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

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Manuscripts

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)

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3 The aim of this study was to explore the experiences and needs of younger people living with
4 dementia – to facilitate an understanding of the issues that impact on them, and to identify
5 opportunities for the development of services that might be a better ‘fit’ with the unique context of
6 their needs.
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9

10 **Methods**

11 **Sample**

12
13 Study participants were recruited from a number of YOD support organisations based in the North of
14 England between February 2016 and April 2017. These included small independent organisations as
15 well as larger groups affiliated to national agencies, including the NHS and the Alzheimer’s Society.
16
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19 The maximum diversity sample comprised 14 people with young onset dementia who all obtained
20 their diagnosis before the age of 65 (see Table 1). Of these, five interviews were paired (person with
21 dementia and their carer) but the carer voices are not reported on here.
22
23

24 **Interviews**

25 Interviews took place at a time and place convenient to participants, usually their home or community
26 support group premises. Written informed consent to audiotape interviews was obtained. The
27 research team developed an interview topic guide in partnership with members of a dedicated study
28 advisory group which comprised twelve people who were either living with YOD (seven) or were the
29 carers of people living with YOD (five). The interview guide was further revised through the study’s
30 steering group which included representatives from service providing agencies, health practitioners
31 specialising in dementia care, and members of the research team. Interviews were semi-structured,
32 narrative driven and explored issues including: participants’ experiences of diagnosis; their trajectory
33 of knowledge about the condition; use and experiences of statutory and non-statutory health and
34 social care services; engagement with information resources and support organisations; and the
35 impact of dementia on their daily lives. Interviews were conducted by LR and MO, elicited between 30
36 and 120 minutes of audio-recording each and were fully transcribed by an external transcription
37 company.
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42 **Analysis**

43 In line with a growing number of other studies on the lived experience of dementia, interpretative
44 phenomenological analysis (IPA) was applied. (28). IPA is an established method for researchers to
45 explore the experience of individuals going through illness and the meanings people attach to those
46 experiences. (29) IPA fosters the incorporation of individual perspectives, and the idiosyncratic
47 meanings that participants attached to elements of their experience, which is particularly important
48 given our limited knowledge of the experience of living with YOD. The relevance for using IPA with
49 people with chronic illness has also been highlighted, as the approach accepts that participants are
50 their own experts. (30) Analysis was undertaken by LR with independent verification of emergent
51 themes with TW using a small subset of five transcripts.
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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)

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4 I didn't think of it as an illness, I just thought I was having . . . but you know you just think
5 the job is very stressful and you always have a, 'oh well, we were busy last night.'
6 (Participant 4)
7

8
9 Even after people decided to seek help, it could be difficult to get a firm diagnosis, and there was often
10 a reported struggle to be heard by health professionals:
11

12 The doctors and consultants were saying, 'no, you're too young to have dementia'. At this
13 time I was about 49. So their thinking was it could be depression or stress because I was still
14 working at this point. (Participant 1)
15

16
17 [Speaking about her GP] She put me on some tablet anyway, she said it was depression. . . I
18 said to her, look it's getting that bad I'm looking after children, I can't do it. (Participant 3)
19

20
21 Participants had mixed views on the actual process of receiving a diagnosis. As with the process of
22 being told about any life changing illness, interpersonal issues relating to the communication
23 awareness and empathy of health care practitioners was important on an individual level. However,
24 regardless of how the news was delivered, and the psychosocial support that may have been available,
25 there was unanimity over the shock of actually receiving a diagnosis:
26

27
28 . . . and then they proceeded to tell me that I had Alzheimer's. At which point I just froze
29 completely. (Participant 1)
30

31 [They said] it's early onset Alzheimer's disease, just out of the blue like that. Well I was
32 numb. (Participant 3)
33

34 . . . it was awful. I felt like I was hit by a sledgehammer. . . I felt as though somebody had
35 pulled the plug out of everything. (Participant 5)
36
37

38
39 At a practical level, a recurring issue was the amount of supporting documentation and information
40 that participants were given at the point of diagnosis, and how this could be overwhelming.
41

42 . . . and you're bombarded with, take this, take that, take this, take that. All these leaflets
43 and basically all you want to do is sit down and think it through yourselves. (Participant 9)
44

45
46 I was given a pile of documents and I went home and put them in a cupboard. I have spoken
47 to a number of people and it is a shared experience. It's all just too much to take on board
48 and really, just a page would have done to point out the services. (Participant 10)
49

50
51 The predominance of leaflets as opposed to face-to-face support was also highlighted:
52

53 When I got home I was so angry, all the leaflets went straight in the bin. That was my way of
54 thinking, I don't need the bloody leaflets, they don't mean anything to me. . . so yeah,
55 leaflets weren't I mean for me. The thing that would have helped me most would've been for
56
57

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2
3 someone to be around outside my consultation room and approach me. Not approach my
4 husband, but approach me maybe. I don't know, maybe offered me somewhere on my own
5 rather than me going out in a big black cloud into nothingness. (Participant 1)
6

7
8 Some participants felt that post-diagnosis support was lacking. One acknowledged that she was coping
9 with the help of her husband, but would have appreciated an occasional offer of support:

10
11 . . . maybe every six to twelve months to say, 'we're here!' Particularly some emotional
12 support. So I'd like somebody, not to take it out on, you know, somebody to talk to.
13 (Participant 9)
14

15
16 A similar lack of agency was acknowledged by another participant:

17
18 Nobody says, you know, 'how does that make you feel?' In my view there still isn't any
19 opportunity, three years down the line and I still haven't been able to voice how it made me
20 feel then, how I felt coping with it for the last couple of years and how my feelings are
21 towards the future. (Participant 1)
22
23

24 25 Superordinate Theme 2: *The impact of living with YOD*

26
27 The impact that dementia had on participants are grouped here into two main areas: *changes in*
28 *function and daily living*, and *emotional and psychological impact*.
29

30 31 *Changes in function and daily living*

32 The impacts on function were wide-ranging. Again, this was not always the direct result of memory
33 loss per se. For example, participants described problems with everyday activities such as dealing
34 with money:
35

36
37 I can't count money; I haven't yet worked that one out. (Participant 2)
38

39
40 Sometimes I don't carry money anymore because I could fumble with it. When I used to go
41 and pay, I couldn't count the change out. (Participant 3)
42

43
44 I was going to the bank, put my card in to get some money out, and I took the card out and
45 left the money. (Participant 7)
46

47
48 I would, for example, go for my lunch or go into a shop and if they said that something was
49 35 pence and I took the change out of my pocket, I couldn't count it. (Participant 10)
50

51 Communication issues, including the inability to maintain concentration during conversations and
52 losing the thread during interaction were highlighted. Frequently reported was an increasing difficulty
53 in 'finding the right word', and other more individualistic effects such as difficulty in recognising faces,
54 pronunciation and speech production. There were less obvious problems too, such as only being able
55 to concentrate on thinking about one thing at a time, which could have a broad impact on many
56
57

1
2
3 aspects of daily life. Participants 4, 12 and 13, described noticing themselves becoming
4 uncharacteristically confused and forgetful at work:
5

6 Well in my job [nursing] I was forgetting a lot of things, which I hadn't done before. I was a
7 perfectionist in my job and I was then forgetting, not forgetting how to do things but – yes, I
8 suppose, in a way. What was happening was I was forgetting parts of what I was doing. . .
9 One night I came back and they said, 'oh, how was such and such a body?' And I went, 'oh, I
10 can't remember what I gave him.' So they were all going round and asking was it this? Was it
11 that? And we have got like 12 of us in the office and they are all shouting out 'oh, is it this or
12 is it that?' And then all of a sudden somebody said the word and I went 'Yes! That's what I've
13 done, that's it' And I got a round of applause. . . (Participant 4)
14
15

16
17 And actually, I think that was the time when I really thought, maybe I have got something.
18 But I wrote the bloody thing and I couldn't remember it. (Participant 12)
19

20
21 I absolutely loved my job and then it just, I started, I realised that it was, I would come in the
22 following day and couldn't remember what I'd worked on the night before. (Participant 13)
23

24 *Emotional and psychological impact*

25 Participants described their struggles and fears around living with dementia. These included
26 uncertainty for the future and concerns about putting themselves at risk while struggling to maintain
27 an image of themselves as 'normal' members of the community. A sense of trying to cover things up,
28 and keep the realities of the condition hidden was evident:
29

30
31 I cover up a lot. . . If I'm in a doctor's surgery I will get a magazine and flip through it. I can
32 read the words but it doesn't make sense what's there. I don't understand what I'm reading
33 but I wouldn't give people the satisfaction of thinking. . . To them they probably just think I'm
34 reading. So really you mask a lot of things just to try and still fit in with society so you're not,
35 like, different. (Participant 3)
36
37

38
39 You know you sort of live a double life almost. You know, you're sort of, 'yeah I'm fine, I'm
40 fine.' But underneath you're thinking well am I going to see my grandkids grow up?
41 (Participant 1)
42

43 The importance of work, not only as a source of income but also of identity, was highlighted by
44 participants. Also what was striking was the deep sense of loss that could occur when people
45 were forced to stop working because of their cognitive difficulties – even if YOD had not yet been
46 formally diagnosed. Eight of the interviewees with YOD were in paid employment at the time of
47 their diagnosis.
48

49
50 I had to give up work and that was devastating, being a carer. When I realised that my clients
51 were in danger, I thought I can't carry on with my job. (Participant 1)
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3 [In a hospital] you see, if you are making a mistake, somebody is going to get hurt. That was
4 the problem. That's why, when I went to see them, they told me I couldn't work anymore.
5 (Participant 4)
6

7
8 Superordinate Theme 3: *The needs of people with young onset dementia*
9

10 The majority of participants felt that the support of their family, friends and other people living with
11 dementia was crucial. Those who did not have spouses often had a key person, possibly a close friend
12 or child, who provided emotional and practical support:
13

14 [Talking about her daughter] She has gone through a lot with me in the last 12 months. . .
15 and we have good communication, she can read me, she knows when I walk through that
16 door in the morning, she knows if it's a good or bad day. (Participant 6)
17
18

19 Dementia-specific community groups were also seen as a significant source of support, and the
20 importance of being able to relate to other people who had been, or were currently going through, a
21 similar experience was highlighted:
22

23 . . . because there is nothing like having somebody who has got the same problem telling
24 you how to cope with it, you know. Because you have been there, you have done it and you
25 have got the t-shirt. I found [name of a high-profile UK dementia activist] was the best
26 ambassador for it, because I looked at him and I thought, that's how I want to be in seven
27 or eight years. (Participant 4)
28
29
30

31 I find that I am getting more support through people from the groups. (Participant 8)
32
33

34 However, participants reported that it was important for the support they were offered to take into
35 account that they may have different needs and interests to older people with dementia. Support
36 groups that were specifically organised for people with YOD, rather than dementia in general were
37 praised because they offered age-appropriate activities and – at their best – helped to develop a sense
38 of independence and empowerment.
39
40

41 I think people of my own age, if they set up a group for them. Because we are probably a bit
42 more able minded to do things, our faculties are probably a little bit better than maybe the
43 older ones are. . . because everything at the moment is based on older people. . .it's like
44 being in school and it's all old war songs. Well I wasn't even born in the war. (Participant 3)
45
46

47 There was also a strong sense that any new initiatives need to acknowledge that not everybody will
48 wish to engage with 'traditional' dementia support group formats – singing groups, reminiscence
49 groups and so on. Again, this was largely because of the perception that these groups catered mainly
50 for older people. Participants, who were still living independently, expressed a need for a less formal
51 approach in how dementia group sessions were booked and arranged:
52
53

54 [If] you have a singing group for dementia, why do I have to make an appointment? Surely I
55 should be able to just walk through the door and go 'hello, I am such a body, I've got young
56
57
58

1
2
3 onset dementia, can I see what you're about please?' I shouldn't have to phone up and
4 have to book in. . . It's the way they run their groups, this phone up and book in. Sorry, but
5 how can anyone with dementia, unless they've got a carer, remember to phone up and
6 book a spot? (Participant 6)
7
8
9

10 Discussion

11 Participants described in detail their particular experiences of receiving a diagnosis of dementia at a
12 relatively young age, and coming to terms with the situation they found themselves in. Currently,
13 although medical and lay awareness about dementia issues in general is on the ascendant, (31) and
14 the idiosyncratic collection of psycho-social issues that it engenders, remain at the margins of public
15 awareness. (32) People who are formally diagnosed can find themselves in a position where, for the
16 purposes of many health and social support interventions, their needs are aggregated with those of
17 people who develop dementia much later in life. On one level this may not appear to be a significant
18 issue; functionally, the symptoms exhibited by both cohorts will be similar, and so too will be the
19 choice of treatments and therapies available. (33) For many people with YOD, however, there are likely
20 to be a whole raft of tangential - often age related - psycho-social issues, such as still being in
21 employment or in a spousal relationship, that have a profound impact on the way in which they come
22 to terms with their condition and whether or not they develop effective ways of living with it.
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27 The findings from this study concur with other work which has highlighted that people with YOD face a
28 range of specific difficulties that do not necessarily impact on older people to the same degree. (34,35)
29 The often lengthy period leading up to the point at which a person recognises that they need to seek
30 help is the first of these. In line with other studies, (36,37) for a number of our participants, the initial
31 signs that something was wrong were not directly related to memory problems, but to wider and more
32 general cognitive anomalies or behavioural changes, with eight participants first noticing problems
33 whilst at work. Basic memory issues such as increasing forgetfulness could be a significant element,
34 but might well only have been one of a variety of sporadic perturbations in spatial awareness or
35 episodes of general confusion. Again, with an older person, the onset of such symptoms might readily
36 indicate the onset of dementia. But with younger people, connections are often not made until much
37 further on in the disease process. (38) In line with studies on self-identity and illness, (39,40) people
38 may attribute these kinds of symptomatic patterns to work stress or other causes such as depression.
39
40
41
42 (41)
43

44 Although, as we have outlined, there have been significant positive developments at both a national
45 and local level in the re-positioning of care pathways and social support for people with dementia,
46 (5,6) it was evident that the process of receiving and accepting a diagnosis of YOD was extremely
47 difficult for most people. At an interactional level there have been few recommendations relating to
48 how health professionals might better adapt their approach to delivering a diagnosis – one that might,
49 for example, more readily take into account the perspective of the younger person. Furthermore,
50 although there have been significant improvements in the provision of relevant health and support
51 information in recent years, (24) this in itself appears to be causing some problems, not least that the
52 major part of it is still skewed towards older patients and their carers. As has been suggested in studies
53 on information provision for other serious conditions (42,43) people in this study reported feeling
54 overwhelmed at the point of diagnosis by the sheer amount of material they were given, to the point
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3 where they simply disengaged with it. For a condition that can place such restrictions on cognitive
4 processes, more effective and streamlined ways of delivering information tailored specifically for those
5 with YOD need to be devised.
6

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8 Unlike those who develop dementia after they reach traditional retirement age, people with YOD will
9 commonly be in employment or eligible for employment at diagnosis. Having to give up work or the
10 prospect of preferred work, and the severe implications this has on many levels, was a recurring
11 theme. Ironically, still being engaged in a work environment and being in a position where subtle
12 changes in behaviour and cognitive ability might be more readily noticed – both by the person
13 themselves and also by their co-workers – could be a significant trigger in prompting people to seek
14 help. Occasionally this decision may be forced upon them, particularly if they work in a field where
15 their ability and actions could be a danger to others, such as healthcare, making the experience
16 particularly difficult.
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19
20 Study participants were clear about the importance they placed on family, friends and peers (other
21 people living with dementia) as a source of support, at both a psychological and practical level. The
22 study suggests, however, that as with information provision and care pathway engagement, attitudes
23 towards formal and informal support groups can be ambiguous. While efforts to provide such support
24 were universally appreciated, there was a definite sense that the traditional forms of dementia
25 focused support group do not always follow formats, or offer activities that younger people wish to
26 engage with. More passive reminiscence based activities, for example, that are very common in care
27 homes and other environments that support older people with dementia, are often focused on periods
28 before some people with YOD were born, and may not resonate well with them.
29
30
31

32 33 **Conclusions**

34 Participants in this study gave detailed accounts of their needs and experiences relating to living with
35 YOD, and described a wide range of issues that affected them. Our findings suggest that those who
36 have a diagnosis of YOD see themselves as distinct from older people with the condition – even if they
37 experience similar symptoms. As awareness of YOD continues to grow, the development (or
38 adaptation) of support services which can take into account the particular requirements of this
39 younger group need to be addressed. Although the number of people with YOD is admittedly
40 extremely small when compared with the number of older people with dementia, there is potential for
41 incremental (and inexpensive) adjustments to existing health and social care interventions which could
42 make a significant difference to their ability to live independently, with good quality of life, for as long
43 as possible.
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47
48

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51 study was: *'Living well with young onset dementia - Humphrey Booth Resource Centre as a hub of
52 excellence in a system of support.'*
53
54

55 **Competing interests.**

56 None
57
58
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60

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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Data Sharing:

No additional data are available.

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55 UK cancer patients. *European Journal of Oncology Nursing*. 2006;10.4:263-272.
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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
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1				
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3				
4	1. Process of diagnosis	<i>Pre-diagnosis</i>	Warning signs, alarm bells, too young	
5		<i>'Hit by a sledge hammer'</i>	Sledgehammer, shock, lack of support, information overload	
6		<i>Post-diagnosis</i>	Benefits, no follow up, looking for answers	
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13	2. Impact of living with young onset dementia	<i>Impact on behavior & function</i>	Activities of daily living, money, cooking, communication, uncharacteristic behavior, loss of self	
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19		<i>Psychological impact</i>	Fear of the future, covering up, living a double life	
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23		<i>Impact on work</i>	Devastation, loss, forgetting things	
24	3. Needs of people with young onset dementia	<i>'They are my rock'</i>	Support, friends and family, spouse	
25				
26				
27		<i>What helps?</i>	Peer support, Open Doors Network, Mount Chapel Champions	
28				
29				
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31				
32		<i>What could be improved?</i>	Raising dementia awareness, it's more than just memory, dementia groups	
33				
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36	4. Living well with young onset dementia	<i>Psychological coping strategies</i>	Positivity, optimism	
37				
38	* not reported on here			
39		<i>Practical coping strategies</i>	Simple things, routine, familiarity	
40				
41				
42		<i>'Trying to keep occupied'</i>		
43				
44				
45			Therapeutic benefits of activity	
46				

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

STROBE statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies that collect health data.

Understanding 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 in manuscript where items are reported
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)	<p>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.</p> <p>RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract.</p> <p>RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.</p>	
2	Explain the scientific background and rationale for the investigation being reported	Page 3		
3	State specific objectives, including any prespecified hypotheses	Page 3		
4	Present key elements of study design early in the paper	Page 3		

1 2 3 4	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Page 3		
5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32	6	<p>(a) <i>Cohort study</i> - Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up</p> <p><i>Case-control study</i> - 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</p> <p><i>Cross-sectional study</i> - Give the eligibility criteria, and the sources and methods of selection of participants</p> <p>(b) <i>Cohort study</i> - For matched studies, give matching criteria and number of exposed and unexposed</p> <p><i>Case-control study</i> - For matched studies, give matching criteria and the number of controls per case</p>	Page 4 (sample)	<p>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.</p> <p>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.</p> <p>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.</p>	
33 34 35 36 37 38 39	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.	
40 41 42 43	8	For each variable of interest, give sources of data and details of methods of assessment (measurement).	N/A – qual study		

1		Describe comparability of assessment methods if there is more than one group		
2				
3				
4	9	Describe any efforts to address potential sources of bias	Page 4	
5				
6				
7	10	Explain how the study size was arrived at	Page 4	
8				
9				
10				
11	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				
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16	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) <i>Cohort study</i> - If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> - If applicable, explain how matching of cases and controls was addressed <i>Cross-sectional study</i> - If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses	N/A stats not used	
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43		..	N/A	RECORD 12.1: Authors should describe the extent to which the investigators had access to the database

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1				population used to create the study population.	
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3					
4				RECORD 12.2: Authors should provide information on the data cleaning methods used in the study.	
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7		..	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.	
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17	13	(a) Report the numbers of individuals at each stage of the study (<i>e.g.</i> , 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>i.e.</i> , 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.	
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29	14	(a) Give characteristics of study participants (<i>e.g.</i> , 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) <i>Cohort study</i> - summarise follow-up time (<i>e.g.</i> , average and total amount)	Page 4		
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42	15	<i>Cohort study</i> - Report numbers of outcome events or summary	N/A		
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1		measures over time		
2		<i>Case-control study</i> - Report		
3		numbers in each exposure		
4		category, or summary measures		
5		of exposure		
6		<i>Cross-sectional study</i> - Report		
7		numbers of outcome events or		
8		summary measures		
9				
10	16	(a) Give unadjusted estimates	Page 5	
11		and, if applicable, confounder-	(Most items N/A –	
12		adjusted estimates and their	we used standard	
13		precision (e.g., 95% confidence	qualitative reporting	
14		interval). Make clear which	methods)	
15		confounders were adjusted for		
16		and why they were included		
17		(b) Report category boundaries		
18		when continuous variables were		
19		categorized		
20		(c) If relevant, consider		
21		translating estimates of relative		
22		risk into absolute risk for a		
23		meaningful time period		
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26	17	Report other analyses done—	Page 5	
27		e.g., analyses of subgroups and		
28		interactions, and sensitivity		
29		analyses		
30				
31	18	Summarise key results with	Page 10	
32		reference to study objectives		
33				
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35	19	Discuss limitations of the study,	Page 2, page 11	RECORD 19.1: Discuss the
36		taking into account sources of		implications of using data that were not
37		potential bias or imprecision.		created or collected to answer the
38		Discuss both direction and		specific research question(s). Include
39		magnitude of any potential bias		discussion of misclassification bias,
40				unmeasured confounding, missing
41				data, and changing eligibility over
42				time, as they pertain to the study being
43				

1				reported.	
2	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)		
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10	21	Discuss the generalisability (external validity) of the study results	Page 11 (conclusions)		
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14	Information				
15	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		
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21		..	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.	
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31: Benichou EI, Smeeth L, Guttman A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD
 32: Statement. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Med*
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Understanding the needs and experiences of people with young onset dementia: a qualitative study

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Manuscripts

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

1
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3 services because mainstream dementia care services are aimed primarily at older adults and are often
4 not suitable to their requirements. (26) Furthermore, services for younger people with dementia are
5 often overlooked in mental health strategies which tend to default to the needs of older adults and
6 they are frequently excluded from working age mental health services, reinforcing dementia as an
7 older person's illness. (27)
8
9

10 The aim of this study was to explore the experiences and needs of younger people living with
11 dementia – to facilitate an understanding of the issues that impact on them, and to identify
12 opportunities for the development of services that might be a better 'fit' with the unique context of
13 their needs.
14
15

16 17 18 **Methods**

19 20 **Sample**

21 The sample comprised 14 people with YOD aged between 57-67 years. Age at diagnosis ranged from
22 52-64 years. All had obtained their diagnosis before the age of 65. Of these, five interviews were
23 paired (person with dementia and their carer) but the carer voices are not reported on here. In-depth
24 analysis of data from a sample of this size is appropriate for IPA.
25
26

27 28 **Patient and public involvement**

29 Study participants were recruited from a number of YOD support organisations based in the North of
30 England between February 2016 and April 2017. These were third sector organisations including a
31 local group affiliated to Age UK, which supported around 50 people with YOD, and a not for profit
32 community interest company providing person centred support to people living with dementia which
33 currently dealt with over 200 referrals a year. Participants were also recruited from an NHS
34 neurological unit which processed the majority of regional referrals for dementia assessment. All
35 participants were given the opportunity to receive ongoing updates from the study, as well as any
36 published outputs.
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39
40 Interviews took place at a time and place convenient to participants, usually their home or community
41 support group premises. Written informed consent to audiotape interviews was obtained. The
42 research team developed an interview topic guide in partnership with members of a dedicated study
43 advisory group which comprised twelve people who were either living with YOD (seven) or were the
44 carers of people living with YOD (five). The interview guide was further revised through the study's
45 steering group which included representatives from service providing agencies, health practitioners
46 specialising in dementia care and members of the research team. Interviews were semi-structured,
47 narrative driven and explored issues including: participants' experiences of diagnosis; their trajectory
48 of knowledge about the condition; use and experiences of statutory and non-statutory health and
49 social care services; engagement with information resources and support organisations; and the
50 impact of dementia on their daily lives.
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52

53
54 Interviews were conducted by LR and MO, elicited between 30 and 120 minutes of audio-recording
55 each and were fully transcribed by an external transcription company. To ensure that the PWD had the
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3 dominant voice during interviews that were conducted with carers present, questions were directed
4 primarily at the PWD; the carer would interject if they felt they had extra information to support what
5 the PWD was saying.
6
7

8 9 **Analysis**

10 In line with a growing number of other studies on the lived experience of dementia, interpretative
11 phenomenological analysis (IPA) was applied. (28). IPA is an established method for researchers to
12 explore the experience of individuals going through illness and the meanings people attach to those
13 experiences. (29) IPA fosters the incorporation of individual perspectives, and the idiosyncratic
14 meanings that participants attached to elements of their experience, which is particularly important
15 given our limited knowledge of the experience of living with YOD. The relevance for using IPA with
16 people with chronic illness has also been highlighted, as the approach accepts that participants are
17 their own experts. (30) Analysis was undertaken by LR with independent verification of emergent
18 themes with TW using a small subset of five transcripts.
19
20
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22 At a practical level, transcripts were first analysed individually and read several times while
23 simultaneously listening to the audio-recording. The written content was formatted into a table to
24 facilitate the annotation process. First, simple, descriptive comments were made while reading and
25 listening to the transcript in order to reveal the content. The process was repeated a second and third
26 time to note linguistic (use of language, laughter and voice tone) and conceptual (questions and
27 interpretations of the text) comments respectively. The conceptual level of annotation is particularly
28 important because it adds depth to the analysis. Various techniques were employed to search for
29 connections across themes, on a case by case basis. These included abstraction (grouping similar
30 themes), polarisation (focusing on differences between themes) and numeration (looking at
31 frequencies of themes). The result was a list of superordinate themes and their respective subordinate
32 themes for each participant.
33
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39 **Results**

40 The analysis revealed four superordinate themes that represent prominent features of participants'
41 stories collectively. The superordinate themes each comprise three subordinate themes (see Table 1)
42 which vary in terms of their contribution from individual participants. In line with IPA philosophy,
43 unique and common elements from the perspectives of participants are therefore represented. The
44 more substantial superordinate Themes 1 to 3 are reported upon here: *the process of diagnosis; the*
45 *impact of living with YOD; and the needs of people with YOD*. The less prominent theme 'living well
46 with YOD' is shown in Table 1 for completeness but not reported on.
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48
49
50

51 **Insert Table 1 about here**

52
53 Superordinate Theme 1: *The process of diagnosis*
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3 Participants talked extensively about how they received their diagnosis and the impact that this had on
4 them, their families, and their wider social circle. The experience was characterised by a distinction
5 between pre and post diagnostic phases. The pre-diagnosis phase was the period when the first subtle
6 signs and changes in behaviour started to occur. It could be a particularly difficult and uncertain time
7 for people who were still likely to be active, working and looking after dependents. It was usual for
8 people who began to experience problems in carrying out their usual routines to battle to maintain
9 control until a point of crisis forced them to seek help. The pre-diagnosis period was only really
10 revealed and assimilated in hindsight, once a person could make retrospective connections between
11 their gradually emerging symptoms – such as confusion and increasing memory problems – and their
12 condition.
13
14
15

16 A lack of awareness relating to YOD was reported by participants in the pre-diagnosis phase. In some
17 cases, this had delayed the point at which they sought help. The interviewees gave a number of
18 examples of signs and symptoms that were experienced during the early stages of their condition, but
19 as these could occur in isolation, and were not always to do with memory issues, they were not
20 immediately seen as indicators of a single underlying condition.
21
22

23 I found that my concentration wasn't the same. I could be stood cooking something and I'd
24 go away and then I'd forget, until the smoke alarm was going off. . . I was decorating the
25 bathroom at the time, I'd got the first piece of paper up then I couldn't fathom out how to
26 match and I thought oh this isn't right . . . I could plug in the vacuum cleaner but I didn't
27 know how to turn it on. (Participant 3)
28
29

30 I didn't think of it as an illness, I just thought I was having . . . but you know you just think
31 the job is very stressful and you always have a, 'oh well, we were busy last night.'
32 (Participant 4)
33
34

35 Even after people decided to seek help, it could be difficult to get a firm diagnosis, and there was often
36 a reported struggle to be heard by health professionals:
37
38

39 The doctors and consultants were saying, 'no, you're too young to have dementia'. At this
40 time I was about 49. So their thinking was it could be depression or stress because I was still
41 working at this point. (Participant 1)
42
43

44 [Speaking about her GP] She put me on some tablet anyway, she said it was depression. . . I
45 said to her, look it's getting that bad I'm looking after children, I can't do it. (Participant 3)
46
47

48 Participants had mixed views on the actual process of receiving a diagnosis. As with the process of
49 being told about any life changing illness, interpersonal issues relating to the communication
50 awareness and empathy of health care practitioners was important on an individual level. However,
51 regardless of how the news was delivered, and the psychosocial support that may have been available,
52 there was unanimity over the shock of actually receiving a diagnosis:
53
54

55 . . . and then they proceeded to tell me that I had Alzheimer's. At which point I just froze
56 completely. (Participant 1)
57
58

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3
4 [They said] it's early onset Alzheimer's disease, just out of the blue like that. Well I was
5 numb. (Participant 3)
6

7 . . . it was awful. I felt like I was hit by a sledgehammer. . . I felt as though somebody had
8 pulled the plug out of everything. (Participant 5)
9

10
11 At a practical level, a recurring issue was the amount of supporting documentation and information
12 that participants were given at the point of diagnosis, and how this could be overwhelming.
13

14 . . . and you're bombarded with, take this, take that, take this, take that. All these leaflets
15 and basically all you want to do is sit down and think it through yourselves. (Participant 9)
16

17
18 I was given a pile of documents and I went home and put them in a cupboard. I have spoken
19 to a number of people and it is a shared experience. It's all just too much to take on board
20 and really, just a page would have done to point out the services. (Participant 10)
21

22
23 The predominance of leaflets as opposed to face-to-face support was also highlighted:
24

25
26 When I got home I was so angry, all the leaflets went straight in the bin. That was my way of
27 thinking, I don't need the bloody leaflets, they don't mean anything to me. . . so yeah,
28 leaflets weren't I mean for me. The thing that would have helped me most would've been for
29 someone to be around outside my consultation room and approach me. Not approach my
30 husband, but approach me maybe. I don't know, maybe offered me somewhere on my own
31 rather than me going out in a big black cloud into nothingness. (Participant 1)
32

33
34 Some participants felt that post-diagnosis support was lacking. One acknowledged that she was coping
35 with the help of her husband, but would have appreciated an occasional offer of support:
36

37 . . . maybe every six to twelve months to say, 'we're here!' Particularly some emotional
38 support. So I'd like somebody, not to take it out on, you know, somebody to talk to.
39 (Participant 9)
40

41
42 A similar lack of agency was acknowledged by another participant:
43

44
45 Nobody says, you know, 'how does that make you feel?' In my view there still isn't any
46 opportunity, three years down the line and I still haven't been able to voice how it made me
47 feel then, how I felt coping with it for the last couple of years and how my feelings are
48 towards the future. (Participant 1)
49

50
51
52 Superordinate Theme 2: *The impact of living with YOD*
53

54 The impact that dementia had on participants are grouped here into two main areas: *changes in*
55 *function and daily living, and emotional and psychological impact.*
56

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:

1
2
3
4 I cover up a lot. . . If I'm in a doctor's surgery I will get a magazine and flip through it. I can
5 read the words but it doesn't make sense what's there. I don't understand what I'm reading
6 but I wouldn't give people the satisfaction of thinking. . . To them they probably just think I'm
7 reading. So really you mask a lot of things just to try and still fit in with society so you're not,
8 like, different. (Participant 3)
9

10
11 You know you sort of live a double life almost. You know, you're sort of, 'yeah I'm fine, I'm
12 fine.' But underneath you're thinking well am I going to see my grandkids grow up?
13 (Participant 1)
14

15 The importance of work, not only as a source of income but also of identity, was highlighted by
16 participants. Also what was striking was the deep sense of loss that could occur when people
17 were forced to stop working because of their cognitive difficulties – even if YOD had not yet been
18 formally diagnosed. Eight of the interviewees with YOD were in paid employment at the time of
19 their diagnosis.
20

21
22 I had to give up work and that was devastating, being a carer. When I realised that my clients
23 were in danger, I thought I can't carry on with my job. (Participant 1)
24
25
26
27

28 [In a hospital] you see, if you are making a mistake, somebody is going to get hurt. That was
29 the problem. That's why, when I went to see them, they told me I couldn't work anymore.
30 (Participant 4)
31
32

33 Superordinate Theme 3: *The needs of people with YOD*

34

35 The majority of participants felt that the support of their family, friends and other people living with
36 dementia was crucial. Those who did not have spouses often had a key person, possibly a close friend
37 or child, who provided emotional and practical support:
38
39

40 [Talking about her daughter] She has gone through a lot with me in the last 12 months. . .
41 and we have good communication, she can read me, she knows when I walk through that
42 door in the morning, she knows if it's a good or bad day. (Participant 6)
43
44

45 Dementia-specific community groups were also seen as a significant source of support, and the
46 importance of being able to relate to other people who had been, or were currently going through, a
47 similar experience was highlighted:
48
49

50 . . . because there is nothing like having somebody who has got the same problem telling
51 you how to cope with it, you know. Because you have been there, you have done it and you
52 have got the t-shirt. I found [name of a high-profile UK dementia activist] was the best
53 ambassador for it, because I looked at him and I thought, that's how I want to be in seven
54 or eight years. (Participant 4)
55
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2
3 I find that I am getting more support through people from the groups. (Participant 8)
4

5 However, participants reported that it was important for the support they were offered to take into
6 account that they may have different needs and interests to older people with dementia. Support
7 groups that were specifically organised for people with YOD, rather than dementia in general were
8 praised because they offered age-appropriate activities and – at their best – helped to develop a sense
9 of independence and empowerment.
10

11
12 I think people of my own age, if they set up a group for them. Because we are probably a bit
13 more able minded to do things, our faculties are probably a little bit better than maybe the
14 older ones are. . . . because everything at the moment is based on older people. . . it's like
15 being in school and it's all old war songs. Well I wasn't even born in the war. (Participant 3)
16
17

18 There was also a strong sense that any new initiatives need to acknowledge that not everybody will
19 wish to engage with 'traditional' dementia support group formats – singing groups, reminiscence
20 groups and so on. Again, this was largely because of the perception that these groups catered mainly
21 for older people. Participants, who were still living independently, expressed a need for a less formal
22 approach in how dementia group sessions were booked and arranged:
23
24

25
26 [If] you have a singing group for dementia, why do I have to make an appointment? Surely I
27 should be able to just walk through the door and go 'hello, I am such a body, I've got young
28 onset dementia, can I see what you're about please?' I shouldn't have to phone up and
29 have to book in. . . It's the way they run their groups, this phone up and book in. Sorry, but
30 how can anyone with dementia, unless they've got a carer, remember to phone up and
31 book a spot? (Participant 6)
32
33

34 35 Discussion

36 Although our sample was relatively small, for an in-depth qualitative study of this nature it was entirely
37 adequate. Participants described in detail their particular experiences of receiving a diagnosis of
38 dementia at a relatively young age, and coming to terms with the situation they found themselves in.
39 Currently, although medical and lay awareness about dementia issues in general is on the ascendant,
40 (31) and the idiosyncratic collection of psycho-social issues that it engenders, remain at the margins of
41 public awareness. (32) People who are formally diagnosed can find themselves in a position where, for
42 the purposes of many health and social support interventions, their needs are aggregated with those
43 of people who develop dementia much later in life. On one level this may not appear to be a significant
44 issue; functionally, the symptoms exhibited by both cohorts will be similar, and so too will be the
45 choice of treatments and therapies available. (33) For many people with YOD, however, there are likely
46 to be a whole raft of tangential - often age related - psycho-social issues, such as still being in
47 employment or in a spousal relationship, that have a profound impact on the way in which they come
48 to terms with their condition and whether or not they develop effective ways of living with it.
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54 The findings from this study concur with other work which has highlighted that people with YOD face a
55 range of specific difficulties that do not necessarily impact on older people to the same degree. (34,35)
56 The often lengthy period leading up to the point at which a person recognises that they need to seek
57

1
2
3 help is the first of these. In line with other studies, (36,37) for a number of our participants, the initial
4 signs that something was wrong were not directly related to memory problems, but to wider and more
5 general cognitive anomalies or behavioural changes, with eight participants first noticing problems
6 whilst at work. Basic memory issues such as increasing forgetfulness could be a significant element,
7 but might well only have been one of a variety of sporadic perturbations in spatial awareness or
8 episodes of general confusion. Again, with an older person, the onset of such symptoms might readily
9 indicate the onset of dementia. But with younger people, connections are often not made until much
10 further on in the disease process. (38) In line with studies on self-identity and illness, (39,40) people
11 may attribute these kinds of symptomatic patterns to work stress or other causes such as depression.
12
13 (41)
14
15

16 It was evident that the process of receiving and accepting a diagnosis of YOD was extremely difficult
17 for most people. At an interactional level there have been few recommendations relating to how
18 health professionals might better adapt their approach to delivering a diagnosis – one that might, for
19 example, more readily take into account the perspective of the younger person. Furthermore,
20 although there have been significant improvements in the provision of relevant health and support
21 information in recent years, (24) this in itself appears to be causing some problems, not least that the
22 major part of it is still skewed towards older patients and their carers. As has been suggested in studies
23 on information provision for other serious conditions (42,43) people in this study reported feeling
24 overwhelmed at the point of diagnosis by the sheer amount of material they were given, to the point
25 where they simply disengaged with it. For a condition that can place such restrictions on cognitive
26 processes, more effective and streamlined ways of delivering information tailored specifically for those
27 with YOD need to be devised.
28
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30

31 Unlike those who develop dementia after they reach traditional retirement age, people with YOD will
32 commonly be in employment or eligible for employment at diagnosis. Having to give up work or the
33 prospect of preferred work, and the severe implications this has on many levels, was a recurring
34 theme. Ironically, still being engaged in a work environment and being in a position where subtle
35 changes in behaviour and cognitive ability might be more readily noticed – both by the person
36 themselves and also by their co-workers – could be a significant trigger in prompting people to seek
37 help. Occasionally this decision may be forced upon them, particularly if they work in a field where
38 their ability and actions could be a danger to others, such as healthcare, making the experience
39 particularly difficult.
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44 Study participants were clear about the importance they placed on family, friends and peers (other
45 people living with dementia) as a source of support, at both a psychological and practical level. The
46 study suggests, however, that as with information provision and care pathway engagement, attitudes
47 towards formal and informal support groups can be ambiguous. While efforts to provide such support
48 were universally appreciated, there was a definite sense that the traditional forms of dementia
49 focused support group do not always follow formats, or offer activities that younger people wish to
50 engage with. More passive reminiscence based activities, for example, that are very common in care
51 homes and other environments that support older people with dementia, are often focused on periods
52 before some people with YOD were born, and may not resonate well with them.
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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.

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

1. Process of diagnosis	<i>Pre-diagnosis</i>	Warning signs, alarm bells, too young
	<i>'Hit by a sledge hammer'</i>	Sledgehammer, shock, lack of support, information overload
	<i>Post-diagnosis</i>	Benefits, no follow up, looking for answers
2. Impact of living with young onset dementia	<i>Impact on behavior & function</i>	Activities of daily living, money, cooking, communication, uncharacteristic behavior, loss of self
	<i>Psychological impact</i>	Fear of the future, covering up, living a double life
	<i>Impact on work</i>	Devastation, loss, forgetting things

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3 **3. Needs of people with young**
4 **onset dementia**

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'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

<p>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</p>	Page 1
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	Page 2

Introduction

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

Methods

<p>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**</p>	Page 4 (last para) page 5 (1 st para)
<p>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</p>	Page 5 (3 rd para)
<p>Context - Setting/site and salient contextual factors; rationale**</p>	Page 4 (3 rd para)
<p>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**</p>	Page 4 (3 rd / 4 th paras)
<p>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</p>	Page 12('Ethical review')
<p>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**</p>	Page 4 (primarily last para)

1 2 3 4 5	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)
6 7 8	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 (4 th para)
9 10 11 12	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)
13 14 15 16	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 (1 st para)
17 18 19 20	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 5 (2 nd para)

Results/findings

23 24 25 26	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
27 28 29	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	As above

Discussion

32 33 34 35 36 37	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
38 39	Limitations - Trustworthiness and limitations of findings	Page 2

Other

42 43 44	Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	None (page 12)
45 46 47	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.

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**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

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3 not suitable to their requirements. (26) Furthermore, services for younger people with dementia are
4 often overlooked in mental health strategies which tend to default to the needs of older adults and
5 they are frequently excluded from working age mental health services, reinforcing dementia as an
6 older person's illness. (27)
7

8
9 The aim of this study was to explore the experiences and needs of younger people living with
10 dementia – to facilitate an understanding of the issues that impact on them, and to identify
11 opportunities for the development of services that might be a better 'fit' with the unique context of
12 their needs.
13

14 15 16 **Methods**

17 18 19 **Sample**

20 The sample comprised 14 people with YOD aged between 57-67 years. Age at diagnosis ranged from
21 52-64 years. All had obtained their diagnosis before the age of 65. Of these, five interviews were
22 paired (person with dementia and their carer) but the carer voices are not reported on here. In-depth
23 analysis of data from a sample of this size is appropriate for IPA.
24
25

26 27 **Recruitment**

28 Study participants were recruited from a number of YOD support organisations based in the North of
29 England between February 2016 and April 2017. These were third sector organisations including a
30 local group affiliated to Age UK, which supported around 50 people with YOD, and a not for profit
31 community interest company providing person centred support to people living with dementia which
32 currently dealt with over 200 referrals a year. Participants were also recruited from an NHS
33 neurological unit which processed the majority of regional referrals for dementia assessment. All
34 participants were given the opportunity to receive ongoing updates from the study, as well as any
35 published outputs.
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37

38 39 **Interviews**

40 Interviews took place at a time and place convenient to participants, usually their home or community
41 support group premises. Written informed consent to audiotape interviews was obtained. Interviews
42 were semi-structured, narrative driven and explored issues including: participants' experiences of
43 diagnosis; their trajectory of knowledge about the condition; use and experiences of statutory and
44 non-statutory health and social care services; engagement with information resources and support
45 organisations; and the impact of dementia on their daily lives.
46
47

48 Interviews were conducted by LR and MO, elicited between 30 and 120 minutes of audio-recording
49 each and were fully transcribed by an external transcription company. To ensure that the PWD had the
50 dominant voice during interviews that were conducted with carers present, questions were directed
51 primarily at the PWD; the carer would interject if they felt they had extra information to support what
52 the PWD was saying.
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55 56 **Patient and public involvement**

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3 The research team developed an interview topic guide in partnership with members of a dedicated
4 study advisory group which comprised twelve people who were either living with YOD (seven) or were
5 the carers of people living with YOD (five). The study's steering group, which included representatives
6 from service providing agencies, health practitioners specialising in dementia care and members of the
7 research team, also contributed to the development of the initial interview guide. Both groups
8 commented on subsequent revisions of the guide as the project developed.
9

10 11 12 **Analysis**

13 In line with a growing number of other studies on the lived experience of dementia, interpretative
14 phenomenological analysis (IPA) was applied. (28). IPA is an established method for researchers to
15 explore the experience of individuals going through illness and the meanings people attach to those
16 experiences. (29) IPA fosters the incorporation of individual perspectives, and the idiosyncratic
17 meanings that participants attached to elements of their experience, which is particularly important
18 given our limited knowledge of the experience of living with YOD. The relevance for using IPA with
19 people with chronic illness has also been highlighted, as the approach accepts that participants are
20 their own experts. (30) Analysis was undertaken by LR with independent verification of emergent
21 themes with TW using a small subset of five transcripts.
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26 At a practical level, transcripts were first analysed individually and read several times while
27 simultaneously listening to the audio-recording. The written content was formatted into a table to
28 facilitate the annotation process. First, simple, descriptive comments were made while reading and
29 listening to the transcript in order to reveal the content. The process was repeated a second and third
30 time to note linguistic (use of language, laughter and voice tone) and conceptual (questions and
31 interpretations of the text) comments respectively. The conceptual level of annotation is particularly
32 important because it adds depth to the analysis. Various techniques were employed to search for
33 connections across themes, on a case by case basis. These included abstraction (grouping similar
34 themes), polarisation (focusing on differences between themes) and numeration (looking at
35 frequencies of themes). The result was a list of superordinate themes and their respective subordinate
36 themes for each participant.
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42 **Results**

43 The analysis revealed four superordinate themes that represent prominent features of participants'
44 stories collectively. The superordinate themes each comprise three subordinate themes (see Table 1)
45 which vary in terms of their contribution from individual participants. In line with IPA philosophy,
46 unique and common elements from the perspectives of participants are therefore represented. The
47 superordinate themes were: *the process of diagnosis; the impact of living with YOD; the needs of*
48 *people with YOD; living well with YOD.*
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53 **Insert Table 1 about here**

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56 Superordinate Theme 1: *The process of diagnosis*
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4 Participants talked extensively about how they received their diagnosis and the impact that this had on
5 them, their families, and their wider social circle. The experience was characterised by a distinction
6 between pre and post diagnostic phases. The pre-diagnosis phase was the period when the first subtle
7 signs and changes in behaviour started to occur. It could be a particularly difficult and uncertain time
8 for people who were still likely to be active, working and looking after dependents. It was usual for
9 people who began to experience problems in carrying out their usual routines to battle to maintain
10 control until a point of crisis forced them to seek help. The pre-diagnosis period was only really
11 revealed and assimilated in hindsight, once a person could make retrospective connections between
12 their gradually emerging symptoms – such as confusion and increasing memory problems – and their
13 condition.
14
15

16
17 A lack of awareness relating to YOD was reported by participants in the pre-diagnosis phase. In some
18 cases, this had delayed the point at which they sought help. The interviewees gave a number of
19 examples of signs and symptoms that were experienced during the early stages of their condition, but
20 as these could occur in isolation, and were not always to do with memory issues, they were not
21 immediately seen as indicators of a single underlying condition.
22
23

24 I found that my concentration wasn't the same. I could be stood cooking something and I'd
25 go away and then I'd forget, until the smoke alarm was going off. . . I was decorating the
26 bathroom at the time, I'd got the first piece of paper up then I couldn't fathom out how to
27 match and I thought oh this isn't right . . . I could plug in the vacuum cleaner but I didn't
28 know how to turn it on. (Participant 3)
29
30

31 I didn't think of it as an illness, I just thought I was having . . . but you know you just think
32 the job is very stressful and you always have a, 'oh well, we were busy last night.'
33 (Participant 4)
34
35

36 Even after people decided to seek help, it could be difficult to get a firm diagnosis, and there was often
37 a reported struggle to be heard by health professionals:
38
39

40 The doctors and consultants were saying, 'no, you're too young to have dementia'. At this
41 time I was about 49. So their thinking was it could be depression or stress because I was still
42 working at this point. (Participant 1)
43
44

45 [Speaking about her GP] She put me on some tablet anyway, she said it was depression. . . I
46 said to her, look it's getting that bad I'm looking after children, I can't do it. (Participant 3)
47
48

49 Participants had mixed views on the actual process of receiving a diagnosis. As with the process of
50 being told about any life changing illness, interpersonal issues relating to the communication
51 awareness and empathy of health care practitioners was important on an individual level. However,
52 regardless of how the news was delivered, and the psychosocial support that may have been available,
53 there was unanimity over the shock of actually receiving a diagnosis:
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3 . . . and then they proceeded to tell me that I had Alzheimer's. At which point I just froze
4 completely. (Participant 1)
5

6 [They said] it's early onset Alzheimer's disease, just out of the blue like that. Well I was
7 numb. (Participant 3)
8
9

10 . . . it was awful. I felt like I was hit by a sledgehammer. . . I felt as though somebody had
11 pulled the plug out of everything. (Participant 5)
12

13
14 At a practical level, a recurring issue was the amount of supporting documentation and information
15 that participants were given at the point of diagnosis, and how this could be overwhelming.
16

17 . . . and you're bombarded with, take this, take that, take this, take that. All these leaflets
18 and basically all you want to do is sit down and think it through yourselves. (Participant 9)
19

20
21 I was given a pile of documents and I went home and put them in a cupboard. I have spoken
22 to a number of people and it is a shared experience. It's all just too much to take on board
23 and really, just a page would have done to point out the services. (Participant 10)
24

25
26 The predominance of leaflets as opposed to face-to-face support was also highlighted:
27

28 When I got home I was so angry, all the leaflets went straight in the bin. That was my way of
29 thinking, I don't need the bloody leaflets, they don't mean anything to me. . . so yeah,
30 leaflets weren't I mean for me. The thing that would have helped me most would've been for
31 someone to be around outside my consultation room and approach me. Not approach my
32 husband, but approach me maybe. I don't know, maybe offered me somewhere on my own
33 rather than me going out in a big black cloud into nothingness. (Participant 1)
34
35

36
37 Some participants felt that post-diagnosis support was lacking. One acknowledged that she was coping
38 with the help of her husband, but would have appreciated an occasional offer of support:
39

40 . . . maybe every six to twelve months to say, 'we're here!' Particularly some emotional
41 support. So I'd like somebody, not to take it out on, you know, somebody to talk to.
42 (Participant 9)
43
44

45 A similar lack of agency was acknowledged by another participant:
46

47 Nobody says, you know, 'how does that make you feel?' In my view there still isn't any
48 opportunity, three years down the line and I still haven't been able to voice how it made me
49 feel then, how I felt coping with it for the last couple of years and how my feelings are
50 towards the future. (Participant 1)
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54 Superordinate Theme 2: *The impact of living with YOD*
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3 The impact that dementia had on participants are grouped here into two main areas: *changes in*
4 *function and daily living*, and *emotional and psychological impact*.
5

6 *Changes in function and daily living*

7 The impacts on function were wide-ranging. Again, this was not always the direct result of memory
8 loss per se. For example, participants described problems with everyday activities such as dealing
9 with money:
10

11
12 I can't count money; I haven't yet worked that one out. (Participant 2)
13

14
15 Sometimes I don't carry money anymore because I could fumble with it. When I used to go
16 and pay, I couldn't count the change out. (Participant 3)
17

18
19 I was going to the bank, put my card in to get some money out, and I took the card out and
20 left the money. (Participant 7)
21

22
23 I would, for example, go for my lunch or go into a shop and if they said that something was
24 35 pence and I took the change out of my pocket, I couldn't count it. (Participant 10)
25

26 Communication issues, including the inability to maintain concentration during conversations and
27 losing the thread during interaction were highlighted. Frequently reported was an increasing difficulty
28 in 'finding the right word', and other more individualistic effects such as difficulty in recognising faces,
29 pronunciation and speech production. There were less obvious problems too, such as only being able
30 to concentrate on thinking about one thing at a time, which could have a broad impact on many
31 aspects of daily life. Participants 4, 12 and 13, described noticing themselves becoming
32 uncharacteristically confused and forgetful at work:
33

34
35 Well in my job [nursing] I was forgetting a lot of things, which I hadn't done before. I was a
36 perfectionist in my job and I was then forgetting, not forgetting how to do things but – yes, I
37 suppose, in a way. What was happening was I was forgetting parts of what I was doing. . .
38 One night I came back and they said, 'oh, how was such and such a body?' And I went, 'oh, I
39 can't remember what I gave him.' So they were all going round and asking was it this? Was it
40 that? And we have got like 12 of us in the office and they are all shouting out 'oh, is it this or
41 is it that?' And then all of a sudden somebody said the word and I went 'Yes! That's what I've
42 done, that's it' And I got a round of applause. . . (Participant 4)
43
44
45

46 And actually, I think that was the time when I really thought, maybe I have got something.
47 But I wrote the bloody thing and I couldn't remember it. (Participant 12)
48

49
50 I absolutely loved my job and then it just, I started, I realised that it was, I would come in the
51 following day and couldn't remember what I'd worked on the night before. (Participant 13)
52

53 *Emotional and psychological impact*

54 Participants described their struggles and fears around living with dementia. These included
55 uncertainty for the future and concerns about putting themselves at risk while struggling to maintain
56
57

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3 an image of themselves as 'normal' members of the community. A sense of trying to cover things up,
4 and keep the realities of the condition hidden was evident:
5

6 I cover up a lot. . . If I'm in a doctor's surgery I will get a magazine and flip through it. I can
7 read the words but it doesn't make sense what's there. I don't understand what I'm reading
8 but I wouldn't give people the satisfaction of thinking. . . To them they probably just think I'm
9 reading. So really you mask a lot of things just to try and still fit in with society so you're not,
10 like, different. (Participant 3)
11
12

13 You know you sort of live a double life almost. You know, you're sort of, 'yeah I'm fine, I'm
14 fine.' But underneath you're thinking well am I going to see my grandkids grow up?
15 (Participant 1)
16

17 The importance of work, not only as a source of income but also of identity, was highlighted by
18 participants. Also what was striking was the deep sense of loss that could occur when people
19 were forced to stop working because of their cognitive difficulties – even if YOD had not yet been
20 formally diagnosed. Eight of the interviewees with YOD were in paid employment at the time of
21 their diagnosis.
22
23

24 I had to give up work and that was devastating, being a carer. When I realised that my clients
25 were in danger, I thought I can't carry on with my job. (Participant 1)
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30 [In a hospital] you see, if you are making a mistake, somebody is going to get hurt. That was
31 the problem. That's why, when I went to see them, they told me I couldn't work anymore.
32 (Participant 4)
33
34

35 Superordinate Theme 3: *The needs of people with YOD* 36

37 The majority of participants felt that the support of their family, friends and other people living with
38 dementia was crucial. Those who did not have spouses often had a key person, possibly a close friend
39 or child, who provided emotional and practical support:
40
41

42 [Talking about her daughter] She has gone through a lot with me in the last 12 months. . .
43 and we have good communication, she can read me, she knows when I walk through that
44 door in the morning, she knows if it's a good or bad day. (Participant 6)
45
46

47 Dementia-specific community groups were also seen as a significant source of support, and the
48 importance of being able to relate to other people who had been, or were currently going through, a
49 similar experience was highlighted:
50
51

52 . . . because there is nothing like having somebody who has got the same problem telling
53 you how to cope with it, you know. Because you have been there, you have done it and you
54 have got the t-shirt. I found [name of a high-profile UK dementia activist] was the best
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3 ambassador for it, because I looked at him and I thought, that's how I want to be in seven
4 or eight years. (Participant 4)
5

6 I find that I am getting more support through people from the groups. (Participant 8)
7

8
9 However, participants reported that it was important for the support they were offered to take into
10 account that they may have different needs and interests to older people with dementia. Support
11 groups that were specifically organised for people with YOD, rather than dementia in general were
12 praised because they offered age-appropriate activities and – at their best – helped to develop a sense
13 of independence and empowerment.
14

15
16 I think people of my own age, if they set up a group for them. Because we are probably a bit
17 more able minded to do things, our faculties are probably a little bit better than maybe the
18 older ones are. . . because everything at the moment is based on older people. . .it's like
19 being in school and it's all old war songs. Well I wasn't even born in the war. (Participant 3)
20
21

22 There was also a strong sense that any new initiatives need to acknowledge that not everybody will
23 wish to engage with 'traditional' dementia support group formats – singing groups, reminiscence
24 groups and so on. Again, this was largely because of the perception that these groups catered mainly
25 for older people. Participants, who were still living independently, expressed a need for a less formal
26 approach in how dementia group sessions were booked and arranged:
27

28
29 [If] you have a singing group for dementia, why do I have to make an appointment? Surely I
30 should be able to just walk through the door and go 'hello, I am such a body, I've got young
31 onset dementia, can I see what you're about please?' I shouldn't have to phone up and
32 have to book in. . . It's the way they run their groups, this phone up and book in. Sorry, but
33 how can anyone with dementia, unless they've got a carer, remember to phone up and
34 book a spot? (Participant 6)
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39 Superordinate Theme 4: *Living well with young onset dementia* 40

41 A powerful theme from the interviews was people's descriptions of how they were coping and getting
42 on with their lives and the many inspirational stories and examples that they gave. The need to
43 engage in meaningful activity in order to maintain their wellbeing was very strong. Participants
44 showed a remarkable ability to remain positive throughout their illness and for some this was viewed
45 as a coping strategy, actively seeking to protect this optimism:
46

47 My doctor put it right the other week, when she said if she didn't have all my test
48 results in front of her, she wouldn't believe I had dementia. I think if I carry on doing
49 different things and if I keep moving the dementia can't catch me. (Participant 15)
50 I came to the conclusion that reading things like that are not going to do me any good.
51 They are just going to send me into a pit of despair which is something I wasn't going
52 to do...(later)...I don't think about the future. I have the thing that yesterday is history,
53 tomorrow's a mystery and today is the present and that's why they call it a gift.
54 (Participant 20)
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3 Not everybody, however, has the ability to confront their illness with a positive attitude. It is
4 therefore important to consider other strategies that people can draw on to help themselves
5 to live well. Strategies that might be more inclusive and open to the wider population of
6 people living with dementia. Individuals are hugely resourceful and have impressive
7 management strategies that should be documented and these are quite often very simple
8 things:
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14 Speak slowly, speak calmly, speak in words I can understand, that's the main
15 important thing. I may not remember what you've just told me so please can you
16 write it down for me, or I can write it down so that when I go away from here I know
17 what you've told me. (Participant 2)
18

19
20 Simply keeping things routine and familiar could also be a very effective coping strategy.
21 Participant 4 for example, acknowledged that she struggled more when out of a routine and
22 the familiarity of her house helped because she knew where everything was and how to get to
23 it. Participant 20 said that he now struggled to watch television, but he refused to give up and
24 adapted this activity with the following example:
25

26 I can't remember the last time I watched a film because ten minutes in and I have
27 forgotten exactly what is happening. So I rarely watch television, but if I do, I watch
28 something where there is no plot to follow, so I will watch things like Animal Planet
29 because you are just looking at animals then, there is no plot actually to it. (Participant
30 20)
31

32 The need to keep active and the therapeutic benefits of activity were themes common to all
33 participants. Examples included learning to swim, taking up gardening, raising and forming
34 companionship with a dog, giving talks nationwide on the experience of living with dementia,
35 raising awareness, becoming involved in research, campaigning and gaining employment in a
36 caring capacity to support others to live well with dementia. Participants made the important
37 link between activity and wellbeing:
38

39
40 So they are the first things that helped me to live well. And then I think, also, was the
41 swimming was the main one for me. More so probably than the young onset group.
42 (Participant 4)
43

44 If you sit at home and vegetate, you're dead. Because the longer you do it, the worse
45 it gets. So you need to get yourself out doing something, anything, regardless. Clean
46 the house or something like this. Do something. I was lucky because we knew we were
47 going to get a dog and we've got the dog and everybody loves him (Participant 7)
48

49 That's why I have my crosswords in the morning paper. I was told to keep the brain
50 ticking over and active. And now, believe it or not, it's only today – a Tuesday – that I
51 don't have anything to do. (Participant 12)
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53 The positive for us is that as I say we travel, we go and do different things...we're just
54 trying to keep occupied. (Participant 15)
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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

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3 where they simply disengaged with it. For a condition that can place such restrictions on cognitive
4 processes, more effective and streamlined ways of delivering information tailored specifically for those
5 with YOD need to be devised.
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8 Unlike those who develop dementia after they reach traditional retirement age, people with YOD will
9 commonly be in employment or eligible for employment at diagnosis. Having to give up work or the
10 prospect of preferred work, and the severe implications this has on many levels, was a recurring
11 theme. Ironically, still being engaged in a work environment and being in a position where subtle
12 changes in behaviour and cognitive ability might be more readily noticed – both by the person
13 themselves and also by their co-workers – could be a significant trigger in prompting people to seek
14 help. Occasionally this decision may be forced upon them, particularly if they work in a field where
15 their ability and actions could be a danger to others, such as healthcare, making the experience
16 particularly difficult.
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19
20 Study participants were clear about the importance they placed on family, friends and peers (other
21 people living with dementia) as a source of support, at both a psychological and practical level. The
22 study suggests, however, that as with information provision and care pathway engagement, attitudes
23 towards formal and informal support groups can be ambiguous. While efforts to provide such support
24 were universally appreciated, there was a definite sense that the traditional forms of dementia
25 focused support group do not always follow formats or offer activities that younger people wish to
26 engage with. More passive reminiscence-based activities, for example, that are very common in care
27 homes and other environments that support older people with dementia, are often focused on
28 periods before some people with YOD were born and may not resonate well with them.
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31
32 When talking about living well with dementia, the intention is not to make light of the experience of
33 dementia, it's more about challenging the stereotype. Previous research on the experience of living
34 with dementia often serves to fuel this negative image of what it might be like to live with the
35 condition. What we need to start to focus on are ways of understanding the positive experiences,
36 strengths and capabilities that people draw on to improve their own wellbeing.
37
38

39 Strengths and weaknesses of the study

40 This was an in-depth qualitative study focusing on the lived experience of people diagnosed with YOD.
41 Although our sample was relatively small, for an in-depth qualitative study of this nature, utilising an
42 interpretive phenomenological approach, it was entirely adequate. We were able to interview a
43 representative cross-section of participants in terms of socio-demographic status, age and gender. A
44 potential weakness of the study could be that as some participants were interviewed together with
45 their carer, this might have influenced what they said. Where it was not possible to interview
46 participants alone, we tried to ensure that the 'voice' of the person with YOD was not overshadowed.
47 The regional nature of the study might also have influenced reports on issues such as engaging with
48 services. However, this may have been offset by the socio-demographic spread of participants, which
49 covered a range of high and low socio-economic status individuals and included people who had
50 engaged with both NHS and private services.
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55 In terms of unanswered questions for future research, and the implications for policy makers and
56 clinicians that these might have, the study has particularly highlighted the need for more detailed work
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3 on the way in which information is tailored to the needs of younger people at point of diagnosis. In
4 particular, how to more clearly differentiate what is available for this group from the material offered
5 to older patients. In one sense, the success of current awareness raising initiatives for dementia in
6 general may have worked against those who are diagnosed when younger. While they are clearly now
7 becoming more visible, they are still not sufficiently defined as a group to attract a coherent cross-
8 service collection of material that would be less alienating to them.
9

10 11 12 13 14 15 **Conclusions**

16
17 This study used innovative participatory methods and built on existing work in this area by examining
18 post-diagnostic support in a region with relevant service provision for YOD. Participants gave detailed
19 accounts of their needs and experiences relating to living with YOD and described a wide range of
20 issues that affected them. Our findings are largely in line with other studies that have begun to focus
21 on this group, (15) and confirms that those who have a diagnosis of YOD see themselves as distinct
22 from older people with the condition – even if they experience similar symptoms. We show that peer
23 support is crucial for people living with YOD, as is the need for them to engage in YOD-specific groups
24 with age-appropriate activities.
25
26

27
28 There have been significant positive developments at both a national and local level in the re-
29 positioning of care pathways and social support for people with dementia (5,6). In parallel with these
30 there have also been a number of high profile dementia focused initiatives that set out to actively
31 address the needs of people with YOD as well as older people. Two prime examples are *Dementia*
32 *Friendly Communities* run by the Alzheimer’s Society, (44) and the *Dementia Engagement and*
33 *Empowerment Project (DEEP)*, (45) which aims to bring together groups of people with dementia from
34 across the UK and support attempts to improve services. As awareness of YOD continues to grow, the
35 development (or adaptation) of support services such as these which take into account the particular
36 requirements of this younger group need to be maintained. Although the number of people with YOD
37 is admittedly extremely small when compared with the number of older people with dementia, there
38 is potential for incremental (and inexpensive) adjustments to existing health and social care
39 interventions which could make a significant difference to their ability to live independently, with good
40 quality of life, for as long as possible.
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50 study was: *‘Living well with young onset dementia - Humphrey Booth Resource Centre as a hub of*
51 *excellence in a system of support.’*
52
53

54 **Competing interests.**

55 None
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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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Superordinate theme**Subordinate theme****Key words and issues**

Superordinate theme	Subordinate theme	Key words and issues
1. Process of diagnosis	<i>Pre-diagnosis</i>	Warning signs, alarm bells, too young
	<i>'Hit by a sledge hammer'</i>	Sledgehammer, shock, lack of support, information overload
	<i>Post-diagnosis</i>	Benefits, no follow up, looking for answers
2. Impact of living with young onset dementia	<i>Impact on behavior & function</i>	Activities of daily living, money, cooking, communication, uncharacteristic behavior, loss of self
	<i>Psychological impact</i>	Fear of the future, covering up, living a double life
	<i>Impact on work</i>	Devastation, loss, forgetting things

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3 **3. Needs of people with young**
4 **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

13 **4. Living well with young**
14 **onset dementia**

15 * not reported on here

Psychological coping strategies

Positivity, optimism

Practical coping strategies

Simple things, routine, familiarity

'Trying to keep occupied'

Therapeutic benefits of activity

25 *Table 1: Superordinate and subordinate themes from IPA analysis of all participants living*
26 *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

<p>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</p>	Page 1
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	Page 2

Introduction

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

Methods

<p>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**</p>	Page 4 (last para) page 5 (1 st para)
<p>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</p>	Page 5 (3 rd para)
<p>Context - Setting/site and salient contextual factors; rationale**</p>	Page 4 (3 rd para)
<p>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**</p>	Page 4 (3 rd / 4 th paras)
<p>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</p>	Page 12('Ethical review')
<p>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**</p>	Page 4 (primarily last para)

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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 (4 th 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 (1 st para)
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 5 (2 nd 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.

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**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

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