

Title:

The experience of children with parents diagnosed with young onset dementia: A systematic literature review

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ACCEPTED VERSION

ABSTRACT

Background: Young onset dementia (YOD) may develop rapidly, and affect those who have dependent children. Currently, there remains a lack of understanding of the impact on children living with a parent with YOD.

Aim: The aim of this systematic literature review is to explore published literature in order to understand the impact on children living with a parent with YOD.

Methods: A systematic search of the following databases: Medline; PsychINFO; CINAHL and Scopus for literature published from 1/1/2013 to 31/12/2018.

Results: Three major themes were identified, firstly *coping* encompassed two sub-themes of *avoiding the situation* and *being empowered*. Secondly, *change* encompassed two sub-themes of *change of personality* and *change of family role*, and lastly *loss*.

Conclusion: There remains a need to raise awareness and develop support services for children of parents with YOD. Community nurses are the best place healthcare professionals to identify and support the needs of both the person with YOD and their children.

KEYWORDS

young onset dementia, experience, children, literature review, parents

Key points

- There are approximately 42,000 people under the age of 65 living with young onset dementia in the UK.
- Initial symptoms of young onset dementia include behavioural and personality changes, depression or problems with coordination or balance and not cognitive impairment.
- Individuals with young onset dementia may have school age children.

- Children living with a parent with young onset dementia have identified the need to cope with changes and loss.

Background

Young onset dementia (YOD), which includes vascular dementia and frontotemporal dementia, is defined as being diagnosed in individuals before the age of 65, and accounts for 9% of the global population with dementia (Alzheimer's Association, 2015; World Health Organization, 2012). In the UK, there is an estimated 42,000 people under the age of 65 living with dementia (Alzheimer's Association, 2015). The average age of YOD onset is 55, although may occur as young as 24 (Allen et al., 2009).

Initial symptoms of YOD include behavioural and personality changes, depression or problems with coordination or balance (Mendez, 2006; Fernández-Matarrubia et al. 2013). Cognitive impairment occurs later in the trajectory of the disease, which has the negative impact of a delayed diagnosis (Papageorgiou et al. 2009). The symptoms of YOD affects those who are in employment with financial and family responsibilities, and possibly dependent children (Gelman & Rhames., 2018).

The impact on the family of an individual diagnosed with YOD, includes financial burden as they may lose the ability to continue employment (Thompson, 2011). Additionally, spouses and older children of the individual with YOD may have to commence payed work or increase their employment hours (Allen et al., 2009). This occurs alongside supporting and caring for their family member with YOD, and even younger children often assume caring responsibilities (Cass et al., 2011).

However, to date there has not been a specific review of literature to explore the impact and experiences of children living with a parent who has a diagnosis of YOD (Svanberg & Stott, 2011). Research has focused on the impact of YOD on the person with the diagnosis and

their primary caregivers, such as spouses (Green and Kleissen 2013; Johannessen et al., 2017; Pang and Lee 2017; Rabanal et al., 2018; Thorsen et al., 2018).

In addition to the lack of an overview on specific research exploring the experiences of children living with a parent with YOD, support and care through service provision, tends to focus on people with late onset dementia and their family members (Allen et al., 2009). There is also a lack of guidance in the literature on service needs of these young family members (Hutchinson et al., 2016).

The global public health action response to dementia 2017 -2025, by the World Health Organization (2017) includes the aim to improve the quality of life of people with dementia, their caregivers and families. In order to achieve this mission, it is vital to understand children experiences of living, supporting and caring for a parent with YOD, and to develop a theoretical view of children's perspective to support the development of appropriate guidelines, support and service provision (Hutchinson et al., 2016).

Aim

The aim of this systematic literature review is to explore published literature in order to understand the impact on children living with a parent with YOD.

Method

A systematic search of published literature from the following databases Medline; PsychINFO; CINAHL and Scopus published between 1/1/2013 and 31/12/2018. Hand searching of relevant journals and reference lists of identified papers was completed.

Inclusion criteria were: peer reviewed primary qualitative studies published in English, children and adolescents aged from 10 - 24 years experiences of living with a parent with YOD, or who meet the specified age range at the time of their parent's diagnosis, Exclusion

criteria were: quantitative or mixed-method studies, parents diagnosed with late onset dementia or other cognitive diseases, or secondary analysis studies. A qualitative systematic review of the literature is important as supports the understanding of ‘What is it like to live with a parent with YOD?’ from the lived experience of children/young adults, which quantitative data would not be sufficient to provide an in depth and comprehensive answer (Given, 2008; Seers, 2015).

The search strategy was: ‘children’ or ‘child’ or ‘son’ or ‘daughter’ or ‘adolescence’ or ‘teenager’ OR ‘parent’. AND ‘Presenile dementia’ OR ‘Alzheimer disease’ OR ‘Young onset dementia’ OR ‘Early onset dementia’ OR ‘Younger onset dementia’ OR ‘dementia’ AND ‘Experience’ OR ‘perceptions’ OR ‘attitudes’ OR ‘views’ OR ‘emotions’ OR ‘perspectives’ OR ‘opinions’.

All studies were evaluated for robustness by the CASP checklist for qualitative research (CASP, 2017), which is an established and comprehensive checklist that answers the following questions: are the results of the study valid? What are the results? and Will the results help locally?

Data was extracted from each paper, and thematic synthesis as described by Thomas and Harden (2008) was completed. This approach includes three phases: line-by-line coding of the results of primary research, organising the codes into descriptive themes and finally, the development of analytical themes (Thomas and Harden, 2008). This process was completed by the first author and discussed in depth with the second author.

Results

The systematic searches yielded a total of 1029 results after the exclusion of duplicates, following the reading of titles and abstracts 17 full papers were obtained, of which ten met

the inclusion and exclusion criteria, refer to the PRISMA diagram (Moher et al. 2009) in Figure 1. The only element of the studies that was consistently not reported across studies was the relationship between researcher and participants, which may not have been adequately considered (CASP, 2017).

Of the included studies, six were completed in the UK (Sikes & Hall, 2018a; Sikes & Hall, 2018b; Hall & Sikes, 2018; Allen & Allen, 2009; Hall & Sikes, 2017; Sikes & Hall, 2017), two in Australia (Hutchinson et al., 2016a; Hutchinson et al., 2016b), and one in the Netherlands (Millenaar et al., 2014) and the USA (Gelman & Rhames., 2018), refer to Table 1 for more information on each study.

Three major themes were identified: the theme of *coping* encompassed two sub-themes: avoiding the situation and being empowered. The theme of *change* encompassed two sub-themes: change of personality and change of family role, and the last theme was *loss*.

Theme 1: Coping

Children living with a parent diagnosed with YOD applied different coping strategies, ranging from avoidance (Hutchinson et al., 2016; Millenaar et al., 2014; Sikes & Hall., 2018; Allen et al., 2009; Sikes & Hall., 2017) and being empowered by the situation (Hutchinson et al., 2016b; Millenaar et al., 2014; Gel man & Rhames., 2018; Allen et al., 2009).

Avoiding the situation

Children tried to distance themselves from the diagnosis and their parent with YOD.

Distancing included both a physical distance and an emotional distance (Hutchinson et al. 2016a; Millenaar et al. 2014; Sikes & Hall, 2017). For example, one way of distancing themselves from the situation was refusing to talk about the impact of YOD:

“My sister tells me my mother could pass away and then I think: I do not want to know! Things have to remain pleasant around here so we don’t have to talk about it.” (Millenaar et al., 2014, p. 2005).

Children of a parent with YOD applied emotional distraction through the need to continue routines and maintain a sense of normality. This was achieved through engagement in their education (Sikes & Hall, 2018a; Allen et al. 2009; Hutchinson et al. 2016b). For example, one child spoke about their need to maintain normality and distance themselves for their home situation:

“This Masters is the last piece of the jigsaw, and one of the reasons I did it was so I wasn’t at home... it’s given me normality in all of this...” (Sikes & Hall, 2018, p. 599-600).

Other avoidant coping strategies identified included emotion-focused coping and the use of alcohol abuse, smoking to enable them to distance themselves from the situation (Allen et al. 2009). For example, one child explained:

“Depending what time I get off and then evenings it’s always drink loads of drinking.” (Allen et al., 2009, p. 471).

Being empowered

Some children attempted to address the challenges of living with a parent with YOD through adaptive coping, in which they adjusted to their parent’s needs and supported both parents (Hutchinson et al. 2016b; Millenaar et al. 2014; Gelman & Rhames, 2018; Allen et al. 2009) and through these processes empowered themselves.

Children discussed adaptive coping through changing their daily routine and commitments to support those of their parent with YOD. Amongst changing their daily routines and commitments, some children reported the realization of the need to achieve their goals:

“You try to pay attention to your parent’s needs as much as possible, whatever is happening you try to adapt your life to his needs.” (Millenaar et al (2014, p. 2005).

“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).

Theme 2: Change

Children discussed change, which included both the change of their parent diagnosed with YOD (Allen et al., 2009; Sikes & Hall, 2018; Hall & Sikes., 2018; Gelman & Rhames, 2018; Hall & Sikes, 2017), and the change of family roles due to one parent being diagnosed with YOD (Allen et al., 2009; Millenaar et al., 2014; Hall & Sikes., 2018., Gel man & Rhames., 2018).

Change in personality

Children discussed the progress of YOD and the changes that occurred in their parents, which included memory loss, disinhibition, difficulties in pronunciation and driving (Allen et al. 2009; Gelman & Rhames, 2018; Hall & Sikes, 2017). Children felt a distinctive personality change within their parent with YOD, and these dementia-specific symptoms posed challenges to these children:

“He (father with YOD) comes into the room inappropriately, if you’re getting changed.” (Hall & Sikes, 2017, p.1208).

Children discussed their parent’s change in personality, by exploring how their parent used to be and how they would now react to situations. One child found it difficult to invite friends round to their house, as their father had acted angrily to a visitor:

“My mom’s friend came over and my father yelled: “What the hell do you want, what the hell do you want?” (Gelman & Rhames, 2018).

Change of family role

Children discussed the changing roles within their family, and their role of becoming a parent rather than a child, and taking responsibilities for both their parent's health and well-being (Allen et al. 2009; Millenaar et al. 2014; Hall & Sikes, 2018; Gelman & Rhames, 2018). One child discussed the change of role from being a child to caring for their father:

“But, me being in the position that I have with my father, I have to take care of my father; the one who's supposed to be taking care of me, I'm taking care of him” (Gelman & Rhames, 2018, p. 343).

One child discussed the change in family roles, as they had taken on the role of their father, due to his deterioration with YOD:

“I try to comfort and to support my mother when my father is being difficult. He used to be the one comforting her but now he does not see when she needs him, therefore it is my job now.” (Millenaar et al. 2014, p. 2004).

Theme 3: Loss

Children also discussed the gradual loss of their parent with YOD. Children recognized their parent was still physically present, but they had progressively and profoundly altered in terms of their personality and characteristics (Sikes & Hall, 2017; Gelman & Rhames, 2018; Hutchinson et al. 2016a; Allen et al. 2009; Sikes & Hall, 2017). Children discussed the emotional stress of losing their parent, whilst they were still present:

“The most difficult thing is losing your parent slowly and progressively ... because I've been a Daddy's girl my whole life ... and I don't have that anymore.” (Gelman & Rhames, 2018, p. 344).

“The person is physically there but there’s also grief of losing someone ...That person is not here anymore. But they are. But I can’t reach them. But they’re right there ...”

(Hutchinson et al. 2016a, p. 618).

For some children, the loss was discussed in terms of future loss, and the expectations of the loss that was still to come, as their parent with YOD would not be there to support and teach them:

“I would be different if dad didn’t have FTD. He would have taught me things. Taught me the business, I could have asked him about things – girlfriends. Adult male talk.

Working with dad.” (Allen et al. 2009, p. 466).

Discussion

The overarching themes of this review regarding the experiences of children living with a parent with YOD include coping, change and loss, each of these concepts now will be discussed with regard to wider literature.

Coping

The finding of *coping* identified from this review is similar to the experience of children with a parent diagnosed with cancer (Walczak et al. 2018). Children coping with a parent with YOD or cancer both reported adaptive and avoidant approaches of coping. However, children with a parent with cancer most frequently reported adaptive coping (Walczak et al. 2018), whilst children with a parent with YOD more frequently reported avoidant coping (Hutchinson et al. 2016; Millenaar et al. 2014; Sikes & Hall. 2018; Allen et al. 2009; Sikes & Hall. 2017).

The difference between living and supporting a parent with YOD compared to cancer may be due to the challenging and difficult behaviours of a parent with YOD (Hall & Sikes., 2017),

and a lack of acceptance and increased stigma regarding dementia by society (Hutchinson et al., 2016a). The differences in social acceptance of dementia and cancer may lead to different coping approaches. Therefore, raising social awareness of YOD is likely to reduce stigma and discrimination by increasing knowledge and understanding of the disease (Harris & Keady, 2009).

Change

The finding of *change* identified from this review, is similar to the loss of identity and role described by family members caring for a relative with cognitive impairment due to Parkinson's disease (Lawson et al. 2018). Although Lawson et al. (2018) focus on spouses, rather than children, the similarity of the challenges of change caused by changing roles within the family and social groups is evident (Lawson et al., 2018).

The diagnosis of YOD compared to Parkinson's disease may be lengthy, and during this time, children may experience doubt and uncertainty (Roach & Drummond., 2014). The doubt and uncertainty of children of a parent with YOD may be due to the changing personality of their parent, and challenging behaviours that have no explanation. There is the need for knowledge of YOD to be widely disseminated and in formats that will support children of a parent with YOD to gain specific and practical information (Millenaar et al., 2014).

Loss

The findings of *loss* identified from this review are different from older children with a parent diagnosed with late onset dementia (Hwang et al. 2017). Older children experienced family conflicts in relation to caring responsibilities, and the need to explore approaches to sustain caring for their parent (Hwang et al. 2017). However, the similarities of changing roles and care responsibilities demonstrate the need for appropriate social support for the person living with dementia, which will simultaneously support the needs of the person's family.

Over all, this review highlights the importance of the need for policy makers to be aware of young people's psychological well-being and development needs, when living with a parent with YOD. The needs of families with a member with YOD are important to be recognized and addressed to prevent families from breaking down (Gelman & Greer, 2011). Nurses are the best-placed health professionals to identify the psychological needs, of family members, and especially children with a parent with YOD, who need practical and emotional support and help in supporting and caring for their parent with YOD (Bramble et al., 2009).

Limitations

There are a number of limitations within this review. Only papers published in English were included. The age range of children within the studies, ranged from 6 years to over 21, and due to the diverse age range, children may have had different experiences.

Conclusion

This review synthesized the existing research to gain knowledge and awareness of the experiences and needs of children living with a parent with YOD. The themes of *coping*, *change and loss* were identified. The positive coping strategies of children were empowering and enabled them not only to live their lives, but to challenge the disease. However, it is imperative children are supported to manage challenges, and services are tailored and available to support children of a parent with YOD. Change presented children with further challenges, which was caused by dementia-related changes of the parent with YOD and the need to care for their parent. The need remains to raise public awareness of YOD, and provide practical service and support to release children from care providing responsibilities. While the theme of *loss* highlights children's emotional distress caused by their parent's diagnosis, by promoting communication between families and children who are in the same situation, it is likely that children are able to gain peer support, and reduce their emotional

distress. Community nurses are the best placed healthcare professionals to identify the needs of children with a parent with YOD and support and sign-post their families to relevant services.

Reflective questions

- Considering the fact that 45,000 people are living with young onset dementia in the UK, and in the early stages cognitive impairment is not a symptom, how would you assess someone where concerns about their behaviour had been reported?
- Children within the home of parents with dementia are often overlooked by healthcare professionals, how would you approach and discuss a child's experience of their parent's illness?
- Family health and well-being is an important goal of all healthcare professionals, how would you as a nurse ensure the needs of the children in the family are assessed and addressed?

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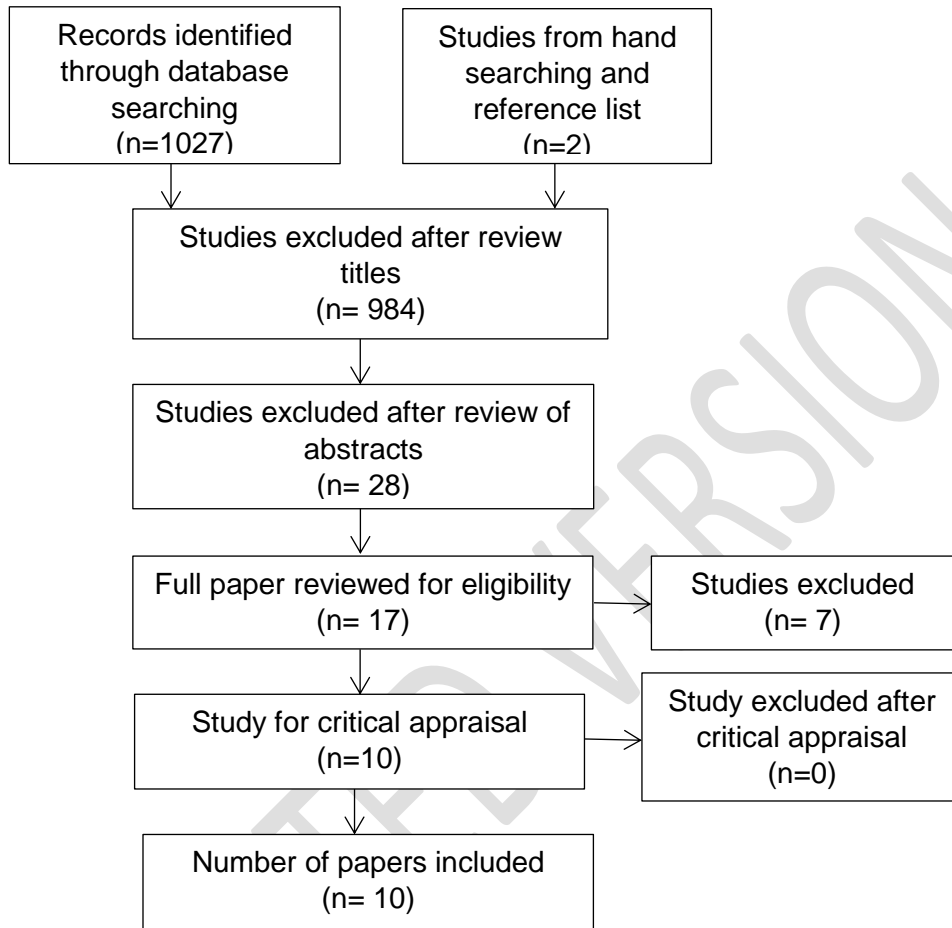
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Figure1. PRISMA Flow chart of study selection



Adapted from Moher et al. (2009).

Table 1: Overview of included studies

Author (year) (country)	Methods Study design Participants	Data analysis	Findings	Limitations
Hutchinson 2016 Australia	Semi-structured interviews Participants (n=12) Male (n=1) Female (n=11) Aged 8-24	Thematic analysis	Themes: -emotional toll of caring -keeping the family together -grief and loss and psychological distress	Females were over represented in sample
Allen 2009 England	Grounded theory Interviews Participants (n=12) Male (n=5) Female (n=7) Aged 13-24	Thematic analysis	Five major themes: (1) damage of dementia (2) reconfiguration of relationships (3) caring (4) strain (5) coping	All those recruited it was their father who had dementia.
Millenaar 2014 Netherlands	Semi-structured interviews Participants (n=14) Male (n=6) Female (n=8) Aged 15-27	Thematic analysis	Three major themes: (1) the impact of dementia on daily life (2) coping with the disease (3) the need for care and support.	Only children older than 14 years were included the sample may be biased

Sikes & Hall 2018 England	Narrative autobiographical Interview Participants (n=26) Aged 6-31	Thematic analysis	Themes: -locating parental dementia with reference to educational milestones -dementia-specific challenges -education as an escape/coping mechanism -dementia and educational choices -educational institutions' responses	The findings are mainly focused on the impact of parent's YOD on educational career of children
Gelman 2018 USA	In-depth interviews Participants (n=8) Aged 3-18 at the time of parent's diagnosis	Thematic analysis	Three themes: -abrupt interruption/disruption of child's developmental course -adaptation, coping and growth -lack of YOD information and relevant services	A small sample of only four families, in a specific geographic area with perhaps better access to medical and social services than most. Furthermore, in all of the families interviewed it is the father who has YOD.
Sikes & Hall 2018 USA	Autobiographical Interviews Participants (n=19) Aged 8-31	Thematic narrative analysis	Not the same person narratives	The participants were self- selecting and the majority, although not all, are white, British and middle class
Hutchinson 2016 Australia	Flexible, in depth semi- structured interviews Participants (n=12) Male (n=1)	Thematic analysis	Three themes: (1) Invisibility (2) Connectivity (3) being empowered	Females were over represented in the sample

	Female (n=11) Aged 8-24			
Hall & Sikes 2018 England	narrative autobiographical Interviews Participants (n=22) Aged 7-31	Thematic analysis	Themes: -realizing some-thing was “wrong” with their parent -navigating an illness that characteristically entails an unpredictable trajectory and messy time scale -consequences for their own lives	The sample was self- selecting and the majority of participants were White, British, and middle class
Hall & Sikes 2017 England	narrative autobiographical Interviews Participants (n=22) Aged 7-31	Thematic analysis	The process of narrating dementia: - “Taboo” subjects; Portrayals of dementia by people without dementia	Self-selecting sample
Sikes & Hall 2017 England	narrative autobiographical Interviews Participants (n=22) Aged 7-31	Thematic analysis	Themes: -diagnosis -ongoing Loss -life on Hold -missing Landmark Events -envy -coping or Not.	Self-selecting sample of mainly white, British, middle- class, participants.