

# BMJ Open Understanding the needs and experiences of people with young onset dementia: a qualitative study

Luisa I Rabanal, John Chatwin, Andy Walker, Maria O'Sullivan, Tracey Williamson

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Salford Institute for Dementia, University of Salford, Salford, UK

## Correspondence to

Dr John Chatwin;  
[j.r.chatwin@salford.ac.uk](mailto:j.r.chatwin@salford.ac.uk)

## ABSTRACT

**Aim** Despite an estimated 40 000 people diagnosed with young onset dementia (YOD) in the UK, there is a general lack of awareness of the condition when compared with late onset dementia. The aim of this study was to explore the experiences and needs of people living with YOD (younger than 65 years) and gain an understanding of the issues that impact on them.

**Setting** Participants' homes, support group premises or university rooms.

**Participants** 14 people with a diagnosis of YOD from a northern UK city.

**Design** Semistructured, in-depth interviews were audio recorded, transcribed and analysed cross-sectionally following principles of interpretative phenomenological analysis.

**Results** Four superordinate themes are reported on 'process of diagnosis', 'the impact of living YOD', 'needs of people with YOD' and 'living well with YOD'. Nine subordinate themes captured participant experiences of developing cognitive difficulties, after being diagnosed with YOD, and subsequently living with the condition. Key issues that emerging included a lack of general awareness of YOD; how this can delay help seeking; commonalities in prediagnosis trajectories; retrospective understanding of prediagnosis symptom patterns; the difficulties of obtaining a firm diagnosis; the importance of face-to-face support and difficulties associated with daily living. Participants also described the emotional and psychological impact of the condition and the importance of formal and informal support networks.

**Conclusions** People who have a diagnosis of YOD regard themselves as distinct from older people with dementia. Despite similar symptoms, the context in which they experience the condition creates a range of distinct psychosocial concerns not commonly well addressed by health and social care services. As awareness of YOD continues to grow, the development (or adaptation) of services that take into account the idiosyncratic needs of people with YOD should be addressed.

## BACKGROUND

There are 850 000 people living with dementia in the UK.<sup>1</sup> The condition is increasingly recognised as a serious health and social challenge because it not only affects the person with the illness but also directly impacts their family, their carers and their wider social

## Strengths and limitations of this study

- This was an in-depth qualitative study focusing on the lived experience of people diagnosed with young onset dementia.
- A representative sample of participants were interviewed, with variations in socio-demographic status, gender and age at diagnosis.
- The principles of interpretative phenomenological analysis were utilised to analyse the data.
- The sample was relatively small, and participants were drawn from a single region in the UK.
- Some participants were interviewed together with their carers, which could have influenced what they reported.

circle.<sup>2</sup> In the UK, tackling dementia is high on the health policy agenda, and there have been a series of initiatives since the launch of the National Dementia Strategy,<sup>3</sup> aimed at raising awareness of the condition and improving the care available.<sup>4-7</sup> Similarly, the challenges encountered by those who care for people with dementia—either on a formal or informal basis—are increasingly acknowledged.<sup>8</sup> There have been a number of studies<sup>9-11</sup> and policy initiatives<sup>12 13</sup> focusing on this particular group.

Although dementia is often associated with ageing, it not only affects older adults. According to estimates based on expert opinion, in 2013 there were over 40 000 people in the UK living with dementia who were younger than 65 years.<sup>1</sup> This estimate is still widely quoted, however the actual number of people who currently have young onset dementia (YOD) is unknown. Although there is now a 15-year history of studies focusing on people with YOD,<sup>14</sup> they are still a relatively marginalised group, and largely absent from active involvement in the development of services. Cases of undiagnosed YOD are very common, with reports as high as 30%–50%<sup>15</sup> and again, this may be attributed partly to the general perception that dementia is a condition of old age.<sup>16</sup> Younger people who

develop the condition are likely to present with a wider variety of symptoms compared with those older than 65 years,<sup>17</sup> and this too can complicate matters. Memory loss and cognitive impairments, which are strongly associated with dementia, may not be the main presenting problem for a younger person, and the sometimes ill-defined symptoms that characterise the initial stages of the condition are often ascribed to other conditions such as depression or stress.<sup>14 18</sup> People with frontotemporal dementia, for example, can initially present with personality changes as their primary symptom, and younger people may also have difficulties with visuospatial and semantic tasks.<sup>19</sup> Another reason why people with YOD are currently viewed as a marginalised population may be related to the psychosocial limitations that the condition can impose.<sup>20</sup> This often includes social isolation<sup>21</sup> and fears of stigma.<sup>19</sup> As a result of this the likelihood that a person will become engaged in public activism or campaigning is low.<sup>18</sup>

For people who receive a diagnosis of dementia at a relatively young age, the implications can be different from those who develop the condition in later years, beyond the traditional retirement age. The implications can be particularly severe<sup>22</sup> with a person having YOD being more likely to be still in paid employment, and may have dependents including spouses, children and/or ageing parents to support.<sup>14 21</sup> Post diagnosis, individuals can remain in relatively good physical health for many years, but the awareness of an inevitably accelerated mental deterioration, and the implications this will have, is in itself a source of great stress for both the person with the condition and those around him or her.<sup>23</sup> It can also be difficult for younger people to access appropriate community and residential services because mainstream dementia care services are aimed primarily at older adults and are often not suitable to their requirements.<sup>24</sup> Furthermore, services for younger people with dementia are often overlooked in mental health strategies, which tend to default to the needs of older adults and they are frequently excluded from working age mental health services, reinforcing dementia as an older person's illness.<sup>25</sup>

The aim of this study was to explore the experiences and needs of younger people living with dementia to facilitate an understanding of the issues that impact on them, and to identify opportunities for the development of services that might be a better 'fit' in the unique context of their needs.

## METHODS

### Sample

The sample comprised 14 people with YOD aged between 57 and 67 years. Age at diagnosis ranged from 52 to 64 years. All had obtained their diagnosis before the age of 65. Of these, five interviews were paired (person with dementia and their carer), but the carer voices are not reported here. In-depth analysis of data from a sample of this size is appropriate for interpretative phenomenological analysis (IPA).

### Recruitment

Study participants were recruited from a number of YOD support organisations based in the north of England between February 2016 and April 2017. These were third sector organisations including a local group affiliated to Age UK, which supported around 50 people with YOD, and a not-for-profit community interest company providing person-centred support to people living with dementia, which currently dealt with over 200 referrals a year. Participants were also recruited from a National Health Service's neurological unit, which processed the majority of regional referrals for dementia assessment. All participants were given the opportunity to receive ongoing updates from the study, as well as any published outputs.

### Interviews

Interviews took place at a time and place convenient to participants, usually their home or community support group premises. Written informed consent to audio-tape interviews was obtained. Interviews were semistructured, narrative-driven and explored issues including participants' experiences of diagnosis; their trajectory of knowledge about the condition; use and experiences of statutory and nonstatutory health and social care services; engagement with information resources and support organisations and the impact of dementia on their daily lives.

Interviews were conducted by LR and MO, which elicited between 30 and 120 min of audio-recording each, and were fully transcribed by an external transcription company. To ensure that the person with dementia (PWD) had the dominant voice during interviews that were conducted with carers present, questions were directed primarily at the PWD; the carer would interject if they felt they had extra information to support what the PWD was saying.

### Patient and public involvement

The research team developed an interview topic guide in partnership with members of a dedicated study advisory group, which comprised 12 people who were either living with YOD (seven) or were the carers of people living with YOD (five). The study's steering group, which included representatives from service providing agencies, health practitioners specialising in dementia care and members of the research team, also contributed to the development of the initial interview guide. Both groups commented on subsequent revisions of the guide as the project developed.

### Analysis

In line with a growing number of other studies on the lived experience of dementia, IPA was applied.<sup>26</sup> IPA is an established method for researchers to explore the experience of individuals going through illness and the meanings people attach to those experiences.<sup>27</sup> IPA fosters the incorporation of individual perspectives, and

the idiosyncratic meanings that participants attached to elements of their experience, which is particularly important given our limited knowledge of the experience of living with YOD. The relevance of using IPA for people with chronic illness has also been highlighted, as the approach accepts that participants are their own experts.<sup>28</sup> Analysis was undertaken by LR with independent verification of emergent themes with TW using a small subset of five transcripts.

At a practical level, transcripts were first analysed individually and read several times while simultaneously listening to the audio-recording. The written content was formatted into a table to facilitate the annotation process. First, simple descriptive comments were made while reading and listening to the transcript in order to reveal the content. The process was repeated a second and third time to note linguistic (use of language, laughter and voice tone) and conceptual (questions and interpretations of the text) comments. The conceptual level of annotation is particularly important because it adds depth to the analysis. Various techniques were employed to search for connections across themes, on a case-by-case basis. These included abstraction (grouping similar themes), polarisation (focusing on differences between themes) and numeration (looking at frequencies of themes). The result was a list of superordinate themes and their respective subordinate themes for each participant.

## RESULTS

The analysis revealed four superordinate themes that represent prominent features of participants' stories collectively. The superordinate themes each comprise

three subordinate themes (see [table 1](#)), which vary in terms of their contribution from individual participants. In line with IPA philosophy, unique and common elements from the perspectives of participants are therefore represented. The superordinate themes were *the process of diagnosis*, *the impact of living with YOD*, *the needs of people with YOD* and *living well with YOD*.

### Superordinate theme 1: the process of diagnosis

Participants talked extensively about how they received their diagnosis and the impact that this had on them, their families and their wider social circle. The experience was characterised by a distinction between prediagnostic and postdiagnostic phases. The prediagnostic phase was the period when the first subtle signs and changes in behaviour started to occur. It could be a particularly difficult and uncertain time for people who were still likely to be active, working and looking after dependents. It was usual for people who began to experience problems in carrying out their usual routines to battle to maintain control until a point of crisis forced them to seek help. The prediagnosis period was only really revealed and assimilated in hindsight, once a person could make retrospective connections between his or her gradually emerging symptoms, such as confusion and increasing memory problems, and their condition.

A lack of awareness relating to YOD was reported by participants in the prediagnosis phase. In some cases, this had delayed the point at which they sought help. The interviewees gave a number of examples of signs and symptoms that were experienced during the early stages of their condition, but as these could occur in isolation and were not always to do with memory issues, they were not immediately seen as indicators of a single underlying condition.

**Table 1** Superordinate and subordinate themes from interpretative phenomenological analysis of all participants living with young onset dementia

Superordinate theme	Subordinate theme	Key words and issues
1. Process of diagnosis	Prediagnosis 'Hit by a sledge hammer'	Warning signs, alarm bells, too young Sledgehammer, shock, lack of support, information overload
	Postdiagnosis	Benefits, no follow-up, looking for answers
2. Impact of living with young onset dementia	Impact on behaviour and function	Activities of daily living, money, cooking, communication, uncharacteristic behaviour, loss of self
	Psychological impact	Fear of the future, covering up, living a double life
	Impact on work	Devastation, loss, forgetting things
3. Needs of people with young onset dementia	'They are my rock'	Support, friends and family, spouse
	What helps?	Peer support, postdiagnostic support groups.
	What could be improved?	Raising dementia awareness, it's more than just memory, dementia groups
4. Living well with young onset dementia	Psychological coping strategies	Positivity, optimism
	Practical coping strategies	Simple things, routine, familiarity
	'Trying to keep occupied'	Therapeutic benefits of activity

I found that my concentration wasn't the same. I could be stood cooking something and I'd go away and then I'd forget, until the smoke alarm was going off... I was decorating the bathroom at the time, I'd got the first piece of paper up then I couldn't fathom out how to match and I thought oh this isn't right . . . I could plug in the vacuum cleaner but I didn't know how to turn it on. (Participant 3)

I didn't think of it as an illness, I just thought I was having . . . but you know you just think the job is very stressful and you always have a, 'oh well, we were busy last night.' (Participant 4)

Even after people decided to seek help, it could be difficult to get a firm diagnosis, and there was often a reported struggle heard by health professionals:

The doctors and consultants were saying, 'no, you're too young to have dementia'. At this time I was about 49. So their thinking was it could be depression or stress because I was still working at this point. (Participant 1)

[Speaking about her GP] She put me on some tablet anyway, she said it was depression... I said to her, 'Look it's getting that bad. I'm looking after children. I can't do it'. (Participant 3)

Participants had mixed views on the actual process of receiving a diagnosis. As with the process of being told about any life-changing illness, interpersonal issues relating to the communication awareness and empathy of healthcare practitioners was important on an individual level. However, regardless of how the news was delivered, and the psychosocial support that may have been available, there was unanimity over the shock of actually receiving a diagnosis:

... and then they proceeded to tell me that I had Alzheimer's. At which point I just froze completely. (Participant 1)

[They said] it's early onset Alzheimer's disease, just out of the blue like that. Well I was numb. (Participant 3)

... it was awful. I felt like I was hit by a sledgehammer... I felt as though somebody had pulled the plug out of everything. (Participant 5)

At a practical level, a recurring issue was the amount of supporting documentation and information that participants were given at the point of diagnosis, and how this could be overwhelming.

... and you're bombarded with, take this, take that, take this, take that. All these leaflets and basically all you want to do is sit down and think it through yourselves. (Participant 9)

I was given a pile of documents and I went home and put them in a cupboard. I have spoken to a number of people and it is a shared experience. It's all just too

much to take on board and really, just a page would have done to point out the services. (Participant 10)

The predominance of leaflets as opposed to face-to-face support was also highlighted:

When I got home I was so angry, all the leaflets went straight in the bin. That was my way of thinking, I don't need the bloody leaflets, they don't mean anything to me... so yeah, leaflets weren't I meant for me. The thing that would have helped me most would've been for someone to be around outside my consultation room and approach me. Not approach my husband, but approach me maybe. I don't know, maybe offered me somewhere on my own rather than me going out in a big black cloud into nothingness. (Participant 1)

Some participants felt that postdiagnosis support was lacking. One acknowledged that she was coping with the help of her husband but would have appreciated an occasional offer of support:

... maybe every six to 12 months to say, 'we're here!' Particularly some emotional support. So I'd like somebody, not to take it out on, you know, somebody to talk to. (Participant 9)

A similar lack of agency was acknowledged by another participant:

Nobody says, you know, 'how does that make you feel?' In my view there still isn't any opportunity, 3 years down the line and I still haven't been able to voice how it made me feel then, how I felt coping with it for the last couple of years and how my feelings are towards the future. (Participant 1)

### Superordinate theme 2: the impact of living with YOD

The impact that dementia had on participants is grouped here into two main areas: *changes in function and daily living* and *emotional and psychological impact*.

#### Changes in function and daily living

The impacts on function were wide-ranging. Again, this was not always the direct result of memory loss per se. For example, participants described problems with everyday activities such as dealing with money:

I can't count money; I haven't yet worked that one out. (Participant 2)

Sometimes I don't carry money any more because I could fumble with it. When I used to go and pay, I couldn't count the change out. (Participant 3)

I was going to the bank, put my card in to get some money out and I took the card out and left the money. (Participant 7)

I would, for example, go for my lunch or go into a shop and if they said that something was 35 pence

and I took the change out of my pocket. I couldn't count it. (Participant 10)

Communication issues, including the inability to maintain concentration during conversations and losing the thread during interaction, were highlighted. Frequently reported was an increasing difficulty in 'finding the right word', and other more individualistic effects such as difficulty in recognising faces, pronunciation and speech production. There were less obvious problems too, such as only being able to concentrate on thinking about one thing at a time, which could have a broad impact on many aspects of daily life. Participants 4, 12 and 13 described noticing themselves becoming uncharacteristically confused and forgetful at work:

Well in my job [nursing] I was forgetting a lot of things, which I hadn't done before. I was a perfectionist in my job and I was then forgetting, not forgetting how to do things but—yes, I suppose, in a way. What was happening was I was forgetting parts of what I was doing... One night I came back and they said, 'oh, how was such and such a body?' And I went, 'oh, I can't remember what I gave him.' So they were all going round and asking was it this? Was it that? And we have got like 12 of us in the office and they are all shouting out 'oh, is it this or is it that?' And then all of a sudden somebody said the word and I went 'Yes! That's what I've done, that's it'. And I got a round of applause... (Participant 4)

And actually, I think that was the time when I really thought maybe I have got something. But I wrote the bloody thing and I couldn't remember it. (Participant 12)

I absolutely loved my job and then it just, I started, I realised that it was, I would come in the following day and couldn't remember what I'd worked on the night before. (Participant 13)

### Emotional and psychological impact

Participants described their struggles and fears around living with dementia. These included uncertainty for the future and concerns about putting themselves at risk while struggling to maintain an image of themselves as 'normal' members of the community. A sense of trying to cover things up and keep the realities of the condition hidden was evident:

I cover up a lot... If I'm in a doctor's surgery I will get a magazine and flip through it. I can read the words but it doesn't make sense what's there. I don't understand what I'm reading but I wouldn't give people the satisfaction of thinking... To them they probably just think I'm reading. So really you mask a lot of things just to try and still fit in with society so you're not, like, different. (Participant 3)

You know you sort of live a double life almost. You know, you're sort of, 'yeah I'm fine, I'm fine.' But

underneath you're thinking well am I going to see my grandkids grow up? (Participant 1)

The importance of work, not only as a source of income but also of identity, was highlighted by the participants. Also what was striking was the deep sense of loss that could occur when people were forced to stop working because of their cognitive difficulties—even if YOD had not yet been formally diagnosed. Eight of the interviewees with YOD were in paid employment at the time of their diagnosis.

I had to give up work and that was devastating, being a carer. When I realised that my clients were in danger, I thought I can't carry on with my job. (Participant 1)

[In a hospital] you see, if you are making a mistake, somebody is going to get hurt. That was the problem. That's why, when I went to see them, they told me I couldn't work anymore. (Participant 4)

### Superordinate theme 3: the needs of people with YOD

The majority of participants felt that the support of their family, friends and other people living with dementia was crucial. Those who did not have spouses often had a key person, possibly a close friend or child, who provided emotional and practical support:

[Talking about her daughter] She has gone through a lot with me in the last 12 months... and we have good communication. She can read me. She knows when I walk through that door in the morning. She knows if it's a good or bad day. (Participant 6)

Dementia-specific community groups were also seen as a significant source of support, and the importance of being able to relate to other people who had been or were currently going through a similar experience was highlighted:

... because there is nothing like having somebody who has got the same problem telling you how to cope with it, you know. Because you have been there, you have done it and you have got the t-shirt. I found [name of a high-profile UK dementia activist] was the best ambassador for it, because I looked at him and I thought, that's how I want to be in 7 or 8 years. (Participant 4)

I find that I am getting more support through people from the groups. (Participant 8)

However, participants reported that it was important for the support they were offered to take into account that they may have different needs and interests compared with older people with dementia. Support groups that were specifically organised for people with YOD, rather than dementia in general, were praised because they offered age-appropriate activities and—at their best—helped to develop a sense of independence and empowerment.

I think people of my own age, if they set up a group for them. Because we are probably a bit more able

mind to do things. Our faculties are probably a little bit better than maybe the older ones are... because everything at the moment is based on older people... it's like being in school and it's all old war songs. Well I wasn't even born in the war. (Participant 3)

There was also a strong sense that any new initiatives need to acknowledge that not everybody will wish to engage with 'traditional' dementia support group formats—singing groups, reminiscence groups and so on. Again, this was largely because of the perception that these groups catered mainly for older people. Participants, who were still living independently, expressed a need for a less formal approach in how dementia group sessions were booked and arranged:

[If] you have a singing group for dementia, why do I have to make an appointment? Surely I should be able to just walk through the door and go 'hello, I am such a body, I've got young onset dementia, can I see what you're about please?' I shouldn't have to phone up and have to book in... It's the way they run their groups, this phone up and book in. Sorry, but how can anyone with dementia, unless they've got a carer, remember to phone up and book a spot? (Participant 6)

#### Superordinate theme 4: living well with YOD

A powerful theme from the interviews was people's descriptions of how they were coping and getting on with their lives and the many inspirational stories and examples that they gave. The need to engage in meaningful activity in order to maintain their well-being was very strong. Participants showed a remarkable ability to remain positive throughout their illness and for some this was viewed as a coping strategy, actively seeking to protect this optimism:

My doctor put it right the other week, when she said if she didn't have all my test results in front of her, she wouldn't believe I had dementia. I think if I carry on doing different things and if I keep moving the dementia can't catch me. (Participant 15)

I came to the conclusion that reading things like that are not going to do me any good. They are just going to send me into a pit of despair, which is something I wasn't going to do...(later)...I don't think about the future. I have the thing that yesterday is history, tomorrow's a mystery and today is the present and that's why they call it a gift. (Participant 20)

Not everybody, however, has the ability to confront their illness with a positive attitude. It is therefore important to consider other strategies that people can draw on to help themselves to live well. Strategies that might be more inclusive and open to the wider population of people living with dementia. Individuals are hugely resourceful and have impressive management strategies that should be documented and these are quite often very simple things:

Speak slowly, speak calmly, speak in words I can understand. That's the main important thing. I may not remember what you've just told me so please can you write it down for me, or I can write it down so that when I go away from here I know what you've told me. (Participant 2)

Simply keeping things routine and familiar could also be a very effective coping strategy. Participant 4, for example, acknowledged that she struggled more when out of a routine and the familiarity with her house helped because she knew where everything was and how to get to it. Participant 20 said that he now struggled to watch television, but he refused to give up and adapted this activity with the following example:

I can't remember the last time I watched a film because 10 minutes in and I have forgotten exactly what is happening. So I rarely watch television, but if I do, I watch something where there is no plot to follow, so I will watch things like Animal Planet because you are just looking at animals then, there is no plot actually to it. (Participant 20)

The need to keep active and the therapeutic benefits of activity were themes common to all participants. Examples included learning to swim, taking up gardening, raising and forming companionship with a dog, giving talks nationwide on the experience of living with dementia, raising awareness, becoming involved in research and campaigning and gaining employment in a caring capacity to support others to live well with dementia. Participants made the important link between activity and well-being:

So they are the first things that helped me to live well. And then I think, also, was the swimming was the main one for me. More so probably than the young onset group. (Participant 4)

If you sit at home and vegetate, you're dead. Because the longer you do it, the worse it gets. So you need to get yourself out doing something, anything, regardless. Clean the house or something like this. Do something. I was lucky because we knew we were going to get a dog and we've got the dog and everybody loves him (Participant 7)

That's why I have my crosswords in the morning paper. I was told to keep the brain ticking over and active. And now, believe it or not, it's only today—a Tuesday—that I don't have anything to do. (Participant 12)

The positive for us is that as I say we travel, we go and do different things...we're just trying to keep occupied. (Participant 15)

## DISCUSSION

Participants described in detail their particular experiences of receiving a diagnosis of dementia at a relatively

young age, and coming to terms with the situation they found themselves in. The principal findings of the study included a lack of general awareness of YOD; how this can delay help seeking; commonalities in prediagnosis trajectories; retrospective understanding of prediagnosis symptom patterns; the difficulties of obtaining a firm diagnosis; the importance of face-to-face support and difficulties associated with daily living. Participants also described the emotional and psychological impact of the condition and the importance of formal and informal support networks.

Currently, although medical and lay awareness about dementia issues in general is on the ascendant,<sup>29</sup> the idiosyncratic collection of psychosocial issues that it engenders remain at the margins of public awareness.<sup>30</sup> People who are formally diagnosed can find themselves in a position where, for the purposes of many health and social support interventions, their needs are aggregated with those of people who develop dementia much later in life. On one level this may not appear to be a significant issue; functionally, the symptoms exhibited by both cohorts will be similar and so too will be the choice of treatments and therapies available.<sup>31</sup> For many people with YOD, however, there are likely to be a whole raft of tangential—often age-related—psychosocial issues, such as still being in employment or in a spousal relationship, that have a profound impact on the way in which they come to terms with their condition and whether or not they develop effective ways of living with it.

The findings from this study concur with other work, which has highlighted that people with YOD face a range of specific difficulties that do not necessarily impact on older people to the same degree.<sup>32 33</sup> The often-lengthy period leading up to the point at which a person recognises that they need to seek help is the first of these. In line with other studies,<sup>34 35</sup> for a number of our participants, the initial signs that something was wrong were not directly related to memory problems, but to wider and more general cognitive anomalies or behavioural changes, with eight participants first noticing problems while at work. Basic memory issues such as increasing forgetfulness could be a significant element, but might well only have been one of a variety of sporadic perturbations in spatial awareness or episodes of general confusion. Again, with an older person, the onset of such symptoms might readily indicate the onset of dementia. But with younger people, connections are often not made until much further on in the disease process.<sup>36</sup> In line with studies on self-identity and illness,<sup>37 38</sup> people may attribute these kinds of symptomatic patterns to work stress or other causes such as depression.<sup>39</sup>

It was evident that the process of receiving and accepting a diagnosis of YOD was extremely difficult for most people. At an interactional level there have been few recommendations relating to how health professionals might better adapt their approach to delivering a diagnosis—one that might, for example, more readily take into account the perspective of the younger

person. Furthermore, although there have been significant improvements in the provision of relevant health and support information in recent years,<sup>22</sup> this in itself appears to be causing some problems, not least that the major part of it is still skewed towards older patients and their carers. As has been suggested in studies on information provision for other serious conditions,<sup>40 41</sup> people in this study reported feeling overwhelmed at the point of diagnosis by the sheer amount of material they were given, to the point where they simply disengaged with it. For a condition that can place such restrictions on cognitive processes, more effective and streamlined ways of delivering information tailored specifically for those with YOD need to be devised.

Unlike those who develop dementia after they reach traditional retirement age, people with YOD will commonly be in employment or eligible for employment at diagnosis. Having to give up work or the prospect of preferred work, and the severe implications this has on many levels, was a recurring theme. Ironically, still being engaged in a work environment and being in a position where subtle changes in behaviour and cognitive ability might be more readily noticed—both by the person themselves and also by their co-workers—could be a significant trigger in prompting people to seek help. Occasionally this decision may be forced on them, particularly if they work in a field where their ability and actions could be a danger to others, such as healthcare, making the experience particularly difficult.

Study participants were clear about the importance they placed on family, friends and peers (other people living with dementia) as a source of support, at both a psychological and practical level. The study suggests, however, that as with information provision and care pathway engagement, attitudes towards formal and informal support groups can be ambiguous. While efforts to provide such support were universally appreciated, there was a definite sense that the traditional forms of dementia focused support group do not always follow formats or offer activities that younger people wish to engage with. More passive reminiscence-based activities, for example, that are very common in care homes and other environments that support older people with dementia are often focused on periods before some people with YOD were born and may not resonate well with them.

When talking about living well with dementia, the intention is not to make light of the experience of dementia, it's more about challenging the stereotype. Previous research on the experience of living with dementia often serves to fuel this negative image of what it might be like to live with the condition. What we need to start to focus on are ways of understanding the positive experiences, strengths and capabilities that people draw on to improve their own well-being.

### Strengths and weaknesses of this study

This was an in-depth qualitative study focusing on the lived experience of people diagnosed with YOD.

Although our sample was relatively small, for an in-depth qualitative study of this nature, utilising an interpretive phenomenological approach, it was entirely adequate. We were able to interview a representative cross-section of participants in terms of sociodemographic status, age and gender. A potential weakness of the study could be that as some participants were interviewed together with their carer, this might have influenced what they said. Where it was not possible to interview participants alone, we tried to ensure that the 'voice' of the person with YOD was not overshadowed. The regional nature of the study might also have influenced reports on issues such as engaging with services. However, this may have been offset by the sociodemographic spread of participants, which covered a range of high and low socioeconomic status individuals and included people who had engaged with both National Health Service and private services.

In terms of unanswered questions for future research, and the implications for policymakers and clinicians that these might have, the study has particularly highlighted the need for more detailed work on the way in which information is tailored to the needs of younger people at the point of diagnosis. In particular, how to more clearly differentiate what is available for this group from the material offered to older patients. In one sense, the success of current awareness raising initiatives for dementia in general may have worked against those who are diagnosed when younger. While they are clearly now becoming more visible, they are still not sufficiently defined as a group to attract a coherent cross-service collection of material that would be less alienating to them.

## CONCLUSIONS

This study used innovative participatory methods and built on existing work in this area by examining postdiagnostic support in a region with relevant service provision for YOD. Participants gave detailed accounts of their needs and experiences relating to living with YOD and described a wide range of issues that affected them. Our findings are largely in line with other studies that have begun to focus on this group,<sup>14</sup> and confirms that those who have a diagnosis of YOD see themselves as distinct from older people with the condition, even if they experience similar symptoms. We show that peer support is crucial for people living with YOD, as is the need for them to engage in YOD-specific groups with age-appropriate activities.

There have been significant positive developments at both a national and local level in the repositioning of care pathways and social support for people with dementia.<sup>5 6</sup> In parallel with these developments, there have also been a number of high-profile dementia-focused initiatives that set out to actively address the needs of people with YOD as well as older people. Two prime examples are Dementia Friendly Communities run by the Alzheimer's Society,<sup>42</sup> and the Dementia Engagement and Empowerment Project (DEEP),<sup>43</sup> which aims to bring together

groups of people with dementia from across the UK and support attempts to improve services. As awareness of YOD continues to grow, the development (or adaptation) of support services such as these which take into account the particular requirements of this younger group need to be maintained. Although the number of people with YOD is admittedly extremely small when compared with the number of older people with dementia, there is potential for incremental (and inexpensive) adjustments to existing health and social care interventions, which could make a significant difference to their ability to live independently, with good quality of life, for as long as possible.

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**Patient consent** Obtained.

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