

**RESEARCH ARTICLE**

# “Falling through the cracks”; Stakeholders' views around the concept and diagnosis of mild cognitive impairment and their understanding of dementia prevention

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**Objectives:** Many people live with an awareness of mild cognitive changes that increase their dementia risk. Previous authors describe the uncertainties of this liminal state, between cognitive health and dementia, where being “at risk” can itself be an illness. We ask how services respond to people with memory concerns currently, and how a future, effective and inclusive dementia prevention intervention might be structured for people with memory concerns.

**Methods/Design:** We conducted qualitative interviews with 18 people aged 60+ years with subjective or objective memory problems, six family members, 10 health and social care professionals and 11 third sector workers. Interviews were audio-recorded, transcribed and analysed using an inductive thematic approach.

**Results:** Three main themes were identified: (1) acknowledging the liminal state, compounded by current, discordant health service responses: medicalising memory concerns yet situating responsibilities for their management with patients and families; (2) enabling change in challenging contexts of physical and cognitive frailty and social disengagement and (3) building on existing values, cultures and routines.

**Conclusions:** Effective dementia prevention must empower individuals to make lifestyle changes within challenging contexts. Programmes must be evidence based yet sufficiently flexible to allow new activities to be fitted into people's current lives; and mindful of the risks of pathologising memory concerns. Most current memory services are neither commissioned, financially or clinically resourced to support people with memory concerns without dementia. Effective, large scale dementia prevention will require a broad societal response.

**KEYWORDS**

cognitive concerns, dementia, mild cognitive impairment, prevention

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## 1 | INTRODUCTION

Dementia is the greatest health and social challenge of our time, with the number of people living with the disease projected to rise to 115 million by 2050.<sup>1</sup> As a sequelae of the drive across Western countries towards early dementia diagnosis, to optimise benefits from symptomatic treatments and advice, many people are being identified by health services as experiencing memory concerns and cognitive problems that put them at increased dementia risk. Mild Cognitive Impairment (MCI—objective cognitive symptoms and absence of dementia), affects a fifth of people over 65;<sup>2</sup> and Subjective Cognitive Decline (SCD—self-reported experience of cognitive decline and unimpaired performance on cognitive tests) half of people over 65.<sup>3</sup>

In sociological terms, MCI and SCD are contested categories. Most people experiencing them do not develop dementia. While most people with memory concerns do not seek help from services, many do. Awareness of increased dementia risk can drive lifestyle change,<sup>4</sup> but also causes anxiety.<sup>5</sup> Dementia prevention is a political priority in many countries, fuelled by optimism about the preventative potential of lifestyle change and health promotion.<sup>6</sup> A third of dementia cases are attributable to potentially modifiable dementia risk factors. These include cardio-metabolic dysfunction (diabetes and cardiovascular risks), physical inactivity, social isolation, hearing loss, mental illness, alcohol and smoking.<sup>7</sup> There is also evidence that interventions targeting dementia risk factors reduce cognitive decline.<sup>8</sup> NICE (The National Institute for Health and Care Excellence)<sup>9</sup> and PHE (Public Health England)<sup>10</sup> guidelines advocate dementia prevention through planning health services that “emphasise the need for, and help people to maintain, healthy behaviours throughout life”, with a focus on physical activity.<sup>9</sup> A recent review found limited evidence regarding the implementation of such policies.<sup>11</sup> No current evidence-based interventions exist that are scalable for delivery to large populations.<sup>12</sup>

In this article, we ask how services and society respond to people with memory concerns, and how a dementia prevention intervention should be designed for people with memory concerns. Our primary aim is to explore how people with MCI or SCD and other stakeholders involved in their wellbeing and care (family members, National Health Service and third sector professionals and commissioners) consider future dementia prevention (APPLE-Tree Programme) should be designed for and delivered to this group.

## 2 | METHODS

The APPLE-Tree programme protocol is published elsewhere.<sup>13</sup> London (Camden and Kings Cross) Research Ethics Committee (Reference: 19/LO/0260) and UK Health Research Authority (HRA) approved this study in April 2019.

### 2.1 | Sampling and recruitment

We interviewed people aged 60+ years with subjective or objective memory problems without dementia or significant functional

### Key points

- We explored how services currently respond to people with memory concerns and how a future dementia prevention intervention might be structured for people with memory concerns.
- We found that people with memory concerns find themselves in a liminal, transitional state, between health and dementia, with professionals locating responsibility for managing and monitoring memory concerns with patients.
- Effective dementia prevention must empower individuals to make lifestyle changes within challenging contexts and prevention programmes must be sufficiently flexible to allow new activities to be fitted into people's lives.

impairment; family members in at least monthly contact with them, and health and social care professionals and third sector workers involved in commissioning or supporting this group. We purposively selected participants for diversity in gender, age, ethnicity and location (urban, semi-urban and rural). Participants who lacked capacity were excluded.

Participants were recruited from NHS memory, primary care and IAPT (Improving Access to Psychological Therapies) services; UCL and third sector organisations across London, South England and North-west England. We recruited people who had been told they had MCI/SCD; and those with memory concerns who had not sought NHS help, via third sector organisations.

### 2.2 | Procedures

We conducted semi-structured, face-to-face qualitative interviews with participants between July and September 2019. At their preference, two people with memory concerns were interviewed with their family member and two family members were interviewed together. Other interviews were individual. One interview was conducted in Italian; the remainder were in English. Participants gave written, informed consent before interviews.

Topic guides were based on our research aim and revised iteratively to explore issues raised in interviews. We showed participants prompt cards listing potential lifestyle changes: being more physically or mentally active; looking after your physical and mental health/wellbeing and improving sleep; eating more healthily (and a description of a Mediterranean-style diet); and reducing alcohol. Topic guides explored: how people with memory concerns are best motivated and supported to make targeted behavioural changes, potential barriers and facilitators to participating in an active dementia prevention programme and to its delivery (for professionals and third sector workers). The topic guide is appended as a supplementary file.

Interviews lasted around 45 minutes. We ceased recruitment and determined that thematic saturation was reached when no new themes emerged. We asked people with memory concerns to complete the Quick Mild Cognitive Impairment screen (Qmci).<sup>14</sup>

## 2.3 | Data analysis

We used NVivo 12 qualitative analysis software and an inductive thematic analysis approach.<sup>15</sup> Data collection and analysis was iterative. Interviews were digitally recorded, anonymised and professionally transcribed. Ten transcripts were independently coded by co-authors and codes compared. MPo and HM then developed and applied a coding frame to remaining transcripts, in discussion with other authors; revising it to ensure it applied to all interviews (two further iterations). We identified and discussed emerging themes.

## 3 | RESULTS

### 3.1 | Sample characteristics

45/52 (87%) participants approached took part. We interviewed 18 people with memory concerns, six family members, 10 health and social care professionals and 11 third sector workers. The Qmci was completed with all people aged 60+ except one, who had a diagnosis of MCI. The median Qmci score was 55.5 for participants with memory concerns recruited from NHS services and 63 for those from the third sector. Demographic characteristics of participants are shown in Tables 1-3.

### 3.2 | Thematic analysis

We identified three main themes responding to our research question of how an active prevention intervention should be designed and delivered for people with memory concerns. These were: (1) acknowledging the liminal state, (2) enabling change in challenging contexts and (3) building on existing values, cultures, and routines.

#### 3.2.1 | Theme 1: Acknowledging the liminal state

This theme reflects the “lostness” or state of “falling through the cracks” encountered by people with memory concerns who find themselves in a liminal, transitional state, between health and dementia. By contrast, professionals identified a clear dichotomy between dementia and wellness. As “well” people, those with memory concerns were considered fully able to manage their cognitive condition. In clinical encounters, NHS memory service professionals prioritised explaining risk of progression to dementia, the importance of seeking help if symptoms worsened, and advice to self-initiate lifestyle change—by “signposting” to appropriate service and groups. In some professional

accounts, there was a sense that therapeutic nihilism may underlie this “signposting” away, but there was also a practicality to it, as memory services are only commissioned to treat people with dementia. Memory concerns were conceptualised either as a risk factor, or a diagnosis that they had no mandate to treat. This approach often left people with memory concerns and their families feeling alone and unsure what to do; holding the responsibility to self-monitor and self-manage, without support from services.

#### 1.1 “The only plan I didn’t have in place was to keep my memory”

Interviewees living with memory concerns and their family members described a liminal state—between the normality of retirement, holiday plans, and doubts and fears about how memory concerns might affect them in the future. They described the uncertainty and fluidity of the experience of undiagnosed memory problems.

Because I was very busy as a businessman before I retired and I was very conscious before I retired that I had to have the plan in place to do things. The only plan I didn't have in place was to keep my memory, so there we go, that's where it is.

Person with memory concerns, not “diagnosed” by services (PWMC15).

Accounts of people with memory concerns and staff appeared to acknowledge a need to identify with wellness and move away from the illness position. This was implicit in the following account:

*I think you have got to be outward-looking and connect with people. If possible, with people who are in one or another way worse off than you are, so that you can help them in a little way. I think helping other people helps your mental wellbeing.*

#### Person with diagnosis of MCI (PWMC5).

Most people with memory concerns referred to a clinical encounter where memory concerns were acknowledged and discussed, as a defining event in how they understood and responded to their memory concerns. There was a divergence between how professionals and people with memory concerns perceived these encounters, which we describe in the two subsequent sub-themes.

#### 1.2 “People need to be given the facts”

Professionals located responsibility to reduce the risk of dementia and to contact services if symptoms worsened with the client:

I think people need to be given facts. So they need to be told, you know, your chance of this progressing to full-blown dementia is 10-15% a year or whatever it is. And we should tell them, this is not inevitable, that you will go on to have dementia. We've caught this early, you can change it by lifestyle. This is what you need to do. So you need to give them those very clear messages that the carrots, almost literally, rather than the sticks. So that they have got that incentive.

**TABLE 1** Characteristics of persons with memory concerns

Characteristics	n (%) or mean (SD)	
Age	74.9 (7.86) Range 60-91	
Gender	Female	4 (22.2)
	Male	14 (77.8)
Ethnicity	White British	14 (77.8)
	White Other	1 (5.6)
	Black British Caribbean	1 (5.6)
	Other	1 (5.6)
	Irish/Indian	1 (5.6)
Marital status	Single	2 (11.1)
	Married	9 (50)
	Divorced	4 (22.2)
	Widowed	3 (16.7)
Education	Secondary	6 (33.3)
	Further	5 (27.8)
	Degree	6 (33.3)
	Postgraduate	1 (5.6)
Living situation	Living alone	7 (38.9)
	Living with relative	11 (61.1)
Type of memory difficulties	Mild cognitive impairment	5 (27.8)
	Memory concerns	8 (44.4)
	Other	1 (5.6)
	None	2 (11.1)
	Unable to specify	2 (11.1)
Onset of memory difficulties	0-1 Years	5 (27.8)
	1-3 Years	4 (22.2)
	3-5 Years	3 (16.7)
	5+ Years	4 (22.2)
	Not specified	2 (11.1)
qMCI scores	53.1 (38.5) Range 52-75	

General practitioner (ST2).

In this next quote, there is an implicit suggestion that the professional role is information provider—and it is up to the clients how they respond.

But we don't see them again. With MCI diagnoses, we're not commissioned to hold on to MCI patients [...] we're doing an audit at the moment looking at how many people come back later and whether they come back later than we would have liked. Because I tend to feel like we did an MCI diagnosis three years ago. They're now coming back and they're already

**TABLE 2** Characteristics of family members

Characteristics	n (%) or mean (SD)	
Age	54.7 (22.8) Range 29-82	
Gender	Female	5 (83.3)
	Male	1 (16.7)
Ethnicity	White British	2 (33.3)
	Black British Caribbean	2 (33.3)
	Other	2 (33.3)
	Single	2 (33.3)
Marital status	Married	4 (66.7)
	Education	Secondary
Degree		3 (50)
Other		1 (16.7)
Living with person with memory difficulties	Yes	4 (66.7)
	No	2 (33.3)
Employment	Unemployed	2 (33.3)
	Retired	3 (50)
	Other	1 (16.7)
Relationship to person with memory difficulties	Spouse	2 (33.3)
	Children	4 (66.7)

moderate. And you think, why didn't you come back two years ago?

Consultant old age psychiatrist, describing work in memory service (ST9).

This location of responsibility onto clients with memory concerns appeared to stem from service configurations, as memory services were not commissioned to treat people without dementia:

So, you're talking about people that might have MCI instead. Yes, unfortunately there's not as much. The service is commissioned in a way that almost that dementia diagnosis is a bit of a gatekeeper, really. And it's as soon as they have that then all of our services flood in.

Assistant psychologist, memory service (ST10).

Some of the memory service professionals were concerned about the impact of prognostic uncertainty and the lack of services and information available for clients with SCD/MCI:

A large group of people with these problems I think struggle with this uncertainty that they've got some sort of problem. They've come concerned about dementia and they've gone away still a bit concerned but not specifically told that they don't have dementia.

**TABLE 3** Characteristics of health and social care professionals

Characteristics		n (%)
Gender	Female	14 (66.7)
	Male	7 (33.3)
Ethnicity	White British	16 (76.2)
	White Other	2 (9.5)
	Black British African	1 (4.8)
	Black British Caribbean	1 (4.8)
	Black Other	1 (4.8)
Professional role	Old Age Psychiatrist	2 (9.5)
	General Practitioner	1 (4.8)
	Clinical Psychologist	1 (4.8)
	Sport Assistant	1 (4.8)
	Clinical Nurse Specialist	1 (4.8)
	Practice Nurse	1 (4.8)
	Memory Team Manager	1 (4.8)
	Dementia Service Admin	1 (4.8)
	Dementia Advisor	1 (4.8)
	Assistant Psychologist	1 (4.8)
	Sport and Health Manager	1 (4.8)
	CEO of Third Sector	2 (9.5)
	Day Opportunities Manager	1 (4.8)
	Occupational Therapist	1 (4.8)
	Operations Manager	1 (4.8)
	Memory Support Assistant	1 (4.8)
	Publicity Officer	1 (4.8)
Facilities Support Service Manager	1 (4.8)	
Support, Time and Recovery Worker	1 (4.8)	
Time working in dementia care	1–3 Years	2 (9.5)
	3–5 Years	2 (9.5)
	5–10 Years	7 (33.3)
	10+ Years	10 (47.6)

Academic old age psychiatrist (ST1).

There was also a sense of nihilism in the professionals' accounts about the likelihood that people with memory concerns would be able to benefit from lifestyle changes:

This gentleman was in his 80s, and he'd drank and smoked since the age of 12. He was visually impaired, had moments of depression, based on the seasons. Actually, when we were looking at the quality of life, let him drink, because he's got very little to look forward to.

CEO of a third sector organisation (ST12).

## 1.3 "I do not know what to do"

Most participants and family members, who recalled discussions with health professionals about memory, described a deficit of after care and advice:

No. And I don't think [memory concerns] was taken that seriously. I don't think [the doctor] saw it as a problem. I saw it as a problem but I don't think he did.

Person with memory concerns, not "diagnosed" by services (PVMC15).

For many, the information provided within the interview about dementia risk factors was new:

But I don't know what to do. Yes, I need to know what's out there because I would do it if I knew what was out there. I'd go to coffee mornings, you know, things like that.

Person with diagnosis of MCI (PVMC1).

## 1.4 "My father is now a lost patient"

Family members often felt situated between the roles of a relative and a carer. Some people with memory concerns and family members however stressed the reciprocity of their relationships; for a daughter and father, this meant that they could do activities together.

In fact, my daughter challenged me. She's doing the Pier to Pier Swim in the [Name of Island], [Name of Towns], which is two miles. Come on dad, you can do this. So yes, we're both doing it next Saturday.

#### Person with memory concerns (PWMC14).

At other times, this uncertainty of role left relatives unsure when to intervene:

Like I said, my father is now a lost patient, because it's up to him whether he is worried about it or not. There's a lack of information out there as to what you can do, what there is available out there. I'm sure there is a lot. That's an important thing as well. Information.

#### Daughter of person with MCI (FM6).

Some staff members reported providing advice directly to family members, which suggested they saw the family members as carers:

The advice might be given to the carer rather than the person with memory problems.

#### Third sector service manager (ST15).

### 3.2.2 | Theme 2: Enabling change in challenging contexts

We identified three sub-themes, describing potentially challenging contexts of which a dementia prevention programme should take account. Cognitive and physical frailties, and low self-confidence were barriers that people with memory concerns and professionals had experienced being overcome with support. This ran counter to professional accounts in the previous theme, which placed responsibility for introducing lifestyle changes solely on people with memory concerns and their families.

#### *2.1 Social disengagement*

Longstanding social disengagement, often preceding acknowledgement of memory concerns was perceived as challenging to reverse:

I suppose, it's to a degree once you've retired and you've been working and you've been busy, yes, your social life is full because a lot of it was entertaining customers anyway. So if you stop that immediately, you'd have nothing.

#### Person with diagnosis of MCI (PWMC6).

This barrier related to losses: of social contacts, physical strength and confidence:

Yes. I think it's very easy once you've retired, especially if you're on your own to just become isolated and not really do very much. And once you start doing that, I think that then it becomes harder to get back out and do things.

#### Support worker, third sector organisation (ST16).

##### *2.2 Increasing frailty and challenges*

Memory concerns and concomitant physical frailties were challenging contexts in which to increase social engagement and activity. Tailoring advice to the individual as part of the intervention programme was suggested by many to mitigate this:

Yes, I think that's really what it is, isn't it, somebody's got to feel comfortable in a situation, particularly if they are worried about memory, they don't want to be somewhere that makes them even more worried about it. So, I think activity would depend on what they can do, as well.

#### Third sector worker (ST18).

##### *2.3 Need to build self-confidence*

While physical and cognitive problems may prohibit involvement in some activities, associated loss of confidence was mostly perceived as the greatest barrier for joining a dementia prevention intervention group.

Yes, I think it's that confidence thing of feeling that they're losing part of themselves a little bit and they don't want to make a fool of themselves or they don't want to get things wrong. And they don't want to turn up on the wrong day or be late.

#### Primary care, practice nurse (ST17).

One person with memory concerns reflected on the value of supporting someone to overcome the barrier of joining a group, as after attending one session, it gets easier:

Yes. You only walk in once, don't you? You are only a stranger once.

#### Person with memory concerns (PWMC2).

### 3.2.3 | Theme 3: Building on existing values, cultures and routines

#### *3.1 "Go with the grain of what they're already doing"*

All participants stressed that recommendations should fit in with people's preferences and routines:

So again, try and go with the grain of what they're already doing, and go with what they want to do, rather than imposing something on them. I think sending them off to the gym can be... you know, people don't always want to go in the Lycra or go swimming or whatever. So yes, it's find out what they do at the moment, and then try and optimise what they're already doing.

#### General practitioner (ST2).

##### 3.2 Importance of social and cultural influences

Participants highlighted the need to consider people's social and cultural backgrounds when delivering the intervention programme. This was, for example, demonstrated by their responses regarding the likelihood of people adopting a Mediterranean-style diet.

Too fancy, actually. I am brought up a very ordinary Scot. A very down-to-earth Scot. These words [olive oil, passata] are just not in my vocabulary or my life at all.

#### Person with diagnosis of MCI (PWMC5).

Participants suggested that people would be more likely to attend groups and activities in cultural community spaces or churches they already visit regularly:

So, he likes to go to the pub... He doesn't drink, but he just likes to sit in that environment. He is a Punjabi man, there is one Punjabi centre where he loves to go, I encourage him to go to the Punjabi centre. So, he goes there twice a week.

#### Support time recovery worker, memory service (ST21).

##### 3.3 Role of gender

Similarly, it was also important that activities were tailored to possible perceived gender differences.

The other thing, now they've started a knitting group in our local library for any age group, but mainly women are in it and they're knitting.

#### Wife of person with MCI (FM3).

We have the yoga that isn't for everybody. And walking football obviously will only be for men. It isn't just for men, but obviously it would normally be men who'll be interested in it.

#### Support worker, third sector organisation (ST16).

## 4 | DISCUSSION

We identified three themes: (1) acknowledging the liminal state, (2) enabling change in challenging contexts, and (3) building on existing values, cultures, and routines; that may inform how a future dementia prevention programme might be designed and delivered.

Our first theme highlights the liminal position of people with memory concerns—between illness and normality reflecting previous work,<sup>5</sup> which we extended by exploring professional and carer perspectives. Dean, Jenkinson, Wilcock and Walker,<sup>16</sup> previously highlighted the ambiguity around the carer role in people with MCI. Unlike individuals diagnosed with dementia, people with MCI do not necessarily have a family member who identifies as “carer” but more as a “concerned relative or friend” (p. 476). Carole Levine described caregiving as living “in a liminal space with no sense of when, where, or how the caregiving journey would end.”<sup>17</sup> For family members of people with memory concerns, there was sometimes also confusion about to what extent it had begun.

For people with memory concerns, this liminal position conferred a sense of responsibility for their own wellbeing, that was also disempowering. Half of over 65s in the UK fear dementia more than any other condition,<sup>18</sup> so it is unsurprising that interventions discussing dementia risk are anxiety-provoking. A more helpful response would, from our findings, situate responsibility for dementia prevention at a societal level, as reflected in the work of Liebing,<sup>19</sup> and be enabling rather than medicalising. This may require non-traditional, less hierarchical care models. Expert interventions are generally brief, expensive, and challenging to sustain beyond facilitated sessions. Groups formed by volunteers with the goal of preventing dementia in Japan were cohesive and sustainable.<sup>20</sup> Perhaps the loss of fidelity to an evidence-based approach in these volunteer models finds compensation in sustainability, which may stem from their support of active citizenship. Our new coproduced APPLE-Tree intervention programme, which we developed from this work, is situated as a cognitive wellbeing course. It does not explicitly reference dementia.

Linked to this liminal position, between wellness and illness, our second theme acknowledges the challenging contexts in which a future, inclusive dementia prevention programme must operate—of social disengagement, frailty and lack of confidence. Outside the context of responsibility for service provision, professionals acknowledged that people with memory concerns required help and response to circumvent these challenges.

Our final theme acknowledges the importance of previous roles in the development and delivery of a future dementia prevention intervention. For any activity or lifestyle change to be successfully adopted and sustained, it should consider preferences, routines and habits potentially built over decades; and be realistic for the person's current abilities. Gendered expectations could limit engagement in certain activities but also create a sense of familiarity, comfort and belonging within certain groups. The importance of tailoring advice and activities to the individual in order for an intervention to be effective and acceptable for individuals with memory concerns was a clear message by our study participants. Tailoring interventions to



individuals' interests and needs, especially for individuals with memory concerns, has been recommended elsewhere.<sup>7,9,21</sup>

We recruited participants from a broad range of organisations that provide care to people living with SCD and MCI, including NHS and third sector organisations thereby maximising diversity and encompassing a wider range of professional expertise. We only included professionals who often worked with people with memory concerns. However, our sample were inevitably drawn from those who self-identify with memory concerns, and mostly from those who explicitly sought help for such services.

## 5 | CONCLUSION

Effective dementia prevention must empower individuals to make lifestyle changes within challenging contexts. Programmes must be evidence-based yet sufficiently flexible to allow new activities to be fitted into people's current lives. They must also be mindful of the risks of pathologising memory concerns. Most current memory services are neither commissioned, financially or clinically resourced to support people living with memory concerns without dementia. Effective, large scale dementia prevention will require a broad societal response.

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### CONFLICT OF INTEREST

None declared.

### AUTHOR CONTRIBUTIONS

MPo, HM conducted the interviews and analysis, drafted and edited the manuscript; PR conducted some of the interviews, was involved in the analysis of the interviews and provided key revisions of the manuscript; MPa conducted some of the interviews, was involved in the analysis of the interviews and provided key revisions of the manuscript; AB, CC and MR were involved in the analysis of the interviews and provided key revisions of the manuscript; AB, SM-T, PH, ZW, EA, NB, JH, PR and JW are co-investigators on the grant funding the study, and such have been involved in the conception and design of the study; all co-authors revised the manuscript for intellectual content and approved the final version.

### DATA AVAILABILITY STATEMENT

The authors are willing to allow the journal to review the data if requested.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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