration is given as to how this term is defined and measured. Further research is required in order to continue to broaden our understanding of the experiences of family caregivers of people with dementia, including those supporting a parent with YOD and to determine the responsiveness of the MSPSS.

References

Barca, M. L., Thorsen, K., Engedal, K., Haugen, P. K., & Johannessen, A. (2014). Nobody asked me how I felt: Experiences of adult children of persons with young-onset dementia. *International Psychogeriatrics, 26*(12), 1935-1944. https://doi.org/10.1017/S1041610213002639

Cheavens, J. (2000). *Hope and depression: Light through the shadows.* In C. R. Snyder (Ed.), *Handbook of hope: Theory, measures, and applications* (p. 321–340). Academic Press. https://doi.org/10.1016/B978-012654050-5/50019-1

Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*(2), 310-357. https://doi.org/10.1037/0033-2909.98.2.310

Dias, R., Santos, R.L., Sousa, M.F.B., Nogueira, M.M.L., Torres, B., Belfort, T., & Dourado, M.C.N. (2015). Resilience of caregivers of people with dementia: A systematic review of biological and psychosocial determinants. *Trends in Psychiatry and Psychotherapy*, *37*(1), 12-19 https://doi.org/10.1590/2237-6089-2014-0032

Duggleby, W.D., Swindle, J., Peacock, S. & Ghosh, S. (2011).. A mixed methods study of hope, transitions, and quality of life in family caregivers of persons with Alzheimer's disease. *BMC Geriatrics 11,* 88 https://doi.org/10.1186/1471-2318-11-88

Gelman, C. R., & Rhames, K. (2018). In their own words: The experience and needs of children in younger-onset Alzheimer's disease and other dementias families. *Dementia, 17*(3), 337-358. https://doi.org/10.1177/1471301216647097

Hall, M., & Sikes, P. (2017). "It would be easier if she'd died": Young people with parents with dementia articulating inadmissible stories. *Qualitative Health Research, 27*(8), 1203-1214. https://doi.org/10.1177/1049732317697079

Hogan, B. E., Linden, W., & Najarian, B. Social support interventions: Do they work? *Clinical Psychology Review, 22*(3), 381-440. https://doi.org/10.1016/S0272-7358(01)00102-7

Hutchinson, K., Roberts, C., Daly, M., Bulsara, C., & Kurrle, S. (2016). Empowerment of young people who have a parent living with dementia: A social model perspective. *International Psychogeriatrics, 28*(4), 657-668. https://doi.org/10.1017/S1041610215001714

Hutchinson, K., Roberts, C., Kurrle, S., & Daly, M. (2016). The emotional well-being of young people having a parent with younger onset dementia. *Dementia, 15*(4), 609-628. https://doi.org/10.1177/1471301214532111

Lett, H. S., Blumenthal, J. A., Babyak, M. A., Catellier, D. J., Carney, R. M., Berkman, L. F., Burg, M. M., Mitchell, P., Jaffe, A. S., & Schneiderman, N. (2009). Dimensions of social support and depression in patients at increased psychosocial risk recovering from myocardial infarction. *International Journal of Behavioral Medicine, 16*(3), 248-258. https://doi.org/10.1007/s12529-009-9040-x

Millenaar, J. K., van Vliet, D., Bakker, C., Vernooij-Dassen, M. J., Koopmans, R. T., Verhey, F. R., & de Vugt, M. E. (2014). The experiences and needs of children living with a parent with young onset dementia: Results from the NeedYD study. *International Psychogeriatrics, 26*(12), 2001-2010. https://doi.org/10.1017/S1041610213001890

Ng, C. G., Mohamed, S., See, M. H., Harun, F., Dahlui, M., Sulaiman, A. H., Zainal, N. Z., & Taib, N. A. (2015). Anxiety, depression, perceived social support and quality of life in Malaysian breast cancer patients: a 1-year prospective study. *Health and Quality of Life Outcomes, 13*, 205. https://doi.org/10.1186/s12955-015-0401-7

Pessotti, C.F.C., Fonseca, L.C., Tedrus, G.M.A.S., & Laloni, D.T. (2018). Family caregivers of elderly with dementia Relationship between religiosity,

resilience, quality of life and burden. *Dementia & Neuropsychologia*, *12*(4), 408-414. https://doi.org/10.1590/1980-57642018dn12-040011

Pione, R. D. (2020). *The development of the PPOM-C for family carers of people with dementia: Psychometric properties and factor structure.* Unpublished clinical psychology doctoral thesis, Department of Clinical, Educational, and Health Psychology, University College London.

Smerglia, V. L., Miller, N. B., Sotnak, D. L., & Geiss, C. A. (2007). Social support and adjustment to caring for elder family members: A multi-study analysis. *Aging & Mental Health, 11*(2), 205-217. https://doi.org/10.1080/13607860600844515

Stoner, C. R., Orrell, M., & Spector, A. (2018). The Positive Psychology Outcome Measure (PPOM) for people with dementia: Psychometric properties and factor structure. *Archives of Gerontology and Geriatrics, 76*, 182-187. https://doi.org/10.1016/j.archger.2018.03.001

Svanberg, E., Stott, J., & Spector, A. (2010). 'Just helping': Children living with a parent with young onset dementia. *Aging & Mental Health, 14*(6), 740-751. https://doi.org/10.1080/13607861003713174

Zhang, S., Zhang, S., Edwards, H., Yates, P., Li, C., & Guo, Q. (2014). Self-Efficacy Partially Mediates between Social Support and Health-Related Quality of Life in Family Caregivers for Dementia Patients in Shanghai. *Dementia and Geriatric Cognitive Disorders, 37*(1-2), 34-44. https://doi.org/10.1159/000351865

Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment, 52*(1), 30-41. https://doi.org/10.1207/s15327752jpa5201_2

Appendices

Appendix 1: Invitation to Participants

LONDON'S GLOBAL UNIVERSITY

Are you caring for a family member with dementia?

Researchers at UCL are looking for adult family carers of people with dementia to complete an online questionnaire.

Why is this research important?

Much of the research with family carers of people with dementia looks at concepts such as perceived burden, depression and anxiety. More recently, there has been a focus on the positive aspects of caring, including hope, resilience and social support, which have been found to be protective against caregiver burden.

As this is a new area of research, there isn't yet agreement on how best to measure these concepts in carers of people with dementia. This study aims to determine whether two questionnaires: The Multidimensional Scale of Perceived Social Support (MSPSS) and the Positive Psychology Outcome Measure (PPOM; a measure of hope and resilience) can be reliably used with carers. The results of this study will help us determine whether the questionnaires can be used in research trials and clinical practice and understand the links between social support, hope and resilience, mood and quality of life.

Who can take part?

This project is for people who are caring for a family member with dementia. Participants must be age 18+, live in the UK and be able to access the questionnaires online, provide informed consent and communicate in English.

What will I be asked to do?

Participants will be asked to fill in an online survey about social support, hope and resilience, mood and quality of life. This survey should take approximately 30 minutes to complete. Some participants will be contacted 4 weeks later to complete two of these measures again.

How will the research be used?

The final results will be published in the form of two freely available doctoral theses and will be submitted for publication in academic journals. We aim to disseminate the findings more widely to the public and clinical and academic audiences through conferences, reports and newsletters. We hope that these measures will be used in research and clinical practice.

For more information and to complete the survey please visit: http://tiny.cc/carerqu

If you have any questions or would like to discuss the research further, please get in touch with Anna Cartwright (a.cartwright.17@ucl.ac.uk) or Rich Pione (r.pione.17@ucl.ac.uk).

Appendix 2: Outline of Individual Contributions

Literature Review

AC formulated the research questions, designed the research protocol, conducted the literature searches, reviewed the literature and wrote the paper. RP and AC independently contributed to the thematic synthesis by examining similarities and differences between initial codes, grouping them into a hierarchical structure and assigning descriptive codes to capture the meaning of these groups. RP and AC then discussed these in order to decide upon a final hierarchical structure.

Empirical Paper

AC and RP jointly decided which two measures to include to measure concurrent validity and created the qualitrics survey. During recruitment, RP and AC took it in turns to monitor Join Dementia Research Network and send emails to participants. Scoring of the SF-12 was performed independently by RP and AC and cross-checked. Data analysis and write-up were conducted independently.

Appendix 3: Letter of Ethical Approval

UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

8th March 2019

Professor Aimee Spector
Department of Clinical, Educational and Health Psychology
UCL

Dear Professor Spector,

Notification of Ethics Approval with Provisos
Project ID/Title: 15139/001: Online validation of the Multidimensional Scale of Perceived Social Support (MSPSS) and Positive Psychology Outcome Measure (PPOM) for family carers of people with dementia

Further to the review of your re-submitted application at the February meeting of the UCL REC, I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **1st March 2020**.

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Office of the Vice Provost Research, 2 Taviton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/

Appendix 4: Participant Information Sheet

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY
UNIVERSITY COLLEGE LONDON
1-19 TORRINGTON PLACE
LONDON
WC1E 6BT

Participant Information Sheet for family carers of people with dementia

UCL Research Ethics Committee Approval ID Number: 15139/001

Title of Study: Online validation of the Multidimensional Scale of Perceived Social Support (MSPSS) and Positive Psychology Outcome Measure (PPOM) for family carers of people with dementia

Department: Research Department of Clinical, Educational and Health Psychology.

Name and Contact Details of the Researcher(s): Anna Cartwright (a.cartwright.17@ucl.ac.uk); Richard Pione (r.pione.17@ucl.ac.uk)

Name and Contact Details of the Principal Researcher: Professor Aimee Spector (a.spector@ucl.ac.uk)

1. **Invitation to participate**
   You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information and discuss it with others if you wish. Feel free to contact us if anything is not clear or if you would like more information. Thank you for reading this information sheet.

2. **What is the project's purpose?**
   This study is aiming to determine the reliability and validity of two questionnaires that are used in research with carers of people with dementia and to increase understanding of the roles that social support, hope and resilience play in caring for a person living with dementia. We aim to better understand how these factors may be related to mood and quality of life.

3. **Why have I been chosen?**
   You have been invited to take part in this research, as you have had contact with a service or website that supports dementia-related research. **To complete these questionnaires, you must identify as an adult (age 18+) unpaid family carer of a person with dementia, have access to the internet to complete questionnaires online and be able to understand written English**.

4. **Do I have to take part?**
   It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to agree to a consent form on the next page. You are free to withdraw at any time without giving a reason. If you decide to withdraw, you can contact the researchers to request for your data to be deleted.

5. **What will happen to me if I take part?**
   You will be asked to provide some information about yourself, such as your age, gender, ethnicity and marital status and to complete four questionnaires online. The questionnaires include questions relating to hope and resilience, social support, mood and quality of life. This should take approximately 25-35 minutes to complete. We will also ask you to provide an email address, so that we can send an email invitation to some participants approximately four weeks later, asking you to complete two of the questionnaires again. This second set should take approximately 10 minutes to complete.

6. **What are the possible disadvantages and risks of taking part?**
   We do not consider that taking part will involve any disadvantages or specific risks or that it would cause you any harm.

7. **What are the possible benefits of taking part?**
   If you do decide to take part in this project, you will be making a valuable contribution in helping us improve understanding of how personal strengths and social support are related to mood and quality of life in carers of people living with dementia.

8. **What if something goes wrong?**
   If you are unhappy or dissatisfied with any aspect of your participation, we would ask you firstly to speak to one of the researchers, so that we can try to address your concerns and find a solution. Alternatively, you can speak to the project supervisor; Professor Aimee Spector (see contact details below). Should you feel that a complaint has not been handled to your satisfaction, then you can contact the Chair of the UCL Research Ethics Committee at: ethics@ucl.ac.uk

9. **Will my taking part in this project be kept confidential?**
   All the information that we collect about you will be kept strictly confidential. Any personal details (i.e. your email address) are kept securely on an encrypted device and stored separately from the information collected during the study. All other data will be pseudoanonymised: a unique code will be linked to your data, from which you will not be identifiable. You will not be identified in any reports or publications.

   We will also ask your permission for us to store, in anonymised form, the information that we collect from you for long-term use, in data archives provided by University College London. This would mean that information could be shared with accredited researchers in future so that they might understand more and learn from the information we collect. No one would be able to identify you from this archived information.

10. **Limits to confidentiality**
    Confidentiality will be respected subject to legal constraints and professional guidelines.

11. What will happen to the results of the research project?

The results of this study will be presented within Doctorate theses and published in scientific journals. Participants can be kept informed of the progress of the project and results, should they express a desire to receive further information.

12. Data Protection Privacy Notice

Notice:

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

If you would like to find out more about this privacy notice, please click here.

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows: email address

Your personal data will be processed for the purposes outlined in this notice. It will be collected and stored using the Qualtrics questionnaire programme. Qualtrics are compliant with all GDPR regulations. You can find out more about how Qualtrics store data at: https://www.qualtrics.com/uk/platform/gdpr/

The legal basis that would be used to process your personal data will be performance of a task in the public interest.

The lawful basis used to process *special category personal data* will be for scientific and historical research or statistical purposes.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

13. Who is organising and funding the research?

The study is being organised by Anna Cartwright and Richard Pione; trainee clinical psychologists at University College London (UCL). The research is being funded by the Department for Clinical, Educational and Health Psychology, University College London.

14. Contact for further information

For more information about this research, please contact:
FAO Anna Cartwright / Richard Pione, Trainee Clinical Psychologist
Research Department of Clinical, Educational and Health Psychology
University College London
1-19 Torrington Place
London
WC1E 7HB
Tel: 020 7679 4466
Email: a.cartwright.17@ucl.ac.uk; r.pione.17@ucl.ac.uk

If you have any concerns or complaints about anything to do with this study, please contact:

Prof. Aimee Spector
Research Department of Clinical, Educational and Health Psychology
University College London
1-19 Torrington Place
London
WC1E 7HB
Tel: 020 7679 1844
Email: a.spector@ucl.ac.uk

Thank you for taking the time to consider taking part in this research study.

Appendix 5: Informed Consent Form

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY
UNIVERSITY COLLEGE LONDON
1-19 TORRINGTON PLACE
LONDON
WC1E 6BT

CONSENT FORM FOR FAMILY CARERS FOR PEOPLE WITH DEMENTIA IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet.

Title of Study: Online validation of the Multidimensional Scale of Perceived Social Support (MSPSS) and Positive Psychology Outcome Measure (PPOM) for family carers of people with dementia
Department: Department of Clinical, Educational and Health Psychology
Name and Contact Details of the Researcher(s): Anna Cartwright (a.cartwright.17@ucl.ac.uk) and Rich Pione (r.pione.17@ucl.ac.uk).
Name and Contact Details of the Principal Researcher: Aimee Spector (a.spector@ucl.ac.uk)
Name and Contact Details of the UCL Data Protection Officer: Lee Shailer (l.shailer@ucl.ac.uk)
This study has been approved by the UCL Research Ethics Committee: Project ID number: 15139/001

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking each box below I am consenting to this element of the study. I understand that it will be assumed that unticked boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Tick Box
1.	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction and would like to take part in the online questionnaires.	
2.	I consent to participate in the study. I understand that my personal information (i.e. my email address) will be used for the purposes explained	

	to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing.	
3.	I understand that my participation is completely voluntary and that I am free to withdraw at any time, without giving reason. I understand that withdrawing will not affect my healthcare or legal rights. I understand that if I withdraw from the study, I can contact the researchers to request that they delete any data already provided.	
4.	**Use of the information for this project only** I understand that all personal information will remain confidential and that my email address will be stored securely and separately from the data collected during the study. All other data will be pseudoanonymised and stored securely. All efforts will be made to ensure I cannot be identified from the data. It will not be possible to identify me in any publications.	
5.	I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	
6.	I understand that no promise of guarantee of benefits have been made to encourage me to participants.	
7.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researchers undertaking this study.	
8.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	
9.	I agree that my anonymised research data may be used by others for future research. [No one will be able to identify you when this data is shared.]	
10.	I understand that the information I have submitted will be published as a report and that I can contact the researchers to request further information and the progress and findings of the project.	
11.	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and confirm that I fall under these inclusion criteria.	
12.	I am aware of who I should contact if I wish to log a complaint.	
13.	**Use of information for this project and beyond** I would be happy for the data I provide to be archived, in anonymous form, at University College London (UCL) and understand that other authenticated researchers will have access to my anonymised data.	
14.	I voluntarily agree to participate in this study	

Appendix 6: Measures on Qualtrics

MSPSS, HADS-D and SF-12 have been removed in case of copyrighting issues

What is your age (in years)?

Gender

- ○ Male
- ○ Female
- ○ Other (please describe)

How would you describe your ethnic origin?

- ○ White British
- ○ Irish
- ○ Gypsy or Irish Traveller
- ○ Other White Background (please describe)
- ○ Black British
- ○ Black African
- ○ Black Caribbean
- ○ Other Black Background (please describe)
- ○ Indian
- ○ Pakistani
- ○ Bangladeshi
- ○ Chinese
- ○ Other Asian Background (please describe)
- ○ Black Caribbean and White
- ○ Black African and White
- ○ Asian and White
- ○ Other Mixed Ethnic Background (please describe)
- ○ Other Ethnic Group (please describe)

Current Employment Status

- ○ Full-time employment
- ○ Part-time employment
- ○ Unemployed
- ○ Self-employed
- ○ Home-maker
- ○ Student
- ○ Retired

Highest Level of Education

- ○ Postgraduate degree or equivalent
- ○ Undergraduate degree or equivalent
- ○ Higher education
- ○ A Level or equivalent
- ○ GCSE grades A*-C or equivalent
- ○ Other qualifications (please describe)
- ○ No qualification

What is your relation to the person with dementia for whom you care?

- ○ I am their husband
- ○ I am their wife
- ○ I am their son
- ○ I am their daughter
- ○ I am their son-in-law
- ○ I am their daughter-in-law
- ○ Other (please speficy)

Are you currently living with the person for whom you care?

- ○ Yes
- ○ No
- ○ Other (please describe)

- ○ Engaged
- ○ Divorced
- ○ Other (please describe)

Are you the primary carer? (i.e. are you the main person responsible for providing care?)

- ○ Yes
- ○ No
- ○ Other (please describe)

What is the diagnosis of the person for whom you care?

- ○ Alzheimer's Disease
- ○ Vascular Dementia
- ○ Mixed Alzheimer's (i.e. Alzheimer's Disease & Vascular Dementia)
- ○ Dementia with Lewy Bodies
- ○ Parkinson's Dementia
- ○ Frontotemporal Dementia
- ○ Other (please specify)
- ○ I don't know

How long ago were they diagnosed with Dementia?

- ○ 0-6 months
- ○ 7-12 months
- ○ 1-2 years ago
- ○ 3-4 years ago
- ○ 5-6 years ago
- ○ 7-8 years ago
- ○ 9-10 years ago
- ○ More than 10 years ago

How long have you been supporting the person with dementia?

0-6 months	7-12 months	1-2 years	3-4 years	5-6 years	7-8 years	9-10 years	More than 10 years
○	○	○	○	○	○	○	○

The PPOM

Instructions

We would like to know how you have been feeling over the **past month**. Please answer the below questions by **selecting one number** (0, 1, 2, 3 or 4) that most closely reflects how you have felt for each question. Please answer all the questions. If you are unsure, circle the number that is your best guess.

	0- Not true at all	1 - Rarely true	2 - Sometimes true	3 - Often true	4 - True nearly all the time
1. I have a positive outlook on life	○	○	○	○	○
2. I can see positive things in difficult situations	○	○	○	○	○
3. I can recall happy/joyful times	○	○	○	○	○
4. I have inner strength	○	○	○	○	○
5. I can give and receive care/love	○	○	○	○	○
6. I have a sense of direction in life	○	○	○	○	○
7. I believe that each day has potential	○	○	○	○	○
8. My life has value and worth	○	○	○	○	○
9. I am able to adapt to things	○	○	○	○	○
10. I am able to deal with whatever happens	○	○	○	○	○
11. I am able to see the humorous side	○	○	○	○	○
12. I can cope with stress well	○	○	○	○	○
13. I can bounce back	○	○	○	○	○
14. I can stay focused	○	○	○	○	○
15. I am an emotionally strong person	○	○	○	○	○
16. I can handle unpleasant feelings	○	○	○	○	○

Where did you hear about this research?

- ○ Join Dementia Research
- ○ Age UK
- ○ SweetTree
- ○ Camden Carers
- ○ Through a friend/family member
- ○ Via social media
- ○ Other (please specify)

Thank you for taking the time to complete this questionnaire. If you would like to add any further comments, please do so here: