

Childhood perspectives of parental young onset dementia: A qualitative data synthesis

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Cathal Blake^{ORCID} and Louise Hopper^{ORCID}

School of Psychology, Dublin City University, Dublin, Ireland

Abstract

Background: While it is less common, young onset dementia manifests at a significantly younger age (< 65). Many people with young onset dementia are parents; however, little is known about impact of the condition on children and young adults. A qualitative thematic analysis was conducted to synthesise the literature on the perspectives of children and young adults with a parent living with young onset dementia.

Methods: Electronic databases were searched in order to identify all peer-reviewed literature in relation to the perspectives of children and young adults with a parent living with young onset dementia. A thematic analysis was conducted on the relevant literature.

Results: The electronic database search resulted in 15 full texts articles. Four main themes with related subthemes emerged from the thematic analysis. The four main themes were: changing family dynamics; psychological and physical strain; stigma and coping strategies.

Conclusion: The current synthesis outlines the perspectives of children and young adults with a parent living with young onset dementia. There is a significant lack of research in this area which adds to the stereotypical view of dementia as an older person's disease. This can lead to children and young adults being impacted by lack of awareness and stigma resulting in significant psychosocial problems. As the number of people living with dementia (including young onset) is set to increase, future research with children and young adults with a parent with young onset dementia is important in order to better support this cohort.

Keywords

Parental young onset dementia, psychological and physical strain, stigma, coping strategies

Corresponding author:

Cathal Blake, School of Psychology, Dublin City University, Glasnevin, Dublin 9, Ireland.

Email: cathal.blake25@mail.dcu.ie

Background

While age is the biggest risk factor for dementia, younger people can develop the condition as well. This is known as ‘young onset’, ‘early onset’ or ‘presenile dementia’ (Koopmans & Rosness, 2014). For the purposes of this paper, it will be referred to as young onset dementia. Estimating the prevalence rates of young onset dementia is problematic due to a number of factors. There can be a delay of 4 years, on average, from onset of symptoms to diagnosis (van Vliet et al., 2013; Draper et al., 2016) and a significant proportion of people living with dementia do not receive a clinical diagnosis (Prince et al., 2011). The scarcity of studies of younger cohorts, the reliance on registered data, the lack of a definitive definition of young onset dementia and the arbitrary cut-off age of 65 may also contribute (Koopmans & Rosness, 2014). A systematic review and meta-analysis by Hendriks and colleagues (2021) posit that the prevalence of young onset dementia is 119 per 100,000 for people aged between 30 and 64, or four million people approximately. This equates to almost nine percent of diagnosed dementia cases worldwide (WHO, 2019). Evidence outlines a greater heritable risk, and a wider range of symptoms for young onset dementia (Mendez, 2006) compared to late onset dementia – that is, those diagnosed after 65 years of age (Alzheimer’s Society, 2015) often leading to the condition being misdiagnosed (Mendez, 2006). People with young onset dementia may experience symptoms such as depression, anxiety, agitation, aggression, apathy, delusions and/or hallucinations, which can add to a misdiagnosis (Sampson et al., 2004). This can result in people with young onset dementia being diagnosed with a psychiatric/psychological issue rather than a neurodegenerative condition. For example, Woolley and colleagues (2011) outlined that almost one third (28.2%) of people with young onset dementia were misdiagnosed with a psychiatric disorder prior to a definitive diagnosis, particularly if the subtype resulted in behavioural issues. More often than not, individuals are physically healthy with relatively few comorbid conditions. As a result, many people with young onset dementia have reported issues with healthcare professionals when attempting to obtain a diagnosis (Johannessen & Moller, 2013).

Post diagnosis, people with young onset dementia may face significant societal challenges (Rossor et al., 2010). Many are typically at an active stage of life and may be involved in important roles and have varying degrees of life responsibilities. People with young onset dementia may have parenting, employment, financial or caring commitments which can often lead to issues adjusting and accepting a diagnosis (Sansoni et al., 2016).

People are often faced with significant lifestyle changes which may include withdrawal from employment, driving cessation and the loss of various hobbies/activities resulting in social isolation (Spreadbury & Kipps, 2019). Changes may occur with relationships, both familial and societal, and young onset dementia can also affect individuals’ sense of purpose leading to feelings of marginalisation (Harris, 2004; Roach & Drummond, 2014). As a result, people with young onset dementia report feeling a reduced sense of self/personhood with many citing feeling a loss of identity and reduced self-esteem (Clemerson et al., 2014). Conversely, some people with young onset dementia report that the experience of the condition has been relatively positive as it has assisted in strengthening their relationship with a spouse/partner (Harris, 2004; Johannessen & Moller, 2013).

When compared with late onset dementia, many people with young onset dementia are cared for in the home by informal carers, typically a family member or friend (Newbrunner et al., 2013). Wawrziczny and colleagues (2016) report that spouses/partners and/or children typically provide the majority of care. Caring may involve several elements such as emotional and/or more hands on supports with household tasks and personal care. Carers have reported significant issues when attempting to manage the behavioural and psychological symptoms of dementia. Many carers experience feelings of grief similar to the loss of a loved one as they struggle to balance caring with

various other obligations (Sansoni et al., 2016) while others have reported feeling inadequate or ill prepared for their new role (de Vugt & Verhey, 2013).

Caring can involve a continual adaptation to an ever-changing situation for a prolonged period and can result in negative psychological and physical outcomes (Svanberg, Stott & Spector, 2010) and is associated with a higher demands (Arai et al., 2007). Several factors may influence the decision to care for a person with young onset dementia at home. For example, entry to an institution may depend on the carers' competency levels supporting the person with dementia or the amount of assistance received from other family members such as children (Bapista et al., 2016; Roach et al., 2014). However, the lack of services for people with young onset dementia may also be a contributory factor. Most, if not all, dementia services cater to older adults and are situated in older-adult settings (Guss et al., 2006; Withall, 2013). This leads many family members to adopt the role of carer and reinforces the current perception of dementia as a disease of old age (Flynn & Mulcahy, 2013).

Service providers may often be ill-equipped to cater to the complex needs of people with young onset dementia and may be unable to offer the specialised services needed for this cohort (Sansoni et al., 2016). Richardson and colleagues (2016) reported that the development of specialised services for people with young onset dementia and their families are required. Similar reviews by Sansoni and colleagues (2016) and Spreadbury and Kipps (2019) have also outlined the lack of specialised services, poor post-diagnostic pathways, limited information for family carers and the scarcity of age-appropriate support services. As a result, people with young onset dementia remain on the periphery of traditional dementia care pathways when compared to late onset dementia (Ducharme et al., 2013).

There has been an increased interest in young onset dementia, particularly in the last 15 to 20 years. Numerous reviews and meta-analyses have focused on the experiences of people with young onset dementia, while others have examined the role of caring from the perspectives of spouses or partners. However, children may be faced with a parent with a progressive, degenerative disease and may be required to assist with certain care giving tasks.

Cass and colleagues (2011) outlined the negative affect on children's psychological and physical health who experience a parent living with a significant health condition or disability. Similarly, evidence has highlighted the challenges of parental illness and/or disability and negative educational outcomes for children (Sikes & Hall, 2018). Children of a parent with young onset dementia report that the physical and emotional toll is significant (Gelman & Greer, 2011); however, families may require children's support (Adelman et al., 2014).

Evidence from research with spouses/partners may not be applicable to younger people. Spreadbury and Kipps (2019) suggest that children's responses to caring for a parent with young onset dementia may vary considerably when compared to adults. Younger people may adopt differing coping mechanisms, learn new techniques in order to feel useful and bring a sense of unity to their family (Joseph et al., 2012). Several analyses (van Vliet et al., 2010; Svanberg et al., 2011; Cabote et al., 2015; Baptista et al., 2016; Millenaar et al., 2016; Sansoni et al., 2016; Spreadbury & Kipps, 2019) have include children's experiences of young onset dementia. However, the findings incorporate the overall family narrative and do not focus solely on children, leading to a significant gap in the research (Richardson et al., 2016). Cabote and colleagues (2015) have examined the experiences of children separately from adults, though the analysis included only two studies exclusively based on younger people's perspectives.

Rationale and aims

To the best of our knowledge, there have been six analyses of the literature on children's and young adults experiences of having a parent with young onset dementia (Gelman & Greer, 2011; Poole & Patterson 2020; Wang & Brooke, 2020; Cartwright et al., 2021; Chirico et al., 2021; Grundberg et al., 2021) with one review (Wang & Brooke, 2020) synthesising purely qualitative data. This is likely to lead to a significant gap in the research in relation to the perspectives of children and young adults with a parent with young onset dementia.

The current analysis will focus exclusively on qualitative data and synthesise the evidence utilising thematic analysis to explore this cohorts perspectives of young onset dementia. The specific aim is to critically examine the evidence in order to understand the impact of living with a parent with young onset dementia has on their lives.

Methodology

Seven electronic databases including PubMed, Medline, Embase, CINAHL Complete, PsychInfo, Scopus and Web of Science were searched in order to identify all contemporary peer-reviewed literature in relation to the research aim.

Inclusion criteria

Inclusion depended on the studies being written in English and published in peer-reviewed journals. The electronic search did not include any time/date limit. See [Table 1](#) for inclusion and exclusion criteria, databases and search terms used.

Data collection

Abstracts were screened in the first instance, and subsequently full texts were screened in order to gauge eligibility for inclusion based on the inclusion/exclusion criteria outlined in [Table 1](#). Reasons for article rejection were recorded and are outlined in the PRISMA flow chart ([Figure 1](#)). Items of data extracted include information in relation to publication (authors, date, country, study aims), eligibility (participant characteristics, methodology, and analysis) and raw data (in the form of participant quotations and relevant themes).

Data analysis and synthesis

[Thomas and Harden's \(2008\)](#) approach to thematic synthesis was employed, and the synthesis and subsequent analysis were also assisted by contemporary studies in relation to this approach ([Soilemezi & Linceviciute, 2018](#)). Thematic analysis is one of a range of methodologies utilised in research synthesis that sits alongside meta-ethnographic and meta-syntheses ([Dixon-Woods et al., 2005](#)). According to [Boyatzis \(1998\)](#), thematic analysis is a process that may be utilised with most qualitative methodologies. This approach was used in this paper as it allowed the researcher to immerse fully in the data in order to identify, develop and extract the relevant themes. Furthermore, this method is increasingly being utilised in health and social science research particularly in relation to the evaluation of participants' experiences ([Booth, 2016](#)).

The first stage involved reading and re-reading of the included papers in order to identify information pertaining to the context of the current review. The second stage involved screening data

Table 1. Inclusion and exclusion criteria guiding study selection, databases and search terms.**Inclusion criteria**

Primary qualitative studies focused on the perspectives of children, adolescents and young adults with a parent with young onset dementia

Qualitative methodologies such as interviews and focus groups

Included both biological children and stepchildren

Studies with descriptions of the data collection and analysis procedures

People with younger onset dementia defined as an individual diagnosed before the age of 65 years

Studies published in English

Studies published in academic peer-reviewed journals

Exclusion criteria

Quantitative or mixed method methodologies

Studies that include or are focused on people with younger onset dementia

Studies that include or are focused on spouses/partners

Unpublished research – that is, grey literature, position papers, poster presentations and theses

Studies not reported in English

Databases and search terms

Databases	Search terms
Scopus	'young onset dementia' OR 'early onset dementia' OR 'presenile dementia' OR 'YOD'
Medline	OR 'PwYOD' OR 'EOD' 'PwEOD' OR 'working age' OR 'under 65 years' AND
PubMed	'children' OR 'child' OR 'son' OR 'daughter' OR 'stepchildren' OR 'adolescents' OR
Web of Science	'teenager' OR 'teen' OR 'teens' OR 'youth' or 'kids' OR 'young carer' OR 'young
Embase	adult' AND
PsychInfo	'parent' OR 'parents' OR 'parental' OR 'mother' OR 'father' OR 'dad' OR 'mom' OR
CINAHL Complete	'guardian' OR 'legal guardian' OR 'stepmother' OR 'stepfather' OR 'folks'

in the 'findings/results' section of the included papers to identify themes emerging from the data that related to the research question. The papers were examined in chronological order (from earliest publication date) and were then compared with subsequent papers in order to recognise similar themes across the included papers. This process continued until data saturation was reached, and no new themes emerged from the data. The steps followed during this process are outlined in [Table 2](#).

Results

The electronic database search yielded 887 articles. Following the removal of duplicates and those not meeting inclusion criteria, 15 full texts articles were included in the synthesis (see [Figure 1](#)).

Characteristics of included studies

In total, the current synthesis included 15 articles from six countries (see [Table 3](#)) representing the narratives of 129 participants. The age of participants ranged from 6 to 31 years with only two articles ([Nichols et al., 2013](#); [Baker et al., 2018](#)) focusing solely on participants under the age of 18 years (age range: 9–18 years). The studies by Sikes and Hall used the same sample of participants ($n = 24$). Similarly, [Hutchinson et al. \(2016a\)](#) used the same sample ($n = 12$) for both studies.

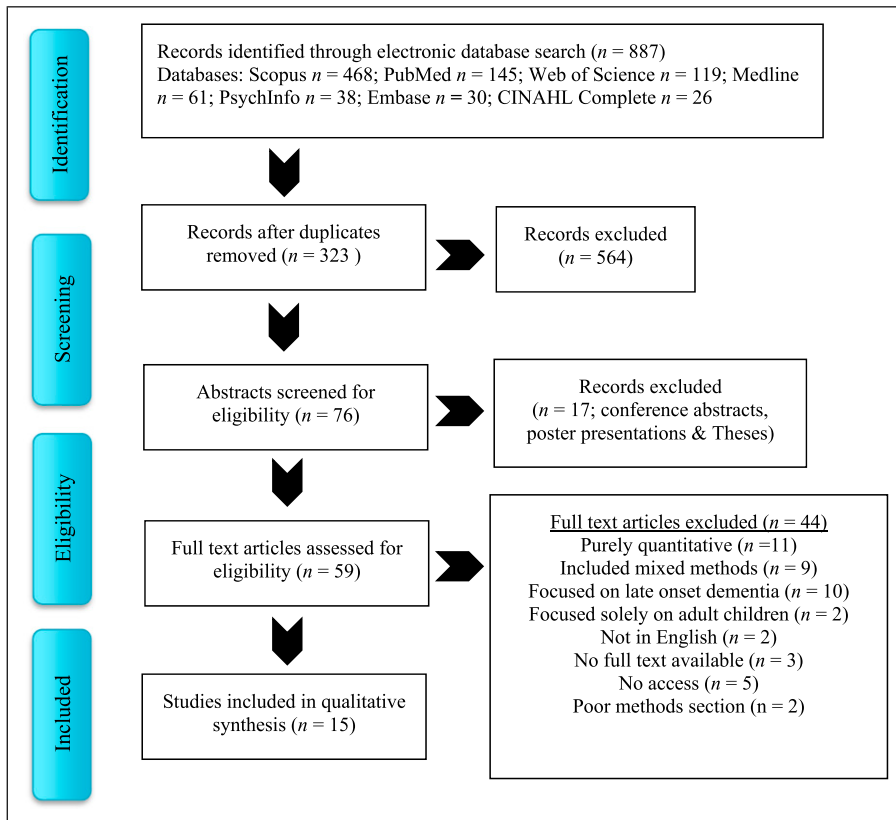


Figure 1. PRISMA flow chart of study selection process (adapted from Moher et al., 2009).

Table 2. Steps followed during the data synthesis.

- 1 Purposeful reading of the journal articles in order to understand the context, to appraise the quality of the study in order to extract relevant data
- 2 Identified themes were extracted from the results/finding's sections, and from the discussion sections of the journal articles
- 3 Themes extracted from the results/finding's sections were classed as primary data (i.e. quotes directly from participants)
- 4 Themes extracted from the discussion sections were classed as secondary data (i.e. the authors' interpretations)
- 5 Both raw data and secondary data were compared and contrasted within and between journal articles, and subsequently coded for meaning in relation to the research question
- 6 Purposeful re-reading of the journal articles in order to ensure coding and thematic analysis was appropriate before final write-up

Table 3. Details of studies included in the qualitative synthesis.

Study/Year/Country	Aims	Sample	Age at time of interview	Methods	Theoretical approach	Quality Appraisal
Smolovatz (2003) USA	To identify changes in parent-adolescent relationships and in family dynamics when a family member with Alzheimer's or similar dementia moves into the household	17 participants	12–19 years	One-to-one semi-structured interviews	Family systems theory	Good
Allen et al. (2009) United Kingdom	To explore the impact on young people's wellbeing of having a parent with younger onset dementia	12 participants	13–24 years	One-to-one semi-structured interviews	Grounded theory	Good
Nichols et al. (2013) Canada	To learn more about the needs and experiences of young carers for patients of frontotemporal dementia (FTD) in order to create a relevant support website for young caregivers to dementia patients	14 participants	11–18 years	Focus group interviews	Thematic analysis	Good
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 participants	15–27 years	One-to-one semi-structured interviews	Inductive content analysis	Good
Hutchinson, et al. (2016) ^b Australia	To explore the lived experience of young people living with a parent with young onset dementia from the perspective of the social model of disability. Focus on exploring what impact society has on the emotional well-being of the young people	12 participants	10–33 years	One-to-one semi-structured interviews	Social model of disability	Good
Hutchinson, et al. (2016) ^a Australia	To explore what are the lived experiences of young people having a parent with younger onset dementia from the perspective of the social model of disability. Secondly, we explored influencing factors that could enable these young people to be included and supported within their community	12 participants	10–33 years	One-to-one semi-structured interviews	Social model of disability	Good
Sikes & Hall (2017) United Kingdom	To add to the literature by re-presenting the grief-related perceptions and experiences of children and young people who have a parent with a young onset dementia	22 participants	6–31 years	Autobiographical: Participants are simply invited to tell their stories of parental dementia	Life historical and narrative approach/thematic analysis	Good
Hall & Sikes (2018) United Kingdom	To explore young people's experiences of disruptions to existing family practices, and how they perpetuate a relationship with their parent in the face of dementia	22 participants	8–31 years	Autobiographical: Participants are simply invited to tell their stories of parental dementia	Family practices approach	Good
Hall & Sikes (2018) United Kingdom	To examine the implications dementia has for the relationship between children and their parents – specifically, how individuals 'do' and display family when their parent's personality and capacity to function as previously has been undermined	22 participants	6–31 years	Autobiographical, one-to-one in-depth interviews	Life historical and narrative approach/thematic analysis	Good
Sikes & Hall (2018) United Kingdom	To explore the consequences of parental young onset dementia on children's educational careers	24 participants	6–31 years	Life historical and narrative approach	Grounded theory/thematic analysis	Good
Gelman & Rames (2018) USA	To explore the impact of children living at home with a parent with YOD in order to better understand their experience and more effectively respond to their unique needs	10 participants	13–20 years	One-to-one semi-structured interviews	Thematic analysis	Good
Baker et al. (2018) Australia	To elicit stakeholder priorities for the message content of an education programme to improve dementia awareness among youth; specifically, what do children need to know about dementia?	6 participants	9–16 years	One-to-one semi-structured interviews and focus groups	Tripartite framework	Good
Gelman & Rames (2020) USA	How do the parents without YOD understand and negotiate their ever-changing parenting role, and how do their children experience it?	8 participants	15–20 years	One-to-one semi-structured interviews	Thematic analysis	Good
Lovenmark (2020) Sweden	To describe how children, in their own narratives, construct themselves as subjects growing up and caring for a parent with dementia	12 participants	15–25 years	Discourse analysis of participant blogs	The epistemological perspective	Good
Hall & Sikes (2020) United Kingdom	The perceptions and experiences of children and young people who have a parent with young onset dementia, this article explores the ways in which the condition impacted their life courses	23 participants	6–31 years	Narrative biographical approach with a limited longitudinal element	Life historical and narrative approach/thematic analysis	Good

* References included in the appendix

Baker and colleagues interviewed 28 children in total; however, only six had experience of living with an adult with young onset dementia.

Quality appraisal

In order to appraise the quality of the selected studies the Critical Appraisal Skills Programme qualitative checklist was used (Critical Appraisal Skills Programme, 2018). The Critical Appraisal Skills Programme assists the review process by providing the reviewer with 10 questions to consider in relation to each individual studies validity, value and findings. The questions require the reviewer to simply answer with either a 'yes', 'no' or 'cannot tell' response. The Critical Appraisal Skills Programme is the most prevalent tool used to assess the quality of studies during the qualitative synthesis process (Majid & Vanstone, 2018) and as such was used in the current review. Any studies that were deemed to be of poor quality were omitted (Dixon-Woods et al., 2004).

The aims, methods, participant recruitment and study design were outlined in all cases. The majority of studies utilised one-to-one semi-structured interviews, while focus group interviews and auto-biographical narratives were also used. One study (Nichols et al., 2013) was vague in relation to data collection. A minority of studies recognised the influence the research team may exert on participants. All studies were cognisant of ethical considerations. Two studies (Gelman & Rhames, 2018, 2020) offered participants monetary reward for participation; however, ethical approval was received from a university institutional review board. Key quotes were used by all studies to illustrate themes and subthemes; therefore, each study was deemed to be of sufficient quality to be included in the synthesis (see Table 4).

Thematic synthesis

The four main themes with related subthemes that emerged from the analysis are presented in Table 5. To support the analysis, direct participant quotations (primary data) and the authors interpretations (secondary data) were utilised. Primary data are presented in the form of participant quotations in italicised text, and secondary data interpretations are presented in non-italicised text.

Theme 1: *changing family dynamics*

Relationships and roles within the family are significantly negatively affected following a diagnosis of young onset dementia; however in some instances, the change can also be positive.

Role and relationship change. The changing nature of the roles and relationships within the family was outlined in seven studies (see Table 5). Children and young adults, particularly the male participants, reported the need to adopt the role of family protector, specifically if the person with young onset dementia was their father (Allen et al., 2009; Baker et al., 2018; Millenaar et al., 2014). One male participant described how he felt this need: '*I am the man of the family, I must be strong. If the family is threatened then, I must protect them*' (Allen et al., 2009, pp. 466). Another young male participant described how his role changed from student to employee as a result of his father's diagnosis: '*Since I was 15, when I knew that dad wasn't going to be bringing in any money for mum, it kind of put me more towards work than university and college*' (Allen et al., 2009, pp. 467).

The sense of the changing relationship with a father with young onset dementia was not restricted to male participants. One nineteen-year-old female described how her relationship with her father had changed significantly: '*You miss them being a parent. Normally you are father and child, but*

Table 4. Quality appraisal of included studies using the [Critical Appraisal Skills Programme \(2018\)](#) qualitative checklist.

Study	Aim	Method	Design	Recruitment	Data collection	Relationship	Ethical issues	Analysis	Findings	Value
Szinovacz (2003)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Allen et al. (2009)	✓	✓	✓	✓	✓	●	✓	✓	✓	✓
Nichols et al. (2013)	✓	✓	✓	✓	●	●	●	✓	✓	✓
Millenaar et al. (2014)	✓	✓	✓	✓	✓	x	✓	✓	✓	✓
Hutchinson, et al. (2016)b	✓	✓	✓	✓	✓	x	✓	✓	✓	✓
Hutchinson, et al. (2016)a	✓	✓	✓	✓	✓	x	✓	✓	✓	✓
Sikes & Hall (2017)	✓	✓	✓	✓	✓	✓	✓	●	✓	✓
Hall & Sikes (2018)	✓	✓	✓	✓	✓	x	✓	●	✓	✓
Hall & Sikes (2018)	✓	✓	✓	✓	✓	x	✓	●	✓	✓
Sikes & Hall (2018)	✓	✓	✓	✓	✓	✓	✓	●	✓	✓
Gelman & Rhames (2018)	✓	✓	✓	✓	✓	x	x	✓	✓	✓
Baker et al. (2018)	✓	✓	✓	✓	✓	x	✓	✓	✓	✓
Gelman & Rhames (2020)	✓	✓	✓	✓	✓	x	x	✓	✓	✓
Lövenmark (2020)	✓	✓	✓	✓	✓	x	✓	✓	✓	✓
Hall & Sikes (2020)	✓	✓	✓	✓	✓	x	✓	✓	✓	✓

Key: ✓ = criteria met ● cannot tell or criteria partially met x = criteria not met.

now we are on the same level because he does not think like an adult anymore' (Millenaar et al., 2014).

Parenting the parent. Evidence of children and young adults having to adopt a parental role was described in six studies (see Table 5). Research has illustrated that the situation can have a significant negative impact both physically and emotionally as a result. However, families may require their children's support and children often play a pivotal role in the care of a parent with young onset dementia (Adelman et al., 2014). One nineteen-year-old male described adopting the role of parent for his father in order to assist with caring tasks: *'I've had to do some things for him that no kid should ever have to do for their father. I had to wash his clothes after he had an accident and shower him, you know... I had to do that'* (Gelman & Rhames, 2018).

Participants reported how they were required to help with the needs of their parent with young onset dementia, similar to looking after a child. A girl aged eight had been assisting with her mother's needs for almost 10 years: *'...you'd have to be awake at seven, when she woke up to say hi, good morning, you'd have to prompt her to get up and change her and dress her, put her socks on, it was a pleasure to be able to do that for her'* (Hutchinson, et al., 2016b). A fifteen-year-old male described how the parent/child relationship had completely turned on its head: *'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, pp. 343).

Adjusting future plans. The adjustment of future plans was outlined in 10 studies (see Table 5). Participants reported how parental young onset dementia had impacted on their future plans in relation to employment, travel and education (Sikes & Hall, 2017). Participants described feeling stuck as their future plans were put on hold. A male participant aged 27 illustrated how his future plans for independence were put on hold: *'I planned to move out a while ago, but now I feel like I cannot leave anymore since my mother will be alone with him. I did not tell her that because I do not want her to feel guilty'* (Millenaar et al., 2014, pp. 2004). A twenty-two-year-old female had a similar experience: *'I wasn't entirely sure last summer what I wanted to do...I felt my life had been put on hold and I wasn't getting anywhere'* (Sikes & Hall, 2018, pp. 601). One twenty-eight-year-old female summed it up: *'It affects my life choices as well because I'd probably be looking at having kids soon if it wasn't for this...I think all kind of family plans are gonna be on hold...you don't know how long each stage is gonna last'* (Sikes & Hall, 2017, pp. 331).

Chance to bond. The opportunity for children and young adults to bond with other family members during adversity was outlined in six studies (see Table 5). Despite the negative changes to the family, parental young onset dementia can sometimes bring some positives to relationships (Szinovacz, 2003; Millenaar et al., 2014; Gelman & Rhames, 2020). Participants reported being closer to their parent(s) as they shared their emotions openly. An eighteen-year-old male described bonding with his mother: *'We have gotten closer to my mother, who took on the roles of both parents. We're her outlets, people to vent to. We do that, too. We don't keep secrets; we try to be very honest and open'* (Gelman & Rhames, 2020, pp. 685). Similarly, young people described how they bonded with other siblings. An eighteen-year-old female described providing emotional support to her younger sister which has allowed them to bond: *'I think mum will try and cover her emotions up. I'm [sister's name] big sister and she does come to me a lot, like she always talks to me about things so if she has got problems or anything she needs to talk about she'll come and tell me...'* (Allen et al., 2009, pp. 471).

Theme 2: psychological and physical strain

A parent diagnosed with young onset dementia can place significant psychological and physical strain on children and young adults.

Financial worries. In three studies (see Table 5) children and young adults reported how parental young onset dementia can impact them financially, particularly if the person with young onset dementia is the main breadwinner (Gelman & Rhames, 2018; 2020). Children and young adults outlined the psychological strain as a result of worrying about money. A nineteen-year-old female described the psychological strain lack of finances can cause: *‘So, money’s so so stressful...money is always a problem. Even when we’re not talking about the problems, it’s hard to do anything because money is really tight’* (Gelman & Rhames, 2018, pp. 347). Another nineteen-year-old male participant outlined how the lack of money resulted in psychological strain for himself and his siblings: *‘I essentially support myself financially. I pay for my own tuition, I pay for my car, when I’m at school I pay for my food. I pick myself up and, you know, whenever my sisters need money which, frankly they don’t because they have jobs, but whenever they needed money, whenever they needed rides, or whenever they needed whatever, I was there’* (Gelman & Rhames, 2020, pp. 683).

Anger and guilt. Five studies (see Table 5) outlined how children and young adults can feel anger and guilt as a result of parental young onset dementia (Hutchison, et al., 2016a; Sikes & Hall, 2017; Hall & Sikes, 2018; 2020). Many participants described feeling significant anger and negativity towards their parent with young onset dementia due to being forced to change future plans. One female participant outlined this anger: *‘...that made me really angry and just negative towards Mum. But I think she would have died if she knew that I had passed up those scholarships but there was no one else there’* (Hutchison, et al., 2016a, pp. 616). Similar feelings were expressed by another female participant: *‘I feel like this big pot of boiling water that’s constantly about to overflow so the smallest thing can set me off’* (Hutchison, et al., 2016a, pp. 619). One male participant described feeling anger tinged with grief and sadness for a former life: *‘I miss my mother as much as I miss my dad. I miss mum’s life’s spark. I walk around all day and feel angry’* (Lövenmark, 2020, pp. 712). Feelings of anger can subsequently result in feelings of guilt. One thirty-year-old female described getting angry with her mother, followed by immediately feeling guilty.

Young onset dementia can be akin to an emotional rollercoaster for young people: *‘And then I feel guilty because I’ve told her sometimes... “Mum I can’t do this, I’m not talking about this here. I feel like we spend our whole lives talking about it, I’m out”. I went back and I said to her friends you probably think I’m harsh but I just can’t deal with it sometimes’* (Sikes & Hall, 2017, pp. 333).

Grief and loss. In nine studies (see Table 5) children and young adults reported significant feelings of grief and loss similar to the death of a parent. Evidence from Nichols, et al (2013) described feelings of frustration, helplessness and loneliness in children and young adults, subsequently leading to feelings loss and grief. Similar evidence was highlighted by Gelman and Greer (2011) with children and young adults reporting a sense of loss, almost as if their parent were deceased. One eighteen-year-old male described missing his father: *‘I would be different if dad didn’t have frontotemporal dementia. 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, pp. 466). A male aged 22 described frustration and grief: *‘The person is physically there but there’s also grief of losing someone... That person is not here anymore. But they are. But I can’t reach them. But they’re right there...is hard emotional circumstance for anyone to deal with...especially a young person who*

really doesn't have that emotional framework and faculties to kind of try to process it' (Hutchinson, et al., 2016b, pp. 618).

A female aged 22 described similar feelings: *'It's like I explained to someone, you start grieving even though they're standing right in front of you...when eventually her body dies, I'm not entirely sure how upset I'll be...'* (Sikes & Hall, 2017, pp.330).

Financial worries Behavioural and psychological symptoms of dementia are typically characterised as behavioural symptoms (Finkel et al., 1997) arising from impairments in cognition (Stern et al., 1997) which can significantly impact on the day-to-day activities of people with young onset dementia (Lyketsos et al., 1997). Nine studies (see Table 5) outlined the impact of behavioural and psychological symptoms of dementia on children and young adults with a parent with young onset dementia (Allen et al., 2009; Nichols et al., 2013; Millenaar et al., 2014; Hutchinson, et al., 2016a). An eighteen-year-old male described the changes: *'... it feels really weird when like someone you know acts a certain way their whole life then all of a sudden they start changing and becoming a different person'* (Nichols et al., 2013, pp. 23).

A nineteen-year-old female outlines subtle changes in her father: *'At that moment, I did not think anything was wrong. I just thought he was in a bad mood, which happens to anyone at times'* (Millenaar et al., 2014, pp. 2003). However, the impact of behavioural and psychological symptoms of dementia may also result in significant changes accompanied by aggression and violence. A twenty-one-year-old female described witnessing aggression: *'My dad was getting worse and March was the time when he started to get a lot worse, more aggressive with mum so she was upset and like saying "What do I do? What do I do?"'* (Allen et al., 2009, pp. 469).

Another nineteen-year-old female witnessed similar aggression combined with violence: *'I was so scared...because he'll freak out at any single moment...I'd be up all hours of the night thinking he's going to strangle my mother...One day I came out of the shower and he threw a lamp against the wall. I called the police and he got out on the roof with some rope and said he was going to hang himself'* (Gelman & Rhames, 2018, pp. 343).

Care and domestic tasks. Research has illustrated how children and young adults may often find themselves having to support and care for a parent with a progressive, degenerative disease as they assist with certain caregiving tasks and domestic chores (Adelman et al., 2014). In six studies (see Table 5), children and young adults reported significant physical strain as a result of caregiving tasks and extra domestic chores (Allen et al., 2009; Millenaar et al., 2014; Hutchinson, et al., 2016b; Hutchison, et al., 2016a; Sikes & Hall, 2017; Hall & Sikes, 2018).

One female described this: *'She said like well this is the sort of thing you're going to be dealing from now on and you're your mum's only sort of resource...I just remember thinking like God it's...you're not giving me much options here'* (Hutchinson, et al., 2016b, pp. 662). Similarly, younger children also face concerns in relation to the other parent. A thirteen-year-old male outlined this concern: *'She is under too much stress. She has to go to work, run the house and everything, she has to clean the house and everything, and she has not got enough time'* (Allen et al., 2009, pp. 470). A nineteen-year-old male explained how his mother required assistance: *'My mom and I have to take over more chores in the household since my father cannot do everything anymore, which causes some friction sometimes'* (Millenaar et al., 2014, pp. 2004).

A sixteen-year-old female described both the physical and psychological strain as she assists with her father resulting in a negative impact on her education and sleep: *'He'd be out of bed a lot at night and we'd hear the door go and he'd be out of bed and sometimes mum would fall asleep or mum would be find it hard coss he'd like have to get up early for work in the morning. And even though I had school I have to help mum and so I'd have to go and try and put him back into bed. But he'd just*

get out again as soon as I got back into my bed I'd hear the door go again so I ran back down' (Allen et al., 2009, pp. 467).

Theme 3: stigma

Stigma may be characterised as deviating from the perceived social norms (Scambler, 2009) and as people with young onset dementia may be impacted by behavioural and psychological symptoms of dementia, they may be perceived as deviating from normal behaviour.

Lack of awareness. In seven studies (see Table 5) children and young adults reported the effects of the lack of awareness in relation to parental young onset dementia (Nichols et al., 2013; Millenaar et al., 2014; Baker et al., 2018; Gelman & Rhames, 2018). In particular, the perception of dementia as an 'older persons' disease can lead to issues for children, as a twenty-three-year-old male outlined: '*It was the dementia side of things as well because when you are 14, 15, people who have dementia are normally really old people...*' (Sikes & Hall, 2018, pp. 600).

Similarly, the hidden nature of young onset dementia appeared to lead to issues with awareness when compared to visible illnesses. One participant outlined this comparison: '*The biggest speed bump for them to get over is the fact that she hasn't got a broken back, she hasn't got a broken arm, it's all in there [point to head], which we don't understand... when you see somebody who's physically disabled, you can kind of see people get that instant sympathy and they communicate better with them, they're a more open to being patient, where when it's somebody who's got a mental disability, they don't see it'* (Baker et al., 2018, pp. 679). A female aged 23 described having difficulty with her employer: '*People are given leeway once someone has died but I've been dealing with my mum dying for a long time and losing her, continually losing her, and I don't feel I necessarily get the same breathing space like if someone had lost someone'* (Sikes & Hall, 2017, pp. 332).

A 17-year-old female explained that young onset dementia may be difficult for her friends to comprehend: '*I find it really difficult with some of my friends who really don't get it and it's not their fault that they don't get it and that's what I need to keep telling myself because...they might be coming out with stuff like "oh my grandma had it, you know, she wasn't great, she was a bit forgetful" and I'm like "yeah, hmm hmm"*' (Sikes & Hall, 2018, pp. 600).

Familial and societal stigma. The lack of public awareness combined with the erroneous views of people with mental health difficulties can result in fear and subsequent stigmatisation (Hayward & Bright, 1997; Morgan et al., 2002). The stigma associated with mental health conditions (Goffman, 1963; Werner et al., 2010; Gove et al., 2016) may also be associated with young onset dementia, particularly if the effects of behavioural and psychological symptoms of dementia are present. In nine studies (see Table 5) children and young adults reported facing both familial and social stigma (Allen et al., 2009; Nichols et al., 2013; Millenaar et al., 2014; Gelman & Rhames, 2018).

A thirteen-year-old male described social stigma: '*Strangers...like stare at you when he's not like acting quite normal. I haven't had any umm friends round while he's been like he is like to see him'* (Allen et al., 2009, pp. 469). A female participant reported: '*I get really mad when people treat her not like a citizen and not like a person...it annoys the crap out of me'* (Hutchinson, et al., 2016a, pp. 619). Similarly, another female outlined: '*...other people before they knew what he was diagnosed with, their opinion started to change too, because he was acting a different way than what he used to. And that kind of left a lasting impression on the people who don't talk to our family so much'* (Nichols et al., 2013, pp. 23).

Table 5. Summary of main themes and subthemes uncovered in the synthesis

Study	Changing family dynamics			Psychological and physical strain					Stigma		Coping strategies		
	Role and relationship change	Parenting the parent	Chance to bond	Adjusting future plans	Financial worries	Anger and guilt	Grief and loss	Effects of BPSD*	Care and domestic tasks	Lack of awareness	Familial and societal	Family and peer support	Positive and negative distraction
Szinovacz (2003)	■	■	■	■	—	—	—	—	—	—	■	—	—
Allen et al. (2009)	—	—	—	—	—	—	■	■	■	—	■	■	■
Nichols et al. (2013)	—	—	■	—	—	—	—	■	—	■	■	■	—
Millenaar et al. (2014)	—	■	—	■	—	—	—	■	■	■	■	■	■
Hutchinson, et al. (2016)b	—	—	—	—	■	—	—	—	—	—	■	■	■
Hutchinson, et al. (2016)a	—	■	—	■	—	■	■	■	■	—	—	—	■
Sikes & Hall (2017)	—	■	—	■	—	■	■	■	■	■	■	■	—
Hall & Sikes (2018)	—	■	■	■	—	—	■	■	—	—	—	—	—
Hall & Sikes (2018)	—	—	■	■	—	■	■	■	■	■	■	■	—
Sikes & Hall (2018)	—	—	—	—	—	■	■	■	■	—	—	—	■
Gelman & Rhames (2018)	■	—	—	■	■	—	—	■	—	■	■	■	■

(continued)

Table 5. (continued)

Study	Changing family dynamics				Psychological and physical strain					Stigma		Coping strategies	
	Role and relationship change	Parenting the parent	Chance to bond	Adjusting future plans	Financial worries	Anger and guilt	Grief and loss	Effects of BPSD*	Care and domestic tasks	Lack of awareness	Familial and societal	Family and peer support	Positive and negative distraction
Baker et al. (2018)	—	—	■	—	—	—	—	—	—	■	—	—	—
Gelman & Rhames (2020)	—	—	■	■	■	—	■	—	—	—	—	—	—
Lövenmark (2020)	—	—	—	■	—	—	■	—	—	—	—	■	—
Hall & Sikes (2020)	■	—	—	■	—	■	■	—	—	■	—	—	■

* Behavioral and psychological symptoms of dementia

Children and young adults spoke about how society perceives other illnesses differently: *'It's so different having a parent sick with something physical like cancer to a parent sick with something like Alzheimer's...there's this real shame around Alzheimer's. No one wants to talk about it. No one wants to acknowledge it. Everyone wants to say she's fine, there's such denial. Where with dad it's much more, how's your dad and how's chemo and oh you poor things'* (Hutchinson, et al., 2016a, pp. 618). Children and young adults also reported facing stigma from within their own extended families. A fifteen-year-old male reported: *'My outside family don't really understand and they're not getting it yet and it's people that should. Like my dad's brother hasn't been around'* (Gelman & Rhames, 2018, pp. 345).

Theme 4: coping strategies

Children and young adults outlined various strategies they use in order to cope with the complex issues that they face following a parent being diagnosed with young onset dementia.

Family and peer support. In nine studies (see Table 5), children and young adults outlined the need for, and the use of, support from both their family members and peers (Nichols et al., 2013; Millenaar et al., 2014; Hutchinson, et al., 2016b; Gelman & Rhames, 2018). A female aged 19 outlined the need for information and support: *'It would be nice to talk to someone who knows what we can expect so that we'll know what we can do for my father to make it easier for him and, at the same time, more bearable for us'* (Millenaar et al., 2014, pp. 2006).

Participants outlined how support from peers and family members can be vital as coping strategy. A male aged 19 described: *'Fortunately, I have a friend who works with [older people] with dementia who I can talk to. She can also give me advice, which helped me a lot'* (Millenaar et al., 2014, pp. 2006). Similarly, an eleven-year-old female also used her peer group to cope: *'I kind of get some support from my friends because they try to imagine what it's like. I think it's good to get support from your friends - just someone else. We get a lot of support from mom, but I think it's good to get support from other people, because sometimes it's just not a good time to talk to my mom about that stuff, or if it's just been a bad day'* (Nichols et al., 2013, pp. 26).

Positive distraction. In seven studies (see Table 5), children and young adults illustrated how they used distraction to assist them with coping. Distraction as a coping mechanism is characterised as coping with a stressful or emotional situation by diverting attention away from it (Cooper et al., 2001). Participants reported utilising a variety of methods to distract them. Several participants described how they used education. A female aged 17 outlined how she uses college as an escape: *'I can just come in, even on my days off...I can paint, I can draw, I can make a mess, I can make things, I can tear things apart, break things. And you can get away with everything being an art student because it's art...I've thrown myself into my work. I love art, it's my therapy...College is my stability'* (Sikes & Hall, 2018, pp. 599).

A male participant aged 22 described how postgraduate education helped to bring some normalcy to life: *'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...I've got friends here...that you can just do normal things with, go to the pub, go to lectures, normality...'* (Sikes & Hall, 2018, pp. 599/600). Other participants described using friends as a distraction. A female participant outlined: *'Friends provide me with relief precisely because they are not going through the same thing as me and they can provide distraction or they cannot remind me of it'* (Hutchinson, et al., 2016b, pp. 662).

Negative distraction. However, due to the psychological strain faced by many children and young adults, some participants reported using harmful distraction mechanisms. One male aged 23 described using alcohol: ‘Depending what time I get off and then evenings it’s always drink loads of drinking’ (Allen et al., 2009, pp. 471). Another male aged 22 described self-harm: ‘A brilliant distraction that I made for myself, just to kind of give me a bit of a mental distance, or something, from having to think about it. I stabbed myself in the thigh with the fork, just because I didn’t understand what was happening and I just was I guess just really gritting my teeth against freak out and depression and anxiety and dealing with the whole situation. I couldn’t quite comprehend what was happening. But I knew something was bad. Something was very bad’ (Hutchinson, et al., 2016a, pp. 620). A male aged 19 outlined how self-harm may lead to a significantly worse outcome: ‘I was self-harming, I was going to take my own life as well’ (Allen et al., 2009, pp. 471).

Discussion

The current synthesis analysed the qualitative literature in order to understand the perspectives of children and young adults with a parent living with young onset dementia. Qualitative data from a total of 15 studies met the criteria for inclusion and were appraised for quality using the Critical Appraisal Skills Programme checklist. The current synthesis uncovered four main themes with related subthemes which highlighted the perspectives of children and young adults including; changing family dynamics; psychological and physical strain; stigma and coping strategies.

Participants reported how a parent receiving a diagnosis of young onset dementia can affect the whole family, with normal family roles and future plans impacted (Nichols et al., 2013; Millenaar et al., 2014; Hutchinson, et al., 2016a). In particular, participants described how they may have to become a parental figure as the condition progresses (Hall & Sikes, 2020) and take on more responsibilities in the household (Gelman & Rhames, 2018; 2020).

Participants reported that the changing family dynamic can have a significantly negative impact on their physical and psychological health with many reporting feelings of anger, guilt, grief and loss (Hutchinson, et al., 2016a; Hutchinson, et al., 2016b). Specifically, participants outlined how the effects of behavioural and psychological symptoms of dementia can be stressful (Hall & Sikes, 2018; Gelman & Rhames, 2018). The perception of dementia as a disease of ‘old age’ prevails and there is a significant lack of awareness in relation to young onset dementia. As a result, children and young adults described facing stigma from both family members and wider society (Allen et al., 2009; Nichols et al., 2013; Millenaar et al., 2014; Hutchinson, et al., 2016b).

A parental diagnosis of young onset dementia can severely affect the family’s finances, particularly if the person with young onset dementia is the main bread winner, and participants described the impact that financial instability can have (Hutchinson, et al., 2016b; Gelman & Rhames, 2018).

Conversely, a parent receiving a diagnosis of young onset dementia can present the opportunity for the family to become closer. Participants described bonding with family members as a result of the new situation (Hall & Sikes, 2018; Baker et al., 2018) which may also be used as a coping strategy (Sikes & Hall, 2017). Responding to distressing situations typically involves coping strategies. According to Lazarus and Folkman (1984), coping strategies may focus on either the problem (managing the stressor) or the emotion (changing ones thinking about the stressor) through cognitive reappraisal or disengagement.

Children and young adults described how they use various coping strategies, with many using distraction (Millenaar et al., 2014; Hutchinson, et al., 2016b; Hutchinson, et al., 2016a). Using distraction as a coping strategy typically involves the diversion of attention (Cooper et al., 2001) and

has been used during medical procedures with some efficacy (Diette et al., 2003). Participants outlined several coping strategies including consulting with peers and the immersion in education (Gelman & Rhames, 2018; Hall & Sikes, 2020). However, for some participants the situation was particularly difficult and they reported using alcohol and self-harm in order to cope (Allen et al., 2009; Hutchinson, et al., 2016a)

Strengths and limitations

Every measure was put in place in order to enhance the quality of the current synthesis. However, quality appraisal is a subjective process and as a result is susceptible to interpretation and bias. According to Majid and Vanstone (2018) the Critical Appraisal Skills Programme qualitative checklist is not without criticism. Much of the critique centres around the articles extracted using the method, which may comply, but not necessarily contribute to the development of the literature (Dixon-Woods et al., 2007). Five articles from the United Kingdom utilised the same sample across their studies (Sikes & Hall, 2017; 2018; Hall & Sikes, 2018a; 2018b; 2020) while two articles from Australia also used the same sample across both studies (Hutchinson, et al., 2016b; Hutchinson, et al., 2016a). However, these articles were included in the synthesis as they varied in their focus and sources. The current synthesis includes individuals perspectives from six countries; Australia, Canada, Netherlands, Sweden, United Kingdom and USA.

These countries may be characterised as wealthy Western countries. It may be reasonable to assume that perspectives of parental young onset dementia may differ significantly in countries with different cultural, social and economic norms. Similarly, included articles were published in English and may not be representative of non-English speaking countries. Therefore, findings from the current synthesis may not be panoptic. There is a significant lack of qualitative research specifically examining children and young adults' perspectives. In particular, research with children and adolescents under the age of 18 is extremely rare. The current synthesis only found two studies examining the perspectives of children under 18 years of age (Nichols et al., 2013; Baker et al., 2018).

Implications and recommendations

Children and young adults face significant issues when a parent is diagnosed with young onset dementia. The emotional and physical toll was reported with feelings of anxiety, anger, guilt and grief. Many children and young adults have illustrated resilience in the coping strategies employed. However, for some participants the situation may lead to negative consequences for both physical and psychological health. Following a diagnosis, counselling specifically for children and young adults may help alleviate the psychological strain. Similarly, the formation of peer support groups where children and young adults can share their experiences with those in a similar position would be advantageous. Education and awareness programmes about neurodegenerative conditions in relation to younger people being affected may assist in dispelling the current stereotypical perception of dementia. Similarly, education and awareness programmes about general brain health may also be beneficial.

Conclusion

The current synthesis outlines the perspectives of children and young adults with a parent living with young onset dementia. There is a significant lack of research in this area which compounds the

stereotypical view of dementia as an older person's disease. This can lead to children and young adults being impacted by lack of awareness and stigma resulting in significant psychosocial problems. As the number of people living with dementia (including young onset dementia) is set to increase, future research with children and young adults with a parent with young onset dementia is important in order to better support this cohort.

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ORCID iDs

Cathal Blake  <https://orcid.org/0000-0003-1523-8807>

Louise Hopper  <https://orcid.org/0000-0002-9382-5241>

Supplemental material

Supplemental material for this article is available online.

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Cathal Blake is a mature postgraduate student in his third year of his PhD in the School of Psychology in DCU. He completed his undergraduate degree in psychology in DCU, graduating in 2019 with a First-Class Honours. As part of his degree, he undertook three-year-long modules in research methods and his final year project (FYP) investigated caregivers’ experiences of young onset dementia (YOD) was published in 2021 in the *International Journal of Care and Caring*. He has successfully completed two internships in the School of Psychology: The Home Run Bus project (DCU_REC_2017_099) and Actifcare project (DCU_REC_2014_090). He also undertook research in collaboration with the Alzheimer Society of Ireland (ASI) and the Irish Dementia Working Group (IDWG) that examined the experiences of people with dementia have when using public transport (DCU_REC_2019_117). Cathal has presented his findings at various conferences such as Engaging Ageing: New Frontiers of Ageing: Research, Policy and Practice in Croke Park; the 10th International Dementia Conference in the Helix in DCU; the 29th Alzheimer Europe Conference in the Hague, Netherlands; the 30th Alzheimer Europe Conference which took place online and at the Early Graduate Group Conference hosted by the Psychological Society of Ireland (PSI). Cathal also worked in the Holly Day Clinic in James Connolly Memorial Hospital, Blanchardstown Dublin. Among other health related factors, the Holly Day Clinic specialises in the diagnosis and treatment of Alzheimer’s disease/Dementia. Cathal is also a member of the INTERDEM Academy.

Louise Hopper is an Assistant Professor in the School of Psychology, and she has worked on a range of projects with adults including those living with cognitive impairment and dementia. Dr. Hopper teaches research methods and statistics on the undergraduate and MSc Psychology (Conversion) programmes in DCU and she has significant expertise in the quantitative and qualitative methodologies required for this study. Furthermore, Dr. Hopper is the Chair of the Psychology Ethics Committee, and she has supervised research assistants, INTRA students, undergraduate and postgraduate researchers in a variety of different research fields.