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'It's definitely *not* Alzheimer's': Perceived benefits and drawbacks of a mild cognitive impairment diagnosis

Tim Gomersall[1]*, Sarah Kate Smith[2], Charlotte Blewett[3] and Arlene Astell[2]

[1]Department of Behavioural & Social Sciences, University of Huddersfield, UK
[2]School of Health & Related Research, University of Sheffield, UK
[3]Doncaster & Bassetlaw Hospitals NHS Foundation Trust, UK

Objectives. To understand the perceived benefits and drawbacks of a mild cognitive impairment (MCI) diagnosis from the perspective of those living with the label.

Methods. Participants were included if they had recently (within 6 months) received a MCI diagnosis. We also recruited close family members to gain their perspectives. Each was interviewed separately with a semi-structured topic guide covering three areas: (1) experience of cognitive impairments and changes in the individual; (2) impact of cognitive impairment(s) on daily activities and social relationships; and (3) experience of the diagnosis process and living with the label. Transcribed interviews were stored in Nvivo®. Grounded theory procedures of memo writing, open coding, constant comparison, and focused coding were used to derive conceptual themes.

Results. Eighteen dyads were interviewed. The overarching themes surrounding diagnosis benefits and drawbacks were as follows: (1) emotional impact of the diagnosis; (2) practical benefits and limitations of the diagnosis, in terms of (a) understanding one's symptoms and (b) access to clinical support. Although participants were glad to have clinical support in place, they expressed frustration at the lack of clarity, and the lack of available treatments for MCI. Consequently, living with MCI can be characterized as an ambivalent experience.

Conclusion. As a clinical label, MCI appears to have little explanatory power for people living with cognitive difficulties. Work is needed to clarify how clinicians and patients communicate about MCI, and how people can be helped to live well with the label. Despite an emerging body of prognostic studies, people with MCI are likely to continue living with significant uncertainty.

Statement of contribution

What is already known on this subject?

Mild cognitive impairment is a state of cognitive decline between normal cognitive ageing and dementia. This clinical category has been an important domain of academic debate over recent years. From a clinical perspective, diagnosing MCI is a helpful way to enable communication between health professionals, and a diagnosis can be important for patients in need of support and education. However, diagnosis can be

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**Correspondence should be addressed to Tim Gomersall, Senior Lecturer in Psychology, Department of Human and Health Sciences, University of Huddersfield, Queensgate, Huddersfield HD1 3DH, UK (email: T.Gomersall@hud.ac.uk).*

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fraught with difficulties, while patients have reported significant uncertainty about the label. This study aimed to examine the perceived benefits and drawbacks of receiving a MCI diagnosis.

What does this study add?

- The emotional impact of a MCI diagnosis is complex and raised conflicting and fluctuating emotions in our participants' accounts – most notably worry and relief.
- Participants were glad to have clinical support available to call on; however, they were frustrated at the lack of 'treatments' available for MCI and were often anxious to slow any cognitive decline down
- Health psychologists will have an important role to play in understanding and improving clinical communication about MCI

Mild cognitive impairment (MCI) describes a level of cognitive impairment between that seen in 'normal' ageing and dementia. MCI was identified in the clinical literature as early as the mid-1990s (e.g., Petersen, 1995), but interest in the syndrome increased following the publication of formal MCI criteria by Ronald Petersen's Mayo Clinic team (Petersen *et al.*, 1999). These criteria consisted of (1) memory complaint, preferably corroborated by an informant; (2) objective memory impairment; (3) preserved general cognition; (4) intact activities of daily living; and (5) no dementia. Petersen *et al.* (1999) followed a cohort of people who met these criteria and found a greater rate of cognitive decline than that seen in healthy older adults over time, but not as great as that observed in a comparison group of people with mild Alzheimer's disease (AD). In addition, the MCI group showed impairment only in memory, while those with mild AD had accompanying deficits in other cognitive domains. Consequently, it was argued that MCI was a distinct clinical syndrome worthy of further study.

Since then, MCI has been a subject of debate and investigation with respect to prevalence (Ward, Arrighi, Michaels, & Cedarbaum, 2012), existence and prognostic value of different subtypes (Mitchell & Shiri-Feshki, 2009; Petersen, 2004), medical management (Petersen, 2003), and the clinical utility and ethical implications of the label (Beard & Neary, 2013; Sabat, 2006; Werner & Korczyn, 2008; Whitehouse & Moody, 2006). Such debates are reflected in diagnostic manuals, which conceptualize MCI differently: While the ICD 10 lists MCI as a discrete category, focusing on clinical presentation (World Health Organization, 2004), the Diagnostic and Statistical Manual (DSM V) makes no reference to MCI (American Psychiatric Association, 2013). Instead mild neurocognitive disorder is listed, and clinicians are required to state the disease process underlying the cognitive impairment. Recently, attention has focused on consolidating MCI as a clinical entity (Albert *et al.*, 2011; Petersen, 2016), and seeking to prevent transition to dementia (e.g., Allan, Behrman, Ebmeier, & Valkanova, 2016). However, while research is beginning to show promising predictive value of some biomarkers for defining subtypes and estimating the probability of progression to dementia (Petersen *et al.*, 2009), these are often unavailable in routine clinical practice. Additionally, not everyone with MCI will progress to dementia or AD, and some will live with the syndrome for the rest of their lives, or even revert to normal cognitive function (Mitchell & Shiri-Feshki, 2009; Sachdev *et al.*, 2013). Consequently, a number of social scientists have come to view recent nosological changes associated with MCI as examples of what the historian of psychiatry, Nikolas Rose (2006), has called 'disorders without borders' – that is, progressive erosion of what counts as 'normal' (Beard, 2016; Beard & Neary, 2013; Moreira *et al.*, 2008). Others have cautioned against the 'Alzheimerization' of MCI, emphasizing the importance of understanding the psychosocial and occupational needs of each individual (Fang *et al.*, 2017; Whitehouse & Moody, 2006).

Amid these debates, it is important to keep in mind the complex, sometimes paradoxical implications that clinical labels can have for those living with them. Although referring to someone as 'cognitively impaired' can leave them open to stigma (Beard & Neary, 2013; Saunders, de Medeiros, & Bartell, 2011), clinical labels can help make sense of symptoms (Verhaeghe, 2008) and enable access to various forms of clinical and occupational support. Recently emerging research has highlighted the experience of living with MCI (Gomersall *et al.*, 2015), but little is known about the perceived benefits and drawbacks of an MCI diagnosis from the perspective of those living with the label. This article examines the experience of receiving an MCI diagnosis in terms of the benefits and drawbacks this diagnosis confers on individuals and their families.

Methods

Ethics

This study was granted ethical clearance by the South Yorkshire NHS Research Ethics Committee in the UK. Signed informed consent was taken from people with MCI and their family members separately, and participants were debriefed at the end of the interviews. During the fieldwork, we did encounter an unanticipated ethical issue. Some participants did not recall hearing the term MCI, and some sought advice and even treatment from the interviewers. In these cases, we explained what we understood about MCI from the research literature while emphasizing we were not qualified to offer medical advice or treatment, and asking the participants whether they wished us to re-refer them to the collaborating memory clinic. In addition, we ensured continued informed consent.

Participants

Participants were included if they were recently (within 6 months) diagnosed with MCI, fluent English speakers, able to provide informed consent, with no other known neurocognitive conditions. CB, a clinician in the memory clinic service, identified everyone who had been coded as having MCI within the last 6 months on the clinic database. To our knowledge, no participants had subsequent contact with the memory clinic from the date of the recorded diagnosis. We also recruited a family member of each participant to gain their perspective. Although purposive sampling is often recommended for qualitative studies (Devers & Frankel, 2000), opportunity sampling was used due to the small pool of potential participants with a recent MCI diagnosis from the collaborating Memory Service.

Figure 1 illustrates the UK National Institute for Health and Care Excellence dementia diagnosis pathway, which is also followed for MCI. First, an evaluation is conducted with a dementia screening instrument such as the Addenbrooke's Cognitive Assessment – Revised (Mioshi, Dawson, Mitchell, Arnold, & Hodges, 2006) and blood tests are taken to rule out possible non-neurological causes of cognitive decline. If this evaluation is inconclusive, further neuropsychological tests are available – including CT scans and more detailed assessments of specific cognitive domains. When a person receives an MCI diagnosis, they have a post-diagnosis needs assessment, including support from occupational therapy and lifestyle change suggestions. However, no specific treatments are currently recommended for MCI in the United Kingdom. Rather, people showing signs of MCI are regularly monitored, with a follow-up in 6–12 months. This approach to clinical management differs between countries – for example, in the US clinicians may treat MCI with Cholinesterase inhibitors.

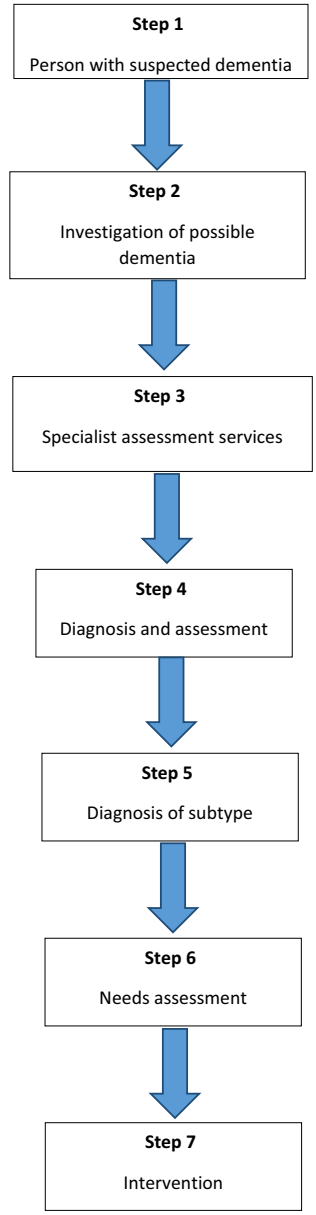

Figure 1. Diagnostic process for dementia and mild cognitive impairment. [Colour figure can be viewed at wileyonlinelibrary.com]

Data collection and management

Interviews were conducted using semi-structured topic guides (Appendix 1). People with MCI and their family members were each asked to cover three key areas: (1) experience of cognitive impairments and changes in the person; (2) impact of cognitive impairment(s) on daily activities and social relationships; and (3) experience of the diagnosis process and living with the label. Although clinical MCI criteria specify that daily activities should remain intact, we wished to examine people's experience, as recent

qualitative research has found that more complex activities may be affected (e.g., Binegar, Hynan, Lacritz, Weiner, & Cullum, 2009; Kim *et al.*, 2009; Nygård, Pantzar, Uppgard, & Kottorp, 2012). In follow-up probes, open-ended and action-oriented questions were used to encourage storytelling. The interviewers (TG and SKS) alternated between interviewing people diagnosed with MCI and their family members, to ensure a balance between their interviewing styles in each group. Interviews were transcribed verbatim, including key non-linguistic communication markers (e.g., laughter, crying, long pauses), and anonymized transcripts were entered in Nvivo® for storage and analysis. In addition to the qualitative data, we used the Montreal Cognitive Assessment (MoCA, Nasreddine *et al.*, 2005) to gain an indication of the current level of cognitive performance of our participants with MCI.

Analysis

A grounded theory analysis (Charmaz, 2014) was undertaken. First, TG and CB assigned open codes, line-by-line, to each interview transcript. At this point, we remained grounded in the data using participants' words as coding labels where possible, and by freely applying new codes to the interviews as new ideas emerged. An initial phase of constant comparison was conducted independently by two coders, in which we sought to identify recurring patterns in the data, and to reduce the codes to increased levels of abstraction. Memos were written and linked to specific parts of interview texts to record our developing ideas about the data. Then, we compared our respective coding labels, asking ourselves what was going on in the data and which labels best captured the phenomenon being described. These labels became our themes, which were further compared and reduced. While a variety of themes were developed, this article focuses on one particularly important phenomenon: the perceived benefits and drawbacks of a MCI diagnosis. This overarching issue of 'benefits and drawbacks' showed three thematic dimensions: the affective impact of the diagnosis; understanding one's problems; and the impact of clinical support.

Trustworthiness and reflexivity

A sample of four randomly selected interviews was independently double-coded using the final coding framework, and Nvivo® was used to calculate the kappa statistic. Kappa gives an estimate of inter-rater agreement between 0 (chance agreement) and 1 (perfect agreement). Values between .21 and .4 were taken to indicate fair agreement, .41 to .6 indicated moderate agreement, and .61 to .8 indicated substantial agreement (Viera & Garrett, 2005). We also discussed any notable differences between the two coders, and whether we needed to rethink any of our conceptual themes.

Grounded theory has roots in symbolic interactionism (Corbin & Strauss, 2014) which posits that meaning is co-constructed between researchers and participants. Therefore, we sought to recognize how our own characteristics and assumptions impacted the data collection and interpretation (Finlay & Gough, 2003). In this case, the research design, and the way we approached the data, was largely driven by our interest as clinicians and academic psychologists in the impact of MCI on the person's sense of self, and their experiences of clinical services and labelling. Our epistemological standpoint was critical realism (Bhaskhar, 2014) – we assumed participants' words 'gave voice' to a real experience, but their accounts (and our interpretations) were coloured by surrounding cultural, social, and linguistic contexts – including the availability of the MCI label itself.

Findings

Participants

Of 42 eligible people with MCI identified on the clinic database, nine women and nine men agreed to participate. Their ages ranged from 60 to 93 years (mean = 77.4 ± 8.6). MoCA scores ranged from 14 to 30 (mean 22.7 ± 3.9, Table 1), suggesting some participants scored outside the bounds of what would typically be expected in MCI (i.e., 18–26). Participants were homogeneous in terms of ethnicity, with all identifying as white British. There was some spread in terms of socioeconomic status, with most participants completing high school education to age 16, three having obtained a first degree, and one having a higher degree. The English Indices of Multiple Deprivation (IMD) were used to give some indication of the relative deprivation of the areas in which our participants lived. The IMD combine data on seven domains to provide an overall measure of deprivation in small areas in England: income; employment; education, training, and skills; health and disability; crime; barriers to housing services; and living environment. As can be seen in Table 1, our participants tended to cluster in the top and bottom deciles of deprivation, reflecting the pattern seen in the city we conducted our fieldwork. The relatives of people with MCI included four daughters, six husbands, six wives, and two sons. Relatives' ages ranged from 42 to 87 years old (mean = 66.4 ± 16 years, Table 2). The kappa value for inter-rater agreement on the coding was 0.475, indicating moderate agreement.

Table 1. Participant characteristics

	N	Mean (*SD*)
Gender		
Female	9	
Male	9	
Age (Years)		
60–70	3	77.4 (8.6)
71–80	9	
81+	6	
MoCA		22.7 (3.9)
IMD (by decile)		
1–2	7	
3–4	0	
5–6	1	
7–8	6	
9–10	4	
Education		
High School	13	
College to 18	1	
1st degree	3	
2nd degree	1	

IMD, Indices of Multiple Deprivation (2015 data). Lower IMD scores represent more deprived areas; MoCA, Montreal Cognitive Assessment score; *SD*, standard deviation.

Table 2. Participant's relative's characteristics

Relatives	*N*	Average (*SD*)
Gender		
Female	10	
Male	8	
Relationship		
Daughter	4	
Husband	6	
Son	2	
Wife	6	
Age (Years)		66.4 (16.0)

SD, standard deviation.

Benefits and drawbacks of a MCI diagnosis

Between relief and worry: The affective impact of a MCI diagnosis

Participants expressed a wide range of emotional responses to diagnosis, including sadness, anger, loss, rationalization, and humour. However, the two most commonly cited responses to the diagnosis were worry and relief. Many participants expected to receive a diagnosis of dementia or AD and were glad to hear this was not the case. In one narrative, a participant had previously been told she had AD based on the result of her CT scan. She described being 'devastated, absolutely wiped out' on hearing this, and when she was later given the MCI diagnosis, she was 'over the moon':

Extract 1.

> *Alison:* She says 'yeah you haven't got it [AD]' she says 'it could be a lead up to it but not everybody has a lead up to it', she says 'you just do what they say. Follow what they say' she says 'and I'm booking you in to see whoever it is this lady er to help you' I says 'but they said they were gonna you were gonna get he did he said we'd give you some tablets. . . to help you' and she says 'we've not had no note for any tablets' she said er. . . 'go to see this here lady er first and see how you get on with that' and y'know, blah-blah-blah. So. . . I'm doing what they say.
> *Int:* Of course, of course.
> *Alison:* Yeah.
> *Int:* So. . . what did you make of that information you first got? You've said a bit about. . .
> *Alison:* I were over the flippin moon! (laughs) (woman with MCI, 69 years old)

This sense of relief was seen throughout the interviews, suggesting widespread fear about the possibility of developing dementia or specifically AD. Unusually, in one case, a participant had been worried about brain cancer. In Extract 2, she hints that she had a similar (mis)diagnosis of AD, but her reaction is very different to the previous participant. The diagnosis is described, colloquially, as 'a touch of Alzheimer's', and her main response seems to be curiosity ('ooh, what's that?') and concerns about medication ('have I got to take tablets?'). Her account highlights how prior knowledge of different conditions can impact how a person anticipates, and responds to, clinical terminology:

Extract 2.

> *Angela:* . . .[H]e says, 'I think we'll have a brain scan' – I says '*a brain scan*?!' he says 'it's alright, it's nothing to worry about, it's just your, you might be having some trouble with your memory' so anyway, I says 'I don't want that'. I were thinking of cancer really.
> *Int:* Oh right, I see.
> *Angela:* You do think of cancer first thing. So she said 'no', she says 'we'll give you', she says 'no I don't think, don't worry' – I were worried when I first went up there.
> *Int:* Mm, I'm sure, yeah.
> *Angela:* Anyway, he says 'well', he says um 'we'll give you a brain scan.' 'What? To see if I'm all there?' so he says 'no' he says anyway, he got me in for a brain scan. Look at your brain so I says 'yeah' and he shows me the diagram he says 'your brain's alright – and believe me you haven't got cancer' so I says 'you sure? That's what's been frightening me, losing it' so he says 'no love' he says 'no' he says 'I think you've got a touch of Alzheimer's'. (long pause) 'ooh, what's that? Have I got to take tablets?' (woman with MCI, 76 years old)

Many participants continued to worry that MCI could develop into dementia, with this concern being expressed in 21 interviews. 'Alison', who we met in extract 1 when she spoke about her relief when the diagnosis being downgraded from Alzheimer's to MCI, went on to describe how the new diagnostic label failed to assuage her worries, given the similarities between MCI and dementia: 'I thought: I haven't got it, well, what have I got then? And I were reading that and I thought: what's this? This is more or less saying a similar thing to er. . . dementia'. However, others were reassured at the diagnosis, and the relationship of MCI to dementia and AD was interpreted in heterogeneous ways. One participant, an 89-year-old retired transport conductor, suggested the clinicians 'more or less said that there were no danger from Alzheimer's for me'. Another – a 60-year-old wife of a man with MCI – reported never hearing the term at all:

Extract 3.

> *Int:* Ok, ok, erm and at what point in this process did you actually hear this term mild cognitive impairment, when did you?
> *Lucy:* Well I don't recall ever hearing it, it wasn't until we got the letter from you.
> *Int:* Interesting, right.
> *Lucy:* So, then [husband] went and saw his doctor, and to ask him and he said don't worry about that, don't worry about that, just carry on, it's nothing to get worried about, but erm then [husband] said you know if you feel like being part of that research yes, good for you get on with it, but that wasn't, he just wanted to know what this err diagnosis was cos it sort of came out of the blue.
> *Int:* Right, right, I mean that is a concern from my perspective, if we are erm. . .
> *Lucy:* Maybe if we hadn't been listening. . .
> *Int:* What words do you remember them saying in the clinic when they, was there any sort of specific diagnosis?
> *Lucy:* No, no only that his memory had got less, you know he had scored less, and maybe it was like I was quite shocked and maybe I didn't listen any more, maybe they actually said something and because I was ooo, it had gone down when I was expecting it to be the same as or slightly better. . . (wife of man with MCI, 60 years old)

Although we attempted to resolve this issue by clarifying that MCI denotes a stage of cognitive impairment rather than a definite aetiological diagnosis, and offered to

re-refer them to the specialist clinic, our findings offer an important cautionary note for researchers and clinicians working with people with memory impairment. Given the apparent heterogeneity in clinical communication our participants reported – with some saying terms like 'Alzheimer's' and 'dementia' had been used within the diagnostic pathway, and others not remembering any clinical terms being used at all – researchers may be well advised to avoid using the term MCI in participant information when working with this population, instead using lay terms such as 'memory loss'. Nevertheless, whatever diagnostic terminology the participants recalled hearing, worry and uncertainty around prognosis were widespread. This was expressed by people with MCI and their families, with both groups struggling to deal with ongoing changes in relationships, and fears that the person with MCI could become dependent:

Extract 4.

> *Fiona:* The thing that frightens me is that I'm going to have to be. . . ((long pause, sighs)) dependent on someone.
> *Int:* Mm.
> *Fiona:* And I'll not be able to remember things. That's the frightening thought. (woman with MCI, 80 years old)

Extract 5.

> *Int:* Was that the kind of emotion that you associate with all those kind of events you talk about, so, you know, where you. . .?
> *Joanne:* It scares me, yeah [. . .] because it. . .you just think, wow, because he's always been this. . .rock that you went to and he sorted things out, and as I say, I. . .I always looked after the kids, I did my job – I was a teacher, I did the house, I did the food, I did the laundry, but I hadn't got a clue who the car was insured with or whether the house was insured or. . .not a clue! Stupid. . .a really silly situation, but I suddenly thought, you know, I really don't know. . .anything! And, again, I've sort of, over this time, said to [husband], 'Perhaps you could show me how to that. . .' and now, I insure the house, I insure the car, and I am learning a lot, um, but it's scary. . . (wife of man with MCI, 75 years old)

Practical benefits and drawbacks of a MCI diagnosis

Understanding what's wrong

One benefit of diagnosis is being able to name one's condition and understand likely prognosis. However, our participants struggled to make sense of the MCI label. They particularly seemed to find the term 'cognitive' problematic. The participants had clearly not come across the term outside of their engagement with medical and research professionals:

Extract 6.

> *Int:* I mean what ((tsk)) what does the term mean to you, mild cognitive impairment – if you had to. . . ((tails off))?
> *John:* Well I had to go and look it up, it didn't mean anything to me at all. Mild I understand, impairment I understand, aah. . . I wasn't sure what was cognitive and what wasn't. So I did. . . resort to the dictionary. Um. . . I wouldn't say I was unduly surprised by the diagnosis 'cause um. . . clearly something's not right and it's got to be teased out I suppose. (man with MCI, 76 years old)

Extract 7.

> *Int:* So thinking also about that clinic they er... they gave you this diagnosis called mild cognitive impairment.
> *Susie:* What do they call it?
> *Int:* Mild cognitive impairment.
> *Susie:* Connitive impairment?
> *Int:* Cognitive impairment.
> *Susie:* Cognitive?
> *Int:* Um... so what does that term mean to you if I were to say 'mild cognitive impairment'?
> *Susie:* I haven't a clue. (Woman with MCI, 76 years old)

Sometimes, during the interviews, we were asked what MCI *does* mean, and we found ourselves facing an ethical conundrum: On the one hand, we felt an obligation to our participants to try and explain the meaning of the label, yet we had to emphasize that, as the interviewing researchers were not clinicians, we were unable to provide any medical advice. While it would be easy to blame participants' desire for clarification on imprecise clinical communication, the above examples suggest that it may be the MCI label itself which is difficult to interpret. Furthermore, it was not only the 'cognitive' part of the label participants had a problem with – there was a sense among some that describing their impairments as 'mild' failed to grasp the depth of their difficulties:

Extract 8.

> *Peter:* She were telling me I were grieving and I said 'no it's not, it's memory, it's not got to do with grievance' (pause) and I still think it's [...] I I can't put it down... in my mind the fact that I've got a bad memory has not been caused by grievance.
> *Int:* No, because you've said already that... this was happening before your wife died.
> *Peter:* Yes, and I couldn't get through to 'em [...] And I've I've tried but for some reason I can't do it I can't... ((tails off)) seem to, to make 'em understand that it's not that. And in that book that I'm reading [*The Chimp Paradox* by Steve Peters], there it's, it goes into your mind. And I read something in there and I said to [son] 'this is what I've been telling them all the time – it's not grievance'. ((pause)) there's something in there that told me that I'm right and they're wrong, but what... I forget now what that was. (Man with MCI, 86 years old)

Such accounts were widespread, with almost half our participants questioning the MCI diagnosis. Often, this arose from a conflict between 'official' and 'unofficial' truths (Gomersall, Madill, & Summers, 2012) in which people trusted what they felt at an embodied, experiential level over the abstract discourse of medicine. This certainly seems to be the case for the participant above, who is sure in his own mind that his cognitive decline indicates an organic illness, rather than part of grieving. The interviewer and interviewee perform interactional work in which both imply his perspective is more 'true' than that of the medical professionals: The participant appeals to the authority of the book he has been reading as evidence 'that I'm right and they're wrong'. The interviewer provides further detail to support the participant's assessment ('this was happening before your wife died').

Several participants were similarly unconvinced about the diagnosis, and believed more was going on than the doctors had uncovered. One retired clinician we interviewed was concerned that 'it [MCI] could be [...] fairly defined by various people using it and I

can understand it might, could lead to misunderstanding of the depth of problems you're experiencing'. In one especially poignant example, a participant believed the clinicians were protecting him from the risk he would have posed to himself had he been diagnosed with Alzheimer's:

Extract 9

> *Brian:* . . .[T]he first thing he said to me was 'it is definitely *not* Alzheimer's'. . . and I thought – why has he said that? Why did he say that? Is he, are they trying to block it out for what I said? ((long pause)) you know what I told the doctor, don't you?
> *Int:* No I'm not sure.
> *Brian:* Right well what I did say was I said 'if you tell me I've got Alzheimer's. . . I'm not long for this world' I said 'because I can't cope with that'.
> *Int:* Mm-hmm.
> *Brian:* Um. . . and I upset her, I upset the girl she were, I were so sorry that I'd said it but she'd asked me and er. . . and I thought – I wonder if he's telling me this and I have got it? Are they telling me [it's MCI] because they don't want me to do. . . ((tails off)). (Manwith MCI, 60 years old)

Conversely, some participants believed that MCI inappropriately appends a diagnostic label to the ageing process. These participants engaged in a kind of lay critique of diagnostic creep, suggesting there was little sense in treating memory impairment at their stage of life as an 'illness'. One 84-year-old woman recounted how her friend 'roared with laughter' upon learning she would be attending the memory clinic. However, while some participants critiqued the reliability or usefulness of the MCI label, others accepted the diagnosis with deference to clinical judgement. One woman explained that she preferred not to know too much about her cognitive impairment. She wished to live her life without dwelling on her memory problems, trusting the experts to manage any clinical issues:

Extract 10.

> *INT:* Okay. So what did they tell you about the scan? Did they sort of give you some results from that or. . .?
> *Veronica:* No, no, no.
> *INT:* So you didn't hear back. . .
> *Veronica:* The thing with me, I tend to just do as they say and that's it, you know what I mean. I don't really ask a lot of questions but I think the less you know, the better it is ((laughing)), you know what I mean? I know it sounds a bit silly that but. . .
> *INT:* No, no, I mean, that. . .
> *Veronica:* I don't want to know. Just get on with it, yeah! [. . .] You're in the best hands, aren't you? I mean, you can sit at home and feel sorry for yourself, but if you don't do nowt about it, that's it, so you've got to do what. . .you've got to make the best of what you can, haven't you? (woman with MCI, 81 years old)

Practical benefits and drawbacks: Medical management

Seeking medical advice can, potentially, offer a range of practical benefits. Naming a condition can change a set of signs and symptoms into a 'known' condition, potentially opening options for clinical management and the relief of suffering. However, in the UK, no specific treatments are currently recommended for the

medical management of MCI, and this was a source of frustration to several participants, with many desiring medical management to arrest further decline. One participant, upon arriving at the interview, asked if we could provide antidementia drugs. Almost half of our participants spontaneously stated that what they most desired from the memory clinic was a cure (e.g., Extract 11), and one daughter of a man with MCI even reported seeking memory-enhancing drugs for herself (Extract 12):

Extract 11.

> *Fiona:* It would be lovely to come up with a medicine that just kept your head working properly, I don't think there'll ever manage to do that somehow. Not unless there's some vitamins or something you know that help but it would be lovely if you could think there was and to me that even if they didn't do that much good it could do good to yourself sort of thing, you'd feel more that you could do things. (woman with MCI, 80 years old)

Extract 12.

> *Amy:* I'll definitely end up with what me Dad's got, hundred million percent because my memory is atrocious! It is er, cannot remember things, it's driving me mad and one of girls, (name) is same and she keeps buying all these medications which are coming out on market now to supposedly boost your memory. (Daughter of man with MCI, 47 years old)

Although the desire for medication was voiced by multiple participants, others were hesitant about over-medicating. In some cases, the key advantage of seeking medical advice was not to find a way to medically 'treat' their memory loss – what they wanted was a sense that support was there, and could be called upon, if and when it was needed – as we see in Extract 13:

Extract 13.

> *Int:* So they're following you up?
> *David:* Yeah, and I, I appreciate it.
> *Int:* Right.
> *David:* I know if there's something radically wrong with me, then they'll let me know, and if there's anything that could be done, it'll be done.
> *Int:* So it sounds like you're kind of. . . reassured by the memory service?
> *David:* Yes it, it is a reassurance that if there is anything wrong with me they'll at least try to put it right – and if they can't ((laughs)) oh well! That's it. (Man with MCI, 89 years old)

Clinical services, then, were important to our participants not simply in terms of dispensing appropriate treatments, but as a reassuring source of support they knew they could draw on when needed. In the interim, without any specific medicines to slow down or prevent cognitive decline available for prescription, our participants reported a range of informal self-management strategies to maintain cognition – crosswords, puzzles, 'brain training' games, and diary keeping. In line with previous research in MCI and AD, and with the move towards treating patients as experts on their illnesses, our participants took the lead on managing the changes they experienced, with clinical services playing a supporting role in the background of their lives.

Discussion

Mild cognitive impairment describes a decline in cognition between 'normal' cognitive ageing and dementia. Given the persistent problems with early detection and treatment of dementia (Vernooij-Dassen *et al.*, 2005), MCI may be a helpful label to manage cases of uncertain dementia status. Although MCI is a useful category from clinical and research perspectives, few of our participants identified with the label, and found it had limited explanatory power for clarifying their problems. In common with previous research, we also found that MCI could cause some interactional difficulties for participants – for instance, in terms of 'courtesy stigma' (Beard & Neary, 2013), or in difficulties to explaining their diagnosis to friends and family. However, in contrast to the work of Beard (2016) on reactions to receiving an MCI/early AD diagnosis, few of our participants appeared to have embarked on an 'illness career'. Some of the impairments reported by participants posed a threat to their identities and independence, but the general pattern was one of attempting to exercise their cognitive abilities and make small adaptations to enable continued participation in valued activities. Additionally, none of our participants had joined AD support groups. The emphasis was on trying to continue living 'normally'.

Diagnostic labels can be thought of as 'master signifiers' – they take multiple sources of complex information, and reduce them to a label which explains the whole. As Verhaeghe (2008) puts it, 'a name always carries with it [. . .] the illusion of control and mastery. Nothing is worse than not being able to name something; once a name has been found, it seems manageable' (p. 61). This, perhaps, is one reason why so many people describe feelings of relief when they receive a serious diagnosis – it can make legible what had previously been impenetrable, threatening, unknowable. In some cases, this phenomenon of relief at receiving a serious diagnosis has even been noted in studies of dementia (Robinson *et al.*, 2011). In our interviews, although participants were relived not to have been diagnosed with dementia, their relief was tempered by continued uncertainty.

Our participants appeared to interpret MCI in many and varied ways. On the one hand, some participants were unfamiliar with the technical term 'cognitive'; yet the banality of the terms 'mild' and 'impairment' may also have compounded difficulties in understanding. This certainly points to the significance of work in behavioural economics showing a gulf between lay and expert understandings of technical language (Bruine de Bruin & Bostrom, 2013; Fischhof, 1995). However, it is not simply that clinical experts have a more sophisticated understanding of the 'real' nature of MCI – as our data showed, our participants offered sophisticated criticisms of MCI as a clinical entity. For instance, the idea that the symptoms of MCI may be part of the ageing process was mentioned by several participants. Others suggested they may have a better grasp of the extent of their memory problems than standardized clinical testing could offer, as they lived with the impairment day-to-day. Finding a way to bridge the gap between lay and expert perspectives, for instance using a structured way to explain the meaning of cognition in clinical consultations, may aid communication. Although some researchers have examined the various ways clinicians communicate with people with MCI (e.g., Saunders *et al.*, 2011), as yet no research exists on developing and testing ways to communicate an MCI diagnosis in terms of patient satisfaction and understanding.

The potential for MCI to progress to dementia was a source of further uncertainty for our participants. Despite an increasing number of prognostic MCI studies (e.g., Rosenberg *et al.*, 2013), it is not possible in routine clinical practice to predict who will go on to develop more serious neurocognitive conditions, or indeed who will revert to previous

levels of functioning (Sachdev *et al.*, 2013). Although clinicians can offer general information on risk of progressing to dementia among the population of people with MCI, risk communication is a highly complex and ethically fraught business. Several different conceptions of risk, underpinned by very different ontological and statistical assumptions, are routinely used in patient counselling (O'Doherty, 2006). It was evident from Our interviews that people were interpreting risk in a variety of ways. Some were convinced they had dementia anyway, or were inevitably heading in that direction, while others read the information as meaning that MCI was part and parcel of ageing. Most, however, fell between these extremes, with some awareness of the risk of progressing to dementia. It may be that those who live with cognitive impairments are personally aware of problems that are not picked up by standardized testing, as a number of our participants suggested – and indeed, self-reported memory complaints have demonstrated some prognostic value in previous studies (Mitchell & Shiri-Feshki, 2009).

Another finding was the desire among several participants for medical management. While MCI may be treated with Cholinesterase inhibitors in the United States, no pharmacological treatments are recommended for MCI in the United Kingdom – and the greater part of research efforts have been devoted to behavioural and other non-pharmacological approaches to management. What clinical services can do to support people with MCI to live well and maintain cognitive function, both medically and occupationally, is an important question to address in coming years as increasing numbers of people present to clinical services with potential prodromal dementia.

As with any qualitative research, the generalizability of our findings is limited. We were unable to purposively recruit participants, and consequently, our sample was relatively homogeneous in terms of age, ethnicity, and geographical location. This latter point is especially important – there are likely to be wide variations nationally in how MCI is diagnosed in clinical practice, and so our data only provide a snapshot of one clinic in the North of England. However, our work is not the first piece of research to have identified problems in understanding MCI (Beard & Neary, 2013; Blieszner, Roberto, Wilcox, Barham, & Winston, 2007; Lingler *et al.*, 2006), and so our findings lend support to the possibility that this is a persistent issue.

In conclusion, MCI is a difficult category to understand from a lay perspective. The complex relationship between MCI, serious neurocognitive disorders, and 'normal' ageing is a source of uncertainty and confusion among people living with the diagnosis, and the lack of recommended medical treatments can be a source of frustration. Work is needed to understand how MCI is discussed in clinical consultations, and what can be done to support people in managing their cognitive difficulties.

Conflict of interest

All authors declare no conflict of interest.

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References

Albert, M. S., DeKosky, S. T., Dickson, D., Dubois, B., Feldman, H. H., Fox, N. C., . . . Snyder, P. J. (2011). The diagnosis of mild cognitive impairment due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia*, *7*, 270–279. https://doi.org/10.1016/j.jalz.2011.03.008

Allan, C. L., Behrman, S., Ebmeier, K. P., & Valkanova, V. (2016). Diagnosing early cognitive decline—when, how and for whom? *Maturitas*, *96*, 103–108. https://doi.org/10.1016/j.maturitas.2016.11.018

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. Arlington, VA: Author.

Beard, R. (2016). *Living with Alzheimer's: Managing memory loss, identity, and illness*. New York, NY: New York University Press.

Beard, R. L., & Neary, T. M. (2013). Making sense of nonsense: Experiences of mild cognitive impairment. *Sociology of Health & Illness*, *35*(1), 130–146. https://doi.org/10.1111/j.1467-9566.2012.01481.x

Bhaskar, R. (2014). *The possibility of naturalism: A philosophical critique of the contemporary human sciences*. London: Routledge.

Binegar, D. L., Hynan, L. S., Lacritz, L. H., Weiner, M. F., & Cullum, C. M. (2009). Can a direct IADL measure detect deficits in persons with MCI? *Current Alzheimer Research*, *6*(1), 48. https://doi.org/10.2174/156720509787313880

Blieszner, R., Roberto, K. A., Wilcox, K. L., Barham, E. J., & Winston, B. L. (2007). Dimensions of ambiguous loss in couples coping with mild cognitive impairment*. *Family Relations*, *56*, 196–209. https://doi.org/10.1111/j.1741-3729.2007.00452.x

Bruine de Bruin, W., & Bostrom, A. (2013). Assessing what to address in science communication. *Proceedings of the National Academy of Sciences.*, *110*(Suppl. 3), 14062–14068. https://doi.org/10.1073/pnas.1212729110

Charmaz, K. (2014). *Constructing grounded theory*. Thousand Oaks, CA: Sage.

Corbin, J., & Strauss, A. (2014). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage.

Devers, K. J., & Frankel, R. M. (2000). Study design in qualitative research–2: Sampling and data collection strategies. *Education for Health*, *13*, 263–271. https://doi.org/10.1080/13576280050074543

Fang, M. L., Coatta, K., Badger, M., Wu, S., Easton, M., Nygård, L., . . . Sixsmith, A. (2017). Informing understandings of mild cognitive impairment for older adults: Implications from a scoping review. *Journal of Applied Gerontology*, *36*, 808–839. https://doi.org/10.1177/0733464815589987

Finlay, L., & Gough, B. (2003). *Reflexivity: A practical guide for researchers in health and social sciences*. Oxford, UK: Blackwell Science.

Fischhof, B. (1995). Risk perception and communication unplugged: Twenty years of process. *Risk Analysis*, *15*, 137–145. https://doi.org/10.1111/j.1539-6924.1995.tb00308.x

Gomersall, T., Astell, A., Nygård, L., Sixsmith, A., Mihailidis, A., & Hwang, A. (2015). Living with ambiguity: A metasynthesis of qualitative research on mild cognitive impairment. *The Gerontologist*, *55*, 892–912. https://doi.org/10.1093/geront/gnv067

Gomersall, T., Madill, A., & Summers, L. K. M. (2012). Getting one's thoughts straight: A dialogical analysis of women's accounts of poorly controlled type 2 diabetes. *Psychology & Health*, *27*, 378–393. https://doi.org/10.1080/08870446.2011.583649

Kim, K. R., Lee, K. S., Cheong, H. K., Eom, J. S., Oh, B. H., & Hong, C. H. (2009). Characteristic profiles of instrumental activities of daily living in different subtypes of mild cognitive impairment. *Dementia and Geriatric Cognitive Disorders.*, *27*, 278–285. https://doi.org/10.1159/000204765

Lingler, J. H., Nightingale, M. C., Erlen, J. A., Kane, A. L., Reynolds, C. F., Schulz, R., & DeKosky, S. T. (2006). Making sense of mild cognitive impairment: A qualitative exploration of the patient's experience. *The Gerontologist*, *46*, 791–800. https://doi.org/10.1093/geront/46.6.791

Mioshi, E., Dawson, K., Mitchell, J., Arnold, R., & Hodges, J. R. (2006). The Addenbrooke's Cognitive Examination Revised (ACE-R): A brief cognitive test battery for dementia screening. *International Journal of Geriatric Psychiatry*, *21*, 1078–1085. https://doi.org/10.1002/gps.1610

Mitchell, A. J., & Shiri-Feshki, M. (2009). Rate of progression of mild cognitive impairment to dementia–meta-analysis of 41 robust inception cohort studies. *Acta Psychiatrica Scandinavica*, *119*, 252–265. https://doi.org/10.1111/j.1600-0447.2008.01326.x

Moreira, T., Hughes, J. C., Kirkwood, T., May, C., McKeith, I., & Bond, J. (2008). What explains variations in the clinical use of mild cognitive impairment (MCI) as a diagnostic category? *International Psychogeriatrics*, *20*, 697–709. https://doi.org/10.1017/S1041610208007126

Nasreddine, Z. S., Phillips, N. A., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., … Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society*, *53*, 695–699. https://doi.org/10.1111/j.1532-5415.2005.53221.x

Nygård, L., Pantzar, M., Uppgard, B., & Kottorp, A. (2012). Detection of activity limitations in older adults with MCI or Alzheimer's disease through evaluation of perceived difficulty in use of everyday technology: A replication study. *Aging & Mental Health*, *16*, 361–371.

O'Doherty, K. (2006). Risk communication in genetic counselling: A discursive approach to probability. *Theory & Psychology*, *16*, 225–256. https://doi.org/10.1177/0959354306062537

Petersen, R. C. (1995). Normal aging, mild cognitive impairment and Alzheimer's disease. *The Neurologist*, *4*, 326–344

Petersen, R. C. (2003). Mild cognitive impairment clinical trials. *Nature Reviews Drug Discovery.*, *2*, 646–653. https://doi.org/10.1038/nrd1155

Petersen, R. C. (2004). Mild cognitive impairment as a diagnostic entity. *Journal of Internal Medicine*, *256*, 183–194. https://doi.org/10.1111/j.1365-2796.2004.01388.x

Petersen, R. C. (2016). Mild cognitive impairment. *CONTINUUM: Lifelong Learning in Neurology*, *22*(2, Dementia), 404–418.

Petersen, R. C., Roberts, R. O., Knopman, D. S., Boeve, B. F., Geda, Y. E., Ivnik, R. J., … Jack, C. R. (2009). Mild cognitive impairment: Ten years later. *Archives of Neurology.*, *66*, 1447–1455. https://doi.org/10.1001/archneurol.2009.266

Petersen, R. C., Smith, G. E., Waring, S. C., Ivnik, R. J., Tangalos, E. G., & Kokmen, E. (1999). Mild cognitive impairment: Clinical characterization and outcome. *Archives of Neurology*, *56*, 303–308. https://doi.org/10.1037/e314192004-003

Robinson, L., Gemski, A., Abley, C., Bond, J., Keady, J., Campbell, S., … Manthorpe, J. (2011). The transition to dementia–individual and family experiences of receiving a diagnosis: A review. *International Psychogeriatrics*, *23*, 1026–1043. https://doi.org/10.1017/s1041610210002437

Rose, N. (2006). Disorders without borders? The expanding scope of psychiatric practice. *BioSocieties*, *1*, 465–484. https://doi.org/10.1017/S1745855206004078

Rosenberg, P. B., Mielke, M. M., Appleby, B. S., Oh, E. S., Geda, Y. E., & Lyketsos, C. G. (2013). The association of neuropsychiatric symptoms in MCI with incident dementia and Alzheimer disease. *The American Journal of Geriatric Psychiatry*, *21*, 685–695. https://doi.org/10.1016/j.jagp.2013.01.006

Sabat, S. R. (2006). Mild cognitive impairment: What's in a name? *Philosophy, Psychiatry, & Psychology*, *13*(1), 13–20. https://doi.org/10.1353/ppp.2006.0046

Sachdev, P. S., Lipnicki, D. M., Crawford, J., Reppermund, S., Kochan, N. A., Trollor, J. N., … Lux, O. (2013). Factors predicting reversion from mild cognitive impairment to normal cognitive functioning: A population-based study. *PLoS One*, *8*(3), e59649. https://doi.org/10.1371/journal.pone.0059649

Saunders, P. A., de Medeiros, K., & Bartell, A. (2011). 'Oh he was forgettable': Construction of self identity through use of communicative coping behaviors in the discourse of persons with cognitive impairment. *Dementia*, *10*, 341–359. https://doi.org/10.1177/1471301211407805

Verhaeghe, P. (2008). *On being normal and other disorders: A manual for clinical psychodiagnostics*. London, UK: Karnac Books.

Vernooij-Dassen, M. J., Moniz-Cook, E. D., Woods, R. T., Lepeleire, J. D., Leuschner, A., Zanetti, O., . . . Iliffe, S. (2005). Factors affecting timely recognition and diagnosis of dementia across Europe: From awareness to stigma. *International Journal of Geriatric Psychiatry*, *20*, 377–386. https://doi.org/10.1002/gps.1302

Viera, A. J., & Garrett, J. M. (2005). Understanding interobserver agreement: The kappa statistic. *Family Medicine*, *37*, 360–363.

Ward, A., Arrighi, H. M., Michaels, S., & Cedarbaum, J. M. (2012). Mild cognitive impairment: Disparity of incidence and prevalence estimates. *Alzheimer's & Dementia*, *8*(1), 14–21. https://doi.org/10.1016/j.jalz.2011.01.002

Werner, P., & Korczyn, A. D. (2008). Mild cognitive impairment: Conceptual, assessment, ethical, and social issues. *Clinical Interventions in Aging*, *3*, 413–420.

Whitehouse, P. J., & Moody, H. R. (2006). Mild cognitive impairment: A 'hardening of the categories'? *Dementia*, *5*(1), 11–25. https://doi.org/10.1177/1471301206059752

World Health Organization (2004). *International statistical classification of diseases and related health problems*. Geneva, Switzerland: Author.

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Appendix 1: Semi-structured topic guides

Topic guide

Introduction: Reiterate the purpose of the interview, and the form it will take. Emphasize role as learner, and interest in the participant's own 'insider' knowledge, experiences, and stories.

Topic 1. Changes in the person and relationships

Can you tell me about the time you first noticed a change in yourself?

- (if not covered above) – clarify domain(s) of impairment
- Follow-up to gain as many particular incident narratives as possible: What happened then?

How do you find your (memory/attention/speech – use pt's word) at the moment?

- As many examples as possible
- Pick up on things pt mentions and push for particular narratives – 'what happened at that time?'

Sometimes, when people are diagnosed with problems in (attention/memory/use pt's word), they can change in other ways, too. Have you noticed any other changes recently?

- As many examples as possible.
- Push for particular narratives – 'what happened at that time?'

Can you think of any ways your relationships have changed recently?

Topic 2. Hobbies and activities

One thing we would like to find out about is whether living with someone with (use pt's word) affects the things people enjoy doing on a day-to-day basis. So, please can you tell me about the things you enjoy doing?

- If needed, clarify this could be anything they like: professional activities, hobbies, household work, seeing family and friends, etc.
- Push for particular narratives – 'can you tell me about any times you've done X?'
- As many examples as possible.

Do you have any ideas about what might help you keep up with (activity) in future years?

Topic 3. Experience of diagnosis

Was there anything in particular that made you decide to go to the doctor about (use pt's word)?

- Push for as many particular narratives as possible

Thinking about your first visit to the memory clinic, can you tell me a bit about what happened on that day?

- Explore thoughts/feelings during the visit with the participant. Issues to cover if pt does not mention them: experience of referral; experience of assessment process; what the doctor told them was the diagnosis (and how they said it).

Interview close

Summarize the interview: reiterate all key issues/stories. Clarify that you have understood him/her in the way they wish. Ask participant: *Is there anything we've not covered, or anything else you'd like to tell me?*

Partners' topic guide

Introduction: Reiterate the purpose of the interview, and the form it will take. Emphasize role as learner, and interest in the participant's own 'insider' knowledge, experiences, and stories.

Topic 1. Changes in the person and relationship

Can you tell me about the time you first noticed a change in (partner)?

- (if not covered above) – clarify domain(s) of impairment
- Follow-up to gain as many particular incident narratives as possible: What happened then?

How do you find (partner)'s (memory/attention/speech – use pt's word) at the moment?

- As many examples as possible
- Push for particular narratives – 'what happened at that time?'

Sometimes, when people are diagnosed with problems in (attention/memory/use pt's word), they can change in other ways, too. Have you noticed any other changes in (partner) recently?

- As many examples as possible.
- Push for particular narratives – 'what happened at that time?'

Can you think of any ways your relationship with (partner) has changed recently?

Topic 2. Hobbies and activities

One thing we would like to find out about is whether living with someone with (use pt's word) affects the things people enjoy doing on a day-to-day basis. So, please can you tell me about the things you enjoy doing?

- If needed, clarify this could be anything they like: professional activities, hobbies, household work, seeing family and friends, etc.
- Push for particular narratives – 'can you tell me about any times you've done X?'

(If not explored after above question): Have (partner)'s problems affected (activities x, y, z) in any way?

- As many examples as possible.

Do you have any ideas about what might help you keep up with (activity) in future years?

Topic 3. Experience of diagnosis

Was there anything in particular that made you decide to go to the doctor about (use pt's word)?

- Push for as many particular narratives as possible

Thinking about your first visit to the memory clinic, can you tell me a bit about what happened on that day?

- Explore thoughts/feelings during the visit with the participant. Issues to cover if pt does not mention them: experience of referral; experience of assessment process; what the doctor told them was the diagnosis (and how they said it).

Interview close

Summarize the interview: reiterate all key issues/stories. Clarify that you have understood him/her in the way they wish. Ask participant: *Is there anything we've not covered, or anything else you'd like to tell me?*