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Understandings of mild cognitive impairment (MCI): a survey study of public and professional perspectives

Abstract

Purpose: This paper reports the findings of a survey study exploring perceptions about cognitive impairment. These findings are relevant to public health campaigns and education programmes.

Design/methodology/approach: A survey exploring respondents views and knowledge about MCI was circulated via UK networks. 417 respondents completed the survey, including people living with cognitive impairment (n=10), care partners (n=23), older adults (n=83), younger adults (n=83), general healthcare professionals (n=96), dementia specialist healthcare professionals (n=48), and dementia specialists (n=40).

Findings: Respondents were more confident in their knowledge about dementia than cognitive impairment but wanted more information about both conditions. Younger adults were uncertain about many aspects of MCI, and were the most likely to view MCI as a normal part of ageing. Diet (45.1%, n=188) and personal behaviour (63.8%, n=266) were the least endorsed possible causes of MCI, suggesting a lack of awareness of lifestyle choices as risk factors for MCI.

Originality: The results highlight the need to provide education and awareness raising about MCI to enable people to seek help in a timely manner and be able to make informed lifestyle choices which may reduce their risk of MCI and dementia. Implementing education about MCI and dementia in schools is a key target as younger people were the most uncertain or misinformed about these topics. It is clear that further public health initiatives around MCI are both warranted and welcomed by the general public.

Key Words: dementia, knowledge, mild cognitive impairment, MCI, perceptions, survey

Introduction

The term mild cognitive impairment (MCI) refers to cognitive decline, which is more than expected due to normal ageing, but does not meet the criteria for a dementia diagnosis (Reichelt et al. 2021). Globally, there is an estimated prevalence of MCI of 6-12% (Sachdev et al. 2015), almost double the 4.6-8.7% estimated international prevalence of dementia (Prince et al. 2015). The incidence of cognitive impairment is estimated to rise by 83% in the UK from 2002 to 2031 (Comas-Herrera et al. 2007) highlighting the growing number of people impacted by MCI.

MCI has been identified as a potential risk factor for dementia with an estimated 6.4-8% of people living with MCI progressing to dementia annually (Michaud et al. 2017), compared to 1-2% of older adults without MCI (Petersen et al. 2005). However, the outcome for people living with cognitive impairment is not homogenous, as people may progress to dementia, remain stable, or revert to previous levels of cognitive functioning (Patel and Holland 2012). With the increased understanding of modifiable risk factors for dementia (Livingston et al. 2020), it may be possible to prevent progression to dementia in some cases.

Research suggests that the symptoms of cognitive impairment are often attributed to normal ageing, including among family members of people living with cognitive impairment or dementia (Jones et al. 2010; Kuo and Shyu 2010), and clinicians (Kuo and Shyu 2010; Werner et al. 2013). This conflation between normal ageing and cognitive impairment is concerning as it could result in people delaying or avoiding seeking help for their symptoms (Birt et al. 2020) and could therefore result in missed opportunities to treat reversible cases.

Increased public awareness about dementia and modifiable and preventable risks of developing dementia was a key aim of the Prime Minister's Challenge on Dementia 2020 (Department of Health 2015). As MCI is a possible precursor of dementia, it is important to consider public awareness of cognitive impairment and understanding of potential causes

including where lifestyle changes may alter the risk of cognitive impairment. For example, physical activity is associated with better cognitive function among older people (Liu et al. 2020), people living with mild cognitive impairment (Hahn and Andel 2011) and people living with dementia (Elliott-King et al. 2019), and thus physical activity may be a protective factor in reducing the risk of MCI and dementia (Sumic et al. 2007). Similarly, nutrition and diet have been identified as modifiable risk factors of cognitive dysfunction (Scarmeas et al. 2018), and also show promise in alleviating cognitive deficits for people living with MCI (Hahn and Andel 2011).

Increasing understanding of MCI has been identified as a public health priority (Winblad et al. 2016), but recommendations relating to MCI are inconsistent across national and international guidelines (Kasper et al. 2020). Exploring the current understanding of cognitive impairment across public and professionals could enable the provision of targeted information campaigns and identify areas of consideration for future recommendations. Given the importance of public awareness and understanding of this condition, the key aim of this study was to explore the perceptions and knowledge of a diversity of people about the identity of cognitive impairment, and potential causes, consequences, and treatments.

Method

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).

Survey

Following a review of the literature around perceptions and attitudes towards cognitive impairment and dementia, including previous research exploring illness

representations amongst people living with MCI (Lin et al. 2012), a bespoke, self-administered survey was used to conduct a cross-sectional study. The survey consisted of 35 items within three key sections: (1) demographic information, (2) questions about the definition, identification, causes, consequences, potential treatments and interventions of cognitive impairment, and (3) a vignette about an individual experiencing symptoms which could be labelled as MCI. Most of the items required respondents to choose their answer(s) from a range of options. There were two free-text items which asked respondents to describe cognitive impairment and dementia using their own words. This provided the opportunity to explore the language respondents used themselves to describe cognitive impairment and dementia. The survey was available both online and as a paper version, and took approximately 15-20 minutes to complete (survey available in Appendix 1). The online survey was hosted on SurveyMonkey from July 2015 to February 2016. All respondents provided informed written consent to participate.

Data Collection

An opportunistic sampling approach was adopted, with information about the study circulated via a range of networks to reach the widest number of potential respondents. This included services within NHS Trusts in England working with people living with cognitive impairment, mailing lists at the University of Worcester, UK, charity and community-based organisations working with older adults and people living with cognitive impairment and dementia, special interest groups, and professional memberships. Information about the study was also shared on social networking sites such as Facebook and Twitter. People were encouraged to share information about the study with their own networks.

Completed surveys were received from 417 respondents, with the online survey yielding far more responses (n=394, 94.5%) than the paper survey (n=23, 5.5%).

Respondents were asked to select which of six different respondent groups they most identified with, and two additional groups were created for the purpose of analysis where respondents had selected multiple options (Table 1). The average age of respondents was 51.0 (SD = 16.3 years). Respondents were predominantly female (77.5%), highly educated (44.8% educated to higher degree level) and identified as white (93.8%). Respondent characteristics are summarised in Table 1. Responses to all survey items are presented in Appendix 2.

Data Analysis

Data were collated and analysed using SPSS. Kruskal-Wallis analyses were conducted, with post-hoc Dunn-Bonferroni pairwise comparisons between respondent groups. Z-tests were used to assess differences between all respondents' responses to different survey items.

[INSERT TABLE 1]

Results

The results of the survey are grouped into five key categories:

(1) Knowledge of cognitive impairment and dementia
(2) Definitions of cognitive impairment
(3) Understanding the causes of cognitive impairment
(4) Understanding the consequences of cognitive impairment
(5) Understanding treatments and lifestyle changes

The qualitative responses span these categories and relevant points are highlighted within each section. The response rate to free-text items was 90.2% (n=376) describing cognitive impairment, and 91.1% (n=380) describing dementia.

Knowledge of Cognitive Impairment and Dementia

The majority of respondents (88.0%, n=367) had heard of cognitive impairment. Significantly more respondents knew someone who had a diagnosis of dementia than cognitive impairment (dementia = 79.1% [n=330], cognitive impairment = 57.3% [n=239], Z=-8.064, p<0.001). Younger adults were the least likely to know someone with a diagnosis of cognitive impairment (31.3%, n=26) or dementia (66.3%, n=55). Respondents discussed their prior knowledge and experience when describing cognitive impairment: '*I have answered these questions on my experience of caring for my husband and my description is based on him*' (Female, 70, Older Adult). In contrast, several respondents voiced their uncertainty about cognitive impairment, reporting '*I wouldn't be able to describe it with any confidence*' (Male, 68, Care Partner) and '*this survey is the first time I've heard of it!*' (Male, 29, Younger Adult).

Significantly more respondents had read information about dementia than cognitive impairment (dementia = 91.1% [n=380], cognitive impairment = 68.8% [n=287], Z=-8.838, p<0.001). Younger and older adults were the least likely to have read information about both dementia (85.5%, n=71; 72.1%, n=64 respectively) and cognitive impairment (38.6%, n=32; 39.8%, n=64 respectively).

Most respondents (61.4%, n=256) agreed or strongly agreed with the statement 'I have a good understanding of what cognitive impairment is'. Respondent groups differed in their responses to this ($X^2(7)=119.657$, p<0.001). Specialist healthcare professionals (SpHCPs; 91.7%, n=44), and healthcare professionals (HCPs; 88.5%, n=85) were the most likely to agree or strongly agree with this statement. Significant differences (all p<0.001) between groups were observed, with older and younger adults differing from specialists, SpHCPs, and HCPs. Care partners (p<0.001) also differed from HCPs. The majority of all

respondents (82.0%, n=342), and over 78% of respondents in each group, agreed or strongly agreed they wanted to know more about cognitive impairment.

Significantly more respondents (Z=-8.061, p<0.001) showed confidence in their own understanding of dementia (82.3%, n=343) than cognitive impairment (61.4%, n=256). HCPs (97.9%, n=94) and SpHCPs (95.8%, n=46) were the most likely to agree or strongly agree that they have a good understanding of dementia, and people living with cognitive impairment (60.0%, n=6) and older adults (63.9%, n=53) were the least likely to agree with this. Respondent groups differed in their responses to this statement ($X^2(7)=57.311$, p<0.001), with older adults differing significantly from HCPs, SpHCPs, and specialists (p<0.001, p<0.001 and p=0.012 respectively). Younger adults differed from HCPs (p<0.001) and SpHCPs (p<0.025), while care partners only differed from HCPs (p=0.031). The majority of all respondents (81.8%, n=341), and over 77% of respondents in each group, agreed or strongly agreed they wanted to know more about dementia.

Definitions of Cognitive Impairment

Most respondents (65.5%, n=273) stated cognitive impairment was not a normal part of ageing. Groups differed in their responses to this ($X^2(7)=25.821$, p=0.001) with younger adults, who were the least likely to view cognitive impairment as distinct from normal ageing (44.6%, n=37), differing from HCPs and 'Other' respondents (p=0.003, p=0.020 respectively).

The majority of respondents (93.8%, n=391), including over 84% of respondents in each group, stated cognitive impairment affects people both over and under the age of 65. Older adults (84.3%, n=70) were the least likely to report that cognitive impairment affects people of all ages, and older adults (14.5%, n=12) and younger adults (10.8%, n=9) were the most likely to answer 'Don't know'. While there was a difference between respondent

groups ($X^2(7)=22.691$, $p=0.002$) post-hoc testing revealed only HCPs differed significantly from older adults ($p=0.008$). Respondents frequently referenced ageing in their description of cognitive impairment, describing cognitive impairment as '*a natural part of the ageing process*' (Male, 60, SpHCP), and as '*somewhere between normal ageing and dementia*' (Male, 77, Older Adult). Respondents' descriptions of dementia were situated as something which '*most commonly occurs in the elderly but sometimes affects younger people*' (Female, 81, Older Adult). No respondents described dementia as part of the normal ageing process.

Respondents were divided about whether memory and thinking problems are a normal part of getting older, with 48.4% (n=202) answering 'True' and 45.6% (n=190) responding 'False' to this. Groups differed in their responses to this question ($X^2(7)=26.599$, $p<0.001$) with younger adults (65.1%, n=54) the most likely to agree with this and SpHCPs (31.3%, n=15) and HCPs (37.5%, n=36) the least likely to agree. Younger adults differed from HCPs and SpHCPs ($p=0.001$, $p=0.004$ respectively), and older adults differed from HCPs alone ($p=0.042$).

Most respondents (62.4%, n=260) stated cognitive impairment is not a form of dementia. However, groups differed in their views ($X^2(7)=28.196$, $p<0.001$) with SpHCPs (85.4%, n=41) and HCPs (78.1%, n=75) most likely to view cognitive impairment as distinct from dementia. Post-hoc testing revealed SpHCPs, and HCPs differed from both younger adults ($p=0.008$, $p=0.015$ respectively) and older adults ($p=0.010$, $p=0.021$ respectively). In their descriptions of cognitive impairment, respondents viewed this as '*not so bad as to have dementia*' (Female, 52, Specialist), and as '*the start of dementia*' (Female, 70, Care Partner). Similarly, dementia was described as '*full blown cognitive impairment*' (Male, 72, Older Adult) and some respondents referenced their description of cognitive impairment stating '*same as above, just a more severe version*' (Female, 58, Younger Adult).

Most respondents (69.5%, n=290) stated cognitive impairment is not a mental illness. However, there was a degree of uncertainty among specialists (25.0%, n=10), older adults (20.5%, n=17), care partners (21.7%, n=5), and people living with cognitive impairment (20.0%, n=2) about this, with approximately one fifth of these groups responding 'Don't know'. While groups differed in their responses to this statement ($X^2(7)=16.591$, p=0.020), post-hoc testing revealed no significant differences.

When presented with a vignette of an individual experiencing symptoms which could be labelled as mild cognitive impairment (see Appendix 1), the most endorsed term across all respondents was 'mild cognitive impairment' (56.7%, n=237). 'Memory problems' (54.4%, n=227) was the next most endorsed term, followed by 'Stress' (42.4%, n=177).

Understanding the Causes of Cognitive Impairment

Respondents were asked whether any of eight presented options (getting older, genetics, abnormal brain changes, head injury, diet, stress or worry, personal behaviour, physical health problems) could cause cognitive impairment. Nearly three quarters of respondents endorsed all except two of the listed factors as possible causes of cognitive impairment. Diet (45.1%, n=188) was the least endorsed option, with 26.6% (n=111) responding 'Don't know' to this. Both younger adults (37.3%) and older adults (18.1%) were the least likely to endorse diet, with both groups differing significantly from HCPs (older adults, p<0.001; younger adults, p=0.040). Personal behaviour (63.8%, n=266) was the second least endorsed option, with 18.9% (n=79) responding 'Don't know' to this. Respondent groups differed in their responses to this statement ($X^2(7)=14.506$, p=0.043) but post-hoc testing revealed no significant differences. In their descriptions of cognitive impairment, respondents frequently discussed potential causes, reporting that cognitive impairment '*can be a symptom of dementia, brain injury, stroke and can have a range of other causes*' (Female, 48, HCP) and

'*causes of cognitive impairment may include: acquired brain injury e.g., through a traumatic brain injury, brain infection, stroke, etc.*' (Female, 37, Other). Respondents recognised the role of the brain in cognitive impairment, highlighting that in cognitive impairment '*some of the functions of the brain are not working as they used to (or as we would expect)*' (Male, 54, Specialist).

Understanding the Consequences of Cognitive Impairment

Only 0.7% (n=3) of respondents thought people with cognitive impairment would automatically develop dementia. Care partners (30.4%, n=7), older adults (27.7%, n=23) and younger adults (27.7%, n=23) were the most uncertain about this. Significant differences were observed between groups ($X^2(7)=42.482$, $p<0.001$) with HCPs and SpHCPs differing from younger adults ($p<0.001$, $p=0.001$ respectively), older adults ($p=0.001$, $p=0.006$ respectively) and care partners ($p=0.005$, $p=0.007$ respectively). When describing cognitive impairment, respondents viewed this as '*an early warning indicator that someone may go on to develop dementia*' (Female, 49, HCP) but did not describe an inevitable progression to dementia.

The majority of respondents (83.7%, n=349) stated people with cognitive impairment are still the same person they used to be. People living with cognitive impairment (40%, n=4) and care partners (21.7%, n=5) were the most likely to report people living with cognitive impairment are no longer the same person they used to be. Differences between groups were present ($X^2(7)=34.045$, $p<0.001$) with HCPs and SpHCPs differing from both older adults ($p=0.001$, $p=0.016$ respectively) and care partners ($p=0.011$, $p=0.034$ respectively). One respondent described cognitive impairment as '*an inability to do what you could formerly do*' (Female, 66, Older Adult) but the descriptions of dementia highlighted a

much greater loss of ability and personhood: '*The body of the person is still there but the mind is incapable of remembering what happened yesterday*' (Female, 69, Older Adult).

Most respondents (72.9%, n=304) did not view cognitive impairment as being easy to live with. However, there was uncertainty around this, with 22.3% (n=93) of respondents, including 37.3% (n=31) of older adults, and 35.0% (n=14) of specialists, answering 'Don't know'. Specialists (52.5%, n=21) and older adults (53.0%, n=44) were also the least likely to answer 'False' to the statement 'Cognitive impairment is easy to live with'. HCPs and SpHCPs differed significantly from older adults ($p<0.001$, $p<0.001$ respectively) and specialists ($p=0.006$, $p=0.003$ respectively). Respondents' descriptions of cognitive impairment discussed this having '*an impact on daily life*' (Female, 37, Care Partner) and '*an impact on their quality of life*' (Female, 55, Specialist). Some respondents discussed the emotional impact of cognitive impairment, highlighting how cognitive impairment '*can also affect perceptions, feelings and behaviours*' (Female, 47, SpHCP) and people living with cognitive impairment '*will feel frightened, possibly isolated, embarrassed*' (Female, 55, Other).

Most respondents (60.0%, n=250) stated people with cognitive impairment do not lose their independence, strongly supported by HCPs (77.1%, n=74) and SpHCPs (72.9%, n=35). However, respondent groups differed on this question ($X^2(7)=33.578$, $p<0.001$) with HCPs and specialists differing from care partners ($p=0.001$, $p=0.022$ respectively). HCPs also differed from younger adults ($p=0.010$), and older adults ($p=0.035$). Respondents did not widely discuss independence in their descriptions, but there were references to '*some tasks in daily life being more difficult to complete independently*' (Female, 47, SpHCP), contrasted with statements that cognitive impairment '*doesn't have a major effect on their abilities to manage day-to-day*' (Female, 48, HCP).

Most respondents (65.7%, n=274) thought people with cognitive impairment lose their self-confidence. There was no significant difference between groups in their responses ($X^2(7)=11.951$, p=0.102). However, people living with cognitive impairment (100%, n=10) and care partners (78.3%, n=18) were the most likely to report a loss of self-confidence suggesting that his may be a lived reality for these groups.

The majority of respondents (89.4%, n=373) stated people with cognitive impairment can still live a full and happy life. Respondent groups differed in their views about this ($X^2(7)=24.775$, p=0.001) with older adults (19.3%, n=16) being the most uncertain about this, differing from HCPs (p=0.001) and SpHCPs (p=0.015).

Few respondents (26.1%, n=109) viewed cognitive impairment as permanent. Respondent groups differed in their responses to this item ($X^2(7)=26.154$, p<0.001) with SpHCPs differing from people living with cognitive impairment (p=0.012) and care partners (p=0.020). Older adults (49.4%, n=41), care partners (47.8%, n=11), and younger adults (47.0%, n=39) were the most uncertain about this. People living with cognitive impairment (60.0%, n=6) were the most likely to view cognitive impairment as permanent.

Understanding Treatments and Lifestyle Changes

Most respondents (66.9%, n=279) stated there are treatments available which can help people living with cognitive impairment. SpHCPs (87.5%, n=42) and HCPs (86.5%, n=83) were the most likely to report there are treatments available which can help, whereas just over half of care partners (52.2%, n=12) and older adults (50.6%, n=42) were uncertain about this. The difference between groups was significant ($X^2(7)=38.434$, p<0.001) with HCPs and SpHCPs differing from older adults (p<0.001, p=0.001 respectively). HCPs also differed from younger adults (p=0.010).

Around half of all respondents (52.8%, n=220) reported that cognitive impairment cannot be cured, while 34.3% (n=143) were uncertain about this. People living with cognitive impairment (80.0%, n=8) were the most likely to be uncertain, and approximately half of older adults (51.8%, n=43), younger adults (51.8%, n=43), and care partners (52.2%, n=12) answered 'Don't know' to this statement. Respondent groups differed in their responses to this statement ($X^2(7)=18.070$, $p=0.012$) but post-hoc testing revealed no significant differences between groups.

The majority of respondents (85.1%, n=355) stated that staying active can help treat the symptoms of cognitive impairment. There were uncertainties within respondent groups, with people living with cognitive impairment (20%, n=2), care partners (17.4%, n=4), younger adults (16.9%, n=14), and older adults (13.3%, n=11) being the most likely to respond 'Don't know'. Respondent groups did not differ significantly in their responses to this statement ($X^2(7)=10.582$, $p=0.158$).

There was a high level of uncertainty amongst respondents about whether cognitive impairment was preventable, with 44.1% (n=184) of respondents answering 'Don't know'. However, people living with cognitive impairment (60.0%, n=6), SpHCPs (52.1%, n=25) and HCPs (41.7%, n=40) were the most likely to state cognitive impairment was not preventable. Respondent groups did not differ significantly in their responses to this statement ($X^2(7)=6.446$, $p=0.489$).

Discussion

The results of this survey highlight that MCI, as a concept, is difficult for professionals, patients, and the public to grasp. Given the potential reversibility of some cases of cognitive impairment, and the increased risk of dementia, it would seem prudent to ensure societal awareness of cognitive impairment is enhanced. This could facilitate timely

help seeking and enable reversible and preventable cases to be identified and treated, offering personal, societal and economic benefits.

Healthcare professionals and specialists often differed in their responses to survey items compared to lay respondent groups. This is not unexpected, but highlights the need to explore sources of information for diverse groups of individuals and to consider what information is provided, or available, to lay audiences and people living with cognitive impairment about this condition. Cancer survivors, for instance, who are satisfied with the information they have received generally have a better health-related quality of life and reduced anxiety and depression (Husson et al. 2011).This suggests that improved information provision for other chronic illnesses such as MCI may offer similar benefits.

The lack of knowledge about dementia and cognitive impairment among younger adults supports existing research showing lower knowledge about dementia among younger people (Isaac et al. 2017; Van Patten and Tremont 2018). In the present study, younger adults were the most likely to view cognitive impairment as part of normal ageing, thus associating the ageing process with a decline in cognitive abilities. This highlights the importance of raising awareness about cognitive impairment and dementia among younger people, possibly implementing this within schools to ensure widespread awareness and knowledge. A one-hour dementia awareness programme for secondary school children showed improvements in dementia knowledge and confidence and was well received by learners (Parveen et al. 2015). Developing interventions such as this to incorporate MCI awareness and education could be an effective public health initiative, ensuring people are well informed about these conditions at the earliest possible stage. Intergenerational exchange programmes have also been successful in improving understanding and awareness of dementia and reducing stigma among primary and secondary school pupils (Atkinson and Bray 2013). To date, no programmes have included MCI in school education and awareness,

but these successes in dementia awareness suggest that similar programmes focused on, or incorporating, MCI could yield similar benefits.

Respondents had more experience, and self-reported confidence in their knowledge, of dementia compared to cognitive impairment. This indicates a need for greater awareness of cognitive impairment, but also highlights the positive work done so far to raise awareness about dementia in the UK. Over three quarters of respondents wanted to know more about both cognitive impairment and dementia, suggesting a desire for more information to be available and accessible, and that people are not afraid of these topics. Most respondents wanted to know more about cognitive impairment despite also stating they had already read information about this, which suggests the information already accessed did not adequately satisfy their information needs.

Diet was the least endorsed potential cause of cognitive impairment suggesting respondents may be uncertain or ill-informed about the role of diet and lifestyle factors in cognitive health despite the media discourse around this (Peel 2014). Currently, there is no recommended pharmacological treatment for people living with MCI in the UK (Alzheimer's Society 2020). A growing body of research supports the benefits of lifestyle interventions on cognitive health (Abbott et al. 2004; Hahn and Andel 2011; Elliott-King et al. 2018; Scarmeas et al. 2018) so it is promising respondents viewed a healthy lifestyle as beneficial for people living with cognitive impairment, but potentially concerning they did not display recognition of the role of healthy lifestyle factors in the causation of cognitive impairment.

Future research should explore what information different people want in-depth, and consider strategies such as school awareness programmes, online information provision, or even media campaigns to address these needs and increase knowledge and confidence. Longitudinal studies would also further the knowledge base in this area, and enable identification of any shifts in knowledge and confidence over time or with the introduction of

public health initiatives. Notwithstanding structural and contextual factors which impact the ability of different groups to make 'healthy lifestyle choices' future information provision could focus more on diet and lifestyle aspects of cognitive health. If information about the role of diet and lifestyle factors in cognitive health were provided sensitively and tailored appropriately it could support people to make informed choices which may contribute, at the population level, to the incidence of cognitive impairment and dementia reducing.

A key limitation of this survey was the self-selection of respondent group membership. This may have resulted in the creation of groups which were not entirely representative of the populations stipulated. However, this self-selection is arguably also a key strength of the study, as it allowed respondents to identify the group *they* felt most affinity with, rather than being arbitrarily assigned to a group based on characteristics they may not choose to identify with. The sample included in this study is also not wholly representative of the population due to respondents being predominantly female, white, and highly educated. The responses offer a cross-sectional view, and a longitudinal study would yield more comprehensive results.

Notwithstanding these limitations, this study offers a focused insight into societal perceptions of cognitive impairment. Overall, respondents' knowledge level of both MCI and dementia was encouraging, and there was a desire to know more about both dementia and cognitive impairment. Public health initiatives and education around MCI are both warranted and welcomed across a range of population groups.

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Table 1: Respondent characteristics

		n (%)
Respondent Group	Living with cognitive impairment	10 (2.4)
	Care partner	23 (5.5)
	Younger adult	83 (19.9)
	Older adult	83 (19.9)
	Healthcare professional	96 (23.0)
	Specialist	40 (9.6)
	Specialist healthcare professional*	48 (11.5)
	Other (undeclared and multiple groups)*	34 (8.2)
Gender	Male	91 (21.8)
	Female	323 (77.5)
	Undeclared	3 (0.7)
Age	<20	2 (0.5)
	21-30	55 (13.2)
	31-40	64 (15.3)
	41-50	75 (18.0)
	51-60	101 (24.2)
	61-70	57 (13.7)
	71-80	43 (10.3)
	81-90	13 (3.1)

	91-100	2 (0.5)
	Undeclared	5 (1.2)
Marital status	Single (never married)	63 (15.1)
	Married / Civil partnership	226 (54.2)
	Cohabiting	69 (16.5)
	Divorced	25 (6.0)
	Widowed	29 (7.0)
	Undeclared	5 (1.2)
Educational qualification	Higher degree (PhD, Masters)	187 (44.8)
	Post-graduate qualification	7 (1.7)
	Professional qualification	41 (9.8)
	First degree (BSc, BA)	122 (29.3)
	A-Level or equivalent	37 (8.9)
	GCSE or equivalent (O-Level)	16 (3.8)
	Undeclared/None	7 (1.7)
Employment status	Employed	271 (65.0)
	Unemployed or looking for work	3 (0.7)
	Retired	99 (23.7)
	In full-time education	17 (4.1)
	Other (‘Other’ and multiple groups)	21 (5.0)
	Undeclared	6 (1.4)
Ethnicity	White	391 (93.8)

	Black	2 (0.5)
	Asian	5 (1.2)
	Mixed	5 (1.2)
	Other	10 (2.4)
	Undeclared	4 (1.0)

* Created for purpose of analysis based on responses

Appendix 1

Appendix Table 1: Table of questionnaire items relating to understandings of cognitive impairment and response options

Question	Response Option
Have you head of cognitive impairment before?	Yes No
Do you know anybody personally who has ever been given a diagnosis of cognitive impairment (memory and thinking difficulties)?	Yes – family member Yes – friend Yes – myself Yes – other No
Do you know anybody personally who has ever been given a diagnosis of dementia?	Yes – family member Yes – friend Yes – myself Yes – other No
Have you ever read any information about cognitive impairment?	Yes – as part of my job role Yes – as part of my studies Yes – for personal or other reasons No
Have you ever read any information about dementia?	Yes – as part of my job role Yes – as part of my studies Yes – for personal or other reasons No

I have a good understanding of what cognitive impairment is	Strongly agree Agree Neither Disagree Strongly disagree
I want to know more about cognitive impairment	Strongly agree Agree Neither Disagree Strongly disagree
I have a good understanding of what dementia is	Strongly agree Agree Neither Disagree Strongly disagree
I want to know more about dementia	Strongly agree Agree Neither Disagree Strongly disagree
Cognitive impairment is a normal part of ageing	True False Don't know
Cognitive impairment is a form of dementia	True False

	Don't know
Cognitive impairment only affects people over the age of 65	True False Don't know
People with cognitive impairment will definitely develop dementia	True False Don't know
There are treatments available which can help people with cognitive impairment	True False Don't know
Cognitive impairment is a mental illness	True False Don't know
People with cognitive impairment are no longer the same person that they used to be	True False Don't know
Memory and thinking problems are a normal part of getting older	True False Don't know
Cognitive impairment can be cured	True False Don't know
Cognitive impairment is permanent	True False Don't know

Cognitive impairment is easy to live with	True False Don't know
People with cognitive impairment lose their independence	True False Don't know
People with cognitive impairment lose their self-confidence	True False Don't know
Staying active can help to treat the symptoms of cognitive impairment	True False Don't know
Cognitive impairment is preventable	True False Don't know
People with cognitive impairment can still live a full and happy life	True False Don't know
If a friend asked you what cognitive impairment was, how would you describe it?	[Free text response]
If a friend asked you what dementia was, how would you describe it?	[Free text response]
Beth is 67 and works full-time as a receptionist. Recently, Beth has noticed that she is forgetful at work and has missed a couple of meetings and	Mild cognitive impairment Mild neurocognitive disorder Early stage dementia

personal appointments. Beth has also been having trouble finding the right words to describe things at times. Which of the following terms do you think best describes what Beth is experiencing?	Early stage Alzheimer's disease Memory problems Questionable dementia Age related cognitive decline Age associated cognitive decline Age associated memory impairment Benign senescent forgetfulness Getting older Stress Depression Physical health problems Mental health problems Don't know Other
Do you think the following can cause cognitive impairment: • Getting older • Genetics • Abnormal brain changes • Head injury (recently or in the past) • Diet • Stress or worry • Personal behaviour (e.g. levels of physical and/or mental activity)	Yes No Don't know

- Physical health problems

Appendix 2

Appendix Table 1: Responses to questionnaire items about prior knowledge and experience of cognitive impairment and dementia

	% (n) responding Yes								
	LwCI	**CP**	**OA**	**YA**	**HCP**	**Sp**	**Sp HCP**	**Other**	**Total**
Heard of cognitive impairment	70.0% (7)	91.3% (21)	79.5% (66)	73.5% (61)	99.0% (95)	92.5% (37)	100.0% (48)	94.1% (32)	88.0% (367)
Know somebody personally who has been given a diagnosis of cognitive impairment	80.0% (8)	65.2% (15)	41.0% (34)	31.3% (26)	71.9% (69)	57.5% (23)	85.4% (41)	67.6% (23)	57.3% (239)
Know somebody personally who has been given a diagnosis of dementia	80.0% (8)	91.3% (21)	75.9% (63)	66.3% (55)	82.3% (79)	80.0% (32)	89.6% (43)	85.3% (29)	79.1% (330)
Read any information about cognitive impairment	70.0% (7)	69.6% (16)	39.8% (33)	38.6% (32)	93.8% (90)	80.0% (32)	95.8% (46)	91.2% (31)	68.8% (287)
Read any information about dementia	90.0% (9)	87.0% (20)	77.1% (64)	85.5% (71)	100.0% (96)	97.5% (39)	100.0% (48)	97.1% (33)	91.1% (380)

LwCI = Living with cognitive impairment, CP = Care partner, OA = Older adult, YA = Younger adult, HCP = Healthcare professional, Sp = Specialist, Sp HCP = Specialist healthcare professional.

Appendix Table 2: Responses to questionnaire items about confidence around understanding of cognitive impairment and dementia and desire to know more about these

	% (n) responding Agree/Strongly Agree								
	LwCI	**CP**	**OA**	**YA**	**HCP**	**Sp**	**Sp HCP**	**Other**	**Total**
Good understanding of cognitive impairment	50.0% (5)	34.8% (8)	34.9% (29)	32.5% (27)	88.5% (85)	72.5% (29)	91.7% (44)	85.3% (29)	61.4% (256)
Want to know more about cognitive impairment	100.0% (10)	78.3% (18)	78.3% (65)	79.5% (66)	81.3% (78)	90.0% (36)	81.3% (39)	88.2% (30)	82.0% (342)
Good understanding of dementia	60.0% (6)	69.6% (16)	63.9% (53)	72.3% (60)	97.9% (94)	90.0% (36)	95.8% (46)	94.1% (32)	82.3% (343)
Want to know more about dementia	80.0% (8)	78.3% (18)	77.1% (64)	80.7% (67)	84.4% (81)	90.0% (36)	79.2% (38)	85.3% (29)	81.8% (341)

LwCI = Living with cognitive impairment, CP = Care partner, OA = Older adult, YA = Younger adult, HCP = Healthcare professional, Sp = Specialist, Sp HCP = Specialist healthcare professional.

Appendix Table 3: Responses to questionnaire items about identification and definitions of cognitive impairment

	% (n) responding True								
	LwCI	**CP**	**OA**	**YA**	**HCP**	**Sp**	**Sp HCP**	**Other**	**Total**
Cognitive impairment is a normal part of ageing	20.0% (2)	21.7% (5)	21.7% (18)	32.5% (27)	19.8% (19)	20.0% (8)	20.8% (10)	14.7% (5)	22.5% (94)
Cognitive impairment is a form of dementia	40.0% (4)	26.1% (6)	14.5% (12)	24.1% (20)	15.6% (15)	22.5% (9)	8.3% (4)	26.5% (9)	18.9% (79)
Cognitive impairment only affects people over the age of 65	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	2.9% (1)	0.2% (1)
Cognitive impairment is a mental illness	10.0% (1)	21.7% (5)	20.5% (17)	20.5% (17)	13.5% (13)	12.5% (5)	14.6% (7)	26.5% (9)	17.7% (74)
Memory and thinking problems are a normal part of getting older	50.0% (5)	39.1% (9)	59.0% (49)	65.1% (54)	37.5% (36)	50.0% (20)	31.3% (15)	41.2% (14)	48.4% (202)

LwCI = Living with cognitive impairment, CP = Care partner, OA = Older adult, YA = Younger adult, HCP = Healthcare professional, Sp = Specialist, Sp HCP = Specialist healthcare professional.

Appendix Table 4: Responses to the questionnaire item relating to labelling the symptoms presented in a vignette

	% (n) endorsing each term								
	LwCI	**CP**	**OA**	**YA**	**HCP**	**Sp**	**Sp HCP**	**Other**	**Total**
Mild cognitive impairment	70.0% (7)	73.9% (17)	59.0% (49)	45.8% (38)	57.3% (55)	60.0% (24)	52.1% (25)	64.7% (22)	56.8% (237)
Mild neurocognitive disorder	10.0% (1)	13.0% (3)	4.8% (4)	4.8% (4)	11.5% (11)	12.5% (5)	14.6% (7)	8.8% (3)	9.1% (38)
Early stage dementia	20.0% (2)	21.7% (5)	7.2% (6)	18.1% (15)	21.9% (21)	17.5% (7)	18.8% (9)	17.6% (6)	17.0% (71)
Early stage Alzheimer's disease	30.0% (3)	8.7% (2)	6.0% (5)	15.7% (13)	17.7% (17)	17.5% (7)	12.5% (6)	20.6% (7)	14.4% (60)
Memory problems	60.0% (6)	56.5% (13)	57.8% (48)	51.8% (43)	52.1% (50)	60.0% (24)	47.9% (23)	58.8% (20)	54.4% (227)
Questionable dementia	20.0% (2)	17.4% (4)	12.0% (10)	18.1% (15)	22.9% (22)	32.5% (13)	20.8% (10)	14.7% (5)	19.4% (81)
Age related cognitive decline	20.0% (2)	39.1% (9)	24.1% (20)	24.1% (20)	22.9% (22)	22.5% (9)	16.7% (8)	35.3% (12)	24.5% (102)
Age associated cognitive decline	30.0% (3)	13.0% (3)	12.0% (10)	22.9% (19)	11.5% (11)	22.5% (9)	16.7% (8)	17.6% (6)	16.5% (69)
Age associated memory impairment	30.0% (3)	26.1% (6)	41.0% (34)	27.7% (23)	14.6% (14)	25.0% (10)	16.7% (8)	32.4% (11)	26.1% (109)
Benign senescent forgetfulness	10.0% (1)	8.7% (2)	10.8% (9)	7.2% (6)	6.3% (6)	10.0% (4)	4.2% (2)	8.8% (3)	7.9% (33)
Getting older	30.0% (3)	17.4% (4)	33.7% (28)	34.9% (29)	16.7% (16)	15.0% (6)	12.5% (6)	14.7% (5)	23.3% (97)
Stress	40.0% (4)	56.5% (13)	36.1% (30)	37.3% (31)	49.0% (47)	40.0% (16)	41.7% (20)	47.1% (16)	42.4% (177)
Depression	20.0% (2)	30.4% (7)	10.8% (9)	18.1% (15)	31.3% (30)	17.5% (7)	35.4% (17)	32.4% (11)	23.5% (98)

Physical health problems	10.0% (1)	26.1% (6)	9.6% (8)	9.6% (8)	16.7% (16)	15.0% (6)	22.9% (11)	14.7% (5)	14.6% (61)
Mental health problems	20.0% (2)	17.4% (4)	6.0% (5)	12.0% (10)	20.8% (20)	20.0% (8)	20.8% (10)	23.5% (8)	16.1% (67)
Don't know	0.0% (0)	17.4% (4)	2.4% (4)	13.3% (11)	9.4% (9)	12.5% (5)	10.4% (5)	5.9% (2)	9.1% (38)
Other	20.0% (2)	30.4% (7)	14.5% (12)	10.8% (9)	29.2% (28)	10.0% (4)	45.8% (22)	23.5% (8)	22.1% (92)
Average number of terms endorsed	4.4 (3.5) 1-11	4.8 (3.5) 1-14	3.5 (2.4) 1-11	3.7 (3.2) 1-17	4.1 (3.5) 1-17	4.1 (3.6) 1-16	4.1 (3.5) 0-16	4.4 (2.8) 1-11	4.0 (3.2) 0-17

LwCI = living with cognitive impairment; CP = care partner; YA = younger adult; OA = older adult; HCP = healthcare professional; Sp HCP = specialist healthcare professional.

Appendix Table 5: Respondents endorsements of potential causes of cognitive impairment

	% (n) endorsing as potential cause of cognitive impairment								
	LwCI	**CP**	**OA**	**YA**	**HCP**	**Sp**	**Sp HCP**	**Other**	**Total**
Getting older	80.0% (8)	73.9% (17)	69.9% (58)	73.5% (61)	75.0% (72)	70.0% (28)	72.9% (35)	67.6% (23)	72.4% (302
Genetics	70.0% (7)	65.2% (15)	57.8% (48)	69.9% (58)	83.3% (80)	77.5% (31)	81.3% (39)	79.4% (27)	73.1% (305)
Abnormal brain changes	70.0% (7)	87.0% (20)	55.4% (46)	86.7% (72)	99.0% (95)	92.5% (37)	97.9% (47)	82.4% (28)	84.4% (352)
Head injury	90.0% (9)	91.3% (21)	68.7% (57)	92.8% (77)	100.0% (96)	95.0% (38)	97.9% (47)	94.1% (32)	90.4% (377)
Diet	60.0% (6)	39.1% (9)	18.1% (15)	37.3% (31)	62.5% (60)	52.5% (21)	54.2% (26)	58.8% (20)	45.1% (188)
Stress or worry	90.0% (9)	82.6% (19)	68.7% (57)	77.1% (64)	95.8% (92)	82.5% (33)	89.6% (43)	82.4% (28)	82.7% (345)
Personal behaviour	50.0% (5)	60.9% (14)	47.0% (39)	69.9% (58)	72.9% (70)	65.0% (26)	72.9% (35)	55.9% (19)	63.8% (266)
Physical health problems	70.0% (7)	65.2% (15)	41.0% (34)	65.1% (54)	93.8% (90)	77.5% (31)	93.8% (45)	76.5% (26)	72.4% (302)

LwCI = Living with cognitive impairment, CP = Care partner, OA = Older adult, YA = Younger adult, HCP = Healthcare professional, Sp = Specialist, Sp HCP = Specialist healthcare professional.

Appendix Table 6: Responses to questionnaire items about consequences and impact of cognitive impairment

	% (n) responding True								
	LwCI	**CP**	**OA**	**YA**	**HCP**	**Sp**	**Sp HCP**	**Other**	**Total**
People with cognitive impairment will definitely develop dementia	0.0% (0)	4.3% (1)	0.0% (0)	1.2% (1)	0.0% (0)	0.0% (0)	0.0% (0)	2.9% (1)	0.7% (3)
People with cognitive impairment are no longer the same person that they used to be	40.0% (4)	21.7% (5)	15.7% (13)	6.0% (5)	3.1% (3)	10.0% (4)	4.2% (2)	5.9% (2)	9.1% (38)
Cognitive impairment is easy to live with	0.0% (0)	0.0% (0)	8.4% (7)	3.6% (3)	2.1% (2)	10.0% (4)	0.0% (0)	0.0% (0)	3.8% (16)
People with cognitive impairment lose their independence	30.0% (3)	43.5% (10)	16.9% (14)	19.3% (16)	13.5% (13)	15.0% (6)	18.8% (9)	32.4% (11)	19.7% (82)
People with cognitive impairment lose their self-confidence	100.0% (10)	78.3% (18)	65.1% (54)	66.3% (55)	61.5% (59)	57.5% (23)	62.5% (30)	73.5% (25)	65.7% (274)
People with cognitive impairment can still live a full and happy life	80.0% (8)	82.6% (19)	78.3% (65)	86.7% (72)	97.9% (94)	92.5% (37)	97.9% (47)	91.2% (31)	89.4% (373)

LwCI = living with cognitive impairment; CP = care partner; YA = younger adult; OA = older adult; HCP = healthcare professional; Sp HCP = specialist healthcare professional.

Appendix Table 7: Responses to questionnaire items about the permanence and possible treatments for cognitive impairment

	% (n) responding True								
	LwCI	**CP**	**OA**	**YA**	**HCP**	**Sp**	**Sp HCP**	**Other**	**Total**
Cognitive impairment is permanent	60.0% (6)	34.8% (8)	22.9% (19)	20.5% (17)	26.0% (25)	35.0% (14)	20.8% (10)	29.4% (10)	26.1% (109)
There are treatments available which can help people with cognitive impairment	60.0% (6)	47.8% (11)	45.8% (38)	59.0% (49)	86.5% (83)	67.5% (27)	87.5% (42)	67.6% (23)	66.9% (279)
Cognitive impairment can be cured	0.0% (0)	8.7% (2)	3.6% (3)	8.4% (7)	16.7% (16)	20.0% (8)	16.7% (8)	8.8% (3)	11.3% (47)
Staying active can help to treat the symptoms of cognitive impairment	60.0% (6)	82.6% (19)	85.5% (71)	78.3% (65)	90.6% (87)	87.5% (35)	87.5% (42)	88.2% (30)	85.1% (355)
Cognitive impairment is preventable	0.0% (0)	4.3% (1)	6.0% (5)	15.7% (13)	30.2% (29)	22.5% (9)	22.9% (11)	20.6% (7)	18.0% (75)

LwCI = living with cognitive impairment; CP = care partner; YA = younger adult; OA = older adult; HCP = healthcare professional; Sp HCP = specialist healthcare professional.