

## article

# A qualitative investigation into family carers' experiences of living with/caring for a person with young-onset dementia

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Ageing is a significant risk factor for developing dementia; however, some people develop symptoms before the age of 65. Although less common, it is referred to as young-onset dementia. Estimating prevalence rates in Ireland is difficult, as there has been little study around what it is like to live with/care for this cohort; consequently, it is poorly understood. Nine primary carers were interviewed using semi-structured one-to-one interviews. Interview data were analysed with inductive thematic analysis. Themes included sense of loss, diagnostic issues, appropriateness of services, stigma and carer strain, illustrating the complex nature of caring for someone with young-onset dementia.

**Key words** young-onset dementia • carer strain • stigma • diagnostic process • sense of loss

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## Introduction

'Dementia' is an umbrella term that refers to a group of neurological diseases, the symptoms of which include a progressive, degenerative and irreversible decline in mental functioning, and that is most prevalent in older adults (O'Shea, 2007). However, some people develop symptoms before the age of 65. Although less common, it is typically referred to as young-onset dementia (YOD).

YOD affects people before the age of 65 and manifests itself during the active stage of the individual's life. YOD can thus have a severe impact on their remaining productive years and can significantly affect the various roles and obligations an individual may have in society (Werner et al, 2009). For example, cessation of employment may cause significant financial hardship to both the individual and the family, and may serve to lower an individual's sense of belonging, purpose and engagement in daily life (Sperlinger and Furst, 1994; Harris and Keady, 2009).

A loss of selfhood combined with the cognitive, behavioural and functional symptoms experienced by people with YOD (PwYOD) has been found to severely affect their sense of quality of life and general well-being (Teng et al, 2012). PwYOD

often have to revise their life expectations and make forced changes and adjustments to their future plans. This revision is paramount if they are to cope physically and emotionally with these new challenges and to function adequately in daily life (Huber et al, 2011). PwYOD who are parents may feel that their parental role has been undermined (van Vliet et al, 2010), and as they withdraw further and further from their daily routine, they may experience increased feelings of social isolation (Beattie et al, 2004).

YOD also effects the individual's environment, including familial and social circles. Existing evidence shows that PwYOD are typically cared for at home for significantly longer when compared to individuals with late-onset dementia (LOD) (Freyne et al, 1999). Admission to residential care invariably depends on carer competency to support the person with dementia in the home (Williams et al, 2001).

However, as almost all dementia care in Ireland is situated in services for older adults, PwYOD may rely solely on family for assistance (Harris and Keady, 2009). Furthermore, PwYOD are often bypassed by community healthcare protocols, so care and support falls to family members, typically a spouse or partner (Freyne et al, 1999; Williams et al, 2001; Arai et al, 2007; O'Shea, 2007; Flynn and Mulcahy, 2013). In some cases, children are also impacted by YOD. Research shows that children can feel a sense of loss, almost as if the parent had died, as they may find themselves supporting and caring for a parent with a progressive, degenerative disease (Gelman and Greer, 2011). Despite the emotional toll, family carers require their children's support, and children often play a pivotal role in the care of a parent with YOD (Adelman et al, 2014).

Carers report that they are extremely ill-prepared for their new role (Bakker et al, 2013) – a role that involves continually adapting over an extended period to an ever-changing situation, resulting in a high degree of strain (de Vugt and Verhey, 2013). Family carers have reported a significant negative impact on both their psychological and physical well-being as the strain of care increases exponentially (de Vugt and Verhey, 2013). Many carers have to continue as a parent while remaining in paid employment, on top of providing full-time care, often putting immense additional demands on their time (Millenaar et al, 2016). Extremely high levels of strain can significantly increase depressive symptoms among carers (Verhey et al, 2007; van Vliet et al, 2010) and can manifest in two types: objective strain (practical or physical aspects) and subjective strain (psychological and emotional aspects).

To compound the issue, many younger adults who display cognitive, behavioural and functional symptoms may be misdiagnosed; dementia may not even be considered (Millenaar et al, 2016). Ducharme and colleagues (2013) reported that timely diagnosis is important, particularly in explaining the behavioural difficulties that may have emerged prior to diagnosis, and to ensure PwYOD receive appropriate services sooner (Allen et al, 2009).

Yet, a diagnosis of YOD is often extremely difficult (Beattie et al, 2004) and timely diagnosis, in particular, requires vast improvement, particularly in Ireland. Armari and colleagues (2013) reported that over 70 per cent of carers stated that the diagnostic process was severely problematic. Factors associated with misdiagnosis include: misreading of symptoms; denial by PwYOD; refusal by the individual to seek help; environmental issues; and the inaction of the family doctor (van Vliet et al, 2011). Timely diagnosis may also assist with the provision of disease-specific information

to support care planning, which may provide some relief for family members (Allen et al, 2009).

As a diagnosis often brings a sense of uncertainty, a timely diagnosis appears to help family members seek and find suitable explanations from health service providers for the difficulties encountered (Ducharme et al, 2013). Their worry is that without adequate support services, PwYOD will be left 'in limbo', with a diagnosis but without support. As outlined, almost all dementia services are specifically designed for older adults in Ireland; therefore, many services have trouble addressing the needs of PwYOD (Chemali et al, 2011). PwYOD and their family carers may experience marginalisation, as they are left outside existing service pathways (Koopmans and Thompson, 2013). Svanberg and colleagues (2010) argue that not enough is known about the unmet needs of PwYOD and their families. Significant research is therefore required to gain salient knowledge of the specific issues that families experience during the various stages of YOD.

This insight will prove invaluable in assisting with the development of adequate support services for PwYOD and their families. In Ireland, it is estimated that 55,000 people are diagnosed with dementia, with approximately 4,000 living with YOD (HSE, 2016); this is likely to be an underestimate due to the scarcity of data relating to YOD. The main aims of the project reported here were to investigate family carers' experiences of living with, and caring for, individuals diagnosed with YOD in Ireland. The main areas of focus were:

- seeking and getting a timely diagnosis;
- adjusting to the diagnosis/post-diagnosis supports;
- impact on PwYOD and carer(s);
- impact on other family members living with PwYOD;
- coping strategies;
- primary carers' needs and unmet needs; and
- availability, appropriateness and use of health and social care supports and services.

## Materials and methods

### *Design*

To achieve the study aims, a qualitative research design was utilised using a personal semi-structured one-to-one interview with the primary family carers of PwYOD. Primary family carers may be defined as any relative, friend or partner who has a significant relationship and provides assistance (physical, social and/or psychological) to a person with a life-threatening, incurable illness (Hudson and Payne, 2009).

### *Participants*

Nine participants were recruited for the study through the Alzheimer Society of Ireland (ASI), the Dementia Carers Campaign Network (DCCN), Alzheimer cafes and carer support groups for people caring for PwYOD. Participants were provided with a plain-language statement containing information about the aims and methodology of the project and a consent form.

The sample comprised family carers of PwYOD (both living at home and resident in long-term care facilities). Sample size is consistent with similar research, for example, [Flynn and Mulcahy \(2013\)](#) used a similar methodology and interviewed seven family carers, generating in-depth descriptions of participants' perspectives. Demographic information and inclusion criteria for the family carers and PwYOD are outlined in [Table 1](#).

### *Materials and setting*

Interviews were conducted either in a public place, in a place preferred by the participant or by phone. Interview questions were adapted from previous research to examine the unmet needs of family carers in an Irish context ([Millenaar et al, 2016](#)). Materials used during the qualitative research design by the researcher included audio-recording equipment and notebooks. All evaluation material, including recorded material, transcribed data and participant information, was stored on password-protected computer files.

### *Procedure*

If interest in participating was expressed, the researcher/supervisor sent a plain-language statement to the potential participant. This contained an invitation to participate, further information about the study and contact details for the research team. Those who expressed an interest in taking part were asked to contact the research team to discuss the requirements of the study in more detail and the informed consent process. On receipt of informed consent, the researcher scheduled a convenient time and location for the one-to-one interviews. Initially, the interviews were to be conducted in a quiet comfortable room at various Alzheimer cafes or at the venues hosting family support groups. However, several participants specifically requested that the interview be conducted in their own home, while other participants were happy to speak with the researcher by phone. Interviews conducted in participants' homes adhered to an appropriate risk-management procedure.

A person-centred approach was taken in managing the data-collection session(s). Interviews lasted between 30 and 60 minutes; the number and length of sessions depended on individuals' capabilities and plans for that day. If the researcher noticed that a person appeared tired, or if they expressed that they were struggling on the day of the interview, the interview was shorter or rescheduled. The researcher also ensured that participants had adequate breaks. Interviews were audio recorded and later transcribed intelligent verbatim and anonymised.

### *Ethical considerations*

Ethical approval was granted for the study. Risk associated with participation in the study was moderate, as no deception was involved. Participants were assigned pseudonyms to ensure anonymity and confidentiality. The right to withdraw from the study was clearly communicated, and a support pack outlining dementia-specific and more general supports that are available was offered to participants at the end of the interview process.

**Table 1: Demographic information and inclusion criteria for the family carers and PwYOD**

Carer	Relationship to PwYOD	PwYOD	Age of first signs of CI	Age first diagnosed	Current age	Subtype of dementia
Mary	Wife	John	48	56	63	Alzheimer's disease
Joan	Carer/helper	Olive	55	62	68	Alzheimer's disease
Mark	Husband	Joyce	60	61	65	Alzheimer's disease
Patricia	Sister	Ann	45	48	54	Pick's disease
Rita	Wife	Pat	44	45	47	FTD
Maria	Wife	Bernard	58	63	65	FTD
Martina	Wife	Terry	51	55	61	Logopenic progressive aphasia
Frank	Husband	Irene	56	58	Deceased aged 66 (2015)	FTD
Ruth	Daughter	Seamus	57	59	Deceased aged 66 (2012)	Alzheimer's disease

Notes: The inclusion criteria were as follows: the person with dementia was diagnosed prior to 65 years of age and therefore meets the criteria for YOD; the diagnosis meets DSM-V criteria and assessment was conducted by a clinical professional; the primary family carer currently/used to reside with the PwYOD; and the primary family carer consents to participate. All names are pseudonyms. CI – cognitive impairment. FTD – frontotemporal dementia.

### Data analysis

Interview data were analysed by applying an inductive qualitative thematic analysis using open coding and categories derived directly from the interview material (Hsieh and Shannon, 2005; Elo and Kyngas, 2008). All narratives were utilised in this analysis. The researcher read the transcripts thoroughly, line by line, to identify meaning units (such as words, sentences or paragraphs that relate to the same meaning), with the aim of condensing the material. Corresponding meaning units were grouped together and several themes and sub-themes emerged from the data. Transcripts were then reread to ensure goodness of fit of themes and data, and anchor quotes were selected that represented each theme and sub-theme.

### Results

Detailed thematic analysis of the interview transcripts uncovered five main themes and related sub-themes (see Table 2).

#### Theme 1: sense of loss

Many interviewees spoke of a sense of loss as a result of the dementia diagnosis. Despite their loved one still being alive, this loss was palpable, leading to significant feelings of loneliness:

‘Truthfully, I hope you don’t mind me saying this, I really do miss the intimacy, I really do. And I just feel so lonely, sorry [visibly upset]. I miss having a friend that I really trust, to be honest.... So, I do miss him terribly, I really do.’ (Mary, wife)

‘Oh, I think, well, they were both obviously devastated ... it changed their whole plans for the future ... and I suppose if she dwells on it, she knows, like,

**Table 2: Themes and related sub-themes extracted from the data through thematic analysis**

<p><b><u>Theme 1: sense of loss</u></b>  <i>Sub-themes:</i>                      → Loneliness</p> <p><b><u>Theme 2: diagnostic process</u></b>  <i>Negative diagnostic sub-themes:</i>                      → Difficulty gaining a timely diagnosis/lack of awareness among general practitioners (GPs)                      → Shock associated with the diagnosis                      → Poor/lack of communication from healthcare professionals  <i>Positive diagnostic sub-themes:</i>                      → Sense of relief                      → Adjusting to the diagnosis/coping strategies employed                      → Enhanced communication with healthcare providers</p>	<p><b><u>Theme 3: stigma</u></b>  <i>Sub-themes:</i>                      → Public perceptions of dementia                      → Social isolation</p> <p><b><u>Theme 4: lack of services</u></b>  <i>Sub-themes:</i>                      → Lack of age-appropriate services                      → Services located in older adult settings                      → Geographical lottery as to availability</p> <p><b><u>Theme 5: strain of care</u></b>  <i>Sub-themes:</i>                      → Financial strain                      → Physical strain                      → Psychological strain</p>
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she may never see, or remember or be in the present for her son's marriage or having grandchildren.' (Joan, carer/helper)

'Well, I'll just tell ya. When a mother, when a woman goes out of the house, the house dies like.... I mean, I'm here now in a big house, there's four bedrooms, there's three bathrooms, there's a big, big studio, sun room, there's a porch and, like, there's no one here now ... all gone now, totally gone.' (Mark, husband)

'*Company* ... [audibly upset] *I'm ok ... it's a lonely life* ... yeah, so it's the companionship.' (Martina, wife)

## *Theme 2: diagnostic process*

### *Difficulty gaining a timely diagnosis and lack of awareness among GPs*

The overlapping of some symptoms with other mental health conditions, across YOD subtypes, appears to make a differential diagnosis difficult: "She had been attending psychiatrists in [large hospital] over a long number of years.... I got a phone call one day to say that she was in his office, she was very confused ... maybe he knew more at that stage than he was saying to me" (Patricia, sister). The younger age of onset also seems to delay a timely diagnosis: "Because his own GP told me, when I went to him about it, he said, 'Ahh, it couldn't be.... Ahh, it couldn't be Alzheimer's, or it couldn't be dementia ... he's too young for that, I don't think it's that'" (Mary, wife). A lack of awareness of YOD among GPs could further complicate the diagnostic process, and led to some PwYOD being prescribed unnecessary medication: "Her own GP thought she was going through the change, and was putting her on happy tablets for a while until I started going back again.... That's when she really realised there was something wrong" (Mark, husband). Several participants found poor (or a lack of) communication by primary healthcare professionals during the initial diagnostic period extremely upsetting:

'She left there with a diagnosis. She was on her own and she came out and sat in the car and cried. And then she drove home and she told her husband and son.' (Joan, carer/helper)

'Your woman, a young doctor in there, she rang me at work a few days later and she told me over the phone that it was early cognitive impairment ... what's early cognitive impairment? I didn't know where to go, not one doctor or anybody gave me any information, or a leaflet, or a booklet, nothing, nothing.' (Mary, wife)

'The results came back from the UK ... there was a conversation, again in a hurry, in a kinda, "I've got five minutes, let's talk", which was, I think she mentioned the word "Pick's" or "Pick's disease". But everything else went over my head, I heard nothing, nothing.' (Patricia, sister)

### *Shock associated with the diagnosis*

Participants also spoke about the initial shock of the diagnosis, particularly on hearing the term ‘dementia’, which many found significantly disturbing:

‘No, I didn’t, I totally and utterly panicked. I had a bit of a meltdown mentally I was so broken over it... I didn’t, I didn’t stop crying... I haven’t stopped crying [visibly upset].’ (Mary, wife)

‘We were just sitting at home and we were totally, like, totally upset. I was anyway, and she was upset as well... Ahh, my eldest son had to leave home, he left home because of it ... my eldest son can’t handle it, can’t handle at all, at all, at all [audibly upset].’ (Mark, husband)

‘That was the first time I heard the word “dementia”, I remember ... I had to sit down, I was like, “What?” It was just, “What? Mother of God!” It was just like “boom”, and I said, “Do you mean dementia? Do I understand what you’re talking about?”’ (Patricia, sister)

‘I suppose shock ... he was gutted, devastated, because he didn’t think he was going to get that diagnosis ... his immediate reaction was shock, horror ... he never accepted his diagnosis.’ (Martina, wife)

### *Sense of relief*

Participant narratives also revealed some positives to be gained from the diagnosis. For example, some participants spoke about the relief the diagnosis offered, which allowed for care plans to be instigated:

‘To be honest, and to be a little selfish, it was almost a relief with the diagnosis, a pathway to get help that was needed and to try and sort out my life as well.’ (Patricia, sister)

‘So, I suppose I was relieved in a very strange way that this is what’s wrong with him, I now knew. I mean, like a label, for some reason, seemed to help a little bit... Erm, again, I think they all felt, “At least now we know” ... We did feel a certain relief, “Now we know what we’re dealing with.”’ (Maria, wife)

### *Adjusting to the diagnosis/coping strategies*

Another positive to emerge following the diagnosis were the different ways family carers and PwYOD adjusted and coped. Participants spoke about: capturing memories; involvement in community and research engagement; using friends and family members; and seeking and engaging with support services to talk about the impact of their spouse’s or partner’s diagnosis:

‘She contacted the [local Alzheimer’s organisation] ... there was a wonderful nurse there, and she asked her would she consider getting involved in research.



I think that was the turnaround point for her ... and it's kind of, she has been positive since.' (Joan, carer/helper)

'I've done more courses than anybody I know.... I took a whole week's holiday from work and I went to this place every day.... I've done all the courses, I've gone to all the seminars, I've done the research.... And I, one of our friends is a photographer and video maker, and she's going to do a video of the two of us in the nursing home, just for me.' (Mary, wife)

'Oh, I told all my friends straight away. I told my mother straight away. I told everybody. Anyone that was close to us, I told them all.... I go to the Alzheimer's cafe; I go to my [local] dementia support group every Wednesday.... You know, so those two help, yeah.' (Mary, wife)

'So, I got in touch with the [local Alzheimer's organisation] and tried to learn as much as I could about it, you know, educate myself a bit.' (Mark, husband)

'We've all gone to counselling at this stage anyway, just, you know, that has been the makings of us, that they went and had their own little sessions and spoke about everything.... Their counsellor was outstanding ... in showing them coping mechanisms as well.' (Rita, wife)

### *Enhanced communication with healthcare providers*

Participant narratives highlighted how adjusting to the diagnosis fostered a positive reciprocal relationship with healthcare professionals. This seemed to enhance positive communication, allowing for a good working relationship that provided direction about next appropriate steps:

'He doesn't use the word "dementia" at all, he says "cognitive impairment".... He spoke to the kids, he spoke really, really well to all of us, he was very gentle with the kids, but he was very direct to all of us as well, but he's gentle.' (Rita, wife)

'Then somebody else, a social worker in [large hospital], put us in touch with somebody else. So, a nice lady used to come regularly on the other days, she was from rehab, that was a big help, you know.' (Frank, husband)

'We were dealing with a young guy and a very nice social worker ... the social worker handed me a pack and there was things like his driving had to be tested, we were told about the Alzheimer's café... We maybe were even given an appointment, or told to ring to make an appointment.' (Maria, wife)

### *Theme 3: stigma*

The experience of stigma was commonly reported in the narratives. Participants spoke about a misunderstanding among the general public that dementia is an older

person's disease. Several interviewees reported incidences of stigma resulting in social isolation for them and the person in their care:

'Oh yeah, a couple of people did move away. A few people said to me, "If I were you, I'd get that checked, I'd get a second opinion, I don't think he has dementia." They just couldn't believe it, he's so healthy.' (Mary, wife)

'She said that people, and to this day, people in her own village, will cross the road when they see her.' (Joan, carer/helper)

'All her friends have totally avoided her, yeah.... Since she has got a lot worse, everyone has kind of kept away.... In a restaurant, if ... she's using two forks and I don't catch her in time, you can see people looking at her like, it's strange.' (Mark, husband)

'We have lost family and friends along the way, family more so, they just don't come to us anymore. It's just they don't believe it ... and my son didn't want to tell anyone, nobody was to know.' (Rita, wife)

'I used to bring him up to work with me when he was aware, and he used to get the bus into town to meet a friend. And he was thrown off the bus because he couldn't find his money or lost his wallet.' (Martina, wife)

#### *Theme 4: lack of services*

The apparent lack of services for PwYOD emerged from several participant narratives:

'She languished in [large hospital] for the best part of a year, in a ward with three other women coming and going.... It was shocking ... I didn't know what to do, I was trying to help my sister.... Nobody knew what to do with her.... She was curled up in the foetal position in her bed.... The women in the ward would say, "You won't believe what was going on here this morning, you won't believe the way this one spoke to her, shouting at her", I was shocked, shocked, shocked [audibly upset].' (Patricia, sister)

'Like, for your partner, you try to have the best for her. She went into [regional hospital] here in Galway, and it's like something in medieval times, f\*\*king hell ... she was in a room with two other women, they were quite old, they hadn't Alzheimer's, and her clothes was all missing ... one had a problem with her bowel, the other was getting sick all the time, and my wife is only a young woman [audibly upset].' (Mark, husband)

'The department of old-age psychiatry see nobody under 65 ... there's a huge difference because they're familiar with dementia, erm, regular psychiatrists not so much, they're not dealing with it as much, you know.' (Ruth, daughter)

Participants also commented that the services available are mostly located in older adult care and are inadequate for the needs of younger adults:

'I was handed a list of over 200 nursing homes and told to go pick one, normal nursing homes for grannies – and my sister is in her late 40s. You'd go in, and it was old people, dementia people, I was absolutely shocked [audibly upset].' (Patricia, sister)

'I would say that there are no facilities or services in place for young people with dementia. It's a very lonely, very lonely path to go down.... I tried to organise day care for him; they told me that there were no facilities for day care for younger people, that if he was to go to day care, it would be older people.' (Martina, wife)

Narratives highlighted a geographical lottery in receiving appropriate services. Some carers acknowledged that where they live affords them the opportunity to access services:

'I was working at this time, and my daughter was going off to college, and they were offering day care. And it wasn't too far from me, and I worked nearby as well. So, I used to bring her on certain days of the week, and she was quite happy there, you know.' (Frank, husband)

'Erm ... everything seemed to be available, the help was there.... I phoned my local health office.... I asked to speak to the district nurse.... I think I probably got the most wonderful district nurse that there ever was in existence.... She, you know, immediately responded and said she would come visit the house, and not, you know, don't worry.' (Maria, wife)

When appropriate services were available, this had a positive outcome for carers and PwYOD:

'Before this, he was getting a little bit depressed, a little bit anxious, he felt he was a strain on everyone.... But he does look forward to the carers coming. He has a great laugh with them, and it's lovely to see him interacting in the public domain.... Just fantastic he has something to talk about when he comes home.' (Rita, wife)

'We were referred to the memory clinic in [two large hospitals]. I must say, I was impressed.... I got to know the Alzheimer's Society, got to know people there ... and there was a woman there who was very helpful ... they offered me respite care as well.... I actually went through the best times really as regards local services for the condition.' (Frank, husband)

Evidence also emerged about how age-appropriate activities could enhance personhood and promote independence in PwYOD:

'We are meeting somebody next week to try to get him into special activities, like gardening, computers and things like that.... Trying to do something different for him. Ehh, just to change it a little bit but gentle ... just maybe to change because he is so young, you know, to give him a purpose again....

We are coming out the other side now; really, the last six months, the package has helped.’ (Rita, wife)

‘She was given a little role to do to keep her busy, you know. But the change in my sister within a week or two.... They just put their arms around her and they put their arms around me. They had a little routine.... She had her activities, she was well fed, she was safe, she had her bedroom, she had her medication, everything was looked after, after spending a year lying in a bed – in prison, basically [audibly upset].’ (Patricia, sister)

### *Theme 5: strain of care*

Participants spoke about the impact of caring over long periods of time. Finding dementia-specific age-related care can be extremely costly, adding to financial pressures on families. This can be compounded by a double economic strain on families, as PwYOD may cease employment but not be eligible for state financial assistance:

‘Financially, it’s going to break me, it is. I have to pay the bills, I’m paying for his nursing home bills, I pay for his GP, dentist, chiropractor, I pay for everything. And now I’m going to have to get a wheelchair, it’s going to cost me two or three grand, you know what I mean? And I’m paying all the bills in the house. There’s no grants or anything, I’m left carrying the whole f\*\*king thing, the whole lot.’ (Mary, wife)

‘I’ve had a couple of life experiences, but I’ve never gone through anything like this in my life. The other nightmare for me, as a relative, was the whole “Fair Deal”<sup>[1]</sup> thing, trying to fill in the forms, sending them off. They come back and they’re not right. Jesus, and because I wasn’t married to my sister, I had no legal, no next of kin, no legal right.’ (Patricia, sister)

‘Like, he was the person in charge, and I didn’t query it, which left me in a financial mess.... I knew he was going to lose everything, and why take away his work skills now ... in actual fact, it was a big mistake because it got us into a lot of, a bigger financial mess than we were already in.’ (Martina, wife)

Participants also spoke about how caring for someone with significant cognitive impairment takes a toll on their physical and psychological health:

‘So, as time went on, then I was at home all the time, and then I got a mini-stroke, right, and I had to go into hospital. So, my daughter had to come, they all had to come. My sister had to come to try and take care of her [audibly upset].’ (Mark, husband)

‘That’s what I’m telling ya, this is why I ended up nearly breaking down completely.’ (Mary, wife)

‘What I want for him – and our kids think the same thing – we want him to get a stroke, heart attack, sepsis; we don’t want him to stay going the way

he is... We can move on as a family and get on with our lives ... that makes me feel guilty, like, why should I say that?' (Martina, wife)

'All this landed in my lap, I had no idea anything was going on. At one stage, because I was losing my mind myself, I was picturing myself in shagging [in hospital] under one of these specialists, I had gone crazy.' (Patricia, sister)

However, appropriate services helped reduce the negative effects of a YOD diagnosis. Narratives highlighted significant reduction in pressures on carers when support was provided:

'I do think about it from time to time [audibly upset], it's so hard ... if we hadn't got the care package, I think he would probably be in care somewhere, and I would probably have had a nervous breakdown. If I'm 100 per cent honest, I could be after having a nervous breakdown.' (Rita, wife)

'How lucky am I, where he is, is unbelievable, that's just, I can't speak highly enough of it... Himself is like a different person in there, he is so happy, so relaxed. And there's more of like an emergence of what he used to be like, you know, he's – I'm just thrilled for him that this is the way he is now.' (Maria, wife)

## Discussion

This study examined carers' experiences of YOD in Ireland. Five themes emerged from the participant narratives: sense of loss; diagnostic issues; stigma; lack of services; and strain of care. Many individuals who receive a diagnosis have difficulty with factors such as parenting, finances or spouse/partner relationships (Bakker et al, 2013), and many carers feel a significant sense of loss as a result. Other studies have shown how primary carers' roles necessarily change in response to the demands placed upon them, leading to feelings of frustration, helplessness and loneliness (Nichols et al, 2013). The study reported here mirrored these findings; many narratives highlighted the loneliness of the post-diagnostic journey. The study also observed the impact of timely and differential diagnoses. Our findings support previous evidence about this, particularly in relation to explaining behavioural difficulties that can emerge pre-diagnosis (Ducharme et al, 2013) and the need for appropriate post-diagnostic services (Allen et al, 2009), which have clear benefits for PwYOD and their families.

Unfortunately, due to the overlapping of symptoms with other mental health conditions, healthcare professionals sometimes struggle to make a dementia diagnosis. For example, there appears to be a lack of understanding of YOD among GPs, and some symptoms of YOD may be attributed to other conditions, such as anxiety, depression or personality disorders (Bakker et al, 2013). The implications of a misdiagnosis can lead to individuals with neurodegenerative diseases, such as YOD, being treated for psychological/psychiatric disorders (Jorm, 2001; Weder et al, 2007). Similar findings emerged in this study, with several PwYOD being misdiagnosed initially, only for a diagnosis of dementia to be given much later.

This delay not only prolonged the diagnosis and further referral, but also resulted in PwYOD being prescribed medications that were costly, had worrying side effects

and, ultimately, were ineffective. A misdiagnosis may also delay the transition period for PwYOD and their families. For example, [Roach and colleagues \(2016\)](#) posit that a timely diagnosis assists individuals to transition sooner, thus allowing for meaningful activity to continue while maintaining a sense of personhood. This study observed similar outcomes. Several participants in the study mentioned benefits of receiving an accurate diagnosis. Despite the initial shock, it had a positive impact for many, such as a sense of relief, enhanced communication with healthcare and service providers, and implementation of coping strategies. Obtaining a timely diagnosis allowed for engagement with services to seek assistance with planning the care their family member required. Furthermore, a diagnosis also afforded participants the opportunity to educate themselves about the condition. This emerged from the data as a significant coping strategy, and is similar to findings reported by [Bunn and colleagues \(2012\)](#). The study thus uncovered both positive and negative issues related to the diagnostic process.

For some, poor communication with healthcare professionals also served to exacerbate an already difficult situation. Barriers to efficient, effective, diagnosis may arise from systemic failures but can also result from people not recognising the early symptoms of YOD due to the sociocultural context and stigma associated with dementia ([Liebson et al, 2005](#)). This study found negative impacts relating to stigma, specifically in terms of social isolation, for example, the disappearance of friends and family once the diagnosis was shared. Some PwYOD were singled out and publicly avoided, probably due to low public understanding of the condition.

Many chronic illnesses can be perceived as deviation from norms, leading to some individuals living with such conditions becoming stigmatised ([Scambler, 2009](#)). In relation to mental health, and more specifically mental illness, factors that may contribute to the development of stigma result from erroneous views, including that: individuals with mental health issues are dangerous; there are extremely poor outcomes for mental health conditions; individuals are themselves responsible for their conditions; and there is a perceived difficulty in engaging in normal social roles when a mental health condition is diagnosed ([Hayward and Bright, 1997](#)). Given the effects of dementia on factors such as memory, judgement and behaviour, this disease is often viewed by the general public as primarily a mental health condition, leading to the fear and misunderstandings often associated with other mental illnesses ([Morgan et al, 2002](#)). Social stigma may also hinder an individual's willingness to engage with specialised dementia service providers. This situation highlights the lack of education and understanding of dementia, and of YOD in particular, in Ireland. All study participants spoke of cognitive and behavioural symptoms that emerged before the age of 65. Such symptoms were subsequently understood by them to be the cause of the stigma they and the PwYOD encountered.

The issues around services for PwYOD, specifically the lack of appropriate services and service settings, highlighted the problems arising from the location of most services in older adult settings that are wholly inadequate for younger adults. These findings support [Morhardt's \(2012\)](#) claim that older adult settings are not equipped to meet younger people's needs. From an Irish perspective, this study highlights the geographical inequities that exist within service provision. Participants stated that accessing services depended on their location in the country, with many areas outside Dublin having no services whatsoever.

Barriers to service use in YOD appear to be uniquely challenging, reflecting the complex nature of dementia in midlife. Offering services in geriatric settings to people

who are neither suitable nor eligible for such care results not only in a reluctance to use such services, but also in severe dissatisfaction when they are utilised (Cations et al, 2017). This lack of appropriate services significantly adds to pressures on primary carers and other family members. Consistent with previous research (for example, Flynn and Mulcahy, 2013), participants in this study reported aspects of care that cause significant strain. Financial strain was a recurrent theme for carers when their family members were diagnosed while still in employment, resulting in participants struggling to pay for care and support their family with reduced income. Furthermore, there appears to be limited support from the Irish state, as entitlements for individuals under 65 are lacking (Cahill et al, 2012). Substantial physical and psychological impacts were also associated with caring for a family member with YOD. Several participants reported the emotional and physical toll that caring for their spouse/partner had on their lives. Similar findings emerged from research conducted by Roach et al (2008), which further highlighted the complexities involved in caring for individuals with YOD.

### *Strengths and limitations*

The current study included nine primary carers who are caring for PwYOD. The small sample size means the findings cannot be generalised to all carers of PwYOD. However, the findings provide insights specific to experiences of YOD in Ireland. It is hoped that such insights may help in the development of more representative research of this relatively small, but nevertheless important, cohort who are living with dementia.

This study was part of a final-year undergraduate degree programme, with no access to a clinical population or to children living with a PwYOD. Further research should include a wider range of participants, including children and PwYOD themselves, as well as PwYOD who live alone. Future research should also focus on the dynamics of family groups (that is, multiple participants within each family) to examine different impacts based on individuals' roles within the family unit.

### **Conclusion**

This study provides an insight into the lives of primary family carers of a person diagnosed with YOD in Ireland. The themes that emerged shed light on several factors that affect primary carers, including the sense of loss, stigma, diagnostic issues, the lack of services and the strain of care. These findings demonstrate that PwYOD and their families need specialised health and social care supports, particularly community-based supports, to live well with the condition. Furthermore, the needs of carers of PwYOD should not be considered to be the same as those of carers of people with LOD given the difference in life stage at the onset of dementia. The study also highlighted the difficulty of initial timely diagnosis and misdiagnosis, suggesting a need for education and awareness regarding YOD and potentially specialised multidisciplinary assessment. Nevertheless, receiving a timely diagnosis is just the first step; this study highlights a severe lack of appropriate services for PwYOD, resulting in a significant strain of care for primary carers. The complex nature of YOD requires different specialised diagnostic and care pathways, as well as interventions and supports, than are in place for people with LOD. Research is needed to capture the needs of PwYOD themselves, and to further explore how best to meet the needs of all living with YOD.



## Note

<sup>1</sup> The Nursing Home Support Scheme (NHSS), also known as ‘Fair Deal’, is a scheme under which the cost of nursing home care is managed through the Health Service Executive (HSE) paying either the full or part of the cost and allowing those charged with paying the resident’s portion of the cost to defer the charge. Eligibility is based on two assessments. The first looks at the care needs of the older person, their capacity to live independently and at available supports at home and in the community. The second assessment looks at the financial resources (income, property and some expenses) available to the older person (see: [www.ageaction.ie](http://www.ageaction.ie)).

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## Conflict of interest

The author declares that there is no conflict of interest.

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