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

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ABSTRACT

Aim

Despite over 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 (LOD). The aim of this study was to explore the experiences and needs of people living with young onset dementia (under 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

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

Results

Three superordinate themes are reported on: 'process of diagnosis', 'the impact of living with young onset dementia' and 'needs of people with young onset dementia'. Nine subordinate themes captured participant experiences of developing cognitive difficulties, being diagnosed with YOD, and subsequently living with the condition. Key issues emerging included: a lack of general awareness of YOD; how this can delay help seeking; commonalities in pre-diagnosis trajectories; retrospective understanding of pre-diagnosis symptom patterns; the difficulties of obtaining a firm diagnosis; the importance of face-to-face support; 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 psycho-social concerns not commonly well addressed by health and social care services. As awareness of YOD continues to grow, the development (or adaptation) of services which take into account the idiosyncratic needs of people with YOD should be addressed.

Strengths and limitations of the study

- People with a diagnosis of YOD are a marginalised and under-represented patient group. Studies addressing their subjective needs are uncommon.
- The study provides insights into the experiences of people living with YOD and the process of engaging with health and social support networks.
- Care was taken to sample a cadre with as wide a range of characteristics as possible, including gender and socio-demographic variations.

- The sample was relatively small and participants were drawn from a single region.

Background

There are 850,000 people living with dementia in the UK (1). 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 on their family, their carers and their wider social circle. (2) In the UK, tackling with dementia is high on the health policy agenda, and there have been a series of initiatives since the launch of the National Dementia Strategy, (3) aimed at raising awareness of the condition and improving the care available. (4,5,6,7) Similarly, the challenges encountered by those who care for people with dementia – either on a formal or informal basis – are increasingly acknowledged. (8) There have been a number of studies, (9,10,11) and policy initiatives (12,13) focusing on this particular group.

Although dementia is often associated with ageing, it not only affects older adults. There are currently over 40,000 people in the UK living with dementia who are under 65 years of age. (14) However, people with young onset dementia (YOD) (15) are largely absent from studies that have focused on the subjective experience of dementia and the development of services. Cases of undiagnosed YOD are very common, with reports as high as 30-50% (16) and again, may be attributed partly to the general perception that dementia is a condition of old age (17). Younger people who develop the condition are likely to present with a wider variety of symptoms compared to those over 65 years, (18) 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. (19,15) 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. (20) Another reason why people with YOD are currently viewed as a marginalised population may relate to the psycho-social limitations that the condition can impose. (21) This often includes social isolation, (22) and fears of stigma (20). As a result of this the likelihood that a person will become engaged in public activism or campaigning is low. (23)

For people who receive a diagnosis of dementia at a relatively young age (in their forties and fifties), the implications can be different from those who develop the condition in later years, beyond traditional retirement age. The implications can be particularly severe (24) with a person having YOD being more likely to still be in paid employment, and may have dependents including spouses, children and/or ageing parents to support. (15,22) 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 them. (25) 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. (26) 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. (27)

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’ with the unique context of their needs.

Methods

Sample

Study participants were recruited from a number of YOD support organisations based in the North of England between February 2016 and April 2017. These included small independent organisations as well as larger groups affiliated to national agencies, including the NHS and the Alzheimer’s Society.

The maximum diversity sample comprised 14 people with young onset dementia who all obtained their diagnosis before the age of 65 (see Table 1). Of these, five interviews were paired (person with dementia and their carer) but the carer voices are not reported on here.

Interviews

Interviews took place at a time and place convenient to participants, usually their home or community support group premises. Written informed consent to audiotape interviews was obtained. The research team developed an interview topic guide in partnership with members of a dedicated study advisory group which comprised twelve people who were either living with YOD (seven) or were the carers of people living with YOD (five). The interview guide was further revised through the study’s steering group which included representatives from service providing agencies, health practitioners specialising in dementia care, and members of the research team. Interviews were semi-structured, narrative driven and explored issues including: participants’ experiences of diagnosis; their trajectory of knowledge about the condition; use and experiences of statutory and non-statutory 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, elicited between 30 and 120 minutes of audio-recording each and were fully transcribed by an external transcription company.

Analysis

In line with a growing number of other studies on the lived experience of dementia, interpretative phenomenological analysis (IPA) was applied. (28). IPA is an established method for researchers to explore the experience of individuals going through illness and the meanings people attach to those experiences. (29) 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 for using IPA with people with chronic illness has also been highlighted, as the approach accepts that participants are their own experts. (30) Analysis was undertaken by LR with independent verification of emergent themes with TW using a small subset of five transcripts.

Results

Fourteen people aged 57-67 years, with YOD were interviewed including eight women and six men. See Table 1. In-depth analysis of data from a sample of this size is fitting with IPA.

Insert Table 1 about here

Emergent themes

IPA revealed four superordinate themes that represent prominent features of participants' stories collectively. The superordinate themes each comprise three subordinate themes (see Table 2) 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 more substantial superordinate Themes 1 to 3 are reported upon here: *the process of diagnosis; the impact of living with young onset dementia; and the needs of people with young onset dementia.* The less prominent theme 'living well with young onset dementia' is shown in Table 2 for completeness but not reported on.

Insert Table 2 about here

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 pre and post diagnostic phases. The pre-diagnosis 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 pre-diagnosis period was only really revealed and assimilated in hindsight, once a person could make retrospective connections between their 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 pre-diagnosis 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.

> 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 to be 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 health care 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 mean 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 post-diagnosis 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 twelve 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, three 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 are 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 anymore 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 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 young onset dementia*

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 seven or eight 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 to 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 minded 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)

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. Currently, although medical and lay awareness about dementia issues in general is on the ascendant, (31) and the idiosyncratic collection of psycho-social issues that it engenders, remain at the margins of public awareness. (32) 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. (33) For many people with YOD, however, there are likely to be a whole raft of tangential - often age related - psycho-social 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. (34,35) 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, (36,37) 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 whilst 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. (38) In line with studies on self-identity and illness, (39,40) people may attribute these kinds of symptomatic patterns to work stress or other causes such as depression. (41)

Although, as we have outlined, there have been significant positive developments at both a national and local level in the re-positioning of care pathways and social support for people with dementia, (5,6) 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, (24) 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 (42,43) 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 upon 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.

Conclusions

Participants in this study 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 suggest that those who have a diagnosis of YOD see themselves as distinct from older people with the condition – even if they experience similar symptoms. As awareness of YOD continues to grow, the development (or adaptation) of support services which can take into account the particular requirements of this younger group need to be addressed. 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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Competing interests.

None

Ethical review.

Approval for the study was obtained from the Health Research Authority – Preston Research Ethics Committee. (REC Reference Number: 15/NW/0921.)

Author contributions:

JC led on the writing and participated in the analysis. LR gathered the data, led the analysis and participated in the writing. TW conceived the research idea and study design, and participated in the analysis and writing. MO undertook some interviews and analysis, and writing. AW contributed to writing. All authors commented on and approved the final version of the manuscript.

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No additional data are available.

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Participant	Gender	Age at diagnosis
1	Female	55
2	Female	52
3	Female	57
4	Female	61
5	Male	59
6	Female	58
7	Male	64
8	Male	54
9	Female	61
10	Male	57
11	Female	55
12	Male	62
13	Female	56
14	Male	62

Table 1: Age at diagnosis and gender of participants

Superordinate theme	**Subordinate theme**	**Key words and issues**

1. Process of diagnosis	*Pre-diagnosis*	Warning signs, alarm bells, too young
	'Hit by a sledge hammer'	Sledgehammer, shock, lack of support, information overload
	Post-diagnosis	Benefits, no follow up, looking for answers
2. Impact of living with young onset dementia	*Impact on behavior & function*	Activities of daily living, money, cooking, communication, uncharacteristic behavior, 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, Open Doors Network, Mount Chapel Champions
	What could be improved?	Raising dementia awareness, it's more than just memory, dementia groups
4. Living well with young onset dementia *** not reported on here**	*Psychological coping strategies*	Positivity, optimism
	Practical coping strategies	Simple things, routine, familiarity
	'Trying to keep occupied'	Therapeutic benefits of activity

Table 2: Superordinate and subordinate themes from IPA analysis of all participants living with young onset dementia

ORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational stud ollected health data.

anding the needs and experiences of people with young onset dementia: a qualitative study

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location manuscri where ite reported
bstract					
	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	Page 2 (abstract)	RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included. RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract. RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.	
on					
d	2	Explain the scientific background and rationale for the investigation being reported	Page 3		
	3	State specific objectives, including any prespecified hypotheses	Page 3		
gn	4	Present key elements of study design early in the paper	Page 3		

	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Page 3		
s	6	*(a) Cohort study* - Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study* - Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study* - Give the eligibility criteria, and the sources and methods of selection of participants *(b) Cohort study* - For matched studies, give matching criteria and number of exposed and unexposed *Case-control study* - For matched studies, give matching criteria and the number of controls per case	Page 4 (sample)	RECORD 6.1: The methods of study population selection (such as codes or algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided. RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided. RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.	
	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.	N/A – qual study	RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.	
es/ nt	8	For each variable of interest, give sources of data and details of methods of assessment (measurement).	N/A – qual study		

		Describe comparability of assessment methods if there is more than one group			
	9	Describe any efforts to address potential sources of bias	Page 4		
	10	Explain how the study size was arrived at	Page 4		
e	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	N/A quant methods not used		
	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) *Cohort study* - If applicable, explain how loss to follow-up was addressed *Case-control study* - If applicable, explain how matching of cases and controls was addressed *Cross-sectional study* - If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses	N/A stats not used		
s and ethods		..	N/A	RECORD 12.1: Authors should describe the extent to which the investigators had access to the database	

				population used to create the study population. RECORD 12.2: Authors should provide information on the data cleaning methods used in the study.	
		..	N/A	RECORD 12.3: State whether the study included person-level, institutional-level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided.	
s	13	(a) Report the numbers of individuals at each stage of the study (*e.g.*, numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram	Page 4	RECORD 13.1: Describe in detail the selection of the persons included in the study (*i.e.,* study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.	
e data	14	(a) Give characteristics of study participants (*e.g.*, demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) *Cohort study* - summarise follow-up time (*e.g.*, average and total amount)	Page 4		
ata	15	*Cohort study* - Report numbers of outcome events or summary	N/A		

		measures over time *Case-control study* - Report numbers in each exposure category, or summary measures of exposure *Cross-sectional study* - Report numbers of outcome events or summary measures			
ts	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Page 5 (Most items N/A – we used standard qualitative reporting methods)		
yses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	Page 5		
	18	Summarise key results with reference to study objectives	Page 10		
s	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Page 2, page 11	RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being	

				reported.	
on	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Page 11 (conclusions)		
bility	21	Discuss the generalisability (external validity) of the study results	Page 11 (conclusions)		
rmation					
	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Page 11		
ty of aw ng		..	N/A (original interview transcripts etc. are not publicly available for ethical reasons)	RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	

: Benchimol EI, Smeeth L, Guttmann A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD
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Understanding the needs and experiences of people with young onset dementia: a qualitative study

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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 (LOD). The aim of this study was to explore the experiences and needs of people living with YOD (under 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

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

Results

Three superordinate themes are reported on: 'process of diagnosis', 'the impact of living YOD' and 'needs of people with YOD'. Nine subordinate themes captured participant experiences of developing cognitive difficulties, being diagnosed with YOD, and subsequently living with the condition. Key issues emerging included: a lack of general awareness of YOD; how this can delay help seeking; commonalities in pre-diagnosis trajectories; retrospective understanding of pre-diagnosis symptom patterns; the difficulties of obtaining a firm diagnosis; the importance of face-to-face support; 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 psycho-social concerns not commonly well addressed by health and social care services. As awareness of YOD continues to grow, the development (or adaptation) of services which take into account the idiosyncratic needs of people with YOD should be addressed.

Strengths and limitations of the study

- The study utilises interpretative phenomenological analysis (IPA) to provide insights into the experiences of people living with YOD and the process of engaging with health and social support networks.
- Care was taken to sample a cadre with as wide a range of characteristics as possible, including gender and socio-demographic variations.

- The sample was relatively small and participants were drawn from a single region. The sample size is appropriate for an in-depth qualitative study of this nature.

- Some of the interviews were together with carers. This could potentially have impacted on what was reported by the person with YOD.

Background

There are 850,000 people living with dementia in the UK (1). 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 on their family, their carers and their wider social circle. (2) In the UK, tackling with dementia is high on the health policy agenda, and there have been a series of initiatives since the launch of the National Dementia Strategy, (3) aimed at raising awareness of the condition and improving the care available. (4,5,6,7) Similarly, the challenges encountered by those who care for people with dementia – either on a formal or informal basis – are increasingly acknowledged. (8) There have been a number of studies, (9,10,11) and policy initiatives (12,13) 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 under 65 years of age (14). This estimate is still widely quoted, however the actual number of people who currently have YOD is unknown. Although there is now a 15 year history of studies focusing on people with young onset dementia (YOD) (15) 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% (16) and again, may be attributed partly to the general perception that dementia is a condition of old age (17). Younger people who develop the condition are likely to present with a wider variety of symptoms compared to those over 65 years, (18) 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. (19,15) 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. (20) Another reason why people with YOD are currently viewed as a marginalised population may relate to the psycho-social limitations that the condition can impose. (21) This often includes social isolation, (22) and fears of stigma (20). As a result of this the likelihood that a person will become engaged in public activism or campaigning is low. (23)

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 traditional retirement age. The implications can be particularly severe (24) with a person having YOD being more likely to still be in paid employment, and may have dependents including spouses, children and/or ageing parents to support. (15,22) 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 them. (25) 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. (26) 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. (27)

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' with the unique context of their needs.

Methods

Sample

The sample comprised 14 people with YOD aged between 57-67 years. Age at diagnosis ranged from 52-64 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 on here. In-depth analysis of data from a sample of this size is appropriate for IPA.

Patient and public involvement

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 an NHS 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 took place at a time and place convenient to participants, usually their home or community support group premises. Written informed consent to audiotape interviews was obtained. The research team developed an interview topic guide in partnership with members of a dedicated study advisory group which comprised twelve people who were either living with YOD (seven) or were the carers of people living with YOD (five). The interview guide was further revised through the study's steering group which included representatives from service providing agencies, health practitioners specialising in dementia care and members of the research team. Interviews were semi-structured, narrative driven and explored issues including: participants' experiences of diagnosis; their trajectory of knowledge about the condition; use and experiences of statutory and non-statutory 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, elicited between 30 and 120 minutes of audio-recording each and were fully transcribed by an external transcription company. To ensure that the 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.

Analysis

In line with a growing number of other studies on the lived experience of dementia, interpretative phenomenological analysis (IPA) was applied. (28). IPA is an established method for researchers to explore the experience of individuals going through illness and the meanings people attach to those experiences. (29) 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 for using IPA with people with chronic illness has also been highlighted, as the approach accepts that participants are their own experts. (30) 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 respectively. 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 more substantial superordinate Themes 1 to 3 are reported upon here: *the process of diagnosis; the impact of living with YOD; and the needs of people with YOD.* The less prominent theme 'living well with YOD' is shown in Table 1 for completeness but not reported on.

Insert Table 1 about here

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 pre and post diagnostic phases. The pre-diagnosis 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 pre-diagnosis period was only really revealed and assimilated in hindsight, once a person could make retrospective connections between their 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 pre-diagnosis 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.

> 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 to be 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 health care 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 mean 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 post-diagnosis 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 twelve 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, three 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 are 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 anymore 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 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 seven or eight 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 to 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 minded 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)

Discussion

Although our sample was relatively small, for an in-depth qualitative study of this nature it was entirely adequate. 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. Currently, although medical and lay awareness about dementia issues in general is on the ascendant, (31) and the idiosyncratic collection of psycho-social issues that it engenders, remain at the margins of public awareness. (32) 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. (33) For many people with YOD, however, there are likely to be a whole raft of tangential - often age related - psycho-social 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. (34,35) 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, (36,37) 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 whilst 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. (38) In line with studies on self-identity and illness, (39,40) people may attribute these kinds of symptomatic patterns to work stress or other causes such as depression. (41)

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, (24) 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 (42,43) 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 upon 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.

Conclusions

This study used innovative participatory methods and built on existing work in this area by examining post-diagnostic 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, (15) 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 re-positioning of care pathways and social support for people with dementia (5,6). In parallel with these 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, (44) and the *Dementia Engagement and Empowerment Project (DEEP)*, (45) 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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Competing interests.
None

Ethical review.
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Author contributions:
JC led on the writing and participated in the analysis. LR gathered the data, led the analysis and participated in the writing. TW conceived the research idea and study design, and participated in the analysis and writing. MO undertook some interviews and analysis, and writing. AW contributed to writing. All authors commented on and approved the final version of the manuscript.

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No additional data are available.

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Superordinate theme	**Subordinate theme**	**Key words and issues**
1. Process of diagnosis	*Pre-diagnosis*	Warning signs, alarm bells, too young
	'Hit by a sledge hammer'	Sledgehammer, shock, lack of support, information overload
	Post-diagnosis	Benefits, no follow up, looking for answers
2. Impact of living with young onset dementia	*Impact on behavior & function*	Activities of daily living, money, cooking, communication, uncharacteristic behavior, 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, post-diagnostic support groups.
	What could be improved?	Raising dementia awareness, it's more than just memory, dementia groups
4. Living well with young onset dementia *** not reported on here**	*Psychological coping strategies*	Positivity, optimism
	Practical coping strategies	Simple things, routine, familiarity
	'Trying to keep occupied'	Therapeutic benefits of activity

Table 1: Superordinate and subordinate themes from IPA analysis of all participants living with young onset dementia

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Page/line no(s).

Title and abstract

Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 2

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Page 3 (last para) page 4 (1st / 2nd para)
Purpose or research question - Purpose of the study and specific objectives or questions	

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Page 4 (last para) page 5 (1st para)
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Page 5 (3rd para)
Context - Setting/site and salient contextual factors; rationale**	Page 4 (3rd para)
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Page 4 (3rd / 4th paras)
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 12('Ethical review')
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Page 4 (primarily last para)

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 4 (last para) Page 16 (table 1)
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 4 (4th para)
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Page 4 (last para)
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Page 5 (1st para)
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 5 (2nd para)

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pages 5 to page 10
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	As above

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Pages 10 to 11
Limitations - Trustworthiness and limitations of findings	Page 2

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	None (page 12)
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Funder Acknowledged (page 12)

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
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Understanding the needs and experiences of people with young onset dementia: a qualitative study

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

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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 (LOD). The aim of this study was to explore the experiences and needs of people living with YOD (under 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

Semi-structured, 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 young onset dementia'. Nine subordinate themes captured participant experiences of developing cognitive difficulties, being diagnosed with YOD, and subsequently living with the condition. Key issues emerging included: a lack of general awareness of YOD; how this can delay help seeking; commonalities in pre-diagnosis trajectories; retrospective understanding of pre-diagnosis symptom patterns; the difficulties of obtaining a firm diagnosis; the importance of face-to-face support; 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 psycho-social concerns not commonly well addressed by health and social care services. As awareness of YOD continues to grow, the development (or adaptation) of services which take into account the idiosyncratic needs of people with YOD should be addressed.

Strengths and limitations of the study

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

Background

There are 850,000 people living with dementia in the UK (1). 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 on their family, their carers and their wider social circle. (2) In the UK, tackling with dementia is high on the health policy agenda, and there have been a series of initiatives since the launch of the National Dementia Strategy, (3) aimed at raising awareness of the condition and improving the care available. (4,5,6,7) Similarly, the challenges encountered by those who care for people with dementia – either on a formal or informal basis – are increasingly acknowledged. (8) There have been a number of studies, (9,10,11) and policy initiatives (12,13) 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 under 65 years of age (14). This estimate is still widely quoted, however the actual number of people who currently have YOD is unknown. Although there is now a 15 year history of studies focusing on people with young onset dementia (YOD) (15) 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% (16) and again, may be attributed partly to the general perception that dementia is a condition of old age (17). Younger people who develop the condition are likely to present with a wider variety of symptoms compared to those over 65 years, (18) 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. (19,15) 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. (20) Another reason why people with YOD are currently viewed as a marginalised population may relate to the psycho-social limitations that the condition can impose. (21) This often includes social isolation, (22) and fears of stigma (20). As a result of this the likelihood that a person will become engaged in public activism or campaigning is low. (23)

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 traditional retirement age. The implications can be particularly severe (24) with a person having YOD being more likely to still be in paid employment, and may have dependents including spouses, children and/or ageing parents to support. (15,22) 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 them. (25) 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. (26) 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. (27)

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' with the unique context of their needs.

Methods

Sample

The sample comprised 14 people with YOD aged between 57-67 years. Age at diagnosis ranged from 52-64 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 on here. In-depth analysis of data from a sample of this size is appropriate for 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 an NHS 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 audiotape interviews was obtained. Interviews were semi-structured, narrative driven and explored issues including: participants' experiences of diagnosis; their trajectory of knowledge about the condition; use and experiences of statutory and non-statutory 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, elicited between 30 and 120 minutes of audio-recording each and were fully transcribed by an external transcription company. To ensure that the 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 twelve 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, interpretative phenomenological analysis (IPA) was applied. (28). IPA is an established method for researchers to explore the experience of individuals going through illness and the meanings people attach to those experiences. (29) 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 for using IPA with people with chronic illness has also been highlighted, as the approach accepts that participants are their own experts. (30) 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 respectively. 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; living well with YOD.*

Insert Table 1 about here

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 pre and post diagnostic phases. The pre-diagnosis 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 pre-diagnosis period was only really revealed and assimilated in hindsight, once a person could make retrospective connections between their 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 pre-diagnosis 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.

> 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 to be 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 health care 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 mean 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 post-diagnosis 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 twelve 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, three 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 are 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 anymore 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 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 seven or eight 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 to 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 minded 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 young onset dementia*

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 wellbeing 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 of 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 ten 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, campaigning and gaining employment in a caring capacity to support others to live well with dementia. Participants made the important link between activity and wellbeing:

> 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 principle findings of the study included: a lack of general awareness of YOD; how this can delay help seeking; commonalities in pre-diagnosis trajectories; retrospective understanding of pre-diagnosis symptom patterns; the difficulties of obtaining a firm diagnosis; the importance of face-to-face support; 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, (31) and the idiosyncratic collection of psycho-social issues that it engenders, remain at the margins of public awareness. (32) 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. (33) For many people with YOD, however, there are likely to be a whole raft of tangential - often age related - psycho-social 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. (34,35) 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, (36,37) 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 whilst 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. (38) In line with studies on self-identity and illness, (39,40) people may attribute these kinds of symptomatic patterns to work stress or other causes such as depression. (41)

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, (24) 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 (42,43) 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 upon 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 wellbeing.

Strengths and weaknesses of the 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 socio-demographic 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 socio-demographic spread of participants, which covered a range of high and low socio-economic status individuals and included people who had engaged with both NHS and private services.

In terms of unanswered questions for future research, and the implications for policy makers 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 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 post-diagnostic 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, (15) 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 re-positioning of care pathways and social support for people with dementia (5,6). In parallel with these 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, (44) and the *Dementia Engagement and Empowerment Project (DEEP)*, (45) 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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Competing interests.
None

Ethical review.

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Author contributions:

JC led on the writing and participated in the analysis. LR gathered the data, led the analysis and participated in the writing. TW conceived the research idea and study design, and participated in the analysis and writing. MO undertook some interviews and analysis, and writing. AW contributed to writing. All authors commented on and approved the final version of the manuscript.

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Superordinate theme	Subordinate theme	Key words and issues
1. Process of diagnosis	*Pre-diagnosis*	Warning signs, alarm bells, too young
	'Hit by a sledge hammer'	Sledgehammer, shock, lack of support, information overload
	Post-diagnosis	Benefits, no follow up, looking for answers
2. Impact of living with young onset dementia	*Impact on behavior & function*	Activities of daily living, money, cooking, communication, uncharacteristic behavior, 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, post-diagnostic support groups.
	What could be improved?	Raising dementia awareness, it's more than just memory, dementia groups
4. Living well with young onset dementia * not reported on here	*Psychological coping strategies*	Positivity, optimism
	Practical coping strategies	Simple things, routine, familiarity
	'Trying to keep occupied'	Therapeutic benefits of activity

Table 1: Superordinate and subordinate themes from IPA analysis of all participants living with young onset dementia

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Page/line no(s).

Title and abstract

Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 2

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Page 3 (last para) page 4 (1st / 2nd para)
Purpose or research question - Purpose of the study and specific objectives or questions	

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Page 4 (last para) page 5 (1st para)
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Page 5 (3rd para)
Context - Setting/site and salient contextual factors; rationale**	Page 4 (3rd para)
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Page 4 (3rd / 4th paras)
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 12('Ethical review')
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Page 4 (primarily last para)

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 4 (last para) Page 16 (table 1)
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 4 (4th para)
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Page 4 (last para)
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Page 5 (1st para)
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 5 (2nd para)

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pages 5 to page 10
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	As above

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Pages 10 to 11
Limitations - Trustworthiness and limitations of findings	Page 2

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	None (page 12)
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Funder Acknowledged (page 12)

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.0000000000000388