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Experiences and needs of children who have a parent with young onset dementia: A meta-ethnographic review.

Running head: Parental young onset dementia: Children's experiences

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Experiences and needs of children who have a parent with young onset dementia: A meta-ethnographic review.

Objectives: The aim of the present review was to critically evaluate empirical evidence regarding the needs and experiences of children who have a parent with young onset dementia (YOD). **Methods:** A systematic search of five databases was carried out and the resulting 16 studies were reviewed using a meta-ethnographic approach. **Results:** Three main themes arose from the data: ‘Dementia Impact’, which describes how the child experiences the deterioration in their parent and changes to relationships; ‘Psychological Impact’, comprising the child’s private emotional experiences and the psychological consequences of changes in roles; and ‘Practical Impact’, detailing the ways in which children adapt their lives in response to parental YOD, and children’s needs for support. **Conclusions:** These themes synthesise the existing literature and produce a line of argument explaining the experience of children whose parents have YOD. **Clinical Implications:** Information and policies regarding YOD should take account of the experiences of patients’ children and should include targeted support for children of parents with YOD.

Keywords: young onset dementia, working age dementia, children, parents, needs.

Introduction

Young Onset Dementia

In the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), dementia is categorised as Major Neurocognitive Disorder (American Psychiatric Association, 2013). Dementia involves a progressive loss of cognitive function that is caused by one or more of a range of different underlying diseases of the brain (World Health Organisation [WHO], 2012). Despite being considered a disease of older age, up to 9% of dementia diagnoses worldwide are given before age 65 (WHO, 2019), and are referred to as “young onset dementia” (Alzheimer’s Society, 2015). Young onset dementia (YOD) carries a greater hereditary risk than dementia diagnosed at age 65 or older (termed “late onset dementia” or LOD; Alzheimer’s Society, 2015). YOD can also present with a wide range of symptoms, which can frequently lead to misdiagnosis (Mendez, 2006).

YOD presents significant psychological, social and practical challenges linked to the life stage at which people are affected. The person’s young age makes the diagnosis much less expected than for older people and disrupts the anticipated life cycle, which can exacerbate the distress experienced by the person and their family (Greenwood & Smith, 2016). People with YOD may also be excluded from relevant services such as residential care, may find it difficult to access financial support such as pensions or winter fuel allowance, or may find that activities in dementia services are inappropriate for their age group (Alzheimer’s Society, 2015). By definition, people with YOD are of working age, and therefore may be more likely to be the family’s financial provider. People with YOD typically describe a deep sense of loss at having to give up work due to dementia, and report a significant impact upon their identity as well as income (Rabanal et al., 2018).

Impact of YOD on Caregivers

Importantly, people with YOD may be parents of relatively young children or may have dependent parents who are still alive, thus the impact on the family can be greater than that of late onset dementia (LOD; Werner [et al.](#), 2009). Caregivers of people with YOD report higher levels of burden (Freyne [et al.](#), 1999) and greater perceived difficulty in coping with behavioural symptoms than caregivers of people with LOD despite similar clinical features (Arai [et al.](#), 2007). [Additionally, 66% of caregivers of people with YOD](#) perceive their wellbeing as poor or very poor (Williams [et al.](#), 2001).

Whilst caregivers of people with YOD are often spouses, their children may also have a caregiving role. A “young carer” is defined as a young person under the age of 18 who helps to look after a relative who is unwell, disabled or misuses drugs or alcohol (Carer’s Trust, 2015). Young carers are often significantly impacted by their caring role (Cree, 2003). For example, children whose parents have a serious physical illness are at higher risk of experiencing anxiety, depression, somatic complaints and social withdrawal (Barkmann [et al.](#), 2007). Similarly, children whose parents have a mental illness reported worrying about their parent and receiving little information or support (Stallard [et al.](#), 2004).

Adult-children can also be affected by parental illness, regardless of whether they still reside with the parent. Adult-children of parents with mental illness reported feeling uncertain, struggling to connect with their ill parent and with peers and having to grow up quickly and take on responsibility (Foster, 2010). Compared to spousal caregivers, Conde-Sala [and colleagues](#) (2010) found higher levels of caregiver burden in adult-children of people with dementia and higher levels of guilt in adult-children who did not live with the parent with dementia. Adult-children may

have additional responsibilities, such as employment or their own children, which can add to the impact of supporting a parent with dementia (Wang *et al.*, 2011).

Although the impact of parental illness is beginning to be better understood, services often do not offer specific support for children of patients under their care, particularly within mental health services (Somers, 2007). Internationally, the involvement of caregivers in dementia services is a key priority (WHO, 2012).

However, whilst many services for YOD involve or offer support to caregivers, there do not appear to be any services specifically aimed at children of people with YOD.

Additionally, the extent to which caregiver support groups and training courses are suitable for children, particularly those aged under 18, is unclear.

Rationale

Although there have been several reviews of research examining caregiving in YOD, most have explored the experiences of family caregivers in general, with spousal caregivers forming the vast majority of participants (Baptista *et al.*, 2016; Millenaar *et al.*, 2016; Spreadbury & Kipps, 2019; Svanberg *et al.*, 2011; van Vliet *et al.*, 2010). One review (Cabote *et al.*, 2015) considered children and spouses separately but only explored two studies that directly examined the child's experiences.

To date, there has been only one attempt to review the literature on children's experiences of parental YOD. Gelman & Greer (2011) conducted a narrative review of the literature on child caregivers (more generally) and found that, at the time, there were no published studies specifically exploring children's experiences of parental YOD. They reviewed three studies indirectly addressing the topic before presenting a case-study of a family intervention for YOD, but the review did not adopt a systematic methodology. Over recent years there has been increasing research

interest in the experiences of children of people with YOD, yet, to date, there has & been no review of this emerging body of literature.

The present review will therefore synthesise and critically evaluate empirical evidence regarding the experiences and needs of children who have a parent with YOD. Specifically, it will address the following questions:

- What is the experience of children of people with YOD?
- What is the impact of YOD on children's psychosocial wellbeing?
- What support needs do children of people with YOD have?

Methods

Systematic Literature Search

A systematic search for relevant studies was carried out using psychology, medicine, gerontology and nursing databases. Five online databases were searched:

PsychINFO, Embase, PubMed, Cumulative Index of Nursing and Allied Health Literature (CINAHL) and Web of Science. Reference lists of selected papers were searched manually for additional relevant papers. See Table 1 for search terms.

Inclusion and Exclusion Criteria

Studies were included if they were written in English, published in peer-reviewed journals and discussed empirical studies. No date limit was put on the search. See Table 2 for inclusion and exclusion criteria.

Classification of Studies

Sixteen studies were included in the final review. See Figure 1.

Quality Assessment

The quality appraisal framework suggested by Caldwell [et al.](#), (2011) was used. Each paper was rated by two assessors, with a resulting inter-rater reliability of $K = 0.85$ ($p > .001$), indicating a good level of agreement.

Characteristics of Studies

See Table 3 for a summary of the key characteristics of the 16 studies included in the present review.

All studies had similar aims; to explore the impact, meanings, perceptions, experiences and/or needs of children related to their parent's YOD. Fifteen studies were qualitative; 14 gathered data through interviews and one through a focus group (Nichols [et al.](#), 2013). One study used a mixed-methods approach (Svanberg [et al.](#), 2010), though the focus was on qualitative analysis of the interviews, with three questionnaires used as supporting data. All papers scored within a range of 21-35 on the quality appraisal tool. Lower scores were predominantly due to insufficient detail on methodological aspects.

[Ages of participants](#) ranged from 6 to 37 years across the studies. Two studies included only participants aged 11-18 (Nichols [et al.](#), 2013; Svanberg [et al.](#), 2010), and four included only adult-children aged over 18 (Aslett [et al.](#), 2017; Barca [et al.](#), 2014; Johannessen [et al.](#), 2015; Johannessen [et al.](#), 2016). The remaining studies included participants across the full age range. Nine of the studies were conducted in the UK, three in Norway, two in Australia, one in the Netherlands and one in the USA.

Notably, six of the 16 studies arose from the same dataset (Hall & Sikes, 2016, 2017, 2018; Sikes & Hall, 2017, 2018a, 2018b), while two further studies were also based on single dataset (Hutchinson, Roberts, Daly [et al.](#), 2016a; Hutchinson,

Roberts, Kurrle & Daly, 2016b). One study (Johannessen et al., 2016) followed up participants from another study (Johannessen et al., 2015). Therefore, 10 of the 16 papers were based on interviews with just three participant groups.

Analytic Review Strategy

The 16 papers determined from the systematic search were analysed using a meta-ethnographic approach, first described by Noblit and Hare (1988).

Results

Table 4 details the main themes and subthemes that were developed from the meta-ethnographic analysis.

Dementia Impact

The first theme, 'Dementia Impact' describes how the child experiences the deterioration of their parent as a result of YOD. Inevitably, their parent changes as the dementia progresses, and the child witnesses and has to make sense of these changes for themselves. Relationships also change as a result of dementia, most notably the child's relationship with the parent who has dementia, but also with other people as the changes in their parent create conflict or alienate the child from others who do not understand their experiences.

Two subthemes comprise this theme: *Changes in Parent* and *Changes in Relationships*.

Changes in Parent.

Children observed a number of changes to their parent's functioning and behaviour as a result of YOD. They spoke about their parent losing abilities and a deterioration or regression in the parent's behaviour, which many described as their parent

becoming “like a child” (Aslett et al., 2017; Johannessen et al., 2015; Svanberg et al., 2010). [Eleven of the 16 studies](#) talked of parental behaviours that the child found difficult to manage and experience, such as aggression, sexual behaviours, communication difficulties, incontinence, hallucinations and falls. In particular, participants struggled with the constant process of change in their parent: “Every time I see him he’s the worst he’s ever been and the best he’ll ever be.” (Sikes & Hall, 2017, p. 330).

[Children in 11 studies](#) also talked about their parent changing as a person. Some participants felt that their parent would hate the person they have become, and others said that they themselves now dislike their parent. [In one study, children](#) compared their parent’s dementia to other illnesses in which the parent is unwell [or deteriorating](#) but remains the person they know, [such as cancer, Motor Neurone Disease or Multiple Sclerosis](#) (Hall & Sikes, 2017).

The diagnosis of YOD helped some children to make sense of the changes in their parent and helped them to explain their parent’s behaviour to others. For others, however, the diagnosis meant that there was no hope for recovery or improvement in their parent, unlike with other illnesses. Additionally, the diagnosis brought uncertainty about the progression of the illness and the amount of time the child had left with their parent.

Changes in Relationships

The changes children observed in their parent invariably led to a different type of parent-child relationship. Many children spoke about taking on additional responsibilities and providing some form of care for their parent. However, some children spoke about rejecting the label of “young carer”, feeling that they were “just helping” (Svanberg et al., 2010, p. 743). [In 9 of the 16 studies, children](#) described the &

change in relationship with their parent as a role-reversal, or “becoming a parent to my parent” (Johannessen et al., 2015, p. 250). Some adult-child participants reflected on the inability of their parent to be a grandparent and support them with their own children (Aslett et al., 2017). Conversely, one study reported an experience of the parent remaining a parental figure but losing their orientation to the present and treating the child age-inappropriately (Hall & Sikes, 2016).

Other relationships were also affected by parental YOD and were often characterised by emotional distancing. Participants spoke about friendships becoming more superficial and extended family withdrawing as they felt unable to share their experiences with others. Conflict between family members also occurred, as disagreements arose between children and their siblings or well-parents regarding the care of their parent with YOD. Two studies also reported on experiences of discrimination from the wider public (Hutchinson et al., 2016a; Hutchinson et al., 2016b), although these were from the same dataset and may not replicate in other groups of children.

However, relationship change was not all negative, and [children in six studies](#) discussed emotional support from friends or partners, and from siblings in the same situation. Other participants talked about feeling closer to their well-parent as a result of sharing care tasks and providing mutual support, and some talked about improvements in a previously strained relationship with the parent with YOD.

Psychological Impact

As the child tries to make sense of and adjust to the changes in their parent with dementia and in their own relationships, they experience a range of overwhelming emotions. Grief forms a key part of the ‘Psychological Impact’ of parental YOD on children as they process the gradual and continual loss of their parent. Feelings &

towards the parent with dementia, the well-parent and the caring role itself also arise & in response to the changes that YOD brings about.

This second theme comprises two subthemes: *Personal*, incorporating the child's personal and private emotional experiences; and *Interpersonal*, referring to psychological and emotional consequences of their new roles and relationships.

Personal

In 15 of the 16 studies, children reported feeling stressed by changes in their parent and by the demands of their caring role. Questionnaire-based data indicated high levels of caregiver burden in more than half of participants (Svanberg et al., 2010), though there were only 12 participants in this study which limits the generalisability of this finding. Eleven studies reported participants feeling overwhelmed, with some children indicating that the stress of having a parent with dementia had become such that they felt they could no longer cope and had even tried to end their lives (Allen et al., 2009; Hall & Sikes, 2018; Sikes & Hall, 2018). Some participants also talked about the shock of learning about the hereditary risk of YOD, and the resultant worry and stress about their own future (Aslett et al., 2017).

Children also reported feeling angry and upset at the changes in their parent. All 16 studies reported participants experiencing psychological distress or "emotional chaos" (Johannessen et al., 2015, p. 249), and some participants had sought help from mental health services. Svanberg et al. (2010) found that four of their 12 participants scored above the cut-off indicating depression or other mood disorders on a questionnaire measure. Some participants reported feeling hurt and upset at the changes in their relationship with their parent, while others felt embarrassed or ashamed by their parent's behaviour. One study, however, reported participants experiencing "positive emotions arising from the situation" (Nichols et al. &

al., 2013, p. 23), though the authors did not provide participant quotes to evidence & this so it is unclear to what emotions this might refer.

Grief emerged as an element of children's experiences across all of the papers. In particular, children spoke of feeling that they were losing their parent and going through a process of constant grieving with each new change in them. Some talked about the loss of shared experiences with their parent, such as the parent teaching them to drive or remembering their birthday, and others simply stated, "You miss them being a parent." (Millenaar et al., 2014, p. 2004). Elements of grief were reported at different stages of the parent's dementia: shock and denial at the initial diagnosis, relief and sorrow when the parent moved to a care home, gradual loss of the parental relationship throughout the dementia process, and the anticipatory loss of a shared future with the parent. [Twelve papers](#) spoke explicitly about death and participants' anticipatory grieving, with one participant reporting that they felt they were "...waiting [...] to be told that he's died because you know it's coming...you just don't know how long you've got to wait." (Sikes & Hall, 2017, p. 330).

Interpersonal

The parent's changing abilities caused many participants to worry about their parent's safety, future deterioration and the possibility of needing a care home. Additionally, [ten studies](#) reported children's concerns for their well-parent and the strain that the caring role had put on them. Many children spoke about hiding their own feelings in order to protect both parents and to avoid placing additional strain on the well-parent.

Guilt also formed part of many children's experiences of their changed relationship to their parent with YOD, [with 12 papers mentioning guilt in some form](#). Some reported feeling guilty at continuing their own lives whilst their parent was &

living in a care home. Others reported guilt at their responses to the parent's behaviour, such as getting frustrated with them. Additionally, some reported feeling guilty about how they had thought badly of their parent before they learned that the changes in them were due to YOD.

Despite the challenges, participants in [four studies](#) reported positive aspects of caregiving or a positive psychological impact. Some children reported taking pride in their caring role and finding it rewarding (Hutchinson et al., 2016b). Others spoke about how caring had made them a "better person" (Svanberg et al., 2010, p. 744) and given them a level of maturity and confidence that they felt they would not otherwise have had. Additionally, a moderate to high mean resilience score was found in one study, suggesting that those participants were coping relatively well with their situation (Svanberg et al., 2010), though this finding would benefit from replication.

Practical Impact

The changes in their parent and the resulting caring role lead to a number of practical challenges, both in day-to-day life and in children's life goals and plans. Some of these practical difficulties are unavoidable consequences of living with and supporting a parent with YOD, and others are decisions that the child makes themselves in order to manage their feelings about parental YOD. Children of people with YOD have unique needs for support and are under-recognised by services, as both the caring role and the dementia occur at a life stage where such changes would not usually be expected.

This final theme contains two subthemes: *Adapting*, which refers to ways in which children have to adapt their lives because of parental YOD, and *Needs for Support* which describes the types of support that children feel they need.

Adapting

Unsurprisingly, children reported that parental YOD had an impact on their day-to-day lives beyond caregiving demands. [Six studies](#) reported that children experienced disrupted sleep due to their parent's behaviour during the night or due to worrying about their parent. Some children reported struggling to concentrate or missing a lot of school, with consequences for their educational achievement. [In five of the 14 papers involving adult children, participants](#) reported difficulties balancing caring for their parent with other responsibilities such as university work or their own children. One study reported on the neglect that some children experience when the parent with YOD is unable to work or to care for them, for example financial struggles, inadequate nutrition and poor hygiene (Hutchinson et al., 2016b).

Feelings of guilt and grief led children to make changes to the plans and ideas they had for themselves. [Eight studies](#) described children feeling that they had [delayed life events, with four saying that children felt their life was "on hold"](#) (Aslett et al., 2017; [Hall & Sikes, 2017](#); Sikes & Hall, 2017; [Sikes & Hall, 2018b](#)). [Ten studies mentioned children](#) changing their plans to spend more time with their parent or to fulfil their caring role. This included delaying moving away from home, delaying having their own children, and making decisions about further education and work that enabled them to stay closer to their parent or provide for the family. Some children felt that parental YOD had a different impact dependent on the child's age and gender, for example younger siblings missing out more on their parent's involvement in developmental milestones such as weddings and having children ([Hall & Sikes, 2017](#)), and different care roles being apportioned based on gender ([Barca et al., 2014](#)).

Children employed a number of coping mechanisms to reduce and manage & the psychological impact of their parent's deterioration. Avoidant strategies included explaining away changes in their parent, distracting themselves with other activities, and moving out of the family home. Additionally, children found ways of re-appraising their situation to make it more manageable, such as normalising caregiving, accepting uncertainty and the new version of their parent, and "living in the moment" (Aslett et al., 2017, p. 14) or taking things "one day at a time" (Allen et al., 2009, p. 472). Interestingly, a follow-up study with adults who, as children, had grown up with a parent with YOD, found that most participants reported experiencing an improvement in their own wellbeing and relationship with their parent after gaining physical or cognitive distance from the situation (Johannessen et al., 2016).

Needs for Support

Participants in [12 of the 16 studies](#) spoke about other people not understanding the child's unique experience of having a parent with YOD. Some participants reflected that other people didn't understand that someone of their parent's age could have dementia. One study reported a participant's view that other people expected her to be "grateful that your Mum is still here and she's not dead" (Hall & Sikes, 2017, p. 1207), reflecting their lack of understanding at the experience of losing a parent while they are still alive. Many children felt they would benefit from meeting other young people whose parents have YOD, and those who had already done so reported experiencing a sense of understanding that came from the shared experience (Johannessen et al., 2016).

Across [eight of the studies](#), children talked about their difficulties in accessing appropriate support and services, both for their parent and for themselves.

Some children spoke about difficulty accessing services in general, in terms of having to “battle” for support (Johannessen et al., 2015, p. 251), or finding that services were aimed at older adults and weren’t appropriate for their younger parent with dementia. Some participants described feeling “powerless” with services because of their age (Svanberg et al., 2010, p. 744), and about not being recognised as an individual with their own needs separate to their well-parent and parent with dementia. **One study reported participants feeling that** support should be more readily available (Barca et al., 2014). Most of those who had received support from professionals had found it helpful. However, some reported that professionals and services were unsupportive or unhelpful, because they were unfamiliar to the child or didn’t provide guidance on how to respond (Nichols et al., 2013). Millenaar et al.’s (2014) participants identified that the timing of help and support is crucial; they felt that support in the early stages was unnecessary, but later into their parent’s illness they wanted more involvement with professionals.

Eight studies specifically identified a need for information and guidance. Children often felt that they needed more information in relation to their parent’s diagnosis, particularly in the early stages of the illness when they were noticing changes in their parent. In addition, one study reported children’s wish to receive practical guidance **around how best to support their parent** (Millenaar et al., 2014). **Four studies** talked about the need for more public information about dementia to reduce the discrimination that results from others not understanding: “What I wish today, is that everyone just had to know what dementia is. That you should grow up knowing that it is an illness. So that you do not have to be ashamed.” (Barca et al., 2014, p. 1941).

Discussion

Overall, findings from all 16 reviewed studies showed remarkable convergence, and the refutational synthesis found only two differences. The first difference was the reporting of “positive emotions” in relation to parental YOD (Nichols et al., 2013), as opposed to the more difficult emotions arising in the majority of studies. However, other reviewed studies identified positive aspects of the caregiving role itself (Hutchinson et al., 2016b; Johannessen et al., 2016; Nichols et al., Svanberg et al., 2010), which has also been detailed elsewhere in the literature (Lloyd et al., 2016). It may therefore be these positive aspects of caregiving to which Nichols et al. (2013) refer. The second difference was the experience of a parent remaining in the parental role (in contrast to a reversal of parent-child roles), though with confusion as to the child’s age (Hall & Sikes, 2016). However, this was still experienced as a *Change in Relationship* and therefore did not alter that subtheme.

The present review aimed to address three research questions. Findings of the review will now be discussed in relation to each research question.

What is the experience of children of people with YOD?

The present review produced a ‘line of argument’ synthesis (Noblitt & Hare, 1988), explaining the experience of having a parent with YOD. Children experience changes in their parent and in their relationships, which have a significant psychological impact, affecting their feelings towards themselves and others. These changes in their parent and the resulting feelings cause practical difficulties in children’s day-to-day lives, leading them to make changes to their daily life and also to their life plans. Children have unique and specific needs for different types of support at different stages of their parent’s illness.

One of the key findings from the present review in terms of children's & experiences was that of grief and loss. The experience of grief in dementia caregivers in general is well established in the literature. Grief has been identified in the early stages after diagnosis (Garand et al., 2012), throughout the illness (Dupuis, 2002; Ott et al., 2007) and after the death of the person with dementia (Collins et al., 1993; Schulz et al., 2006). There is some evidence to suggest that adult-children and spouses of people with dementia experience grief differently (Meuser & Marwit, 2001; Ott et al., 2007), with children experiencing relief and less grief than spouses when the person with dementia moved to a care-home, and children employing avoidance and denial in the early stages, in comparison to spouses' sadness and reality-focus.

These findings are in line with those from the present review. Children reported grief at different stages of the illness, and spoke of anticipatory grief in the form of waiting for their parent to die. The subtheme *Changes to Relationships* also encompasses the sense of "losing" the parent with dementia. Children spoke about avoidant coping strategies, though also discussed a number of appraisal-based strategies, which may reflect those children whose parents were at a later stage of the illness, or may indicate a difference in younger children's coping compared to the adult-children in the dementia grief literature. Johannessen et al.'s (2016) follow-up study supports the finding that children experience relief at their parent's care-home placement, as children's wellbeing increased with physical and psychological distance from their parent.

What is the impact of YOD on children's psychosocial wellbeing?

Parental YOD was found to have a significant impact on children's psychosocial wellbeing, as evidenced in the theme 'Psychological Impact' as well as subthemes &

Changes in Relationships and Adapting. However, in order to fully explore this & question it is useful to compare the experiences of parental YOD with those of parental LOD, in order to identify aspects of the psychosocial impact of parental dementia that are unique to YOD.

Interestingly, the literature relating to experiences of parental LOD is largely quantitative and therefore difficult to compare to the findings of the present review. However, studies have reported that adult-children of people with LOD experience similar elements of psychological impact as reported in the present review, including anxiety and depression (Dura [et al.](#), 1991; Pinguart & Sörensen, 2011; Wang [et al.](#), 2011), guilt (Meuser & Marwit, 2001), as well as grief responses, as detailed above. Changes to relationships have also been reported in the LOD literature, including impact on friendships and marital relationships as well as the parent-child relationship, consistent with findings in the present review (McDonnell & Ryan, 2014; Meuser & Marwit, 2001; Ward-Griffin [et al.](#), 2007). Additionally, adult-children have been found to experience personal growth as a result of caring for a parent with LOD (Ott [et al.](#), 2007), consistent with findings on positive aspects of caregiving reported in the present review.

It is possible, therefore, that many aspects of children's experiences of parental dementia are similar for both LOD and YOD. However, the present review highlighted a number of elements that may be unique to parental YOD. The first is the significance of the parent's young age in terms of other people's lack of understanding and lack of appropriate support; the social impact on children. Children in the studies reviewed here reported others struggling to understand how their parent could have dementia at a young age, which they experienced as invalidating of their own experiences. This is in line with the observation that YOD

“is ‘out of time’ with people’s expectations and hopes.” (Greenwood & Smith, 2016, p. 105), and highlights the need for more public information about YOD. In terms of support, a review of the literature on caregivers’ use of services for LOD found the main reasons for low levels of service uptake were that caregivers felt they did not need services or were reluctant to access them; service availability was not a major factor in the decision (Brodaty *et al.*, 2005). In contrast, participants in the present review reported that services were not appropriate for their young parent, despite a desire to access them.

The second difference is the heightened genetic risk in YOD, which contributed to the psychological distress of participants in the present review in terms of worry for themselves in the future. Thirdly, although there were some adult-children in the reviewed studies, the majority of the participants were aged under 25. Those who were older were often reflecting retrospectively on experiences from their teens. In contrast, the majority of studies in the LOD literature appear to involve only adult participants, with the average age of children in a meta-analysis being 51.08 years (Pinquart & Sörensen, 2011). This has important implications for children’s support needs, discussed below.

What support needs do children of people with YOD have?

The unique experience of children of people with YOD gives rise to a particular set of support needs. The young age of most children of a parent with YOD means the parental changes occur at a time when children’s identity and increasing independence tend to be the most salient concerns (Erikson, 1968). A synthesis of the literature on young carers’ experiences found that caring became an important part of adolescents’ emerging identity, which helped to reduce feelings of guilt and anxiety (Rose & Cohen, 2010). This may therefore be one way in which some &

adolescents resolve the impact on their identity associated with caring for a parent & with YOD. Adolescents may have particular needs for emotional support in order to safely explore their identity and independence in the context of their caring role. It may be this group for whom peer support, possibly through collaboration between young carer and dementia services, would be most beneficial.

In contrast, relationships and commitment tend to be the focus for young adults (Erikson, 1968), and indeed adult-children seemed to place particular importance on the need for supportive relationships and the achievement of some distance from the parental situation (Aslett et al., 2017; Barca et al., 2014; Johannessen et al., 2016). It may be harder for younger children and adolescents to achieve the same level of psychological and physical distance from their parent when they are still financially and emotionally dependent. However, adult-children had additional commitments that impacted upon their caring role and levels of stress, such as their own children or university work. These older children may therefore need more practical support to help them juggle their responsibilities.

Both older and younger children spoke about their difficulties in accessing appropriate services, information and guidance about YOD. The Young Dementia Network (2016) provide guidelines for service commissioners to help make services more accessible to this group of patients. In addition, the findings of the present review highlight the need for services to specifically ask about children when assessing and diagnosing dementia, particularly YOD, in order to consider the needs of the whole family when providing support.

Limitations

One limitation of the existing literature on young people's experiences of parental YOD is the reliance on the same datasets for a number of different papers. Eight of

the 16 papers arose from just two sets of data; two of those papers reported findings & from separate interviews with the same participants, while six papers came from just one dataset (Hall & Sikes 2016, 2017, 2018; Sikes & Hall, 2017, 2018a, 2018b).

Whilst the authors took a different focus to the reporting of findings, this biases the literature towards the experiences of just one group of young people and one interviewer's questions. Care has been taken in the present review to report on findings from these six papers in the context of a single study, and to ensure that the themes and subthemes developed were represented across the full spectrum of studies reviewed.

In addition, the present review only considered studies that were published in English, and all took place in Western countries. Caregiving experiences cannot be assumed to be the same across cultures, and indeed important differences have been raised in terms of expectations of children caring for relatives between Western and non-Western cultures (e.g. Connell & Gibson, 1997; Lee & Sung, 1997; Robson, 2004).

Unfortunately, none of the reviewed studies provided findings from only younger children (under 11), and those papers that included younger participants did not separate findings by age group. This makes it difficult to draw conclusions about the specific experiences and needs of this younger group.

Future research

The themes presented here are representative of the existing literature on children's experiences of parental YOD. However, given the limited pool of data in this field to date, a broader range of participants from different cultural, ethnic and social backgrounds would contribute significantly to the evidence base. Additionally, research involving younger participants and findings separated by age group would

provide a more complete picture of the impact of parental YOD at different stages of development.

The quantitative data presented here arose from just one study (Svanberg et al., 2010) and would benefit from replication in future studies. In particular, exploration of quantitative measures of caregiver burden, emotional distress and resilience would contribute further to the understanding of children's experiences. This would also allow for a closer comparison between experiences of parental YOD and LOD, given the largely quantitative nature of the LOD literature.

A deeper consideration of the unique aspects of parental YOD would also add to the understanding in this field. For example, future research in the young carer field may wish to separate dementia from other parental illnesses. Studies in the dementia caregiver literature may also benefit from considering children as a group unique from spouses or other familial carers.

Conclusion

The present review has identified similarities to the experiences of other caregivers but has also highlighted the unique aspects of children's experiences of parental YOD. Children are experiencing the gradual and ongoing loss of their parent at an age where they are also developing their own identity and sense of self. They experience struggles to access services, both because of a lack of available support for YOD in general, and because their needs are different to spouses and adult caregivers. Children need to be empowered in their caregiving roles with the right information and opportunities, so that they can make choices for themselves and their parent with YOD.

Clinical Implications

- Service providers should ask about and offer support to clients' children when diagnosing dementia, particularly YOD.
- Dementia public awareness campaigns should include YOD as a specific element.
- Collaboration between young carer and dementia services should be considered for targeted support for children.

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Table 1 *

Search Terms for Systematic Search. (

Concept &	Search terms &
Young onset dementia &	Young onset dementia Early onset dementia Working age dementia Presenile dementia Frontotemporal dementia* Frontotemporal degeneration* Dementia under 65 Early onset Alzheimer's disease Young onset Alzheimer's disease
Children &	Child Children Son Daughter Young carer Parent Mother Father

* Frontotemporal dementia (or degeneration) was included as a specific search term, as this type of dementia is most commonly diagnosed in people under the age of 65 (Alzheimer's Society, 2016), and is often used as a standalone term in research.

The search terms were combined as follows: (((dementia OR Alzheimer*) N3 ("early onset" OR "young* onset" OR "working age" OR "under 65" OR "presenile"))) OR ((front*) N3 (dementia OR degeneration))) AND ((child* OR son OR sons* OR daughter* OR "young carer") OR (mother* OR father* OR parent*))).

Titles, abstracts, full texts and key words were searched.

Table 2*Inclusion and Exclusion Criteria for Systematic Search.*

	Inclusion &	Exclusion &
Research design	Qualitative, quantitative or mixed methods studies	Review papers, opinion papers
Quality	Peer-reviewed empirical studies	Unpublished or grey literature, non-peer-reviewed sources
Concepts &	Experience or impact of having a parent with young onset dementia	Epidemiology or genetics, interventions or treatments
Sample &	Children of people who were diagnosed with dementia under the age of 65. No upper or lower age limit for child.	Children of people with late-onset dementia, other family caregivers, patients with dementia, children of people with other physical or mental health conditions

Table 3*Summary Characteristics of the Studies*

Authors	Year	Title	Location	Aims	Participants	Methodology	Main findings	Quality rating (Kappa)
Allen, Oyebode & Allen	2009	Having a father with young onset dementia: The impact on well- being of young people	UK	Explore impact of parental YOD on children's wellbeing	12 young people aged 13-24 years, 7 female, 5 male	Qualitative. Interviews; grounded theory	5 main categories: <i>Damage of Dementia</i> , <i>Reconfiguration of Relationships</i> , <i>Strain</i> , <i>Caring and Coping</i> - overarching theme of <i>One Day at a Time</i>	35 (K = 1.00, <i>p</i> <.001)
Aslett, Huws, Woods & Kelly-Rhind	2017	'This is killing me inside': The impact of having a parent with young-onset dementia	UK	Explore personal meaning attached to having a parent with YOD, impact on self and relationships	5 participants aged 23-36 years, 2 male, 3 female	Qualitative. Interviews; IPA	5 super-ordinate themes: <i>"Like I know them but I don't know who they are"</i> , <i>"You just look up to them for all your life and then now they're looking to you for help"</i> , <i>"I feel like she can get things off her chest"</i> , <i>"You're never going to understand until you are in my position"</i> ,	35 (K = 1.00, <i>p</i> <.001)

									<i>"Hang on a minute, this could happen to...to me"</i>
									2 main themes: <i>Experiences in Social Relationships</i> (Changes in Roles and Relationships, Individuals with Different Family Contexts and Experiences), and <i>Experiences and Needs Related to Services</i> (Being Seen as a Person with Individual Needs, Targeted Groups, Need for Information)
Barca, Thorsen, Engedal, Haugen & Johannessen	2014	Norway	Nobody asked me how I felt: experiences of adult children of persons with young-onset dementia	Explore how adult children experience parental YOD and what needs they have	14 participants aged 20-37 years, 12 female, 2 male	Qualitative. Interviews; modified grounded theory			35 (K = 1.00, p<.001)
Hall & Sikes	2016	UK	How do young people "do" family where there is a diagnosis of dementia?	Explore perceptions and experiences of parental YOD and impact on family practice and display	22 participants aged 6-31 years, 18 female, 4 male	Qualitative. 2-3 interviews; thematic analysis			21 (K = 1.00, p<.001)
									3 main themes: <i>Disruption to Existing Practices, Continuities, and Reconceptualisation of Relationships</i>

Hall & Sikes	2017	<p>“It would be easier if she’d died”: Young people with parents with dementia articulating inadmissible stories</p>	UK	<p>Explore inadmissible stories in relation to parental YOD</p>	<p>22 participants aged 6-31 years, 18 female, 4 male</p>	<p>Qualitative. 2-3 interviews; thematic analysis</p>	<p>3 main themes: <i>The Process of Narrating Dementia</i>, “Taboo” Subjects (I don’t like my ill parent, Death or other illnesses as preferable, Difficult dementia behaviours), and <i>Portrayals of Dementia by People Without Dementia</i></p>	<p>26 (K = 0.80, p<.001)</p>
Hall & Sikes	2018	<p>From "What the Hell Is Going on?" to the "Mushy Middle Ground" to "Getting Used to a New Normal": Young People's</p>	UK	<p>Explore perceptions and experiences of parental YOD</p>	<p>22 participants aged 7-31 years, 18 female, 4 male</p>	<p>Qualitative. 2-3 interviews; thematic analysis</p>	<p>3 overarching themes: <i>Something is Amiss</i>, <i>Navigating the Pathway</i>, and <i>The Unpredictability of Dementia</i></p>	<p>26 (K = 0.78, p = .001)</p>

Hutchinson, Roberts, Kurrle & Daly	2016b	The emotional well-being of young people having a parent with younger onset dementia	Australia	Explore lived experiences of parental YOD from the perspective of a social model of disability and explore impact of society on the emotional wellbeing of children of YOD	12 participants aged 10-33 years, 1 male, 11 female	Qualitative. Interviews; thematic analysis	4 main themes: <i>Emotional Toll of Caring, Keeping the Family Together, Grief and Loss, and Psychological Distress</i>	33 (K = 0.73, p<.001)
Johannessen, Engedal & Thorsen	2015	Adult children of parents with young-onset dementia narrate the experiences of	Norway	Investigate and interpret metaphorical expressions of experiences of	14 participants aged 18-30, 9 female, 5 male	Qualitative. Interviews; phenomenologic al hermeneutic approach	4 core metaphors: <i>"My parent is sliding away", "Emotional chaos", "Becoming a parent to my parent" and "A battle"</i>	33 (K = 0.77, p = .001)

		their youth through metaphors		parental YOD				
Johannessen, Engedal & Thorsen	2016	Coping efforts and resilience among adult children who grew up with a parent with young-onset dementia: a qualitative follow- up study	Norway	Explore the influence of parental YOD on adolescent development, coping strategies and recent changes to situation	14 participants aged 18-30 years, 9 female, 5 male	Qualitative. Follow-up interviews; modified grounded theory	Main category “ <i>Detachment</i> ” (Moving Apart, Greater Personal Distance, Calmer Emotional Reactions)	34 (K = 1.00, <i>p</i> <.001)
Millenaar, van Vliet, Bakker, Vernooij-	2014	The experiences and needs of children living with a parent with	Netherlands	Explore experiences and needs of children living with parents	14 participants aged 15-27 years, 8 female, 6 male	Qualitative. Interviews; inductive content analysis	3 main themes: <i>Impact of Dementia on Daily Life</i> (Changing Relationships, Managing Responsibilities versus Maintaining Own Life, Concerns About	33 (K = 1.00, <i>p</i> <.001)

Dassen, Koopmans, Verhey & de Vugt	young onset dementia: results from the NeedYD study		with YOD			Future Perspectives), <i>Coping with the Disease</i> (Process of Acceptance, Avoidance, Relief of the Situation, Dealing with Changes), and <i>Need for Care and Support</i> (Timing of Care, Understanding of Dementia, Value of Communication and Social Support, Desire for Practical Guidance)	
Nichols, Fam, Cook, Pearce, Elliot, Baago, Rockwood & Chow	When Dementia is in the House: Needs Assessment Survey for Young Caregivers	USA and Canada	Explore experiences of parental frontotemporal dementia and children's needs at different points in illness	14 participants aged 11-18 years, 10 female, 4 male (including 2 grandchildren living with person with dementia)	Qualitative. Focus group; thematic analysis	7 themes: <i>Emotional Impact of Living with a Parent with FTD, Caregiving, Coping, Diagnosis, Relationships, Support, and Symptoms</i>	30 (K = 0.61, <i>p</i> = .009)

Sikes & Hall	2017	UK	Explore dementia grief in parental YOD	22 participants aged 7-31 years, 18 female, 4 male	Qualitative. 2-3 interviews; thematic analysis	6 themes: <i>Diagnosis, Ongoing Loss, Life on Hold, Missing Landmark Events, Envy, and Coping or Not</i>	29 (K = 0.68, p = .002)
Sikes & Hall	2018a !	UK	Explore implications of "still the same person" narrative for parental YOD	19 participants aged 8-31 years, 16 female, 3 male	Qualitative. 2-3 interviews; thematic analysis	7 themes: <i>"They Had to Hollywood it", My Parent is a Different Person, My Parent Doesn't Know Me, My Parent is Not Very Nice, My Parent is Aggressive, My Parent is Suspicious, and My Parent Can't Talk to Me</i>	30 (K = 0.64, p = .003) !

statistics !

themselves", "Like a child", Missing
Out, The Grieving Process, "Trying to
remember"), *Learning to Live with It*
("Just helping", "Getting on with it",
"Making sacrifices", "Growing up",
"Detaching myself", "Looking on the
bright side", "Becoming a better
person"), *Going Through it Together*
(Working as a Team, Choosing to Share,
"Taking the pressure off"). Quantitative:
4 above cut-off for depression or mood
disorders, 7 above cut-off for high
burden, mean resilience level 'moderate'.

Table 4

Main Themes and Subthemes.

Main theme	Subthemes
Dementia Impact	<i>Changes in Parent</i> <i>Changes in Relationships</i>
Psychological Impact	<i>Personal</i> <i>Interpersonal</i>
Practical Impact	<i>Adapting</i> <i>Needs for support</i>

Figure 1

PRISMA Flow Diagram

