Yemm, H., Peel, E., & Brooker, D. (2023). "I guess you can interpret it in a number of ways like kind of a milder or the mildest form of dementia?": multi-stakeholder perceptions of cognitive impairment. *Dementia: The International Journal of Social Research and Practice.* https://doi.org/10.1177/1471302231201596

"I guess you can interpret it in a number of ways like kind of a milder or the mildest form of dementia?": multi-stakeholder perceptions of cognitive impairment

Abstract

Introduction: Mild cognitive impairment (MCI) has a high prevalence and is a risk factor for dementia. Furthering understanding of MCI has been identified as a public health priority. This research aimed to explore views about the causes of cognitive impairment and identify associations between cognitive impairment, dementia, and normative ageing.

Method: Semi-structured qualitative interviews were conducted with 22 participants with different stakeholder perspectives on the area of MCI in England, and analysed thematically.

Results: Our analysis focuses on two main themes: 1) causes of cognitive impairment, and 2) ageing, dementia, and dying. Most participants viewed cognitive impairment as a transitional state between normative ageing and dementia. Participants expressed their fear of cognitive impairment and dementia, and made clear links between cognitive impairment and dying. Participants also showed an awareness of the links between lifestyle factors and cognitive health. However, linkage between lifestyle and cognition was discussed only when explicitly asked, suggesting that this was not especially salient for participants when considering the causes and risk factors for cognitive impairment.

Conclusion: The results of this study highlight key areas for future public health initiatives, such as a focus on the multitude of benefits offered by adopting a healthy diet and physical exercise in reducing risk of cognitive impairment.

Keywords: ageing, cognitive impairment, dementia, MCI, perceptions, perspectives

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Introduction

Mild cognitive impairment (MCI) can be conceptualised as an intermediate state between normative ageing and dementia (Jongsiriyanyong & Limpawattana, 2018). The global prevalence of MCI is estimated to be 15.56%, with prevalence increasing with age (Bai et al., 2022). It is estimated the incidence of cognitive impairment will rise, with a recent study estimating an increase of 76.2% in the USA from 2020 to 2060 (Rajan et al., 2021), and an estimated increase of 83% in the UK alone from 2002 to 2031 (Comas-Herrera et al., 2007). Whilst MCI is not a guaranteed precursor of dementia, there is an increased risk of dementia amongst people living with MCI, with an estimated 8-15% annual progression rate (Petersen, 2016). The prognosis for people living with MCI is uncertain, with four potential courses; remittent, whereby normal cognitive function is recovered over time; fluctuating, in which cognition changes between MCI and normal cognitive function; stable, wherein cognitive impairment neither worsens nor improves over time; and progressive, by which cognitive function worsens over time and ultimately progresses to dementia (Kaduszkiewicz et al., 2014).

Although the risk of MCI increases with age (Han et al., 2022; Luck et al., 2010), there are a number of modifiable risk factors for MCI which can increase or decrease the likelihood of developing MCI in later life. For example, nutrition and diet have been linked to cognitive health (Scarmeas et al., 2018), as has physical activity (Clark et al., 2016; Elliott-King et al., 2019; Hahn & Andel, 2011; Liu et al., 2020). However, while research shows promising results on cognition from lifestyle changes, knowledge and awareness of these modifiable risk factors in relation to dementia among the population is low (Nagel et al., 2021; Parial et al., 2021).

Recent new advances in pharmaceutical treatment for dementia, particularly early-stage cognitive impairment have yielded promising results. Lecanemab, which has been licensed for use in the USA by the FDA (US Food and Drug Administration, 2023) has shown to reduce cognitive and functional decline, together with a reduction of amyloid markers when trialled in a population with mild cognitive impairment or mild dementia (van Dyck et al., 2022). As such, the focus on identifying cognitive impairment with a potential dementia pathology is becoming increasingly imperative. Early modelling of the outcomes and benefits

from lecanemab suggest improvements in both long-term health outcomes and associated formal and informal care costs (Tahami Monfared et al., 2022). However, it must be noted that lecanemab is not without safety concerns (Walsh et al., 2022) and therefore it is not certain whether this will be approved for use internationally. Notwithstanding these safety implications, the development still shines a light on the need to identify people living with MCI as a key population who may benefit greatly from pharmaceutical advances.

MCI as a diagnostic label can result in feelings of confusion and uncertainty (Banningh et al., 2008; Dean & Wilcock, 2012; Garand et al., 2009). This is due in part to the lack of prognostic certainty around MCI. In a recent review of the literature and circumstances surrounding MCI, Katz et al. (2021) describe the uncertainty and instability of MCI as a diagnostic entity. However, the authors also acknowledge three key reasons why MCI has persisted as a diagnostic label: 1) there is a need for a predementia stage in order for early intervention to take place; 2) biomarker identification generally supports the notion that people living with MCI present with biomarkers related to Alzheimer’s disease; 3) the influence of the pharmaceutical industry and other markets targeting cognitive health (Katz et al., 2021). Whilst the authors present arguments and considerations which suggest these three reasons for the continued use of MCI as a diagnostic label may not be wholly appropriate, it is my view that the syndrome categorised as MCI will continue to present regardless of the label that is chosen to be applied. As such, it is essential that we further our understanding of the lived experiences of families affected by MCI and seek to continue to develop and refine MCI as a diagnostic entity such that some of the uncertainty and instability may be overcome in time. Since MCI was first outlined as a diagnostic entity in 1999 (Petersen et al., 1999), the knowledge base around this concept has already expanded and grown considerably (Lee, 2023). MCI is a construct which will undoubtedly benefit from further development, but which cannot be disregarded due to current uncertainties and complexities.

Over recent years, dementia has increasingly become an international public health priority, with the World Health Organization (WHO) member states adopting a global action plan on dementia in 2017 (World Health Organization, 2017). Similarly, dementia has been

the focus of UK government policy and initiatives (Department of Health, 2015; NHS England, 2019). Despite recognition of increasing awareness and understanding of MCI as a public health priority (Winblad et al., 2016), recommendations for MCI are inconsistent across guidelines internationally (Kasper et al., 2020). For example, a recent review of international guidelines found that four out of 13 documents recommended physical activity interventions for MCI, and only three recommended dietary and nutritional interventions (Chen et al., 2021).

There is a paucity of literature to date which aims to explore knowledge and beliefs about cognitive impairment (Anderson et al., 2009). To inform future guidance, it is important to identify what current public awareness and understanding of cognitive impairment is. Similarly, understanding knowledge and awareness among healthcare professionals is key to informing future training initiatives to ensure that healthcare professionals are best equipped to support people living with cognitive impairment, and to provide guidance and advice around reducing the risk of cognitive impairment among the wider population. As such, this study aimed to provide a qualitative exploration of public and professional knowledge of cognitive impairment, particularly considering what participants consider the potential causes and risks of cognitive impairment to be, whether participants view cognitive impairment as preventable or avoidable in any way, and how people perceive the association between normal ageing, cognitive impairment and dementia.

Methods

Interviews and participants

Individual semi-structured interviews were conducted to explore participants views about cognitive impairment. It has previously been suggested that interviews are more likely to be acceptable to people experiencing cognitive difficulties than a self-administered questionnaire (Cheston et al., 2000; van Baalen et al., 2010). Participants were invited to interview following participation in a survey study exploring understanding of cognitive impairment from a wide range of different perspectives (Yemm et al., 2022). As part of this survey, participants were asked to indicate whether they would be interested in taking part in an interview. Of the 44 survey respondents approached, 20 agreed to be interviewed. It

was not possible to control for who put themselves forwards to be interviewed but the decision was made to use this convenience sample of participants from different perspectives who expressed an interest in the area of sharing their views on cognitive impairment. Given the exploratory nature of this study, participants included 6 experts by experience (people living with cognitive impairment, and care partners), 6 experts by training (representing a diversity of professions and experience including physiotherapists, social care professionals, and Dementia Friends Champions), and the 8 general public (6 older adults aged 65 or more, and 2 younger adults). This mix of participants was designed to capture a breadth of views about cognitive impairment in order to understand the range of knowledge and understanding across groups. As people living with MCI were underrepresented in this sample two further participants were recruited via the researchers' networks. Therefore, in total 22 participants took part in 21 interviews (one interview was with a couple). Participants' ages ranged from 24-82, with a mean age of 51.9 years. Thirteen females and nine males were interviewed. Details of participants are presented in Table 1.

Eighteen interviews were conducted in the participant's home and three took place in a private office at the University of Worcester. For one interview, a spouse couple were interviewed together, and for two other interviews the participant elected to have someone else in the room. One of these was a personal assistant and the other was a colleague. The remaining 18 interviews were conducted individually. The interviews ranged in time from thirty minutes to two hours and seventeen minutes (mean interview length was one hour six minutes).

Ethical approval for this study was obtained from the Institute of Health & Society at the University of Worcester, from all participating NHS Trusts, and from North East – Tyne & Wear South NHS Research Ethics Committee (Ref: 15/NE/0227). All participants were provided with detailed written and verbal information about the study and were given the opportunity to ask any questions. Participants provided informed written consent and were assured that they were free to withdraw from the study at any time without having to provide a reason for this decision. Interview questions focused on participants knowledge, understanding and views about cognitive impairment, including the language, labels and

terminology used around cognitive impairment, possible causes of cognitive impairment, prevention and treatment of cognitive impairment, and differences between cognitive impairment and dementia.

[INSERT TABLE 1 ABOUT HERE]

Data analysis

All interviews were transcribed verbatim, with personal and identifying information anonymised to protect participants confidentiality. Pseudonyms are used to present data in this article. A critical realist position was adopted, supporting the notion that individual knowledge and perspectives of reality are constructed and influenced by their own experiences. This stance acknowledges that perspectives of cognitive impairment will be impacted by personal and wider societal views, but acknowledges that, however these views may be shaped, this does not deny the existence and reality of cognitive impairment. In framing the approach taken in this study, it is important to note the position and experiences of the researcher who undertook the data collection and analysis, Heather Yemm. My own experiences are framed through the lens of dementia, having experienced a family member receive a diagnosis of dementia. Reflecting on this, I realised there was a significant period of time where my relative lived with an undiagnosed cognitive impairment and that this time was actually very difficult for them and the wider family. This experience has shaped my own views of the importance of recognising cognitive impairment in a timely manner, and the need to support families affected by cognitive impairment. I have also worked as a researcher in the area of dementia since 2011 and thus have had the opportunity to hear many narrative experiences of dementia and cognitive impairment from those people living with it, and also family members, and health and social care professionals. I was conscious not to let my own feelings impact the questions that I asked participants, and very aware of my own perceptions as I conducted data analysis, ensuring that I explored all themes present in the data and not only those that related to my own personal feelings. A thematic analysis approach was undertaken, with all themes identified grounded firmly in the data. The analysis followed several stages as outlined by (Braun & Clarke, 2021). First, transcripts were read and reread alongside listening to the audio files of the interviews. During this stage, brief notes were made about possible codes and patterns in the interview data. Transcripts were then uploaded to NVivo 11 (QSR International) where each transcript was coded line-by-line. Every transcript was reviewed several times. Codes were then reviewed, and initial themes were generated. Finally, all of the transcripts were reread, cross-referencing with the themes to

confirm that these were representative of what participants had discussed and ensure that no new themes were being generated.

Results

Following analysis of the interviews, two major themes were identified, each comprising several subthemes; 1) causes of cognitive impairment, 1a) controllability of cognitive impairment, 1b) lifestyle factors, 1c) brain damage or injury, and 2) ageing, dementia and dying, 2a) age of onset of cognitive impairment, 2b) normative ageing, 2c) differentiating cognitive impairment and dementia, 2d) death and dying.

Causes of cognitive impairment

In their discussions, participants considered whether cognitive impairment was within an individual's control and whether it was ultimately an inevitability. Participants also posited a range of potential causes of cognitive impairment, including brain damage and lifestyle factors.

Controllability of cognitive impairment

All participants were asked whether they thought cognitive impairment could be avoided or prevented, and were also asked if there was anything in particular that they thought could cause cognitive impairment. In their responses to these questions, participants considered whether cognitive impairment was within an individual's control, with nine participants stating that despite the possibility to mediate or avoid certain risks, there are causes of cognitive impairment that are not always possible to circumvent and thus cognitive impairment is inevitable. These views were expressed by five members of general public including both of the younger adult interviewees, alongside three care partners and one specialist:

Grace: well we spoke earlier about healthy diet and exercise and socialising

Interviewer: yeah

Grace: and I think once you have done all of those things I don't know anything else you can do that would stop it

Interviewer: yeah

Grace: I don't know if there is anything, if there's a magic pill you can take!

Grace (female, 70, care partner) discusses how cognitive impairment is not preventable *per se*, but that there are controllable lifestyle factors that may help prevent the onset of cognitive impairment. Grace also references "a magic pill" which, whilst being a common turn of phrase in the UK, also suggests a desire for a simple, quick solution to preserve cognitive health. The younger adult interviewees highlighted a view of cognitive impairment as an inevitability:

Interviewer: what do you think could be potential causes or risk factors for cognitive impairment?

James: that's really interesting. I- I mean part of me thinks it's somewhat inevitable no matter what your lifestyle or background is but I think it it seems, that it might be exacerbated through bad physical health

James (male, 32, younger adult) expresses a perception that some people may experience cognitive impairment no matter what they try to do to prevent it. However, James articulates some conflict in his own views, highlighting on the one hand that lifestyle cannot stop the inevitability of cognitive impairment whilst simultaneously suggesting that cognitive impairment might be "exacerbated through bad physical health". The perception of cognitive impairment as a potential inevitability was shared by a few other participants, with Irene (female, 73, older adult) expressing that "I do feel it's something that's just going to happen to some people".

In contrast, several participants held a view that cognitive impairment was not inevitable. For example, Pauline (female, 72, older adult) reported that she had enough experience with older adults "to think that it's not inevitable". This view was shared by all but one expert by training, all interviewees living with cognitive impairment, two care partners, and three members of general public. However, even amongst these participants, there was a general perception, including for both younger adults, that most older adults

would experience some degree of cognitive impairment and that cognitive impairment is "something that's related to getting old" (Edward, male, 69, older adult).

Generally, participants were divided in their views about the controllability of cognitive impairment, with approximately half of the participants sharing a view of cognitive impairment as an inevitability that could not be prevented, and half of the participants expressing a perception of cognitive impairment as something which was not inevitable. The discussions of controllability in cognitive impairment highlight the uncertainty in the aetiology of cognitive impairment (Saunders et al., 2022). It is interesting to note that the majority of specialists posited that cognitive impairment was not inevitable, compared to all younger adults who viewed cognitive impairment as an inevitability that could be expected as a result of ageing.

Brain damage or injury

Most participants referenced brain damage or brain injury in their conversations about cognitive impairment, and also discussed the factors which could result in such brain damage, including substance use, illness and infection, nutritional deficiencies, poor dietary choices, stress and trauma. Clive (male, 24, younger adult) highlighted the range of factors he viewed as potential causes of cognitive impairment:

> Clive: erm any damage to different parts of the brain, so, er impact or, any kind of alcohol drugs that kind of thing. I supp- I've heard of like extreme stress or trauma can often impair different parts of er cognitive faculties, or even bias them in certain ways so like shape memories and remembering

Clive highlights both substance use and stress and trauma in his description of the causation of cognitive impairment, linking these factors to a resultant brain damage. Pauline (female, 72, older adult) outlined a number of potential causes of cognitive impairment, also referencing brain damage but referring to accidents and genetics rather than brain damage resulting from personal actions:

Pauline: well I suppose genetics erm y'know like brain damage in the womb that sort of thing

Interviewer: yeah

Pauline: and indeed brain damage, in later life erm ac- accidents and head injuries

The description put forward by Pauline takes a life course stance, highlighting how brain damage can occur at any stage of life, from foetal development to an accident at any age. The causes presented by both Clive and Pauline are representative of those postulated by many other participants, highlighting the view of the majority of participants that cognitive impairment is the result of brain damage or brain injury generally caused by an identifiable factor such as substance use, stress, genetics, or a head injury. Eleven interviewees from a range of participant groups discussed substance abuse and stress, but only two participants (one care partner and one specialist) explicitly referenced genetics, and no participants living with cognitive impairment or younger adults discussed head injury as a possible cause of cognitive impairment.

One participant, James (male, 32, younger adult), identified the discussion of cognitive impairment in relation to brain damage as something which could be viewed as negative or insulting:

James: and that that's how it always f- come across to me. It just like, it's weird because the idea of like, living with some kind of brain damage it feels like I'm saying something pejorative

Interviewer: yeah

James: or something slightly insulting and I'm like I'm trying to like disassociate those two states in my own mind, but it does feel that like yeah it is some kind of very mild, brain, nerve, kind of thing?

However, James was uncertain, and almost apologetic, in sharing this view, suggesting that he was uncertain about how to word what he was trying to communicate and thus may not

have had the most confidence in his own thoughts around this. Whilst this view was only put forward by one participant, it is an important perspective to consider, particularly in light of the consideration of stigma around cognitive impairment and societal and self-perceptions of people living with cognitive impairment.

From the examples presented here, it is evident that most participants considered cognitive impairment to be a result of brain damage, with a number of underlying causes of brain damage postulated. Moreover, from the account offered by James, together with the view of brain damage as result of lifestyle choices such as substance use, it is also suggested that this view of brain damage in relation to cognitive impairment may be viewed in a negative light, with cognitive impairment being perceived as the result of lifestyle factors. Brain damage was discussed as a cause for cognitive impairment by fourteen interviewees, including all four interviewees living with cognitive impairment, both younger adults, three specialists, two care partners, and three older adults. It is noteworthy that three specialists did not discuss brain damage, however, this could be due to the inherent uncertainty surrounding the aetiology of cognitive impairment where some cases could be transient and may not involve physical changes in the brain.

Lifestyle factors

Most participants remarked that healthy lifestyle factors, such as diet and exercise, potentially had a wide range of health benefits, both physically and cognitively. These conversations typically arose following a question relating to whether cognitive impairment could be avoided or prevented. As such, these participants highlighted the importance of staying active and making healthy lifestyle choices to reduce the risk of cognitive impairment. Interestingly, this topic was rarely discussed by participants before being explicitly asked about it. For example, in response to a question relating to the possible role of diet in cognitive impairment, Grace (female, 70, care partner), responded that she had never considered that diet may have any impact on the brain or cognition, but that being prompted to consider it she assumed a healthy diet could be beneficial for both cognitive and physical health:

Grace: I've never thought about it having any impact on your brain but, I don't see why it wouldn't. I mean they say drink plenty of water and that helps to hydrate your brain as well so

Interviewer: yeah

Grace: I suppose a healthy diet, yeah

Interviewer: yeah

Grace: for every aspect of your life really

Once participants were prompted to consider the role of healthy lifestyle factors in relation to cognitive impairment, there was a general view communicated that cognitive health was indeed related to factors such as diet and exercise. For example, Dianne (female, 82, older adult) stated that a healthy lifestyle might delay or even prevent the onset of many ailments, including cognitive impairment, expounding the view that what is good for the body is also good for the brain:

Dianne: I think this applies to any impairment of health

Interviewer: yeah

Dianne: and the, the brain needs nourishment, it needs clear arteries and

Interviewer: yeah

Dianne: so I think it does have an effect

Interviewer: yeah so it's sort of that anything that's good for the-

Dianne: and exercise

Interviewer: yeah

Dianne: people that have had a good healthy lifestyle may not get the onset as early as people that are more, what you call them potato cabbages?

Dianne's discussion of the brain needing "nourishment" and "clear arteries" implies an understanding of the role of the cardiovascular system in cognitive health, highlighting the relationship between physical and cognitive health. The reference to "potato cabbages" suggests that Dianne was conflating both "cabbage" and "couch potato", both common terms in England to refer to someone who is lazy, though "cabbage" is more strongly associated with a lack of mental ability, and "couch potato" would generally have more of a physical association. Similar to Dianne's discussion about delaying or preventing the onset of cognitive impairment, Nina (female, 74, older adult) postulated that people could potentially prevent cognitive impairment by staying physically active and getting fresh air:

Nina: mmm no I think that you can do things about it

Interviewer: yeah

Nina: and certainly that sort of thing, and and also the physical thing y'know just just fresh air

Interviewer: yeah

Nina: and moving, even moving and walking as much as you can, because it's so easy to be lazy

Nina posits that fresh air is beneficial for health, highlighting this before referencing the benefits of moving. This is an interesting expression as it also draws upon the noted benefits of engaging with nature (Besser, 2021; Bustamante et al., 2022; Zijlema et al., 2017). Alongside references to physical activity, participants also discussed the role of diet:

Pauline: I think I've read enough liberal newspapers to know that the more you walk the better your head is

Interviewer: yeah

Pauline: and I think the Mediterranean diet is good for everything

Interviewer: yeah

Pauline: erm whether or not I quite believe that

Pauline (female, 72, older adult), explained that she assumed a "Mediterranean diet" would have benefits for general health, both physical and cognitive. However, Pauline is not confident in the benefits of this dietary approach. This scepticism about the role of dietary factors in cognitive health was also echoed by Adam (male, 31, specialist) who remarked that despite noting the role of diet and nutrition "it always seems to be a bit of sketchy evidence". Whilst many participants shared the view of the benefit of healthy lifestyle factors in cognitive health, there were some clear alternative perspectives. For example, when asked whether diet or physical exercise could play a role in cognitive health, Robert (male, 56, living with cognitive impairment) responded "not that I know of". Similarly, when asked the same question, Edward (male, 69, older adult) reported that he did not believe diet could have any beneficial impact on cognitive health:

> Edward: yeah. well I tend to th- er I may be wrong, but I tend to think of those as a bit of wishful thinking the idea that you can eat fish and it'll, it'll enable you to have a better memory or remember things better or carrots or whatever it is
>
> Interviewer: yeah
>
> Edward: but I don't really believe it, erm, no

Edward expresses a disbelief that a healthy lifestyle can prevent cognitive decline, but he does frame this with expressions of uncertainty, explicitly stating "I may be wrong". These views presented by Edward and Robert contrast with the perspectives put forward by fifteen participants who highlighted the potential benefits of healthy lifestyle factors for cognitive health. The benefits of healthy lifestyle factors were discussed by all six specialists, two care partners, three people living with cognitive impairment, one younger adult, and three older adults. The fact that all specialists were aware of the role of lifestyle factors in cognitive health is reassuring as it suggests that those individuals who are in a position to communicate information about lifestyle modifications are well informed about this.

Participants' discussions highlighted a view that diet and exercise play a role in cognitive health. However, this was not a consensus view, with varying levels of conviction,

and lifestyle factors were rarely discussed until participants were explicitly asked about the role of diet and exercise in cognitive health. This suggests that lifestyle factors such as diet and exercise did not have strong associations with cognitive health for participants, despite the growing evidence to support the role of lifestyle factors in reducing the risk of cognitive impairment and dementia.

Ageing, dementia and dying

Participants frequently discussed cognitive impairment in the context of ageing and dementia, drawing distinctions and parallels across the three concepts. Whilst participants were at no point asked about death or dying, and cognitive impairment was never presented within the research as a terminal or end of life condition, there was a discourse among many participants about this.

Age of onset of cognitive impairment

There was a view shared by many participants that cognitive impairment could occur at any age, though several participants reported that it was more frequent among older adults. For example, Fiona (female, 76, care partner) stated that cognitive impairment could occur at any age but that it would be more likely as people get older:

> Fiona: erm, I mean it can er, affect anybody at any age really
>
> Interviewer: yeah
>
> Fiona: but er I would think there's probably more tendency as people get older

Similarly, James (male, 32, younger adult) explains "most older people … I would say the vast majority of those are, have what I might characterise as some kind of cognitive impairment" and Sarah (female, 54, specialist) discusses her opinion that "as ages get greater in old age I think it's gonna be more common for everybody to experience a level of cognitive impairment". The phrasing of Sarah's comment suggests a view of cognitive impairment as an inevitability amongst older adults, with "everybody" experiencing cognitive impairment to some extent as they age. This normalising of cognitive difficulties in later life is not uncommon, and has been observed in communication between healthcare professionals and

patients in a memory clinic (Peel, 2015). Overall, participants reported an association between cognitive impairment and ageing, with the prevalence of cognitive impairment increasing by age, but there was also a recognition that cognitive impairment could occur at any age. All but one specialist highlighted that cognitive impairment could occur at any age. This suggests that this group of participants are generally well informed about cognitive impairment and are able to consider this as a concept distinct from normative ageing. There was a mix of views about the relationship between age and cognitive impairment across other participant groups.

Normative ageing

Across their discussions, participants made frequent reference to the distinction, or lack of, between cognitive impairment and normative ageing. Many participants stated that cognitive impairment and normative ageing were distinct entities, with Fiona (female, 76, care partner) reporting "they are two different things I think yes". Similarly, Pauline (female, 72, older adult) stated that there was a difference between the two, but also felt that most people would experience a degree of cognitive decline as a result of ageing:

> Pauline: no I've met enough, I I've met and seen enough ol- old old people who are alright to think that it's not inevitable, but I also think you know, you most people will be affected
>
> Interviewer: yeah
>
> Pauline: to some extent. I know I'm slower erm, than I was er to do things and to think things quite often er so I think er I think that would be most people

Here, Pauline discusses how her own cognitive function has slowed and that she thus thought most people would have similar experience. This view was shared by a few participants over the age of 60 who reported that their peer group were experiencing cognitive decline, stating "we are all much more forgetful than we were" (Grace, female, 70, care partner). Louise (female, 30, specialist) reported that cognitive decline was inevitable as a result of ageing, but that this cognitive decline did not necessarily constitute a cognitive impairment:

> Louise: because you can and you should be able to take things slower so erm, no I don't think everybody would get a a cognitive impairment I think there's getting older and slowing down erm, but then the cognitive impairment I would say is sort of the next step on when you're starting to have difficulty with, with a few things

The perception that there would be a "slowing down" of cognitive abilities as a result of normative ageing was shared by several other participants, with Oscar (male, 73, specialist) reporting that there would be "a normal range of rate of impairment with age". This view was shared by all six specialists, all four care partners, both younger adults, five older adults, and one person living with cognitive impairment. This suggests a general view across participants of ageing as something which infers cognitive decline to some extent, but that this will not inevitably reach the level of cognitive impairment.

Differentiating between cognitive impairment and dementia

In the interviews, all participants were asked whether they would differentiate between cognitive impairment and dementia or whether the two were related or even synonymous. For many participants, there was a view that cognitive impairment was related to dementia, but distinct in some way. For example, Clive (male, 24, younger adult) viewed cognitive impairment as "an aspect of dementia" and Grace (female, 70, care partner) positioned cognitive impairment as "a phase before dementia".

In their conversations about cognitive impairment, participants frequently used dementia as a benchmark against which they measured the severity of cognitive impairment. Several participants discussed how cognitive impairment was "not as erm alarming or as erm tch like detrimental as dementia" (Louise, female, 30, specialist). Similarly, James (male, 32, younger adult) discussed cognitive impairment in the context of dementia:

> James: I understand cognitive impairment to be a certain er I guess you can interpret it in a number of ways like kind of a milder or the mildest form of dementia? Which suggests that there is like kind of er an ex- er that people expect their mind to be ordered in a certain way so this kind of incorporates things like forgetfulness

When dementia was referenced, it was generally posited as something which more people had heard of and were more familiar with than cognitive impairment. Robert (male, 56, living with cognitive impairment) explained how discussing cognitive impairment in reference to dementia enabled people to understand it better because they hadn't heard of cognitive impairment, but they were aware of dementia:

Robert: cos they haven't got a clue what you're on about

Interviewer: yeah

Robert: same reason like, they haven't heard of it

Interviewer: yeah

Robert: but if I say dementia then yes, then they know

Interviewer: yeah

Robert: cos I I sort of I've been saying it's sort of like one step before dementia, and then they understand a little bit more then

Overall, participants viewed cognitive impairment as something which was related to dementia, but which differed in terms of severity. Cognitive impairment was also viewed as potential precursor to dementia, but participants discussions about any increased risk of dementia resulting from cognitive impairment varied. There were no notable differences between participant groups in their views about the relationship between dementia and cognitive impairment, with the majority of all participant groups discussing cognitive impairment in the context of dementia.

Death and dying

Throughout the interviews, nine participants discussed death and dying, including two people living with cognitive impairment, two care partners, two specialists, both younger adults, and one older adult. Brian (male, 71, older adult) felt that it would be better to die than to live with progressive cognitive impairment:

Brian: it starts off with cognitive impairment which is a steady y'know it's the start and it might never get with any luck any worse than that, well only luck because you die before it gets any worse

Similarly, Clive (male, 24, younger adult) discussed how his mother had said she would want to die if she were to experience a loss of cognitive function:

Clive: my mum has said that if she ever loses like cognitive control she wants to be er euthanized, which I can actually understand erm as difficult as it is to talk about

Interviewer: yeah

Clive: cos the idea of being alive but not being able to live almost is, er it's terrifying

The fear of cognitive impairment and dementia is palpable in this statement with Clive's explicit use of the word 'terrifying' and reference to it being 'difficult…to talk about'. Clive's description of cognitive decline as "being alive but not being able to live" is very powerful and suggests a view of people living with cognitive impairment as no longer the same person that they once were; comparable almost to someone who is in a vegetative state. This fearful view, with a preference for death over living with cognitive impairment, was shared by several participants overall.

Dementia and cognitive impairment were discussed as a living death or terminal diagnosis by several participants. William (male, undisclosed age, living with cognitive impairment) discussed cognitive impairment as "like a living death" due to the risk management and restriction strategies which he felt may "take away anybody's purpose". Similarly, James (male, 32, younger adult) stated that if his parents were diagnosed with cognitive impairment, he would view them as being on a palliative trajectory:

James: y'know cos I I have some underst- well I think I have some understanding of what a cognitive impairment is, so therefore I would be looking for those and I would probably start to like mother my parents and like think ok like and I know it sounds like

> I'd be putting them on a kind of like an end life pathway like without even meaning to

This highlights the views of participants who perceived cognitive impairment as a terminal condition. When participants discussed cognitive impairment in this manner, there was an underlying fear of cognitive impairment in their accounts. There was no particular difference between participant groups in their discussions of death and dying, with all participants who raised this discussing cognitive impairment in the context of either a living death or in relation to being a condition that would result in death or persist until death.

Discussion

The results of this study have key implications for policymakers, particularly in considering the development of information and awareness campaigns. Whilst research supports the role of healthy lifestyle factors such as diet and physical activity in cognitive health (Clark et al., 2016; Elliott-King et al., 2019; Etgen et al., 2011; Hahn & Andel, 2011; Liu et al., 2020; Scarmeas et al., 2018), the role of diet was not discussed by participants until this was raised by a question from the researcher, suggesting that this factor was often not viewed as a key risk factor or possible cause of cognitive impairment. However, once diet was addressed, most participants agreed that this may play a role in cognition, though one participant explicitly stated that this was not something she had ever thought about before. This is a highly salient finding, especially when taken together with the results of our survey which found that diet was the least endorsed potential cause of cognitive impairment (Yemm et al., 2022). It is reassuring that all specialist interviewees discussed the role of lifestyle factors in cognitive health, though one specialist highlighted that they felt the evidence base around this was not conclusive. This highlights the need for further research and clear dissemination of research results surrounding lifestyle factors, but also suggests that specialists possess knowledge which should be shared with the wider patient and public population to ensure people are able to make informed lifestyle choices. A positive correlation between overall knowledge and modifiable risk factors has been identified in a survey of dementia knowledge (Ashworth et al., 2021), suggesting that increasing awareness of cognitive impairment may enhance knowledge of modifiable risk factors. The World Health

Organization has recently released guidelines around reducing the risk of cognitive impairment and dementia which focus on lifestyle interventions (World Health Organization, 2019). Adopting these guidelines and embedding them within public health policy internationally could reduce the incidence of cognitive impairment and dementia by empowering people to make informed lifestyle choices which may reduce their risk of cognitive decline.

Throughout the interviews, participants made frequent references to death and dying, despite this not being a topic addressed by the interview questions. There was a view among some participants that cognitive impairment was a terminal illness, and others considered that it would be "lucky" to die before cognitive impairment progressed. This association between cognitive impairment and death supports the view of people living with Alzheimer's disease that "they are neither fully dead nor do they appear to be fully alive" (Behuniak, 2011). This view is highly stigmatising, though not surprising given the negative portrayal of people living with dementia in the media, framing dementia as a separation of the body and the mind and rendering those living with dementia as losing their identity and societal value (van Gorp & Vercruysse, 2012). The recent self-advocacy movement among people living with dementia is aiming to address such stigmatising views, with many advocates citing challenging stigma and discrimination as a key incentive for activism (Weetch et al., 2021).

It was clear that participants were more familiar with the concept of dementia than cognitive impairment, with cognitive impairment often being discussed in reference to dementia. It has been suggested that dementia is the most feared health condition among older adults (Corner & Bond, 2004; Schiff et al., 2000) and feared by the wider public (Olsen et al., 2019). This fear was evident in participants' discussions, with the use of terms such as "terrifying". There is a high prevalence of often negatively framed media portrayals of dementia (Peel, 2014; Van Gorp & Vercruysse, 2012) which is likely to contribute to participants fearful language around cognitive impairment. Similarly, the manner in which participants discussed ageing and its association with cognitive impairment suggested a negative perception of ageing as a whole. Both younger adult interviewees perceived cognitive impairment to be an inevitability, and something that everyone would experience as they age.

This is in stark contrast to the majority of specialist interviewees who stated that cognitive impairment was not inevitable and, in some cases, could be prevented. Western societies generally hold a negative perception of ageing, and this can result in an internalised ageist stigma among older adults (Kotter-Grühn, 2015). Such internalised negative ageing stereotypes can be implicit, operating below the individuals own awareness (Levy, 2003). Given the recognition of increasing awareness and understanding of MCI as a public health priority (Winblad et al., 2016), it is important to consider how levels of fear are impacted by education about dementia and cognitive impairment (Draper et al., 2010), and how ageing stigma and stereotypes can be challenged, including at a young age to reduce negative perceptions of cognitive impairment as an inevitable consequence of ageing.

There are a number of key limitations which must be acknowledged in this study. The cross-sectional nature of the research resulted in a time and context limited exploration of views. It would be beneficial to consider in future research exploring whether perspectives and perceptions change over time and what factors might contribute to changing perspectives. As participants in this study were all living in England, and slightly more females than males, the sample is not representative of the wider population. However, as with most qualitative research, the aim of this study was to provide a rich and detailed account of respondents' views about cognitive impairment. It must also be acknowledged that this study was discussing MCI; a contested and uncertain diagnostic entity (Katz et al., 2021). However, the experience of cognitive impairment is pervasive and unlikely to cease to exist due to prognostic uncertainties and lack of diagnostic criteria consensus, thus this study still sheds important light on the understanding and awareness of cognitive impairment distinct from, but also entwined with, normative ageing and dementia.

In conclusion, this study provides insights into perceptions of cognitive impairment. Participants identified cognitive impairment as the result of a fundamental change within the brain, which itself could be the result of a range of factors including accident or injury, genetics, and substance use. Lifestyle factors, such as diet, that may contribute to the risk of cognitive impairment were not discussed by participants without prompting, highlighting the need to reinforce the link between cognitive and physical health in future information

campaigns. There was frequent reference to death and dying in participants discussions of cognitive impairment, highlighting a negative, progressive, and terminal view of MCI. Future research should consider how information provision and awareness campaigns provide realistic information which increases understanding but also aims to reduce fear and stigma around cognitive impairment.

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Table 1: Demographics of interview participants

Pseudonym	Group	Age	Gender
Clive	Younger Adult	24	Male
James	Younger Adult	32	Male
Dianne	Older Adult	82	Female
Edward	Older Adult	69	Male
Irene	Older Adult	73	Female
Nina	Older Adult	74	Female
Pauline	Older Adult	72	Female
Brian*	Older Adult	71	Male
Beth*	Care Partner	63	Female
Fiona	Care Partner	76	Female
Grace	Care Partner	70	Female
Tracy	Care Partner	57	Female
Katie	Cognitive Impairment	37	Female
Robert	Cognitive Impairment	56	Male
Victor	Cognitive Impairment	Not disclosed	Male
William	Cognitive Impairment	Not disclosed	Male
Helen	Healthcare Professional	27	Female
Adam	Specialist	31	Male
Louise	Specialist	30	Female
Mary	Specialist	71	Female
Oscar	Specialist	73	Male

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Sarah	Specialist	54	Female

* Spouses interviewed together