

Cognitive impairment in later life:
Understanding lay, professional and
memory service user perspectives

Heather Yemm

A thesis submitted in partial fulfilment of the University's
requirements for the Degree of Doctor of Philosophy

2017

University of Worcester

Acknowledgements

There are so many people that I want to thank for their support and guidance during this PhD. First and foremost, my thanks go to my wonderful supervisors, Professor Dawn Brooker and Professor Elizabeth Peel; without your tireless support, reassurance and expert advice this thesis would certainly have not been possible. Thank you for always being there to support me and for having faith in me even when my own wavered. To my previous supervisors, Dr Jon Catling, Dr Victoria Mason and Professor Dominic Upton, thank you for starting me on this journey.

To my wonderful friends and colleagues who have eased the pressures of the thesis and made sure I stayed focused, thank you so much. Thank you to everyone at the Association for Dementia Studies, with a special thanks to Jen, Izzie and Teresa – I'll never forget our office chats and movie nights. To all my fellow postgraduate students, especially Bekki, Erika and Amy, thank you for all the lunch breaks and pub trips (and for letting me stay during my long-distance period!). Thank you to all my wonderful research colleagues at Gateshead, especially Alison, Yvonne, Maria & Sophie, who have been an amazing support through the final few months of my studies and been such fantastic colleagues and friends. A special mention must also go to Bryony; thank you so much for all of your help – you must be sick of the sound of my voice by now! Ashley, Matt, Christina, David (and Alex), Jen, Andy, Kayleigh, Al, Joe & Mariu; you have all been my best friends for so long and I can't thank you all enough for your support and love. My eternal gratitude in particular goes to Ashley – I look forward to many more scotch egg crême eggs and adventures in the years to come.

I am immensely grateful to my wonderful family who have supported me through this process and always welcomed me with a hot meal and a huge hug. To my wonderful parents, Ian and Jo, thank you for everything. You've both always been an inspiration to me and I couldn't have made it through any of this without your love and support. My beautiful baby nephew Noah was born during the final stages of writing this thesis and I now look forward to spending more time with him and my fabulous sister and brother-in-law, Caroline and Mike. Thank you, Caroline, for being the best big sister in the world, and to you and Mike for both always welcoming me with a smile and support even in the bleakest of moments. My gratitude also goes to my extended family, my wonderful grandparents Malcolm and Irene who have always supported and encouraged me, and my family-in-law, Alan, Pat, Ali, Gav, Nia, Belle, Joe, Tony,

Cath, Charlie, Cait and Niamh, who have been an endless source of support and laughter. Diolch yn fawr.

I want to thank my long-suffering husband Yemm; we've had highs and lows throughout the last 5 years but I'm so glad you've been by my side every step of the way and I can't wait to finally be at a point in our life where neither of us is a student anymore! Your love and support means the world to me and I couldn't have done any of this without you. I love you.

Most importantly, I want to thank all of the participants who kindly gave up their time and shared their views with me. Without each one of you, this thesis would never have been possible.

Abstract

This thesis explores what a range of people know and understand about cognitive impairment. The research presented here also explores the language and terminology that people use when discussing cognitive impairment. In order to do so, a mixed methods design was employed, involving three related studies; a systematic review of the literature about knowledge and understanding of mild cognitive impairment (MCI), a questionnaire study exploring respondents' knowledge and understanding of cognitive impairment, and an interview study building on the results of the questionnaire and exploring perceptions of cognitive impairment in-depth.

The systematic review included 30 studies; 20 qualitative articles and 10 survey studies. The questionnaire study received 417 responses predominantly from England, but including some international responses. Questionnaire respondents were drawn from six population groups: people living with cognitive impairment, care partners, younger adults, older adults, healthcare professionals, and dementia specialists. Twenty-one semi-structured interviews were conducted with representatives from each of these six participant groups.

The findings from these studies suggest that most participants were able to offer a definition of cognitive impairment, highlighting similar symptoms (focusing on memory problems) and causes (such as brain damage and ageing). Participants discussed cognitive impairment in the context of dementia and were uncertain as to whether the two were synonymous or different. Where participants felt that cognitive impairment and dementia were different, they were unable to articulate these differences suggesting that the boundaries between cognitive impairment and dementia are not clear to the wider population. Participants offered causation accounts and narratives which suggested both controllable and uncontrollable factors may play a role in cognitive health, but participants generally claimed that cognitive impairment was beyond an individual's personal sphere of control.

Participants identified that professionals and the lay population used different language and labels when discussing cognitive impairment and most felt that MCI was not an acceptable or appropriate label. The use of the word memory in diagnostic services for cognitive impairment and dementia (such as memory clinic, memory assessment service) is challenged as this may contribute to the perception that cognitive impairment and dementia are conditions which are solely or primarily characterised by a memory impairment.

The results of the studies inform the development of an illness representation model of cognitive impairment, providing a framework on which to base future information resources, media messages and public health and awareness campaigns. This thesis has begun to address a key gap in the literature, considering the views of a range of populations about cognitive impairment. However, future research is needed to explore factors which influence perspectives about cognitive impairment and to consider whether these perspectives change over time and can be influenced by educational campaigns and information.

Table of Contents

| | |
|---|----|
| Acknowledgements..... | 2 |
| Abstract | 4 |
| Table of Contents | 6 |
| List of Tables..... | 9 |
| List of Figures | 9 |
| Chapter 1: An Introduction to Mild Cognitive Impairment..... | 11 |
| 1.1 History of Mild Cognitive Impairment (MCI)..... | 11 |
| 1.1.1 Benign Senescent Forgetfulness (BSF) | 11 |
| 1.1.2 Clinical Dementia Rating Scale (CDR) | 12 |
| 1.1.3 Global Deterioration Scale (GDS) | 12 |
| 1.1.4 Age Associated Memory Impairment (AAMI) | 13 |
| 1.1.5 Age Consistent Memory Impairment (ACMI) & Late-life-forgetfulness (LLF) | 13 |
| 1.1.6 Age Related Cognitive Decline (ARCD), Age Associated Cognitive Decline (AACD) & Mild Cognitive Disorder (MCD) | 14 |
| 1.1.7 Mild Cognitive Impairment (MCI)..... | 15 |
| 1.1.8 Mild Neurocognitive Disorder (mNCD) | 17 |
| 1.1.9 Diagnostic Labelling of Cognitive Impairment | 17 |
| 1.2 Current & Predicted Prevalence and Incidence of MCI | 21 |
| 1.3 Subtypes of MCI | 21 |
| 1.4 MCI as a Diagnostic Label..... | 24 |
| 1.5 Progression from MCI to Dementia | 26 |
| 1.6 MCI as an “At Risk State” | 27 |
| 1.7 Policy and Practice Around MCI..... | 28 |
| 1.8 Knowledge and Understanding of Cognitive Impairment..... | 30 |
| 1.9 Summary of the Literature | 31 |
| 1.10 Aims..... | 31 |
| 1.11 Research Questions..... | 32 |
| Chapter 2: Methodological Approach..... | 33 |
| 2.1 Introduction..... | 33 |
| 2.2 Mixed Methods Research | 33 |
| 2.2.1 Current Research..... | 36 |
| 2.3 Critical Realism | 36 |
| 2.4 Reflexivity | 38 |
| 2.5 Design..... | 39 |
| 2.6 Participants..... | 40 |
| 2.6.1 Multiple Perspectives | 40 |
| 2.6.2 Exclusion Criteria | 44 |
| 2.7 Terminology | 44 |
| 2.8 Ethical Issues | 45 |
| 2.8.1 Ethical Approval | 45 |
| 2.8.2 Ethical Considerations..... | 45 |
| 2.9 Summary | 47 |
| Chapter 3: Knowledge and understanding of mild cognitive impairment: a systematic review and thematic synthesis of qualitative and quantitative research..... | 48 |
| 3.1 Chapter Overview..... | 48 |
| 3.2 Introduction..... | 48 |
| 3.3 Method..... | 49 |
| 3.3.1 Systematic search strategy..... | 49 |

| | |
|---|-----|
| 3.3.2 Selection Process..... | 50 |
| 3.3.3 Critical Appraisal..... | 52 |
| 3.3.4 Sensitivity analysis..... | 52 |
| 3.3.5 Synthesis Approach..... | 52 |
| 3.4 Results..... | 55 |
| 3.4.1 MCI symptoms..... | 81 |
| 3.4.2 Causes of MCI..... | 86 |
| 3.4.3 Association with dementia..... | 89 |
| 3.4.4 Lack of information..... | 91 |
| 3.4.5 MCI as a diagnostic label..... | 93 |
| 3.4.6. Changed person..... | 97 |
| 3.5 Discussion..... | 99 |
| 3.5.1 Views of experts on MCI..... | 104 |
| 3.5.2 Limitations..... | 105 |
| 3.6 Conclusions..... | 106 |
| 3.7 Summary..... | 106 |
| Chapter 4: Towards an Illness Representation Model of Cognitive Impairment..... | 108 |
| 4.1 Introduction..... | 108 |
| 4.2 Labelling theory..... | 109 |
| 4.3 Attribution theory..... | 113 |
| 4.4 Common-sense model of illness representation..... | 116 |
| 4.5 Factors Influencing the Development of Representations..... | 120 |
| 4.5.1 Social/Self-identity..... | 120 |
| 4.5.2 Prevalence..... | 121 |
| 4.5.3 Personal risk/Susceptibility..... | 121 |
| 4.5.4 Age..... | 122 |
| 4.5.5 Fear and avoidance..... | 123 |
| 4.6 MCI illness representation model..... | 123 |
| 4.6.1 Identity..... | 123 |
| 4.6.2 Consequences..... | 124 |
| 4.6.3 Cause..... | 124 |
| 4.6.4 Timeline..... | 126 |
| 4.6.5 Controllability..... | 126 |
| 4.7 Conclusion..... | 126 |
| 4.8 Summary..... | 129 |
| Chapter 5: A Survey Exploration of Perceptions About Cognitive Impairment..... | 130 |
| 5.1 Introduction..... | 130 |
| 5.2 Research Questions..... | 131 |
| 5.3 Method..... | 134 |
| 5.3.1 Recruitment of Target Participants..... | 134 |
| 5.3.2 Materials..... | 136 |
| 5.3.3 Questionnaire Development..... | 136 |
| 5.3.4 Piloting the Questionnaire..... | 138 |
| 5.4 Data Analysis..... | 146 |
| 5.5 Results..... | 147 |
| 5.5.1 Respondent Characteristics..... | 150 |
| 5.5.2 Prior Knowledge of Cognitive Impairment and Dementia..... | 152 |
| 5.5.3 Confidence in Knowledge of Cognitive Impairment and Dementia..... | 154 |
| 5.5.4 Definitions and Identification of Cognitive Impairment..... | 157 |
| 5.5.5 Understanding the Consequences of Cognitive Impairment..... | 160 |

| | |
|--|-----|
| 5.5.6 Understanding the Permanence of Cognitive Impairment..... | 163 |
| 5.5.7 Understanding about Treatments and Lifestyle Changes..... | 163 |
| 5.5.8 Understanding About the Causes of Cognitive Impairment..... | 166 |
| 5.5.9 Attribution and Labelling of Symptoms Presented in the Vignette..... | 168 |
| 5.5.10 Impact of Respondent Characteristics on Questionnaire results..... | 170 |
| 5.5.11 Qualitative Responses..... | 172 |
| 5.6 Discussion..... | 180 |
| 5.6.1 Implications for Health & Wellbeing..... | 180 |
| 5.6.2 Implications for Public Health & Education Campaigns..... | 183 |
| 5.6.3 Future Research..... | 185 |
| 5.7 Summary..... | 186 |
| Chapter 6: A Qualitative Exploration of Knowledge and Views about Cognitive Impairment . | 188 |
| 6.1 Introduction..... | 188 |
| 6.2 Research Questions..... | 189 |
| 6.3 Method..... | 189 |
| 6.3.1 Participants..... | 189 |
| 6.3.2 Procedure..... | 193 |
| 6.4 Data Analysis..... | 194 |
| 6.5 Results..... | 195 |
| 6.5.1 Accounts of Cognitive Impairment..... | 197 |
| 6.5.2 Causation Accounts..... | 223 |
| 6.5.3 Ageing, Dementia & Death..... | 242 |
| 6.6 Discussion..... | 258 |
| 6.7 Summary..... | 262 |
| Chapter 7: General Discussion..... | 263 |
| 7.1 Overview..... | 263 |
| 7.2 Aim of the Thesis..... | 263 |
| 7.3 Main Findings..... | 263 |
| 7.3.1 Definitions of Cognitive Impairment..... | 263 |
| 7.3.2 Social Isolation..... | 264 |
| 7.3.3 Conflation with Dementia..... | 265 |
| 7.3.4 Fear of Cognitive Impairment and Dementia..... | 266 |
| 7.3.5 Stigma..... | 266 |
| 7.3.6 Normality/Normal Ageing..... | 267 |
| 7.3.7 Brain Disease..... | 268 |
| 7.3.8 Blame and Controllability..... | 268 |
| 7.3.9 Illness Causation..... | 269 |
| 7.3.10 “Them” versus “Us”..... | 270 |
| 7.3.11 Death and Dying..... | 271 |
| 7.3.12 Labelling and Diagnosis..... | 271 |
| 7.4 Implications of Findings..... | 272 |
| 7.4.1 Policy/Government..... | 272 |
| 7.4.2 Media..... | 274 |
| 7.4.3 Public Health Campaigns..... | 274 |
| 7.4.4 Cognitive Impairment Illness Representation Model..... | 275 |
| 7.5 Limitations..... | 278 |
| 7.5.1 Design..... | 278 |
| 7.5.2 Sample..... | 279 |
| 7.5.3 Sample Size..... | 280 |
| 7.5.4 Researcher Influence..... | 280 |

| | |
|---|-----|
| 7.6 Future Directions for Research | 281 |
| 7.7 Conclusion | 283 |
| 8. References..... | 285 |
| Appendix A: Critical Appraisal Skills Programme checklist | 300 |
| Appendix B: Modified Critical Appraisal Skills Programme checklist..... | 302 |
| Appendix C: Introductory Information Leaflet..... | 305 |
| Appendix D: Introductory Letter | 307 |
| Appendix E: Questionnaire..... | 309 |
| Appendix F: Participant Study Report..... | 321 |
| Appendix G: Questionnaire Response Data | 325 |
| Appendix H: Interview Information Sheet | 343 |
| Appendix I: Interview Consent Form..... | 347 |
| Appendix J: Interview Schedule | 349 |
| Appendix K: Transcription Symbols..... | 351 |

List of Tables

| | |
|---|-----|
| Table 1.1: Components of cognitive impairment syndromes in chronological order..... | 19 |
| Table 3.1: Inclusion criteria for articles screened for the systematic review..... | 51 |
| Table 3.2: Summary of themes identified from studies included in the review..... | 56 |
| Table 3.3: Summary table of papers included in the review..... | 57 |
| Table 5.1: Suggestions and comments posited by respondents in pilot stage one..... | 140 |
| Table 5.2: Respondent characteristics for pilot stage two..... | 142 |
| Table 5.3: Table of Item-Total Correlation values for all questionnaire items included in the Cronbach's alpha calculation..... | 144 |
| Table 5.4: Number of questionnaire respondents by participant group..... | 149 |
| Table 5.5: Respondent characteristics across all participant groups..... | 151 |
| Table 5.6: Respondents answering the qualitative free text questions regarding explanations of cognitive impairment and dementia..... | 173 |
| Table 6.1: Interview participants' characteristics..... | 192 |

List of Figures

| | |
|--|-----|
| Figure 1.1: Flowchart outlining MCI subtypes and potential outcomes..... | 23 |
| Figure 2.1: The continuum of ontology, outlining the three key ontological stances..... | 36 |
| Figure 2.2: Flowchart showing research phases and workflow of the study..... | 40 |
| Figure 3.1: Flowchart of the screening process for articles included in the review..... | 54 |
| Figure 4.1: Diagrammatic representation of labelling theory..... | 112 |
| Figure 4.2: Diagrammatic representation of attribution theory..... | 115 |
| Figure 4.3: Diagrammatic representation of the common-sense model of illness representation..... | 117 |
| Figure 4.4: Diagrammatic representation of the MCI illness representation model..... | 128 |
| Figure 5.1: Responses to questionnaire items about prior knowledge and experience of cognitive impairment and dementia..... | 153 |
| Figure 5.2: Responses to questionnaire items about confidence around understanding of cognitive impairment and dementia and desire to know more about these..... | 156 |

| | |
|--|-----|
| Figure 5.3: Responses to questionnaire items about identification and definitions of cognitive impairment..... | 159 |
| Figure 5.4: Responses to questionnaire items about the consequences of cognitive impairment..... | 162 |
| Figure 5.5: Responses to questionnaire items about treatment, lifestyle changes and permanency of cognitive impairment..... | 165 |
| Figure 5.6: Respondents endorsements of potential causes of cognitive impairment..... | 167 |
| Figure 5.7: Respondents endorsements of presented terms and labels for the symptoms presented in the questionnaire vignette..... | 169 |
| Figure 6.1: Thematic map of themes and subthemes..... | 196 |
| Figure 7.1: Diagrammatic representation of the cognitive impairment illness representation model..... | 277 |

Chapter 1: An Introduction to Mild Cognitive Impairment

1.1 History of Mild Cognitive Impairment (MCI)

Over the past century, average life expectancy has increased dramatically, resulting in a substantial increase in the number of people over the age of 65, with those aged over 85 being the most quickly increasing population group (Christensen, Doblhammer, Rau, & Vaupel, 2009). This has led to an increased interest in ageing processes, and researchers and clinical investigators have attempted to clearly define the boundaries of “normal” or “typical” ageing, and at what stage cognitive problems may occur in older adults which can be considered to be beyond the boundary of normal ageing. In this context, identifying cognitive impairment outside of normal ageing is describing a state of cognitive disability which may cause individuals to require additional support and assistance, and which may have an underlying aetiology that could benefit from medical intervention. However, discussing cognitive impairment as contrasted with normal ageing is not intended to present normal ageing as a unitary linear process. On an individual level, people experience ageing differently with different expectations and views about ageing, and what is “normal” in the subjective sense to one person may be very different to what is “normal” for another. Within the context of this thesis “normal ageing” is discussed at a population level, trying to define this in an objective manner, as to what would be defined as normal ageing for the population as a whole. During the past 50 years, there have been a number of different definitions and terms proposed to try and account for the cognitive deficits that are often observed in older adults (but also occur in younger adults) which are either in-line with or beyond the normal expectation for their age but which do not meet the criteria for a dementia diagnosis (see Table 1.1, p.19).

1.1.1 Benign Senescent Forgetfulness (BSF)

In the early 1960s, it was proposed that individuals with mild memory deficits which remained stable over time could be termed as experiencing “benign senescent forgetfulness” (BSF; Kral, 1962). This term was used to describe nursing home residents who exhibited a subjective memory complaint and experienced loss of remote memories, with recent memories remaining intact. However, as further knowledge and research developed, the concept of BSF has been expanded and redeveloped into new definitions and labels in an attempt to best define the syndrome of cognitive deficits which some people experience in adulthood, particularly as older adults.

1.1.2 Clinical Dementia Rating Scale (CDR)

In 1982, with an increase in population ageing being observed (Bischkopf, Busse, & Angermeyer, 2002), a renewed interest in cognitive impairment in older adults resulted in two global rating scales for ageing and dementia to enable clinicians to use a rigorous measure to classify the cognitive performance of older adults. The first of these scales, the Clinical Dementia Rating scale (CDR; Hughes et al., 1982) was proposed to define the boundaries between normal ageing and dementia. This scale offers 5 possible levels of impairment against which individuals can be rated. These levels range from 0, which refers to no dementia, 0.5 which is deemed questionable dementia, 1 which refers to mild dementia, 2 which is moderate dementia, and finally to 3 which is scored as severe dementia. Within the CDR, 0.5 represents a mild memory impairment or 'benign' forgetfulness together with no impairment, or very mild impairment in problem solving skills, and activities of daily living (ADLs). The authors also listed a key exclusion criterion for all levels on the CDR, stating that the observed impairment should not be a result of any present or past psychiatric or medical condition, or the result of substance use. However, the criteria for a CDR rating of 0.5 may be over inclusive, as this could include individuals with probable Alzheimer's disease (Petersen et al., 1999) and thus this scale does not demarcate the boundaries of normal ageing clearly, scoring directly from no dementia to questionable dementia, with no clear mid-ground, suggesting that any identifiable cognitive impairment must be due to a dementia causality. Being given a diagnosis of questionable dementia would be likely to have implications for an individual receiving that diagnosis, as they would have to consider dementia as a very real possibility, when for some people, their experience may be wholly unrelated to dementia.

1.1.3 Global Deterioration Scale (GDS)

Alongside the development of the CDR, Reisberg et al. (1982) produced the Global Deterioration Scale (GDS) which proposed seven possible stages of cognitive function for individuals who may be experiencing a dementia. Within the GDS, the first three stages are the pre-dementia stages, with stage 1 referring to an absence of cognitive decline, whereby the individual does not have any subjective memory complaints, and there is no memory deficit evidenced in clinical interview. The next stage refers to a very mild cognitive deficit. At this stage, the individual expresses subjective memory complaints, but these concerns are not objectively verified, and there are no objective deficits in ADLs. The third stage concerns a mild cognitive decline or impairment, whereby individuals exhibit objective deficits across a range of

cognitive areas, including memory, concentration, orientation, and language. The individual may also exhibit a mild impairment in ADLs. With the inclusion of impaired ADLs in GDS stage 3, this description may also be over inclusive, as individuals with early stage dementia may be misclassified as GDS stage 3. With the publication of the CDR and GDS, the attempts to distinguish normal ageing and dementia begin to become a little more refined, with measurement tools developed to aid clinicians in determining the level of cognitive impairment an individual might be experiencing.

1.1.4 Age Associated Memory Impairment (AAMI)

Four years after the publication of the CDR and the GDS, another term was proposed for the cognitive changes experienced by older adults; “age associated memory impairment” (AAMI; Crook et al., 1986). This term refers to a subjective memory complaint, with evidence of memory impairment in individuals over the age of 50 which is at least one standard deviation (SD) below that of healthy younger adults. However, this concept was deemed to be over-inclusive as it is expected that healthy younger adults would inevitably perform better on tests of cognition and memory than older adults, as there is some natural deterioration of cognitive functioning in older age (O’Brien & Levy, 1992). On the other hand, the exclusion criteria proposed for AAMI were considered to be overly restrictive, as they include the presence of physical health problems such as respiratory or cardiac disease and diabetes, all of which are likely to be experienced concurrently in older adults (Blackford & La Rue, 1989). As such, the construct of AAMI is unlikely to identify a homogeneous population and is a concept which appears to be both overly inclusive and restrictive, potentially resulting in a difficult set of diagnostic criteria for clinicians to utilise.

1.1.5 Age Consistent Memory Impairment (ACMI) & Late-life-forgetfulness (LLF)

To address the limitations of the AAMI construct, Blackford & La Rue (1989) proposed modifications to the criteria to refine the construct to demarcate a more homogeneous population. These revisions included “age consistent memory impairment” (ACMI) and “late-life-forgetfulness” (LLF). ACMI refers to individuals who performed within 1 SD of the age-specific mean on at least 75% of the administered tests, with suggested tests listed in the original article (Blackford & La Rue, 1989). This construct represents individuals who are experiencing cognitive decline as a result of normal ageing rather than an abnormal progression (Blackford & La Rue, 1989). LLF on the other hand refers to individuals who perform between 1 and 2 SD

below the age-specific mean on at least 50% of the administered tests. The authors regarded individuals with LLF to be a group which should be of interest to clinicians, recommending that these individuals should be monitored closely with longitudinal investigations. However, the criteria proposed for the constructs of LLF and ACMI were deemed to lack clinical utility due to the use of age-specific means rather than age and education specific norms, which would enable the criteria to better incorporate individuals who previously had very high cognitive functioning and may have deteriorated compared to peers of a similar educational background, but not enough to bring their scores under that of their less educated peers (Bischkopf et al., 2002).

1.1.6 Age Related Cognitive Decline (ARCD), Age Associated Cognitive Decline (AACD) & Mild Cognitive Disorder (MCD)

Several further definitions of cognitive impairment were proposed in the mid-1990s, including “age related cognitive decline” (ARCD; American Psychiatric Association, 1994), “age associated cognitive decline” (AACD; Levy, 1994) and “mild cognitive disorder” (MCD; World Health Organisation, 1992). ARCD is listed in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV; American Psychiatric Association, 1994) as a V-code, referring to a condition that may require clinical attention, but which is not a confirmed disease or diagnostic construct. ARCD is defined as an objectively verified decline in cognitive function which is not attributable to a physical or psychological health problem. In this sense, ARCD is very similar to AAMI, but expanded to include additional areas of cognitive function, rather than specifying that the deficit should only be in the domain of memory. AACD criteria require individuals to exhibit both subjective and objective cognitive impairment, which have developed gradually and persisted for at least 6 months (Levy, 1994). This impairment could be present in any of five cognitive domains: memory and learning, thinking, attention and concentration, visuospatial functioning and language. Unlike AAMI and ARCD, the key shift in perspective in AACD lies in the fact that this definition requires an individual to exhibit an impairment compared to their peers, rather than judging their cognition against a population of healthy younger adults. The criteria for AACD also require individuals to exhibit an impairment which is 1 SD below the mean value for both an age and education matched population, making AACD a more clinically valid construct than LLF, which only considered age-specific norms rather than incorporating education. The exclusion criteria for AACD also stipulate that the observed cognitive decline should not be the result of a present or previous physical or psychiatric condition. As such, the criteria for AACD may result in some individuals being excluded due to medical issues which may

actually be a co-morbidity alongside cognitive impairment, rather than the cause of the decline in cognitive function. MCD is listed in the International Statistical Classification of Diseases and Related Health Problems (ICD-10; World Health Organisation, 1992) as a provisional definition and refers to a deficit in memory, concentration and learning, often accompanied by mental fatigue. The criteria for MCD explicitly includes cognitive deficits which are the result of a cerebral or systemic disease. As such, MCD diagnoses may reflect multiple underlying aetiologies and result in a heterogeneous population including individuals with impaired cognitive function as a direct result of a pre-existing physical or psychological health issue rather than a population of individuals experiencing cognitive impairment as a separate syndrome.

1.1.7 Mild Cognitive Impairment (MCI)

In 1999, Petersen et al. proposed another revision of these definitions, termed “mild cognitive impairment” (MCI). This term refers to individuals who exhibit a subjective memory complaint, which is objectively verified, alongside preserved ADLs, generally preserved cognitive function and an absence of a clinically diagnosable dementia. Whilst MCI appears to be another attempt to define a syndrome, with only minor advances from some of the earlier concepts, this term gained much wider acceptance. During the 15 years since MCI was first defined by Petersen et al. (1999), there have been a number of elaborations, refinements and revisions of this concept, with interest growing exponentially (Petersen et al., 2009). When MCI was first clearly defined by Petersen and colleagues (1999), the authors stipulated that in order for an individual to be given a diagnosis of MCI, they should present with what the authors termed as “abnormal memory” (Petersen et al., 1999, p.304). However, this definition is focused solely on memory problems and offers no consideration for people who may present with difficulties in other cognitive domains. In more recent years, there has been a shift towards viewing MCI as a more global construct, and as such, the criteria for MCI have been revised to include deficits in more broad cognitive areas (Winblad et al., 2004). This revised description of MCI refers to subjective memory or cognitive difficulties (which are also verified objectively), unimpaired functional abilities, and the absence of a clinically diagnosable dementia (Bruscoli & Lovestone, 2004; Dubois et al., 2007; Frank & Petersen, 2008; Steenland et al., 2008; Winblad et al., 2004). It has been suggested that the MCI label should be applied if there is no disease to which MCI can be attributed (Dubois et al., 2007), however, it is not made clear in the recent definitions and revisions of the MCI criteria how physical health issues should be considered and whether a diagnosis of MCI is appropriate if the individual has a concurrent or underlying illness which

may influence their cognitive functioning. In the original definition of MCI, it is also unclear as to how comorbid and concurrent illnesses were approached in terms of diagnosing MCI. However, the control group criteria in Petersen et al. (1999) specifies that illnesses and treatments for these individuals did not interfere with their cognitive functioning, so it is assumed that this criterion would equally be applied to the MCI group. In this manner, MCI represents a more specific definition of cognitive impairment as a separate syndrome than previous attempts, with a more homogenous population identified by excluding individuals whose cognitive symptoms may be caused by an underlying physical health condition.

Despite MCI being used as a diagnostic term for the past decade in both research and clinical settings, there has long been a debate as to where the boundaries should be drawn between normal ageing, MCI and dementia, with most clinics and research centres relying on individual clinical judgement to make this distinction (Budson & Solomon, 2012; Portet et al., 2006). At present, no single test has been identified as a recommended tool for identifying MCI, though the most frequently used measure is the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). However, it has been suggested that this test lacks sensitivity in identifying individuals with MCI (Hodson & Keady, 2008; Levey et al., 2006) and researchers and clinicians alike are warned against over reliance on the MMSE (Cullen et al., 2007). There is a lack of standardisation with regards to screening tests and cut-off scores for cognitive impairment; consequently, there is variability in diagnostic methods and approaches (Clark et al., 2013; Stephan et al., 2013), resulting in the label of MCI being applied to a heterogeneous population.

The notion of individuals with MCI having unimpaired functional abilities has also been debated in recent years, with a shift towards viewing functional difficulties as acceptable in the criteria for MCI (Dean & Wilcock, 2012). It has been suggested that individuals with MCI may experience a loss of functional skills that is greater than would be expected in normal ageing, but less than the functional deficits observed in dementia (Wadley et al., 2007). However, there have been some notable concerns over this criterion change, as preserved functional abilities is one of the key dimensions that separates MCI from dementia with regards to diagnostic criteria. Morris (2012) warns that the inclusion of individuals with impaired functional abilities may result in people with early stage dementia being misdiagnosed as having MCI, resulting in those individuals not receiving the most appropriate support, treatment and information. Adding further confusion for diagnostic clinicians by altering the criteria for MCI to be more inclusive

could prove to be very problematic by increasing both false positives and false negatives, and serve to increase the heterogeneity of the MCI population.

1.1.8 Mild Neurocognitive Disorder (mNCD)

Recently, MCI has been formalised as a diagnostic code in the Diagnostic & Statistical Manual of Mental Disorders, 5th edition (DSM-V; American Psychiatric Association, 2013), under the label of mild neurocognitive disorder (mNCD), which lists the same criteria as the recent versions of MCI (Winblad et al., 2004; Albert et al., 2011); subjective and objective cognitive impairment and no dementia. However, mNCD differs slightly from the MCI criteria, with the stipulation that cognitive decline should be at a level whereby the individual has to utilise compensatory strategies to help maintain independence (Sachs-Ericsson & Blazer, 2015). As such, mNCD at present appears to be a definition which could be conflated with MCI as the only distinction between the two labels is the explicit reference to compensatory strategies in mNCD resulting in the two labels representing the same symptomology. Having two labels which ostensibly define the same syndrome could serve to increase confusion around cognitive impairment both amongst the general public and research and clinical professionals. Given the wide range of definitions and labels proposed over the past five decades, perhaps now is the time to focus on refining the criteria under one clear label, rather than developing new terms for a similar symptom set. It will be interesting to observe whether the label of mNCD gains the acceptance and support shown to MCI over the coming years.

1.1.9 Diagnostic Labelling of Cognitive Impairment

Early concepts surrounding cognitive impairment in older adults centred around normal ageing and cognitive decline which was seen as the result of the ageing process (BSF, AAMI, ACMI, LLF, ARCD and AACD). In recent years, attempts have been made to define a label and unified set of criteria to describe the experiences of people who have a cognitive impairment which is beyond that which would be expected for their age, and which does not meet the criteria for dementia. This highlights the drive to position cognitive impairment as an entity with a clear diagnostic label.

The multiplicity of terms presented over the past five decades highlights the pervasiveness of the set of symptoms presenting in adults developing a cognitive impairment, and also the notion of cognitive decline as a potential artefact of typical ageing. Table 1.1 (see p.19) shows how similar each different proposed syndrome is, and highlights the circularity of

the criteria suggested over time. However, as each individual with cognitive impairment will have a personal experience of what it is like to live with this, what symptoms they are most aware of, what impact the symptoms have on their life and so on, it is highly unlikely that any single clinical construct of cognitive impairment would incorporate every symptom or every possible outcome for an individual living with cognitive impairment. However, having a well-defined diagnostic that clinicians can use to help people understand their symptoms and which may be helpful in early pharmacological treatments or suggested lifestyle changes has obvious benefits.

Table 1.1: Components of cognitive impairment syndromes in chronological order

| Year | Term | Author(s) | Memory Impairment | Other Cognitive Impairment | Recommended Cognitive Test(s) | Impaired ADLs | Age Criteria |
|------|--|---|-------------------|----------------------------|-------------------------------|---------------|--------------|
| 1962 | Benign senescent forgetfulness | Kral | Yes | No | No | N/S | 60 + |
| 1982 | 0.5 Clinical Dementia Rating scale (Questionable dementia) | Hughes et al. | Yes | Yes | Yes (CDR) | Yes – mild | N/S |
| 1982 | Stage 3 Global Deterioration Scale | Reisberg et al. | Yes | Yes | Yes (GDS) | Yes – mild | N/S |
| 1986 | Age associated memory impairment | Crook et al. | Yes | No | Yes | N/S | 50 + |
| 1989 | Late life forgetfulness | Blackford & La Rue | Yes | No | Yes | N/S | 50-79 |
| 1989 | Age consistent memory impairment | Blackford & La Rue | Yes | No | Yes | N/S | 50-79 |
| 1992 | Mild cognitive disorder | World Health Organisation (ICD-10) | Possible | Yes | No | N/S | N/S |
| 1994 | Age related cognitive decline | American Psychiatric Association (DSM-IV) | Possible | Yes | No | N/S | Unknown |
| 1994 | Age associated cognitive decline | Levy | Possible | Yes | No | No | No limits |
| 1999 | Mild cognitive impairment | Petersen et al. | Yes | No | No | No | N/S |

| Year | Term | Author(s) | Memory Impairment | Other Cognitive Impairment | Recommended Cognitive Test(s) | Impaired ADLs | Age Criteria |
|-------------|------------------------------|--|--------------------------|-----------------------------------|--------------------------------------|----------------------|---------------------|
| 2004 | Mild cognitive impairment | Winblad et al. | Possible | Yes | No | No | N/S |
| 2013 | Mild neurocognitive disorder | American Psychiatric Association (DSM-V) | Possible | Yes | No | Yes – mild | N/S |

N/S = not specified, Yes = required in criteria, No = not required in criteria, Possible = can be present to meet criteria but not required specifically.

(table adapted from Collie & Maruff, 2002)

1.2 Current & Predicted Prevalence and Incidence of MCI

The differences in the methods used to identify people with MCI has led to this being an unstable or unreliable diagnosis, with individuals with MCI representing a heterogeneous population (Levey et al., 2006; Palmer, Musicco, & Caltagirone, 2010; Portet et al., 2006). There is a wide variability in observed prevalence rates for MCI, which may be as a result of differences in the population studied (community- vs. clinic-based sample), the age distribution within the sample, the sample size, prospective vs. retrospective diagnosis, alongside different diagnostic and assessment methods (different cognitive and neuropsychological measures). As a result, studies investigating prevalence and incidence rates of MCI find inconsistent results, ranging from 3-17% of individuals aged over 65 (Portet et al., 2006) and suggest different outcomes for individuals with MCI over time (Forlenza et al., 2010; Levey et al., 2006; Matthews et al., 2008; Mitchell & Shiri-Feshki, 2009; Palmer, Di Iulio, et al., 2010; Stephan et al., 2007). In a community based study, Petersen et al. (2010) found an overall prevalence of MCI of 16%, and it has recently been suggested that 11-17% of older adults (aged over 60 and 65) experience cognitive impairment (Krinsky-McHale & Silverman, 2013) which is approximately double that of dementia (Morris et al., 2001). It has also been suggested that the prevalence of MCI in the population increases with age (Lopez et al., 2003; Petersen et al., 2010), is higher amongst older adults who have never married and decreases with higher education levels (Petersen et al., 2010). Whilst the current prevalence and incidence of MCI is already high amongst older adults, this is set to increase considerably over the next 20 years. Using a predictive model, the Personal Services Research Unit estimated that by 2031, the number of individuals living with MCI or dementia in the UK will be over 850,000, representing an increase of 83% in the incidence of cognitive impairment from 2002 (Comas-Herrera, Wittenberg, Pickard, & Knapp, 2007).

1.3 Subtypes of MCI

Within the umbrella diagnosis of MCI, there are two main subtypes which have been identified: amnesic MCI (aMCI), which refers to memory related impairment, and non-amnesic MCI (naMCI), which refers to impairments in other cognitive domains, but not memory. Both of these subtypes are further divisible into multiple or single domain MCI, resulting in four key subtypes of MCI; amnesic MCI single domain (aMCI-SD) which refers to a sole impairment in memory, amnesic MCI multiple domain (aMCI-MD) which presents as a primary memory impairment, but also impairment in one or more other cognitive domains, non-amnesic MCI

single domain (naMCI-SD) which refers to a single impairment in a cognitive domain other than memory, and non-amnesic MCI multiple domain (naMCI-MD) which features an impairment in multiple cognitive domains, but no memory impairment (Albert et al., 2011; Bondi et al., 2008; Brambati et al., 2009; Gorelick et al., 2011; Petersen & Morris, 2005).

It has been suggested that these subtypes of MCI progress to different outcomes, with aMCI-MD usually progressing to Alzheimer's disease (AD) and vascular dementia (VaD) (Hodson & Keady, 2008; Rossi et al., 2007; Teng, Tingus, Lu, & Cummings, 2009), while individuals with naMCI-SD may be at an increased risk of frontotemporal dementia (FTD) (Rossi et al., 2007) but may also be the most likely to revert to unimpaired cognitive function (Bondi et al., 2008), and naMCI-MD most commonly progresses to a non-AD dementia (Bondi et al., 2008). However, studies report some variability in the outcomes for MCI subtypes, with one article suggesting that aMCI-SD and aMCI-MD may actually be differing stages of progression to AD (Brambati et al., 2009). Further research into the progression of MCI subtypes is required in order to identify whether these subtypes represent distinct entities or whether they represent varying stages of a more unified concept. The four subtypes of MCI and the most likely outcome for each subtype is highlighted in Figure 1.1 showing the variability of prognoses following a diagnosis of MCI.

Despite the potential utility of these subtypes of MCI, for identifying individuals at risk of progression to certain dementias, numerous difficulties have been acknowledged with regards to making a differential diagnosis by subtype. For example, it has been shown that inconsistent use of neuropsychological tests (Hodson & Keady, 2008; Lonie, Herrmann, Donaghey, & Ebmeier, 2008) and failing to appropriately quantify all cognitive domains (Bondi et al., 2008) could lead to inaccurate subtype classification. There has also been discussion as to whether subtyping MCI adds anything to the diagnosis, as MCI subtypes have been identified as being unstable over time (Bondi et al., 2008; Matthews et al., 2008). Whilst characterising MCI by subtype may enable us to identify people most at risk of progressing to certain types of dementia a consensus agreement around how to make a diagnosis by subtype must first be established, particularly with regards to identifying cognitive tests which can assist in making a differential diagnosis. Being able to provide diagnoses by subtype will enable the provision of more comprehensive and detailed prognostic information for individuals who are diagnosed with cognitive impairment.

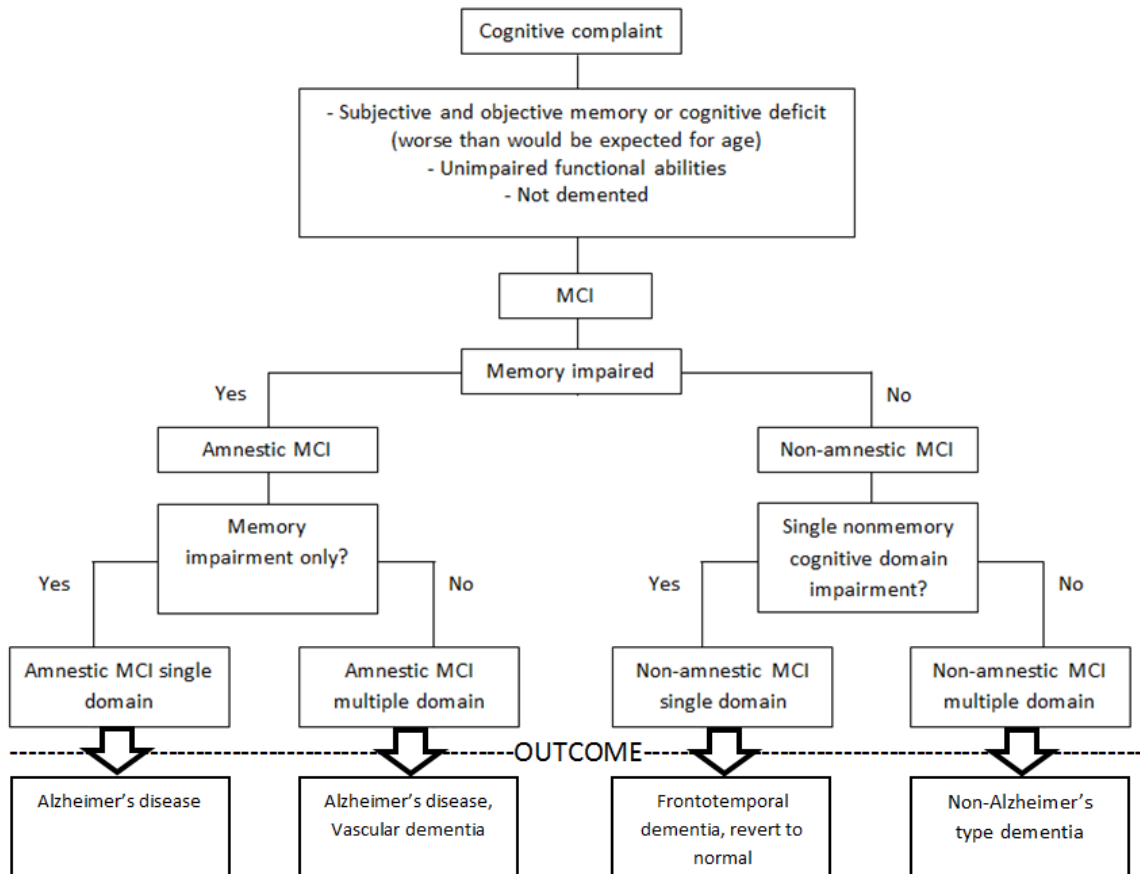


Figure 1.1: Flowchart outlining MCI subtypes and potential outcomes (adapted from Petersen & Morris, 2005)

With the apparent lack of consensus within clinical and research settings regarding MCI subtypes, how to classify them and what the prognosis is for each subtype, it is clear that subtyping MCI at this stage is likely only to add to the confusion and ambiguity around MCI for individuals in receipt of a diagnosis and their families. If subtyping MCI is to hold any clinical utility in the future, it is imperative that appropriate cognitive, neuropsychological or biomarker tests are identified which can facilitate differential diagnosis with a much higher degree of certainty than is currently available. It is also essential that future research seeks to explore the outcomes and prognosis for individuals with MCI with regards to how the different subtypes progress and what this may mean for individuals. It is also important to note that the DSM-V code of mNCD does not consider subtypes, though subtypes are evident for the code of major neurocognitive disorder (the term used to replace “dementia or other debilitating conditions” from the previous edition of the DSM), highlighting the lack of consensus around subtyping MCI. Ultimately, until subtyping is able to offer more detailed information, this certainly appears to be something which should be reserved for research purposes rather than utilised clinically, as providing different subtype labels may only serve to increase confusion around MCI rather than providing any clarity to individuals in receipt of a diagnosis.

1.4 MCI as a Diagnostic Label

Whilst MCI has been used as a diagnostic label in both clinical and research settings, the lack of recommended treatment options available for individuals with MCI and the lack of prognostic information available has raised concerns as to whether MCI is an appropriate clinical diagnostic term (Petersen, 2004). To date, there has been little research conducted which aims to investigate how individuals react to receiving a diagnosis of MCI and the impact of experiencing cognitive difficulties (Mattsson, Brax, & Zetterberg, 2010). It has been suggested that people who are given a diagnosis of dementia often feel a sense of relief (Carpenter et al., 2008). The literature that is available suggests that being given a diagnosis of MCI does not provide the same relief experienced by individuals who are diagnosed with dementia, as there are so many questions that remain unanswered following an MCI diagnosis (Banningh, Vernooij-Dassen, Rikkert, & Teunisse, 2008). Some individuals perceive a diagnosis of MCI as ambiguous and this can result in people worrying about the underlying cause of their cognitive difficulties (Dean & Wilcock, 2012). Studies have also suggested that individuals given a diagnosis of MCI often feel confused and face prognostic uncertainty (Dean & Wilcock, 2012; Garand, Lingler, Conner, & Dew, 2009; Lingler et al., 2006).

With the publication of the DSM-V, the diagnostic code of mNCD has been introduced, which lists similar criteria to MCI and formalises this diagnosis. This is something which has been supported by several key figures in the field of cognitive impairment. Petersen & O'Brien (2006) argued for the inclusion of MCI as a diagnostic class and believe that codifying MCI within the DSM-V would prove beneficial to both researchers and clinicians by ensuring a unified diagnostic definition of the syndrome and thus reducing the heterogeneity of the MCI population. Similarly, Blazer (2013) supported the inclusion of MCI in the DSM-V, highlighting the fact that individuals diagnosed with MCI are often comforted to have clinical recognition of their concerns, and having a codified diagnostic class would enable this to become more common place in clinical practice. However, what has not been addressed in the literature to date is the notion of adding yet another label and another term to the cognitive impairment field. With the inclusion of mild neurocognitive disorder, this marks another advance from what began over 50 years ago with Kral's (1962) BSF and heralds yet another attempt to label the level of cognitive impairment that is below that of dementia but beyond the expectations and norms of typical ageing. To date, there have been so many different labels and terms proposed for cognitive impairment that it is confusing to the educated reader let alone for someone who is actually experiencing cognitive impairment. Given that people already experience confusion and uncertainty on receipt of a diagnosis of MCI (Dean & Wilcock, 2012; Garand et al., 2009), adding additional terms and labels to an already disarrayed situation is likely to only exacerbate this confusion. It has been suggested that future research should seek to explore the public's perceptions of MCI in order to facilitate the development of language which can effectively communicate knowledge about cognitive impairment and ensure that people are able to discuss this with less uncertainty and confusion (Anderson, Day, Beard, Reed, & Wu, 2009). If we are able to establish a consensus regarding the label and diagnostic criteria employed when discussing cognitive impairment, this would hopefully engender a greater sense of confidence around what cognitive impairment is, and potentially provide a more homogenous population for future research and monitoring.

Alongside the clinical labels that have been proposed for cognitive impairment, it is also likely that lay concepts will have developed which people use to talk about cognitive impairment outside of the clinical terminology, or that the clinical terminology is being used with a lay perspective of what the term means, that is, they are used in a way that is distinct from the context in which they were developed (Boyle, 2002). In this way, the general population may hold views and perspectives about cognitive impairment which differ considerably from the

clinical or research definition of the term in question. People living with cognitive impairment will also have a unique experiential perspective about cognitive impairment which may differ from the clinical representation. This is due to the nature of cognitive impairment as a syndrome, rather than a clearly defined disease. A syndrome can be defined as a particular pattern of symptoms, or a clustering of symptoms and signs (Boyle, 2002). As such, people who receive the same diagnostic label for the presenting syndrome of cognitive impairment will generally share at least one symptom but will differ in their range of symptoms as the experience of cognitive impairment is so unique. Added to the heterogeneity of the population of individuals diagnosed with MCI (due to the lack of standardised tests and clear operational diagnostic criteria) this variability of experience could result in MCI being construed on a very individualised level. However, this uniqueness of experience does not mean that cognitive impairment cannot have more clearly defined clinical criteria, as people living with dementia have a similarly unique experience (Kitwood, 1997) but this does not detract from the applicability of the clinical dementia criteria. As such, understanding how people experience cognitive impairment is key to informing refined criteria for MCI but including every possible presenting symptom within the diagnosis is not necessarily the answer.

1.5 Progression from MCI to Dementia

It has been suggested that MCI may represent a transitional stage between normal ageing and early stage dementia (Brooks & Loewenstein, 2010; DeCarli, 2003; Petersen & Morris, 2005), thus individuals experiencing cognitive difficulties (symptoms of MCI) have been identified as a population at an increased risk of developing dementia (Serrano, Rojas, & Allegri, 2011). Whilst it has generally been agreed amongst researchers and clinicians alike that individuals with MCI are at an increased risk of developing dementia compared to the general population (Bondi et al., 2008; Kaduszkiewicz et al., 2010; Rogalski et al., 2009), the exact details of who is most at risk and how to identify these people remains unclear (Matthews et al., 2008; Palmer, Musicco, et al., 2010; Ringman et al., 2009; Stephan et al., 2007). Studies which have explored progression from cognitive impairment to dementia have found varying rates of progression, with an average of 10-15% per annum (Farias, Mungas, Reed, Harvey, & DeCarli, 2009; Petersen et al., 2005, 2009; Petersen et al., 2001), a greatly increased rate of dementia development compared to 1-2% per year observed in older adults without cognitive impairment (Petersen et al., 2005). However, individuals who have been diagnosed as experiencing cognitive difficulties will not all definitely progress to dementia, as some individuals will remain

stable over time, and some will regain normal cognitive functioning (Patel & Holland, 2012). This is particularly evident in community studies, where the reversion rate from cognitive impairment to unimpaired is as high as 40% (Brooks & Loewenstein, 2010). Annual progression rates vary considerably across different studies, with community studies generally showing lower levels of progression than clinic based studies. For example, one article investigating MCI prevalence and progression in community dwelling individuals in France found that, over 4 years, 6.6% of individuals with MCI progressed to dementia, resulting in an average annual progression rate of 1.65%. This is considerably lower than the 10-15% per year estimate from clinical samples. Whilst the majority of progressive cases in this study developed AD, around a third of people progressed to other dementias, including VaD and DLB. It is also important to note that the majority of MCI cases (63%) did not return to normal functioning, providing support for the notion that MCI is a valid diagnostic construct (Artero et al., 2008).

A recent clinic based study monitored people with aMCI, conducting a comprehensive battery of neuropsychological testing annually over a 4-year period (Lonie et al., 2010). Over the course of the study, 41% of participants progressed to dementia with an average annual progression rate of 10%. Of those individuals who had not received a diagnosis of dementia by the end of the study; 18% remained stable and 18% had returned to normal cognitive functioning. 23% of the participants were defined as being “progressive” but had not received a diagnosis of dementia by the end of the study (Lonie et al., 2010). This suggests that individuals with MCI represent a population at an increased risk of developing dementia and may present an important research avenue for identifying predictive factors of dementia. Mitchell & Shiri-Feshki (2009) conducted a meta-analysis of 41 studies investigating the rate of progression to dementia from cognitive impairment and found an overall annual progression rate of 5-10%, highlighting that MCI is not a unified disease, but rather represents a heterogeneous concept.

1.6 MCI as an “At Risk State”

Identifying individuals who may be at an increased risk of developing dementia has been highlighted as a focus in both clinical and research settings, as it allows for potential preventative treatment to be provided which may ameliorate or halt progression to dementia. As such, MCI has been considered, by some, to be prodromal due to the increased risk of dementia this syndrome may confer. MCI is certainly not unique in its status as a potential “at risk state” for a more serious condition. In the field of psychosis, there has been an interest in identifying people who may be at an elevated risk of developing psychosis. These individuals are termed

as experiencing an “at risk mental state” (ARMS; Broome et al., 2005; Mason et al., 2004; Yung et al., 1996). ARMS refers to individuals who are exhibiting symptoms such as attenuated psychotic syndrome, a brief psychotic episode with a duration of under one week, or a trait vulnerability resulting from a first degree relative with a psychotic disorder together with a decline in mental functioning which suggest a risk of psychotic disorder (Yung et al., 2003). In contrast to MCI, ARMS is not considered to be a diagnostic construct, but a term which is used within both clinical and research settings to identify people who are at risk of potentially developing psychosis. Much like MCI, ARMS implies a high, but not inevitable risk state, with some individuals recovering from their symptoms whilst others develop a psychotic disorder (Yung et al., 2005). It is interesting to explore the apparent similarities and differences between ARMS and MCI, as they are two seemingly very similar states, both conferring an increased, but not definite, risk of developing a more serious condition (either dementia or psychosis), and yet they are treated very differently. Whilst MCI (under the label of mNCD) has recently been included as a diagnostic class within the DSM-V, ARMS was suggested for inclusion, but met strong criticism from clinicians and researchers alike who argued that it would be inappropriate to cite ARMS as a diagnostic class due to an inherent lack of effective and recommended treatment (Carpenter, 2009) and potential stigma resulting from being diagnosed as “at risk” of psychosis (Yang, Wonpat-Borja, Opler, & Corcoran, 2010). The same concerns could be expressed for MCI, and yet this syndrome has been included as a diagnostic class despite the potential for similar issues to arise. It is clear that, for both of these “at risk” states, there is much work to be done to fully understand what the risk state labels may mean to individuals who are diagnosed as such, or whether these are syndromes whereby diagnostic disclosure is the best option or not. If there are no effective treatments, no clear prognostic pathway, and the chance of stigma is high, should we really be providing a diagnosis of MCI to individuals? It is clear when looking at the reactions of individuals in the field of psychosis to the proposed inclusion of ARMS that there is much to be considered when providing a diagnosis of being at risk, and further research exploring how a diagnosis of MCI is understood and experienced is imperative, not just for the field of dementia and cognitive impairment, but also to share lessons and learning within the field of psychosis.

1.7 Policy and Practice Around MCI

Given the impact of dementia on people’s lives, this has become the focus of a number of key policies, particularly in the UK with the introduction of the national dementia strategies

and plans in England (Department of Health, 2009), Scotland (The Scottish Government, 2010), Wales (Welsh Assembly Government, 2011) and Northern Ireland (Irish Department of Health Social Services and Public Safety, 2011) and the Prime Minister's Challenge on Dementia (Department of Health, 2012). These national policy documents formalise a number of key challenges and aims for the future of dementia care and research, but there is little to no mention of MCI in any of these documents. There are tenuous links to MCI, with the Prime Minister's Challenge on Dementia (Department of Health, 2015) referring frequently to the importance of reducing the risk of developing dementia, and progressing towards prevention of dementia, so in terms of MCI potentially representing an at risk population, the focus of prevention could well be placed in this direction. It is also addressed as one of the key aspirations within the recent challenge document that the government wish to see improved public awareness with regards to the risk of dementia, and how healthy living may be able to reduce this risk (Department of Health, 2015). However, if the government are seeking improved public awareness of dementia risk, then it would seem prudent to start discussing the potential "at risk state" of MCI and ensuring that people are aware of what this syndrome means.

To date, there is a clear lack of MCI within key policy documents, and guidance around how to best consider and deal with MCI is sparse. In the National Institute for Health and Care Excellence (NICE) guidelines for dementia (National Institute for Health and Care Excellence, 2006), there are three direct references to MCI. Firstly, it is advised that primary care staff should refer individuals who exhibit symptoms of MCI for secondary assessment within a specialist service, to assist with early identification of dementia due to heightened risk within this population. Secondly, it is suggested that services which identify people with MCI should offer subsequent follow-up and monitoring in order to identify signs of possible dementia and enable care to be planned at the earliest possible stage. Finally, the guidelines state that there are no pharmacological treatments which are currently recommended for individuals with MCI. The recommendations outlined in the NICE guidance highlight the importance of MCI within clinical practice in terms of monitoring individuals for their risk of dementia. This sentiment was echoed in a recent European-wide study on guidance for timely diagnosis of dementia in which the importance of structured systems for follow-up and monitoring of individuals diagnosed with MCI was highlighted (Brooker, La Fontaine, Evans, Bray, & Saad, 2014). At present, individuals diagnosed with MCI in the UK are generally discharged from services without a

defined monitoring system in place, contradicting the NICE guidance and European recommendations (Brooker et al., 2014; National Institute for Health and Care Excellence, 2006).

To date, MCI has not been a particular focus of guidance and policy, but given the high prevalence of MCI in the population, this is something which needs to be addressed in future revisions. However, perhaps the first key issue to be considered is the question of the diagnostic label and criteria that is applied to this syndrome. If we are to begin to address how we support individuals with MCI, it is imperative that the same label is used across the population so that there is a unified topic under discussion. If some people elect to start utilising the DSM-V code of mNCD, while others choose to continue with the MCI label, there is likely to be some confusion about what is being discussed. Given the apparent heterogeneity of MCI, and the confusion that this label can provoke amongst researchers, it is highly likely that this confusion and ambiguity around what is meant by the terms MCI or “cognitive impairment” is also prevalent amongst the general population, further highlighting the need to explore what individuals understand and know about MCI, and what language and labels people choose to employ when discussing cognitive impairment.

1.8 Knowledge and Understanding of Cognitive Impairment

Currently, there appears to be a lack of knowledge about MCI in the general population, with a recent study reporting that people living with subjective memory concerns and their family members believed that their presenting symptoms were a part of normal ageing, not recognising or acknowledging that their cognitive decline could be atypical (Jones, Mackell, Berthet, & Knox, 2010). Jones et al. (2010) also found that people were likely to attribute their cognitive difficulties to other medical conditions, believing that the symptoms they were noticing were not a real cause for concern as they were part of a pre-existing illness or condition. As such, people delayed contacting their family doctor for almost a year after first becoming aware of their symptoms, potentially delaying access to relevant treatments and interventions which may be available to them. The results of this study highlight the importance of exploring people’s knowledge and understanding of MCI in order to clarify what cognitive changes or symptoms would be considered to warrant assessment by a healthcare professional in order to facilitate timely diagnosis.

1.9 Summary of the Literature

It is clear that the set of symptoms referenced as MCI represents a prevalent syndrome, something which a large proportion of adults will experience. MCI is also a potential risk factor for dementia, with people living with MCI at an increased, but not certain, risk of developing dementia. MCI is a concept which continues to develop as more research is conducted, being adapted to incorporate new information and advances. However, whilst MCI is a concept which has received a lot of attention in the academic research field, the clinical utility of this label is still contested (Garand et al, 2009). Cognitive impairment as a diagnostic label has been shown to result in feelings of confusion and uncertainty (Banningh et al, 2008, Dean & Wilcock, 2012, Garand et al, 2009). This confusion is likely to be in part due to the lack of prognostic certainty around MCI and highlights a need for future research which can fill some of the existing gaps in the knowledge base around MCI. With the vast number of labels and concepts proposed to account for a fundamentally similar set of presenting symptoms, there is yet to be a label and definition which is universally accepted by researchers and clinicians as an adequate description of the presenting symptoms. The investigation of how people understand and view MCI as a diagnostic label warrants further exploration as it has been suggested that future research should seek to explore the public's perceptions of MCI to facilitate the development of language which can effectively communicate knowledge and advances in this field to the wider population (Anderson et al, 2009).

1.10 Aims

Given the apparent confusions around MCI it is clear that further research is needed to identify what people know about this syndrome and whether the label of MCI is appropriate and acceptable to the wider population. One of the areas that I was keen to explore in this thesis was individual knowledge, views and perspectives about cognitive impairment. As such, I felt that considering cognitive impairment from a health psychology perspective would enable me to identify how cognitive impairment is situated as an illness or health condition, taking into account how people understand cognitive impairment in the context of physical and mental health. To date, literature exploring views and understandings of cognitive impairment has focused primarily on the perspectives of people living with MCI, their carers, and clinicians (see Chapter 3). Thus, this thesis aimed to explore whether different groups of individuals, who may have access to different information resources and different personal experiences of MCI, have

different perspectives and knowledge of this. As such, I aimed to explore the views of six core populations:

- 1) Individuals living with cognitive impairment
- 2) Supporters and care partners of people living with cognitive impairment
- 3) Older adults without cognitive impairment
- 4) Younger adults without cognitive impairment
- 5) Healthcare professionals working with older adults
- 6) Specialists in dementia (academics, researchers, trainers and healthcare professionals with specific dementia expertise)

I felt that including these individuals would enable the research to investigate the views of a range of populations who would all benefit from an understanding and awareness of cognitive impairment (see Chapter 2 for further details). In particular, I felt that an investigation of the labels and terminology that individuals employ when discussing cognitive impairment was warranted in order to develop a better understanding of what language is deemed appropriate and acceptable by different groups of individuals. I was keen to identify where there may be shared languages or clear divisions and miscommunication in the languages used by different people. Understanding where language converges and differs across participant groups will enable the development of information resources which are presented in a unified language, facilitating unambiguous, clear and consistent conversations about cognitive impairment, reducing some of the current confusion and uncertainty. Identifying the knowledge of different individuals and populations will also enable the development of tailored information to address the needs of each population specifically.

1.11 Research Questions

Considering the core aims of this thesis, the research questions that I wanted to explore were:

1. What do different population groups understand about MCI and cognitive changes?
2. What language and terminology do various participant groups use in relation to MCI and cognitive changes?

Chapter 2: Methodological Approach

2.1 Introduction

This chapter provides an overview of the methodological approach adopted for this thesis and provides justification and reasoning for the use of a mixed methods approach and a critical realist stance. I will outline the rationale for my choices regarding methodology and provide an overview of the overarching methodological issues and considerations for this thesis. The specific methods utilised across the three research studies included in this thesis – a systematic review, questionnaire study, and interview study – are detailed in chapters 3, 5 and 6 respectively.

2.2 Mixed Methods Research

Mixed methods research is defined as:

“the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration” (Johnson, Onwuegbuzie, & Turner, 2007, p.123)

Mixed methods research is often referred to as the third research paradigm, sitting alongside, and encompassing, qualitative and quantitative research. The goal of mixed methods research is to utilise the respective strengths of both methodologies, whilst also minimising the weaknesses inherent in these methodological approaches (Johnson & Onwuegbuzie, 2015). Whilst it has frequently been argued that the two methodologies are too distinct to be compared or combined, at their core both qualitative and quantitative methods are concerned with describing data and subsequently developing theories and arguments to explain the results obtained (Sechrest & Sidani, 1995). It is not really possible or plausible to suggest that any methodological paradigm is superior to any other, and there will always be situations and circumstances whereby each paradigm will be the best fit for the research question. It is important that researchers have the freedom to explore and utilise the methodological approach which is most applicable to their research (Johnson & Onwuegbuzie, 2015). Teddlie & Tashakkori (2011) suggest that mixed methods research enables what they term “methodological eclecticism” (p.285). This refers to the freedom of choice afforded to

researchers using a mixed methods approach to select the best possible methods to answer research questions. However, the best approach may be a solely quantitative or qualitative approach, and so mixed methods are not always the optimum choice of all researchers (Teddlie & Tashakkori, 2011).

Ultimately, mixed methods research enables the researcher to generate both broad and in-depth data, exploring both the what (quantitative data) and the how (qualitative data), and to utilise qualitative and quantitative data to provide a detailed and comprehensive analysis and exploration of the topic (Creswell & Plano Clark, 2004). In this sense, a mixed methods research approach has a benefit over either a qualitative or quantitative approach alone by facilitating the combination of views and findings from both approaches.

Greene, Caracelli, & Graham (1989) highlight five key reasons for considering mixed methods research, each of which is addressed in turn here:

I. Triangulation

This relates to looking for convergence and corroboration of results from different methodologies, enabling the results of both quantitative and qualitative research to be drawn together (Östlund, Kidd, Wengström, & Rowa-Dewar, 2011). The mixed methods approach in this study facilitated the corroboration of the findings from the questionnaire phase of the research via the semi-structured interviews. In this way, the research ensured that the broad evidence from the nationwide questionnaire was supported by more in-depth and focused interviews, thus supporting the generalisability of the overall research findings.

II. Complementarity

Complementarity refers to seeking elaboration and expansion of the results of one method by incorporating the results of another method. In terms of complementarity in this thesis, the interview data facilitated elaboration of the quantitative results obtained from the questionnaire, as well as enabling the depth of information obtained from the qualitative study to be compared with the breadth of information from the questionnaire results. In this way, a mixed methods approach facilitated an overview of the generalisability of the study results.

III. Development

This involves using the results from one study to inform the design of another. Development was one of my key motivations for using mixed methods research, as it enabled each phase of the study to inform the design of the subsequent phase, with the results of the systematic review informing the development of the questionnaire, and the results of the questionnaire determining the interview schedule. Development within the research design also ensured that the study was informed and guided by the views of participants, thus enabling participants to be active contributors to the research. Considering participants' views in this manner, allowing the design and development of the research to be participant led is of particular importance when undertaking research with a health behaviour focus as participant's own views are at the heart of this.

IV. Initiation

Initiation refers to finding questions and contradictions that require clarification, thereby initiating a new study or re-framing the research questions. Similar to the notion of development, initiation was viewed as a benefit of using a mixed methods approach in this study. Once each phase of the research was complete, the results enabled identification of any questions requiring clarification or further exploration. In this way, each phase of the research was informed by the preceding phase, ensuring that the study was an iterative process.

V. Expansion

This relates to expanding the breadth and range of research by using different methodological approaches for different research questions. Using mixed methods enabled this thesis to encompass a range of research questions, all focused around a central topic, ensuring that breadth and depth of understanding were taken into consideration. Considering both a broad and detailed view was imperative to this thesis as I was aiming to investigate an area which had not been explored as a focus previously, meaning that neither the breadth or depth of information and data had been captured before.

2.2.1 Current Research

The key aims of this thesis were to investigate people’s current understanding and knowledge of cognitive impairment, and the language and terminology people use to discuss this. As such, I selected a mixed methods approach with each phase of the research being completed sequentially (one after the other). By combining a quantitative questionnaire to provide a breadth of knowledge, with a qualitative research phase involving semi-structured interviews to gain a detailed exploration of individuals’ knowledge and understanding of cognitive impairment, the research was able to obtain a broad and in-depth exploration of the research questions. A mixed methods approach also ensured that the research was an iterative process, with each phase of the study informing the design of the subsequent phase. Similar studies employing mixed methods to investigate knowledge and understanding of dementia have been conducted (McParland, 2014).

2.3 Critical Realism

Prior to commencing any research activities for this study, I was careful to explicitly consider my ontological and epistemological stance as this guided all aspects of the research, including design, analysis and write-up. Epistemology is concerned with the nature of knowledge, and how knowledge can be understood as meaningful, while ontology is the branch of philosophy concerned with the nature of reality, specifically the relationship between the world and human interpretations (Braun & Clarke, 2013). There are three key ontological positions that researchers can hold, which can be conceptualised as being located along a continuum (Figure 2.1).

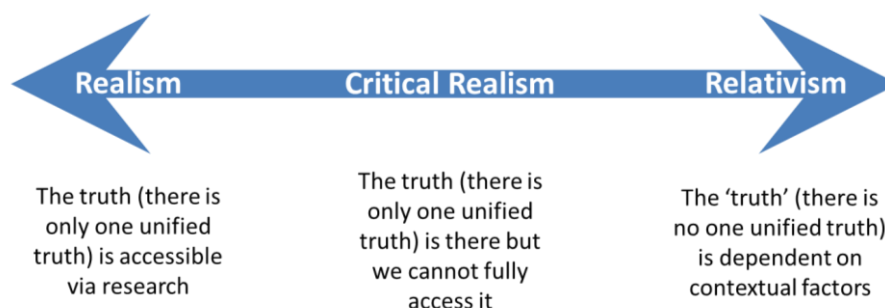


Figure 2.1: The continuum of ontology, outlining the three key ontological stances (adapted from Braun & Clarke, 2013, p.26)

Realism is an ontological stance that assumes there is one singular truth which can be accessed via research. Realism assumes that what is observed in research is a carbon copy of this single truth (Braun & Clarke, 2013). At the other end of the ontology continuum, and in direct contrast to realism, lies relativism. This stance suggests that there are multiple realities, rather than one single, observable truth. Relativists posit that what is 'true' is wholly dependent on contextual factors, so what an individual knows reflects how and where their knowledge was generated (Raskin, 2001). In the middle of these two opposing ontologies sits critical realism. This position views knowledge as socially influenced, but acknowledges that there is a universal truth which exists that research can only ever partially uncover due to the influences exerted on individuals affecting their perception of the truth (Braun & Clarke, 2013).

In this thesis I elected to adopt a critical realist position as I felt this was the most appropriate for the methodological approach and it was also the stance which I felt most comfortable with as a consideration of how people develop their knowledge of the world and thus develop an understanding of health conditions including cognitive impairment. This philosophical stance combines a realist ontology with a constructivist epistemology, embodying the notion that our knowledge of the world is our own construction, and thus there is no way that a wholly objective account of the world could be produced or discovered as all knowledge is influenced by perspective (Maxwell, 2012). Critical realism provides an appropriate paradigm in which to conduct mixed methods research as it acknowledges the philosophical perspectives of both quantitative research and qualitative research. Critical realism encompasses the somewhat positivist stance inherent in quantitative studies in recognising that there is a real world which exists independently of our own beliefs, but tempering this with the qualitative notion that this real world cannot fully be accessed by research due to the diverse range of perspectives and understandings held by individuals as a result of their constructions of knowledge. Critical realism "affirms key realist premises whilst relaxing the strict ontological commitments of theories and methods" (Modell, 2009, p.218). In this way, critical realism offers the opportunity to incorporate a variety of theories and methods in the production of data and in obtaining the views and knowledge of participants (Modell, 2009). Critical realism does not commit to a single methodological approach but supports a range of qualitative and quantitative methods enabling what is known as "critical methodological pluralism" (Zachariadis, Scott, & Barrett, 2013). As the current study was concerned with individuals understanding and knowledge of cognitive impairment, taking into account the fact that people will have different knowledge due to the different ways in which they have constructed their understanding is

essential. The experience of people living with cognitive impairment is influenced by the context in which they live alongside a variable degree of symptomology that may change over time.

It is important here to note that cognitive impairment can be considered through a social constructivist perspective. Under this lens, cognitive impairment can be viewed as a condition which, whilst potentially resulting fundamentally from a physiological basis, is impacted and affected by multiple social factors, including the overarching societal perspective of cognitive impairment, and the relationships and interactions that an individual living with cognitive impairment has with other people. According to this perspective, the way in which every person living with cognitive impairment experiences this will be impacted by a range of social aspects, and the way in which their symptoms present may also be impacted to some degree by social factors. As such, it is important to ensure that people are able to understand and make sense of their cognitive impairment in order to minimise any negative or detrimental impacts of these social factors on the individual. If society hold a positive view of people living with cognitive impairment, and there is an increased awareness and understanding of cognitive impairment, then it may be possible for social aspects to have a positive impact on people living with cognitive impairment and thus potentially make the lived experience of cognitive impairment a more positive situation. The social constructivist view of cognitive impairment also suggests that cognitive impairment may be interpreted differently across individuals and populations as it is not solely defined by its physiological aspects alone; the social factors surrounding cognitive impairment may affect how this is viewed and understood.

2.4 Reflexivity

As this study aims to explore individuals understanding and knowledge of cognitive impairment, the research will focus on individuals' constructions and views of what cognitive impairment is and whether these constructions differ between and within participant groups. Constructivist philosophy suggests that:

“concepts and theories are constructed by researchers out of stories that are constructed by research participants who are trying to explain and make sense out of their experiences and/or lives, both to the researcher and themselves. Out of these multiple constructions, analysts construct something they call knowledge.” (Corbin & Strauss, 2008, p10).

Thus, I felt it was essential that I adopted a reflective approach to the research, exploring ways in which my actions and understandings may impact on the research process and results. The research design for this study enabled me to adapt the key lines of enquiry according to the perspectives of participants and the views and constructs delineated in the literature. A crucial aspect of the critical realist philosophy is that knowledge is never certain and can always be amended or altered with the discovery or addition of new evidence (Maxwell, 2012). I felt that the critical realist stance enabled consideration of my perspectives as a researcher, considering how my own experiences may impact on my interpretation of participants' accounts provided in interviews and how my perspectives informed the design of the questionnaire and interview schedule.

In considering my views and perspectives about cognitive impairment and dementia, I felt it was important to explore my own previous personal experiences of dementia. In 2014 my grandfather passed away after a short-lived diagnosis of dementia. This experience has impacted my own feelings about dementia, as this was the first time that it touched my own life in a very personal manner, and living through the experience of my grandfather not being able to recognise me or my mother, and losing the ability to communicate verbally was something that was very upsetting. Given the recent nature of this experience, I am very aware that this has shaped my views and perspectives of dementia as a cruel condition, something which ultimately stole my grandfather from me and my family and which devastated my mother and her siblings as they watched their father slip away from them, first cognitively and then physically. Assessing my own feelings about this experience enabled me to ensure that my own personal views would not impact on this research and I was conscious to not let my own feelings impact the questions that I asked participants in either the survey or the interviews.

2.5 Design

In order to address the research questions fully, three key phases of research were undertaken: a systematic review, a quantitative questionnaire, and a qualitative study using semi-structured interviews. The research followed a sequential design with each phase being completed prior to the commencement of the subsequent phase (see Figure 2.2). The first phase of the research involved a systematic review of the literature relating to knowledge and understanding of MCI (see Chapter 3). The quantitative phase of the research employed a questionnaire which could be completed on paper and posted or online (see Chapter 5).

Following this, a small sample of individuals who participated in the questionnaire phase of the research were invited to take part in a semi-structured interview (see Chapter 6).

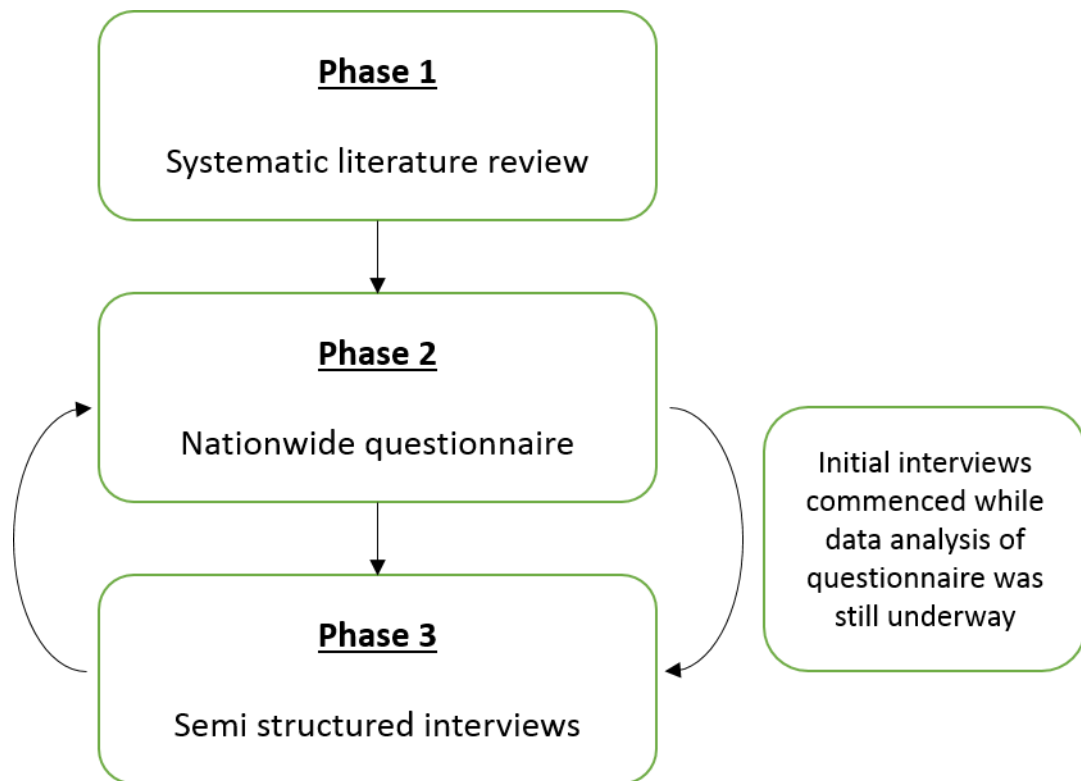


Figure 2.2: Flowchart showing research phases and workflow of the study.

Whilst the sequential design of the research was followed as planned, there was some overlap between the phases and it was not a clean linear process. For example, the data from the questionnaire were still being analysed when the first interviews began. This promoted an inductive approach to the data, as I was immersed in the results of the questionnaire when conducting the first interviews thus the data was fresh in my mind and informed my interview questions. In this way, the overlap of the phases helped me to reflectively combine the data from each phase in a very active manner.

2.6 Participants

2.6.1 Multiple Perspectives

To date, the literature exploring perspectives and knowledge of cognitive impairment have tended to focus on the views of people living with MCI, their family carers and, to a lesser extent, clinicians (see Chapter 3). As such, research findings are limited and may not be relevant

to, or representative of, particular groups, resulting in information resource design which may not meet the needs of other relevant populations. If we are to produce information resources and campaigns to raise awareness of MCI and encourage people to present for more timely assessment and help, then it is important that we understand the knowledge and views of people who are not currently experiencing cognitive impairment as well as those who are. Only by incorporating multiple perspectives can we develop information which is appropriate to the variety of populations who may require access to relevant information. Exploring the views of a wide range of people will enable the development of tailored information to address the needs of people living with a diagnosis of MCI and their families, and raise awareness of the condition potentially reducing stigma and promoting a more positive societal view of MCI.

Participants were recruited into six groups for the purposes of this research:

- (1) people experiencing cognitive difficulties;
- (2) supporters and care partners of individuals experiencing cognitive difficulties;
- (3) older adults without cognitive impairment;
- (4) younger adults without cognitive impairment;
- (5) healthcare professionals working with older adults;
- (6) dementia specialists (academics, researchers, trainers and healthcare professionals with specific dementia expertise).

2.6.1.1 Individuals experiencing cognitive difficulties

I felt that it was imperative to include people living with cognitive impairment in the research, as it is these individuals who are best placed to comment on the terminology and language that they have experienced around cognitive impairment and how they have understood and interpreted this. Gaining the views of this group of participants enabled an exploration of what terms people living with cognitive difficulties had heard during their assessment and diagnosis process, whether “mild cognitive impairment” is an ambiguous or confusing label and how individuals viewed this as a diagnosis. This group were also able to share their understanding of cognitive impairment and how they understood this from a personal, expert perspective.

The inclusion criteria for this group were:

- Aged over 18

- Recent cognitive assessment resulting in confirmed cognitive difficulties (labelled as MCI or an equivalent term), conducted in the last 6 months.
- No evidence of a clinically diagnosable dementia
- Self-identify as experiencing memory and thinking difficulties

2.6.1.2 Supporters and care partners of individuals experiencing cognitive difficulties

Similarly to the group of individuals experiencing cognitive difficulties, I felt that it was important to include this group of individuals in this study as they had personal experience of how cognitive impairment can impact on an individual and their wider social network. This group were able to comment on how they understood and experienced the language and terminology used by different groups of people to discuss cognitive impairment, including identifying the language that they felt most comfortable with.

The inclusion criteria for this group were:

- Aged over 18
- Actively involved with a family member or friend who has confirmed cognitive impairment
- No diagnosis, or known evidence, of cognitive impairment or dementia

2.6.1.3 Older adults without cognitive impairment

I felt that obtaining the opinions of this group of participants was key to understanding awareness of cognitive impairment amongst the population who are most likely to be alert to, and potentially fearful of and at risk of, cognitive difficulties. This group was also able to share their experiences of witnessing friends, family members and their peers be given a diagnosis of cognitive impairment and so were well placed to speak about how they understood the symptoms and diagnoses in their friends and families and how these experiences shaped their concept of what cognitive impairment is.

The inclusion criteria for this group were:

- Aged over 65
- No diagnosis, or known evidence, of cognitive impairment or dementia

2.6.1.4 Younger adults without cognitive impairment

Involving younger adults in this research is key to understanding awareness of cognitive impairment amongst a group of individuals who may be well placed to recognise cognitive difficulties in older relatives, and it is also this group of individuals who will be facing the risk of developing cognitive impairment as they age. It is therefore vital that this population are well informed about cognitive impairment so that they can help older relatives now, and have the knowledge and insight to be self-aware of their own cognition as they age. This group also had their own experiences of family members and older relatives living with cognitive impairment and dementia. Exploring the attitudes and views of this group is key to identifying a unified language which can successfully communicate information and increase awareness about cognitive impairment for future generations.

The inclusion criteria for this group were:

- Aged between 18 and 65
- No diagnosis, or known evidence, of cognitive impairment or dementia

2.6.1.5 Healthcare professionals working with older adults

Obtaining the views of healthcare professionals is imperative, as it has been suggested that some professionals working in health and care settings struggle to recognise the symptoms of cognitive impairment (Kaduszkiewicz et al., 2010) and this could potentially be improved by better information provision. This group were able to comment on the information they have encountered about cognitive impairment as part of their job role and to identify whether they feel that this information is sufficiently able to address the concerns and information needs of the individuals that they work with. They also have direct experience of talking about cognitive impairment to people living with this and therefore could comment on how they achieved this communication, and how their experiences of meeting people living with cognitive impairment constructed their notion of what it means to have cognitive difficulties and how this compares to the available literature about this.

The inclusion criteria for this group were:

- Aged over 18
- Currently working with older adults in a healthcare role

2.6.1.6 Dementia specialists

I felt it was important to obtain the views of this participant group, as dementia specialists were likely to hold a wide range of views about cognitive impairment due to the heterogeneous nature of the syndrome to date. This group were also well placed to comment on the varying language and terminology used to discuss cognitive impairment as a result of their work and their exposure to this syndrome due to the close relationship between cognitive impairment and dementia. Similar to healthcare professionals, this group were well placed to comment on how their experience of working with people living with cognitive impairment had shaped their own knowledge of what it means to have cognitive impairment and could discuss this with regards to the information available about the topic.

The inclusion criteria for this group were:

- Aged over 18
- Currently working in a capacity whereby dementia specialist knowledge is required, or have a keen interest in dementia

2.6.2 Exclusion Criteria

The exclusion criteria for the study were common across all six groups. Any individuals who did not speak English fluently, and where interpreters would be required, were excluded from the research. Requiring the questionnaire or interview schedule to be translated (or involving an interpreter at any stage of the research) could have posed difficulties in the analysis of the data, as it may have resulted in meanings and contexts being lost in translation.

2.7 Terminology

As a key aim of this thesis was to explore the language and terminology that different participant groups were familiar with and elected to use in their discussions of MCI, I made the decision to avoid the use of the phrase “mild cognitive impairment” in the core body of questionnaire items and interview questions. I felt that using the phrase “cognitive impairment” instead would enable participants to consider whether MCI was a label which they themselves would use. I also felt that using this phrase would make the research more accessible to a wider population as MCI may be something which the lay population are unfamiliar with (something which I was keen to explore in this research). There were many different terms which I could have elected to use instead of MCI, such as “memory and thinking difficulties” but I felt that

“cognitive impairment” provided a concise phrase that participants could respond to and also avoided the use of the word “memory” as I was keen to ensure that my choice of terminology for this thesis did not bias participants’ views of cognitive impairment as a concept which predominantly affects memory.

2.8 Ethical Issues

2.8.1 Ethical Approval

Ethical approval 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).

2.8.2 Ethical Considerations

A core tenet of ethical research is to ensure that all participants are provided with detailed information about the research prior to taking part and that they are able to provide informed consent. Written consent was obtained from all participants, with each individual being given up to a week after meeting with me and being provided with all the study information to decide if they wanted to participate. Consent was also viewed as an ongoing process, revisited at every point of communication between myself and participant. Participants were reassured at all times throughout the research that they were free to withdraw from the study at any time without giving a reason. Participants were informed that their decision regarding study participation would not impact on any care and support (including teaching support for students) they were presently receiving or that they may require in the future.

As it is acknowledged that engaging with people experiencing cognitive difficulties is a sensitive area, I was attentive to any signs that participants were anxious or distressed during the study. If a participant appeared to be at all anxious then I halted the interview immediately and discussed with the participant whether they wanted to continue with the study and explored future options, for example, continuing the interview on another day or ceasing participation in the research completely. Participants were assured at all times that it was fine to stop the research, and were reassured that they were not obligated to answer any of the questionnaire or interview questions and that they could ask questions at any point during the process. The supervision team was led by an experienced chartered clinical psychologist so that

I had the added benefit of being able to raise issues or concerns about participants in a confidential and supportive forum.

In order to protect the anonymity and confidentiality of participants in the study, I was careful to ensure that all paperwork arising from the research was kept in a locked filing cabinet in a secure location at all times where only I could access the documentation. All paper and computer data files were coded so that no participants could be identified by anyone other than myself.

To protect the anonymity of participants who took part in an interview, all personal and identifying information in audio recordings was substituted with pseudonyms in transcriptions to ensure the anonymity of transcribed data. Transcribed interview files and audio recordings were stored in a secure folder on the University of Worcester server. Participants were not identified in any documentation relating to the research, and confidentiality was of the utmost concern to me throughout the duration of the project.

It is important in all research that participants are reassured that their contribution is valid and that the time they have taken to participate will not be wasted. It has often been the case with research into cognitive impairment and dementia that the voice of the individual experiencing cognitive difficulties has been ignored or only given credence if it conforms to the researcher's ideal responses (Cheston, Bender, & Byatt, 2000). As such, research participation has sometimes been regarded as a tokenistic exercise (Litherland, 2008) and it is essential that participants are reassured that their responses are valued and will be used to inform further research or provide tangible improvements or advances in the research field (Robinson, 2002). As such, all participants who took part in any phase of this research were asked if they wished to know the study findings and interested individuals were informed of the outcomes (either via post or email) as soon as the research was complete in order to highlight how valuable their contribution was.

In order to conduct a successful interview, it is important that a trust relationship is established between the researcher and the participant (Nygård, 2006), but this raises concerns around ensuring that the issue of attachment is addressed. When engaging with participants, there was a risk that they would develop an expectation that I would maintain contact beyond that required for the research, and that I may even be viewed as a friend (van Baalen, Vingerhoets, Sixma, & de Lange, 2010). It was therefore important for me to minimise the risk

of attachment by consistently reinforcing the researcher-participant relationship and ensuring that participants were aware that the interaction was only temporary.

A flexible approach was adopted when conducting interviews in order to ensure that the interview pace and duration was dictated by the participant. I explained explicitly that participants could take a break from the interview or stop the process at any time without having to provide a reason for this. In this manner, interview participants were protected from engaging in a process which may be too tiring or challenging. Survey respondents were also able to complete the questionnaire in their own time and at their own pace.

As I was working alone, visiting participants in their own homes and in unfamiliar settings, it was essential that I employed a “buddy” system to ensure my own safety. This system involved leaving emergency contact details and details of the research visit with a “buddy” who was able to access these details (which were kept in a sealed envelope in a locked filing cabinet) if I sent an emergency message or did not check in with the buddy at a pre-agreed time.

2.9 Summary

In this chapter I have outlined my motivations for selecting a mixed methods approach in this thesis, and discussed how this research has been informed by critical realism. The design for the research has been presented, and I have explained the selection of participants. Finally, I have discussed key ethical issues pertaining to the study and outlined approaches that have been adopted in order to mediate any potential ethical risks. In the next chapter I will document the process and results of a systematic review which explored all available literature relating to knowledge and understanding of MCI.

Chapter 3: Knowledge and understanding of mild cognitive impairment: a systematic review and thematic synthesis of qualitative and quantitative research

3.1 Chapter Overview

The study reported in this chapter details a systematic review exploring the current literature around knowledge and understanding of mild cognitive impairment (MCI). In this study I aimed to capture all of the available literature which has explored what people know and understand about MCI, critically reviewing this literature and considering where there are gaps in the research to date. This chapter will begin by outlining the background and rationale for conducting this study, followed by a discussion of the methods employed in undertaking this review, and concluding with the results and discussion of the study in the context of this thesis and identifying gaps in the current literature base.

3.2 Introduction

Over the last 50 years, numerous terms have been proposed to account for the degree of reduced cognition that is often experienced by older adults, which is more than would be expected as a result of normal ageing, but not severe enough to warrant a dementia diagnosis. In recent years, the label of MCI has gained widespread acceptance amongst medical practitioners (Beard & Neary, 2013) and has been the focus of a growing body of research (Petersen et al., 2009). However, whilst MCI has been used as a diagnostic label in both clinical and research settings, there is wide variation in the use of MCI in clinical practice (Moreira et al., 2008).

Currently, there is controversy around whether MCI is a clinically relevant diagnostic label or should be viewed solely as a research construct (Garand et al., 2009). It has been suggested that MCI is an ambiguous diagnosis which leads to feelings of confusion and uncertainty (Dean & Wilcock, 2012; Garand et al., 2009). This may be due to the lack of prognostic clarity following a diagnosis of MCI (Aretouli, Tsilidis, & Brandt, 2013) with MCI inferring an increased risk of dementia but not a certain outcome (Farias et al., 2009). It has also been suggested that clinicians struggle to identify MCI in practice due to the difficulties in discriminating between normal ageing, MCI and dementia in clinical evaluations (Kaduszkiewicz et al., 2010). In the most recent version of the Diagnostic and Statistical Manual of Mental

Disorders (5th ed.; DSM-V; American Psychiatric Association, 2013), the diagnostic label of ‘mild neurocognitive disorder’ was included, listing the same diagnostic criteria as MCI and formalising the diagnosis of cognitive impairment. However, this is an American manual, and there has not been a similar amendment made to the European classification system produced by the World Health Organisation (WHO). This could result in a very different pathway for individuals living with cognitive impairment across geographical areas as there is likely to be an increased awareness and acceptance of diagnosing cognitive impairment in areas where the DSM-V is more widely used. It is clear that MCI, under one label or other, is a continued focus of diagnostic services for older adults. Regardless of the label that is applied and whether this is perceived as a ‘formal diagnosis’ or not, people will continue to experience cognitive decline which is not at the level of a dementia but is greater than would be expected for their age and education, and we must consider how we assess and support these individuals.

This review aims to explore the literature around understandings of MCI and what people know about this label and its associated criteria. Exploring how people understand MCI, and what language they feel most comfortable using when discussing cognitive impairment, may enable identification or development of a unified language which can be utilised across participant groups to minimise ambiguity and confusion. Understanding the language that people feel most comfortable using when discussing cognitive impairment may help to raise awareness and reduce stigma around MCI in the general population, encouraging individuals to present for assessment and support in a more timely manner. However, raising awareness could also result in more individuals who are concerned but do not have an objectively tangible deficit (the worried well) presenting to healthcare services. Developing our understanding of perceptions and knowledge around MCI may enable a balance whereby people with cognitive decline are encouraged to seek help and individuals who are concerned but without objective deficits are reassured.

3.3 Method

3.3.1 Systematic search strategy

Searches were conducted through ASSIA, CINAHL plus (via EBSCO), PsycARTICLES, PsycINFO, and PubMed. The following terms were searched as keywords anywhere within the article: “mild cognitive impairment”, MCI, adult, experience*, know*, belie*, understand*, aware*, comprehen*, perce*, view*, attitude*, perspective, whereby the * symbol indicates the

use of a “wild card” in order to include different forms of the same term, e.g., perce* for perception, perceive and perceiving. Only papers published between 1999 and 2014 were included in the literature search, as the term MCI was first presented in the literature by Petersen et al. (1999). Core inclusion criteria are presented in Table 3.1.

3.3.2 Selection Process

Titles and abstracts of articles identified from searches were screened to identify relevant publications. Full text versions of articles that met the inclusion criteria were obtained and assessed for final inclusion. Eligibility of identified articles was recorded to document and monitor the selection process for the review. Duplicates across searches were identified and removed prior to the screening process (see Figure 3.1, p.54). Internal duplicates were those found within the same databases, and external duplicates were duplicates across databases.

Table 3.1: Inclusion criteria for articles screened for the systematic review

| Inclusion criteria | |
|--------------------------------|--|
| Location | International |
| Language | Published in English language |
| Time frame | Published between 1999 and 2014 |
| Population/participants | Adults (aged over 18) |
| Outcome | Studies concerned with exploring participants understanding of MCI Themes relating to individuals understanding, beliefs, knowledge and attitudes about MCI |
| Study type | Primary research Qualitative studies Quantitative studies |
| Type of publication | Full text* Published in peer-reviewed journal |

* if full text was not readily available, additional searches were conducted to locate a full text copy, including inter-library loans. Full text versions were able to be obtained for all of the identified studies selected for inclusion in this study.

3.3.3 Critical Appraisal

The methodological quality of all qualitative papers included in the review was assessed using the Critical Appraisal Skills Programme (CASP; Critical Appraisal Skills Programme, 2013; Appendix A) checklist. The quality criteria in this checklist assessed the credibility, rigour and relevance of studies. For quantitative survey studies, a modified version of the CASP checklist (CASP, 2013; Appendix B) was utilised to review the methodological quality of these papers. For each of the 10 CASP criteria, studies were scored out of three (1 = “No”, 2 = “Yes with restrictions”, 3 = “Yes”) (Elvish, Lever, Johnstone, Cawley, & Keady, 2012; Lins et al., 2014). As the critical appraisal of qualitative research is complex due to the difficulties in synthesising diverse methodologies and epistemologies, there is always a compromise between inclusiveness and quality (Dixon-Woods et al., 2006). Similarly to other synthesis reviews (Lawrence, Fossey, Ballard, Moniz-Cook, & Murray, 2012; Lins et al., 2014; Mukadam, Cooper, & Livingston, 2011), the critical appraisal process was not used to exclude studies, but to weight articles according to their methodological quality. Studies were ranked according to their quality score on the CASP checklist, and themes were compared to ascertain the quality of articles supporting each theme. Quality scores are presented in Table 3.3 (see p.57).

3.3.4 Sensitivity analysis

To ensure the results of the thematic synthesis were not skewed by low quality studies, a sensitivity analysis was conducted. A sensitivity analysis identifies whether the results of a systematic review are robust to the assumptions and process of the review. This is often achieved by removing studies perceived to be of low quality and identifying whether this impacts the results of the review (Bown & Sutton, 2010). None of the articles were particularly low scoring, with all studies scoring 19-26 out of a possible 30. For the purposes of the sensitivity analysis, articles scoring 19 and 20 were removed in order to assess whether the synthesis was still valid without the contribution of these articles. With the removal of the 10 lowest scoring studies (6 qualitative and 4 survey studies), all themes were still supported by at least 6 of the remaining 14 qualitative articles. All of the identified themes were supported by both low quality and high quality articles, suggesting these results have validity and reliability.

3.3.5 Synthesis Approach

To synthesise the results of the studies included in this review, thematic synthesis was selected (Thomas & Harden, 2008) as this methodology is suitable for synthesising studies with

a range of epistemological and methodological approaches (La Fontaine & Oyeboode, 2014) allowing a wide range of studies to be included. In accordance with guidance from Thomas and Harden (2008) all text labelled as “results” or “findings” was analysed for the thematic synthesis.

The analysis involved several key stages as outlined by Braun & Clarke (2006). Firstly, the included articles were read and re-read in order to enable me to become familiar with the material. At this point, brief notes were taken about possible codes, with a particular focus on identifying areas of similarity and difference across the articles. The articles were then uploaded to NVivo 10 (QSR International, 2012), and line-by-line coding was conducted within this programme. Once initial coding had been conducted, I reviewed the codes on paper and began to identify encompassing themes. The initial themes were uploaded to NVivo and codes arranged into a hierarchy within each theme. Initial themes were explored through NVivo to establish where connections could be formed to identify higher order themes. At this point I also referred to the original coding structure and source material to ensure that the identified themes were reflective of the articles included in the review. Lastly, I constructed the final theme structure within NVivo and drew together the hierarchy of themes from the final synthesis. Together with the thematic synthesis, the results of the survey studies were also integrated into this review to consider all of the information currently available about people’s perceptions and views of MCI.

Flowchart of the Screening and Eligibility Evaluation Phases

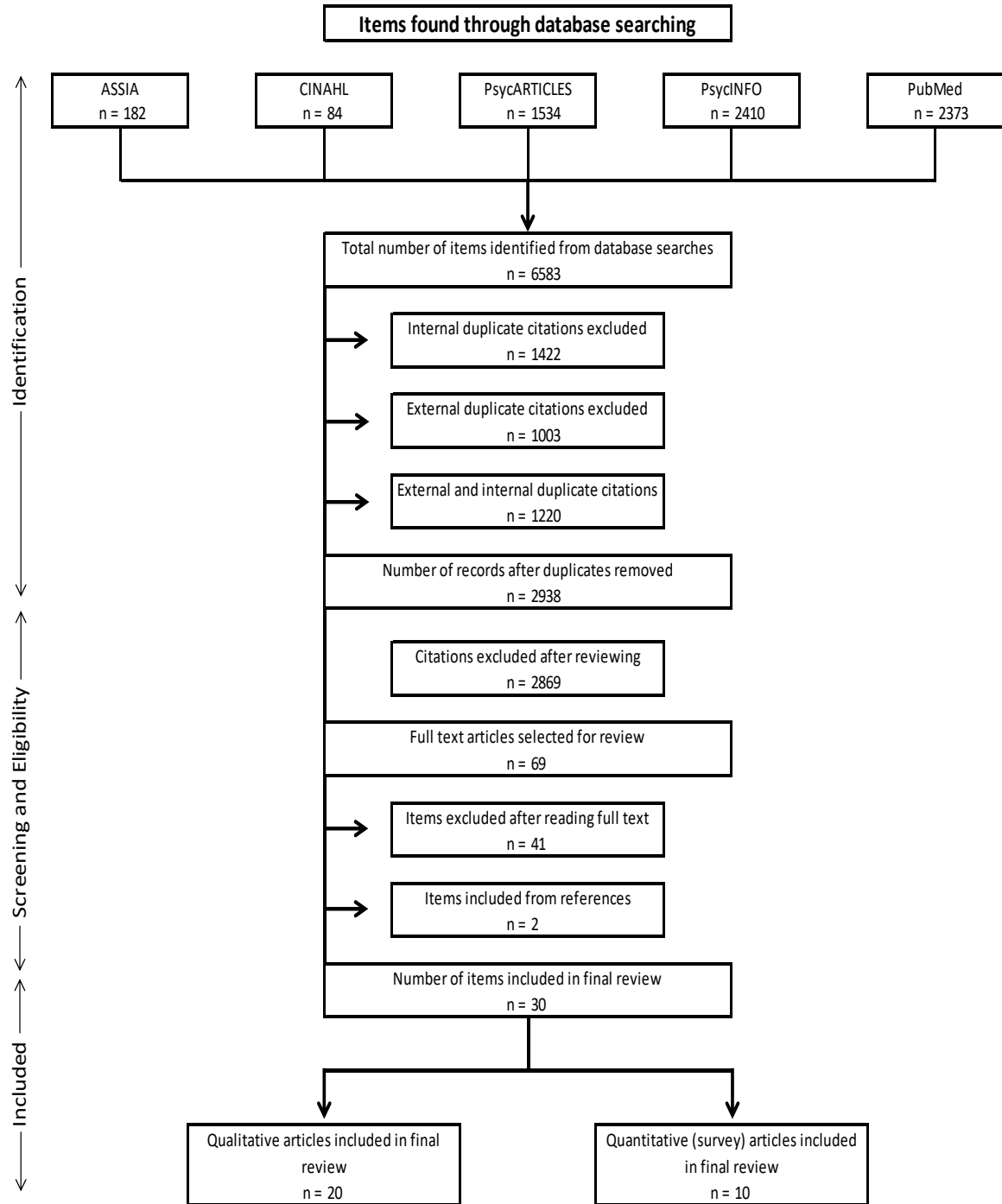


Figure 3.1: Flowchart of the screening process for articles included in the review

3.4 Results

The search yielded 6583 papers, of which 3645 were duplicates. Titles and abstracts of the remaining 2938 articles were screened against the inclusion criteria. The main reason for exclusion was that the studies did not consider views and understandings of MCI. Following the screening process, 28 were selected for inclusion in the review. A hand search of reference lists from the included articles yielded two further articles of interest, resulting in 30 papers being included. The process of screening articles for inclusion is outlined in Figure 3.1 (see p.54).

Following the synthesis of the 20 qualitative articles and 10 survey studies included in this review, I identified six main themes: *symptoms of MCI*, *causes of MCI*, *association with dementia*, *lack of information*, *MCI as a diagnostic label*, and *changed person*. Table 3.2 (see p.56) presents the spread of identified themes across the 30 articles reviewed. All of the themes were supported by at least 10 of the included studies. The themes of *symptoms of MCI*, *causes of MCI*, and *association with dementia* were present in 22 of the articles, suggesting that these were a focus of the articles. A summary of the 30 articles included in the review are presented in Table 3.3 (see p.57). Participants in the articles included clinicians (5 studies), individuals living with MCI (14 studies), care partners or informants of people living with MCI (11 studies), and adults without cognitive difficulties (2 studies). Two studies included care partners of people living with MCI or early stage dementia (Betts Adams, 2008; Frank et al., 2006) as these studies were exploring caring experiences relating to both MCI and dementia. Frank et al. (2006) also included participants living with MCI or early stage dementia to explore the impact of cognitive impairment on individuals living with both mild dementia and MCI. Corner & Bond (2006) reporting on two case studies included one participant living with “mild early stage dementia” (p.7) and her husband, and one older adult without cognitive impairment. Whilst this study did not include participants living with a diagnosis of MCI as such, the focus of the research was on the impact of an MCI label on an individual’s sense of self. The authors explain the difficulties in contacting people living with MCI, resulting in their choice of participants for this study (Corner & Bond, 2006). The majority of the articles included participants from the USA (19 studies) with a small number from the UK (5 studies), Canada (2 studies), the Netherlands (2 studies), Sweden (1 study), China (1 study), Taiwan (1 study), Japan (1 study), Israel (1 study), and Australia and New Zealand (1 study).

Table 3.2: Summary of themes identified from studies included in the review.

| References | Theme | | | | | |
|----------------------------|--------------|---------------|---------------------------|---------------------|---------------------------|----------------|
| | MCI symptoms | Causes of MCI | Association with dementia | Lack of information | MCI as a diagnostic label | Changed person |
| Banningh et al. (2008) | X | X | X | X | X | X |
| Beard & Neary (2013) | X | X | X | X | X | X |
| Berg et al. (2013) | X | X | X | | | X |
| Betts Adams (2008) | X | | X | | X | X |
| Blieszner & Roberto (2009) | X | X | | X | | X |
| Blieszner et al. (2007) | X | X | X | | X | X |
| Corner & Bond (2006) | X | X | X | X | X | |
| Dai et al. (2013) | X | X | X | X | | X |
| Dale et al. (2006) | | X | X | | X | |
| Dale et al. (2008) | | X | X | | X | |
| Frank et al. (2006) | X | X | X | | X | X |
| Kuo & Shyu (2010) | X | X | X | | X | X |
| Lin & Heidrich (2012) | X | X | X | | | |
| Lin et al. (2012) | X | X | X | | | |
| Lingler et al. (2006) | X | X | X | | X | |
| Lu & Haase (2009) | X | X | X | X | X | X |
| Lu et al. (2007) | X | X | | X | X | X |
| McIlvane et al. (2008) | | | X | | | |
| Mitchell et al. (2008) | | | X | | X | |
| Moreira et al. (2008) | | | X | | X | |
| Nakano et al. (2012) | X | | | | | X |
| Parsons-Suhl et al. (2008) | X | | X | | | X |
| Pasymowski et al. (2013) | X | X | | | | X |
| Roberto et al. (2011) | X | X | X | X | | X |
| Roberto et al. (2013) | X | X | | | | X |
| Roberts & Clare (2012) | X | X | X | X | X | X |
| Roberts et al. (2010) | | | X | X | X | |
| Rodakowski et al. (2014) | | X | | | | |
| Rodda et al. (2012) | X | | | | X | |
| Werner et al. (2013) | | X | | | X | |

Table 3.3: Summary table of papers included in the review.

| Study | Quality Score | Location | Research Aims or Questions | Sample | Methodology | Key Findings/Themes |
|-----------------------|----------------------|-----------------|---|--|--|--|
| Banning et al. (2008) | 20 | Netherlands | How do individuals living with MCI experience and cope with their cognitive decline? | 8 individuals (age range = 58-83, mean = 74.8) living with aMCI recruited from the Memory Clinic of Nijmegen. | Guided interviews lasting 60-75 minutes. | <ol style="list-style-type: none"> 1) Changes 2) Attributions 3) Consequences 4) Coping |
| Beard & Neary (2013) | 21 | Worcester, USA | How do people living with MCI make sense of this diagnosis and its potential psychosocial impact? | 18 individuals (age range = 65-85+, mean = 76) with a diagnosis of aMCI (within the last 3 years) recruited from a research registry at an Alzheimer's Disease Centre. | Semi-structured individual interviews. | <ol style="list-style-type: none"> 1) Is what we are experiencing a disease? 2) What is MCI? 3) At least it isn't Alzheimer's disease 4) Implications of associations with Alzheimer's |

| | | | | | | |
|-----------------------|----|-----------------------|--|--|---|--|
| Berg et al. (2013) | 20 | Gothenburg, Sweden | <p>1) What are the personal experiences for individuals who remained as MCI cases over a seven-year period?</p> <p>2) How do individuals comprehend and cope with various stressors evoked by their compromised cognition and the everyday life challenges that may exceed their coping resources?</p> | <p>17 individuals (age range = 57-86) living with stable MCI (aMCI and naMCI) for at least 7 years, recruited from an ongoing study in Gothenburg.</p> | <p>Semi-structured individual interviews lasting 60-120 minutes. Conducted at the participant's home or at the memory clinic.</p> | <p>1) At that time - when I came to the memory clinic</p> <p>2) Adjusting to reduced capacity</p> <p>3) Worries about what is to come</p> <p>4) I have a good life</p> |
|-----------------------|----|-----------------------|--|--|---|--|

| | | | | | | |
|--------------------------|----|----------------|---|--|---|--|
| Betts Adams (2008) | 21 | Cleveland, USA | <p>1) What are the major concerns of spouses and adult children of persons recently diagnosed with AD or MCI?</p> <p>2) What is early caregiving like for them?</p> <p>3) What is the range of emotions they experience?</p> <p>4) How do they feel about informal or formal sources of help?</p> <p>5) Can we identify target areas for social work prevention and intervention?</p> | <p>20 individuals (age range = 45-82). 3 care partners of individuals living with MCI, 17 care partners of individuals with mild or early dementia. All recruited from University Memory and Aging Center, Cleveland's Alzheimer's Disease Research Center, scoring 0.5 or 1 on the CDR.</p> | <p>Semi-structured individual interviews consisting of open-ended questions and lasting around 60 minutes. Interviews were conducted at the university, at the participant's home or at a restaurant.</p> | <p>1) Family member tasks 2) Changes in the relationship 3) Negative emotions 4) Support from others 5) Thoughts of the future</p> |
|--------------------------|----|----------------|---|--|---|--|

| | | | | | | |
|----------------------------|----|--------------------------|---|--|---|--|
| Blieszner & Roberto (2009) | 25 | Virginia & Illinois, USA | <p>1) How do family members manage behavioural changes resulting from MCI?</p> <p>2) What is the impact of having a relative with MCI on care partners' psychological well-being?</p> | 86 primary care partners of people living with MCI (age range = 25-89, mean = 66.9) recruited from 4 hospital based geriatric clinics. | Individual interviews beginning and ending with structured scales, with open-ended questions in the middle. | <p>1) Care partner characteristics and resources</p> <p>2) Stressors</p> <p>3) Strains</p> <p>4) Protective conditions</p> <p>5) Predictors of MCI care partner well-being</p> |
| Blieszner et al. (2007) | 25 | Virginia, USA | To document MCI as an ambiguous loss situation within the context of a key family relationship - marriage. | 73 couples whereby one partner was living with MCI. Age range for individuals with MCI = 60-87 (mean = 75), spouses = 52-89 (mean = 71.2). Recruited from memory clinics in Virginia, USA. | Parallel open-ended face-to-face interviews lasting around 30 minutes for individuals living with MCI and 60 minutes for care partners. | <p>1) Ambiguity surrounding MCI</p> <p>2) Resilience and MCI</p> <p>3) Distress from ambiguous loss associated with MCI</p> |

| | | | | | | |
|----------------------|----|-----------------|--|---|--|---|
| Corner & Bond (2006) | 20 | Unspecified, UK | What is the lived experience of aging and dementia for older people with and without early-stage dementia/MCI? | Two case studies; one spouse dyad of a wife living with mild early stage dementia and her husband, and one older adult without cognitive impairment or dementia. Recruited from a variety of avenues including old age psychiatry service, memory clinic, the Alzheimer's Society and older adult's day centres. | Multiple interviews - it is not clear if these interviews were structured, semi-structured or unstructured, were conducted face-to-face, how long the interviews took, how many interviews each participant was involved in, or where the interviews took place. | <ol style="list-style-type: none"> 1) Different views as to the causes of dementia 2) Normal ageing versus disease 3) Fear and anxiety about dementia 4) How such views influence presentation to health professionals. |
| Dai et al. (2013) | 21 | China | What are the experiences and knowledge of MCI among family members of individuals with MCI? | 13 care partners of individuals living with aMCI. Recruited from memory clinics in Zhongnan Hospital at Wuhan University. | Survey questionnaire (demographic information). In-depth interview lasting 60-180 minutes. | <ol style="list-style-type: none"> 1) Initial recognition of cognitive decline 2) Experience of the diagnosis of MCI 3) Perception of cognitive decline as a normal part of aging |

| | | | | | | |
|-----------------------|----|--------------|---|---|---|---|
| Dale et al. (2006) | 19 | Chicago, USA | Are older adults interested in screening and treatment for MCI? | 149 individuals (ages not specified: 29% <65 years old, 71% ≥65) described as healthy adults aged 35 and older without cognitive impairment. Recruited from 2 university based geriatrics outpatient clinics. | A standardised interview was conducted involving a questionnaire designed for the purposes of this study to assess interest in being screened and treated for MCI. The interviews took an average of 24 minutes to complete and were conducted in a private, confidential area. | Participants expressed an interest in being screened and receiving treatment for MCI. Many participants reported knowing someone with AD. Many participants wanted to know early about having AD, and almost half of the participants stated that they worried about getting AD. Participants who had previously heard of MCI were much less willing to be tested. Those who believed they were likely to develop AD and those who had relatives with AD were much more willing to be tested if a family member suggested that they should. |
|-----------------------|----|--------------|---|---|---|---|

| | | | | | | |
|-----------------------|----|--------------|--|---|---|--|
| Dale et al. (2008) | 19 | Chicago, USA | What correlates with the intention to be tested for MCI in healthy older adults? | 199 individuals (ages not specified: 29% <65 years old, 71% ≥65) aged 35 and older without cognitive impairment. Recruited from adults accompanying 2 patients attending 2 university based geriatrics outpatient clinics. | A standardised interview was conducted involving a questionnaire designed for the purposes of this study to assess interest in being tested for MCI. The interviews took an average of 24 minutes to complete and were conducted in a private, confidential area, such as a private examination room. | Over 60% of the participants do not worry about AD and over 80% do not believe they are more likely to get it than others. Over 80% said they would definitely want to know early if they have AD. Many participants had some experience with those having AD. Over 80% knew someone with AD, with nearly half having a relative with AD, and 40% having cared for someone with AD. Over half of the participants said "definitely no" when asked if they had heard of MCI before. Participants who thought that their memory was already flawed were less likely to seek testing if they notice problems. |
|-----------------------|----|--------------|--|---|---|--|

| | | | | | | |
|------------------------|----|------------|---|--|--|--|
| Frank et al. (2006) | 19 | USA and UK | What is the impact of cognitive impairment on individuals with MCI, mild probable AD and their informants, and is there any overlap and differences between the groups? | 67 participants (people living with MCI = 20; individuals living with AD = 20; MCI informants = 11; AD informants = 16). Mean age of participants: people with MCI = 72, individuals with AD = 77, MCI informants = 73, AD informants = 71. Individuals who met the criteria for MCI, or were given a diagnosis of clinically mild probable AD (within 3 months) and their family members or close friends were recruited from memory clinics. | Focus groups lasting 90 minutes, following a discussion guide developed after a literature review and discussion with clinical experts. All participants also completed a short demographic questionnaire. Researcher observers and focus group facilitators took notes during the sessions, and 4 focus groups in the USA were also videotaped. | <ol style="list-style-type: none"> 1) Uncertainty of diagnosis 2) Skill loss 3) Social/family roles 4) Embarrassment/shame 5) Emotionality 6) Insight 7) Burden |
|------------------------|----|------------|---|--|--|--|

| | | | | | | |
|----------------------|----|--------------------|---|--|---|---|
| Kuo & Shyu (2010) | 24 | Taoyuan, Taiwan | What are the experiences of caregivers' in caring for elders with MCI, their process of becoming aware of elders' changed behaviour and their adoption of different strategies to manage elders' behaviour in the context of the healthcare system and culture of Taiwan? | 10 family care partners (age range = 39-76, mean = 50.8) caring for an individual aged over 65 diagnosed with MCI. Individuals were recruited by purposeful sampling from a memory clinic. | Semi-structured face-to-face individual interviews lasting 40-90 minutes were conducted. These interviews were usually conducted in participants' homes or another place they selected. All interviews were conducted by the same investigator to assure consistency. | <ol style="list-style-type: none"> 1) Ambivalent normalisation 2) Unintentional help seeking 3) Subtle changes 4) Optimistic appraisal 5) Ambivalent anticipation 6) Behavioural management |
|----------------------|----|--------------------|---|--|---|---|

| | | | | | | |
|-----------------------|----|----------------|--|---|--|--|
| Lin & Heidrich (2012) | 24 | Midwestern USA | <p>1) What are the representations of older adults with MCI?</p> <p>2) How do older adults cope with MCI?</p> <p>3) What are the relationships between illness representations and coping?</p> | 63 individuals living with MCI (mean age = 81.16) recruited from 3 primary care clinics and 3 memory clinics in the Midwest of the USA and from the Alzheimer's Disease Centre registers. | <p>1) The Illness Perception Questionnaire-MCI (IPQ-MCI)</p> <p>2) Brief COPE</p> <p>3) The Self-care Behaviors Checklist</p> <p>4) Demographic information</p> <p>5) Montreal Cognitive Assessment (MoCA)</p> <p>6) Geriatric Depression Scale (GDS)</p> <p>7) Older Americans Resources Service schedule of illnesses.</p> | <p>Participants endorsed an average of seven symptoms which they believed to be MCI-related, predominantly focused around cognitive symptoms.</p> <p>Participants reported an average of seven causes of MCI, but only three causes (ageing, heredity and abnormal brain changes) were endorsed by over half of the participants.</p> <p>Only around half of the participants believed they had a clear understanding of MCI. Participants who had been diagnosed with MCI longer had more positive perceptions of their understanding of MCI.</p> |
|-----------------------|----|----------------|--|---|--|--|

| | | | | | | |
|-------------------|----|----------------|--|---|---|---|
| Lin et al. (2012) | 25 | Midwestern USA | <p>1) What are the representations of MCI in people living with MCI?</p> <p>2) What are the relationships between domains of representations and demographic information and health history?</p> | <p>30 individuals diagnosed with MCI for at least 3 months (age range = 60-87, mean = 79.97) recruited from memory clinics at a University hospital and a Veterans Administration hospital.</p> | <p>1) The Illness Perception Questionnaire-MCI (IPQ-MCI)</p> <p>2) Cognitive interviews with 5 participants. These were used to examine whether or not the answers to the questionnaire were valid (i.e. that participants understand and can respond to the intended meaning of the items). Interviews lasted around 15 minutes.</p> | <p>Participants endorsed an average of nine symptoms they believed were related to MCI, predominantly cognition related, including memory loss and language. The least frequently endorsed symptoms (<10%) were somatic symptoms common in older age, for example stiff joints and hearing loss. Participants endorsed an average of four causes of MCI: ageing, heredity, abnormal brain changes, and stress or worry. Approximately half of the participants disagreed with the statements "MCI makes me feel stigmatised" and "MCI makes me lose my independence", and 60% of participants disagreed with the statement "MCI doesn't make any sense to me".</p> |
|-------------------|----|----------------|--|---|---|---|

| | | | | | | |
|--------------------------|----|-----------------|--|---|--|--|
| Lingler et al. (2006) | 26 | Pittsburgh, USA | What is the experience, from the patient's point of view, of living with a diagnosis of MCI? | 12 individuals (aMCI = 6, naMCI = 6; age range = 65-86, mean = 76). Recruited from the University of Pittsburgh Alzheimer Disease Research Center. | Semi-structured interviews lasting 45-60 minutes. Interviews were conducted individually at participants' homes. | <ol style="list-style-type: none"> 1) Only 1 participant explicitly evoked the clinical label MCI 2) Emotional dimension of assigning meaning 3) Cognitive dimension of assigning meaning 4) Emotional and cognitive dimensions as interrelated 5) Perceived implications for the future 6) Contextual factors 7) Expectations of normal ageing 8) Personal exposure to individuals with dementia 9) Concurrent health problems |
| Lu & Haase (2009) | 24 | Indiana, USA | What are the commonalities of the lived experience of being a spouse caregiver of an individual living with MCI? | 11 care partners of people living with aMCI (age range = 47-87, mean = 72) recruited through the Alzheimer Disease Centre Clinic in Indiana. | Open-ended interviews lasting 45-90 minutes. Interviews were conducted individually by 1 of 2 doctorally prepared researchers. | <ol style="list-style-type: none"> 1) Putting the puzzle pieces together: there is something wrong 2) A downward spiral into a world of silence 3) Consequences to caregivers of living in a world of silence 4) Taking charge of care |

| | | | | | | |
|------------------|----|--------------|--|--|--|--|
| Lu et al. (2007) | 24 | Indiana, USA | What are the commonalities of the lived experience of being diagnosed and living with MCI? | 11 individuals living with aMCI (age range = 60-83, mean = 74.5) recruited through the Alzheimer Disease Center Clinic in Indiana. | Open-ended interviews lasting 45-90 minutes. Interviews were conducted individually by 1 of 2 doctorally prepared researchers. | <p>1) Seeing through a glass darkly: Struggling to grasp the reality of MCI</p> <p>2) I'm still able: Finding ways to hold on to a sense of being able</p> <p>3) Resisting entrapment in the world of MCI: Holding on to a sense of self</p> |
|------------------|----|--------------|--|--|--|--|

| | | | | | | |
|------------------------|----|------------------------|--|--|--|--|
| Mcllvane et al. (2008) | 22 | Sarasota, Florida, USA | What are the perceptions of illness, coping responses, and psychologic well-being of people living with MCI and their care partners? | 75 individuals with MCI (age range = 60-91, mean = 77.3) and their care partners (age range = 43-89, mean = 69.5). Recruited from the Sarasota Memorial Hospital Memory Disorder Clinic. | Both individuals with MCI and their care partners completed a structured questionnaire, including the following measures: 1) Center for Epidemiological Studies-Depression Scale (CES-D) 2) Life Satisfaction Index-Z (LSI-Z) 3) Pearlin & Schoolers 7-item measure of Sense of Mastery 4) Short Form Health Survey (SF-36) 5) Perceptions of Illness 6) Brief COPE 7) Perceptions of need for help and caregiving 8) Service use and needs 9) Demographics | Both care partners and people with MCI were within the normal range for all measures of psychologic well-being. Care partners reported on average a 33% likelihood of conversion to AD, whereas people with MCI reported a 20% likelihood of conversion. Almost 40% of people with MCI reported that there was a 0% likelihood of getting AD whereas only 19% of care partners reported a 0% likelihood of their loved one getting AD. Many care partners and people with MCI viewed mental and physical exercise, and staying optimistic as strategies that are either quite a bit or extremely likely to prevent AD. |
|------------------------|----|------------------------|--|--|--|--|

| | | | | | | |
|------------------------|----|-------------------------|--|---|--|--|
| Mitchell et al. (2008) | 20 | Australia & New Zealand | The aim of this research was to determine how practicing clinicians view MCI, their approach to relating the diagnosis to patients and their families, and what follow-up and treatment are recommended. | 143 clinicians working with older adults recruited from the Australian Society for Geriatric Medicine and the New Zealand Geriatrics Society. | Anonymous questionnaire, either in paper form or online, focusing on: 1) Place of diagnosis 2) Importance of separating MCI for dementia 3) Importance of separating MCI from normal cognition 4) Terms used to relate the diagnosis 5) Diagnosis of MCI made in the past year? 6) Inform patients or relatives of the diagnosis of MCI? 7) Treatment recommendations | The importance of separating MCI from dementia was rated as 4 or 5 (1 = not very important, 5 = very important) by 69% of responders, and the importance of separating MCI from normal cognition was rated as 4 or 5 by 68% of responders. Most responders indicated that they always, or nearly always, inform patients (84%) or their relatives (87%) of a diagnosis of MCI. The preferred term to use when relating a diagnosis was MCI (82-89%). |
|------------------------|----|-------------------------|--|---|--|--|

| | | | | | | |
|-----------------------|----|---------------------------------|---|--|--|---|
| Moreira et al. (2008) | 21 | USA, UK, Netherlands and Canada | What explains variations in the clinical use of mild cognitive impairment (MCI) as a diagnostic category? | 37 participants with varying expertise (Neurology = 10, Geriatric Psychiatry = 10, Geriatrics = 5, Primary care = 4, Others = 8). Individuals were international experts in the field of dementia research and practice. | Semi-structured interviews. It is not clear if the interviews were conducted face-to-face or by telephone, or how long the interviews lasted. | <ol style="list-style-type: none"> 1) Organisation of health care 2) Clinical cultures 3) Evidential cultures |
| Nakano et al. (2012) | 20 | Osaka, Japan | What are the emotional experiences of elderly individuals with MCI and their families? | 4 participants (2 individuals with MCI and 2 family members). No details are provided around recruitment or classification of participants. | Semi-structured interviews lasting 37 and 65 minutes were conducted. These interviews were conducted jointly for the individual with MCI and their family member together. | <ol style="list-style-type: none"> 1) Bewilderment regarding memory decline 2) Avoidance of neighbourly relations 3) Fluctuation of confidence in the family 4) Desire to maintain a healthy life |

| | | | | | | |
|----------------------------------|----|---|---|--|---|--|
| Parsons-Suhl <i>et al</i> (2008) | 25 | Newfoundland, Canada | What is the experience of memory loss in the lives of individuals with cognitive impairment associated with early-stage AD? | 12 individuals experiencing memory loss as a result of probable early stage AD or MCI (age range = 59-83). Recruited from a seniors' centre via fliers and snowball sampling. | Single, unstructured face-to-face interviews, conducted at a location most convenient for each of the participants. There are no details provided regarding the location or average duration of the interviews. | 1) Experiencing breakdown 2) Temporality 3) Managing forgetting |
| Pasymowski <i>et al.</i> (2013) | 21 | Virginia, Maryland, Georgia, Indiana, Illinois, USA | 1) How do couples negotiate relationship norms in the context of MCI and its behavioural manifestations? 2) How is second-order change achieved among couples with MCI? What barriers interfere with achieving second-order change? 3) How do husbands adjust to their emergent role as care partner for a wife or partner with MCI? | 22 individuals (11 couples), age ranges: people with MCI = 70-86 (mean=78), care partners = 64-89 (mean=77). Individuals were recruited from memory clinics. Inclusion criteria focused around couples in which a husband was the care partner for his spouse with aMCI. | Semi-structured individual interviews of un-specified length at the individuals' homes or elsewhere (unspecified). | 1) Care partnering is like working 2) MCI influences interpersonal dynamics 3) Shifting roles and responsibilities 4) Modified social relations |

| | | | | | | |
|-----------------------|----|---------------|---|--|--|--|
| Roberto et al. (2011) | 21 | Virginia, USA | <p>1) To what extent are perceptions of MCI congruent among family members?</p> <p>2) What is the interplay between extent of perceived acknowledgement of MCI and the ability for families to cope effectively with changes in an elder's cognitive abilities?</p> | <p>56 family triads (person with MCI (newly diagnosed), primary care partners (PCP) and secondary care partners (SCP)); mean ages: person with MCI = 76.5, PCP = 66.8, SCP = 50.6. Purposive sampling from memory clinics across 6 cities.</p> | <p>Semi-structured individual interviews were conducted with individuals living with MCI and the PCPs. Interviews were conducted in participants' homes, by doctoral-level researchers. Interviews began and ended with structured scales, with open-ended questions in the middle (the data explored in this article). Brief semi-structured telephone interviews were conducted with SCPs by graduate research assistants.</p> | <p>1) Degrees of acknowledgement of MCI</p> <p>2) Background and family context of MCI</p> <p>3) Protective conditions</p> |
|-----------------------|----|---------------|---|--|--|--|

| | | | | | | |
|-----------------------|----|---------------|--|--|---|--|
| Roberto et al. (2013) | 20 | Virginia, USA | <p>1) In what ways does daily life change for married couples in which one partner has MCI?</p> <p>2) How do cognitive changes in people with MCI and changes in the roles and responsibilities of spousal care partners affect the ways in which they perceive themselves and their martial relationship?</p> | <p>40 couples, individuals with MCI (mean age = 74.6) and their care partners (mean age = 71.1). Purposive sampling from memory clinics across 6 cities.</p> | <p>Semi-structured individual interviews were conducted with individuals living with MCI and their care partners. Interviews were conducted in participants' homes. Second and third face-to-face interviews were held on average 13.3 and 37.4 months after the initial interview.</p> | <p>1) Initial adjustments to MCI: Containing daily life</p> <p>2) Adjustment over time: Trajectories of care</p> |
|-----------------------|----|---------------|--|--|---|--|

| | | | | | | |
|------------------------|----|-----------------|--|---|---|--|
| Roberts & Clare (2013) | 24 | North Wales, UK | <p>1) What is the psychological impact of living with the symptoms of MCI and how do people with MCI cope with this in relation to self and/or others?</p> <p>2) How does awareness of the symptoms and the implications of having memory and/or cognitive difficulties influence the experience of MCI?</p> <p>3) How do people with MCI label and describe their difficulties?</p> | <p>25 individuals living with MCI (age range = 60-97). Recruited from specialist memory clinics in North Wales.</p> | <p>Semi-structured individual interviews lasting 11-30 minutes, conducted at the participant's home or at the University.</p> | <p>1) Interdependence 2) Life goes on as normal 3) Disavowal of difficulty 4) Fear and uncertainty</p> |
|------------------------|----|-----------------|--|---|---|--|

| | | | | | | |
|-----------------------|----|--|--|--|--|--|
| Roberts et al. (2010) | 20 | USA - Nationwide (via the American Academy of Neurology) | <p>1) Do clinicians use the MCI label?</p> <p>2) How do they view its benefits and limitations?</p> <p>3) What do they do for patients with MCI?</p> | 420 practicing clinicians (mean age = 54) recruited from the American Academy of Neurology with an ageing, dementia or behavioural neurology practice focus. | A self-administered questionnaire was delivered in multiple formats, including by fax, mail and internet. The authors provide the survey as supplementary material with the article. | <p>The majority of participants (90.1%) reported that they recognised MCI as a clinical diagnosis, with most of those participants also using subtypes including amnesic vs nonamnesic (83.8%) and single vs multiple domain (50.7%).</p> <p>Respondents reported using a variety of medical codes for diagnostic or billing purposes with this population, including MCI (70.3%), memory loss (51.1%), AD (30%), cognitive disorder not otherwise specified (NOS; 22.4%), dementia NOS (15.4%) and amnesic disorder NOS (10.6%)</p> <p>In open-ended responses, a common theme was that an MCI label alerts physicians and families to monitor for changes and progression of symptoms.</p> |
|-----------------------|----|--|--|--|--|--|

| | | | | | | |
|--------------------------|----|-----------------|--|--|--|---|
| Rodakowski et al. (2014) | 21 | Pittsburgh, USA | <p>1) What is the attribution of MCI assigned by individuals with MCI and their care partners?</p> <p>2) To what extent do the dyads agree on the attribution of MCI aetiology?</p> <p>3) What demographic factors influence attribution of MCI aetiology?</p> | 60 dyads of individuals living with MCI (mean age = 71) and their care partners (mean age = 64.2) recruited from the University of Pittsburgh Alzheimer Disease Research Center. | Trained research assistants conducted a standardised interview with each member of the dyad. The primary outcome measure was the Illness Perception Questionnaire (IPQ). The categorisation scheme developed by Anderson et al. (2011) was adapted to describe attributions of MCI aetiology as potentially controllable and uncontrollable factors. | <p>The majority of individuals with MCI attributed their memory difficulties to uncontrollable factors (81.7%), 5.0% indicated potentially controllable factors and 13.3% indicated a medical condition. Both groups most commonly attributed MCI aetiology to heredity and normal ageing, both of which are uncontrollable factors.</p> <p>Care partners reported various lifestyle behaviours as potential causes of MCI (e.g. alcohol use, smoking & dietary health).</p> <p>Care partners were 28.41 times more likely to attribute MCI aetiology to a potentially controllable factor than individuals with MCI.</p> |
|--------------------------|----|-----------------|--|--|--|---|

| | | | | | | |
|---------------------|----|-----------------|---|---|--|--|
| Rodda et al. (2012) | 21 | UK - Nationwide | 1) What is the current practice, familiarity with, and attitudes towards the concept of MCI amongst UK Old Age Psychiatrists? | 453 UK Psychiatrists with Old Age Psychiatry as an area of interest, recruited from the Royal College of Psychiatrists specialist interest group. | A postal survey was sent to clinicians. The questionnaire was designed after a careful review of the literature. | <p>The majority of respondents said that they made the diagnosis of MCI.</p> <p>24% of participants thought that the concept of MCI was more useful for doctors, 10% felt it was more useful for patients, and 65% rated it as the same for both.</p> <p>Some respondents did not consider MCI a helpful concept, and reported that they did not consider it to be a diagnosis.</p> <p>Some respondents commented that they found it useful to be able to give patients a name for their symptoms.</p> <p>79% of participants stated that they required a memory complaint from either the patient or an informant to make a diagnosis of MCI.</p> <p>32% of participants said that they differentiated between subtypes of MCI.</p> |
|---------------------|----|-----------------|---|---|--|--|

| | | | | | | |
|----------------------|----|--------|--|---|---|---|
| Werner et al. (2013) | 22 | Israel | <p>The aim of this research was to explore family physicians' familiarity, knowledge, help-seeking, and treatment preferences regarding MCI.</p> <p>The authors outline the following hypotheses:</p> <p>1) Family physicians will have low levels of knowledge, especially regarding the diagnosis of MCI</p> <p>2) Family physicians will report family physicians as the first help-seeking source</p> <p>3) Family physicians will prefer non-pharmacological treatments</p> | <p>197 family physicians (age range = 28-69, mean = 50.1) recruited from a Health Maintenance Organisation in Israel.</p> | <p>Self-administered structured questionnaire, containing:</p> <p>1) Familiarity with MCI</p> <p>2) Subjective Knowledge</p> <p>3) Objective Knowledge:</p> <p>a) Causes for MCI</p> <p>b) Characteristics and Progression of MCI</p> <p>4) Practice Beliefs</p> <p>5) Preferences Regarding MCI</p> <p>a) Diagnosis and Test Preferences</p> <p>b) Help-seeking Preferences</p> <p>c) Treatment Preferences</p> <p>6) Socio-demographic Characteristics</p> <p>7) Professional Characteristics</p> | <p>The majority of participants (82.2%) reported having heard of MCI.</p> <p>Participants' subjective knowledge of MCI was relatively low, with as many as 30% reporting knowing nothing or almost nothing about it.</p> <p>Participants willingness to learn about MCI was relatively high, with almost half (46.6%) reporting a great extent of willingness to learn about MCI.</p> <p>71.7% of physicians in the study believed that MCI is caused by normal ageing.</p> <p>The majority of participants reported that MCI does not always deteriorate (65%) and does not impair memory only (70%).</p> <p>Overall, participants' objective knowledge of MCI was found to be moderate.</p> |
|----------------------|----|--------|--|---|---|---|

MCI = mild cognitive impairment; aMCI = amnesic MCI; naMCI = nonamnesic MCI; AD = Alzheimer's disease

3.4.1 MCI symptoms

In 22 articles, participants discussed the symptoms of MCI and their observations, experiences or expectations of what MCI was. Within this overarching theme, four key sub-themes were identified: *repetitiveness, forgetting, loss of communication skills, and other symptoms*. Repetitiveness and forgetting were two of the most frequently referenced symptoms of MCI, with both individuals living with MCI and their families stating these were often the symptoms which prompted help-seeking behaviours (Corner & Bond, 2006; Dai et al., 2013; Lu & Haase, 2009; Parsons-Suhl, Johnson, McCann, & Solberg, 2008).

3.4.1.1 Repetitiveness

Repetitiveness was one of the symptoms that was reported as being most noticed by family members of people living with MCI, and one of the first issues that prompted the realisation something was not normal: “I started noticing things. And he [Vern] asked me things over and over and over again. And then we went to all kinds of doctors.” (Blieszner, Roberto, Wilcox, Barham, & Winston, 2007, p.200). A care partner remarked repetition caused other people to think that her husband living with MCI was “strange” (Nakano, Sato, & Nakahara, 2012, p.120), and care partners identified repetition as a cause of family conflict and disharmony:

Perseverating included a wife recounting how her husband persisted in arguing with his grandchildren as he tried to deny his memory problems, numerous family members citing the frustration of being asked the same question over and over, and a wife being unable to decide whether her husband was teasing her or not as he checks up on her repeatedly. (Blieszner & Roberto, 2009, p.16)

Participants living with MCI alluded to the worry and fear their noticed symptoms caused them, particularly with regards to how others would respond to their repetitiveness: “I don’t react spontaneously because I’m afraid to say things I have already told about” (Banningh et al., 2008, p.152). Frank et al. (2006) reported one MCI informant who believed that the person living with MCI was not aware that she was repeating herself: “she does like to repeat stories and doesn’t realize she’s already told them” (p.155). This suggests that people living with MCI may not be aware of their own repetition and this symptom may only be detected by others. As such, social isolation for people living with MCI may be an issue as symptoms may not be

noticed if there is not someone else present to identify early symptoms which the individual themselves may not be aware of at first. Interestingly, there was no exploration of repetition in the survey studies. This could be as a result of a discrepancy between the structure of questionnaire studies and qualitative research in the perceptions and experience of MCI, or may be an artefact of the phenomena under investigation across the articles.

3.4.1.2 Forgetting

Forgetting as a symptom of MCI was highlighted by respondents in 10 of the articles. It was clear that this loss of memory represented a key issue for both individuals living with MCI and their care partners, and they were very aware of this decline: "I'll remember that [my wife] told me that she was going out, but I won't remember with who or where she was going... They're [the diagnosticians] telling me that I can't remember things, and I already know that." (Lingler et al., 2006, p.796). Alongside repetitiveness, memory decline was referred to as one of the first noticeable symptoms of MCI, and it was often this decline that made individuals aware something was changing. A care partner highlighted the recognition of forgetting in her spouse living with MCI:

"He couldn't remember the things we just talked about 30 minutes ago. He has no hearing problem but that was the sign to me that he was not absorbing or retaining what he was hearing." (Lu & Haase, 2009, p.4)

The issue of forgetting was mostly referred to with regards to forgetting people and names. This issue appears reflective of the worry and fear of judgement entangled in participants' discussions of experiencing MCI:

Jerry relied on his wife to remind him of people's names when out in the community rather than explicitly acknowledging his difficulty with people's names in conversation:

"...there was a man and I knew the way he was looking at me that he knew me. I couldn't work out who he was so I asked [wife] quietly" (Roberts & Clare, 2013, p.303)

This quote also shows how individuals living with MCI relied on family members to help them overcome some of the difficulties that they were noticing and as a way of hiding their symptoms from other people. In a survey study by Lin & Heidrich (2012) of 63 individuals living with MCI, over half of participants endorsed the symptoms of memory loss, forgetting events and/or conversations, and forgetting names of friends and/or family members as symptoms they

believed to be MCI-related. A similar study found that 93.3% (n=28) of participants living with MCI believed that memory loss was an MCI-related symptom (Lin, Gleason, & Heidrich, 2012).

That individuals living with MCI themselves articulate experiencing forgetting and memory loss is also echoed by UK psychiatrists, as 79% (n=358) of 453 respondents to an anonymised postal survey stated they required a memory complaint from either the individual or their informant to make a diagnosis of MCI (Rodda, Gandhi, Mukadam, & Walker, 2013). However, it was not clear in this study what constituted a memory complaint with regards to the severity or frequency of memory problems. Sixty percent (n=273) of respondents reported that both memory and non-memory deficits were consistent with a diagnosis of MCI, whilst 80% (n=363) stated that an isolated memory deficit was consistent with an MCI diagnosis (Rodda et al., 2013). This suggests that the survey respondents placed an emphasis on the presence of a memory deficit when diagnosing MCI and thus would be more likely to recognise and diagnose amnesic MCI but may not be as receptive to non-amnesic MCI.

Entangled with the recognition of memory difficulties and forgetting as a symptom of MCI was the notion of normalising this, highlighting that everyone forgets things. Both care partners and people living with MCI claimed that memory problems were a normal or typical part of ageing, and that most older people have a memory deficit. A participant living with MCI reported that his wife is also forgetful and that it was therefore difficult to establish when memory difficulties could be defined as problematic: “But my wife forgets things too. So you know, it is like it depends on who it is that forgets things. When does it become a problem?” (Berg et al., 2013, p.296). This comment also brings to the fore the inherent difficulties in defining differences between what is normal and what is abnormal. This difficulty is not just present in the lay understanding of memory difficulties in the context of ageing, but also in the diagnostic process for MCI whereby there is, as of yet, no clearly defined cut-off score on memory and cognitive tests for diagnosing MCI.

3.4.1.3 Loss of communication skills

One of the symptoms of MCI which was frequently referenced was the decline of language and communication skills. It was noted by several individuals living with MCI that they had started to struggle to find words and to keep up in conversations. This change brought to the fore activities occurring outside their perceived boundaries of normality:

“I’m having difficulty with words. Like in a sentence, when I’m talking to somebody. Ah, I can’t go right along with it. I have to stop because I can’t remember what I was gonna say next and that kinda scared me...Well, I thought, what’s happening here? Is there something wrong with me?” (Parsons-Suhl, Johnson, McCann, & Solberg, 2008, p.35)

Similarly, Banningh et al. (2008, p.152) discussed an individual living with MCI who stated they did not actively participate in conversations any more: “Instead of joining a conversation I just listen”. This difficulty in conversing as normal, or as previously, was highlighted as embarrassing by a wife care partner:

“Sometimes it’s embarrassing because when there are people around he recedes back to his office. He is not comfortable being around large groups...It is hard to carry on a conversation for him because people talk about politics, they talk about the war, they talk about everything and he doesn’t retain what he has heard.” (Lu & Haase, 2009, p.5)

This highlights how some people living with MCI withdrew from social activities either due to a lack of ability to participate in the way that they had previously, or due to embarrassment as a result of their presenting symptoms.

Lin & Heidrich (2012) found over half of the 63 participants living with MCI in their study endorsed the symptom of “trouble finding words” as being MCI-related. In a similar study exploring the illness representations of older adults with MCI, 66.7% (n=20) of participants endorsed “trouble finding words” as an MCI-related symptom (Lin et al., 2012). Word finding and communication difficulties were highlighted as symptoms of MCI by both people living with MCI and their care partners.

3.4.1.4 Other symptoms

There was infrequent reference made to other symptoms of MCI throughout the included articles, but these were mostly conveyed through the voice of the researcher, with few direct quotes from participants, suggesting that these symptoms were less robustly identified than the core issues of forgetting, repetitiveness and, to a somewhat lesser extent, loss of communication skills:

They [people living with MCI] described problems with forgetting names, following instructions, getting lost, and understanding conversation, especially jokes, but generally did not report changes in their mood. Some reported they continued pastimes such as

playing bridge and cooking. However, their informants described a worse picture and talked of getting lost while driving, leaving the stove on, and forgetting important appointments and obligations. They also reported reduced reading and concentration. (Frank et al., 2006, p.158)

The quote here from Frank et al. (2006) is illustrative of one of the other key issues that arose when participants discussed symptoms of MCI; the disagreement between care partners and individuals experiencing MCI. It is not clear from the reviewed articles whether individuals with MCI underestimated their symptoms, lacked awareness, or whether informants over-exaggerated the problems, or felt that there was a bigger impact of these symptoms than the individual themselves did. Given the complexities of MCI, it is likely that both of these possibilities are in action. People with MCI generally have awareness of their situation and thus would be able to recognise their own difficulties, but it is likely that care partners are more vigilant to these deficits, as they feel the stress of taking on extra roles and supporting the individual. As such, care partners may feel the pressure of the situation more than the individual living with MCI thus may be more likely to highlight the difficulties than the individual themselves.

When individuals living with MCI were asked via a survey to identify symptoms they experienced which were MCI-related, 10% (n=3) highlighted physical symptoms, most probably a result of normal ageing, such as stiff joints and visual problems as being MCI-related (Lin et al., 2012). One study of illness representations in older adults with MCI found that there was an approximately equal split of participants living with MCI agreeing (46.7%) and disagreeing (43.3%) with the statement “The symptoms of my condition are puzzling to me” (Lin et al., 2012). This suggests that some people feel more confident and informed about MCI than others, or potentially that some are more aware of their symptoms than others. Alternatively, there may be a range of other influences which impact on individuals’ perceived levels of puzzlement, including social class, ethnicity, gender and educational level. It is unlikely that the root of this difference resides in demographic dissimilarities as the sample for this study was predominantly male (80%), white (96.7%) and married (70%). However, the time since diagnosis varied dramatically across participants from three to 106 months so this could play a role in responses, as people who had a diagnostic label for a longer time period have had longer to begin to understand their situation and to live with their symptoms, developing their understanding and acceptance, and thus may find their symptoms less puzzling.

3.4.2 Causes of MCI

Throughout these articles, participants alluded to what they considered as the cause of MCI symptoms. These causes included: *physical illness, negative attributions, “I’ve been basically that way most of my life”, and normal ageing.*

3.4.2.1 Physical illness

For the most part, participants reported that symptoms were the result of a distinct physical illness or a concurrent health problem. For example, a participant living with MCI attributed the cause of his cognitive difficulties to be the result of hip surgery (Banningh et al., 2008), a family member believed that a stroke had caused memory problems in her relative (Kuo & Shyu, 2010) and Blieszner et al. (2007) identified that ‘Health conditions such as stroke, multiple sclerosis, and Parkinson’s disease as well as previous accidents and contagion were all theorized as the root of the elder’s memory problems’ (Blieszner et al., 2007, p.200).

However, despite the assumption that MCI was the result of a physical health condition, one participant expressed his relief that his diagnosis was not a physical problem: “It’s a lot better than having lung cancer” (Lingler et al., 2006, p.796). One article suggested that some participants may actually prefer a more directly physical cause for their symptoms, as a clear physical root would enable the potential for a cure or effective treatment, which is currently lacking for MCI or dementia:

The doctor referred her to the hospital for further tests. Ron and Rose recall being concerned about this – their worst fear at this stage was that Rose had a brain tumour or that there was a physical explanation for her memory lapses. Implicit in this was the possibility of a cure or some treatment for such a condition. (Corner & Bond, 2006, p.7)

The fact that individuals attempt to define a physical cause for the symptoms of MCI could be due to a lack of knowledge about MCI, a coping mechanism in an attempt to deal with such an intangible condition, or, as inferred in the above quote, a hope for a cure or treatment. This could also be a lasting legacy of the medical model, whereby there is an assumption that an illness has a physical cause and associated treatment. This hope for a treatment may also play a role in the causation narrative with individuals being less motivated to engage in healthy lifestyle interventions aimed to prevent physical and cognitive health deficits if there is a perception that the problem can be cured later. Belief that all illnesses have a potential cure

may also result in people feeling more disheartened and anxious following a diagnosis of MCI, where a cure is not available, as this contradicts their expectations.

3.4.2.2 Negative attributions

Other causes of MCI posited by informants and care partners when symptoms were first noticed were laziness and inattention. There was discussion of resultant conflict in interpersonal relationships, due to an expectation that individuals should pay more attention and stop being lazy to prevent their presenting symptoms. For example, Pasymowski, Roberto, & Blieszner (2013) discussed that a husband was initially frustrated by his wife's emerging MCI as he believed her errors and mishaps resulted from her not paying attention:

"I would assign her tasks that she didn't perform well...I thought that was because she wasn't paying attention...Boy, was I wrong. [That] caused us a great amount of difficulty in our marriage because I am rather aggressive...and I couldn't understand because I know she is smart." (Pasymowski et al., 2013, p.224)

This quote highlights another of the key discussion points around causes of MCI: ambiguity and confusion. Somewhat unsurprisingly, given that many care partners reported that MCI was caused by laziness and inactivity, participants, particularly care partners, claimed that MCI was controllable, and that if individuals stayed active (physically, mentally and socially) they would be able to treat or prevent their symptoms:

Most participants encouraged their family member who was suffering with MCI to go out to associate with others because they believed that interpersonal interaction, such as chatting with others, was beneficial for cognitive health. A spouse stated:

"...of course, I like him to go out. I take a walk with him every morning and evening. I encourage him to go out to chat with the neighbors. If he always stays alone, his cognitive health will decline more quickly." (Dai et al., 2013, p.4)

Family members reported that if the individual would try harder, they would be able to prevent the symptoms they were experiencing, resulting in tension and frustration within the family unit (Roberto, Blieszner, Mccann, & Mcpherson, 2011). Similarly, 20% (n=6) of participants living with MCI stated that MCI was the result of their own behaviour, and 16.7% (n=5) attributed MCI as resulting from becoming less active in their retirement (Lin et al., 2012). This suggests some

individuals felt MCI was controllable, and blamed their own previous activities (or inactivity) for their symptoms.

3.4.2.3 "I've been basically that way most of my life"

Some participants living with MCI in the articles reported that their symptoms were not a new occurrence, and that "I've been basically that way most of my life" (Frank et al., 2006, p.158), therefore they were not concerned by what they were experiencing (Banningh et al., 2008; Blieszner et al., 2007; Frank et al., 2006). In two studies of adults aged over 35, 15% of 149 and 199 participants stated they had always had memory problems (Dale, Hemmerich, Hill, Hougham, & Sachs, 2008; Dale, Hougham, Hill, & Sachs, 2006). This could cause significant delays in help-seeking behaviours if individuals believe their symptoms to be coherent with past experiences.

Similarly, care partners also stated that the individual had always been that way, believing that there was no change from how the person had been throughout their life and that there was nothing presenting of any concern: "Sometimes the elders' long-term habits and behavioral patterns contributed to the ambiguity surrounding the memory loss because any memory problems were easily confused with long-standing behaviors." (Blieszner et al., 2007, p.201). This suggests that care partners may also not recognise the developing symptoms of MCI, misinterpreting lifelong patterns (Blieszner et al., 2007).

3.4.2.4 Normal ageing

Central to many participants' understanding of MCI was the notion that the symptoms of MCI were simply part of normal ageing. Both people living with MCI and their care partners reported that memory decline was a normal part of the ageing process (Banningh et al., 2008; Beard & Neary, 2013; Berg et al., 2013; Blieszner et al., 2007; Kuo & Shyu, 2010). In a survey study of illness representations in older adults living with MCI, 73.3% (n=22) of participants stated "aging" was a cause of MCI; this was the most endorsed cause of MCI in the study (Lin et al., 2012).

Attributing the symptoms of MCI to normal ageing may delay the awareness that there are changes worthy of investigation and assessment. Family members described their perception of changes they first observed in the individual living with MCI as the result of normal ageing: 'Although the caregivers described changes in the elders' behaviour and personality,

they attributed these changes to ageing after comparing the elders' conditions with those of others in the same group' (Kuo & Shyu, 2010, p.3481). Similarly, over 70% of 197 Israeli family physicians reported that MCI was caused by normal ageing (Werner, Heinik, & Kitai, 2013), which is interesting in itself given the diagnostic criteria for MCI as a syndrome distinct from normal ageing (Winblad et al., 2004). However, it is the case that people do experience cognitive changes as they age, for example processing speed slows and declines (Eckert, Keren, Roberts, Calhoun, & Harris, 2010). It may be that this is what the physician respondents were considering in their answers but the diagnostic criteria of not normal ageing makes this difficult to define.

3.4.2.5 Other causes

In a questionnaire study of 30 people living with MCI, more than half stated it was a hereditary condition and that there was a genetic risk factor involved (Lin et al., 2012). Whilst this was not explicitly discussed in the qualitative articles, this was alluded to by a participant living with MCI: "Although it seems to be in our genes I think I am the one who is least affected" (Banningh et al., 2008, p.152). In a survey study of individuals living with MCI, 50% (n=15) of participants believed MCI was the result of abnormal brain changes, and 40% (n=12) attributed MCI to stress and worry (Lin et al., 2012). This suggests that people living with MCI believed there was a wide variety of potential causes for MCI, including causes which were entirely out of their control. By attributing the cause of their symptoms to be out of their personal control, participants may have been defending themselves from feeling that there were any actions they could have taken to protect themselves, or it may simply be that these individuals did not believe that there were controllable causes of MCI.

3.4.3 Association with dementia

Throughout the discussions about MCI, both people living with MCI and their care partners frequently referenced dementia and the associations of memory problems and ageing with dementia. Many participants related a personal experience of dementia, with 82-87% of 149 and 199 adults aged over 35 stating that they had known someone with AD, and 40% had taken care of someone with AD (Dale et al., 2006; 2008). Individuals with a family history of dementia were prone to fearing they would similarly develop dementia or that there may be a hereditary link (Banningh et al., 2008; Berg et al., 2013). Several participants experienced relief when they were not given a diagnosis of dementia:

Examination of the narrative accounts revealed that feelings of relief typically emerged within the context of a looming Alzheimer's disease diagnosis. Thus, for relieved individuals, the meaning assigned to cognitive impairment was entangled with perceptions of the concomitant absence of a dementia diagnosis. (Lingler et al., 2006, p.795)

Participants expressed being relieved after the first investigation at the memory clinic when told that the examination provided no evidence for Alzheimer's disease. "Yes, I was really nervous before the first visit. And when I spoke to the doctor after that investigation, I was told that it was not Alzheimer I had. And it was so wonderful to hear that." (Berg et al., 2013, p.296)

Over 80% of 63 participants living with MCI agreed with the statement "I feel relieved that it is MCI, not AD" (Lin & Heidrich, 2012). These feelings of relief suggest participants may not be aware of the increased risk of dementia, and highlight how frightening people find the prospect of dementia.

Some participants directly referenced their fear of developing dementia (Banningh et al., 2008; Lingler et al., 2006). In one study, 36.7% (n=11) of participants living with MCI believed this would progress to dementia (Lin et al., 2012), while another study of 46 people living with MCI and 29 care partners found that individuals living with MCI reported a 20% likelihood that they would develop dementia in the next five years, but 40% stated there was absolutely no likelihood of developing dementia (McIlvane, Popa, Robinson, Houseweart, & Haley, 2008). Conversely, care partners in this study reported a 33% likelihood of the individual with MCI progressing to dementia in the next five years, and only 19% of care partners stated there was no likelihood of the individual developing dementia (McIlvane et al., 2008). This suggests that there is a wide variability of views regarding dementia risk for individuals living with MCI and their care partners, with care partners being more likely to report the risk of developing dementia than people living with MCI.

In several discussions, it appeared participants focused more on the diagnosis not being dementia, than what the diagnosis actually was:

"Well, to be quite honest. I think I was relieved. I knew that I had a problem. I was concerned probably like everyone would [be], that I had Alzheimer's, and then he [the neurologist] said, "You don't have Alzheimer's" and you know that's like taking a cloud

off your shoulder...So I knew I had the problem, so giving it a title, you can call it anything you want, but it's not Alzheimer's, so I can live with it" (Lingler et al., 2006, p.795)

In a study of adults aged over 35, 41% of 149 participants and 39% of 199 participants worry about developing AD, and 80-92% of these respondents stated that they would want to know as early as possible if they had AD (Dale et al., 2006; 2008), suggesting that people fear dementia, but also want to know if they have cognitive difficulties as soon as possible. This is a complex juxtaposition of views, highlighting that people may not be willing to seek help and assessment for cognitive difficulties due to their fear of dementia, but also want to know as early as possible if they have a dementia. Overall, participants were fearful of dementia, and the perceived impacts and outcomes of a dementia diagnosis were overwhelmingly negative:

Anxiety about memory loss and dementia were common themes in interviews with older people. Dementia was presented as the condition they most feared. Participants' responses to people with dementia and perceptions of the experience of dementia were negative; a loss of independence, control, identity, and dignity were perceived to be inevitable. (Corner & Bond, 2006, p.9)

In a survey study of 420 American Academy of Neurology members, 90% of clinicians reported sometimes or routinely discussing the risk of AD with individuals living with MCI, and 59.1% discussed this in numeric terms to provide clear information about individuals' risk of developing dementia (Roberts, Karlawish, Uhlmann, Petersen, & Green, 2010). It is unclear whether clinicians considered this discussion to be beneficial, or how this discussion was initiated and framed. It is interesting to note this study asked about the risk of AD, not dementia, though people living with MCI are at an increased risk of dementia, rather than a specific increased risk of AD.

3.4.4 Lack of information

Throughout the articles, there was a clear theme around information provision for people with MCI and their families, and it was apparent that people could not access the information they wanted. One of the most frequent references to information provision (in six of the 20 qualitative articles) was around lack of information from medical professionals, particularly at the time of diagnosis:

The couples' lack of understanding about the cause of the elders' memory problems and potential long-term effects on their everyday lives was not surprising given that they received only vague information from their physicians about the diagnosis, related symptoms, and medication that may slow the rate of decline. (Blieszner et al., 2007, p.200)

In a survey of 420 American Academy of Neurology members only 34.5% of clinicians reported either sometimes or routinely providing a written summary of findings for the individual with MCI and their family, suggesting individuals are not always provided with adequate information at time of diagnosis (Roberts et al., 2010). However, it is not clear whether the views of participants regarding a lack of information stemmed from them not receiving appropriate information or whether they may have forgotten or not acknowledged information provided due to the emotive and challenging nature of receiving a diagnosis. It is apparent that providing written information at the point of diagnosis may be beneficial as it would enable people to refer to the information again. One study also found that participants who tried to find information about MCI from sources other than healthcare professionals discovered a paucity of accessible information:

Forced to seek information on their own, some spouses turned to the internet, public library, and occasional brochures they found at doctors' offices for explanations of dementia. But in general, the majority found very little material specific to MCI written for lay audiences. (Blieszner et al., 2007, p.200)

In all of the reviewed articles, no reference was made to any participant having adequate information about MCI, though many participants searched for as much information as possible:

They [people living with MCI] also wanted more knowledge about ways to adjust to MCI to live as well as possible. Participants proactively sought knowledge from healthcare professionals, friends, and other persons who had been diagnosed with MCI, media reports, and the Internet. (Lu, Haase, & Farran, 2007, p.81)

A wife care partner even believed that, thanks to her persistent searches, she now knew more about MCI than healthcare professionals:

“If there is something I don’t understand, I will go on [the computer] and look it up. And sometimes I think I know more than [health professionals] do...I just want to be able, [if] something happens, where I can take care of him as far as [possible] in every situation...”
(Blieszner & Roberto, 2009, p.17)

This suggests that both people living with MCI and their family members are keen to access information about MCI. However, despite this desire to learn more about MCI, it appears that accessible information is currently lacking and individuals struggle to obtain the information that they want to know, particularly from healthcare professionals.

3.4.5 MCI as a diagnostic label

One of the issues I aimed to address was whether MCI is an appropriate and acceptable diagnostic label, and to investigate what people know and understand by the term “mild cognitive impairment”. However, from the studies which were found, there was some discussion of MCI as a diagnostic label, but this was rarely a focus of any great exploration. One study explored the views of clinicians about the use of MCI in clinical practice and found there were a variety of reasons why different clinicians, both across different professions and in different countries, considered MCI as a useful clinical diagnosis or not (Moreira et al., 2008). Overall, the authors of this study concluded that institutional values, context and cultural norms had a considerable impact on the use of MCI as a diagnostic label, and that the variability seen in the use of MCI may reflect the uncertainty of its predictive power for dementia (Moreira et al., 2008).

An important point to raise here is the notion of labelling and diagnosis. Being given a diagnosis generally involves the identification of the nature (and often the underlying cause) of an illness. A label on the other hand, may refer to a more fluid concept or a social construct. For example, in the case of homosexuality, this was a clinical diagnosis in the 1960’s, but was removed from the DSM in 1973. Following this change, “homosexual” became a label but no longer a diagnosis. This change impacted societal perceptions around homosexuality, reducing the stigma that had been inherent in the diagnosis, and facilitating the acceptance of homosexuality. Whilst sexuality is clearly a very distinct concept from that of mental or physical health and illness, this illustrates the impact that defining a term as a diagnosis can have on societal perceptions and attitudes. As such, it is important to consider whether MCI is classed

as a diagnosis or a label, and how this is perceived by individuals living with MCI and within the wider society.

In a survey of 420 American Academy of Neurology members, participants used a variety of terms when diagnosing MCI, including MCI (70.3%), memory loss (51.1%), AD (30%), cognitive disorder not otherwise specified (22.4%), dementia not otherwise specified (15.4%), and amnesic disorder not otherwise specified (10.6%) (Roberts et al., 2010). However, 91% (n=413) of UK psychiatrists stated that they made the diagnosis of “MCI” (Rodda et al., 2013) and 82% of 121 Australian clinicians and 89% of 42 surveyed clinicians in New Zealand reported using the term “MCI” (Mitchell, Woodward, & Hirose, 2008). Interestingly, 44% of clinicians in New Zealand also reported using other terms when diagnosing MCI, including “benign forgetfulness of old age” and “memory not so good”. In Israel, 82.2% of 197 family physicians stated they had heard of MCI, but 30% further stated they knew nothing or almost nothing about it (Werner et al., 2013). This suggests that no consensus has yet been reached in clinical practice as to how to diagnose and label this syndrome. This lack of consistency around the use of MCI as a diagnostic label was also reflected in the information that individuals living with MCI received: ‘Many MCI patients had been told they had “mild memory loss” or “a memory problem what was not too bad”, but most were not given a specific name for their disorder’ (Frank et al., 2006, p.156). Perhaps unsurprisingly, given the diagnostic information provided to individuals experiencing MCI symptoms, participants were not sure what the term “mild cognitive impairment” meant and did not know how to define this (Beard & Neary, 2013, p.138).

Only 23% of adults aged over 35 had definitely heard of MCI (Dale et al., 2006), and 53% stated “definitely no” when asked if they had heard of MCI previously (Dale et al., 2008). However, despite this, a survey of older adults living with MCI found that 60% (n=18) of participants disagreed with the statement “MCI doesn’t make any sense to me” suggesting that terminology may not be the most important thing – having a label is the crucial point, regardless of the specific term applied (Lin et al., 2012). It was also suggested that not having a diagnostic label served to increase participants’ uncertainty and apprehension: ‘Whether or not this reflects the level of information provided at diagnosis, or a lack of knowledge surrounding the MCI term, the absence of a label seemed to increase the uncertainty.’ (Roberts & Clare, 2013, p.305)

Lingler et al. (2006) found that participants living with MCI were satisfied to have professional validation of their symptoms and found comfort in having a name for their symptoms:

“Oh, I feel that it’s a good thing to...to try to get some result for what the heck is going on and why.” The man replied ‘absolutely’ when the interviewer clarified his statement as follows: “So having [or rather] knowing that there is a name for this, makes you feel better than not having anything to call it?” (Lingler et al., 2006, p.796)

However, Roberts & Clare (2013) found some participants living with MCI were not in agreement that a label was necessary or beneficial, and that there was a much wider context that could not be summed up by a simple label:

Although some participants opposed the use of a label, the fact that they acknowledged the issue highlights that they believed there to be something which needed a label, demonstrated by the following comment made by Betty.

“...because I think you can’t live just under a label, there’s other, surrounding, you can have a label, can’t you, you know, but it, that isn’t the whole thing, it needs context” (Roberts & Clare, 2013, p.305)

The belief that having a label is important was also verified in a survey of 420 American Academy of Neurology members with 91.2% of clinicians agreeing with the statement “labelling the problem is helpful for patients and family members”. This group also felt that labelling the symptoms was useful to enable patients to plan for the future (86.6% agree) and a common theme in open-ended responses to the survey was that “a MCI label alerts physicians and families to monitor for changes and progression of symptoms” (Roberts et al., 2010, p.428). In a survey of 453 UK psychiatrists, respondents reported that MCI was a useful diagnosis for doctors (24%), patients (10%) and both doctors and patients (65%), however, some psychiatrists stated that MCI was not a helpful concept and did not consider MCI to be a diagnosis *per se*, while others commented that it was useful to be able to give patients a name for their symptoms (Rodda et al., 2013). Overall, clinicians believed that MCI was a useful diagnosis and that being able to provide a diagnosis was important.

In one of the articles, there was a direct reference made to the word “mild” and how this impacted on participants’ views and understandings about MCI. A participant living with

MCI felt that, since the diagnosis was “mild” this therefore reflected a minor difficulty, and thus prompted a sense of relief:

“Well since he said mild, that, that sort of gave me some relief there, that maybe my...it’s not all that serious and maybe I can get improvement on although they did say there’s no way you can improve it, it’s just a matter of living with it...Hopefully it’s going to get worse; not hopefully, but possibly.” (Case 5, a 78-year-old man with nonamnestic type) (Lingler et al., 2006, p.796)

One of the included articles presented findings from family members of individuals living with MCI in China, allowing a view of diagnosis in this country (with such a different language and culture to the UK). Here, participants were not comfortable with the language used when discussing dementia and MCI:

“When the doctor told us that she was diagnosed with MCI, and she has a high risk to develop AD [“laonian chidai”], my family and I couldn’t accept the diagnosis of “chidai”. Why do doctors call it “laonian chidai”? During this interview, please call it “jiyili zhang’ai” [which mean memory decline or memory loss]...The diagnosis was made by the doctor, but we don’t think that she is serious enough to match the diagnosis...” (Dai et al., 2013, p.5)

Exploring labelling from multiple cultural perspectives is key to furthering our understanding of the acceptability of labels and terms used to discuss cognitive impairment and exploring whether it is possible to establish or identify a single label which is acceptable to people worldwide.

One of the most interesting findings, in my opinion, was the fact that adults aged over 35 indicated they would be more willing to seek assessment if a family member suggested they may have cognitive difficulties (97%) than if they noticed memory problems themselves (81%) (Dale et al., 2008). This suggests it may be crucial to ensure that a wide range of individuals understand what MCI is in order to ensure family members can spot symptoms and prompt help-seeking actions. This also raises concerns for individuals who live alone or are socially isolated.

3.4.6. Changed person

Across the articles included in this review, there was frequent discussion around how living with MCI impacts an individual, their activities, personality and independence. Two key opposing subthemes were identified: *people with MCI aren't who they used to be*, and *the person with MCI is still there*.

3.4.6.1 *People with MCI aren't who they used to be*

Many participants, particularly care partners, discussed the impact of MCI on an individual and how this condition resulted in people losing their previous abilities and their independence. Specific reference was frequently made by family members about how the individual living with MCI was dependent on them and required supervision and monitoring (Betts Adams, 2008; Frank et al., 2006). However, this view of dependency may in part be due to family members' perceptions that people with MCI should stay active in order to prevent cognitive decline:

Spouses who touted this 'use it or lose it' philosophy often took it upon themselves to assign elders household tasks, arrange outings, and engage them in activities to reduce idle-ness. Their goal was to eliminate MCI, which suggests a misunderstanding of the etiology of the condition. (Blieszner et al., 2007, p.202)

There was frequent reference (13 articles) to an individual with MCI as a fundamentally changed person, no longer the person they had been, as exemplified in this quote from the wife of an individual living with MCI: "[I'm] dealing with him as a changed person, 'cause that's not the person I married..." (Betts Adams, 2008, p.14). Family members made particular reference to the changed nature of their relationship with the individual living with MCI. This was reflected in marital relationships, where spouses described a change in the relationship with their husband or wife:

"I got along with my husband when we were younger. At that time, he believed it was his good fortune to marry me. However, lately he didn't like that I stayed with him and he wished that I would leave. I couldn't believe that his personality changed so dramatically." (Kuo & Shyu, 2010, p.3481)

Similarly, adult children frequently discussed changes in their parents and how the parent-child relationship had almost reversed, or dissolved:

“It is certainly not a mother and daughter relationship anymore, it’s just not. She is gone. You want to slap her silly and say “Wake you, where are you?” You know, because she still looks the same. It’s still your mom standing in front of you but she can’t act like your mother anymore.” (Betts Adams, 2008, p.16)

It is clear that MCI was a source of great change within family units, resulting in changed relationships and having a widespread impact.

Individuals living with MCI also viewed themselves as changed individuals, unable to be relied upon and struggling to undertake activities they once used to. This decline evidently caused distress and negative emotions for individuals who were often in shock about changes they were noticing, and were disappointed in themselves. For example, one man living with MCI reported struggling to read, finding it hard to move through the lines of written text: “I get trouble reading it and what actually happens I’ll read a line and then go to the next line, the trouble is when I go to the next line, I’ve missed a line and I go back on the line I’ve already read” (Roberts & Clare, 2013, p.305). One woman living with MCI described her embarrassment and distress when she forgot to perform a sewing task for a bride, a task she had previously done a lot for others:

“I think it started with the sewing. People would ask me to sew something for them and I’d forget about it. They would come to pick it up and I would then remember it. I’d feel so bad not having done it. It was a wedding dress I think. The girl came to try it on and I’d forgotten all about it. Yes, that was the first time I think. I couldn’t believe I did that.” (Parsons-Suhl et al., 2008, p.35)

Interestingly, this participant did not report negative responses from others, but highlighted her internal disappointment in herself. This could be due to no external negative responses being elicited, or it may be that internal blame and embarrassment was a more pervasive emotion. There is a complex interplay between internal and external responses and emotions which may influence how individuals perceive what it means to be labelled with MCI.

3.4.6.2 The person with MCI is still there

There were several references throughout the articles to people with MCI still being capable and able to continue with their previous activities, including maintaining their participation in household and social activities (Roberto, McCann, & Blieszner, 2013), travelling

abroad alone (Roberts & Clare, 2013, p.304), or even taking up new activities, such as mentoring: “There is another young man that I’ve met just out of prison not long ago, and I know I’ll start mentoring him and that’s what I need in my life. I need to be useful; I need to be active” (Lu et al., 2007, p.78). It is interesting to note the use of language here “I need to be useful” suggesting that this man living with MCI may not have felt “useful” since his diagnosis.

It was perceived as important to individuals living with MCI to retain their independence, and, for the most part, this was supported and facilitated by family members. This determination to maintain independence may have arisen from a fear of losing autonomy as a result of their cognitive difficulties, but may also be a result of different personality types or coping mechanisms. Ultimately, there was a clear conflict of opinions between individuals who considered that MCI caused such a change in the individual and their abilities that they became a changed person entirely, and those who viewed individuals with MCI as still the same person, not defined by their cognitive difficulties, and still capable to live independently. There is a plethora of factors to be considered in what constitutes personhood and what makes someone uniquely them.

3.5 Discussion

The discussion of MCI symptoms in 22 articles suggests that this aspect of MCI is an important consideration. The three most prominent symptoms, repetitiveness, forgetting, and loss of communication and language skills, were highlighted by many participants. These particular symptoms were the most noticeable, and potentially the most distressing, to both care partners and individuals experiencing MCI. Several participants remarked that it was due to repeating themselves, alongside forgetting names and faces and being unable to carry out conversations as they previously had, that other people noticed their symptoms and thought that they were acting strangely (Nakano et al., 2012). Other people noticing symptoms was a cause of some distress for participants (both people living with MCI and their care partners) who often wanted to hide their condition. There was a noticeable contrast to this view in a study from China where care partners expressed that MCI was not something to be hidden, but that it was an illness, like any other illness, and not something people should be embarrassed about (Dai et al., 2013). This could be due to the notion of filial piety (Laidlaw, Wang, Coelho, & Power, 2010), so MCI as a condition that is experienced most commonly in older age does not detract from the culture of respect towards older adults. The notion that symptoms were generally first noticed by care partners rather than by the individual themselves raises concerns for people

who are socially isolated as they may not be able to identify their own symptoms and thus may not seek help and assessment unless their symptoms become more severe.

There were infrequent references to physical symptoms, which some individuals viewed as MCI-related. This may be the result of some people trying to find answers for a wide range of symptoms experienced as they grew older, or may be a result of people viewing MCI as inseparable from normal ageing, therefore encompassing all the symptoms they have experienced as they age. Either way, it is clear that people need further information about the symptoms of MCI to ensure that individuals understand what symptoms are associated with MCI, and what are unrelated to MCI, but may present as a result of normal ageing or as symptoms of another health condition. If individuals were better informed about the symptomology of MCI it would enable people to seek appropriate help and advice in a timely fashion. This increased knowledge and understanding amongst the wider population as a whole may also reduce the incidence of the “worried well” presenting for assessment, as it may reassure people as to what cognitive changes are associated with normal ageing, and at what point specialist assessment is recommended.

Inherent with the discussions of MCI symptoms were the methods and strategies employed by participants to cope with these symptoms. Many care partners, particularly spouses, took on the role of acting as the individual’s memory, reminding and prompting them and supporting them to live well. This has direct implications for care practice, as it highlights the importance of providing family care partners with information regarding how best to prompt and support individuals living with MCI as part of the diagnostic/follow-up process, as they play such a crucial role in the care and management of MCI. Care partners also play a key role in recognising early cognitive changes in their loved ones, so ensuring people are aware of how to recognise the symptoms of MCI is essential to help ensure timely diagnoses are made.

Participants posited a variety of causes of MCI, ranging from physical causes, to normal ageing. This is similar to the literature on illness causation accounts for other conditions including breast cancer (Wilkinson, 2000) and type 2 diabetes (Lawton, Ahmad, Peel, & Hallowell, 2007; Lawton, Peel, Parry, & Douglas, 2008; Parry, Peel, Douglas, & Lawton, 2006; Peel, Parry, Douglas, & Lawton, 2005), where participants reported multiple possible causes for their condition. One of the causes of MCI which was discussed most frequently by care partners, but occasionally alluded to by individuals living with MCI, was laziness, inattention and inactivity. Inherent with this thinking was the idea that MCI could be effectively treated or prevented if the

individual was prepared to try harder, or if they engaged with more stimulating activities. Whilst there is some evidence in support of physical activity being associated with reduced risk of MCI (Geda et al., 2010), there is no evidence to date which suggests physical or mental activity can prevent or treat the symptoms of MCI. The media portrayal of dementia may also play a role in this perception due to the discourses around preventing dementia with physical exercise (Peel, 2014). Further information is needed to clarify the role of physical and mental activity in cognitive health to ensure that people do not have false hope about curing MCI, or put unnecessary pressure and expectations on individuals living with MCI to improve their symptoms. This also reflects the views of individuals living with type 2 diabetes who reported contrasting perceptions about the underlying cause of their illness, ranging from their own behaviour or past “wrongdoing” (Lawton et al., 2008, p.895) causing their diabetes, to viewing diabetes as the result of uncontrollable external influences (Lawton et al., 2008; Parry et al., 2006). Accounts of diabetes causation also varied according to cultural background, with Indian and Pakistani participants living with type 2 diabetes being more likely to attribute their illness to external, uncontrollable factors than white participants (Lawton et al., 2008). This cultural difference around causation perspective may span a breadth of illnesses and conditions and thus may also be applicable to causation beliefs of MCI. Further exploration of causation accounts and beliefs across culturally diverse populations is important to identify where population beliefs may differ according to cultural factors, and where beliefs differ or converge according to more personal, individual factors.

For some individuals, there was a perception that the symptoms of MCI were not a new experience, and they had always had memory difficulties. This makes the issue of diagnosing MCI even more difficult, as people are less likely to present for help and assessment until their symptoms become more pronounced. Similarly, the fact that so many people, including some clinicians, viewed MCI as a result of normal ageing is something that needs to be addressed as this does not fit the criteria for MCI (Banningh et al., 2008; Blieszner et al., 2007; Lin et al., 2012; Werner et al., 2013). It is important to explore where the boundaries are perceived to lie between normal ageing, MCI and dementia so that individuals who begin to experience cognitive difficulties may better understand when to seek help. This also raises the issue of when and how to define a cognitive problem; how severe and frequent do cognitive changes have to be to be defined as problematic and who are they a problem for? If the individual themselves has not noticed a cognitive impairment or decline that they believe to be problematic this could be due to a lack of awareness (which could be part of the symptomology), or could result from

the individual being in denial about their cognitive health and the presenting symptoms. Understanding what constitutes a cognitive problem for an individual and what people expect as they age is important to develop a clear picture of what MCI means to people and how to best present clear information explaining what MCI is. Decreasing fear of dementia may also play a key role in helping people recognise cognitive changes as they would potentially be less likely to engage in protective strategies, such as denying the presence of their cognitive difficulties.

The frequent references to dementia is an interesting, but not unexpected finding, as the two concepts are often discussed in parallel, and there is a high prevalence of information and media references to dementia, particularly negatively framed portrayals (Peel, 2014) which may evoke a fearful response in older adults. The fact that so many individuals had a personal experience of dementia is an important consideration for both future research and clinical practice, as it is important that this prior knowledge and awareness is addressed to consider the anxiety a future dementia diagnosis may invoke. Furthermore, how some individuals may choose to view an MCI diagnosis as an explicit ruling out of dementia is a further issue. It is important to explore whether individuals benefit from being told of their risk of dementia following a diagnosis of MCI, and how and when this information should be presented.

It is clear that there is a paucity of information available about MCI. Many people felt they did not receive adequate or sufficient information from healthcare professionals. However, to date, no studies have explored diagnostic practices in any detail. It may be that this information is provided at the time of diagnosis – Roberts et al. (2010) found that 90% of clinicians reported sometimes or routinely discussing the risk of AD with people living with MCI – but individuals forget it or are not able to receive and process this at the time of diagnosis. It certainly appears to be the case that there is little accessible information available about MCI outside of the healthcare setting and this is undoubtedly an issue that needs to be addressed. However, to provide adequate information, future research should seek to address the as yet unanswered questions about MCI such as prognosis and treatment, as well as better understanding what information people want. There is also a note of caution here, as Dale et al. (2006) found that people who had heard of MCI previously were less willing to receive an assessment of their cognition, suggesting that prior knowledge of MCI may actually result in people being more reluctant to engage in help-seeking behaviours. This may again be the result

of the fear of dementia thus reducing this fear may increase help-seeking actions for people with cognitive concerns.

One of the issues I aimed to address in this review was the terminology used when discussing MCI, and how people experienced and understood the label of MCI. Tellingly, very few articles considered this, and those that did were predominantly focused on the opinions of clinicians and academics rather than the views of individuals living with MCI, their families and the wider population. There were several references to the language used around MCI, and it was clear that there was no consensus around this for clinicians, who differed within and across disciplines and countries. However, the most important factor regarding a diagnosis, for both clinicians and patients, was the assignment of a label to validate the symptoms being experienced. This suggests that, whilst further research is needed to explore what people understand about the term MCI, individuals find receiving a label to be reassuring, particularly when they have been fearful of being diagnosed with dementia. Exploring what diagnostic label is most acceptable to a wide range of people will hopefully enable open, transparent discussions about MCI without ambiguity.

The final theme in this synthesis was *changed person*. There were two starkly contrasting opinions about how MCI impacts on an individual. Some viewed people living with MCI as no longer the same person, that they lost their independence and were no longer capable of engaging with their previous hobbies and activities. On the other hand, some people perceived individuals with MCI as still the same person and still independent, capable and valued individuals. This dichotomy of opinion did not appear to stem from any demographic criteria. It may be that some people are just naturally more positive, or it may be that some individuals had more advanced symptoms, or symptoms which impacted more on their day-to-day life. The perception of whether an individual was “changed” or not also raises an interesting question around how we define what constitutes personhood. If someone were to lose a limb and be unable to draw anymore, an activity they previously enjoyed, would we say they were no longer the same person they had been, or would the physical impairment negate this as it is a more obvious “change” than the less visible cognitive changes inherent in MCI? Future research should explore similarities and differences between cognitive and physical impairments and how these impact on perceptions of an individual. Again, the notion of controllability and causality may be drawn into focus here, including an exploration of whether the perceived level of control

an individual has over their own health and circumstances plays a role in how society views that person.

3.5.1 Views of experts on MCI

Following the searches for this review, a special edition of the journal *Dementia* was published focusing on expert reflections on MCI (Peters & Katz, 2015c). This included nine interviews with experts in MCI from a range of disciplines, including neurology, psychiatry, psychology, sociology, social gerontology, epidemiology and the creative arts. The breadth of disciplines encapsulated in these interviews highlights the multi-disciplinary nature of the study of ageing and cognitive health and emphasises the importance of understanding MCI from a variety of perspectives. From the discussions presented, it is clear MCI is still lacking a consensus view, with interviewees presenting distinct opinions around the labels and diagnostic terms they choose to employ and their reasons for this. For example, Dr Petersen stipulated his view of MCI as a useful research entity and that one of the main issues with labelling MCI is the misunderstanding of clinicians and the general population alike that MCI is equivalent to early AD (Katz & Peters, 2015d). Dr Lyketsos, on the other hand, did not support the label MCI and preferred to use the term 'not normal, not demented' for this particular population group (Katz & Peters, 2015b). Similarly, Dr Brayne stated that 'cognitively impaired, not demented' was a much more useful category than MCI (Katz & Peters, 2015a). Dr Morris reported that, in his research, the focus was more on understanding the aetiology of presenting cognitive difficulties, thus the MCI label was not something he employed (Katz & Peters, 2015c). Professor Bond highlighted that MCI is a useful label for clinicians, but is a less valuable label for the individual living with cognitive impairment due to the lack of support, treatment and prognostic information available (Peters & Katz, 2015b). However, despite these differing opinions, both Dr Basting (Peters & Katz, 2015a) and Dr Brayne (Katz & Peters, 2015a) stated that people want a label, seeking validation and reassurance about their subjective concerns.

These expert views support the main finding of this review, which is that, as a diagnostic label, MCI is in need of further consideration. From the discussions presented with the nine experts, many questions for future research and exploration were raised, particularly around how to more accurately define and diagnose MCI. Dr Brayne sums up the current situation around diagnosing MCI very eloquently:

'It is incumbent on us as researchers and clinicians to know that, if we are going to label somebody with a diagnostic label that we should also be reasonably sure that they are going to benefit from that label rather than be harmed by it. My evaluation of the literature is that we do not have that evidence yet.' (Katz & Peters, 2015c, p.359)

It is clear there are many unanswered questions around providing an MCI diagnosis.

3.5.2 Limitations

Whilst this review has highlighted some important areas of interest there are limitations of the studies included. Firstly, there was a lack of reporting clarity in a number of the studies regarding data collection processes and information about participants. As such, there are considerable issues for generalisability and replicability of these studies. It is likely participants who were given a diagnosis of MCI following pre-diagnostic counselling may be more receptive and more accepting of their situation than an individual who received a diagnosis with little or no prior information about what to expect. This creates difficulties around extrapolating from the study results where it is not clear what diagnostic or recruitment process participants were involved in. It is acknowledged that this is difficult information to capture but, where possible, future research should seek to consider the potential impact of the diagnostic process on experiences and perceptions of MCI. Most of the qualitative studies also lacked sufficient description of the analytic methods employed and did not provide much evidence of primary data to substantiate the claims made by the authors. As such, it is difficult to evaluate the credibility of the authors' claims and to assess whether the results are applicable to other populations, or are truly representative of the study population.

There is a lack of longitudinal research with most studies employing one-off data collection methods, thereby only representing information at a specific time point. Longitudinal studies, on the other hand, enable research to consider perspectives across time points, identifying potential changes in perception over time. Longitudinal qualitative methods have been highlighted to have benefits for exploring the needs and experiences of individuals with progressive disorders (which MCI can be) in order to capture the complex and multifaceted changes experienced over time (Carduff, Murray, & Kendall, 2015).

The studies identified in this review were predominantly drawn from a sample of white, middle class populations, with the majority of studies conducted in America. This results in a biased picture of perceptions and experiences of MCI, with a lack of representation from

culturally, ethnically and geographically diverse populations. Understanding the role of cultural differences in the way MCI is perceived is an important consideration for future research. The study by Dai et al. (2013) around perceptions of MCI in China yielded considerably different views from those evident in America and the UK about societal perceptions of people living with MCI, particularly with regards to respect and stigma.

Many studies focused on amnesic MCI and do not consider the non-amnesic variant. If the opinions of individuals living with non-amnesic MCI and their care partners were explored, the symptoms of MCI for this group may differ, and their experiences and views of MCI may also be considerably different.

3.6 Conclusions

This review highlights a number of disagreements and lack of cohesion about the meaning and impact of MCI amongst a variety of individuals. Future research should explore this further to ascertain where these disagreements and differences in perspective lie and amongst whom in order to provide future tailored information. Given the strong association between dementia and MCI, and the fact that many people view MCI as a result of normal ageing, it is important that the boundaries between these three concepts are more clearly delineated if possible. This would ensure people can understand when cognitive decline becomes a potential cause for concern, and when MCI might be progressing to dementia. It is also clear from this review that there is currently a paucity of research which seeks to explore how people understand the term MCI and whether this is an acceptable label for the syndrome that people are experiencing. If there is to be an answer to the debate over the utility of MCI as a clinical diagnosis it is essential that future research explores what this label means to people, including individuals who do not have direct experience or expertise around MCI, and what language individuals use when discussing cognitive impairment. This discussion will hopefully enable the development or identification of a shared language, free of ambiguity and confusion, to enable people to talk together about MCI and raise awareness of this syndrome by allowing discussions to take place across different populations.

3.7 Summary

In this chapter, I have presented a systematic review exploring the literature around knowledge and understanding of MCI. The results of this review have identified gaps in the

current literature base, including a lack of exploration of lay population views around cognitive impairment and a lack of consideration regarding labels and language surrounding cognitive impairment, particularly whether MCI is an appropriate and acceptable label. In the next chapter I will outline theoretical views of illness perception and labelling which, together with the results of the systematic review presented here, have informed the development of an illness representation model of cognitive impairment.

Chapter 4: Towards an Illness Representation Model of Cognitive Impairment

4.1 Introduction

In exploring what people know and understand about MCI, it is important to consider how individuals perceive illness and make sense of experiencing or identifying symptoms and categorising these within a labelled or diagnosed syndrome. It is also essential to consider the role that personal identity and societal and cultural influences play in determining what people understand about an illness and how this then impacts on an individual who is diagnosed or labelled with a particular syndrome. As such, I explored the literature around diagnostic labelling and identified three key theories which were utilised to frame the basis for the subsequent two research studies in this thesis and to provide a foundation on which to develop an understanding of how people may construct their views around what cognitive impairment is. The first of these theories, labelling theory, explains how individuals who are given a diagnostic label are perceived by others, based on societal conceptions of what it means to be labelled. This is particularly relevant to the research here as it suggests that being labelled with MCI may have a direct impact on how that individual is treated by others and the impact this may have on their life. The second theory, attribution theory, suggests that people react differently to a labelled individual depending on the perceived controllability of an illness. As such, if people view MCI as a syndrome which can be prevented then they are more likely to exhibit negative affective reactions towards an individual diagnosed with MCI than if they consider that MCI has a biological, uncontrollable basis. Finally, the common-sense model of illness representation suggests that people develop illness representations to help them make sense of symptoms. Understanding the illness representation of MCI is key to identifying where information provision may be able to raise awareness of MCI and to produce a more definite picture of MCI.

After exploring these three theories, I established a model of MCI illness representation, incorporating core aspects of labelling theory, attribution theory and the common-sense model of illness representation. This model also included the results of the systematic review in Chapter 3 to develop a potential model of how people understand MCI and how media and societal views and portrayals of cognitive impairment may influence individual views. Having a model which represents how people construct their perceptions and understanding of cognitive

impairment will enable a better understanding of what information may be needed to further inform these views, and to identify where and how stigma and negative perceptions may be able to be reduced.

4.2 Labelling theory

Labelling theory was originally proposed by Scheff (1966) who suggested that being labelled as having a mental illness may actually cause mental illness. It was suggested that people learn cultural schemata and stereotypes through media portrayal, comments and jokes present within society. These stereotypes are then internalised, forming the illness representation that people hold. Once someone experiences a mental illness, the learned illness representation is activated and starts to consume their identity. Scheff proposed that, once an individual is labelled as mentally ill, they then have no choice but to embody the expectations that are held in their illness representation, and they subsequently become mentally ill.

A modified version of labelling theory (see Figure 4.1, p.112) was proposed by Link, Cullen, Struening & Shrout (1989), removing the notion of causality from the theory suggested by Scheff. The modified theory maintains that people internalise what it means to be labelled based on the pervasive societal view. Individuals draw on media representations and social interactions to construct a representation of what it is to be labelled as mentally ill. Link et al. (1989) suggest that there are two key components which people learn from social concepts: the degree to which individuals believe that people who are labelled will be devalued, that is, how much of their status will be lost; and the degree to which labelled individuals will be discriminated against. People who are labelled expect that they will be rejected socially as a result of devaluation and discrimination.

Once an individual is diagnosed, and thus formally labelled, the societal views of what it means to be labelled suddenly hold personal relevance. Link et al. (1989) suggest that there are three possible responses to labelling; secrecy, withdrawal and education. Secrecy refers to individuals choosing to hide their diagnosis and situation from others to avoid rejection. People may also withdraw from social interaction, electing to only spend time with those who know about and are accepting of their condition. By withdrawing, people are protecting themselves from the rejection that might occur if they put themselves into a wider social group around people who may not be accepting or understanding about their condition. Thirdly, people may choose to engage in preventative education, attempting to enlighten people about the condition

and alter the social conception of the illness to prevent negative attitudes. Adopting any of these three responses may result in people limiting their quality of life by missing potentially enjoyable social events and being dissatisfied with the level of enjoyment in their life. Due to the uncontrollable negative responses, rejection, devaluation and discrimination that are expected to accompany the label, this may lead to feelings of shame and isolation, resulting in internal stigma, even if no direct external stigmatising responses have been encountered. As a result of both internal and external reactions to labelling, individuals may lack self-esteem and thus may end up in a vulnerable state, more susceptible to additional mental illnesses such as depression and anxiety. This theory sits comfortably within the critical realist stance adopted for this thesis, drawing upon the constructionist aspect of how our knowledge about the world is influenced and developed by our experiences and interactions. However, there is also a realist aspect to labelling theory, suggesting that there is a reality and a truth beyond the construct of the label that can potentially never be wholly accessed. In this sense, labelling theory provides an explanation as to how lived experiences and views of a societal majority influence individual perspectives about a condition which has a fundamental medical and scientific reality.

In the context of MCI, being labelled as having cognitive impairment may impact how individuals perceive themselves and how society views them following diagnosis. Labelling, and the fear of negative outcomes, may also explain why some individuals do not seek help for their presenting symptoms for quite some time after first becoming aware of their cognitive decline. If the societal perception of someone with cognitive impairment is negative, individuals are likely to fear rejection and negativity if they are labelled as experiencing MCI. To date, no studies have explored labelling theory in the context of MCI and whether this theory may help to understand how people experience this diagnosis and what the societal view of people with MCI is. With regards to dementia, Burgener and Berger (2008) found that people living with AD had high levels of perceived stigma, rating high levels of financial insecurity, social rejection, social isolation and internalised shame. If individuals with AD feel this way, this may also be the case for individuals experiencing MCI, as the two syndromes are closely linked, and it may be that people perceive the symptoms of MCI to be indicative of AD and thus treat people with MCI in the same way that they would respond to people living with AD, which is likely to be negatively.

There is no consensus around whether MCI is an appropriate clinical diagnosis, and there is controversy around whether MCI should be viewed as a research construct, rather than a diagnostic label (Garand et al., 2009; Moreira et al., 2008). MCI is not currently a universally

accepted diagnosis, with a wide variation in the use of MCI as a diagnostic label in clinical practice (Moreira et al., 2008). In a recent special edition of the journal *Dementia*, Peters & Katz (2015a) conducted interviews with experts in the field of MCI from a variety of disciplines. The interviewees presented diverse views about the label of MCI and the terminology that they viewed as most appropriate for individuals experiencing these symptoms. However, two of the interviewees, Dr Brayne (Katz & Peters, 2015a) and Dr Basting (Peters & Katz, 2015b) stated that people experiencing cognitive impairment want a label, as this provides validation for their concerns. As such, it is clear that whilst the label of MCI may not be the most appropriate, it is essential to explore what label people assign to cognitive impairment as this is a syndrome which will not cease to exist simply because the label of MCI is not used in some settings. To date, very few studies have explored the impact of being labelled with MCI, though it has been suggested that being diagnosed with MCI does not provide the same relief that people experience when given a diagnosis of dementia (Banningh et al., 2008) and that there is confusion and uncertainty about the future (Dean & Wilcock, 2012; Garand et al., 2009). Identifying the role that labelling theory may play in the impact of a diagnosis of MCI is vital to understanding whether this term is an appropriate clinical diagnosis.

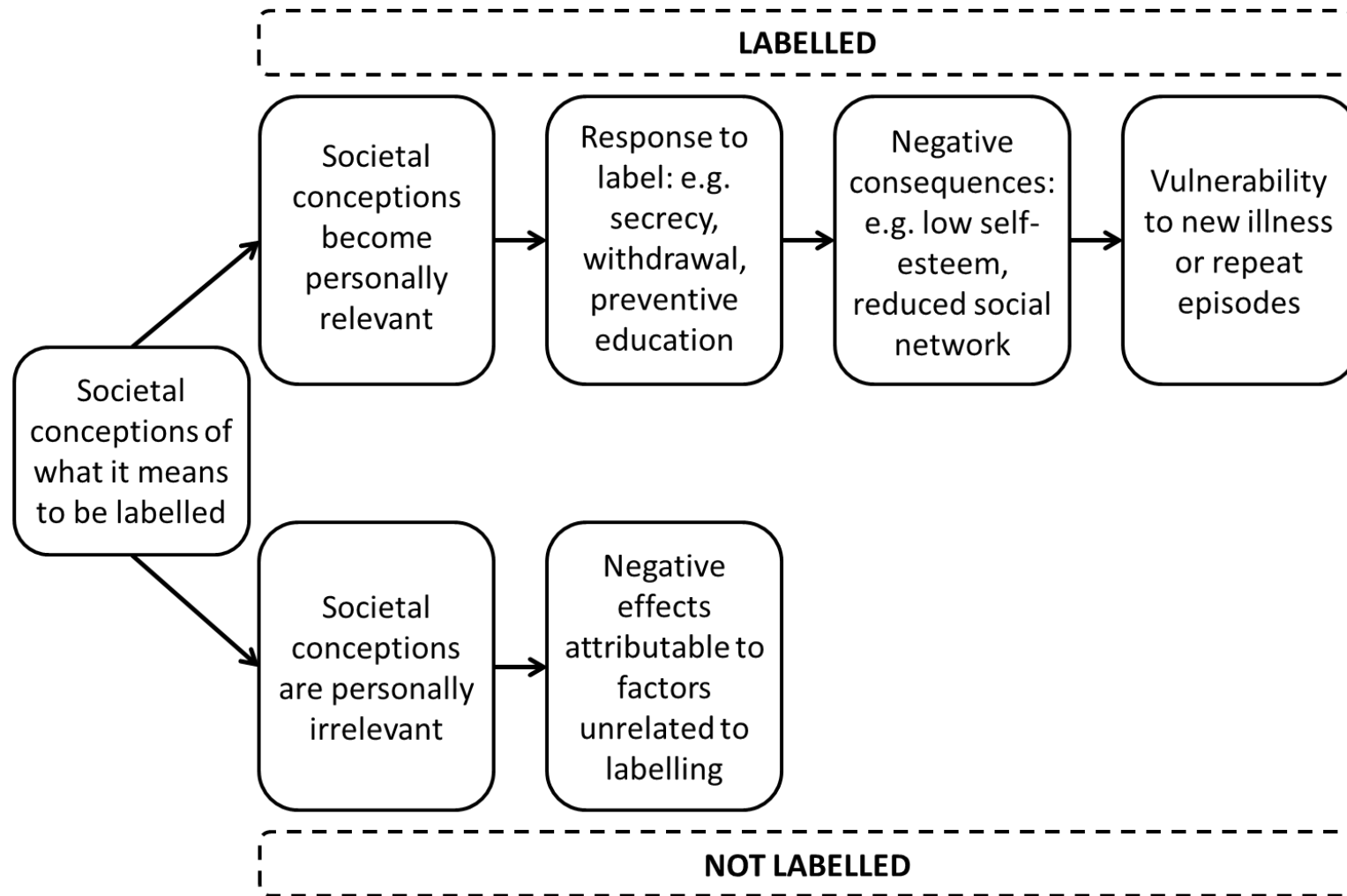


Figure 4.1: Diagrammatic representation of labelling theory (adapted from Link et al., 1989). Societal conceptions of what it means to be labelled determine how an individual responds to being given a diagnosis and this response, in turn, may lead to negative consequences for the individual and increase vulnerability to a new illness or repeat episodes.

4.3 Attribution theory

Weiner (1993) proposed attribution theory, a theory of perceived responsibility and social motivation. He suggested that either anger or sympathy may be elicited in response to certain illnesses and diseases depending on the perceived level of control that an individual has over this. For example, in the case of obesity, if it is assumed that an individual is obese because they have chosen to over-indulge and overeat, the response to this is generally negative, with people displaying anger at the fact that the individual was too lazy to do anything about their condition. As a result of this anger, people are less likely to offer help to the obese individual or to be understanding about their condition. On the other hand, if an individual is obese due to a thyroid problem, something which is completely outside of their control, then people are more likely to be sympathetic to this, and thus more likely to offer help and exhibit positive attitudes towards this individual. Ultimately, people make judgements about whether someone is responsible for what is happening to them, or whether their current situation is beyond their control, and the perceived level of responsibility dictates whether anger or sympathy is elicited, in turn decreasing or increasing social behaviours such as help giving (see Figure 4.2, p.115). From a critical realist perspective, attribution theory fits with the constructionist aspect, suggesting that people construct an idea of whether an individual is responsible for their own situation and circumstances, but also considers the realist view that there is a real world and a truth as to whether someone is or is not responsible. The emphasis in this theory is very much on the constructionist viewpoint but does not contradict the overarching tenets of critical realism.

Whilst labelling theory suggests that individuals living with a label of dementia or MCI may experience negative outcomes and stigma, attribution theory actually suggests the opposite; that people will be more willing to help a “brave sufferer” (Weiner, 1993, p.959). Weiner, Perry & Magnusson (1988) found that, when people rated 10 stigmatizing conditions (AIDS, AD, blindness, cancer, child abuse, drug addiction, heart disease, obesity, paraplegia, and Vietnam War syndrome) on responsibility for these conditions, anger and sympathy responses, and attitudes towards help giving, AD was rated low on perceived responsibility. People living with AD elicited pity and sympathy, rated high on liking, and people responded that they would generally be willing to help these people. This is a stark contrast to that which is suggested by labelling theory. Wadley and Haley (2001) asked female undergraduate students to read vignettes in which an older parent was exhibiting inappropriate social behaviour. Participants

were informed that the parent was experiencing AD, depression, or that they had not been diagnosed with either of these conditions (no label), and they were also told whether this behaviour was congruent with the parent's personality (three levels; congruent, incongruent, no information). The label of AD resulted in more sympathy towards the parent, less blame and a greater willingness to help. This suggests that the label of AD may actually result in positive rather than negative outcomes. As such, labelling theory may need to be adapted to incorporate the potential for positive societal views which may result in sympathetic responses.

The current media portrayal of dementia is one which expounds potential preventative and protective actions and activities, including healthy diet and exercise (Peel, 2014) which suggest that dementia has a controllable causality. Given the close link between dementia and MCI, some people may believe that both dementia and MCI are preventable conditions. According to attribution theory, this media portrayal may result in people responding negatively to individuals who are diagnosed with MCI, perceiving that the individual could have prevented the condition thus resulting in a negative affective reaction.

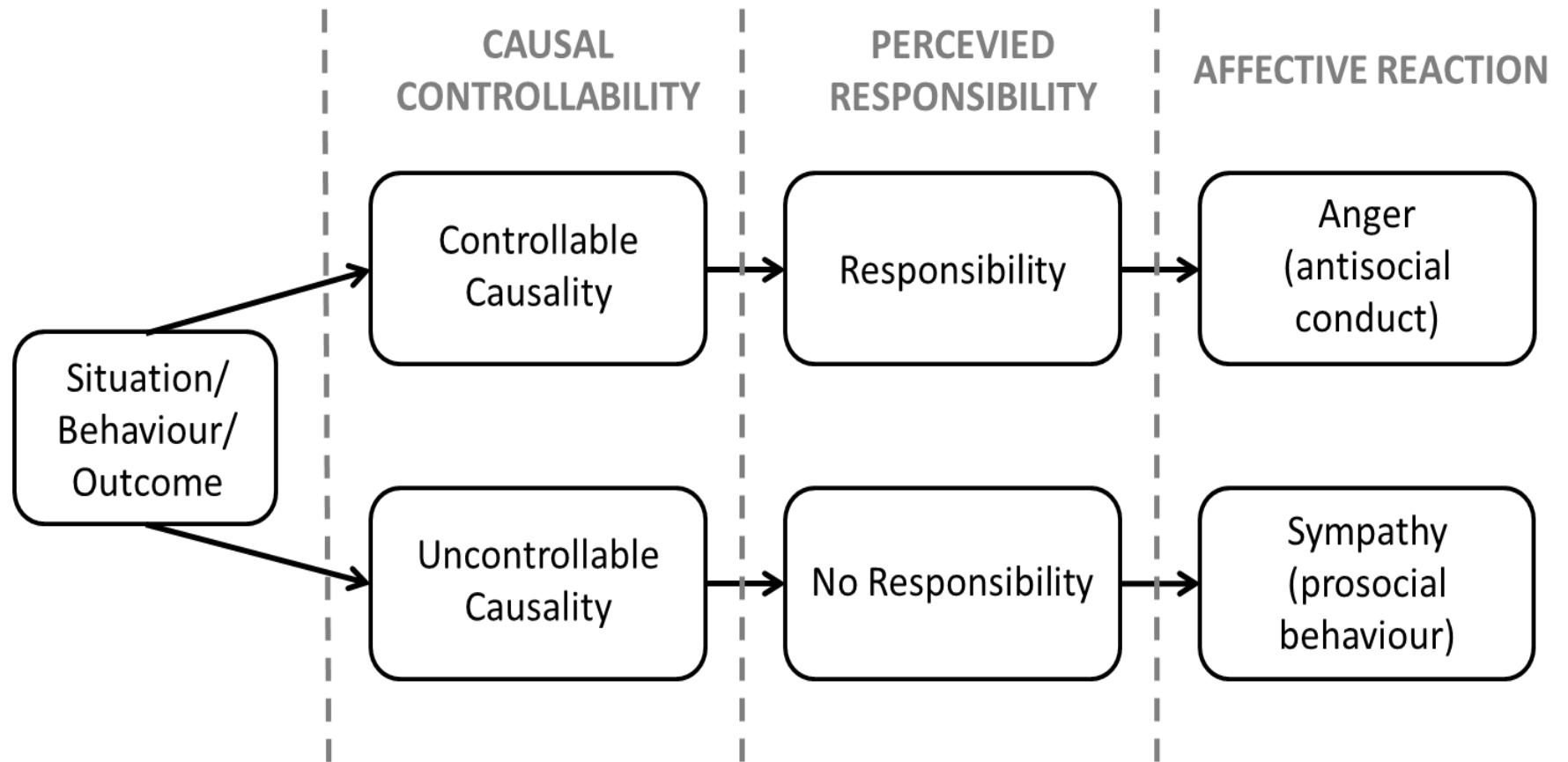


Figure 4.2: Diagrammatic representation of attribution theory (based on Weiner, 1993). People make judgements about whether a particular behaviour or situation is believed to be within an individual’s personal control. The decision around the perceived causal controllability and personal responsibility for a given situation or behaviour determines whether an angry or sympathetic affective reaction is elicited.

4.4 Common-sense model of illness representation

The common-sense model of illness representation (CSM) was suggested by Leventhal, Meyer & Nerenz (1980). This model proposes that people develop illness representations to help them make sense of a particular set of symptoms or a presenting syndrome, providing a framework for understanding the illness, enabling people to know what symptoms to look out for and how to respond and react to presenting symptoms (Morrison & Bennett, 2009). Illness representations are developed and formed through information presented in the media, via personal experience, and from information (conversations and observations) from friends and family (Morrison & Bennett, 2009). Due to the nature of their formation, illness representations can range from vague to intricately detailed. When an individual experiences a symptom, they try to match this symptom to a pre-existing illness representation (Cameron, 2003). This form of symptom recognition and classification may lead to potentially hazardous errors in judgement if a symptom, such as visual disturbance, is assessed as being a migraine based on previous experience or knowledge, when it is actually a sign of something more serious, such as a stroke.

CSM is a dual-processing model, incorporating the objective (cognitive) and subjective (emotional) components of processing illness stimuli in parallel. Individuals actively process the information they receive about an illness, and a coping response, which is considered appropriate, is then elicited. Stimuli which trigger illness representations may be internal or external. Internal stimuli may take the form of direct symptom experience, such as having a headache or a sore throat. External stimuli could include an information leaflet or poster about an illness. If an individual's illness representation about the presented illness suggests that it is preventable then this may result in the person undertaking preventative actions (Diefenbach & Leventhal, 1996). Throughout this process, individuals appraise and revise their views and actions to ensure that they are responding with the most appropriate course of action that they consider they can. These feedback loops enable individuals to be responsive to both internal and external stimuli and changes, facilitating the selection of the most appropriate coping responses in order to achieve a desired outcome. If an individual becomes concerned about their symptoms and struggles to map these to an appropriate illness representation, they may seek information and advice from family and friends, or may choose to seek professional help (Diefenbach & Leventhal, 1996). As such, the structure and content of an illness representation is not concrete, with an individual potentially modifying and adapting their illness representation based on new experiences or information (see Figure 4.3).

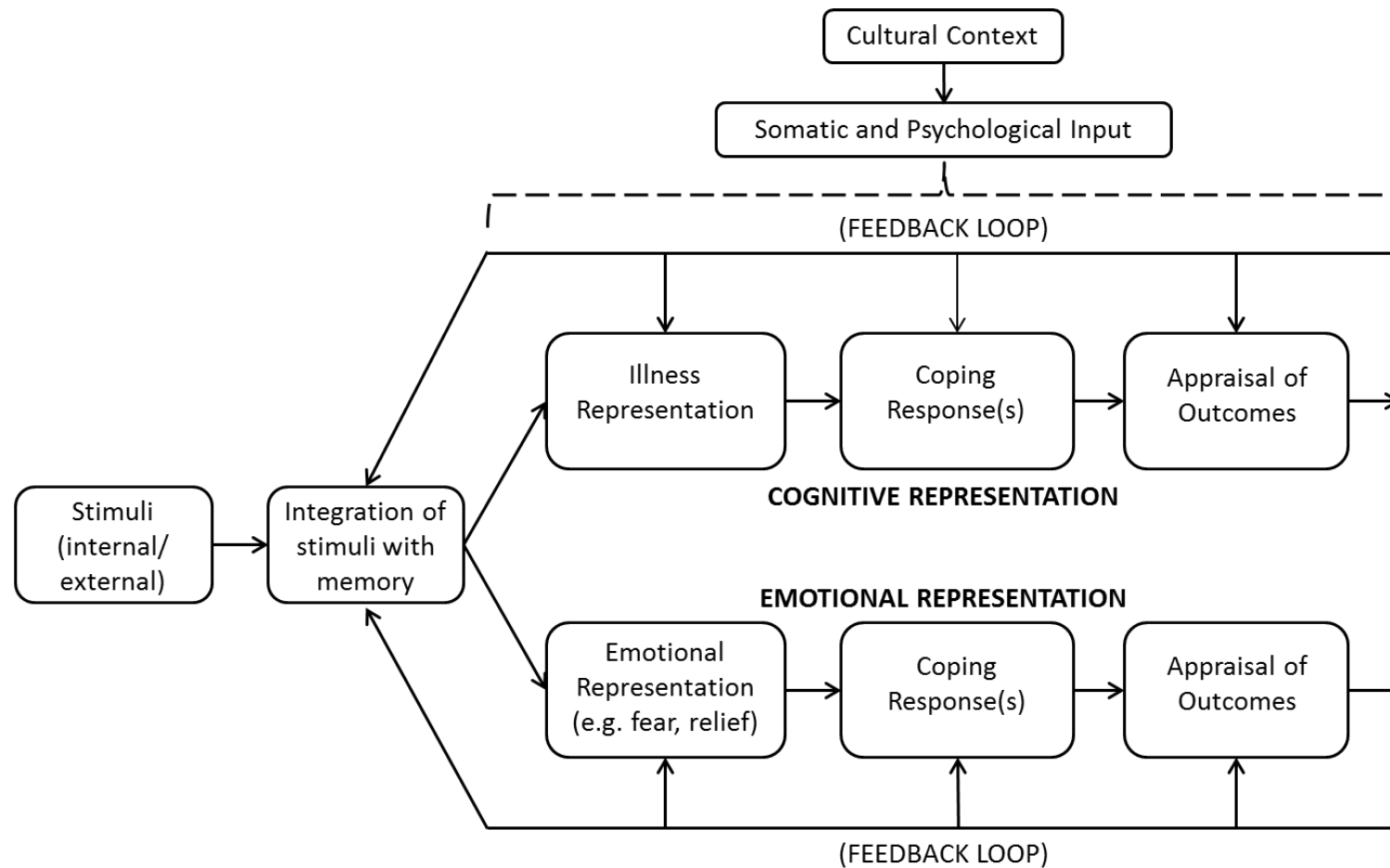


Figure 4.3: Diagrammatic representation of the common-sense model of illness representation (adapted from Leventhal, Nerenz, & Steele, 1984). When an individual encounters a given stimulus, this is mapped onto an illness representation on both a cognitive and emotional level. The representation that is activated then determines the coping responses that are elicited to respond to the stimuli. Outcomes are appraised, and adjustments to the representations and coping responses are made accordingly. Feedback loops enable each process to inform any other part of the model.

Alongside the cognitive processing of illness stimuli, an emotional response is also elicited. The categorisation of symptoms may result in either positive or negative emotions, and these emotions then impact on the coping response selected. For example, an individual who experiences a chest pain may cognitively assess this as being indigestion and thus their emotional response is minimal and positive: “This will get better soon. It’s not serious. I have nothing to worry about”. However, this chest pain could be assessed as being a precursor to heart attack, in which case the emotional response is negative and more pronounced: “This could be fatal. I’m anxious about what might happen”. In the latter case, the strong emotional reaction will most likely prompt the individual to seek help and will motivate a fast and efficient coping response to ensure that medical advice and attention is received quickly, whereas the prior example would result in a minimal response, due to both the low cognitive and emotional valuation placed on the symptoms and associated representation. The interaction of both the emotional and cognitive processes of the CSM determine the course of action that an individual will take upon encountering illness stimuli.

There are five key attributes contained in an illness representation:

1. Identity: The set of symptoms and accompanying label for the illness.
2. Consequences: How the illness will affect life. This could be physically, emotionally, socially, financially, psychologically or via a combination of multiple factors. The consequences of an illness may be short- or long-term.
3. Cause: The factor(s) that may cause an illness. These may be internally or externally located causes, including psychological, emotional, biological, genetic, environmental, or as a direct or indirect result of an individual’s actions and behaviour.
4. Timeline: The timeline that is viewed as associated with the illness, in terms of development and duration. This may be acute, chronic or episodic.
5. Controllability: The extent to which an illness is viewed as controllable or treatable either by the individual experiencing the illness, or by others (such as healthcare professionals). This dimension was added to Leventhal et al.’s (1980) original model by Lau and Hartmann (1983).

When an individual forms an illness representation, it will generally comprise information about all five of the attributes listed, though some attributes may be more clearly defined and established than others. For example, if an individual is experiencing the flu for the first time, they may have some idea that this will most likely last for five days, based loosely on the

experience of a family member. However, when their particular symptoms persist for ten days, the timeline attribute within their illness representation for flu is adapted accordingly and becomes a more certain concept following their own personal experience. Illness representations are fluid concepts which may change over time with the receipt of new information and experiences (Weinman, Petrie, Moss-Morris, & Horne, 1996).

With regards to the methodological stance adopted for this thesis (see Chapter 2), CSM can be considered from a critical realist perspective. Under this stance, CSM outlines an illness as something real, a true aspect of the world as viewed from a realist perspective. However, how each individual perceives this truth and reality of the illness differs according to their construction of what it means to have this illness. In this manner, CSM fits comfortably within the critical realist perspective, as a model which suggests there is a real world but our views and perspectives of this reality are shaped by our experiences and interactions with the world and with other people.

In the context of MCI, Lin et al. (2012) found that some individuals living with MCI correctly identified symptoms, acknowledged ageing, abnormal brain changes and heredity as the causes of MCI, and believed MCI to be somewhat predictable, chronic and controllable through personal strategies, scoring MCI low on emotional distress. However, there was no consistency amongst participants as to whether they had a clear understanding of MCI, with nearly equal numbers of participants agreeing and disagreeing with the statement “The symptoms of my condition are puzzling to me”. Whilst this study begins to explore the illness representations of MCI that individuals hold, to date there have been no studies which seek to identify the illness representations of MCI held by people who do not have personal experience of cognitive impairment. It is essential that the perspectives of multiple populations are considered and compared in order to address differences in beliefs about MCI to facilitate communication and shared decision making amongst individuals living with MCI, their care partners and wider family and social network, and healthcare professionals, thus providing more person-centred care (Lin et al., 2012). There is also the question to be raised as to whether MCI is an illness which can foster an illness representation *per se*. Given the current prognostic uncertainty surrounding MCI, whereby individuals may remain stable over time, progress to dementia or revert to normal, it may be that there are too many aspects of the CSM which cannot be answered as it may be challenging to consider the timeline and controllability of MCI.

The cause of MCI may also be a difficult attribute to answer, as there may be differing aetiologies of MCI, with many different diseases potentially leading to cognitive impairment (DeCarli, 2003).

4.5 Factors Influencing the Development of Representations

The development and modification of illness representations may be affected by a variety of factors, both external and internal influences, which impact upon how an individual perceives and understands an illness.

4.5.1 Social/Self-identity

For most people, there are a number of social identities that they possess at any one time, though the salience of these identities may fluctuate depending on context. For example, a 47-year-old married father of three, who is completing a part-time Master's degree, whilst maintaining employment as an accountant, possesses the social identities of husband, father, student, and accountant to name just a few. Levine and Reicher (1996) proposed a model of symptom evaluation which suggests that the way in which an individual interprets symptoms depends on their current salient social identity, not on pre-existing illness representations. The authors found that, when female participants were defined by their identity as "female" rather than "PE student", they perceived illness or injuries which threatened their physical attractiveness as being more serious. In their proposition for this model, Levine and Reicher (1996) suggest that the feedback process within the CSM relates to long-term changes resulting from the accumulation of new knowledge or experiences, or more broad cultural shifts in perspective. However, the CSM does not stipulate that changes to illness representations are a long-term, slow shift, in fact, the feedback loops appear to be structured in such a fashion that adaptations may be made on a very quick basis. The CSM should be expanded to consider how social identity impacts on the formation and use of illness representations and the model should be probed further to explore the time taken for a change to be made to an illness representation. How an individual views themselves and their identity is key to understanding how threatening they perceive a given illness to be, and as an individual's identity changes with age or differing circumstances, their illness representations may change too. In the case of MCI, if an individual's identity is entangled with intellectual prowess, then this is likely to be perceived as a considerable threat to their identity.

4.5.2 Prevalence

It has been suggested that illness representations may be shaped by the experiences of others, not just in forming the representation, but in the way in which severity and importance is assessed. Jemmott, Ditto & Croyle (1986) found that participants who were presented with a fictitious illness rated this as less serious when the prevalence was high than when the illness was presented as a rarer condition. This suggests that symptoms may be perceived as less serious if it is something that other people are also experiencing (Diefenbach & Leventhal, 1996). It is thus important to consider how the experiences of peer groups may impact on the formation of an illness representation. This is particularly salient in the case of MCI, where the symptoms which an individual experiences may be very similar to the natural progression of ageing, or to the neurodegenerative processes observed in dementia. As such, it is likely that individuals who begin to experience symptoms of MCI and who have not had direct experience of dementia will maintain a belief that their presenting symptoms are not particularly serious as many other people are experiencing what they perceive to be the same thing – particularly if the individual does not assess their lapses in memory and thinking to be a problem or concern.

4.5.3 Personal risk/Susceptibility

People may assess their own perceived susceptibility to an illness when considering whether their presenting symptoms are likely to be an indication of that illness. For example, an individual in their 20s is less likely to assess a chest pain as being indicative of a heart attack than someone in their late 50s due to the lower risk of heart attacks in younger adults as compared with middle-aged and older individuals. Brewer et al. (2007) conducted a meta-analysis of studies assessing the association between vaccination and perceived susceptibility and severity. The authors found that individuals were most likely to be vaccinated against an illness if they believed themselves to be susceptible to it. It also follows that an individual who is presenting with a high temperature, fever and nausea who has never travelled outside of the UK would attribute their symptoms to flu and not to malaria, as their susceptibility and risk for the latter is very slim given their present circumstances. Therefore, it is likely that older adults will perceive themselves as being at high risk for experiencing MCI or dementia as these conditions predominantly present in later life. For individuals who experience young-onset MCI, they may be more likely to attribute their symptoms to stress or depression as opposed to MCI as a unique syndrome. As such, age and circumstances are likely to play a role in perceived

personal susceptibility to MCI and thus whether they would be likely to map any presenting symptoms onto a representation of MCI.

4.5.4 Age

As people age, they expect to experience a decline in their general physical and cognitive health and functioning. It thus presents a challenge for older adults to distinguish between the normal ageing process and a set of symptoms indicative of a specific illness or syndrome (Diefenbach & Leventhal, 1996). This is a particular challenge for individuals experiencing symptoms of MCI, symptoms which nestle in between the cognitive changes observed as a normal part of ageing, and dementia. As such, individuals who experience MCI may perceive these symptoms to be part of normal ageing, as it has been suggested that adults across multiple age groups expect memory to decline with age (Lineweaver, Berger, & Hertzog, 2009; Lineweaver & Hertzog, 1998).

The concept of age is also a flexible construct, and how an individual perceives themselves and their age categorisation is a complex issue. For example, if a child was asked what age was old, they may respond that old could apply to anyone over 30, whereas an 80-year-old may look at their 65-year-old friend and be envious of their youth. As such, whilst research principles generally state that anyone aged over 65 is an older adult, this does not mean that this is how people aged over 65 perceive themselves. Therefore, a 70-year-old woman who is starting to notice problems with her memory and thinking may be alarmed at this as she does not perceive herself to be an older adult and therefore does not believe that she should be experiencing any cognitive decline. On the other hand, a 45-year-old man who is experiencing similar symptoms may not be concerned by this at all as he believes that he is getting old, and that the decline he is noticing is thus part of this ageing process.

The impact of age can also be seen in the uncertainty that people are willing to tolerate when they encounter a threat to their health. Leventhal, Leventhal, Schaefer & Easterling (1993) found that adults aged 65 and over were more likely to seek medical help faster than adults aged between 40 and 55, particularly when the symptoms they experienced were believed to be potentially serious. The middle-aged participant group avoided seeking help due to fearing what might be found, whereas the older adults preferred to remove the uncertainty and worry about the illness by seeking help sooner. However, when symptom severity was perceived to be mild, there was no significant difference between older and middle-aged adults with both

reporting waiting and watching before seeking help. This has particular implications for the recognition and assessment of MCI, where symptoms are, by very definition, mild, and thus older adults experiencing symptoms are likely to wait and see how things progress before seeking help. It is therefore likely that people experiencing symptoms consistent with MCI are likely to not seek help due to low perceived seriousness of their symptoms, even though older adults may otherwise generally seek help more promptly than middle-aged individuals for illnesses that are perceived to be more serious.

4.5.5 Fear and avoidance

When an illness representation suggests that a particular illness is uncontrollable, this can be very anxiety provoking and may result in people avoiding seeking assessment, fearing the possible diagnosis and associated lack of treatment; avoiding the threat (Diefenbach & Leventhal, 1996). In the context of cognitive decline in adults, this threat avoidance may result in people being reluctant to seek help and assessment for symptoms because they are fearful of dementia. The media portrays dementia in a very negative light, as a condition to be feared (Peel, 2014), thus it is likely that this fear is assimilated into people's illness representations of dementia, and therefore people experiencing cognitive difficulties are likely to avoid the threat of dementia by not seeking help and assessment.

4.6 MCI illness representation model

Drawing on the three theories outlined above, I would suggest that the way in which people perceive and understand MCI will be impacted by the connotations of the label and whether this is considered to be a condition which people can prevent or control. In other words, are people personally responsible for MCI? Several studies have begun to consider illness representation of MCI but have focused on the views of people living with MCI (Hurt, 2006, Lin et al., 2012; Lin & Heidrich, 2012) and have not yet considered the perspectives and representations of people without cognitive impairment. Based on the results of the systematic review presented in Chapter 3, it is possible to clarify some of the five key attributes of the CSM of illness representation for MCI.

4.6.1 Identity

A number of key symptoms were identified which were attributed to MCI. These included repetitiveness, forgetting, and loss of communication skills. A study of illness

representations found that about half of older adults with MCI agreed and disagreed with the statement “The symptoms of my condition are puzzling to me”, suggesting that some people are not certain what symptoms fall under the MCI label, or possibly that some people are not fully aware of their symptoms (Lin et al., 2012). As such, it is evident that forgetting, repetitiveness, and loss of communication skills are generally accepted as symptoms attributable to MCI, but there is still confusion around the specific identity of MCI and what the full gamut of symptoms are. The evidence from the reviewed studies suggests that people want validation of their symptoms but further research is needed to explore whether the specific label of MCI is acceptable and appropriate as a clinical diagnosis.

4.6.2 Consequences

Throughout the articles reviewed in Chapter 3, there was frequent reference to how living with MCI affects a person, particularly with regards to their activities, independence and personality (Betts Adams, 2006; Frank et al., 2006; Kuo & Shyu, 2010; Parsons-Suhl et al., 2008; Roberts & Clare, 2013). A number of studies suggested that people with MCI were no longer who they used to be, with the individual now being dependent, requiring constant monitoring and supervision. The impact of MCI on relationships was often mentioned, with spouses feeling that their loved one was no longer the same person they married, and children feeling that they had lost the parent child relationship (Betts Adams, 2006). Individuals living with MCI expressed the embarrassment they felt when they noticed their memory problems (Parsons-Suhl et al., 2008) suggesting that MCI is a source of internal stigma and shame, with people trying to hide their symptoms from others. However, some individuals living with MCI were keen to maintain their independence and continued with their previous activities. There is a clear difference of opinion as to whether MCI has serious consequences for an individual, or whether they are able to continue their normal routines and activities without difficulty. As such, it is important to explore in more detail what people perceive the consequences of MCI to be, and what the overarching societal view of the impact of MCI is.

4.6.3 Cause

The main causes of MCI identified were physical illness, negative attributions, personal skills, and normal ageing. Many participants stated that the symptoms of MCI were the result of a physical illness or concurrent health problem, suggesting conditions such as stroke, multiple sclerosis, Parkinson’s disease and previous accidents and infections were responsible for the

presenting cognitive difficulties (Blieszner et al., 2007). Some participants were relieved that their symptoms were not the result of an underlying illness such as a brain tumour or cancer. However, it is not clear from the studies why participants attributed MCI to physical causes, though it has been suggested that this may be due to the implied possibility of a cure or treatment for a physical illness (Corner & Bond, 2006). Some care partners reported that the symptoms their loved one was experiencing were the result of laziness and inattention, and there was a view that if the person tried harder and was more active (physically, mentally and socially) then they would be able to prevent MCI. Similarly, approximately a fifth of participants living with MCI believed that their symptoms were the result of their own behaviour and could be attributed to becoming less active in their retirement (Lin et al., 2012). This suggests that both care partners and, to a lesser extent, individuals living with MCI considered MCI to have a controllable causality.

Some participants viewed their symptoms as not new and that they had always experienced cognitive difficulties (Banningh et al., 2008; Blieszner et al., 2007; Dale et al., 2008, 2006; Frank et al., 2006). As such, they did not perceive their presenting symptoms as a cause for concern. For those participants who did acknowledge a change in their cognitive functioning, there was a prevailing perception that this was a normal part of the ageing process and that most people their age were experiencing similar symptoms (Lin et al., 2012). This view was not just held by individuals with MCI, but also by the majority of family physician respondents in Israel (Werner et al., 2013), and care partners (Kuo & Shyu, 2010). Other potential causes posited for MCI included genetics, abnormal brain changes, stress and worry.

Research to date suggests that there are a number of causes which people view as responsible for MCI, with many attributing the symptoms to a physical illness (Blieszner et al., 2007) or personal actions (Dai et al., 2013). Opinions regarding the cause of MCI often differ somewhat between care partners and individuals living with MCI, with the former being more likely to attribute MCI to controllable factors. This suggests that there may be some discrepancies between the causality of MCI assigned by different populations and the propensity to attribute this to controllable causes suggests the role of attribution theory in MCI may result in negative reactions of others towards individuals with MCI, fostering stigma.

4.6.4 Timeline

The only aspect of the CSM which was not addressed in the thematic synthesis was the timeline factor. Lin et al. (2012) found that participants living with MCI viewed MCI as long lasting, but somewhat predictable. However, there has been no exploration of what timeline people without cognitive impairment perceive as applicable to MCI, and whether people believe that this syndrome is chronic, acute or cyclical. This is an aspect which needs further exploration, particularly amongst populations beyond just those living with MCI.

4.6.5 Controllability

Both individuals living with MCI and their care partners viewed MCI as personally controllable, with care partners stating that if the individual tried harder they would be able to prevent their cognitive decline. However, this view of controllable causality was not universal, with only a fifth of participants living with MCI stating that their presenting symptoms were a result of their own behaviour. Lin et al. (2012) found that individuals living with MCI viewed MCI as controllable through both personal strategies and medical treatment. This suggests that MCI is generally viewed as controllable. This is supported by the current media portrayal of dementia, suggesting that people can take part in activities which can prevent cognitive decline (Peel, 2014). The perceived controllability of MCI may result in a negative societal reaction towards individuals living with MCI, as suggested by attribution theory.

4.7 Conclusion

By bringing together the three theories presented here, it is expected that the illness representation of MCI, if it is possible to produce one, will be impacted by the societal beliefs and connotations of what it means to be labelled as experiencing cognitive impairment. It is also expected that perceived personal responsibility for MCI will play a key role in the societal view of this (see Figure 4.4, p.128). Current research suggests that people view MCI as a syndrome which could be prevented, and is within an individual's personal control. As such, it is hypothesised that affective reactions to people living with MCI will be negative, and the societal view of MCI will be negative overall.

As MCI is a syndrome which individuals struggle to differentiate from normal ageing, it is expected that people will perceive this as a low threat, and that this will also be a condition which people are deemed not to be responsible for, as one cannot halt the ageing process, so if

MCI is viewed as a disease of old age then this is something which cannot be controlled. However, the media portrayal of dementia is one which highlights the possible preventative and protective actions that an individual may be able to undertake, such as eating healthily and engaging in physical activity (Peel, 2014). As such, people may perceive dementia and MCI to be conditions which are within an individual's control, and thus there may be a high level of stigma associated with MCI. It may also be the case that different groups hold different illness representations based on their current knowledge and understanding of cognitive impairment. Modelling the results of the subsequent research studies onto the framework proposed here will enable a deeper understanding of the way society perceives MCI, facilitating an exploration of how to encourage individuals to seek help in a timely manner, and how to reduce any presenting stigma. In doing so, this could allow people experiencing MCI to have a better quality of life and facilitate the development of information campaigns to raise awareness of MCI, reduce stigma and construct appropriate illness representations.

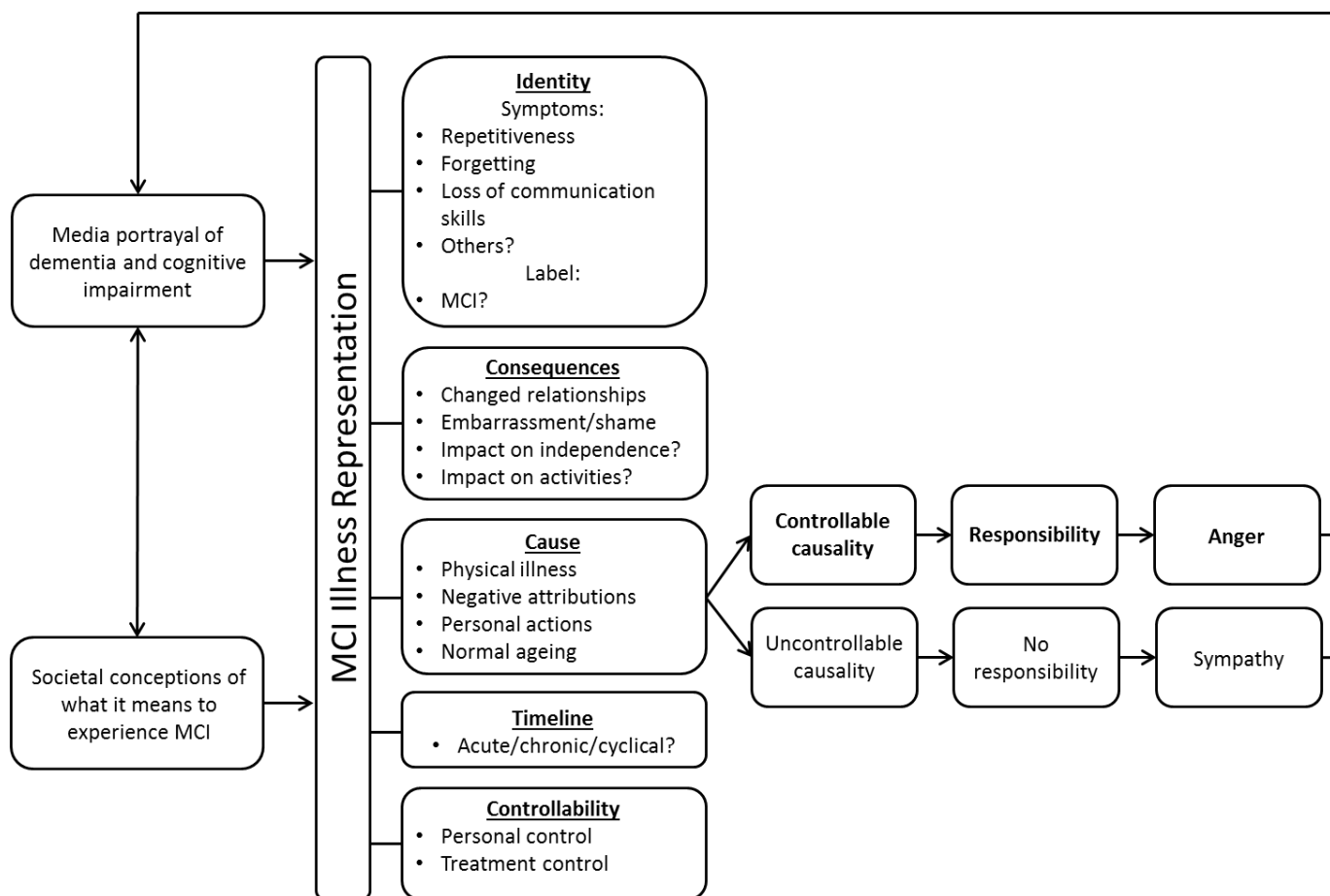


Figure 4.4: Diagrammatic representation of the MCI illness representation model. This model incorporates labelling theory, attribution theory and the common-sense model of illness representation. Societal conceptions of what it means to experience MCI directly influence the illness representation of MCI, and determine the perceived causal controllability of MCI. It is suggested that MCI is perceived to be a controllable condition, and that the societal conceptions of this syndrome will be generally negative. However, this model may differ amongst populations, with healthcare professionals being far more likely to assess MCI as having an uncontrollable causality as they are less likely to be impacted by the media portrayal of cognitive impairment.

4.8 Summary

Combining aspects of labelling theory, attribution theory and CSM, I have suggested an illness representation model of MCI which may be able to account for how individual perspectives of MCI are formed and developed, considering the role that societal and media views may play in the formation of individual understanding. This model incorporates the results of the first research study; a systematic review of literature relating to knowledge and perspectives of MCI. Following the subsequent two research studies, a nationwide questionnaire (Chapter 5) and in-depth semi-structured interviews (Chapter 6), this model will be further developed and refined (see Chapter 7). In the next chapter, I will outline the second research study included in this thesis; a survey study exploring the views of a range of people about cognitive impairment.

Chapter 5: A Survey Exploration of Perceptions About Cognitive Impairment

5.1 Introduction

The study reported in this chapter explored what a wide range of people understand about cognitive impairment and the terminology and language that people use when discussing this, including whether mild cognitive impairment (MCI) is a label that they have encountered previously. At present, there is a paucity of literature exploring what people understand about cognitive impairment and how people interpret the labels used to explain and discuss this. This has contributed to a debate over whether MCI is a clinically relevant diagnostic label or a term which should only be utilised in the research setting (Garand et al., 2009).

A systematic review of the literature available about understandings of MCI found a number of disagreements and a general lack of consistency around the meaning and impact of MCI (see Chapter 3). The results of this review highlight a lack of research investigating the views of the lay population about cognitive impairment, as the studies identified explored the views of people living with cognitive impairment, their care partners and, to a lesser extent, healthcare professionals. Given the high prevalence of MCI (Krinsky-McHale & Silverman, 2013), and the lack of knowledge about MCI in the general population (Jones et al., 2010), research is warranted into public perceptions of MCI in order to develop information resources which can effectively communicate knowledge about this syndrome and raise awareness and understanding (Anderson et al., 2009).

Exploring the current knowledge and understanding of cognitive impairment across people directly affected by cognitive impairment, lay people of different ages, and health care professionals could enable the provision of targeted information campaigns. Exploring language use around cognitive impairment will also enable discussions between healthcare professionals and the wider lay population which are free from ambiguity and confusion. Identifying where different population groups may have contrasting or converging views about cognitive impairment will highlight areas for collaborative work to align these perspectives, such as bringing together expert working groups incorporating membership from different populations to develop information resources and awareness campaigns which discuss cognitive impairment in a manner that is accessible and informative to both experts and a lay population.

5.2 Research Questions

- What do people living with cognitive impairment, care partners, older adults, younger adults, dementia specialists, and healthcare professionals understand about cognitive impairment and do these views differ significantly?
 - As this is an exploratory study, drawing together the views of multiple populations for the first time, I did not propose specific hypotheses in terms of the views of respondent groups across the questionnaire, beyond the expectation that respondent groups may differ given their range of experiences and expertise, but I probed the data to consider where views may differ between respondent groups on particular questionnaire items.
- Is cognitive impairment something which respondents have heard of before?
 - It is hypothesised that healthcare professionals and dementia specialists will be the most familiar with the concept of cognitive impairment and most confident in their own knowledge of cognitive impairment.
- Have more people heard of, and met someone living with, dementia than cognitive impairment?
 - It is hypothesised that more respondents will have experience and self-reported knowledge of dementia than cognitive impairment due to the lack of information available about cognitive impairment (see Chapter 3).
- Where do respondents position cognitive impairment in relation to normal ageing and dementia?
 - It is hypothesised that respondents will show a conflation of cognitive impairment with normal ageing (see Chapter 3) but that healthcare professionals and dementia specialists will not show this conflation due to their increased expertise in this area. It is also hypothesised that respondents will not conflate dementia and cognitive impairment as these are generally perceived as more distinct concepts, with people diagnosed with cognitive impairment expressing relief that they do not have dementia (Lin & Heidrich, 2012; Lingler et al., 2006).
- Do respondents view cognitive impairment as a mental illness?
 - No previous research appears to have explored views of cognitive impairment as a mental illness or not, thus there are no hypotheses in relation to this

question. However, it is important to explore this as positioning cognitive impairment as a mental illness may have implications in terms of labelling theory (Link et al., 1989) and stigma.

- Do respondents consider cognitive impairment to be a definite precursor to dementia?
 - Based on the results of McIlvane et al. (2008), who found that care partners were more likely to report the risk of developing dementia than people living with mild cognitive impairment, it is hypothesised that care partners will report that cognitive impairment is a definite precursor to dementia and that respondents living with cognitive impairment will be less likely to report this.
- What do respondents view as the main consequences of cognitive impairment?
 - Based on the results of the systematic review (see Chapter 3) it is hypothesised that there will be a mix of views across respondents as to whether cognitive impairment is perceived to fundamentally change who a person is or whether someone living with cognitive impairment is still viewed as the same person as they were before the onset of cognitive impairment.
- Do respondents view cognitive impairment as permanent?
 - Given the lack of prognostic clarity for people living with cognitive impairment, I was keen to explore whether cognitive impairment was subsequently viewed as a permanent condition or whether this may be considered to be a more transient syndrome.
- Do respondents consider cognitive impairment to be treatable and/or curable?
 - It is hypothesised that most respondents will not consider cognitive impairment to be treatable or curable, as there are currently no recommended treatment options for people living with cognitive impairment (National Institute for Health and Care Excellence, 2006).
- Do respondents view cognitive impairment as preventable?
 - It is hypothesised that healthcare professionals and dementia specialists will be the least likely to consider cognitive impairment to be preventable, as it is expected that these respondents will have greater knowledge surrounding the variety of causal factors for cognitive impairment, and will be less likely to view cognitive impairment as preventable in order to promote their own sympathetic responses as per attribution theory (Weiner, 1993).
- What factors do respondents consider may cause cognitive impairment?

- It is hypothesised that respondents will endorse a variety of causes for cognitive impairment, including normal ageing (see Chapter 3).
- What terms and labels do respondents apply to describe cognitive impairment symptoms?
 - It is hypothesised that healthcare professionals and dementia specialists will be the most likely to endorse “mild cognitive impairment” as a label due to the prevalence of this term in current research literature.
- Does gender impact views of cognitive impairment?
 - It is hypothesised that females may hold different perspectives of cognitive impairment due to the increased prevalence of dementia amongst females (Erol, Brooker, & Peel, 2015) and thus females may have an increased awareness or fear of cognitive impairment and dementia compared to males.
- Does age impact views of cognitive impairment?
 - It is hypothesised that younger adults may hold different perspectives of cognitive impairment as this is a condition for which risk increases with age and thus younger adults may not have thought much about cognitive impairment before due to the fact that they are less at risk of experiencing it themselves.
- Does having prior knowledge and experience of cognitive impairment and/or dementia impact views of cognitive impairment?
 - It is hypothesised that people who have prior knowledge and experience will have greater confidence in their own understanding of cognitive impairment and/or dementia as a result of their previous experiences. It is also hypothesised that these previous experiences may impact or influence their views about cognitive impairment.
- How do respondents describe cognitive impairment and dementia in their own words, and are their descriptions of cognitive impairment and dementia similar or distinctly different?
 - As this is an exploratory study, there are no clear hypotheses regarding how respondents will describe cognitive impairment or dementia, however, it is suggested that respondents may report some of the negative views posited in media portrayals about dementia (Peel, 2014).

5.3 Method

In order to answer these questions, I designed a survey style questionnaire which could be completed either by post or online. This survey was completed by people who were representative of six participant groups (see Chapter 2).

5.3.1 Recruitment of Target Participants

One hundred paper recruitment packs were distributed to NHS Trusts to pass out to individuals living with cognitive impairment, their care partners, and healthcare professionals. Inclusion and exclusion criteria for the six groups outlined below are provided in Chapter 2.

5.3.1.1 Individuals experiencing cognitive difficulties

Respondents were recruited from five NHS Trusts working with adults experiencing cognitive difficulties. Staff in specialist NHS memory assessment and dementia services identified potential respondents.

5.3.1.2 Care partners

NHS Trusts working with adults experiencing cognitive difficulties also provided recruitment packs to supporters and care partners.

5.3.1.3 Older adults without cognitive impairment

Respondents were recruited through contacts in organisations working with older adults, including charity and community based organisations such as the University of the Third Age, Age UK and the 1000 Elders Project at the University of Birmingham. Potential respondents were identified within these organisations, where the research was introduced to individuals via an electronic mailing list.

5.3.1.4 Younger adults without cognitive impairment

Respondents in this participant group were recruited via a number of avenues. Firstly, the charity and community organisations recruiting older adults without cognitive impairment were asked to inform younger individuals involved in their service about the research. Secondly, I utilised various mailing lists within the University of Worcester to raise awareness of the study to both staff and students.

5.3.1.5 Healthcare professionals

Healthcare professionals (HCPs) working with older adults were recruited from within the NHS Trusts involved in the recruitment of individuals with cognitive impairment and care partners. HCPs were provided with information about the research by their service manager. I attended staff meetings and provided information about the study. HCPs were also recruited via mailing lists of special interest groups and professional memberships such as the Faculty for the Psychology of Older People (FPOP) and Health Education England.

5.3.1.6 Dementia specialists

Individuals working in the field of dementia in a variety of capacities (such as researchers and teachers or trainers) were recruited via a number of avenues including dementia and older adult charitable organisations, and universities across the UK with a specialist dementia centre or department. The Contact, Help, Advice and Information Network (CHAIN) for Dementia was also used to raise awareness of the research. Information about the research was only provided electronically.

5.3.1.7 Snowball recruitment and social media

Details of the study and online access to the questionnaire were made available through social networking sites such as Facebook and Twitter. Respondents were encouraged to share information about the research amongst their own networks.

5.3.1.9 Participant Group Self-selection

I decided that respondents should self-select their respondent group membership. This was the only way that I felt it would be possible to enable snowball recruitment and online survey access. Otherwise different links would have been required for each participant group and sharing of these links may not have been appropriate where a care partner shared the information with younger and older adult friends without caregiving experience. As such, the survey included an item which asked respondents to identify the respondent group they belonged to. This resulted in a potential blurring of the boundaries between respondent groups as the people selecting each particular group may not have satisfied the specific inclusion criteria.

This also resulted in the creation of two additional participant groups at the point of data analysis; “specialist healthcare professionals” where respondents identified as being both a HCP and a dementia specialist, and “other (undeclared and multiple groups)” where respondents did not respond to this item or identified as belonging to multiple groups.

5.3.2 Materials

The recruitment pack provided to potential participants contained:

- a) an information leaflet (Appendix C)
- b) a covering letter (Appendix D)
- c) a copy of the questionnaire (Appendix E)
- d) a freepost envelope

For those respondents who received information about the survey electronically, the covering letter was provided as an email and the introductory information was presented electronically at the start of the survey process.

5.3.3 Questionnaire Development

The questionnaire (Appendix E) was devised for this study drawing on the results of the systematic review (see Chapter 3), considering the illness representation model of MCI (see Chapter 4) and previous research exploring illness representations amongst people living with MCI (Lin et al., 2012). The questionnaire consisted of 3 key sections: demographic information, questions pertaining to the definition and identification of cognitive impairment, and a short vignette about an individual experiencing symptoms which could be labelled as MCI. The demographic section included respondents’ gender, age, geographical location, marital status, ethnicity, employment status, education, and asked respondents to self-identify a respondent group. Most items in the questionnaire were quantitative responses, requiring respondents to select from a set of pre-defined options. This was so that the questionnaire could provide a unified dataset enabling comparison of respondents’ views between respondent groups by compiling a dataset with clearly defined responses to predetermined items. However, I also wanted to consider the language and terms that respondents used to discuss cognitive impairment and, to a lesser extent, dementia, and so I included two free-text response items (details below) to enable the questionnaire to explore cognitive impairment in respondents own words, and with less confined parameters than the quantitative items.

Respondents were asked if they had ever heard of cognitive impairment, whether they knew anybody with a diagnosis of cognitive impairment, and if they knew anybody with a diagnosis of dementia. Respondents were asked whether they had read any information about cognitive impairment and dementia, and for what reasons they had done so. A five point Likert scale was presented with respondents asked to rate four statements about their own knowledge and desire to know more about both cognitive impairment and dementia.

The questionnaire section about defining cognitive impairment included 16 statements which respondents were asked to rate as “True”/“False”/“Don’t know”. These questions were based on the results of the systematic review (see Chapter 3). The focus of these statements was around the illness representation model of MCI (see Chapter 4).

Labels given to cognitive impairment were also a key focus of this research, and a short vignette was presented to explore this:

“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 personal appointments. Beth has also been having trouble finding the right words to describe things at times.”

Respondents were asked to select as many of the 17 presented terms (including “Don’t know” and “Other” response options) that they considered best described what Beth was experiencing. The labels presented included a number of historical clinical and research terms for cognitive impairment (see Chapter 1).

Two free-text response questions were also included in the questionnaire. These questions asked respondents “If a friend asked you what cognitive impairment was, how would you describe it?” and the same question about dementia instead of cognitive impairment. Respondents were asked to write their answer in their own words and were encouraged to write as much or as little as they chose. I felt that including these free-text questionnaire items would enable this study to explore how people discussed both cognitive impairment and dementia without being constrained by the terms and language that I had chosen to employ in the questionnaire.

5.3.3.1 Online Questionnaire

An online version of the questionnaire was hosted on SurveyMonkey (www.surveymonkey.co.uk) from July 2015 to February 2016. The online questionnaire

followed the same format and contained the same questions as the paper version (Appendix E). Respondents followed a specific link to access the online questionnaire which was provided in the information sent to potential respondents. The first page respondents were presented with was the full information about the survey as provided to respondents in recruitment packs (see Appendix C). Respondents clicked “Next” to move on to the consent form where they were asked to respond to each statement to show their consent to take part. Respondents clicked “Next” to continue with the questionnaire. Following this, questions 1-9 were presented. None of the items here were set as mandatory. Respondents could skip any questions they did not want to answer. The next screen presented respondents with questions 10 and 11, and a fourth page contained questions 12-19. Respondents were then presented with a page which thanked them for their participation and asked them to record any additional comments. Once respondents clicked “Next” on this page, they were then asked to complete their contact details if they would like to receive a summary of the research findings (see Appendix F) or find out more about taking part in an interview. This page was laid out in the same order as the final page of the paper questionnaire and was not mandatory (respondents did not have to include their contact details).

5.3.4 Piloting the Questionnaire

A pilot study was conducted to assess the validity and reliability of the study questionnaire. There were two parts to the pilot study; first, a group of experts by experience were asked to review the content of the questionnaire, and secondly a small sample of respondents were asked to complete the survey to assess the construct validity of the questionnaire.

5.3.4.1 Sample/Respondents

5.3.4.1.1 Pilot Stage One

Four respondents took part in the pilot stage one. Respondents were recruited from the LINK group, who are experts by experience who advise on research and teaching activities at the University of Worcester. LINK group members are individuals living with dementia and cognitive impairment, and past and current care partners. The LINK members were approached through the LINK lead lecturer who provided a brief overview of the research and asked interested individuals to consent for their contact details to be passed on to me. I then provided interested individuals with a copy of the questionnaire and a feedback form that asked:

1. Is the layout of the questionnaire clear and easy to follow?
2. Are the questions easy to understand, or do you think there are questions which need to be rewritten or not included?
3. Is the questionnaire easy to complete or is it too complicated?
4. Any additional comments?

Respondents were asked to return their comments to me via post or email. The comments that were received were predominantly positive. All stated that the questionnaire layout was clear and “easy to use and straightforward”. Several respondents suggested small changes to the questionnaire and accompanying information. These suggestions and my response are outlined in Table 5.1.

Table 5.1: Suggestions and comments posited by respondents in pilot stage one.

| Suggestion/Comment | Response |
|---|--|
| Likert agreement scale responses are confusing. | This is a standard scale used in many questionnaires. Only one respondent identified a concern about this. The decision was taken to continue to use this scale. |
| The vignette item may be difficult to answer due to the wide range of causes that could play a role in what Beth was experiencing. | I acknowledge that this question may prove thought provoking, but I felt that there was no better way to address this and, as the respondent themselves identified, there was a free text field where respondents could enter additional terms or responses that they felt relevant. |
| Some of the questionnaire items where respondents had to circle answers would be better presented as tick boxes. | I had previously trialled this design and found that the layout made the questionnaire exceptionally long and appear daunting, so I decided to leave the questions with circle responses. In the online version of the questionnaire, these responses involved selecting circle buttons. |
| The background colour should be amended and the font size increased. | <p>The background colour choice was based on recommendations from Dillman (2000) and I also felt that this colour choice would facilitate easy reproduction should any respondent wish to photocopy the survey for a friend. As such, I decided to maintain the colour scheme. In the online version, no such background colour was employed and questions were simply presented as black text on a white background with blue headings and function buttons.</p> <p>A large print version of the questionnaire was already available, and the online version could be adapted to the best font size for respondents via the use of browser tools.</p> |
| There was a change of wording between the introductory information letter and the questionnaire. In the letter, MCI was used but this changed to cognitive impairment throughout the survey. The use of the word “mild” could influence responses. | I completely agree with this view. The MCI reference was removed and I ensured that all references throughout the introductory letter and questionnaire were to cognitive impairment. |

Following this stage of the pilot study, I also reflected upon the items that were included and felt that the question about causes of cognitive impairment should include “physical health problems”. This was an oversight in the initial development of the questionnaire, as a key finding of the systematic review (see Chapter 3) was that several people living with cognitive impairment and their care partners identified physical health problems and illnesses as a potential cause of cognitive impairment. Several other minor word changes were included in this stage of the questionnaire drafting process.

5.3.4.1.2 Pilot Stage Two

Twenty-six respondents took part in pilot stage two. Respondents were drawn opportunistically from professional colleagues, associates and their families. Respondent characteristics are presented in Table 5.2. Respondents were provided with a full study recruitment pack and were asked to complete the survey and to give feedback about the questionnaire and accompanying information. Only a small number of respondents suggested changes. These changes were simple grammatical and slight wording corrections.

Table 5.2: Respondent characteristics pilot stage two

| | | n (%) |
|----------------------------------|----------------------------------|--------------|
| Gender | Male | 11 (42.3) |
| | Female | 15 (57.7) |
| Age | 21-30 | 16 (61.5) |
| | 31-40 | 6 (23.1) |
| | 41-50 | 3 (11.5) |
| | 51-60 | 1 (3.8) |
| Marital status | Single / Cohabiting | 17 (65.4) |
| | Married / Civil partnership | 6 (23.1) |
| | Divorced | 2 (7.7) |
| | Other | 1 (3.8) |
| Educational qualification | Higher degree (PhD, Masters) | 17 (65.4) |
| | First degree (BSc, BA) | 6 (23.1) |
| | A-Level or equivalent | 2 (7.7) |
| | GCSE or equivalent (O-Level) | 1 (3.8) |
| Employment status | Employed | 19 (73.1) |
| | Unemployed or looking for work | 1 (3.8) |
| | In full-time education | 5 (19.2) |
| | Other (multiple options) | 1 (3.8) |
| Ethnicity | White | 24 (92.3) |
| | Asian | 2 (7.7) |
| Participant Group | Living with cognitive impairment | 1 (3.8) |
| | Younger adult | 24 (92.3) |
| | Healthcare professional | 1 (3.8) |

5.3.4.2 Internal consistency

To assess the reliability of the study questionnaire, Cronbach's alpha was calculated on the responses obtained for pilot stage two. For the purposes of this analysis, questions which related to information about respondents (demographic information and questions relating to experience of cognitive impairment and dementia) were excluded. Items contained within questions 7, 10 and 11 were included in this analysis (41 items in total). Cronbach's alpha uses inter-item correlations to assess whether items measure the same domain or overall concept (Rattray & Jones, 2007). The closer the alpha value is to 1.00, the greater the internal consistency. The alpha score for this questionnaire was 0.771, suggesting a high internal consistency.

5.3.4.3 Item discrimination

To identify whether each individual item in the questionnaire was able to discriminate between respondents with differing knowledge, the score on each item (questions 7, 10 and 11) was correlated with the overall test score for responses obtained for pilot stage two. One respondent's answers were excluded from this analysis due to missing data, resulting in 25 responses being included. Of the 41 questionnaire items included, several had a rather low item-total correlation. It is conventionally recommended that any items which score below 0.3 should be discarded. However, as the overall Cronbach's alpha value would not increase by much, if at all, with the deletion of these items (see Table 5.3), I decided to retain these. This decision was also based on the results of the systematic review (see Chapter 3) which suggested that all of the included items warranted investigation.

Table 5.3: Table of Item-Total Correlation values for all questionnaire items included in the Cronbach's alpha calculation.

| | Questionnaire Item | Corrected Item-Total Correlation | Cronbach's Alpha if Item Deleted |
|------------|---|---|---|
| 7a | Cognitive impairment is a normal part of ageing | 0.506 | 0.753 |
| 7b | Cognitive impairment is a form of dementia | 0.562 | 0.748 |
| 7c | Cognitive impairment only affects people over the age of 65 | 0.285 | 0.768 |
| 7d | People with cognitive impairment will definitely develop dementia | 0.275 | 0.765 |
| 7e | There are treatments which can help people with cognitive impairment | 0.479 | 0.752 |
| 7f | Cognitive impairment is a mental illness | 0.095 | 0.774 |
| 7g | People with cognitive impairment are no longer the same person that they used to be | 0.234 | 0.767 |
| 7h | Memory and thinking problems are a normal part of getting older | 0.368 | 0.760 |
| 7i | Cognitive impairment can be cured | 0.527 | 0.753 |
| 7j | Cognitive impairment is permanent | 0.329 | 0.762 |
| 7k | Cognitive impairment is easy to live with | 0.378 | 0.763 |
| 7l | People with cognitive impairment lose their independence | 0.615 | 0.748 |
| 7m | People with cognitive impairment lose their self-confidence | 0.488 | 0.752 |
| 7n | Staying active can help to treat the symptoms of cognitive impairment | 0.554 | 0.747 |
| 7o | Cognitive impairment is preventable | 0.362 | 0.760 |
| 7p | People with cognitive impairment can still live a full and happy life | 0.260 | 0.767 |
| 10a | Mild cognitive impairment | -0.171 | 0.781 |
| 10b | Mild neurocognitive disorder | 0.000 | 0.771 |
| 10c | Early stage dementia | 0.058 | 0.772 |
| 10d | Early stage Alzheimer's disease | -0.003 | 0.773 |
| 10e | Memory problems | -0.081 | 0.777 |
| 10f | Questionable dementia | -0.480 | 0.787 |
| 10g | Age related cognitive decline | 0.154 | 0.769 |
| 10h | Age associated cognitive decline | -0.275 | 0.783 |
| 10i | Age associated memory impairment | -0.019 | 0.776 |
| 10j | Benign senescent forgetfulness | -0.122 | 0.776 |
| 10k | Getting older | 0.233 | 0.767 |
| 10l | Stress | -0.063 | 0.777 |
| 10m | Depression | 0.145 | 0.770 |
| 10n | Physical health problems | -0.193 | 0.774 |
| 10o | Mental health problems | -0.270 | 0.780 |
| 10p | Don't know | 0.370 | 0.764 |

| | | | |
|------------|---|-------|-------|
| 10q | Other | 0.200 | 0.769 |
| 11a | Getting older | 0.395 | 0.763 |
| 11b | Genetics | 0.227 | 0.767 |
| 11c | Abnormal brain changes | 0.271 | 0.766 |
| 11d | Head injury (recently or in the past) | 0.087 | 0.771 |
| 11e | Diet | 0.319 | 0.763 |
| 11f | Stress or worry | 0.303 | 0.765 |
| 11g | Personal behaviour (e.g. being physically and/or mentally active) | 0.554 | 0.753 |
| 11h | Physical health problems | 0.760 | 0.748 |

5.4 Data Analysis

SPSS version 22 and 23 was used for data entry and analysis. Questionnaire items were numerically scored to allow for data analysis. For the questions which featured a three point response scale of “True”/“Don’t know”/“False”, responses were scored as:

- 0 = Unanswered
- 1 = False
- 2 = Don’t know
- 3 = True

Responses were scored in this manner as this is the common-practice when scoring Likert-type response scales. I positioned “Don’t know” in between “True” and “False” as this is generally the positioning of a “Neutral” response for Likert scales and thus I felt that “Don’t know” was reflective of this neutral stance, representing a viewpoint which was neither “True” nor “False” and which sits between the two opposing stances in the same manner as a neutral response. I felt that it was important to include “Don’t know” as a response option and to include this as a scoring option as an uncertain response is just as important as a clarified stance of “True” or “False”. Understanding questionnaire items which respondents are uncertain about may highlight areas for additional information provision or future research.

For the questionnaire items regarding respondents self-reported understanding of cognitive impairment and dementia and their desire to know more about these, responses were scored as:

- 0 = Unanswered
- 1 = Strongly disagree
- 2 = Disagree
- 3 = Neither
- 4 = Agree
- 5 = Strongly disagree

Again, this scoring pattern reflects the standard practice regarding scoring of Likert-type responses (Sullivan & Artino Jr, 2013).

Summary and descriptive statistics were computed for demographic information and to provide an overview of the percentage responses by participant group for each question.

Kruskal-Wallis analyses were calculated, with post-hoc pairwise comparisons via Dunn-Bonferroni, to explore whether there were any significant differences between participant groups. Wilcoxon signed rank tests were conducted to explore differences between questionnaire responses across the whole study sample. A series of categorical bivariate analyses were calculated (using chi-square) to explore differences between demographic groups in their responses to the questionnaire, and Cramer's V was computed to consider the strength of identified relationships. Similar analyses have been conducted in survey explorations of knowledge and understanding of dementia (McParland, Devine, Innes & Gayle, 2012).

For the two free-text response items, responses were analysed using thematic analysis to provide a rich account of the data. Semantic analysis was conducted, aiming to explore the explicit meanings posited by respondents. An inductive approach was adopted and themes which were identified were grounded in the data, though I did consider how the emerging themes may map onto the quantitative questionnaire data during analysis. The analysis process followed several key stages as outlined by Braun & Clarke (2006). Firstly, responses to these questionnaire items were read and re-read so that I was familiar with the responses and fully immersed in what respondents had written to describe both cognitive impairment and dementia. At this point, brief notes were taken about possible codes that I felt were present in the data, with a particular focus on identifying patterns across the responses to each question, and considering where responses to the question about cognitive impairment differed or were similar to responses to the item about dementia. The responses were then uploaded to NVivo 11 (QSR International) and line-by-line coding was conducted in NVivo. At this stage, I went through the responses to each question multiple times, developing and growing the list of codes at each pass. The codes were then printed from NVivo so that I could review these by hand on paper and begin to identify encompassing themes which represented patterns across the codes. These initial themes were then uploaded into NVivo and the existing codes were arranged into a hierarchical structure within the encompassing themes. Following this, I re-read respondents answers to the questionnaire items, cross referencing their responses with the identified themes to ensure that the themes were representative of respondents answers. Once I was confident that the identified themes were reflective of the data, analysis was viewed as complete.

5.5 Results

A total of 417 completed questionnaires were entered into the analysis with numbers of respondents in each participant group shown in Table 5.4 (see p.149). Via SurveyMonkey 519

responses were recorded, but 102 were incomplete and thus not included in analysis. Due to the snowball recruitment and online access, it is not possible to deduce a response rate to survey requests. However, it is clear that the number of respondents living with cognitive impairment and their care partners was much lower than other participant groups (see Table 5.4). Only 23 paper copies of the questionnaire were returned. Details of respondents' answers to each questionnaire item are provided in Appendix G.

Table 5.4: Number of questionnaire respondents by participant group

| Participant Group | n (% of total) |
|---|-----------------------|
| 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) |

5.5.1 Respondent Characteristics

Respondent characteristics are summarised in Table 5.5. The average respondent was female (77.5%) in their early fifties (average age 51, SD=16.3 years), highly educated (44.8% educated to higher degree level) and identified as white (93.8%) and married (54.2%). This high proportion of female respondents could be due to the populations sampled, as healthcare professionals are predominantly female (Yar, Dix, & Bajekal, 2006) and there is also a high proportion of female employees amongst university staff (Higher Education Statistics Agency, 2015). There was also an under representation of individuals aged 30 and under (13.8%). This is likely the result of the respondent populations as only 13% of university staff are aged under 31 (Higher Education Statistics Agency, 2015). Similarly, the high proportion of highly educated respondents may also be the result of the participant groups, as most healthcare roles and university positions require a high level of educational qualification.

Table 5.5: Respondent characteristics across all participant groups

| | | n (%) |
|----------------------------------|-------------------------------------|--------------|
| 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) |

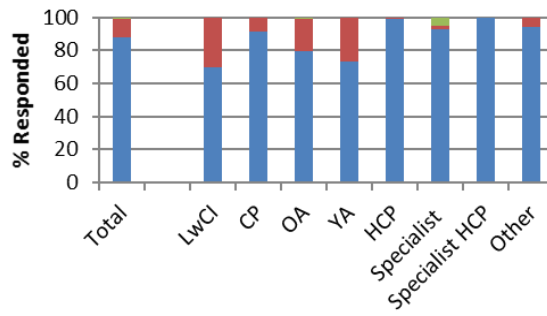
5.5.2 Prior Knowledge of Cognitive Impairment and Dementia

The majority of respondents (88.0%) stated that they had heard of cognitive impairment before, though over a quarter (26.5%) of younger adults stated that they hadn't. Interestingly, 30.0% of people living with cognitive impairment stated that they hadn't heard of this before. This may be due to respondents not fully understanding what was meant by cognitive impairment, highlighting the differing labels used to talk about memory and thinking difficulties. Over half (57.3%) of respondents stated that they knew someone with a diagnosis of cognitive impairment. The majority of both older (57.8%) and younger adults (67.5%) stated that they did not know anybody who had received a diagnosis.

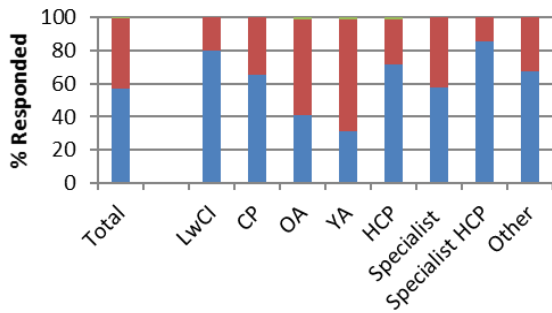
When asked about dementia, the majority of respondents (79.1%) stated that they knew someone with a dementia diagnosis, with a significant increase ($Z=-8.064$, $p<0.001$) of over 20% compared to the number of people stating that they knew someone with a diagnosis of cognitive impairment. This is reflective of the increased rate of dementia diagnoses as compared to cognitive impairment diagnoses, but could also be a result of respondents interpreting a family member or friend's cognitive difficulties as dementia due to increased awareness of dementia.

Nearly 70% of respondents have read about cognitive impairment. Younger adults (38.6% had read information) and older adults (39.8% had read information) were the least likely to have read information. Of those who had read about cognitive impairment, 20.1% had done so as part of their job role, and 14.9% had read information for personal or other reasons. The majority of respondents (91.1%) stated that they had read information about dementia. The number of younger adults (85.5%) who have read information about dementia is slightly higher than older adults (77.1%) suggesting that older adults have accessed more information about dementia. Significantly more respondents ($Z=-8.838$, $p<0.001$) had read information about dementia (91.1%) than cognitive impairment (68.8%). Figure 5.1 shows total population and participant group responses to questionnaire items about prior knowledge and experience of cognitive impairment and dementia.

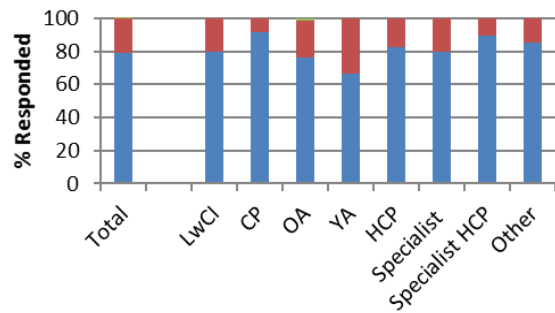
Have you heard of cognitive impairment before?



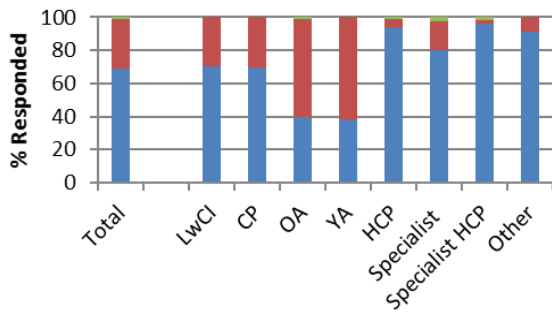
Do you know anybody personally who has ever been given a diagnosis of cognitive impairment?



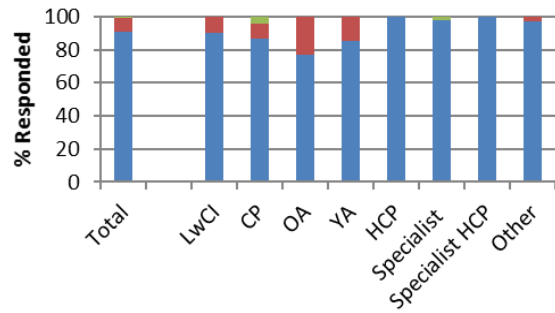
Do you know anybody personally who has ever been given a diagnosis of dementia?



Have you ever read any information about cognitive impairment?



Have you ever read any information about dementia?



■ Yes ■ No ■ Undeclared

Figure 5.1: Responses to questionnaire items about prior knowledge and experience of cognitive impairment and dementia. LwCI = living with cognitive impairment; CP = care partner; YA = younger adult; OA = older adult; HCP = healthcare professional; Specialist HCP = specialist healthcare professional.

5.5.3 Confidence in Knowledge of Cognitive Impairment and Dementia

Most respondents (61.4%) agreed or strongly agreed with the statement “I have a good understanding of what cognitive impairment is”. Older adults (38.6%), younger adults (43.4%), individuals living with cognitive impairment (40.0%) and care partners (30.4%) all had the highest rates of disagreement with this statement, suggesting that these respondents had the least confidence in their own knowledge about cognitive impairment.

Kruskal-Wallis analysis revealed a significant difference between participant groups ($X^2(7)=119.657$, $p<0.001$), and subsequent post-hoc testing via Dunn-Bonferroni analyses revealed that HCPs reported a significantly greater confidence in their understanding than older adults ($p<0.001$), younger adults ($p<0.001$), and care partners ($p<0.001$). Specialist HCPs reported a significantly greater confidence in their understanding of cognitive impairment than older adults ($p<0.001$) and younger adults ($p<0.001$). Dementia specialists also reported a significantly higher confidence in their knowledge than younger adults ($p<0.001$) and older adults ($p=0.001$). This is not surprising, as HCPs, specialist HCPs and specialists had also read the most information about cognitive impairment so it would be assumed that their confidence about this would be greater than younger and older adults. Similarly, respondents in the “Other” participant group (85.3%) reported a significantly higher confidence in their understanding than older adults ($p<0.001$), care partners ($p=0.019$) and younger adults ($p<0.001$). However, it is not possible to draw any conclusions about these observed differences due to the varied nature of respondents included in this participant group.

Over 78% of respondents in each group (82.0% of respondents overall) stated that they wanted to know more about cognitive impairment with only 4.8% of respondents disagreeing with this. Kruskal-Wallis analysis revealed that the participant groups did not significantly differ in their self-reported desire to know more about cognitive impairment ($X^2(7)=6.490$, $p=0.484$). However, 100% of respondents living with cognitive impairment stated that they wanted to know more about this and only 50% claimed they had a good understanding of this, suggesting this group would benefit from further information about the condition they are living with.

Similarly, the majority of respondents (82.3%) reported that they had a good understanding of dementia, with significantly fewer respondents disagreeing with the statement “I have a good understanding of what dementia is” than “I have a good understanding of what cognitive impairment is” ($Z=-8.061$, $p<0.001$). The four groups who were the least

confident in their own understanding of dementia (answering either disagree or strongly disagree) were individuals living with cognitive impairment (30.0%), care partners (13.0%), older adults (14.5%), and younger adults (12.0%). Participant groups differed significantly ($X^2(7)=57.311$, $p<0.001$) in their self-reported understanding of dementia. HCPs reported significantly greater confidence in their understanding of dementia than older adults ($p<0.001$), younger adults ($p<0.001$), and care partners ($p=0.031$). Respondents in the “Other” participant group reported a significantly higher confidence in their understanding of dementia (94.1%) than older adults ($p=0.003$). Specialist HCPs also reported greater confidence in their understanding of dementia than older adults ($p<0.001$) and younger adults ($p=0.025$), and specialists were more confident than older adults ($p=0.012$). This is not surprising, as it would be expected that HCPs, specialists and specialist HCPs would have encountered more information and have more experience of dementia and so their confidence in their own knowledge of this is likely to be higher.

The majority of respondents (81.8%) stated that they wanted to know more about dementia. Interestingly, specialists (90.0%) were the most likely to respond in this way, though over 77% of each participant group shared this view. This suggests that respondents do not have confidence in their current understanding of dementia, despite most people stating that they had a good understanding of this. Participant groups did not differ significantly on their stated desire to know more about dementia ($X^2(7)=4.386$, $p=0.734$) with the majority of all participant groups reporting that they would want to know more. Figure 5.2 shows total population and participant group responses to questionnaire items about respondent’s confidence in their own understanding of cognitive impairment and dementia, and whether they wanted to know more about these.

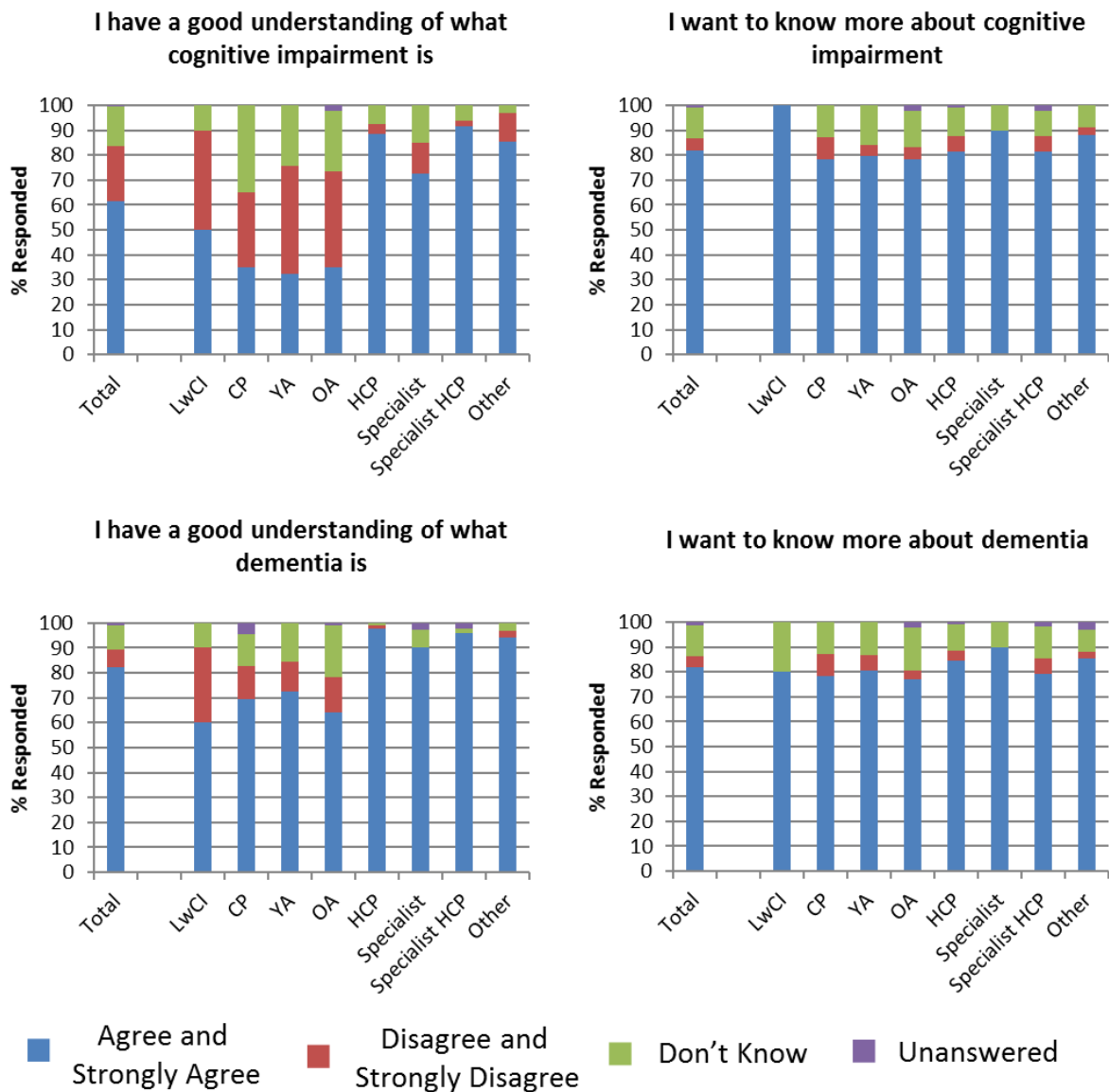


Figure 5.2: Responses to questionnaire items about confidence around understanding of cognitive impairment and dementia and desire to know more about these. LwCI = living with cognitive impairment; CP = care partner; YA = younger adult; OA = older adult; HCP = healthcare professional; Specialist HCP = specialist healthcare professional.

5.5.4 Definitions and Identification of Cognitive Impairment

The majority of respondents (65.5%) reported that cognitive impairment is not a normal part of ageing. Participant groups differed significantly ($X^2(7)=25.821$, $p=0.001$) with HCPs (78.1%, $p=0.003$) and respondents in the “Other” participant group (82.4%, $p=0.020$) more likely to answer “False” to the statement “Cognitive impairment is a normal part of ageing” than younger adults (44.6%). Similarly, 93.8% of respondents (over 84% of respondents in every participant group) reported that cognitive impairment does not only affect people over the age of 65. Older adults and younger adults were the most uncertain about this, with 14.5% and 10.8% responding “Don’t know” respectively. Kruskal-Wallis analysis ($X^2(7)=22.691$, $p=0.002$) revealed that HCPs and older adults differed significantly ($p=0.008$) in their views about this with more HCPs (100.0%) responding “False” to this statement than older adults (84.3%).

There was a nearly equal proportion of respondents answering “True” (48.4%) and “False” (45.6%) to the statement “Memory and thinking problems are a normal part of getting older”. This is an interesting finding as 65.5% of respondents reported that cognitive impairment was not a normal part of ageing, so it would be expected that a similar percentage would respond “False” to this statement. This could be the result of the different terminology employed across the two statements, with one referring to “cognitive impairment” and the other to “memory and thinking problems”. Kruskal-Wallis analysis ($X^2(7)=26.599$, $p<0.001$) revealed that HCPs differed significantly from both younger adults ($p=0.001$) and older adults ($p=0.042$), and specialist HCPs differed significantly from younger adults ($p=0.004$) in their responses, with younger adults (65.1%) being most likely to agree with this statement and specialist HCPs (31.3%) and HCPs (37.5%) being least likely to agree. This suggests an expectation amongst younger adults of cognitive decline as something which affects all older people, but not to the extent of what they would consider to be termed cognitive impairment.

The majority of respondents (62.4%) stated that cognitive impairment is not a form of dementia. However, 40.0% of people living with cognitive impairment reported that this was a type of dementia, suggesting that these individuals may view themselves as living with a form of dementia. This could be reflective of the participant group self-selection thus individuals living with dementia may have completed the questionnaire and self-identified as experiencing cognitive impairment, or it could be that respondents considered dementia and cognitive impairment to be synonymous. Nearly 40% of older adults responded “Don’t know” to the statement “Cognitive impairment is a form of dementia” suggesting that they may not have

understood the statement or that they may have been uncertain about the distinction between cognitive impairment and dementia. Kruskal-Wallis analysis ($X^2(7)=28.196$, $p<0.001$) revealed that specialist HCPs differed significantly from both younger adults ($p=0.008$) and older adults ($p=0.010$), and HCPs differed significantly from both younger adults ($p=0.015$) and older adults ($p=0.021$) in their responses to this statement, with specialist HCPs (85.4%) and HCPs (78.1%) being the most likely to report that cognitive impairment is not a form of dementia.

Nearly 70% of respondents reported that cognitive impairment is not a mental illness. However, approximately one fifth of specialists, older adults, care partners, and people living with cognitive impairment were uncertain about this. This suggests that these individuals may not be confident in what constitutes a mental illness or where to position cognitive impairment in this context. Participant groups differed significantly in their responses to this statement ($X^2(7)=16.591$, $p=0.020$) but post-hoc testing revealed no significant differences. Figure 5.3 shows total population and participant group responses to questionnaire items about identification and definitions of cognitive impairment.

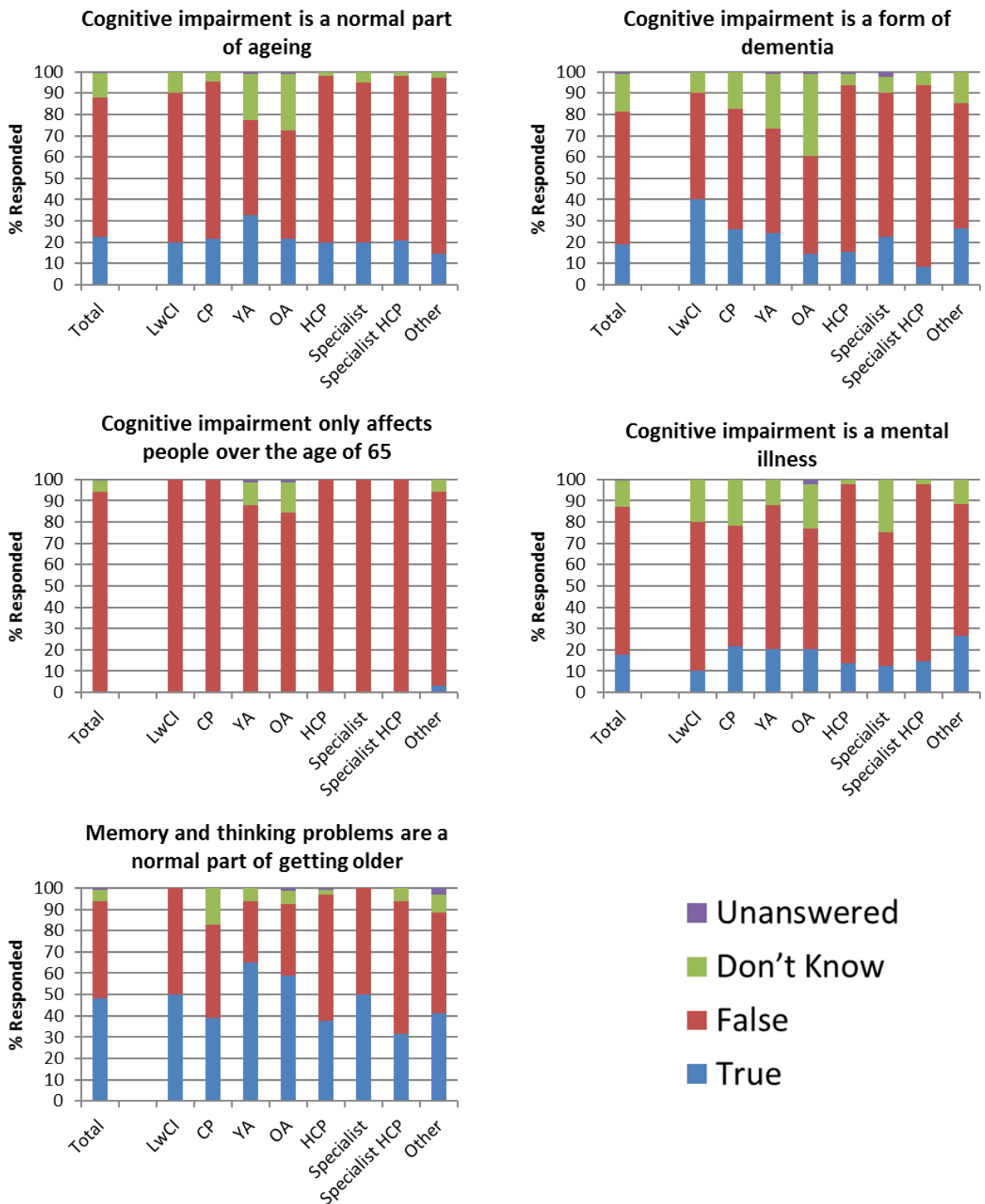


Figure 5.3: Responses to questionnaire items about identification and definitions of cognitive impairment. LwCI = living with cognitive impairment; CP = care partner; YA = younger adult; OA = older adult; HCP = healthcare professional; Specialist HCP = specialist healthcare professional.

5.5.5 Understanding the Consequences of Cognitive Impairment

The majority of respondents (83.0%) reported that cognitive impairment was not a definite precursor of dementia. Kruskal-Wallis analysis ($X^2(7)=42.482$, $p<0.001$) revealed that HCPs differed significantly from younger adults ($p<0.001$), older adults ($p=0.001$), and care partners ($p=0.005$) in their views about this. Specialist HCPs also differed significantly from younger adults ($p=0.001$), older adults ($p=0.006$), and care partners ($p=0.007$) in their responses, with over one quarter of care partners (30.4%), older adults (27.7%) and younger adults (27.7%) answering “Don’t know” to the statement “People with cognitive impairment will definitely develop dementia”.

Nearly 84% of respondents answered “False” to the statement “People with cognitive impairment are no longer the same person that they used to be”. This suggests that most respondents viewed the inherent personhood and values of an individual as unchanged in cognitive impairment. On the other hand, 40% of individuals living with cognitive impairment, 21.7% of care partners and 15.7% of older adults answered “True” to this statement, suggesting that a proportion of these groups consider that cognitive impairment changes who a person is. Kruskal-Wallis analysis ($X^2(7)=34.045$, $p<0.001$) revealed that HCPs differed significantly from both older adults ($p=0.001$) and care partners ($p=0.011$), and specialist HCPs differed significantly from both older adults ($p=0.016$) and care partners ($p=0.034$) in their responses to this statement, with specialist HCPs (4.2%) and HCPs (3.1%) being least likely to claim that people with cognitive impairment are no longer the same person that they used to be.

The majority of respondents (72.9%) reported “False” to the statement “Cognitive impairment is easy to live with”. However, 10% of specialists answered “True” to this, suggesting that this group of respondents held slightly more positive views about the impact of cognitive impairment. Over 20% of respondents answered “Don’t know” to this statement, with 37.3% of older adults, and 35.0% of specialists responding in this way. This suggests that several respondents were either uncertain about the impact of cognitive impairment on an individual’s life or were uncertain as to what was meant by the statement “easy to live with”. Kruskal-Wallis analysis ($X^2(7)=41.937$, $p<0.001$) revealed that HCPs differed significantly from both older adults ($p<0.001$) and specialists ($p=0.006$), and specialist HCPs differed significantly from both older adults ($p<0.001$) and specialists ($p=0.003$) in their responses to this statement. Specialists (52.5%) and older adults (53.0%) were the least likely to respond “False” to this statement.

The majority (60.0%) of all respondents answered “False” to the statement “People with cognitive impairment lose their independence”. However, 43.5% of care partners and 30.0% of individuals living with cognitive impairment answered “True” suggesting that these groups may view cognitive impairment as having a bigger impact on an individual’s independence than others. Kruskal-Wallis analysis ($X^2(7)=33.578$, $p<0.001$) revealed that HCPs differed significantly from care partners ($p=0.001$), younger adults ($p=0.010$), and older adults ($p=0.035$), and specialists differed significantly from care partners ($p=0.022$) in their responses to this statement, with HCPs (77.1%) and specialists (72.5%) being the most likely to state that cognitive impairment does not lead to loss of independence.

The majority of respondents (65.7%) answered “True” to the statement “People with cognitive impairment lose their self-confidence”. All respondents living with cognitive impairment agreed with this, suggesting that they may indeed have lost their self-confidence. On the other hand, approximately a quarter of HCPs (26.0%) and specialists (25.0%) responded “False” to this statement. Participant groups did not differ significantly in their responses to this statement ($X^2(7)=11.951$, $p=0.102$).

When presented with the statement “People with cognitive impairment can still live a full and happy life”, the majority of respondents (89.4%) answered “True”. Eighty percent of respondents living with cognitive impairment answered in this way, suggesting that they are remaining positive and have still been able to live a good quality of life post diagnosis. Kruskal-Wallis analysis ($X^2(7)=24.775$, $p=0.001$) revealed that older adults (19.3%) were the most uncertain about this, differing significantly from HCPs (2.1%, $p=0.001$) and specialist HCPs (0.0%, $p=0.015$) in their responses to this. Figure 5.4 shows total population and participant group responses to questionnaire items about the consequences of cognitive impairment.

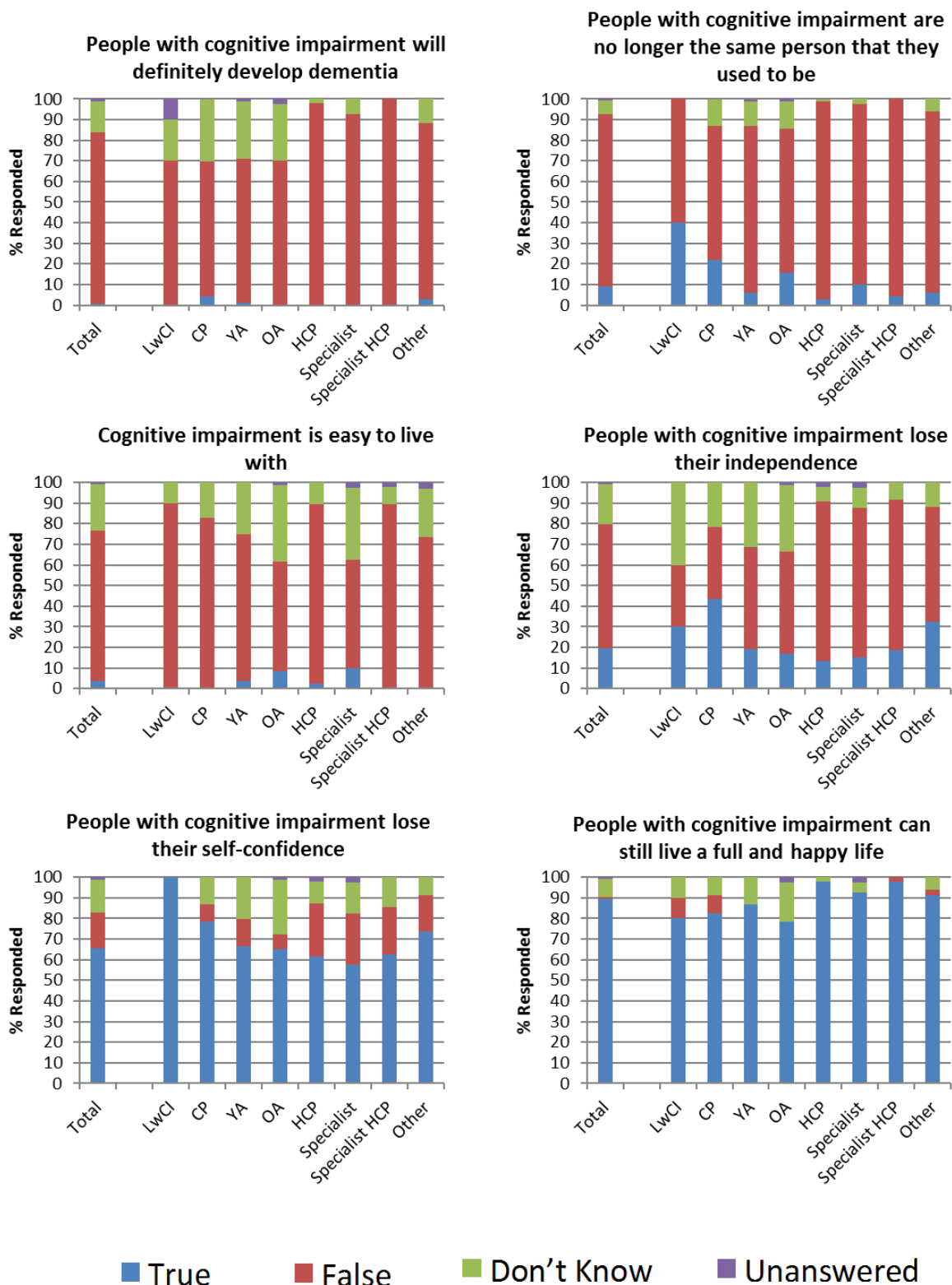


Figure 5.4: Responses to questionnaire items about the consequences of cognitive impairment. LwCI = living with cognitive impairment; CP = care partner; YA = younger adult; OA = older adult; HCP = healthcare professional; Specialist HCP = specialist healthcare professional.

5.5.6 Understanding the Permanence of Cognitive Impairment

Over 40% of respondents answered “False” to the statement “Cognitive impairment is permanent”. This suggests that a number of respondents viewed cognitive impairment as a transient state and not a long-term or chronic condition. In the care partner (47.8%), older adult (49.4%) and younger adult (47.0%) participant groups, nearly half of respondents answered “Don’t know” to this statement, suggesting that, in these groups, many people were uncertain about the permanence of cognitive impairment (see Figure 5.5, p.165). Kruskal-Wallis analysis ($X^2(7)=26.154$, $p<0.001$) revealed that specialist HCPs (70.8%) were the most likely to answer “False” to this statement, differing significantly from people living with cognitive impairment (10.0%, $p=0.012$) and care partners (17.4%, $p=0.020$). This suggests that specialist HCPs held the strongest perception of cognitive impairment as condition which is not permanent.

5.5.7 Understanding about Treatments and Lifestyle Changes

Among all respondents, 66.9% reported that there are treatments available which can help people living with cognitive impairment. This view was particularly evident amongst specialist HCPs (87.5%) and HCPs (86.5%), of whom the majority answered “True” to the statement “There are treatments available which can help people living with cognitive impairment”. Amongst care partners (52.2%) and older adults (50.6%), just over half of respondents answered “Don’t know” to this statement suggesting that these groups in particular were uncertain about the treatment options that may be available or whether current treatments are effective. Kruskal-Wallis analysis ($X^2(7)=38.434$, $p<0.001$) revealed that HCPs differed significantly from both older adults ($p<0.001$) and younger adults ($p=0.010$), and specialist HCPs differed significantly from older adults ($p=0.001$) in their responses, with HCPs (86.5%) and specialist HCPs (87.5%) being more likely to respond “True” to this statement.

Just over half (52.8%) of respondents reported that cognitive impairment is incurable, with over 34% answering “Don’t know” to the statement “Cognitive impairment can be cured”. Amongst individuals living with cognitive impairment, 80% answered “Don’t know” to this statement. Amongst care partners (34.8%), older adults (43.4%) and younger adults (39.8%), over one third of respondents stated that cognitive impairment could not be cured, though over 50% of these groups similarly answered “Don’t know” to this statement. Across all groups, very few respondents answered “True” to this statement. Participant groups differed significantly in

their responses to this statement ($X^2(7)=18.070$, $p=0.012$) but post-hoc testing revealed no significant differences.

The majority of respondents (85.1%) reported that staying active can help treat the symptoms of cognitive impairment. Within participant groups, 13.3% of older adults, 16.9% of younger adults, 20% of people living with cognitive impairment, and 17.4% of care partners were uncertain about this, suggesting that these groups had the least knowledge, or least confidence, about this. Participant groups did not differ significantly in their responses to this statement ($X^2(7)=10.582$, $p=0.158$).

There was a spread of responses to the statement “Cognitive impairment is preventable” across participant groups. Overall, 44.1% of respondents answered “Don’t know” to this statement, suggesting a general uncertainty about whether it is possible to prevent cognitive impairment. However, amongst individuals living with cognitive impairment (60.0%), HCPs (41.7%), and specialist HCPs (52.1%), approximately half of respondents answered “False” to this. Participant groups did not differ significantly in their responses to this statement ($X^2(7)=6.446$, $p=0.489$). Figure 5.5 shows total population and participant group responses to questionnaire items about treatments and lifestyle changes which may impact cognitive impairment, and the questionnaire item regarding permanence of cognitive impairment.

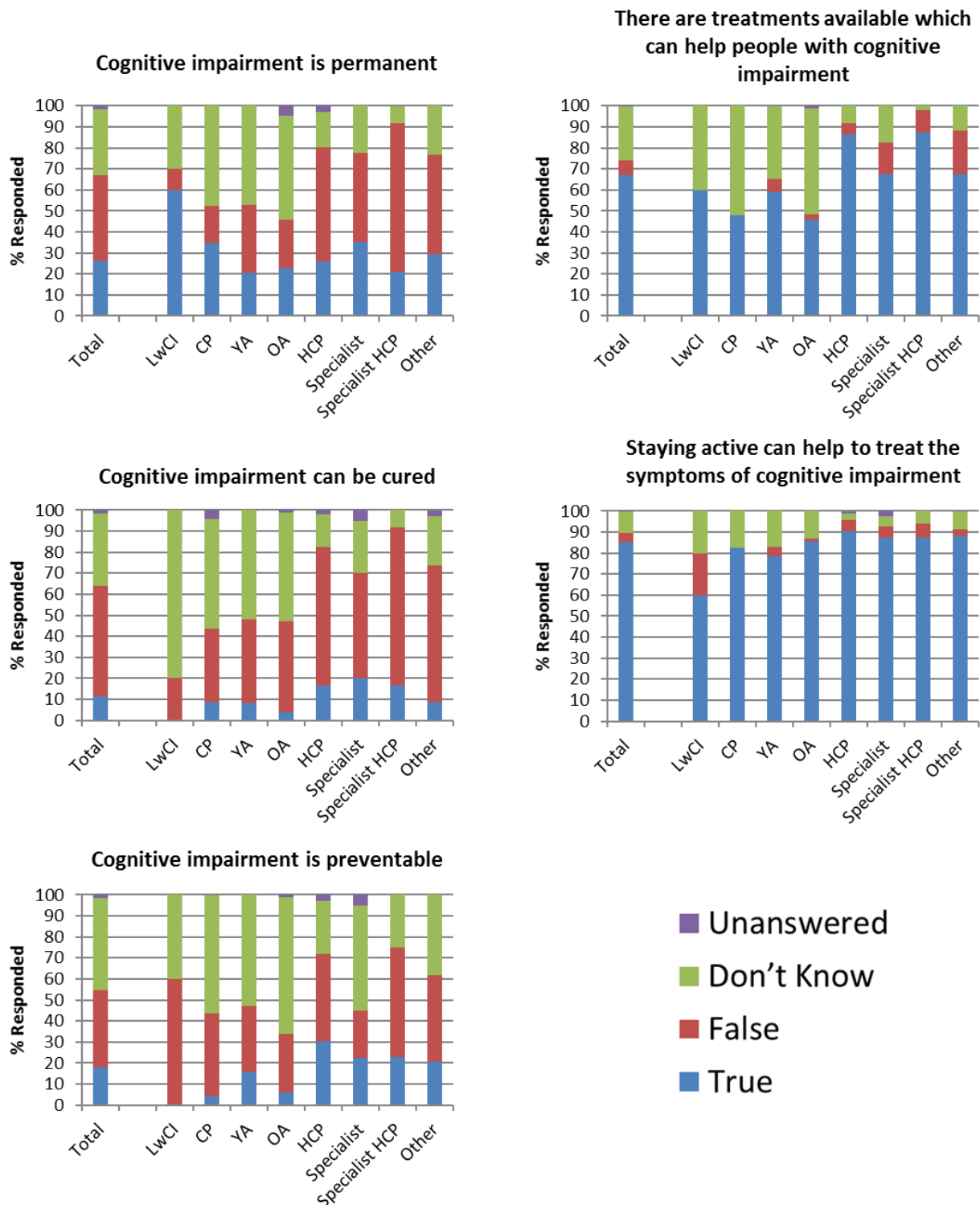


Figure 5.5: Responses to questionnaire items about treatment, lifestyle changes and permanency of cognitive impairment. LwCI = living with cognitive impairment; CP = care partner; YA = younger adult; OA = older adult; HCP = healthcare professional; Specialist HCP = specialist healthcare professional.

5.5.8 Understanding About the Causes of Cognitive Impairment

The majority of respondents (over 72%) endorsed all except two of the listed factors as possible causes of cognitive impairment. Only 45.1% of respondents endorsed diet as a cause of cognitive impairment, with 26.6% responding “Don’t know”. Similarly, 63.8% of all respondents endorsed “personal behaviour” as a potential cause of cognitive impairment, with 18.9% responding “Don’t know”. Despite the overall majority of respondents endorsing similar causes, Kruskal-Wallis analysis revealed that participant groups differed significantly in their endorsements of all the listed causes except “getting older” ($X^2(7)=1.438$, $p=0.984$) which was not significant and “personal behaviour” where participant groups differed significantly in their responses to this statement ($X^2(7)=14.506$, $p=0.043$) but post-hoc testing revealed no significant differences. Older adults and HCPs differed significantly in their endorsement of genetics as a possible cause of cognitive impairment, with more HCPs (83.3%) endorsing this than older adults (57.8%, $p=0.003$). Older adults (55.4%) were the least likely to endorse abnormal brain changes as a potential cause, differing significantly from younger adults (86.7%, $p<0.001$), specialists (92.5%, $p<0.001$), HCPs (99.0%, $p<0.001$), specialist HCPs (97.9%, $p<0.001$), care partners (87.0%, $p=0.006$), and “Other” (82.4%, $p=0.006$). Similarly, older adults (68.7%) were the least likely to endorse head injury, differing significantly from younger adults (92.8%, $p<0.001$), HCPs (100%, $p<0.001$), specialists (95%, $p<0.001$), specialist HCPs (97.9%, $p<0.001$), care partners (91.3%, $p=0.030$) and “Other” (94.1%, $p=0.001$). 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, $p=0.040$) and older adults differing significantly from “Other” (76.5%, $p=0.007$). HCPs (95.8%) were the most likely to endorse stress or worry as a potential cause of cognitive impairment, differing significantly from the two groups least likely to endorse this cause; older adults (68.7%, $p<0.001$) and younger adults (77.1%, $p=0.040$). Participant groups differed significantly in their endorsement of physical health problems ($X^2(7)=71.956$, $p<0.001$), with older adults (41%) being the least likely to endorse this, differing significantly from HCPs (93.8%, $p<0.001$), specialist HCPs (93.8%, $p<0.001$), specialists (77.5%, $p=0.001$), and younger adults (65.1%, $p=0.009$). Younger adults (65.1%) also differed significantly from HCPs (93.8%, $p=0.003$) and specialist HCPs (93.8%, $p=0.031$) with younger adults less likely to endorse this cause. Figure 5.6 shows total population and participant group endorsements of potential causes of cognitive impairment.

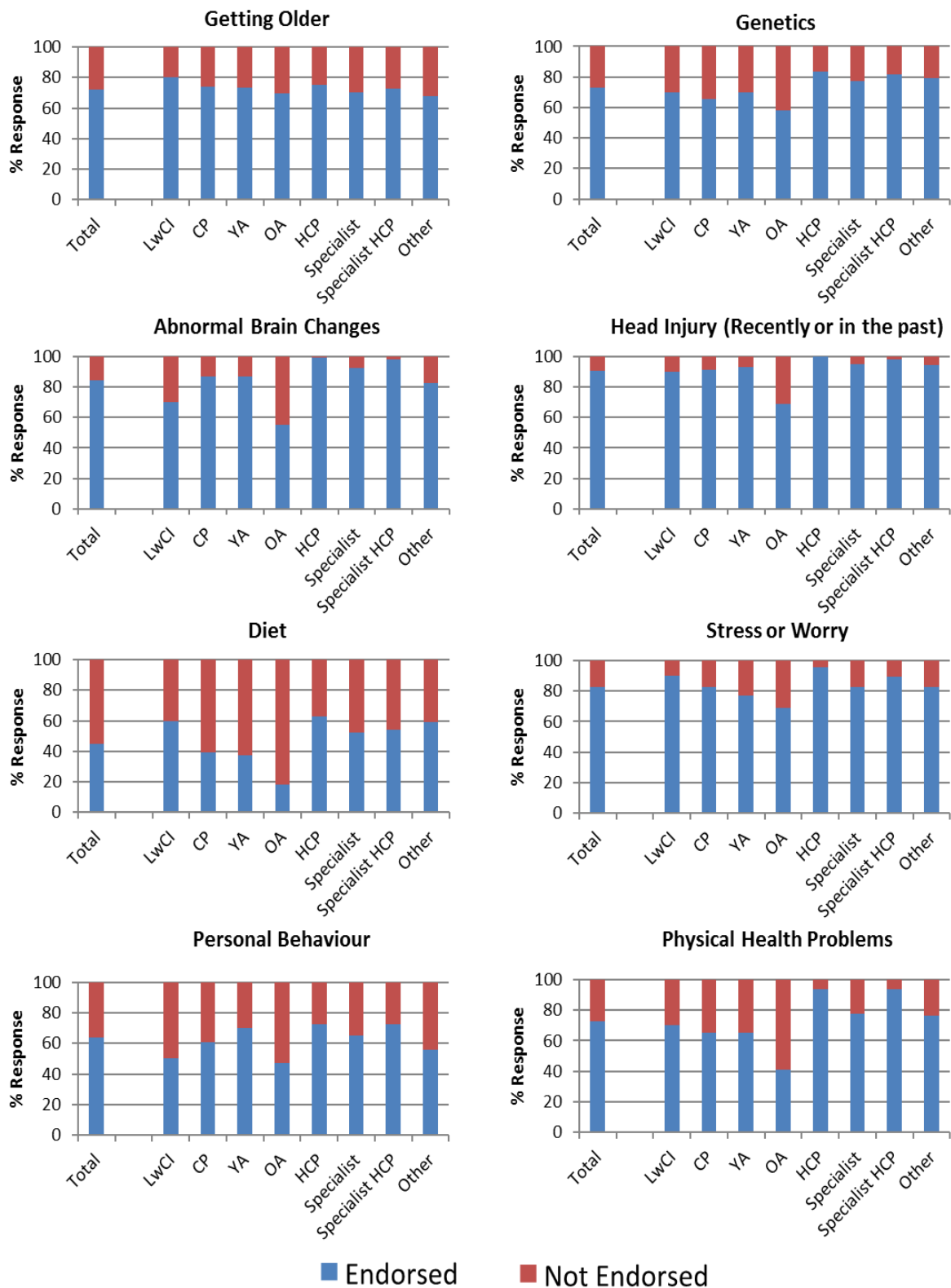
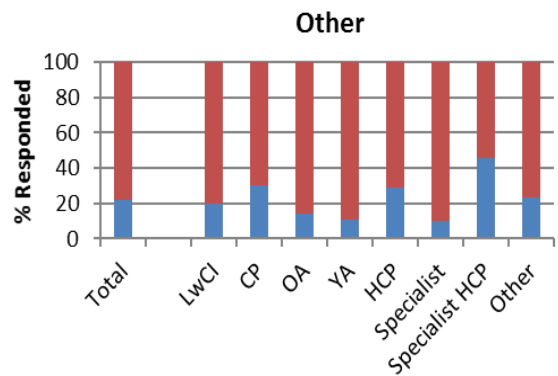
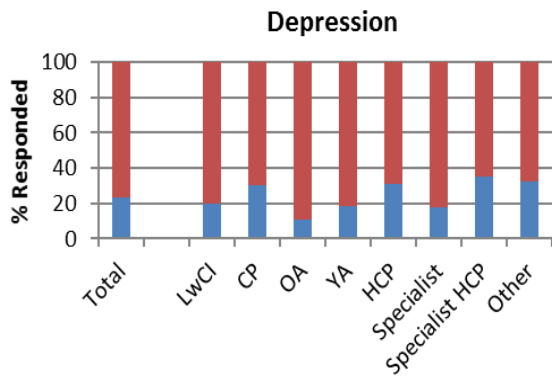
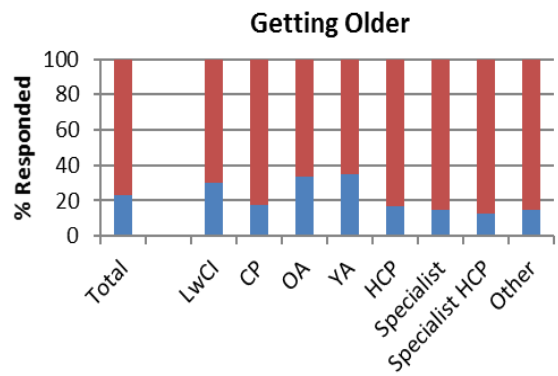
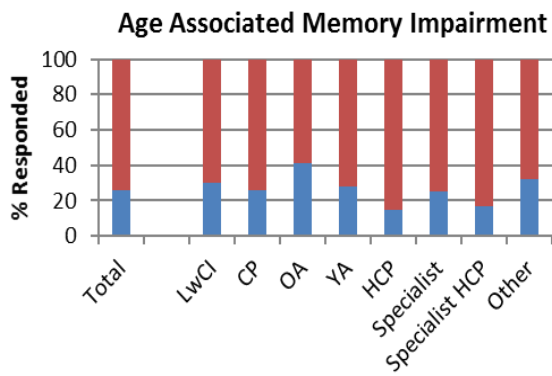
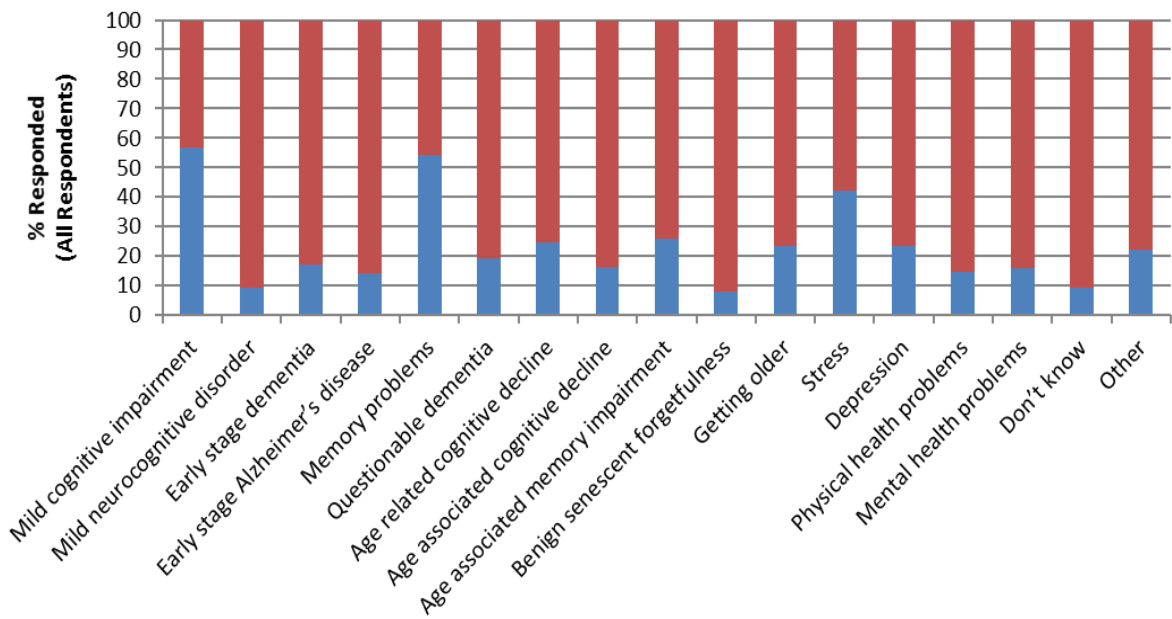


Figure 5.6: Respondents endorsements of potential causes of cognitive impairment. LwCI = living with cognitive impairment; CP = care partner; YA = younger adult; OA = older adult; HCP = healthcare professional; Specialist HCP = specialist healthcare professional.

5.5.9 Attribution and Labelling of Symptoms Presented in the Vignette

All participant groups endorsed on average a similar number of explanations for the symptoms presented by Beth in the vignette (mean=4.0). The most endorsed term was “mild cognitive impairment” (56.8%) suggesting that most people have heard of this label (despite it not being referenced in the questionnaire outside of this question) and understand that this could be applied in this situation. The next most frequently endorsed term was “Memory problems” (54.4%), followed by “Stress” (42.4%). This is not a surprising result as the vignette detailed a woman who was starting to forget things (memory problems) and was still in work (a well-known cause of stress). Chi-square analyses revealed that there was a significant association between participant group and endorsements of four terms. Post-hoc testing was computed via the compare column proportion function in SPSS with Bonferroni corrected p-values. There was a significant association between participant group and endorsements of the term “age associated memory impairment” ($X^2(7)=19.209$, $p=0.008$) with older adults (41.0%) being significantly more likely to endorse this than HCPs (14.6%, $p<0.05$). Participant group and endorsements of the term “getting older” were also significantly associated ($X^2(7)=20.517$, $p=0.005$) but post-hoc testing revealed no significant differences between participant groups. There was a significant association between participant group and endorsements of the term “depression” ($X^2(7)=18.721$, $p=0.009$) with older adults (10.8%) being significantly less likely to endorse this than HCPs (31.3%, $p<0.05$) and specialist HCPs (35.4%, $p<0.05$). Selections of the term “Other” was also significantly associated with participant group ($X^2(7)=31.848$, $p<0.001$) with specialist HCPs (45.8%) selecting this option more than older adults (14.5%, $p<0.05$), younger adults (10.8%, $p<0.05$), and specialists (10.0%, $p<0.05$). This suggests that specialist HCPs viewed the offered list of possible terms as insufficient to explain what Beth was experiencing, offering additional terms relating to the presented vignette more than other participant groups. Figure 5.7 shows total population and participant group endorsements of the presented terms and labels for the symptoms in the vignette.



■ Endorsed ■ Not Endorsed

Figure 5.7: Respondents endorsements of presented terms and labels for the symptoms presented in the vignette. LwCI = living with cognitive impairment; CP = care partner; YA = younger adult; OA = older adult; HCP = healthcare professional; Specialist HCP = specialist healthcare professional.

5.5.10 Impact of Respondent Characteristics on Questionnaire results

To explore the potential impact of respondent characteristics on knowledge and understanding, chi-square analyses were conducted. Cramer's V was calculated to determine the strength of association between significantly associated variables. Cramer's V ranges from 0.00 to 1.00, with values closer to 1.00 indicating a stronger association. Conventionally, values of Cramer's V between 0.0 and 0.1 indicate a negligible association, 0.1-0.2 indicates a weak association, 0.2-0.4 indicates a moderate association, 0.4-0.6 indicates a relatively strong association, 0.6-0.8 indicates a strong association, and 0.8-1.0 indicates a very strong association (Kotrlík, Williams, & Jabor, 2011). Based on the research questions for this study, the variables investigated were gender, age, whether respondents had previously heard of cognitive impairment, whether respondents knew someone living with cognitive impairment, whether respondents knew someone living with dementia, whether respondents had read about cognitive impairment before, and whether respondents had read about dementia before. Full details of all Cramer's V scores across significantly associated variables are presented in Appendix G.

Gender was significant across responses to eight of the 28 statements included in the analysis, although all the associations were weak ($V=0.135-0.260$). The strongest association was between gender and responses to the statement "memory and thinking problems are a normal part of getting older" ($V=0.260$), with females (49.8%) being more likely to answer "False" than males (31.9%). This suggests that women may have a more positive expectation of ageing and do not think that their cognitive abilities will decline as a result of ageing.

Age was significant across nearly all questionnaire items, with the majority of the associations being weak to moderate ($V=0.192-0.383$) and the strongest associations between age and responses to the statement "I have a good understanding of what cognitive impairment is" ($V=0.379$), and endorsements of "physical health problems" as a possible cause of cognitive impairment ($V=0.383$). Respondents aged under 20 (100.0%), 31-40 (79.7%) and 41-50 (82.7%) were the most likely to agree that they had a good understanding of cognitive impairment, suggesting that, on the whole, younger adults had more confidence in their own understanding and knowledge of cognitive impairment. Respondents aged under 20 (100.0%), 31-40 (89.1%), 41-50 (88.0%), and 51-60 (84.2%) were the most likely to endorse physical health problems as a potential cause of cognitive impairment, suggesting that younger adults perceive physical health

to play a role in the causation of cognitive impairment, compared to adults aged 71-80 and 81-90 who were the most likely to respond "Don't know" (41.9% and 46.2% respectively).

Whether respondents had previously heard of cognitive impairment before was significant across 21 of the questionnaire items with associations ranging from weak to moderate ($V=0.124-0.299$). The strongest association was between whether respondents had previously heard of cognitive impairment and whether respondents perceived that they had a good understanding of cognitive impairment ($V=0.299$), with respondents who had heard of cognitive impairment before most likely to agree or strongly agree (67.8%) that they had a good understanding of cognitive impairment.

Knowing someone living with cognitive impairment was also significant across 14 of the questionnaire items, with associations ranging from weak to moderate ($V=0.129-0.315$), and the strongest association between knowing someone with cognitive impairment and responses to "I have a good understanding of what cognitive impairment is" ($V=0.315$). Whether respondents had previously read information about cognitive impairment was significant across 25 of the questionnaire items ($V=0.142-0.450$), with the strongest associations between having read about cognitive impairment and responses to the statements "Cognitive impairment is a form of dementia" ($V=0.357$), and "I have a good understanding of what cognitive impairment is" ($V=0.450$). Respondents who had read about cognitive impairment were the least likely to view cognitive impairment as a form of dementia, which is not surprising as this is a message that one would expect would be conveyed in information resources about cognitive impairment. Respondents who had read about cognitive impairment were also the most likely to have confidence in their own understanding of cognitive impairment.

Having previously read information about dementia was significant across 11 of the included statements, with associations ranging from weak to moderate ($V=0.125-0.286$). The strongest association was between whether respondents had previously read information about dementia and whether respondents perceived that they had a good understanding of dementia ($V=0.286$), with respondents who had read about dementia being more confident in their own understanding of this. Knowing someone living with dementia was very weakly associated with a few questionnaire items ($V=0.132-0.187$).

5.5.11 Qualitative Responses

Two free text items were included in the questionnaire, one which asked how respondents would describe cognitive impairment to a friend and the other which asked how they would describe dementia. Responses to these questions did not appear to differ significantly across participant groups, so the decision was made to consider responses from all respondents as one collective group. The majority of responses to these questions were brief (one or two sentences) though several respondents wrote detailed answers. Not all respondents answered these questions, with 90.2% (376) answering the question about cognitive impairment, and 91.1% (380) answering about dementia (see Table 5.6). Responses to these questions were analysed using thematic analysis (see section 5.4). Seven themes were identified from responses to these questions, each of these themes is explored in details below: *definitions and identification of cognitive impairment and dementia, idiosyncrasies and personal experiences of cognitive impairment and dementia, cognitive impairment in relation to ageing, causal aspects of cognitive impairment and dementia, impact and consequences of cognitive impairment and dementia, contrasting and conflating cognitive impairment and dementia, and "I don't know"*.

Table 5.6: Respondents answering the qualitative free text questions regarding explanations of cognitive impairment and dementia

| Participant Group | Responded to statement regarding cognitive impairment | Responded to statement regarding dementia |
|---|--|--|
| | n (%) | n (%) |
| Living with cognitive impairment | 10 (100.0) | 10 (100.0) |
| Care partner | 21 (91.3) | 21 (91.3) |
| Younger adult | 75 (90.4) | 77 (92.8) |
| Older adult | 79 (95.2) | 80 (96.4) |
| Healthcare professional | 81 (84.4) | 81 (84.4) |
| Specialist healthcare professional | 43 (89.6) | 44 (91.7) |
| Specialist | 34 (85.0) | 34 (85.0) |
| Other (undeclared and multiple groups) | 33 (97.1) | 33 (97.1) |
| Total | 376 (90.2) | 380 (91.1) |

5.5.11.1 Definitions and Identification of Cognitive Impairment and Dementia

Respondents often described cognitive impairment and dementia in similar terms, highlighting comparable symptoms for both conditions. The most frequently referenced symptom across descriptions of both cognitive impairment and dementia was memory problems. Respondents reported that cognitive impairment involved “Loss of memory particularly relating to naming of people and places and things” (Female, 78, Care Partner) and “Not being able to remember simple things, forgetting ‘silly things’. Feeling vague and slightly unaware. Feeling like your memory is going” (Female, 48, Specialist). Similarly, respondents reported that dementia involved “Loss of memory, particularly short-term memory. Failure to recognise familiar people, friends and relatives.” (Male, 66, Older Adult). In this respect, cognitive impairment and dementia were perceived to be similar concepts, with both impacting on memory primarily. Looking at respondents’ statements, it is difficult to differentiate responses to cognitive impairment and dementia in terms of memory, with a few exceptions where the severity and extent of memory loss was highlighted in statements about dementia.

Language, speech and communication difficulties were also highlighted as symptoms of cognitive impairment and dementia. Respondents stated that both conditions impacted communication skills and that people living with cognitive impairment and dementia may be slower in conversation than previously. Respondents described cognitive impairment as “When someone struggles to find the right word can speak slowly and doesn’t remember everything so for example could repeat a question they asked a few minutes earlier.” (Female, 46, Younger Adult). Similarly, respondents reported that for an individual living with dementia “Language and communication can be effected, planning and sequencing, visual perception and social behaviours are some others.” (Female, 24, Specialist HCP). In their descriptions, respondents claimed that cognitive impairment and dementia resulted in people finding it difficult to engage in normal conversation, suggesting that they may not be viewed as individuals who are still able to contribute meaningfully to social activities and interactions. Again, there was no clear difference in responses relating to cognitive impairment and dementia with regard to discussions about communication and language.

Respondents stated that people living with both cognitive impairment and dementia were no longer able to do what they used to. This change in abilities was viewed as a direct result of experiencing memory and thinking problems. Respondents described cognitive impairment as “An inability to do what you could formerly do due to problems of receiving or

processing information, including from the senses – problems of the processing part.” (Female, 66, Older Adult). In direct parallel, respondents claimed that for people living with dementia “The body of the person is still there but the mind is incapable of remembering what happened yesterday but can still remember things from years gone by.” (Female, 69, Older Adult). This statement calls to mind an idea of dementia as a condition in which an individual is still physically alive but no longer able to function as a sentient person; a living or social death (Sweeting & Gilhooly, 1997).

5.5.11.2 Idiosyncrasies and Personal Experiences of Cognitive Impairment and Dementia

Several respondents stated a view that cognitive impairment and dementia were personal experiences and that the presenting symptoms, underlying cause, consequences and impact would all “vary between person to person” (Female, 36, HCP) and that “This is different for everybody and has lots of different causes” (Female, 27, HCP). Respondents highlighted that:

“Different individuals have different strengths and weaknesses, and no two people are the same. Therefore the way in which cognitive impairment may manifest and affect their quality of life, and how they ultimately cope with this, will be different. This is why it is important to understand what the pattern of strengths and weaknesses are, what the cause and prognosis may be, and how the individual can best compensate individually and/or with support and guidance.” (Male, 38, HCP)

It is clear that this respondent viewed individual differences and personality as playing a central role in how someone experiences and copes with cognitive impairment. This view was shared by several other respondents who reported that cognitive impairment was a personal experience and that an individual’s personality may impact upon how they cope with and manage the symptoms and impact of cognitive impairment. Similarly, in their descriptions of dementia, respondents highlighted that “There are different types of dementia and the illness manifests itself differently in different people.” (Female, 48, Specialist) and that “Dementia affects everybody differently.” (Female, 27, HCP).

Cognitive impairment and dementia were often discussed in reference to respondents own experiences. For example, in her response to the statement regarding cognitive impairment, one respondent stated “I have answered these questions on my experience of caring for my husband and my description is based on him.” (Female, 70, Older Adult). Similarly,

when discussing dementia, a respondent stated “I suppose I’d again explain by reference to, for example, several of my relatives some of whom have Alzheimer’s disease, or my former wife with her combined vascular dementia and Alzheimer’s.” (Male, Undeclared Age, Specialist). Several respondents referred directly to their own experiences, suggesting that these influenced their understanding of what cognitive impairment and dementia are and are salient in their own knowledge of these.

5.5.11.3 Cognitive Impairment in Relation to Ageing

Respondents frequently referenced ageing in their descriptions, particularly with regards to the notion of cognitive impairment and dementia as later life conditions, where ageing could be viewed as a potential risk factor. For example, when describing cognitive impairment, respondents stated that “It seems to be more prevalent in older people, over 65 for instance but I don’t know whether that is just age or whether something else is going on too.” (Female, 68, Older Adult) suggesting a view of cognitive impairment as an age-related condition but with other potential causes too. Several respondents identified that cognitive impairment is “typically found in older generations but can appear in younger people too.” (Female, 25, Other). Similarly, dementia was described as a condition which “most commonly occurs in the elderly but sometimes affects younger people” (Female, 81, Older Adult) and respondents identified that “Although the risk of getting a dementia increases with age it can also occur in younger people.” (Female, 61, HCP). In their explanations of cognitive impairment, some respondents stated that cognitive impairment was a “natural part of the ageing process” (Male, 60, Specialist HCP) and that cognitive impairment “affects many of us in our ageing” (Female, 77, Older Adult).

However, some respondents considered cognitive impairment to be distinct from normal ageing. Several respondents reported that cognitive impairment presented a level of cognitive decline which is “slightly higher than we would expect in the normal aging” (Female, 25, Other) and that cognitive impairment is the “Inability to remember things over and above the usual general ‘forgetfulness’ that occurs as we get older” (Female, 73, Older Adult). In their descriptions of cognitive impairment, many respondents also referenced dementia, positioning cognitive impairment as “Somewhere between normal aging and dementia” (Male, 77, Older Adult). Similarly, respondents’ suggested that dementia was something which, whilst more prevalent in older adults, was “not part of the normal ageing process” (Female, 52, HCP) and “beyond the scope of normal ageing” (Female, 33, Other). In their descriptions of dementia, no

respondent stated that this was the result of typical ageing or a part of the normal ageing process.

5.5.11.4 Causal Aspects of Cognitive Impairment and Dementia

In their descriptions of cognitive impairment and dementia, respondents frequently reported potential causes for these conditions. In the case of cognitive impairment, respondents stated a view that this had a range of potential causes, including, but not limited to, dementia, brain damage and, as discussed earlier, normal ageing. For example, respondents stated that cognitive impairment “can be a symptom of dementia, brain injury, stroke and can have a range of other causes.” (Female, 48, HCP) and that “Causes of cognitive impairment may include: acquired brain injury e.g. through traumatic brain injury, brain infection, stroke, etc.” (Female, 37, Other). Similarly, in their descriptions of dementia, respondents reported that “There are several different causes of dementia which are not currently reversible and often are progressive.” (Female, 43, HCP). The causes identified in the descriptions of cognitive impairment were generally factors which would be considered to be outside of an individual’s personal control, suggesting that cognitive impairment was generally viewed as a condition which could not be prevented or avoided. Respondents offered fewer examples and discussions of possible causes in their descriptions of dementia. Where causes were presented, respondents suggested that there were a range of possible factors, again outside of an individual’s control, and highlighted the range of different subtypes of dementia which can present.

Many respondents identified the role of the brain in cognitive impairment and dementia. Respondents highlighted that cognitive impairment was the result of “Problems with the brain” (Female, 52, HCP) and 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 HCP). These explanations of brain damage were also posited in descriptions of dementia, with respondents highlighting dementia as “Physical pathology that affects the brain and therefore leads to both cognitive and physical impairments, according to the area of the brain affected.” (Female, 25, Other) and “a disease of the brain” (Female, 72, Older Adult; Female, 60, Younger Adult), “when the brain has become damaged or diseased” (Female, 53, Specialist). These responses suggest that some respondents may perceive both cognitive impairment and dementia to be conditions which have an underlying physiological basis.

5.5.11.5 Impact and Consequences of Cognitive Impairment and Dementia

Several respondents discussed the impact of cognitive impairment on day-to-day life. Where this occurred, the majority of respondents stated that cognitive impairment did have an impact, but that most people would be able to live a “fairly normal life” (Female, 48, HCP) and that their impaired cognition would not impact their daily life significantly. A number of respondents stated that cognitive impairment would have “an impact on daily life” (Female, 37, Care Partner) or “an impact on their quality of life” (Female, 55, Specialist) but were not clear as to the extent or severity of this impact. A few respondents elaborated slightly more on their views, stating that “This results in some tasks in daily life being more difficult to complete independently. This can also affect perceptions, feelings and behaviours.” (Female, 47, Specialist HCP). A few respondents stated that cognitive impairment would have little to no impact on someone’s day-to-day life from a practical perspective and that it “Doesn’t have a major effect on their abilities to manage day-to-day. Can increase their anxiety and bring their mood down” (Female, 48, HCP). This discussion of the emotional impact of cognitive impairment was raised by a few participants who stated that people living with cognitive impairment “will feel frightened, possibly isolated, embarrassed and feel like they have lost part of who they remember themselves to be, they may feel they have lost control.” (Female, 55, Other).

Respondents also emphasised the emotional impact of dementia, discussing this in very negative emotional language, reporting that dementia is “Horrible. Scary. Changes your whole life. Try to do whatever you can to avoid it.” (Undeclared Gender, 85, Older Adult). This notion of trying to avoid dementia was also echoed by several other respondents who stated that they were scared of dementia and that this is “what I fear at 97, like fear of falling” (Male, 98, Older Adult). When discussing people living with dementia, respondents suggested that “In many cases the individual can be lost in a world that makes no sense to them anymore and that can be frightening and scary.” (Female, 46, Specialist HCP). Both cognitive impairment and dementia were viewed to have negative emotional impacts, but these views were far more pronounced in dementia suggesting that respondents perceived dementia to have a more significant impact emotionally than cognitive impairment.

Many respondents stated that dementia would impact on an individual’s everyday life, and that this would also be a severe impact, with dementia being “a life limiting condition which over time effects a person’s ability to care for themselves, their ability to carry out activities of

daily living and often there are changes in people's personality and their emotional responses." (Female, 48, HCP). Across respondents who discussed the impact of cognitive impairment, there was no consensus as to how and to what extent cognitive impairment would impact on someone's day-to-day life. In contrast, respondents who referred to the impact of dementia were unified in their view that this would impact significantly on an individual's everyday life.

5.5.11.6 Contrasting and Conflating Cognitive Impairment and Dementia

Several respondents identified cognitive impairment as different from dementia. This difference was predominantly focused around the severity of dementia and highlighting that cognitive impairment was "not so bad as to have dementia" (Female, 52, Specialist). For example, when asked to describe cognitive impairment, respondents stated "I think it is the term used for people with memory problems that fall short of dementia" (Male, 87, Older Adult). However, several respondents also stated that cognitive impairment was "the start of dementia" (Female, 70, Care Partner), or that cognitive impairment was "an early warning indicator that someone may go on to develop dementia" (Female, 48, HCP) suggesting a view that people living with cognitive impairment are at an increased risk of dementia.

When asked to describe dementia, respondents stated that this was "Full blown cognitive impairment" (Male, 72, Older Adult) and "a more advanced development of cognitive impairment" (Female, 66, Care Partner). As the question about describing dementia directly proceeded the question which asked respondents to describe cognitive impairment, several respondents referenced their answer about cognitive impairment in their response to this. For example, in their description of dementia respondents stated "Similar to the description above but possibly more severe?" (Female, 36, HCP). The question framing of this statement suggests that this respondent was not confident in her views about dementia and its positioning with cognitive impairment. Another respondent however, echoed this sentiment but with more confidence in her views stating "Same as above, just a more severe version" (Female, 58, Younger Adult). There was no unified view on the relationship between cognitive impairment and dementia, with respondents either viewing the two as distinct concepts or perceiving cognitive impairment as a risk factor or precursor to dementia, or even a term for mild or early dementia.

5.5.11.7 “I don’t know”

Several respondents elected not to answer the questions regarding descriptions of cognitive impairment (9.8%) and dementia (8.9%), which could have been for a multitude of reasons, including lack of knowledge or lack of confidence in their own knowledge. Of those who did answer these questions, some explicitly stated their lack of knowledge. For example, when asked to describe cognitive impairment, respondents stated “No idea!” (Female, 68, Older Adult), “Not sure” (Male, 74, Older Adult) and reported that “I wouldn’t be able to describe it with any confidence” (Male, 68, Care Partner) and “I don’t really know what I would say. Probably have to look it up.” (Female, 58, Younger Adult). Several respondents also referenced this research, reporting that “Before this study I had never heard of cognitive impairment” (Female, 26, Younger Adult) and “This survey is the first time that I’ve heard of it!” (Male, 29, Younger Adult). A few respondents made similar statements to the question regarding dementia, reporting “I do not know sufficient to be useful” (Female, 82, Older Adult) and “Dementia is difficult for me to explain” (Female, 40, Younger Adult). However, respondents overall seemed more confident in describing dementia than cognitive impairment.

5.6 Discussion

The results of this survey study have a number of implications for the health and wellbeing of people living with cognitive impairment and the wider population, and key considerations for public health and information campaigns designed to raise awareness of cognitive impairment.

5.6.1 Implications for Health & Wellbeing

The fact that care partners reported that they did not have a good understanding of cognitive impairment is a particularly important result to note. If care partners are not fully informed about cognitive impairment, then they may misattribute symptoms which could result in them blaming the individual for their symptoms and associated actions (Roberto et al., 2011). This could lead to problems within the relationship and poor communication. However, care partners self-reported low understanding of cognitive impairment could be due to a lack of confidence in their knowledge, possibly due to the stresses and pressure of supporting an individual living with cognitive impairment. People living with cognitive impairment also had a lack of confidence in their own understanding of this, suggesting that these individuals may not

understand what is happening to them and feel uncertain about their own situation, potentially leading to anxiety and depression.

Most respondents reported that people living with cognitive impairment were still the same person that they always had been. However, 40% of individuals living with cognitive impairment and over 15% of care partners and older adults reported that people with cognitive impairment were no longer the same person. It may be that some respondents interpreted the meaning of this statement differently, with some people answering this based on the adaptations that an individual might have to make as a result of cognitive impairment, such as no longer being able to remember recipes for meals that they had once cooked regularly from memory. In this way, the individual could be said to not be the same person as they have lost an ability which was once a defining part of their personality. Exploring how people define personhood, and the role of cognition and cognitive health in defining what makes a person themselves is a direction for future research. Understanding this aspect in more detail could be beneficial in developing strategies to reduce stigma around cognitive impairment and dementia. If people perceive cognitive impairment to fundamentally change who a person is then their responses to an individual living with cognitive impairment may be stigmatising, considering the individual to no longer contribute value to their community and family setting.

One of the MCI criteria is cognitive difficulties which are not impacting upon an individual's ability to function independently (Winblad et al., 2004). Despite this, very few respondents reported that cognitive impairment was easy to live with. As cognitive impairment would generally be considered to comprise memory and thinking difficulties which do not impact on day-to-day life in the same way as dementia (and was introduced as such in the questionnaire information), it is intriguing that so many people considered cognitive impairment to be difficult to live with. In the qualitative responses, respondents identified cognitive impairment as impacting on everyday life but there was a lack of clarity and certainty regarding the level of this impact. This has implications for wellbeing of people living with cognitive impairment as it suggests that these individuals have more day-to-day challenges and difficulties than are currently acknowledged clinically. Similarly, if people view cognitive impairment to be difficult to live with and as impacting quality of life, this may increase fear and stigma and could result in people not engaging in help-seeking behaviour when symptoms present. However, that respondents identified dementia as a condition which would have a severe or pronounced impact on day-to-day life suggests that fear surrounding dementia is likely to be greater than

that surrounding cognitive impairment, thus cognitive impairment may present a state of cognitive decline which people may be more willing to seek assessment and diagnosis for as they may be less anxious about a diagnosis of cognitive impairment than dementia.

Most respondents reported that people with cognitive impairment do not lose their independence; however, a large proportion of care partners disagreed with this. This may be due to the increased burden and stress that care partners feel they have to shoulder in their caregiving role. Similarly, the majority of respondents agreed that people with cognitive impairment lose their self-confidence. This suggests that, overall, respondents viewed cognitive impairment to result in a loss of self-confidence, to be not easy to live with, but that people with cognitive impairment are still independent. This has clear implications for the wellbeing of people living with cognitive impairment as it suggests these individuals may lose their self-confidence, subsequently impacting their quality of life and potentially limiting their social activities.

Most respondents reported that living a healthy and active lifestyle would ameliorate the presenting symptoms of cognitive impairment and possibly help the individual to live a higher quality of life. Given the media discourse around dementia, and the focus on preventing dementia via various strategies such as diet modifications and exercise programmes (Peel, 2014), this is not surprising. This view may foster a perception of cognitive impairment as a controllable syndrome and may result in people placing blame and responsibility for the symptoms of cognitive impairment with an affected individual, according to attribution theory (Weiner, 1993). In contrast, however, diet was the least endorsed potential cause of cognitive impairment, suggesting that many participants did not perceive diet to play a role in the causation or prevention of cognitive impairment. Diet was also only raised by three respondents in their qualitative descriptions of cognitive impairment and dementia suggesting that diet was not at the forefront of respondents' minds when thinking about these conditions. These results suggest that respondents may be confused about the role of diet and lifestyle factors in cognitive impairment. This could be due to respondents displacing any possible blame for cognitive impairment, but holding onto a sense of hope for the future for people living with cognitive impairment that lifestyle changes may offer some positive effects. Personal behaviour was endorsed as a potential cause of cognitive impairment by 63.8% of respondents, making this the second least endorsed cause (behind diet). The uncertainty around this possible cause of cognitive impairment compared to other causes could be due to respondents not wanting to

place blame, or may be due to interpretations of what was meant by “personal behaviour”. However, with the majority of respondents endorsing personal behaviour as a cause of cognitive impairment, this provides support for the notion that MCI is perceived as a controllable entity. As such, according to attribution theory (Weiner, 1993), people may be less likely to exhibit helping behaviours and actions towards individuals experiencing cognitive impairment if they view the individual as responsible for their own situation.

Just under half of respondents reported that cognitive impairment is not permanent, suggesting that they may consider this to be an acute condition which is changeable over time. However, the majority of respondents living with cognitive impairment stated that it is permanent, so this particular group may have less hope or belief in the possibility of treating or curing cognitive impairment. What is not clear from the answers here is what respondents considered the outcomes would be for someone with cognitive impairment if they didn't think it was a permanent condition. It may be that some people answered “False” to the statement “Cognitive impairment is permanent” because of the increased risk of dementia, and thus did not consider cognitive impairment to be a permanent state due to the potential for progression. Alternatively, respondents may view cognitive impairment as a reversible state whereby cognition may improve over time and potentially revert to previous levels of cognitive function. There was a lot of uncertainty around whether cognitive impairment was a permanent condition, particularly amongst care partners, older adults and younger adults. This suggests that care partners do not know whether their loved one will experience cognitive impairment temporarily or permanently. Living with an uncertain illness in this way may result in anxiety and distress, as uncertainty has been shown to be a powerful stressor (Greco & Roger, 2003).

5.6.2 Implications for Public Health & Education Campaigns

From the results of this questionnaire, it is clear that increasing knowledge amongst the general population should be a focus of future information campaigns to ensure that this group of individuals are equipped to recognise the symptoms of cognitive impairment in friends and family members (and potentially themselves) and to support people diagnosed with cognitive impairment. Increased knowledge of cognitive impairment may also reduce the stigma around cognitive impairment. All respondents living with cognitive impairment wanted to know more about this suggesting that information provision following diagnosis needs to be improved in order to address the concerns that these individuals have and enable them to live as well as possible with cognitive impairment. Given that so many respondents (82%) stated that they

wanted to know more about cognitive impairment, despite also stating that they had read information about cognitive impairment (68.8%) it is suggested that the current information people have accessed is not enough to satisfy their information needs. This also suggests that people actively want more information about cognitive impairment; they are not afraid of it and want to be able to access this. Providing information should empower those individuals who are affected, both directly and indirectly, by cognitive impairment. The majority of respondents stated that they wanted to know more about dementia, despite the fact that they had read information about this previously. This suggests that further information and awareness raising around both dementia and cognitive impairment is warranted in order to improve overall knowledge about both of these conditions across the general population.

Respondents who had read information about cognitive impairment were the most likely to view cognitive impairment as not being a form of dementia. In their qualitative responses, respondents were more confident in describing dementia than cognitive impairment, as evidenced by the increased response rate to the question about dementia. This implies that current information campaigns and information resources about dementia (and cognitive impairment to a lesser extent) are communicating key information and that people are receptive to this information, retaining learning and knowledge. It is also clear from the results of this survey that more information is needed, and wanted, about cognitive impairment which is accessible to a wide range of participants.

Over one quarter of care partners, older and younger adults answered “Don’t know” when presented with the statement “People with cognitive impairment will definitely develop dementia”. This suggests that these groups were not as confident in their understanding of whether cognitive impairment will progress to dementia as compared to HCPs and specialist HCPs, and that they may benefit from further information about possible prognoses for people living with cognitive impairment. This uncertainty could be the result of a lack of available information about cognitive impairment for the lay population or may be an artefact of the language used throughout this questionnaire and the way that respondents interpreted “cognitive impairment”. This has implications for public health and education campaigns as it highlights a key challenge in delineating the boundaries between cognitive impairment and dementia and emphasises the importance of raising awareness about cognitive impairment for the lay population.

Improving information around the timeline of cognitive impairment is an important consideration for future information resources and campaigns. Whilst the timeline for cognitive impairment might vary according to the underlying aetiology, it is important to inform people about the potential prognostic outcomes for people living with cognitive impairment, including the statistics around the likelihood of reverting to normal cognitive functioning or progressing to dementia following a diagnosis of cognitive impairment.

Diet was the least endorsed possible cause of cognitive impairment, with less than half of respondents reporting that diet could play a role in the causation of cognitive impairment. In their qualitative responses, very few respondents referenced diet suggesting that this was not something which was at the forefront of their thinking and considerations about cognitive impairment and dementia, though this could also be artefact of the question topic. This is an unexpected result given the current media discourse around the role of healthy lifestyle factors in cognitive impairment and dementia (Peel, 2014). This suggests that this population could benefit from accessible information about the role of diet in cognitive health to ensure that they have the information to make a decision about their dietary choices which may potentially reduce their risk of cognitive impairment and dementia, as well as having numerous other health benefits.

5.6.3 Future Research

Future research should seek to explore the emotional and psychological impact of living with cognitive impairment in order to understand how people feel about their symptoms and how much cognitive impairment does in fact impact on their life and the lives of their family and friends. It may also be that people answered that cognitive impairment was not easy to live with because of the potential stigma around this and the fear of developing dementia. Exploring what makes cognitive impairment difficult to live with in particular would be beneficial to help design support for people living with cognitive impairment that may mediate some of the negative aspects and enable people to live more easily with cognitive impairment.

An exploration of how people think it may be possible to prevent cognitive impairment is also an important avenue for future research in order to promote healthy lifestyle interventions which may help people stay both physically and cognitively healthy for longer. Understanding the role of lifestyle factors in cognitive health and cognitive impairment is a key direction for future research.

Future research should consider the information needs of different participants and establish whether people have access to the information that they need and want. Exploring the information that is currently available and then mapping information needs to available resources will enable gaps in information resources to be filled according to the specific needs and requirements of participants. Understanding information needs of different populations will also enable the development and provision of future information resources which are tailored to the needs of each group.

The stated desire to know more about cognitive impairment highlighted in this survey may be reflective of the gaps in knowledge that are present in the research literature (prognostic information, aetiology etc.) which we are unable to provide the answers to at present. Future research should seek to explore what information people feel they want to know about cognitive impairment and should also seek to address the current knowledge gaps in the research field.

Attempting to probe the labels and terminology used to discuss cognitive impairment in this short survey was challenging. As such, future research should seek to explore this aspect further, identifying the labels for cognitive impairment that people are familiar and comfortable with and where people perceive differences and similarities to lie between these labels.

Whilst this survey has gone some way towards filling the literature gap regarding the views and perspectives of a variety of populations about cognitive impairment, further research is warranted in this area. Undertaking a qualitative exploration of this topic is imperative to developing an understanding of how people view cognitive impairment and the mechanisms and discourses which influence their views.

5.7 Summary

This survey study provides a unique source of information on people's understanding and knowledge of cognitive impairment, providing a national picture from over 400 respondents. However, whilst this survey sheds some light on the knowledge and views of multiple populations about cognitive impairment, it is important to build on this data via a larger scale survey including the views of culturally and geographically diverse respondents. It is also important to further develop this understanding of people's views by employing qualitative methods such as focus groups and interviews to understand how and why respondents have particular views. In the next chapter, I will present the final study included in this thesis; a qualitative study using semi-structured interviews to build on the results of the questionnaire

study presented here and exploring in more depth the views that people have about cognitive impairment.

Chapter 6: A Qualitative Exploration of Knowledge and Views about Cognitive Impairment

6.1 Introduction

This chapter reports the results of 21 interviews exploring people's understandings of cognitive impairment. At present, there is a paucity of literature exploring what people know and understand about cognitive impairment, and very few studies have considered the language that people use to discuss cognitive impairment. A systematic review of the current literature base (Chapter 3) found that studies have not yet considered the views of the lay population, with previous research focusing on the views of people living with cognitive impairment, their care partners and, to a lesser degree, clinicians. As such, research is warranted which explores the views of a wider population, as cognitive impairment is something which could affect anyone either directly or indirectly and which people need to have a knowledge of in order to be alert to the signs and symptoms and to ensure that they are able to support individuals living with cognitive impairment.

A nationwide questionnaire study (Chapter 5) involving respondents living with cognitive impairment, care partners, older adults, younger adults, healthcare professionals and dementia specialists aimed to address this gap in the literature. Whilst this questionnaire made initial progress into exploring what a wide range of people know and understand about cognitive impairment, this was somewhat limited due to the nature of survey design, whereby respondents were restricted in the scope and language of what was discussed. As such, a qualitative exploration, building on the results of the questionnaire study, was designed to facilitate an indepth understanding of peoples knowledge of cognitive impairment which could inform, and be informed by, the predominantly quantitative questionnaire study (see Chapter 2 for a detailed discussion of the mixed methods approach in this thesis).

This study utilised semi-structured interviews to explore participants knowledge and understanding of cognitive impairment, considering the language and labels that they elected to use when given the freedom to discuss cognitive impairment in their own words. Developing an understanding of what people know about cognitive impairment and how they choose to discuss this will enable further development of the mild cognitive impairment illness representation model outlined in Chapter 4. This will subsequently facilitate the development of information resources which can provide appropriate information to a wide range of people,

and identify avenues for future research to address some of the uncertainties which may be present in peoples current knowledge and understanding of cognitive impairment.

6.2 Research Questions

- What do people living with cognitive impairment, care partners, older adults, younger adults, dementia specialists, and healthcare professionals understand about cognitive impairment?
- How do respondents describe cognitive impairment in their own words? What language, labels and terminology do people employ when discussing cognitive impairment?
- How do participants previous experiences of dementia and/or cognitive impairment shape and impact their views?
- Where do participants position cognitive impairment in relation to normal ageing and dementia?
- What do participants view as the main consequences of cognitive impairment?
- Do respondents consider cognitive impairment to be treatable and/or curable?
- Do participants view cognitive impairment as preventable or avoidable in any way?
- What factors do participants consider may cause cognitive impairment?

6.3 Method

Semi-structured interviews were utilised to explore, in-depth, what knowledge and understanding people from a range of backgrounds have about cognitive impairment. It has been suggested that interviews are more likely to be acceptable to people experiencing cognitive difficulties (Cheston et al., 2000; van Baalen et al., 2010). Interview participants were drawn from the previous questionnaire study from the six key participant groups (see Chapter 2): younger and older adults without cognitive impairments, people living with a cognitive impairment, care partners of people living with cognitive impairment, healthcare professionals, and dementia specialists. The interview schedule was developed based on the results of the systematic review (Chapter 3) and survey study (Chapter 5) and was designed to capture participants' own views and perspectives of cognitive impairment.

6.3.1 Participants

All participants who took part in the questionnaire study were asked whether they would potentially be interested in taking part in an interview study. I then contacted a random

sample of respondents who expressed an interest in taking part in an interview. I decided to contact up to eight respondents from each of the six main participant groups identified from the survey study (Chapter 5) as I felt that contacting this number of participants would enable representation from each group in this study. My decision to select participants at random was based on my desire to be unbiased in participant selection, ensuring that I was not aware of individual participant responses to the questionnaire prior to the interview. I felt that if I selected participants based on any other criteria than their self-selected participant group membership that this may influence my interview technique and questions if I was expecting a particular response based on questionnaire responses.

Forty-four respondents were approached about the interviews, of which 26 responded, but 6 were unavailable during the interview period. The remaining 20 respondents all took part in an interview. Subsequently, I met two men living with cognitive impairment who were introduced to me by my supervisory team whom I invited to participate, as people living with cognitive impairment were underrepresented in the interview sample. In total, 22 participants took part, across 21 interviews (one interview was with a husband and wife together). Details of interview participants are presented in Table 6.1 (see p.192).

The circumstances of the four participants living with cognitive impairment warrant some extra discussion as cognitive impairment represents such a heterogeneous population that it is important to consider the individual diagnoses of each participant in relation to the criteria for cognitive impairment.

- Katie was a younger adult living with cognitive impairment who had been given this diagnosis as a secondary diagnosis to an auto-immune condition which she had been living with for a number of years.
- Robert was a younger adult who had recently been diagnosed with cognitive impairment as a stand-alone diagnosis following an experience of memory and thinking difficulties for which he sought assessment.
- Victor was a man living with a diagnosis of cognitive impairment which had been issued following a stroke which he had experienced several years prior.
- William was a man living with a diagnosis of cognitive impairment which had recently been issued following a previous diagnosis of probable Alzheimer's disease.

The variety of circumstances and experiences of these four participants further highlights the heterogeneity of the population of people living with a diagnosis of cognitive impairment. Whilst none of these participants might be viewed as the classical or typical cognitive impairment case, I felt that it was important to understand their views around cognitive impairment as this was a label which they self-identified as living with and thus they had valuable, insightful perspectives around what it means to have cognitive impairment, what cognitive is and how cognitive impairment can impact on an individuals life.

Table 6.1: Interview participants' characteristics

| 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 |
| Sarah | Specialist | 54 | Female |

* Husband and wife interviewed together

6.3.2 Procedure

6.3.2.1 Consent visit

Participants were initially contacted via telephone or email to introduce myself and the research and arrange a convenient time and location to meet and discuss the research in more detail. This consent visit lasted around half an hour. Participants were provided with a detailed information leaflet about the research (Appendix H). Individuals were then given the choice to complete a consent form (Appendix I) immediately or to take some time (up to a week) to decide whether they would like to participate or not. No participants elected to take time to consider their decision, as all participants had seen written information about the study in advance of this consent meeting and were happy to proceed immediately.

In my meeting with participants, I highlighted each statement on the consent form and discussed each one individually to ensure that participants fully understood the research and were able to provide informed written consent. Participants were informed at all stages that they were free to withdraw from the research at any time without having to give a reason, and that their decision around participation would not affect any care or support that they received. Full details of the ethical considerations regarding this study are outlined in Chapter 2.

6.3.2.2 Interview procedure

Eighteen of the interviews were conducted in the participant's home and three were conducted in a private office at the University of Worcester. Interviews were conducted individually, with only the researcher and the participant present, though all participants were given the choice to have a family member or friend with them if they wished. 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 on a one-to-one basis. The interviews ranged in time from thirty minutes to two hours and seventeen minutes, with the average interview lasting one hour and six minutes.

An interview schedule was compiled (Appendix J) to explore participants' knowledge and understanding of cognitive impairment. The interview schedule was based on the results of the questionnaire study outlined in Chapter 5 and aimed to consider participants' perspectives on:

- 1) their own knowledge and views about cognitive impairment
- 2) the language, labels and terminology used around cognitive impairment
- 3) their understanding of cognitive impairment, and mild cognitive impairment (MCI) as a diagnostic construct

6.4 Data Analysis

All interviews were transcribed verbatim. The majority of the interviews were transcribed by myself, but two interviews were transcribed by an external transcriber. This decision was made to maximise my time by utilising external support for transcription but also to ensure that I could use the transcription process to familiarise myself with the interviews and begin immersing myself in the data. For the two interviews which I did not transcribe myself, I checked the transcripts against the audio recordings thoroughly to ensure that I agreed with the transcription. Interviews were transcribed according to the transcription symbols and rules as adapted from Wooffitt (2001). Full details regarding the transcription symbols applied to the interviews are outlined in Appendix K.

Following transcription, interviews were analysed using thematic analysis to provide a deep and rich account of the data. An inductive approach was adopted and the themes identified were grounded firmly in the data rather than being driven by a prior theoretical basis, though the use of an interview schedule did restrain the content of discussions overall. Thematic analysis is a flexible qualitative analysis method which enables a summary of the key features of a large dataset, facilitating identification of both similarities and differences across the dataset. Semantic analysis was conducted, aiming to explore the explicit meanings posited by participants in their interviews.

The analysis followed several key stages as outlined by Braun & Clarke (2006). The analysis process began with me reading and rereading the transcriptions, and playing the audio files concurrently to verify the transcripts. This enabled me to become familiar with the interviews and to be fully immersed in what participants had discussed. At this point, brief notes were taken about possible codes that I felt were present in the data, with a particular focus on identifying patterns across and within the transcripts. The transcripts were subsequently uploaded to NVivo 11 (QSR International). NVivo is a software package designed to aid in the analysis and management of qualitative data and is particularly beneficial for large datasets. As such, I felt that NVivo would be appropriate for use in this study enabling me to work flexibly

with the large amount of data gathered from the interviews. In NVivo line-by-line coding was conducted. At this stage, I worked through each transcript multiple times, developing and expanding the list of codes at each pass. The codes were then printed and I reviewed these by hand on paper, beginning to identify encompassing themes which represented patterns across the codes. These initial themes were then uploaded into NVivo and the existing codes were arranged into a hierarchical structure within the encompassing themes. Finally, I re-read all of the transcripts, cross referencing with the identified themes to ensure that these were illustrative of the source data and reflected what participants had discussed. Throughout every stage of the analysis process, I discussed the emerging codes and themes with my experienced supervisory team to obtain their views and opinions on the analysis process and to seek additional confirmatory or opposing viewpoints. The comments of my supervisors were carefully considered in relation to the analysis of the transcripts, ensuring a rich and detailed analysis which was fully representative of the participants expressed views. Once I, and my supervisory team, were confident that the identified themes were reflective of the data, analysis was considered to be complete.

6.5 Results

Following the analysis of the interviews, three major themes emerged, each containing a number of smaller subthemes. The first of these themes was *accounts of cognitive impairment*. This theme highlights the descriptions of cognitive impairment proposed by participants and includes the subthemes *defining cognitive impairment – symptoms and labels, permanency and idiosyncrasy, the impact of cognitive impairment on daily life, and threat to identity*. The second theme, *causation accounts*, brings together the potential causes of cognitive impairment posited by participants, including whether causes and risk factors were considered to be within an individual's personal control. This theme includes the subthemes of *brain damage or injury, diet and healthy lifestyle factors, and controllability and blame in the causation of cognitive impairment*. The third and final theme, *ageing, dementia and dying*, highlights the accounts of ageing offered by participants throughout the interviews, and the notion of death and dying which was also raised by a number of participants. This theme includes the subthemes of *age of onset of cognitive impairment, normal ageing and normality, differentiating cognitive impairment and dementia, and death and dying*. Figure 6.1 presents a thematic map of the themes and subthemes which were identified from the transcripts.

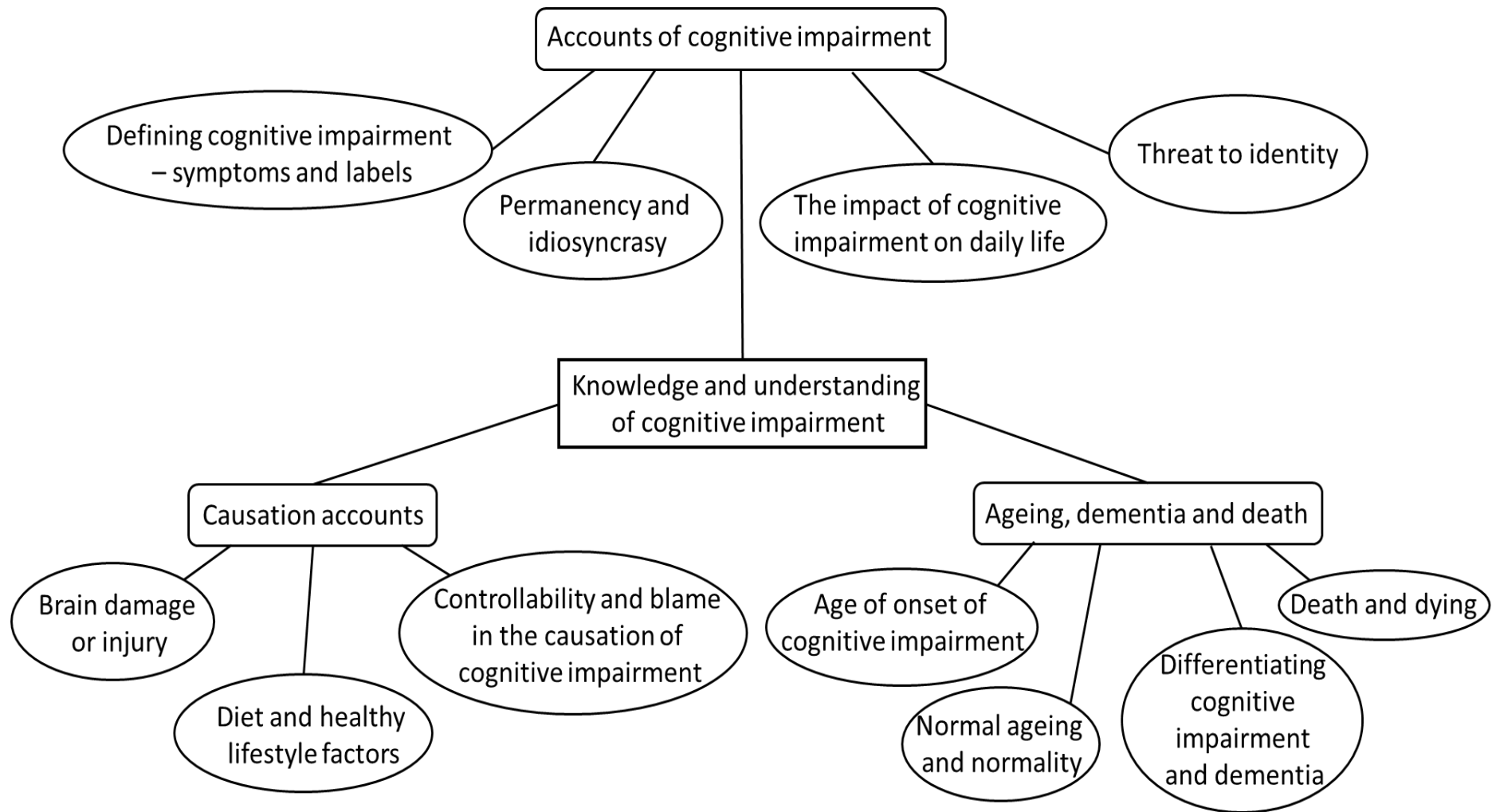


Figure 6.1: Thematic map of themes and subthemes

6.5.1 Accounts of Cognitive Impairment

6.5.1.1 Defining Cognitive Impairment – Symptoms and Labels

The most frequently discussed symptom of cognitive impairment was memory problems, with all participants highlighting memory loss or memory lapses as a symptom they considered was, or could be, directly related to cognitive impairment. Seven participants (Helen, female, 27, HCP; Katie, female, 37, living with cognitive impairment; Mary, female, 71, specialist; Nina, female, 74, older adult; Pauline, female, 72, older adult; Robert, male, 56, living with cognitive impairment; Victor, male, undisclosed age, living with cognitive impairment) stated that memory difficulties were either the biggest problem, or one of the biggest problems, in cognitive impairment. Inherent in this discussion was the notion that people living with cognitive impairment cannot form new memories and therefore cannot learn new information and skills because of the lack of retention. All participants living with cognitive impairment highlighted memory as one of the key symptoms that they were experiencing and expressed how this impacted on their day-to-day life.

For Katie (female, 37, living with cognitive impairment) memory was highlighted as the symptom she noticed the most and which she viewed as having the biggest impact on her life. Katie attempted to explain the experience of cognitive impairment in a manner that might make it more accessible to others by comparing it to “baby brain” (line 3), a state of cognitive confusion that many women experience during pregnancy and in the first months of parenthood (Christensen, Leach, & Mackinnon, 2010).

Extract 1

- 1 Katie: mmm yeah. it just all gets frazzled in your head
- 2 Interviewer: yeah
- 3 Katie: people call it baby brain, when they've just had a baby
- 4 Interviewer: yeah
- 5 Katie: it's ↑basically that ((laughs)) or when you're really
- 6 stressed and it's just like aah
- 7 Interviewer: yeah. and what is your personal experience of cognitive
- 8 impairment sort of?
- 9 Katie: erm: for me my memory's the worst
- 10 Interviewer: yeah

11 Katie: erm if I: try to transfer something into long term
 12 memory it very rarely happens these days ((laughs)) erm
 13 I can't remember what I did yesterday y'know?

14 Interviewer: yeah

15 Katie: erm there's like flashes of information (.) which I
 16 sort of if somebody reminds me I think oh yeah! I
 17 remember that! ((laughs)) but it takes a lot to
 18 actually figure out what's actually happened

Katie highlights that information gets “frazzled” (line 1) in her mind. This is a very powerful word and one which Katie emphasised in her talk. “Frazzled” calls to mind things being very jumbled and disorganised and possibly even burnt or damaged in some way. Katie states that for her, memory is the symptom that affects her the most, and she cannot commit anything to long-term memory or retain information. It is clear from this discussion that Katie’s cognitive impairment impacts on her daily life, something she expands upon throughout the interview. Similarly, Robert (male, 56, living with cognitive impairment) expressed how he had noticed that his memory was declining and that this was the core symptom that he was aware of and that impacted on his life and tasks that he had previously done with ease.

Extract 2

1 Robert: I noticed I was getting I was me memory was going worse
 2 and worse and worse

3 Interviewer: yeah

4 Robert: errr getting things wrong, forgetting things I mean me
 5 mum lives just down the road she's ninety an::d err me
 6 and me brother look after her, and she wanted like
 7 three or four items of shopping (.) getting, by the
 8 time I'd come back here, gone. I'd forgotten it

Potential symptoms of cognitive impairment were also discussed by Helen (female, 27, HCP), a healthcare professional working with older adults, but not specifically in the dementia field. In her talk, Helen highlighted symptoms including a problem with memory and word finding difficulties.

Extract 3

1 Helen: erm::: (.) tch I guess erm::::: (.) .hh (.) anything
 2 kind of m:ore significant memory loss wise then just
 3 kind of being a bit forgetful

4 Interviewer: yeah

5 Helen: something kind of a bit more on a regular basis on a
 6 daily basis, and things more sort of around .hh erm

7 people and places that they're familiar with erm: so we
8 tend to be better at remembering kind of (.) places and
9 faces and that sort of thing

10 Interviewer: yeah

11 Helen: and °not kind of (.) what we had for dinner° .hh erm::
12 (.) and erm: (.) tch word finding ↑difficulties if
13 they're struggling to kind of exp- explain just about
14 something that you would expect them to be able to
15 easily kind of describe to you .hh erm:: (2) I guess
16 erm:: °the early stages? bah::° (4) tch er erm:::
17 ↑yeah not be able to retain information that you've
18 kind of given them .hh erm quite kind of (.) you've
19 sort of told them in the morning and them not being
20 about to remember by the end of the day

21 Interviewer: yeah

22 Helen: not going to say five minutes because that's probably
23 much more in the er sort of later stages .hhh but
24 something that that they're unable to kind of retain
25 the information I suppose .hhh erm: .hhh you kind of
26 just get a feel don't you? you just kind of kno- like
27 if family

28 Interviewer: yeah

29 Helen: with your family you just kind of know

Helen states that the difficulties with memory should be “significant” (line 2) suggesting a view that some level of forgetting is not related to cognitive impairment, but that there is a level at which memory problems become something of significance, and that memory problems should occur regularly. She also explains that this memory loss should include personally salient things rather than things she highlights as more mundane such as “what we had for dinner” (line 11). Helen states that family members would be able to recognise the symptoms of cognitive impairment almost intuitively, highlighting that family members would have a “feel” (line 26) and would just “know” (line 29). This extract highlights the perspective shared by seven participants that memory is the most prominent symptom of cognitive impairment.

However, whilst memory problems was something which all participants living with cognitive impairment described as something they themselves were experiencing, five participants (Adam, male, 31, specialist; Irene, female, 73, older adult; Louise, female, 30, specialist; Oscar, male, 73, specialist; William, male, undisclosed age, living with cognitive impairment) were explicit in their view that cognitive impairment does not always involve a memory problem or that other symptoms may be more prominent. For example, when discussing information needs and provision for people living with cognitive impairment and their

families, Adam (male, 31, specialist) stated it would be important to understand what the individual living with cognitive impairment was experiencing and what they felt they needed help with “cos we can say that (2) it might be their memory, it might be nothing to do with their memory”. In considering the role of memory in cognitive impairment Louise (female, 30, specialist) discussed how she was keen to avoid using the word “memory” (line 3) when naming a support group for people living with cognitive impairment and dementia as she did not want to create the idea that the group was only about memory difficulties.

Extract 4

- 1 Louise: like the group that we started on a Tuesday is with the
2 Alzheimer’s Society, .hh and they have groups they
3 always use the word memory like memory café dementia
4 café
- 5 Interviewer: yeah
- 6 Louise: and I was really keen to get away (.) from that

Similarly, William (male, undisclosed age, living with cognitive impairment) explained how he perceived that cognitive impairment could involve any impairment in cognition, and may not involve an impairment or deficit in memory.

Extract 5

- 1 Interviewer: would you think it always involved memory? or could it
2 be in any area of cognition?
- 3 William: it could be ↑anything
- 4 Interviewer: anything
- 5 William: ab:solutely anything

The examples here highlight how five participants considered that cognitive impairment should not be viewed solely as a memory problem as this may not always be a part of what an individual living with cognitive impairment experiences.

All participants were able to give a description of the symptoms that they perceived to be related to cognitive impairment, focusing mainly on memory loss, communication difficulties, and a loss of previous skills and abilities. For example, in response to a question asking what symptoms might be present in someone living with cognitive impairment, Adam (male, 31, specialist) identified a range of symptoms, including orientation, memory, speech, visual perception and verbal fluency.

Extract 6

- 1 Adam: erm their memory their speech erm (2) sometimes their
2 perception of risks and things like that, and their (1)
3 yeah their ordering of things, tch erm:: pffff I
4 suppose all of things when I think that are all
5 symptoms of (.) well anything that could ↑basically
6 anything really that the ↑brain does y'know
- 7 Interviewer: yeah
- 8 Adam: sometimes their visual perception or .hh erm (3) tch
9 fluency in the way that they actually ↑talk, so yeah a
10 whole host of .h things really basically only the
11 things that I know that can go wrong with the brain
- 12 Interviewer: yeah
- 13 Adam: I would think, °oh°
- 14 Interviewer: yeah
- 15 Adam: those could be symptoms of =
- 16 Interviewer: so it would be quite a wide spectrum
- 17 Adam: = yeah so quite broa:d. most commonly though .hh
18 speech, memory

Here, Adam discusses speech and memory problems as two symptoms that he may perceive as being most attributable to cognitive impairment and as the symptoms he has heard most frequently. He also states that the symptoms of cognitive impairment could be “quite broa:d” (line 17) suggesting he may perceive cognitive impairment to be something that impacts an individual’s life considerably due to the breadth of symptoms which may present. Similarly, Katie (female, 37, living with cognitive impairment) outlined a range of symptoms which she perceived could be part of cognitive impairment.

Extract 7

- 1 Katie: err memory difficulties difficulties with erm
2 translating what’s in your head into verbal or written
3 word
- 4 Interviewer: yeah
- 5 Katie: erm difficulties with processing what other ↑people are
6 saying, difficulties with processing what you’re
7 reading, erm just basically any information going in or
8 out
- 9 Interviewer: yeah
- 10 Katie: it’s not working properly ((laughs)) basically

The examples here from Adam and Katie highlight the range of symptoms that participants presented throughout the interviews. Memory and communication/speech problems were the most frequently referenced symptoms of cognitive impairment, with 21 and 15 participants respectively discussing these symptoms. However, whilst memory was highlighted as a core symptom, five participants explicitly stated that memory should not be viewed as the only symptom and that people living with cognitive impairment may experience cognitive decline which does not necessarily involve a memory impairment.

Fifteen participants referenced a personal experience themselves or of a family member or friend who had experienced what they considered to be cognitive impairment, often as the result of a stroke or other sudden brain injury, or in relation to dementia.

Extract 8

1 Irene: ermm had a friend whose husband had it. erm she managed
2 to keep him at home quite a while. .h got another
3 friend not not a very close friend but another friend
4 whose wife erm got dementia at sixty-two

As such, their descriptions and impressions of cognitive impairment were heavily informed and influenced by these experiences. For example, when asked what she knew about cognitive impairment, Fiona (female, 76, care partner) began her account by explaining that she didn't know "very much about it at all" (lines 1-2) until it was brought into her personal life when a friend experienced a serious brain injury.

Extract 9

1 Fiona: .hh well erm (.) I didn't know very much about it at
2 all until a friend of ours had a serious brain injury
3 about ooh: .hhhh fifteen years ago
4 Interviewer: yeah
5 Fiona: an:d to all intents and purposes when you meet her you
6 wouldn't know there was anything the matter with her at
7 all .hh because it had just damaged one particular bit
8 of the brain
9 [...]
10 Fiona: and then of course when Francis had his first stroke
11 Interviewer: yeah
12 Fiona: that was erm (.) tch I think because hhhh .hhh (.) both
13 times he's had his speech very badly affected and he
14 hadn't really recovered from the first stroke so you're

15 never quite sure if it was the speech or (.) the brain
16 damage. (.) and er I have been to one or two things
17 about the brain an:d realised that bits and pieces do
18 different things and that's affected .hh but living
19 with somebody it's erm (.) tch not quite like the
20 textbooks, because he looks the same and to all intents
21 and purposes he is the same

22 Interviewer: yeah

23 Fiona: and I forget that he can't reason very well .hh and er
24 it doesn't help that he's deaf as well and if he
25 doesn't have his hearing aids in he can't hear ↑either

Fiona then moves on to discuss a more recent personal experience of cognitive impairment in her husband, Francis, following a stroke. Fiona references brain damage and injury for both her friend and her husband, echoing a line of conversation prevalent in 15 participants' discussions about cognitive impairment as the result of a brain change or brain damage (see section 6.5.2.1 for more details). Alongside this, she discusses how she has attended information sessions about the brain and how this has helped her to understand that, in the brain, "bits and pieces do different things" (lines 17-18). However, Fiona explicitly states how the experience of living with someone with cognitive impairment is "not quite like the textbooks" (lines 19-20) implying that the information she has received has not fully prepared her for or helped her to live with someone experiencing a cognitive impairment. For Fiona, this is centred around the invisibility of cognitive impairment and the fact that her husband and friend both still look the same as they did before the onset of any cognitive impairment. This suggests that Fiona's personal experiences of cognitive impairment have informed her view that this is an invisible condition.

This view of cognitive impairment as an invisible illness was also shared by three other participants (Irene, female, 73, older adult; Katie, female, 37, living with cognitive impairment; Louise, female, 30, specialist) who stated that people may be treated differently because their impairment was not as apparent as a more definitely physical illness and they therefore may be subject to pressures from others who think they should be able to do more than they can. When asked about whether she thought people experiencing cognitive impairment could still live well and have a good quality of life, Louise (female, 30, specialist) explained that if an impairment is more visible, as in the case of a broken leg, people are generally more understanding and accepting of a person's limitations.

Extract 10

- 1 Louise: ↑definitely yeah. I mean I I when we're doing training
2 with our staff here I say y'know it's a bit like
3 somebody with a broken ↑leg if I broke my leg you
4 wouldn't just say "oh you can't come to work", everyone
5 would just adapt things
- 6 [...]
- 7 Interviewer: yeah
- 8 Louise: erm: (.) I wouldn't expect some people to go "come on!
9 you can do the stairs you did it last week!" which is
10 what people do with =
- 11 Interviewer: yeah
- 12 Louise: = people with dementia "c'mon::! you can remember
13 this!" ((laughs))
- 14 Interviewer: yeah ((laughs))
- 15 Louise: y'know ((laughs)) but ↑no I think it's just about
16 understanding what it is, the symptoms and most
17 importantly understanding that everybody experiences it
18 differently
- 19 Interviewer: yeah
- 20 Louise: er:m that it's not just a straightforward set of
21 symptoms that you'll have which I suppose is more
22 likely with things that you can see like a broken leg
23 erm (.) tch but with things like dementia its erm (.)
24 it's not well it's not always apparent that people
25 ↑have it and they shouldn't have to ↑announce it

In this extract, Louise states that she thinks people need more information and education about cognitive impairment in order to understand what it really is and what people may experience if they are living with this. Louise highlights how people living with "things like dementia" (line 23) may be unable to perform certain activities or to do things quickly, and that people should be aware of how cognitive impairment may impact someone's abilities and make relevant and appropriate adaptations. However, whilst Louise expresses a view that people should be more understanding and accommodating of cognitive impairment, she also states that people "shouldn't have to announce" (line 25) or explain to people that they are experiencing a cognitive impairment and that people should simply be better prepared to support people living with cognitive impairment routinely. This implies an underlying perception that, with adequate information and education, people may be able to recognise the symptoms of cognitive impairment and that this may then become a less invisible illness.

Whilst Louise was of the opinion that people should not have to make it clear in any way that they are experiencing cognitive impairment, Fiona (female, 76, care partner) considered the best way to overcome the invisibility of cognitive impairment would be to make this clear to other people in some way.

Extract 11

- 1 Fiona: er and .hh hhh (.) it's erm (4) .hh yes it's it's not
2 like having a broken leg or a broken arm or even being
3 blind, I mean being deaf's difficult because you
4 haven't got anything erm .hh to show
- 5 Interviewer: yeah
- 6 Fiona: have you? but erm and I think it's this this (.) er .hh
7 (.) not that I think you should be going round with the
8 label but it y'know it's expecting people to respond in
9 a certain way and if they've had some sort of brain
10 injury they won't
- 11 Interviewer: yeah. yeah so it's almost like you want people to just
12 (.) know
- 13 Fiona: yes
- 14 Interviewer: so that people can be aware and they're not just going
15 "oh what's going on here? this is"
- 16 Fiona: yeah. I mean that was one very useful thing from the
17 stroke association they have a little card that says
18 erm erm "I've had a stroke, er please can you speak
19 slowly and perhaps write things down" or something
20 basically it says "I'm not daft I've had a stroke"

Fiona uses the same analogy as Louise, referencing the visibility of a broken limb as opposed to the hidden nature of cognitive impairment. However, these contrasting viewpoints with regard to whether an individual living with cognitive impairment should have to make this apparent or known to others explicitly somehow highlights the varying perspectives of participants around how people with cognitive impairment should or could present themselves and their symptoms to others.

Sixteen participants offered views on the terminology and labels used when discussing cognitive impairment. Five participants (Adam, male, 31, specialist; Helen, female, 27, HCP; Sarah, female, 54, specialist; Victor, male, undisclosed age, living with cognitive impairment; William, male, undisclosed age, living with cognitive impairment) held the view that cognitive impairment was an umbrella term that could encompass a wide range of things from dementia to learning difficulties. For example, Helen (female, 27, HCP) stated the following in response

to a question about whether she thought there was a difference between cognitive impairment and dementia.

Extract 12

1 Helen: erm:: (2) tch I would I suppose I would look at again I
2 see cognitive impairment as an umbrella term (.) that
3 covers (.) erm (.) tch anything kind of related to the
4 brain I suppose

This suggests a view that cognitive impairment as a term or label is too broad to be applied specifically to cognitive impairment in the context of a defined syndrome such as MCI.

Four participants (Irene, female, 73, older adult; Sarah, female, 54, specialist; Tracy, female, 57, care partner; William, male, undisclosed age, living with cognitive impairment) discussed the different terminologies and language employed by professionals as compared to the lay population. There was a perception that professionals utilise language which is not employed by the wider lay population when talking about cognitive impairment. For example, Irene (female, 73, older adult) explained how if a friend was concerned about their memory or thinking, they would talk to their social group about this but would not use the term cognitive impairment explicitly.

Extract 13

1 Irene: er:: hhh (2) .h if they came and said they thought they
2 were (.) h they wouldn't use the word cognitive
3 impairment

Similarly, Sarah (female, 54, specialist) identified the term MCI as something which she had come across before but that she only ever read about it, and that people would generally refer to this as “memory loss” (line 9) or in the context of dementia in conversation.

Extract 14

1 Interviewer: yeah. erm where have you come across the term before?
2 so mild cognitive impairment where have you heard that
3 before?

4 Sarah: tch it's mainly in erm: (.) articles er: inf- hard
5 copies of infor- it's in information .hh it's I don't
6 hear professionals .hh or anybody else talk about it
7 that way

8 Interviewer: yeah

9 Sarah: they it's always referred to as memory loss or dementia

The fact that Sarah references dementia as a term that could be used to discuss cognitive impairment suggests a perception of cognitive impairment as a condition which has a strong association with dementia, and that the two are closely related if not synonymous (see section 6.5.3.3 for more information about participants' views regarding the relationship between cognitive impairment and dementia).

The distinction between lay and professional language was also highlighted in terms of information provision. In Tracy's (female, 57, care partner) discussion of the information she received regarding her mother's condition, when she was experiencing global cognitive impairment and was admitted to a residential care home, she highlights how beneficial she found it to receive information in "lay language" (line 4) rather than medicalised terms.

Extract 15

- 1 Tracy: and er it's very hard but the information I got from
2 [care home manager] was really (4) it was accurate (1)
3 I found. it was based on lived experience. it didn't
4 medicalise it it put it into lay language
- 5 Interviewer: yeah
- 6 Tracy: which was (1) helpful in terms of (.) seeing where we
7 were going °really°

Tracy also appreciated this information being "based on lived experience" (line 3) suggesting that, for her, having information which shared personal experiences was the most helpful. These extracts suggest a view of the terminology and labels used to discuss cognitive impairment as being different between lay and professional populations, and sometimes between written and spoken information.

When asked about MCI as a term or diagnostic label, 10 participants hadn't heard of this before, including individuals living with cognitive impairment, and weren't entirely sure what it meant or how to define it. For Victor (male, undisclosed age, living with cognitive impairment) there was a focus on the word "mild" (line 1) in the term MCI and how he considered this to be "misleading" (line 1).

Extract 16

- 1 Victor: I think the mild is misleading
- 2 Interviewer: yeah

3 Victor: the mil- the implication in mild is that it's not
4 serious don't have to pay much attention to it it
5 doesn't have any drastic .h impact

6 Interviewer: yeah

7 Victor: and erm that's often not the case .hh so .hh erm I
8 think there should be two terms or and I think the use
9 incipient dementia is (.) erm an alternative expression
10 for mild cognitive impairment where there is a
11 confirmed progression of (.) s- symptom ↑deterioration
12 .hh tch then I think tch that's probably (.) a more
13 accurate term to use for people who are on:: the
14 dementia journey

The suggestion in this extract is that Victor viewed MCI as something that is in fact serious and that does have a pronounced impact on an individual's life. As such, he considered that there should be alternative terms for MCI, including "incipient dementia" (line 9) for those individuals where it could be identified that cognitive impairment would progress to dementia. This suggests a perception that it is possible to identify cases of cognitive impairment that are a precursor to dementia and a notion that those individuals who are not likely to progress to dementia can be provided with a term which is neither MCI or incipient dementia. Whilst this perspective was only expounded so explicitly by one participant, I felt that this viewpoint was important to present as it has clear ramifications for the way in which we label and discuss cognitive impairment and highlights a need to explore how the label of MCI is viewed and understood.

For one participant, Brian (male, 71, older adult), the conversation regarding terminology also extended to the notion of what it meant to receive a diagnosis and how something being diagnosed meant that something was medicalised and "quantified" (line 9).

Extract 17

1 Brian: ↑yeah but in a way the word diagnosis is the thing that
2 (.) rang a bell with me. .hh if you heard people saying
3 "oh (.) so and so Jean's getting very vague .hh and
4 she's having difficulty ↓remembering things" but (.)
5 you'd think yeah well that just sort of Jean y'know is
6 just getting old and like all of us she's just getting
7 more and more ↑forgetful soon as you use the word
8 diagnosis it's suddenly become a sort of medical thing
9 that's been quantified .hh and I suppose one would feel
10 .h that it is the (1) not necessarily all that early
11 stage but that it's the beginning of the end that's how
12 I'd look at it y'know it's the beginning of a =

13 Beth: yeah

14 Brian: = deterioration once it's been diagnosed it's been
15 given a medical sort of acceptance .hh it's the thin
16 end of a wedge which is not going to be happy

For Brian, it was only once cognitive impairment had been diagnosed that this deterioration became salient; once it was “given a medical sort of acceptance” (line 15). He also describes the future for people living with cognitive impairment as “the thin end of a wedge which is not going to be happy” (lines 15-16), implying that cognitive impairment can only ever have a negative outcome. Similarly to the view expressed by Victor (Extract 16), this perspective regarding what it means to receive a diagnosis was only explicitly stated by one participant but I felt that this was a very salient and highly relevant viewpoint and one which was held very strongly by Brian. I feel that this perspective warrants further exploration in future research.

The examples here show how participants highlighted a range of possible symptoms of cognitive impairment, but generally focused on memory and communication problems. Cognitive impairment was presented as an invisible illness, with participants discussing how this lack of visibility may influence public perceptions of cognitive impairment and the reactions of people towards individuals living with cognitive impairment. There were discussions about the terminology and labels used when discussing cognitive impairment and participants highlighted differing language use between professionals and the lay public, and in written information compared to verbal information and general conversation.

6.5.1.2 Permanency and Idiosyncrasy

Participants were generally uncertain as to whether cognitive impairment is permanent or temporary, with nine interviewees (Adam, male, 31, specialist; Dianne, female, 82, older adult; Helen, female, 27, HCP; Katie, female, 37, living with cognitive impairment; Louise, female, 30, specialist; Mary, female, 71, specialist; Nina, female, 74, older adult; Pauline, female, 72, older adult; Sarah, female, 54, specialist) highlighting that permanency “depends on the cause” (Helen, female, 27, HCP). For example, Adam (male, 31, specialist) expressed a view that cognitive impairment was mostly a transient state, something which anyone could experience at some point in their life, but that if the cause was biological or involved a physiological change in the brain then this would present a more permanent state of cognitive impairment.

Extract 18

1 Adam: I see it as more of a transient thing er I think it's
2 some something that all of us can experience

3 Interviewer: yeah

4 Adam: probably experienced it myself at times of stress when
5 you become really really scatty because you've got so
6 much on and .hh y'know you've (.) err y'know I've
7 definitely had those periods myself y'know and as a (.)
8 directly because I've had no sleep or you're stressed
9 all those kind of things .hh so I think yeah we can all
10 dip in and out of it .hhh but then with ↑other people
11 you think well actually hhh is there an actual
12 biological, .h reason for this >there's some< there's
13 some kind of disturbance going on =

14 Interviewer: yeah

15 Adam = biologically and that has caused a permanent .hh
16 cognitive impairment if that biological disturbance
17 can't be corrected which I think when it comes to the
18 brain, is not always possible is it?

This extract offers the view that cognitive impairment is something that Adam has experienced himself, implying that stress may be a cause for cognitive impairment, a view held by 10 other participants. In his discussion, Adam highlights that anyone can “dip in and out of” (line 10) cognitive impairment but that for some people, where there is a biological root, a permanent, pathological change has occurred which cannot be corrected. This suggests a perception that biological causes are not able to be treated successfully yet, and also highlights a view that brain damage cannot be treated or “corrected” (line 17) in the same way that some other ailments can be. There is an implication in Adam’s account that he therefore may not give credence to the concept of brain plasticity as he did not think that the brain could recover from any insults or injuries. However, in contrast, Victor (male, undisclosed age, living with cognitive impairment) referred to a conversation he had with a Professor who gave him great hope in the concept of neuroplasticity and the notion that he might be able to maintain or improve his cognition by stimulating himself mentally, enabling the plasticity of the brain to help him recover from the effects and impacts of his stroke.

Extract 19

1 Victor: she said “keep bombarding your brain Victor and (.)
2 eventually it will form new pathways”. which is how
3 stroke recovery works anyway

4 Interviewer: yeah

5 Victor: so so it's a neuroplasticity response (.) it's sort of
6 we have this enormous homeostatic .hh potential and she
7 explained how it ↑worked.

In this sense, Victor appears to express a view that cognitive impairment could potentially be viewed as a temporary condition as there is a hope for recovery via neuroplasticity. Similarly, Mary (female, 71, specialist) stated how she was reassured that cognitive impairment was “only temporary” (line 2) but understood that it could possibly be permanent in some cases.

1 Extract 20

2 Mary: well (.) erm (6) well from what I've read I'm reassured
3 that sometimes it is only temporary
4 Interviewer: yeah
5 Mary: but erm it might be temporary or permanent
6 Interviewer: yeah
7 Mary: or it could lead to something much worse I suppose.
8 erm:: (2) but it could be either, not (.) one or the
9 other

In this extract, Mary highlights how she has found reassurance about the temporary nature of cognitive impairment, but also perceives that it could be permanent and may progress to “something much worse” (line 6). This view of cognitive impairment as potentially progressive was shared by 15 other participants who stated that cognitive impairment was a condition that would get worse over time and could even develop into dementia. However, eight participants (Adam, male, 31, specialist; Grace, female, 70, care partner; Irene, female, 73, older adult; Louise, female, 30, specialist; Mary, female, 71, specialist; Oscar, male, 73, specialist; Robert, male, 56, living with cognitive impairment; Tracy, female, 57, care partner) expressed a view that cognitive impairment does not always get worse and does not always progress to dementia. For example, Grace (female, 70, care partner) described cognitive impairment as a possible precursor to dementia but stated that it would not always progress to dementia.

Extract 21

1 Grace: er as a ↑precursor
2 Interviewer: yeah
3 Grace: to dementia. not that it would necessarily go along
4 that path

For Robert (male, 56, living with cognitive impairment), there was a hope that cognitive impairment would not get worse, but he thought that it might and was planning for the future.

Extract 22

- 1 Interviewer: d'you think of it as a permanent or a temporary
2 condition? so d'you think this is something that could
3 ever (.) improve? or get worse? d'you think it'll stay
4 the same?
- 5 Robert: err I don't think it'll get better
- 6 Interviewer: yeah
- 7 Robert: er:: hopefully it'll stay the same, but I wouldn't be
8 at all surprised if it goes worse, slowly but surely

Earlier in the interview, Robert discussed his concerns that cooking was becoming a risky activity for him after he accidentally left the hob on and forgot about it. He was concerned that this risk may become more prevalent if his cognition deteriorated in the future and was already planning to use the cooker less and to use the microwave instead. However, despite this lingering concern that his cognition would decline over time, he still maintained a hope that his symptoms would not progress though he did not think that his cognition would ever improve or recover. Robert's concluding statement that he "wouldn't be at all surprised if it goes worse" (lines 7-8) suggests that he views cognitive impairment as something which is very likely to progress over time.

The examples presented here show that participants expressed a view that the permanency of cognitive impairment would depend on the root cause of the impairment. Participants also stated that cognitive impairment could sometimes progress to a more severe level, such as dementia, but that this progression was not a certainty. There was not a unified view amongst participants as to the permanency and progress of cognitive impairment; this is not surprising given the current lack of certainty amongst clinicians and researchers regarding prognosis for people living with cognitive impairment.

Ten participants perceived the future as uncertain for people living with cognitive impairment and felt that there is not a clear prognosis for these individuals. However, 11 participants were confident in their view that cognitive impairment will always get worse. For Grace (female, 70, care partner), this view stemmed from her personal experiences where for anyone she knew who had experienced cognitive impairment this had been the case.

Extract 23

- 1 Grace: don't know if I'm right or wrong but I .h I thought
2 that once you got it that was it and it would just get
3 gradually ↑worse
- 4 Interviewer: yeah so you'd see it as a progressive
- 5 Grace: yes
- 6 Interviewer: changing over time
- 7 Grace: very much so yes
- 8 Interviewer: °ok°
- 9 Grace: that's been my experience of it with anybody I've known
10 =
- 11 Interviewer: yeah
- 12 Grace: = that's had it and so I've always thought that that
13 was just how it was

Grace was clear in her perception that cognitive impairment is permanent and progressive. However, despite this long-standing viewpoint, Grace clarifies that she is not sure if she's correct in this view, and later explains that her perspective has arisen from personal experiences as opposed to any research or independent source. Drawing upon personal experiences was commonplace across the interviews, with 15 participants referencing a personal experience when discussing cognitive impairment (see section 6.5.1.1 for more details).

When discussing cognitive impairment, 16 participants identified that “everybody's different” (Tracy, female, 57, care partner) and that cognitive impairment is “different for everybody” (William, male, undisclosed age, living with cognitive impairment); that this is an individual experience that will vary from person to person, both in terms of the presenting symptoms and also how an individual actually experiences and manages cognitive impairment. For example, Dianne (female, 82, older adult), when asked about possible ways to support people living with cognitive impairment, explained that strategies would differ between people depending on their previous experiences and that “what suits one person may not suit another”. Similarly, Grace (female, 70, care partner), in response to a question about whether there were any ways that we could help or treat cognitive impairment, highlighted how this would depend on the individual and their particular situation.

Extract 24

- 1 Grace: well hh it very much depends on their situation and how
2 bad it is
- 3 Interviewer: yeah
- 4 Grace: erm (.) I think erm (.) for them to have som- if
5 they've not got lots of support friends family .hh then
6 having somewhere they can go where they are with other
7 people
- 8 Interviewer: yeah
- 9 Grace: and socialise I think that's an important thing .hh
10 that erm (.) is worth looking at to ↑provide for people

Grace expressed a perception that it is important for people living with cognitive impairment to socialise and maintain contact and communication with other people. This implies a view that social isolation could have a negative impact on an individual living with cognitive impairment and that socialisation is a key method of support and even treatment. If people did not have this support network in place already then Grace considered it would be beneficial to provide this social support for them.

Within the discussions of individual differences, eight participants (Dianne, female, 82, older adult; Fiona, female, 76, care partner; James, male, 32, younger adult; Katie, female, 37, living with cognitive impairment; Louise, female, 30, specialist; Tracy, female, 57, care partner; Victor, male, undisclosed age, living with cognitive impairment; William, male, undisclosed age, living with cognitive impairment) discussed how an individual's personality may play a role in how someone copes with or manages cognitive impairment. For example, Fiona (female, 76, care partner) explained that her husband had always been stubborn and that she felt his natural determination and stubbornness was aiding his recovery.

Extract 25

- 1 Fiona: he's always been y'know had this very stubborn streak
2 .hh and doesn't let anything get in his way if he wants
3 to do anything hence all this galloping off unless I
4 specifically say "do not go till I come back"
- 5 Interviewer: yeah
- 6 Fiona: ((laughs))
- 7 Interviewer: do you think that determination is helping him recover?

8 Fiona: oh yes

Dianne (female, 82, older adult) explained that multiple aspects of an individual's personality may determine how well they could cope with and accept cognitive impairment.

Extract 26

1 Dianne: it depends on other ↑aspects of their personality =

2 Interviewer: yeah

3 Dianne: = as to whether they cope or they don't cope or how
4 they accept it

Similarly, William (male, undisclosed age, living with cognitive impairment) explained how his mood and quality of life had dipped to a particular low following diagnosis. Though this changed over time, he explained how low he felt post-diagnosis and that the diagnostic process contributed to this emotional downturn, despite his generally positive demeanour and character. William thought that this negative response post-diagnosis was quite common and that many people experience a similar situation following a diagnosis of cognitive impairment or dementia.

Extract 27

1 William: I was in a daze I really didn't and my depression I
2 believe was purely and simply as a result of the ↑way
3 that that message was given to me

4 Interviewer: yeah

5 William: y'know and as soon as I actually started to think about
6 things and to erm (.) rationalise and work things out,
7 I realised that, and after [Professor] had given me her
8 wonderful message, but y'know in the interim there'd
9 been erm probably nine months when I had (.) started to
10 fall apart ↑totally

11 Interviewer: yeah

12 William: y'know erm (.) I suppose it's fairly typical of what
13 happens to people, I stopped showering everyday tch erm
14 stopped getting dressed I was just slopping about in my
15 dressing gown and ma slippers

16 Interviewer: yeah

17 William: watching daytime TV. (.) erm not doing anything in the
18 house to help not doing anything at all (.) just being
19 there

20 Interviewer: yeah

21 William: and that that actually happens quite quickly y'know to
22 people it really does

In this account, William explains how he felt dazed following his diagnosis and firmly considered the depression he subsequently experienced to be a direct result of the way in which his diagnosis was delivered, which he stated was in an insensitive manner. William viewed this negative emotional state following diagnosis as something which was “fairly typical” (line 12) and which other people experience too. The examples presented here highlight the view of eight participants that personality may play a role in how an individual experiences or copes with cognitive impairment.

Overall, participants were somewhat uncertain about the permanency of cognitive impairment and suggested that this may be determined by the underlying cause. There were discussions about whether cognitive impairment was a progressive condition, with participants again being uncertain about this and showing no consensus view. However, participants were more unified in their perception of cognitive impairment as something which varies on an individual level, from a practical, experiential and emotional perspective.

6.5.1.3 The Impact of Cognitive Impairment on Daily Life

Fifteen participants discussed that cognitive impairment would impact on an individual's daily life in some way, though generally they suggested that this impact would be less than that resulting from dementia. All participants living with cognitive impairment highlighted the impact that their symptoms had on their day-to-day life, and Katie (female, 37, living with cognitive impairment) explained how these impacts were not just practical but also emotional, describing the frustration that her husband felt.

Extract 28

1 Katie: erm (.) I have routines so I check my emails sort of
2 when I ↑hear something I think oh I'll check my emails
3 and do it like that but it's still very difficult,
4 people get very frustrated that I ↑can't remember what
5 they said or I tell them something like seven or eight
6 times
7 Interviewer: yeah
8 Katie: erm (.) it's difficult for my husband, obviously
9 ((laughs)) cos (.) I'm just a nightmare .hh even my
10 daughter actually now that she's seven she quite often
11 she'll say “I asked you for bread and butter two
12 minutes ago”, then I'm like “oh yeah! so you did! what

13 am I doing? bread and butter!" ((laughs)) ok ((laughs))
 14 so she's got used to prompting me and remembering for
 15 me and stuff .hh erm, she also does quite often
 16 translate stuff for me I'll say "oh I can't I just
 17 cannot do this in my head" and she'll look at it

18 Interviewer: yeah

19 Katie: and say "oh it's like this" and she's only seven
 20 ((laughs)) erm my husband finds it very ↓difficult
 21 because he can't seem to explain something in a
 22 different ↑way he just repeats the same thing

23 Interviewer: yeah

24 Katie: and I'm like "no I'm not understanding that you need to
 25 explain it from a different angle" and he can't so he
 26 gets

27 ((mobile sounds))

28 Katie: sorry that's my phone, so he gets really frustrated
 29 with it =

30 Interviewer: yeah

31 Katie: = erm (1) so, ↑yeah those are probably the main
 32 difficulties is people getting frustrated at my (.)
 33 inability to .hh to function =

34 ((mobile sounds))

35 Katie: = ((laughs)) erm and my memory and stuff so yeah that's
 36 mainly the impact that it has on me is is frustrating
 37 people

Here, Katie explains how she is acutely aware of how frustrated others are by her forgetfulness and repetition, particularly her husband and daughter. This is an interesting comment given findings which have previously suggested that people living with MCI have poor insight into their own situation (Vogel et al., 2004). It may be that people living with cognitive impairment are actually more aware and have more insight into their own difficulties and the impact of this on other people than first thought. In this account, Katie describes herself as "a nightmare" (line 9) suggesting that she views her cognitive impairment as causing her to behave in a way that is perceived as difficult and challenging to others. Katie explains how her seven-year-old daughter had learned to help her and was now used to prompting her and translating information for her. She explains how frustrating her husband finds her cognitive impairment because she cannot understand information that he is trying to explain to her. Her view of others becoming frustrated with her is also extended to a wider network with her comment "people getting frustrated at my (.) inability to .hh to function" (lines 32-33) suggesting that more than just her

husband and daughter are frustrated by her symptoms and behaviour. For Katie, this frustration that others display is viewed as the main impact that cognitive impairment is having on her, even more so than the symptoms themselves. This suggests that, whilst cognitive impairment may not have the same level of impact as dementia when first viewed, the actual impact felt by an individual living with cognitive impairment may be more multi-faceted and complex than first estimated based on symptomology. Emotional aspects may have a considerable impact on an individual's life, regardless of how pronounced their symptoms are.

For Clive (male, 24, younger adult) the impact on daily life was something which he identified as the crux of determining cognitive impairment as a clear entity.

Extract 29

- 1 Clive: I'd need more information, what's their life =
2 Interviewer: yeah
3 Clive: = like? what's their job like? cos people can get
4 frazzled and (.) they kind of like lose (.) they think
5 their memory's all over the place and that kind of
6 thing (.) as I say until it becomes like problematic
7 (.) that's when you then you realise .hh that it's more
8 than just (.) I'm a bit forgetful
9 Interviewer: yeah
10 Clive: it's like oh actually there is something wrong here and
11 then you have to seek out the services

In this discussion, Clive does not expand on how he would define "problematic" (line 6) or who this would be a problem for. This extract follows a question relating to what the thought process would be if a friend or family member said they were concerned about their memory or thinking, so the reference to "problematic" (line 6) could be referring to the perspective of the individual or from a family or friend perspective.

However, this view of cognitive impairment as a condition which would impact on an individual's daily life was not shared by all participants. Two participants (Edward, male, 69, older adult; Sarah, female, 54, specialist) explicitly stated that cognitive impairment does not impact an individual's life on a day-to-day basis. For example, Sarah (female, 54, specialist), posited a view of cognitive impairment as something which doesn't impact an individual's daily life.

Extract 30

1 Sarah: .hh well it what it would mean to me is that they have
2 a: erm: (.) .hh er hhh er some impact on their
3 functioning with their memory and their thinking .hh
4 that probably doesn't impact on their (2) life

This suggests a view of cognitive impairment as a condition which presents with memory and thinking problems, but that any symptoms experienced by an individual would not significantly impact their daily life. This view was shared by Edward (male, 69, older adult) when discussing information provision about cognitive impairment.

Extract 31

1 Edward: yeah I think one overriding reassuring thing I would
2 find is (.) more information is always a good thing
3 anyway but .hh knowing that it's not uncommon
4 Interviewer: yeah
5 Edward: knowing that it's a lot of an awful lot of people have
6 it and it makes very little difference to their lives
7 if you like
8 Interviewer: yeah
9 Edward: which I'm sure it doesn't.

For Beth (female, 63, care partner) and Brian (male, 71, older adult), there was a view of cognitive impairment as something which would impact someone's life, but not to such an extent that they cannot continue to function mostly independently.

Extract 32

1 Brian: but erm so that er but cognitive impairment you can
2 still basically manage your own life up to (.) m-m-
3 mainly up to that you know, dementia you can no longer
4 manage
5 Beth: yeah
6 Brian: and now you're =
7 Beth: yeah
8 Brian: = you have to be looked after and nursed =
9 Beth: yeah
10 Brian: = but somebody else has to take all =
11 Beth: yeah

12 Brian: = the decisions for you

13 Beth: I'd echo that

Here, Brian suggests that cognitive impairment would have an impact on an individual's ability to manage their own life, but not drastically. Brian continues to expand on this by stating that he would not consider the impact of cognitive impairment to be as pronounced and significant as dementia where an individual would "no longer manage" (lines 3-4). Beth shows her agreement with her husband's perspectives on this by repeating "yeah" (lines 5, 7, 9 and 11) and concluding by stating "I'd echo that" (line 13). This view of cognitive impairment as something which would have an impact, but a lesser impact than dementia, was also shared by three other participants (Adam, male, 31, specialist; Louise, female, 30, specialist; Robert, male, 56, living with cognitive impairment).

The examples provided here highlight the overarching view amongst participants of cognitive impairment as something which would impact on an individual's everyday life, both in terms of the presenting symptoms, but also with regards to the emotional impact of living with a diagnosis and the way that someone may be viewed by others as a result of their symptoms. However, this view was not universal, with two participants contradicting this perception directly and five participants clearly stating that cognitive impairment would impact on someone's life, but not to a great extent, and certainly not to the same level as dementia which was generally viewed by participants to be a condition which is debilitating and in which an individual loses their independence entirely.

6.5.1.4 Threat to Identity

Entrenched with the discussions of cognitive impairment as a condition which impacts on an individual's daily life, were conversations relating to cognitive impairment as a threat to identity. Six participants (Beth, female, 63, care partner; Brian, male, 71, older adult; Clive, male, 24, younger adult; Grace, female, 70, care partner; Irene, female, 73, older adult; William, male, undisclosed age, living with cognitive impairment) discussed how cognitive impairment changes who a person is fundamentally. For example, William (male, undisclosed age, living with cognitive impairment) explained how he reacted following his diagnosis and how he felt that he had changed entirely from the person he used to be.

Extract 33

- 1 William: erm she I remember I was watching Jeremy Kyle and she
2 was sitting in the way and it was really really
3 irritating me the fact that she was in front of me I
4 could not see the telly
- 5 Interviewer: yeah
- 6 William: and and if you knew me you actually know (.) I don't
7 watch TV (.) and she said "well what's your problem?"
8 (1) y'know and she said "you're exactly the same as you
9 were ↑before, except now you know what's wrong" .hh and
10 it was like (.) a switch ((laughs slightly)) I thought
11 "ooh, yeah" ((laughs))
- 12 Interviewer: ((laughs)) yeah
- 13 William: and then a couple of weeks after that [Professor] came
14 and so then (.) ↑yeah (.) so after that I started to
15 become a person again

Here, William explains how he had started watching TV, something which he had not done before receiving his diagnosis, and how a conversation with an expert had helped him to rediscover who he was and to "become a person again" (line 15). This suggests that, for a period of time after receiving his diagnosis, William felt that he was not a person; that he was fundamentally different from who he used to be and that his identity had been altered. Similarly, Clive (male, 24, younger adult) in response to a question about whether he felt that cognitive impairment changed someone's personhood or personality, explained that societal and societal perceptions and reactions to the individual would play a key role in how that person's identity was shaped and defined.

Extract 34

- 1 Clive: to an extent yeah, ermmm (.) but I suppose it depends
2 on how people around them interact with them ((door
3 slams))
- 4 Interviewer: yeah
- 5 Clive: if they start treating this person as (.) an invalid
6 for want of a better word (.) then I think that starts
7 reflecting on how you interact and how you perceive
8 them.

This extract suggests that societal perceptions of cognitive impairment as something which may lead to an individual being treated as "an invalid" (line 5) could result in someone losing their identity as a result of cognitive impairment. In their interview, Beth (female, 63, care partner)

and Brian (male, 71, older adult) described a man that they had met in a care home who was once a judge.

Extract 35

- 1 Brian: yeah I mean there was some old boy who apparently
2 although I think that the girl who told us that he was
3 a high court judge got it wrong but I think he was a
4 judge cos there's pictures of him in his bedroom with
5 his wig on so he must have been a ↑high court judge?
6 I'm not sure where you get the wig?
- 7 Beth: might just have been a ↑circuit judge like yeah
8 whatever anyway
- 9 Brian: but it does make you think y'know here was a man who
10 would've instilled the fear of God into people who
11 appeared in his err court
- 12 Interviewer: yeah
- 13 Brian: both with often y'know errr discipline the lawyers but
14 also the people in the err dock and now y'know there's
15 just this little sort of ↑man who's sort of got a sort
16 of claw like hand that he puts up and nobody's
17 frightened of him ↑now

Here, Brian explains how this man was once a formidable figure who would have been viewed with respect as a powerful man, but now, following a cognitive impairment in later life, he was someone who nobody would fear. This suggests a view of cognitive impairment as a condition which fundamentally changes who a person is, and takes away their previous identity. Similarly, Grace (female, 70, care partner) describes how her friend's mother changed immensely as a result of dementia.

Extract 36

- 1 Grace: I've seen it with a friend's mother, where she had a
2 type of dementia >whether it was Alzheimer's or not I
3 don't know< 'cos ma mum's is vascular dementia but this
4 lady from being a very mild lady was swearing and f-ing
5 and blinding in public and =
- 6 Interviewer: yeah
- 7 Grace: = everywhere so: embarrassing .hhh erm and my friend er
8 had no help really understanding what that was all
9 about

This example highlights how dementia and cognitive impairment were perceived to alter an individual's identity, changing the person from who they had previously been. This also suggests

that cognitive impairment is viewed as something which is embarrassing, something which should be hidden away, and thus positions cognitive impairment as a stigmatising condition.

The extracts from participants' interviews presented here show that, for six participants, cognitive impairment was described as something which changes who a person is fundamentally, altering their personality and threatening their identity. This perception of cognitive impairment as a threat to identity positions this condition as something which is feared and stigmatised. The examples presented here suggest that participants view identity as being entwined with cognition; once cognitive abilities are impaired then this in turn impacts detrimentally on personality and identity.

So here we have seen definitions of cognitive impairment, with reference to the symptoms and labels applied to this syndrome, alongside notions of permanency and idiosyncrasy, the impact of cognitive impairment on day-to-day life, and cognitive impairment as a threat to identity within the first main theme *accounts of cognitive impairment*. It is clear that participants have a view of cognitive impairment as a condition which is influenced by personality and individual differences, and which has a core set of symptoms predominantly focused around memory problems and forgetfulness, but with an understanding that memory is not always affected. When discussing cognitive impairment, people draw upon their own experiences of this, including dementia and cognitive impairment resulting from a stroke, to make sense of cognitive impairment and to explain this. Cognitive impairment is discussed as a threat to identity; something which impacts negatively on an individual's personality and changes who a person is at a core level.

6.5.2 Causation Accounts

Participants highlighted a range of possible causes for cognitive impairment, including brain damage, ageing, poor lifestyle, alcohol, stress, stroke, and genetics. This is similar to the literature on illness causation accounts for other conditions including breast cancer (Wilkinson, 2000) and type 2 diabetes (Lawton, Ahmad, Peel, & Hallowell, 2007; Lawton, Peel, Parry, & Douglas, 2008; Parry, Peel, Douglas, & Lawton, 2006; Peel, Parry, Douglas, & Lawton, 2005), where participants reported multiple possible causes for their presenting illness or condition.

6.5.2.1 Brain Damage or Injury

Fifteen participants discussed cognitive impairment being caused by some form of brain damage or brain injury, and offered a range of factors which could lead to this such as alcohol use, infection, dietary choices, vitamin deficiencies, drugs and medication, stress and trauma. For example, Clive (male, 24, younger adult) explained the range of factors he considered could cause cognitive impairment.

Extract 37

- 1 Clive: eeerrm .hh any damage to different parts of the brain
2 (.) soo (.) er impact or (.) any kind of alcohol drugs
3 that kind of thing
4
5 Clive: (2) ((door slams))
6 I supp- I've heard of like extreme stress or trauma can
7 often impair (.) different parts of er cognitive
8 faculties .hh or even bias them in certain ways so like
shape memories and remembering .hh that's yeah

Similarly, Pauline (female, 72, older adult) outlined the causes that she perceived as potentially responsible for cognitive impairment.

Extract 38

- 1 Pauline: well I suppose genetics erm y'know like brain damage in
2 the womb that sort of thing
3 Interviewer: yeah
4 Pauline: and indeed brain damage (1) in later life .hh erm:: ac-
5 pack accidents and h- head injuries an::d erm: (.) the
6 other thing is (.) well with my father it was vascular
7 dementia so that's about ya circulation I I vaguely
8 think
9 Interviewer: yeah
10 Pauline: .hh an::d (.) just getting older .hhh I I mean
11 ↑actually I suppose in a way I'm cognitively impaired
12 I've just realised cos I do have epilepsy .hh but I
13 forget about it

Here, Pauline identifies that brain damage, at any age, could cause cognitive impairment, whether this is the result of a genetic condition or as a result of an accident in later life resulting in brain damage. She also draws on her personal experience of her father who lived with vascular dementia to discuss the role of "circulation" (line 7) and the vascular system in the causation of cognitive impairment. She moves on to discuss ageing and "getting older" (line 10)

as a possible cause, diverting to talk about her own diagnosis of epilepsy and how this may also cause cognitive impairment. The causes identified by Pauline are very similar to those postulated by 14 other participants, suggesting that the majority of participants viewed brain damage, brain changes or brain injury as the key factor in cognitive impairment, closely followed by ageing (see sections 6.5.3.1 and 6.5.3.2 for more details regarding participants' discussions of cognitive impairment in the context of ageing and the age of onset of cognitive impairment).

For one participant, James (male, 32, younger adult), there was a perception that talking about cognitive impairment in terms of brain damage was something which could be viewed as insulting or pejorative.

Extract 39

- 1 James: I suppose that's what I do think
- 2 Interviewer: yeah
- 3 James: and that that's how it always f- come across to me .hh
4 it just like it's weird because the idea of like (.)
5 living with some kind of brain damage it feels like I'm
6 saying something ↑pejorative
- 7 Interviewer: yeah
- 8 James: or something slightly insulting and I'm like I'm trying
9 to like disassociate those two states in my own mind
10 .hh but it does feel that like yeah it is some kind of
11 very mild .hh (.) brain (.) nerve (.) kind of thing?

In response to a follow-up question as to whether he thought cognitive impairment might be viewed as brain damage based on his earlier responses, James clarified that this was indeed what he thought. However, he expressed a view that this perspective did not sit well with him as he perceived this view to be “pejorative” (line 6) or “insulting” (line 8), stating that he was trying to “disassociate those two states in my own mind” (line 9). Whilst this view was only postulated by one participant, I feel that this is a particularly interesting and relevant perspective in the context of attributing cognitive impairment to be the result of brain damage and so I feel that this viewpoint should be highlighted. Perspectives such as this inform the discussion around stigma in cognitive impairment and how people living with cognitive impairment may be viewed by others, and indeed how they may view themselves in light of their symptoms and/or diagnosis.

Here, it can be seen that most participants considered cognitive impairment to be directly linked to brain damage. However, there were a number of different underlying causes

of brain damage that participants felt may be responsible for this impairment. In the following sections I will outline some of the other causes and risk factors that participants highlighted in these interviews, particularly diet and lifestyle factors and whether participants viewed cognitive impairment to be within the personal control of an individual.

6.5.2.2 Diet and Healthy Lifestyle Factors

Fifteen participants stated that diet and exercise, living a healthy lifestyle, could potentially have a huge range of health benefits, both physically and cognitively and that it was therefore important that people stayed as active and healthy as possible to reduce their risk of developing cognitive impairment. However, this was rarely raised by participants before being explicitly asked about it. For example, Grace (female, 70, care partner), in response to a question about whether diet may play a role in cognitive impairment in any way, explained that she had never considered that diet may have any impact on the brain and subsequently on cognition, but now that she was thinking about it she assumed a healthy diet would be beneficial for cognitive as well as physical health.

Extract 40

- 1 Grace: I've never thought about it having any impact on your
2 brain but (.) I don't see why it wouldn't. I mean they
3 say drink plenty of water and that helps to hydrate
4 your brain as well so I =
- 5 Interviewer: yeah
- 6 Grace: = suppose a healthy diet .hh yeah
- 7 Interviewer: ↑yeah
- 8 Grace: for every aspect of your life really

Similarly, Irene (female, 73, older adult) in response to a question about whether diet and exercise could play a role in the development of cognitive impairment stated "I would have thought just generally keeping healthy active" suggesting that she considered a healthy lifestyle to be potentially protective in terms of cognitive health and abilities. For Dianne (female, 82, older adult), there was a view that a healthy lifestyle may be able to prevent or delay the onset of any health impairment, including cognitive impairment, expounding the perspective that what is good for the body is good for the brain.

Extract 41

- 1 Interviewer: and thinking about things sort of like diet and
2 physical exercise would you say they play any role .h
3 in causing or preventing cognitive impairment?
- 4 Dianne: I think this applies to any impairment of health
- 5 Interviewer: yeah
- 6 Dianne: and the (.) the brain needs nourishment, it needs clear
7 arteries and
- 8 Interviewer: yeah
- 9 Dianne: so I think it †does have an effect
- 10 Interviewer: yeah so it's sort of that anything that's good for the
- 11 Dianne: and exercise
- 12 Interviewer: yeah
- 13 Dianne: people that have had a good healthy †lifestyle .hh may
14 not get the onset as early as people that are more (.)
15 what you call them potato cabbages?
- 16 Interviewer: yeah yeah
- 17 Dianne: and take-aways

Dianne expressed a view that eating well and healthily would also be beneficial for the brain as brain health necessitates “clear arteries” (lines 6-7). This implies an understanding of the role of vascular risk factors in cognitive impairment and a view that keeping the cardiovascular system healthy could be beneficial for both physical and cognitive health. Similarly, Nina (female, 74, older adult) stated that there were healthy lifestyle strategies which could potentially prevent cognitive impairment.

Extract 42

- 1 Nina: °mmm no I think that° you can do things about it
- 2 Interviewer: yeah
- 3 Nina: and certainly .hhh that sort of thing hhh (.) and and
4 also the physical thing y'know just just fresh air
- 5 Interviewer: yeah
- 6 Nina: and moving, even moving and walking as much as you can
7 .hh because it's so easy to be lazy

Here, Nina explains that people can potentially prevent cognitive impairment by staying physically active and getting fresh air. Nina states that it is “so easy to be lazy” (line 7); to avoid mental or physical activity and how this could be detrimental to an individual’s cognitive health.

Whilst this view of healthy lifestyle factors as being beneficial to cognitive health and potentially protective against cognitive impairment was shared by 15 participants overall, this perspective was not universal. For example, Robert (male, 56, living with cognitive impairment), claimed that diet and exercise did not play a role in cognitive abilities or the risk of cognitive impairment.

Extract 43

- 1 Interviewer: and do you think that diet or: physical exercise or
2 anything like that play any role in our cognitive
3 health?
- 4 Robert: not that I know of
- 5 Interviewer: no?
- 6 Robert: no

This view of diet and exercise as unhelpful or unrelated to cognitive health was shared by Edward (male, 69, older adult) in response to a question about whether diet may play a role in cognitive health and the risk of cognitive impairment.

Extract 44

- 1 Edward: yeah. well I tend to th- er I maybe wrong, but I tend
2 to think of those as a bit of wishful thinking the idea
3 that you can eat fish and it’ll .hh it’ll enable you to
4 have a better memory or remember things better or
5 carrots or whatever it is
- 6 Interviewer: yeah
- 7 Edward: but I don’t really believe it .hh erm: no
- 8 Interviewer: no?
- 9 Edward: no

Edward’s perception was that diet did not play a role in causing or preventing cognitive impairment and that the stories presented about foods which could improve memory were optimistic and may be offering false hope. The views presented by Robert and Edward show a clear contrast in perceptions amongst participants, though 15 participants stated that diet and exercise could play a role in cognitive health and the development of cognitive impairment.

In the discussions of diet and exercise, five participants (Adam, male, 31, specialist; Dianne, female, 82, older adult; Helen, female, 27, HCP; James, male, 32, younger adult; Louise, female, 30, specialist) reported that there was an increased awareness of the importance and value of a healthy lifestyle. Dianne (female, 82, older adult) stated that this increased awareness had developed in her lifetime, with people generally now being much more aware of the importance of healthy diet and exercise on overall health.

Extract 45

- 1 Dianne: I mean it's come in my lifetime
2 Interviewer: yeah
3 Dianne: the realisation that diet and exercising I don't mean
4 >I mean it isn't everywhere at the moment< .hh but over
5 the last twenty thirty years .hh people have been
6 talking and been more aware about eating healthy
7 Interviewer: yeah
8 Dianne: others ignore

This could play a role in the claim that the risk of cognitive impairment may be reduced by adopting a healthy lifestyle as this increased awareness may infer a consideration of the benefits of healthy living. This perspective may also be a form of self-preservation, with participants considering that if they themselves follow a healthy lifestyle they may reduce their own risk of cognitive impairment. The view that awareness of healthy lifestyle factors has increased over time suggests that public health messages have been effective overall, however, Dianne explains her view that while some people listen to these messages, “others ignore” (line 8) suggesting that the impact of public health campaigns is not universal.

For James (male, 32, younger adult) there was a view that socio-economic status may play a role in people's awareness of the value and importance of a healthy lifestyle.

Extract 46

- 1 James: like I just think I I never learned anything about like
2 sugar or diabetes or that or (.) how to prevent
3 cognitive impairment at any of my schools and I went to
4 like a local co- like primary school and a comp. .hhh
5 whereas I guess .h I dunno there are more like health
6 and sport opportunities at better schools and like
7 people are just generally more conscious
8 Interviewer: yeah

9 James: of (.) y'know the body and y'know how food .hh and
10 y'know health correspond to that. I ↑think (.)

Here, James explains that people at schools which are “better” (less economically deprived) are able to provide more health and sport opportunities and provide better information and education about how diet impacts on health. This view, whilst only posited by this participant, highlights the need to ensure information and education is available to all and is equitable across economic areas, particularly at schools at other educational establishments.

Linked to talk about the role of diet and exercise was the discussion of vascular risk factors for cognitive impairment. Seven participants (Adam, male, 31, specialist; Dianne, female, 82, older adult; Helen, female, 27, HCP; Louise, female, 30, specialist; Pauline, female, 72, older adult; Tracy, female, 57, care partner; Victor, male, undisclosed age, living with cognitive impairment) reported that cardiovascular problems increased an individual’s risk of developing cognitive impairment as the blood flow may not be sufficient throughout the brain to keep all parts active and healthy. For example, Tracy (female, 57, care partner) drew upon the personal experience of her mother to explain how she thought vascular risk factors may play a role in cognitive health.

Extract 47

1 Tracy: erm I know that there are well certainly in my mother’s
2 thing ((dog barking)) there was the the >if you like<
3 the damage arising from (.) sort of blocked arteries
4 and what have you

5 Interviewer: yeah

6 Tracy: and sort of the vascular

7 Interviewer: yeah

8 Tracy: the vascular aspects of it

Dianne (female, 82, older adult) remarked on the importance of “clear arteries” for cognitive health (see Extract 41). Similarly, when asked about media presentations of cognitive impairment, Louise (female, 30, specialist) discussed the risk factors for vascular dementia centring on cardiovascular risk factors such as high blood pressure and high cholesterol.

Extract 48

1 Louise: y'know erm: (.) there’s a new campaign launching very
2 soon from the pub- public health England about, .hh er
3 it’s called one you which is all about =

4 Interviewer: yeah

5 Louise: = looking after yourself and so that touches on
6 everything, which I think is a really good ↑idea. I
7 suppose I've read about it more in terms of dementia
8 like vascular dementia

9 Interviewer: yeah

10 Louise: where the big causes of that are things like high
11 ↑blood pressure high ↑cholesterol erm:: just generally
12 being unhealthy erm:: so I suppose (.) that links to to
13 cognitive impairment as well

This discussion highlighted a perception that having an unhealthy lifestyle may increase someone's risk of developing cognitive impairment or dementia. Louise discusses a new public health campaign focusing on the importance of "looking after yourself" (line 5) holistically, providing further support to the impact of public health campaigns on public perceptions of health and wellbeing.

The examples presented here highlight that many participants viewed diet and exercise to play a role in cognitive health. However, this view was not universal, and participants rarely raised the discussion of diet and exercise until they were explicitly asked about this. This suggests that diet and exercise were not at the forefront of participants' thoughts and conversations about cognitive impairment. There was a suggestion that public health campaigns accessible to a wide range of people were needed to increase knowledge about the role of diet in cognition, and an implication that health campaigns to increase overall awareness of healthy lifestyle factors had been generally successful. There was evidence of an awareness of the role of the cardiovascular system in cognitive health and the importance of keeping the heart healthy in order to keep the brain healthy.

6.5.2.3 Controllability & Blame in the Causation of Cognitive Impairment

Participants discussed causes which were within an individual's control (such as smoking, drinking, poor diet) as well as those beyond the sphere of personal control (such as stress, normal ageing, brain damage resulting from an accident or illness). This suggests that participants viewed cognitive impairment to be both within and outside of an individual's control depending on the underlying cause. Causation discussions often centred around causes outside of an individual's control (such as brain damage resulting from an illness or injury). This is exemplified in the following extract from Fiona (female, 76, care partner). When asked

whether cognitive impairment could be avoided or prevented, Fiona explains that it depends on the cause.

Extract 49

- 1 Fiona: hhhh I don't know (2) I mean if it's come about by
2 accident
- 3 Interviewer: yeah
- 4 Fiona: er:: you can't avoid accidents
- 5 Interviewer: no
- 6 Fiona: however careful you are and if you're too careful you
7 don't have any fun
- 8 Interviewer: yeah
- 9 Fiona: erm (.) er (4) and I think it can be helped .hh but I
10 don't think it can be prevented y'know I think if you
11 erm keep mentally active er .hh you're less likely to,
12 well no that's not even true is it? .hh cos if you
13 think about people who are academically brilliant they
14 can er .hh succumb to some form of mental erm problem
15 can't they?
- 16 Interviewer: yeah
- 17 Fiona: (4) so (.) perhaps it is ↑inevitable
- 18 Interviewer: yeah so something that's not really within (.) our
19 control then I guess
- 20 Fiona: no. no, I I think as well er ((laughs slightly)) you
21 get the impression that erm if you do everything right,
22 er you'll be ok sort of thing but there's some things
23 that you cannot control

Fiona identifies that she does not perceive cognitive impairment to be preventable *per se* but that it may be possible to mediate some potential risks. Fiona suggests that even if people avoid all possible known risks for cognitive impairment that they may still develop this because not everything can be controlled. This view was proposed by seven other participants (Beth, female, 63, care partner; Brian, male, 71, older adult; Clive, male, 24, younger adult; Fiona, female, 76, care partner; Grace, female, 70, care partner; James, male, 32, younger adult; Irene, female, 73, older adult) who shared the perspective that cognitive impairment was fundamentally not within an individual's personal control.

Related to discussions regarding whether cognitive impairment was within an individual's control, seven participants (Adam, male, 31, specialist; Fiona, female, 76, care

partner; Grace, female, 70, care partner; Irene, female, 73, older adult; James, male, 32, younger adult; Oscar, male, 73, specialist; William, male, undisclosed age, living with cognitive impairment) reported that, while some risks could possibly be avoided or mediated, there may be some causes which could never be evaded or prevented and thus cognitive impairment was not always avoidable or preventable. For example, Oscar (male, 73, specialist) outlines genetic risk factors as a cause of cognitive impairment which cannot be avoided or prevented.

Extract 50

1 Oscar: er: hhhh (5) well one factor one can't do anything
2 about is genetics and there may be a genetic (.) er::
3 proclivity towards MCI in the clinical sense .hh which
4 all these other things aren't gonna exercise or or
5 proper diet and blah blah blah (.) won't affect, so
6 therefore there is presumably a residual .hhh quantity
7 of impairment that one is going to get if one survives
8 to that age that it would have happened at ((coughs))
9 .hh tch people are starting to do research which may
10 tweak genes (.) e- even in people that are alive as
11 opposed to the embryonic or whatever erm so maybe one
12 day those genes will all be detected and switched off
13 .hh or the mutations will be un-mutated or whatever it
14 is .hh so in the long run it may be possible. (2) all
15 this research that one does and all this dementia
16 research is presumably going to hoping to get the stage
17 where no one ever gets it

18 Interviewer: yeah

19 Oscar: rather than curing it when it's there or caring for
20 people better when it's there

Oscar perceives that there are cases of cognitive impairment whereby individuals have no personal control over developing cognitive impairment, even if they try to live a healthy lifestyle and moderate risk factors where possible. However, Oscar also highlights that as research progresses, it may be possible to “tweak genes” (line 10) in order to prevent this genetic risk factor from causing cognitive impairment. Similarly, Grace (female, 70, care partner) claimed that if people lived a healthy life, avoiding all possible risk factors, they may still develop cognitive impairment as it may not always be preventable.

Extract 51

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

3 Interviewer: yeah

- 4 Grace: and I think once you have done all of those things I
 5 don't know anything else you can do (.) that would stop
 6 it
- 7 Interviewer: yeah
- 8 Grace: I don't know if there is anything, if there's a magic
 9 pill you can ↑take!

The examples presented here from Oscar and Grace highlight the view shared by seven participants overall that cognitive impairment may not always be able to be prevented or avoided, suggesting an underlying perception of cognitive impairment as a condition which is outside of an individual's personal control.

Participants expressed contrasting views around whether cognitive impairment was something which could be viewed as inevitable, something which could never be definitely prevented or which would affect most people at a certain age, or a condition which was not inevitable and which could possibly be prevented or just never occur for some individuals. For example, James (male, 32, younger adult) describes cognitive impairment as something which is inevitable and which is unlikely to be prevented or avoided via healthy lifestyle factors.

Extract 52

- 1 Interviewer: what do you think could be potential causes or risk
 2 factors for cognitive impairment? .hh
- 3 James: .h tch that's really interesting I I mean part of me
 4 thinks it's somewhat inevitable no matter what your
 5 lifestyle or background is but I think it it seems (.)
 6 that it might be exacerbated through (1) bad physical
 7 health

However, James expands on this to explain how cognitive impairment could be exacerbated by bad physical health and thus that lifestyle factors may play a role in cognitive health even if they may not be able to fully prevent cognitive impairment. This view of cognitive impairment as an inevitability was also shared by four other participants (Brian, male, 71, older adult; Fiona, female, 76, care partner; Helen, female, 27, HCP; Irene, female, 73, older adult). For example, Irene (female, 73, older adult) stated that that for some people cognitive impairment was something that would just happen, something that was entirely out of an individual's personal control.

Extract 53

- 1 Irene: it's one of these things a hhhh I think probably
2 there's it's it's (.) you're (.) it's gonna happen to
3 some people
- 4 Interviewer: yeah
- 5 Irene: whether they can s:top it happening by the way they
6 live. whether they could stop it happening with drugs
7 at the beginning of it. erm (.) whether their lifestyle
8 is enough to .hh delay it halt it
- 9 Interviewer: yeah
- 10 Irene: delay it possibly halt it probably not. erm tch (.)
11 yeah it's (1) hh I I do feel it's something that's just
12 going to happen to some people
- 13 Interviewer: yeah
- 14 Irene: and you can't avoid it altogether

In this extract, Irene describes cognitive impairment as a condition that will happen to some individuals regardless of their lifestyle or actions. However, Irene also expresses a hopeful view that medications and lifestyle factors may play a role in cognitive health and that there may be hope of delaying the onset of cognitive impairment, but not to halt or prevent it altogether. This suggests a view of cognitive impairment as a condition for which people cannot be held personally responsible and for which an individual is predominantly blameless.

On the other hand, six participants (Beth, female, 63, care partner; Edward, male, 69, older adult; Grace, female, 70, care partner; Louise, female, 30, specialist; Mary, female, 71, specialist; Pauline, female, 72, older adult) stated a view of cognitive impairment as a condition which was not inevitable. For example, Beth (female, 63, care partner) explains how she considers cognitive impairment to be something which is distinct from the natural cognitive decline that people experience as they age.

Extract 54

- 1 Beth: I think that you can get to those sorts of ages and get
2 what I call sort of old age dottiness which doesn't I
3 think of cognitive I think of cognitive impairment as
4 being a sentence, is the precursor of worse things I
5 may be †medically wrong but that's my take on it
6 whereas you could go from the age of say seventy-five
7 to ninety-five being dotty but not getting worse

Here, Beth outlines what she describes as “old age dottiness” (line 2); a state of cognitive decline which is not as severe or progressive as cognitive impairment. Similarly, in his response to a question about whether cognitive impairment and ageing are separate entities, Edward (male, 69, older adult) explains that he views cognitive impairment as related to ageing but not an inevitable consequence of ageing.

Extract 55

- 1 Edward: I would say (.) my feeling is that most people do but
2 not necessarily everyone
- 3 Interviewer: yeah
- 4 Edward: I mean we do know of (.) I know of people who are older
5 than ↑me .hh who are very on the ball and sharp
- 6 Interviewer: yeah
- 7 Edward: and erm .hh er whereas sometimes people who are a bit
8 ↑younger than me are erm er are less so. so I think of
9 it as something that's related to getting old, .hh but
10 not necessarily something that is going to hit
11 everybody

Here, Edward draws on his own personal experiences and social interactions to explain his view of cognitive impairment as something which occurs more frequently in older adults and which is related to ageing, but is not an inevitability and will not affect everyone as they age. Associated with discussions of the potential inevitability of cognitive impairment were conversations about whether cognitive impairment was the result of normal ageing. This is discussed in more detail in sections 6.5.3.1 and 6.5.3.2. The accounts presented here highlight the contrasting viewpoints held by participants regarding the inevitability of cognitive impairment.

When discussing controllability of cognitive impairment and whether cognitive impairment was something society might blame an individual for, viewing people as responsible for their own situation, Beth (female, 63, care partner) reported that society as a whole enjoys being able to place blame on an individual for their own circumstances.

Extract 56

- 1 Beth: but I think though as as a society (.) we love being
2 able to point the finger and say well “sh- y’know he
3 brought it upon himself.” (.) y’know whether it’s
4 ↑diabete:s or:::::::::: obesity y’know people ↑like

5 blaming other people. that's how Nazis y'know, became
6 so ↑popular

7 Interviewer: mmm

8 (2)

9 Beth: it's because you're Jewish it's because you're this
10 it's because you're that

11 (2)

12 Interviewer: yeah. so it's that sort of blame culture that cycles
13 through

14 Beth: mmmm there seems to be a sort of almost a ↑natural
15 human instinct. .hh I think it's also a protective
16 thing "that's not going to happen to me"

17 Interviewer: yeah

18 Beth: it's happened to him because he ↑did these things

19 Interviewer: yeah

20 Beth: so it's almost like going into denial y'know I don't
21 need to worry cos these people did all the wrong things

Beth discusses how this fundamental desire to categorise people and place blame resulted in the rise of the Nazis to power, arising from a desire to blame people for being different in some way. Beth stated that this blame culture within society stemmed from a natural human instinct and a desire to protect oneself from illness by finding a reason why that individual was experiencing it and why one would not experience it. Whilst this view was not explicitly posited by any other participants throughout the interviews, I felt that this was a particularly relevant perspective to highlight here as I feel it raises an important avenue for future discussion regarding the blame culture in illness causation accounts and perspectives. This account also highlights a feature present in all interviews with people who were not themselves experiencing cognitive impairment: a discourse of "them" vs. "us". Participants tended to discuss people living with cognitive impairment as "they" or "them", separating this group of individuals from "me" and "us". This may be a mechanism of self-preservation, protecting one's own identity from the threat of cognitive impairment by making a clear distinction between people living with cognitive impairment and oneself (see section 6.5.1.4 for more details regarding cognitive impairment as a threat to identity).

Irene (female, 73, older adult) claimed that cognitive impairment and dementia were conditions which people placed internal blame upon themselves for, rather than this blame being placed externally or societally, but that external blame and stigma would also play a role.

Extract 57

- 1 Irene: and it's also hh .hhh hhhhh it almost seems like an
2 admission of failure ((sniffs)) and there's whereas a
3 physical illness is not a failure
- 4 Interviewer: yeah
- 5 Irene: but erm but something like dementia is (.) kind of a
6 failure
- 7 Interviewer: ↑yeah. (.) .hh so do you think then
- 8 Irene: it isn't really but it but it that's how you you y'know
9 that's why it's more difficult
- 10 Interviewer: yeah
- 11 Irene: cos it is you see it as a kind of failure
12 [...]
- 13 Irene: I think if it was me I would but I'm not no
- 14 Interviewer: yeah
- 15 Irene: I'm not sure I would judge other people like that
16 [...]
- 17 Irene: yeah I suppose it is it's the stigma of mental illness
- 18 Interviewer: yeah
- 19 Irene: I mean whatever whatever kind of mental illness there
20 is more of an issue about it than a physical illness
- 21 Interviewer: yeah
- 22 Irene: despite the fact that lots of physical illnesses are
23 caused by people's lifestyles. I mean the friend who's
24 disabled she's overweight she's diabetic and she's
25 never looked after her diet
- 26 Interviewer: yeah
- 27 Irene: it's her own fault ((sniffs)) but ((laughs slightly))
28 it still doesn't have the same stigma

This extract is taken just after Irene described how one of her friends has a physical disability which is very evident to onlookers. In contrast to this visible disability, Irene explains how cognitive impairment is viewed as a “failure” (line 6), whereas physical illnesses are not viewed in the same way. However, Irene clarifies that this perception of cognitive impairment and dementia as a failure is a view that she would place upon herself but would not view other people in this way. Irene states that mental illnesses, which she appears to consider cognitive impairment and dementia to be, are still surrounded by more stigma than physical illnesses and

thus may elicit more internal and external stigma. James (male, 32, younger adult) also supported this view of blame for cognitive impairment being more internally located, stating “I think the stigma is from the self”. The examples from these two participants show that the blame and controllability placed around cognitive impairment may be located either internally or externally, with some people feeling that individuals living with cognitive impairment may blame themselves for their own condition in a way that others would not.

Alongside the notion of controllability and blame, participants also discussed whether they thought intellectual ability and previous academic achievement may play a role in cognitive impairment, particularly in terms of protecting against cognitive impairment. For six participants (Edward, male, 69, older adult; Fiona, female, 76, care partner; Grace, female, 70, care partner; Helen, female, 27, HCP; James, male, 32, younger adult; Mary, female, 71, specialist), there was a view that intellectual ability did not play any specific role in developing cognitive impairment and was not a protective factor. For example, when asked about the role of intellectual ability in cognitive impairment, Helen (female, 27, HCP) explained that this was not something she had ever thought about before.

Extract 58

- 1 Helen: ooh:: that's a good question. .hh erm:: no I don't
2 think so, erm:: I think (.) erm::: tch I suppose
3 education and intellect (3) tch erm (2) hmm:: I hadn't
4 really thought about that to be honest (2) tch so
5 thinking that if you're more if you're more
6 intelligent, more intelligent? you're less likely to
7 get dementia?
- 8 Interviewer: yeah
- 9 Helen: .hhh yeah:: cos they always say that like all in the
10 press they're saying "ooh you've got to keep doing
11 these mind games in order to keep your brain active to
12 reduce your risk of getting dementia" but =
- 13 Interviewer: yeah
- 14 Helen: = I don't really think that that er: that that's
15 probably (.) an impact at all to be honest. it's
16 difficult because you've obviously got the risk factors
17 but then there's always the people that you think (.)
18 .hh like with cancer .hh you're gonna have people that
19 will never have smoked a cigarette in their entire
20 years like life and they get lung cancer just because
21 of that's just what's happened
- 22 Interviewer: yeah

23 Helen: so erm:: tch no not really ((laughs))

Here, Helen highlights the message posited in the media that staying active and engaging in mentally stimulating activities such as mind games will reduce the risk of getting dementia, but expands to state that this is not her viewpoint. This extract suggests that Helen does not perceive intellectual ability to have any role in cognitive health and the development of cognitive impairment. Similarly, Edward (male, 69, older adult) explains that he has heard of highly intelligent and intellectual people who have experienced cognitive impairment and so he does not consider intellectual ability to be protective against cognitive impairment.

Extract 59

1 Edward: I've heard of cases of people and heard people talk
2 about someone they've known .hh who has been
3 exceptionally intellectual exceptionally bright
4 Interviewer: mmmm
5 Edward: and alert and perhaps in control of a very high powered
6 job even
7 Interviewer: yeah
8 Edward: and then all of sudden they lose the ability to cope
9 with things of an everyday of an everyday nature .hh
10 erm so I wouldn't have thought that that would protect
11 you from it, no no

This view of intellectual ability as not playing a role in cognitive health and the development of cognitive impairment was shared by just over a quarter of participants and was succinctly summed up by Grace (female, 70, care partner) who stated "I don't think how intelligent you are m- matters".

In contrast to this viewpoint, six participants (Beth, female, 63, care partner; Brian, male, 71, older adult; Irene, female, 73, older adult; Louise, female, 30, specialist; Oscar, male, 73, specialist; Pauline, female, 72, older adult) stated that intellectual or academic ability could offer a degree of protection against cognitive impairment, or an "academic shield" (James, male, 32, younger adult). For example, Oscar (male, 73, specialist) explains that intellectual ability may be protective and cites research he is aware of which supports this stance.

Extract 60

1 Oscar: people say that brain exercises are actually don't make
2 any difference. I'm not sure if that's true .hh but I
3 suspect it's probably true that if you suddenly start

4 doing brain exercises it's probably too late. .hh erm
5 (.) some interesting research shows that an active
6 brain good high linguistic skills and plenty of
7 ↑practice with linguistics in early age even in
8 childhood can reduce much reduce the chance of getting
9 Alzheimer's for example .hh erm so I I presume if one
10 is intellectually active through life that is a good
11 thing

12 Interviewer: yeah

13 Oscar: I don't believe in exercising the brain cos it's not a
14 muscle despite what some people say erm (2) but I I
15 suspect I'd I probably agree that somebody saying "oh
16 I'd better do crosswords all the time and all these
17 exercises" probably not gonna make any difference cos
18 what's happened has happened

However, in this extract, Oscar states that whilst intellectual ability may be protective, he does not "believe" (line 13) that engaging in mental activity after the onset of cognitive impairment will be beneficial as this is too late and will not reverse what has already happened. In a similar vein, Louise (female, 30, specialist) explains her view of the role that intellectual ability may play in cognitive impairment.

Extract 61

1 Louise: I wouldn't like to say y'know all sort of really clever
2 intellectual people won't get a cognitive ↑impairment

3 Interviewer: yeah

4 Louise: its maybe just how they experience it would be
5 different and when they notice the symptoms (.) might
6 be different and they might be more erm inclined to (1)
7 put things in place to ↑try and slow that impairment
8 down

For Louise, the protective nature of intellectual ability can be seen in the way that people who are more intelligent may notice the symptoms of cognitive impairment sooner and may be more motivated and able to put measures in place to slow the progress of cognitive decline. The examples presented here show participants split views around the role of intellectual ability in protecting against cognitive impairment, with approximately equal numbers of participants claiming that intellectual ability is protective and not protective.

Here, I have highlighted respondents' discussions of diet and healthy lifestyle factors, and perceptions of the controllability and blame surrounding cognitive impairment within the theme of *causation accounts*. Participants posited a range of possible causes of cognitive impairment, but viewed brain damage as the primary cause of cognitive impairment, closely

followed by ageing (see sections 6.5.3.1 and 6.5.3.2 for more details regarding participants' views around ageing and the onset of cognitive impairment). Participants also expressed a view that cognitive impairment was generally beyond individual control and that people experiencing cognitive impairment were blameless for their situation. However, when diet and physical exercise were raised, most participants stated that healthy lifestyle factors could play a role in cognitive health, though this view was not unanimous. The causation accounts offered by participants were varied, but shared generally similar views of the possible causes of cognitive impairment, and highlighted that blame placed around cognitive impairment could be experienced both internally and externally.

6.5.3 Ageing, Dementia & Death

Under the theme of ageing and death, participants discussed the difference, or not, between cognitive impairment and normal ageing, and between cognitive impairment and dementia. There was also a discourse of death and dying raised by participants despite no explicit questions being asked about this, which calls to mind the positioning of cognitive impairment as a syndrome which represents unsuccessful ageing. In this context, cognitive impairment may exist as a factor of the fourth age. The division of later life into a third age and fourth age have been extensively discussed by Paul Higgs and Chris Gilleard amongst others (Gilleard & Higgs, 2011; Higgs & Gilleard, 2015). The authors discuss the fourth age as a state of ageing whereby an individual is afflicted by ill health and incapacity. In this vein, cognitive impairment could be viewed as a condition which begins to edge towards the fourth age, with a condition such as dementia being firmly established within this age.

6.5.3.1 Age of onset of cognitive impairment

In their accounts of cognitive impairment, participants made frequent references to ageing and what it means to age both positively and negatively. Entangled with these conversations was the discussion of the age somebody might develop or be at risk of cognitive impairment. For nine participants (Adam, male, 31, specialist; Fiona, female, 76, care partner; Helen, female, 27, HCP; James, male, 32, younger adult; Mary, female, 71, specialist; Oscar, male, 73, specialist; Pauline, female, 72, older adult; Sarah, female, 54, specialist; Victor, male, undisclosed age, living with cognitive impairment), there was a view that cognitive impairment could affect an individual at any age, but 12 participants stated the prevalence and frequency of cognitive impairment was related to age, with older adults being most at risk of cognitive

impairment. Seven participants (Adam, male, 31, specialist; Fiona, female, 76, care partner; Helen, female, 27, HCP; James, male, 32, younger adult; Pauline, female, 72, older adult; Sarah, female, 54, specialist; Victor, male, undisclosed age, living with cognitive impairment) stated that whilst cognitive impairment could occur at any age, it was much more frequent amongst older adults. For example, Fiona (female, 76, care partner) stated that cognitive impairment would be more likely to occur as people get older, but acknowledged that it could affect someone at any age.

Extract 62

1 Fiona: erm (.) I mean it can er (.) affect anybody at any age
2 really
3 Interviewer: yeah
4 Fiona: but er I would think there's probably more tendency as
5 people get older

Similarly, in her account, Helen (female, 27, HCP) explains that cognitive impairment can occur at any age, but that it is more prevalent in later life due to general age related changes in cognition.

Extract 63

1 Helen: yes ((laughs)) I'm not as not as (.) focused (.) as I
2 might think. it can be, it's not an inevitable part of
3 (.) ageing
4 Interviewer: yeah
5 Helen: erm:: but then there are also I also think that there's
6 sort of your kind of normal age related changes that
7 are even- inevitable (.) sort of like memory will get
8 ↑worse
9 Interviewer: yeah
10 Helen: but it might not ever impact on the your life to a
11 point where you're impaired cos impaired kind of to
12 me's like a reduction in function so (.) it might never
13 get to that stage yeah it it might never actually
14 impair your life but you obviously might slow down your
15 you might adapt to it
16 Interviewer: yeah
17 Helen: erm:: .hh but no I wouldn't say it's an inevitable part
18 of getting old and of course you can get it much
19 earlier in life >as well anyway< so if that makes
20 sense?

There is an implication in Helen's conversation that cognitive impairment and normal ageing are distinct concepts, and that whilst typical ageing involves a level of cognitive decline, this is somehow different from what would be termed as cognitive impairment. Similarly, James (male, 32, younger adult) describes how he feels that the majority of older adults that he knows have a degree of cognitive impairment, suggesting he perceives cognitive impairment to be commonplace amongst older adults.

Extract 64

1 James: it seems like most older people, and when I say older
2 I'm talking (.) from like retirement to death (.) or if
3 they're still alive so post-retirement .hh I would say
4 the vast majority of those are have what I might
5 characterise as some kind of cognitive impairment

The perspective of cognitive impairment as more frequent amongst older adults was shared by Sarah (female, 54, specialist), as evidenced in her response to a question about whether she thought everyone would experience cognitive impairment as they aged.

Extract 65

1 Sarah: .hhh I don't think everybody experiences it at the
2 moment. I think .h and it's purely my opinion but as
3 .hh ages get greater in old age I think it's gonna be
4 more common for everybody to experience a level of
5 cognitive impairment

6 Interviewer: yeah

7 Sarah: .h when they're living in their nineties. erm I think
8 that's to be expected. I think our bodies are generally
9 degenerating .hh that has an effect on cognitive (.) er
10 functioning

In contrast to the views expressed by Helen, Sarah states that cognitive impairment is essentially an inevitable part of ageing and that everybody will experience a degree of cognitive impairment if they live to a certain age. Sarah reports that cognitive and physical health are entwined and that, in the same way that our physical health and fitness generally decline as we age, it is to be expected that cognitive health and "functioning" (line 10) would similarly decline, possibly as a result of this physical degeneration. In Louise's (female, 30, specialist) conversation, the perspective that cognitive impairment would be more likely to impact older adults was expressed more implicitly when she stated "cognitive impairment is something that probably a lot of older people might encounter in one way or another". This suggests that Louise views cognitive impairment as a condition which is most likely to affect older people rather than

younger adults. Overall, participants stated that cognitive impairment was related to ageing, with the frequency of cognitive impairment increasing by age, but nearly half of participants stated that cognitive impairment could occur at any age.

6.5.3.2 Normal Ageing and Normality

Normal or typical ageing was discussed by all participants, with frequent reference to whether cognitive impairment was part of, the same as, or distinct from normal ageing. However, 11 participants were clear in their view that cognitive impairment and normal ageing were distinct entities; “they are two different things I think yes” (Fiona, female, 76, care partner). For example, Pauline (female, 72, older adult) stated that there was a difference between normal ageing and cognitive impairment but that most people will experience a degree of cognitive decline.

Extract 66

- 1 Pauline: n::o I've met enough (.) I I've met and seen enough ol-
2 old old people .hh who are ((clicks fingers)) alright
3 (.) to think that it's not inevitable .hh but I also
4 think you know (2) you most people (.) will be affected
- 5 Interviewer: yeah
- 6 Pauline: to some extent .hh I know I'm slower erm: (.) than I
7 was (.) er to do things and to think things quite often
8 er (1) so I think er (1) I think that would be most
9 people

Here, Pauline states that her personal experience of meeting older adults has influenced her view of whether cognitive impairment is an inevitable part of normal ageing, stating that she has met and seen “enough ol- old old people” (lines 1-2) who are still cognitively healthy to think that cognitive impairment is not inevitable. However, despite this experience, Pauline also claimed that most people would experience a cognitive change and decline “to some extent” (line 6). Following this, she discussed how her own cognition had slowed and she thought that most people would experience something similar. This view was shared by five participants over the age of 60 (Beth, female, 63, care partner; Edward, male, 69, older adult; Grace, female, 70, care partner; Mary, female, 71, specialist; Nina, female, 74, older adult) who normalised any cognitive decline that they were noticing by stating “we are all much more forgetful than we were” (Grace, female, 70, care partner); that everyone else in their peer group was experiencing the same.

Similarly, when asked about whether she thought cognitive impairment and normal ageing were the same or different, Louise (female, 30, specialist) reported that everyone's cognitive faculties and abilities would decrease slightly as they aged, though she did not think that this necessarily constituted a cognitive impairment.

Extract 67

- 1 Louise: hmm::: (3) I don't ↑know because I can think of people
2 who are in their ↑nineties who are (2) still sharp as a
3 >I don't know what the phrase is< ((laughs)) but still
4 very sharp
- 5 Interviewer: yeah
- 6 Louise: erm but I suppose they ↑are different to the person
7 that they wer:e y'know when they were in their forties
8 fifties you couldn't y'know if somebody was a a brain
9 surgeon and they're now retired and they're in their
10 eighties, you couldn't plonk them back in an ↑operating
11 theatre erm: but that's not to say that they have a
12 cognitive impairment
- 13 Interviewer: yeah
- 14 Louise: erm, I th- I would probably think it's more down to
15 just changes in lifestyles, and not repeating lots of
16 tasks that you have done
- 17 [...]
- 18 Louise: because you ↑can and you should be able to take things
19 ↑slower so erm (.) no I don't think everybody would get
20 a a cognitive impairment I think (.) there's getting
21 older and slowing down erm (.) but then the cognitive
22 impairment I would say is sort of the next step on when
23 you're starting to have difficulty with, with a few
24 things

Corresponding with Pauline's account, Louise highlighted her personal experience of knowing older adults who did not have cognitive impairment and were "still very sharp" (lines 3-4) and how she therefore did not view normal ageing as equating to cognitive impairment. However, she reported that normal ageing would involve a level of cognitive change whereby people would not necessarily be able to do the things that they could when they were younger but that this was due to the fact that as people retired and stopped doing the activities they used to then they would therefore lose some of these previous abilities. Similarly to Pauline, Louise stated that most people would slow down as a result of ageing, but that cognitive impairment was substantially different to this and would involve more difficulties than the "slowing down" (line

21) of normal ageing. This view was prevalent amongst six participants (Adam, male, 31, specialist; Grace, female, 70, care partner; Louise, female, 30, specialist; Oscar, male, 73, specialist; Pauline, female, 72, older adult; Tracy, female, 57, care partner) who stated that most people's cognition would slow down as they aged, and that there would be "a normal range of (.) rate of impairment with age" (Oscar, male, 73, specialist). This suggests that approximately half of all participants generally viewed ageing to result in a reduction in cognitive abilities, but that this cognitive decline did not always equate to cognitive impairment.

Related to these discussions of ageing and cognition was the idea that if normal or typical ageing and cognitive impairment are indeed different, this difference is hard to quantify or measure. For example, in response to a question about whether cognitive impairment and normal ageing were different, Mary (female, 71, specialist) stated that they were, but that she had heard some people say that they were one and the same.

Extract 68

- 1 Interviewer: would you say that they were different?
- 2 Mary: I think to (.) people (.) that's what I've read anyway
- 3 Interviewer: yeah
- 4 Mary: that people say "oh it's just" or even doct- some
5 doctors say "OH it's just getting old"
- 6 Interviewer: yeah
- 7 Mary: no. it's not just getting old. because what are what
8 age is that?
- 9 Interviewer: yeah
- 10 Mary: y'know I'm only seventy two but I'm experiencing this.
11 is that not a bit early to be having these things? erm
12 so it's not just getting old

The prominent view expressed by Mary was of cognitive impairment and normal ageing as separate entities. To enforce this perspective, Mary calls into question how one would define "old" (line 7) and queries "what age is that?" (lines 7-8). In her own opinion, Mary considers she may be experiencing a degree of cognitive impairment, and feels that at the age of 72, she is too young to have this and therefore she would not perceive cognitive impairment as "just getting old" (line 7 and 12). This difficulty in delineating the differences between cognitive impairment and typical ageing was explicitly stated by three participants (Adam, male, 31, specialist; Mary, female, 71, specialist; Oscar, male, 73, specialist). For example, Oscar (male, 73, specialist)

outlined what he understood cognitive impairment to be, explaining that he considered this to be different from ageing but that he could not clarify what the exact differences are.

Extract 69

1 Oscar: .hh erm I think cognition is (1) all kinds of (1)
2 thinking skills intellectual skills if you like that
3 the brain (.) deals with .hh one is born with a certain
4 level of cognitive ability and as one gets older it
5 gets less good, after a certain age anyway. you're
6 nowhere near the peak of it yet I'm sure. erm (.) but
7 there is a clinical (.) form of imp- so as I say
8 everyone gets worse same as their memory gets worse and
9 so on if that's not part of it .hh erm but there is a
10 clinical kind of .hh cognitive impairment (1) which is
11 testable for and can be monitored err .hh and may lead
12 to forms of dementia but doesn't necessarily .hh erm
13 which is distinct from age related normal cognitive
14 impairment. .hh what the differences are I'm not sure

This suggests a view of cognitive impairment and ageing as separate concepts but highlights the difficulty that participants had in delineating and quantifying the boundaries between normal ageing and cognitive impairment.

Entangled with discussions of ageing and normal or typical ageing, participants raised the discourse of normality, highlighting a view shared by 10 participants that cognitive impairment and dementia can be classed as abnormal, challenging what it is to be normal. For example, Louise (female, 30, specialist) stated that cognitive impairment was something out of the ordinary.

Extract 70

1 Interviewer: so first of all could I ask you to tell me a little bit
2 about what you know about cognitive impairment?
3 Louise: er:: well I know it's erm I ↑think I know ((laughs))
4 it's erm whe::re some kind of your cognitive function
5 is ((laughs)) >it sounds silly but< it's impaired so
6 you have difficulty .hh with (.) some things erm, not
7 to the extent of dementia which is a cognitive
8 impairment and that will get worse and worse and
9 probably the symptoms are have a bigger impact on your
10 ↑life, but I think my understanding is cognitive
11 impairment is ↑where you're experiencing difficulties
12 which you (.) somebody else in your situation >maybe
13 the same age or somethin'< probably wouldn't, it's not
14 not a normal a norm °uh that sounds wrong° but it's not
15 a normal erm (.) tch you're experiencing things that
16 ↑other people aren't if that makes sense? ((laughs))

However, in this account, Louise was not confident in her use of the word “normal”, stating “uh that sounds wrong” (line 14), suggesting that she did not feel that stating cognitive impairment in terms of normality was the most appropriate way to address this, but that this was the first terminology that came to her mind. Similarly, Helen (female, 27, HCP) explained that she would describe cognitive impairment as “that they are having (.) difficulty more difficulty than than would be deemed normal” and William (male, undisclosed age, living with cognitive impairment) stated that for people living with cognitive impairment “something is going on with their cognition that is out of the ordinary”. These examples highlight the perception of cognitive impairment as something out of the ordinary or not normal which was shared explicitly by 10 participants overall.

Eight participants (Adam, male, 31, specialist; Beth, female, 63, care partner; Brian, male, 71, older adult; Fiona, female, 76, care partner; Grace, female, 70, care partner; Irene, female, 73, older adult; Pauline, female, 72, older adult; Tracy, female, 57, care partner) also identified how cognitive impairment could result in people behaving in ways which were not viewed as normal, with people engaging in activities and behaviours that would be perceived as weird or strange. For example, Adam (male, 31, specialist) discusses his view of cognitive impairment as something which is not well understood and how this lack of knowledge and awareness may result in people viewing those experiencing cognitive impairment in a negative or stigmatising light.

Extract 71

1 Adam: erm: (.) that the persons not saying these things
2 because they've got some kind of mythical figure
3 talking to them and they're gonna do something
4 [...]
5 Adam: y'know we're we're so (.) y'know and (.) and also yeah
6 and almost an element of danger with it this person
7 must be dangerous they're a threat to me
8 Interviewer: yeah
9 Adam: what are they gonna do they're unpredictable .hh y'know
10 (.) erm: (2) and yeah and I think people just don't
11 know whats actually causing it or or sometimes possibly
12 even seeing it as partly ↑deliberate

This extract links to the notion of stigma surrounding cognitive impairment as a result of the invisibility and lack of awareness of this condition while conditions which are more physically

obvious or better understood are viewed with more sympathy and understanding (see section 6.5.1.1 for more details regarding participants' views of cognitive impairment as an invisible illness). Similarly, Tracy (female, 57, care partner) states that people living with cognitive impairment will exhibit "weird" (line 8 and 9) behaviour and responses.

Extract 72

- 1 Tracy: erm (2) and I dare say there are some people in some
2 cultures who would probably say it's demonic possession
3 and it and it's because of erm evil spirits and all
4 that sort of thing and .hh you you you can mock it but
5 if that's what somebody's culture and background
6 includes
- 7 Interviewer: yeah
- 8 Tracy: as possible explanations for (.) ↑weird behaviour, or
9 ↑weird responses or (.) inappropriate ↑behaviour

In this context, Tracy states how she understands how cognitive impairment could be viewed in some cultures as "demonic possession" (line 2) as this could provide an explanation for "weird" (line 8 and 9) or "inappropriate" (line 9) behaviours. Pauline (female, 72, older adult) echoed this sentiment when asked what presenting symptoms in a friend or family member might prompt her to consider that the person may be experiencing cognitive impairment.

Extract 73

- 1 Pauline: people doing things: that surprise you because they're
2 not what you would have expected them to do
- 3 Interviewer: yeah
- 4 Pauline: or even saying things that would surprise you because
5 they don't seem to be coming out of (.) where you think
6 their head usually is .hh you know op- opinions that
7 would would surprise you

Here, Pauline identifies that if someone was acting out of the ordinary, saying or doing unexpected or surprising things, this would be a warning sign to her that they might have a cognitive impairment. The frequent references to weird and strange behaviours suggests an underlying stigma inherent in perceptions of cognitive impairment, with participants highlighting how society may consider the behaviours and actions of those living with cognitive impairment to be abnormal and out of the ordinary.

The examples presented here show how cognitive impairment was predominantly viewed by participants to be something out of the ordinary, or abnormal. However, interestingly, this was in direct juxtaposition to participants' perspectives of cognitive impairment as associated with, or even the result of, normal ageing.

6.5.3.3 Differentiating Cognitive Impairment and Dementia

One of the questions that all participants were asked was whether there was any difference between cognitive impairment and dementia or whether the two were related or possibly even terms for the same condition. In response to this question, Clive (male, 24, younger adult) expressed an uncertainty about the difference between cognitive impairment and dementia.

Extract 74

- 1 Clive: I I know very little specifically about (.) either one
2 but I would su::ppose that (1) if you have dementia you
3 might have cognitive impairment, but if you have
4 cognitive impairment you don't necessarily have
5 dementia
- 6 Interviewer: yeah
- 7 Clive: erm (1) so I would say it's probably like an aspect of
8 dementia but it's not like (4) ↑interviewee makes hand
9 gestures
- 10 Interviewer: ((laughs))
- 11 Clive: yeah:: er:: they're separate but they're related I
12 guess
- 13 Interviewer: yeah
- 14 Clive: erm but without knowing specifically about either
15 either one it's hard to say

Clive states his view in the form of a logic puzzle, whereby people living with dementia probably have cognitive impairment but people with cognitive impairment don't "necessarily" (line 4) have dementia. He clarifies that he views cognitive impairment and dementia as separate but related entities where cognitive impairment could be said to be "an aspect of dementia" (lines 7-8). This view was shared by nine participants overall (Adam, male, 31, specialist; Beth, female, 63, care partner; Brain, male, 71, older adult; Clive, male, 24, younger adult; Grace, female, 70, care partner; James, male, 32, younger adult; Louise, female, 30, specialist; Robert, male, 56, living with cognitive impairment; Victor, male, undisclosed age, living with cognitive

impairment), who stated that cognitive impairment was something which could progress to dementia or which conferred a greater risk of dementia. When asked how she would describe cognitive impairment, Grace (female, 70, care partner) replied “a phase before dementia is what is how I would describe it” suggesting a view of cognitive impairment as a precursor to dementia. However, this perspective was not unanimous, and for one participant, Sarah (female, 54, specialist), there was an explicit view that cognitive impairment did not infer a risk of dementia.

Extract 75

- 1 Sarah: I would think they're at no greater risk than anybody
2 else
3 Interviewer: yeah
4 Sarah: it depends on what the causation is for the mild
5 cognitive impairment

In this extract, Sarah is responding to a question about whether cognitive impairment would mean that someone was at a greater risk of developing dementia. Initially, she states that individuals living with cognitive impairment are “at no greater risk than anybody else” (lines 1-2), but she then clarifies this statement to say that “it depends on what the causation is” (line 4). This suggests a view of that the underlying cause is key in determining progression and the development of a dementia but that cognitive impairment does not definitely increase an individual's risk of dementia.

When discussing cognitive impairment, participants often described this with reference to dementia, with seven interviewees (Adam, male, 31, specialist; Edward, male, 69, older adult; Irene, female, 73, older adult; James, male, 32, younger adult; Louise, female, 30, specialist; Mary, female, 71, specialist; Robert, male, 56, living with cognitive impairment) explaining how cognitive impairment was not as bad or serious as dementia. For example, when asked to explain what she knew about cognitive impairment, Louise (female, 30, specialist) discussed this in the context of dementia.

Extract 76

- 1 Interviewer: so it's something sort of slightly out of the ordinary
2 Louise: yeah ↑yeah but not erm not as erm (.) alarming or as
3 erm (.) tch like detrimental as dementia

Louise explains how she views cognitive impairment as not as “alarming” (line 2) or “detrimental” (line 3) as dementia. This implies a view that dementia is more severe and impacts

day-to-day life more than cognitive impairment. Similarly, James (male, 32, younger adult) explained how cognitive impairment could be described as a “milder or the mildest” (line 3) form of dementia.

Extract 77

1 James: I understand cognitive impairment to be: (2) a certain
2 hhh (2) er I guess you can interpret it in a number of
3 ways like .hh kind of a milder or the mildest form of
4 dementia? .hh which suggests that there is like kind of
5 er an ex- (2) er hhh that people expect their mind to
6 be ordered in a certain way so this kind of
7 incorporates things like .hh forgetfulness

However, James did not seem certain in his own description, with his statement about cognitive impairment as a mild form of dementia being asked as a question rather than issued as a clear statement. James explains that people hold certain expectations about their thinking and that memory problems violate these expectations. This suggests a view of cognitive impairment as a condition which primarily affects memory, a view shared by eight participants as discussed in section 6.5.1.1.

Dementia was also referred to as similar, or related, to cognitive impairment but which more people had heard of and which was better understood than cognitive impairment. When asked how people responded to the news that he had cognitive impairment, Robert (male, 56, living with cognitive impairment) explained that most people had been very positive and supportive but that, at first, people did not know what he was talking about because they had not heard of cognitive impairment, as Robert himself had not prior to his assessment and subsequent diagnosis.

Extract 78

1 Robert: some sort of (.) think look at ya blankly
2 Interviewer: yeah
3 Robert: cos they haven't got a clue what you're on about
4 Interviewer: yeah
5 Robert: same reason like, they haven't heard of it
6 Interviewer: yeah
7 Robert: but if I say dementia then yes .hhh then they know
8 Interviewer: yeah

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

Robert stated that he found explaining cognitive impairment with reference to dementia enabled people to understand it as people had heard of dementia. His method of explaining cognitive impairment was to discuss this as “one step before (.) dementia” (lines 9-10) implying a view that his cognition would deteriorate and that he may develop dementia over time.

The examples presented here highlight that participants generally viewed cognitive impairment as something which was related to dementia, but was different in terms of severity. Cognitive impairment was discussed as a potential precursor to dementia or as a condition which implied an increased risk of dementia. However, there was no universal view about the risk of dementia as a result of cognitive impairment.

6.5.3.4 Death and Dying

The discourse of death and dying was raised by nine participants (Adam, male, 31, specialist; Beth, female, 63, care partner; Brian, male, 71, older adult; Clive, male, 24, younger adult; Grace, female, 70, care partner; Helen, female, 27, HCP; Tracy, female, 57, care partner; Victor, male, undisclosed age, living with cognitive impairment; William, male, undisclosed age, living with cognitive impairment), even though none of the interview questions directly addressed the notion of death (unless this was raised by the participant first and a follow-up question was subsequently asked). For Clive (male, 24, younger adult), the notion of death and dying was raised when asked about possible ways of treating or helping people living with cognitive impairment.

Extract 79

1 Clive: erm:: we can help them but I think when it gets to the
2 point where it's (.) impaired (.) .hh then it kind of
3 it's almost palliative, I think, er so it's just
4 helping them live their everyday life as normally as
5 they can

Clive reported that people with cognitive impairment would require palliative care and that all that could be done to help these individuals was to support them to live as well as they could whilst they were still alive. However, he also suggested a view that people with cognitive impairment can still live well for a period of time before care becomes palliative.

In their interview, both Beth (female, 63, care partner) and Brian (male, 71, older adult) had a very negative view of old age, stating it was better to die than to experience what they described in their interview as the “cruel” and “terrible affliction” of ageing, especially if cognitive impairment was involved.

Extract 80

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

Brian is clear on his views about how much better it would be to die than to live with cognitive impairment and that it would be a mark of “luck” (line 3) to die before cognition declined. Similarly, when I disclosed that my grandfather was diagnosed with dementia and passed away very quickly afterwards, Grace (female, 70, care partner) stated that she would not term this fast death unfortunate as she hoped that her mother, living with dementia, would not live much longer.

Extract 81

1 Grace: I wouldn’t say it was unfortunate that he didn’t last
2 very long because I don’t want my mum to (.)
3 Interviewer: no
4 Grace: no she’s got no life at all:

In this extract, Grace discusses her view that her mother, living with dementia has “got no life at all” (line 4) and that her cognitive decline means that she no longer has a full or worthwhile life. Irene (female, 73, older adult) discussed her own experience of knowing a couple in which the wife was living with dementia and how difficult it was for the husband to witness and be involved in this.

Extract 82

1 Irene: erm and I’ve just seen how difficult it is for the for
2 the people. .hh erm y’know I mean I do admire this man
3 who keeps going to see his wife
4 Interviewer: yeah
5 Irene: y’know ten years down the line. she was violent at one
6 time that’s why she had to go into a secure home
7 Interviewer: yeah

8 Irene: now she's just bedridden and doesn't know anybody but
9 Interviewer: yeah
10 Irene: .hhh they've pulled her through ↑pneumonia twice (1)
11 and I think UURGH ((sniff))

Here, Irene suggests a view that perhaps this lady should have been allowed to die from the pneumonia she contracted rather than being treated and saved. Inherent in this view is a perception of people living with advanced dementia as people who should be allowed to die as a result of their condition and not have life prolonging treatment administered. This suggests a potentially fearful view of cognitive impairment and dementia; something which one would rather die than experience.

This viewpoint was shared by six participants overall (Adam, male, 31, specialist; Beth, female, 63, care partner; Brian, male, 71, older adult; Clive, male, 24, younger adult; Grace, female, 70, care partner; Irene, female, 73, older adult) and was echoed by Clive (male, 24, younger adult), when asked to clarify why he had previously stated that the idea of experiencing cognitive impairment was “terrifying”.

Extract 83

1 Clive: not having control over everything is terrifying
2 Interviewer: yeah
3 Clive: my mum has said that if she ever loses like cognitive
4 control she wants to be er euthanized (.) which I can
5 actually understand erm as difficult as it is to talk
6 about
7 Interviewer: yeah
8 Clive: cos the idea of being alive but not (.) being able to
9 live ↑almost is (1) er it's terrifying

In this extract, Clive was clear in his view, highlighted in reference to a perspective he shared with his mother, that if he “ever loses like cognitive control” (lines 3-4) then it would be better to seek euthanasia than to continue living. Clive states that having cognitive impairment is essentially a living death whereby an individual is still alive but is no longer able to live, simply to exist. His explicit view was that this state of existence is “terrifying” (line 1 and 9) and something which he was evidently fearful of, potentially more fearful of this than death.

There were several references to this view of dementia and cognitive impairment as a living death or a terminal diagnosis made by seven participants (Beth, female, 63, care partner;

Brian, male, 71, older adult; Clive, male, 24, younger adult; Grace, female, 70, care partner; James, male, 32, younger adult; Mary, female, 71, specialist; William, male, undisclosed age, living with cognitive impairment). This supports the seminal paper by Sweeting & Gilhooly (1997) who identified the view of caregivers of people living with dementia that dementia resulted in a “social death” (Sweeting & Gilhooly, 1997, p.94). This social death equates to a living death whereby an individual is still physically alive but no longer fully sentient or able to function as a member of society. William (male, undisclosed age, living with cognitive impairment) viewed this living death of cognitive impairment as the result of people not allowing individuals living with cognitive impairment to continue to live their life, restricting their choices and activities.

Extract 84

- 1 illiam: you have to allow people to take calculated risks, you
2 have to be able to take safe ↑risks
- 3 Interviewer: yeah
- 4 William: y’know and and that’s it ((coughs)) I mean if you take
5 away anybody’s (.) purpose, their reason to be, then
6 they have no reason to be
- 7 Interviewer: yeah
- 8 William: and that is like a living death (2)

William stated that individuals living with cognitive impairment should be allowed to take calculated risks. Whilst Clive reported that having cognitive impairment would take away someone’s ability to live, William stated that it was the responses of others to someone living with cognitive impairment that equated to a living death rather than the cognitive impairment itself.

In a similar vein, James (male, 32, younger adult) stated that if his own parents were to experience cognitive impairment, he would view this as being essentially a terminal diagnosis.

Extract 85

- 1 James: .h y’know cos I I have some underst- well I think I
2 have some understanding of what (.) a cognitive
3 impairment is, .hh so therefore I would be looking for
4 those and I would probably start to like mother my
5 parents and like think .hh ok like and I know it sounds
6 like I’d be putting them on a kind of like an end life
7 pathway ((laughs slightly)) like without even meaning
8 to

James explains that if his parents were diagnosed with cognitive impairment he would view them as being on a palliative trajectory and would put them on an “end life pathway” (lines 6-7) even though this would not actually be his explicit intention. This suggests a deep-rooted perspective of cognitive impairment as a condition which heralds the end of life. The notion that James would put his parents in the category of the terminally ill “without even meaning to” (lines 7-8) highlights how some perspectives can be held at on an intrinsic level, whereby people may hold this view in an almost subconscious manner, not intending to feel or act on it, but aware of it nonetheless. This quote from James highlights the views of participants who claimed that cognitive impairment was a terminal condition, or represented a living death. As such, it could be inferred that cognitive impairment is a condition which is viewed as something to be feared; a condition which participants hoped to never experience.

Here, talk relating to the age at which cognitive impairment occurs, cognitive impairment in relation to normal ageing, and death and dying have been presented within the theme of *ageing and death*. The examples presented here highlight a divergence of participants’ views regarding the role of ageing in cognitive impairment, with some participants suggesting that cognitive impairment is an artefact of normal ageing, whilst others stated that cognitive impairment is distinct from ageing. Throughout the interviews, participants made frequent references to death and dying, despite this not being a topic that was addressed in the interview schedule. This highlights cognitive impairment as something which is positioned in the context of later and end of life, viewed as a condition which infers loss, possibly even to the extent of a cognitive death whilst a physical life sustains.

6.6 Discussion

The data presented here suggests that, on the whole, people across a range of participant groups have an understanding of what cognitive impairment is and are able to articulate this. However, there were a number of areas of where participants expressed uncertainty, particularly around where and how to delineate the boundaries between normal ageing, cognitive impairment and dementia. This is not surprising given the lack of clarity around these boundaries in the literature, with no clear solution as to if and how these lines can be drawn.

The symptoms identified by participants corroborate the results of the first phase of research presented in this thesis, a systematic review of the literature exploring understandings

of MCI (see Chapter 3), focusing predominantly on memory. However, several participants were also clear in their view that cognitive impairment does not necessarily involve a memory difficulty. This mirrors the literature on cognitive impairment, particularly MCI, where the first seminal papers on this concept stated memory impairment as a core criterion (Petersen et al., 1999), whilst the criteria have recently been updated to include impairment in any cognitive domain, thus not always requiring a memory deficit (Dubois et al., 2007; Winblad et al., 2004). Interestingly, all four participants living with cognitive impairment identified memory difficulties as a symptom which they had been experiencing, and highlighted this as one of the most noticeable symptoms. The implication of this is that diagnoses of cognitive impairment may still be being made based on the criteria of memory impairment, as suggested in a survey of UK psychiatrists who stated the requirement of a memory complaint in their diagnosis of MCI (Rodda et al., 2013).

Most participants reported that cognitive impairment impacts on an individual's day-to-day life, though they suggested that this impact would be less pronounced than in dementia. This is not an unexpected finding as one of the key criteria for MCI is that activities of daily living should be unimpaired (Winblad et al., 2004). However, "impact" can be defined in numerous ways and further research exploring what is meant by how cognitive impairment may impact an individual's life is warranted, particularly as the four participants living with cognitive impairment all stated that this impacts on their day-to-day life, both in terms of the symptoms but also the emotional impacts of cognitive impairment, either depression following diagnosis or the emotional impact resulting from the awareness of the frustration of others.

Participants expressed a view that cognitive impairment was an invisible illness and that because there was no obvious physical clue that an individual was living with cognitive impairment, people did not respond in a sympathetic or appropriate manner. However, participants were not unified in their views as to whether people living with cognitive impairment should have to advertise their condition or to announce their diagnosis to others in some way. As such, there is a suggestion that people should be able to somehow learn to recognise cognitive impairment in others without individuals having to inform people of their condition. This discourse of cognitive impairment as an invisible illness links to the literature on other chronic illnesses which are not readily apparent, including conditions such as Sjogren's syndrome and sarcoidosis (Donoghue & Siegel, 2000). It has been suggested that having an invisible illness may result in people having higher contextual ages than age-matched peers

without illness (Kundrat & Nussbaum, 2003). As such, people living with the invisible illness of cognitive impairment may feel that they are older than they are chronologically, and other people may view them in this manner too.

The perception held by many participants of cognitive impairment and dementia as negative, unpleasant conditions which are to be feared places them on the cusp of the 'fourth age'. This is a stage of ageing representative of people whose later life is affected by ill health and incapacity (Higgs & Gilleard, 2015). The views about cognitive impairment held by participants position this as a form of unsuccessful ageing, limiting people's ability to live independently and to maintain social activities (Bowling & Dieppe, 2005). As such, cognitive impairment could be situated as a condition which moves beyond the third age of active, healthy and successful ageing but does not quite enter into the fourth age. In this sense, cognitive impairment can be viewed as a condition which sits between these two ages, where an individual is no longer fully active and healthy but would not generally be viewed as incapacitated. However, situating cognitive impairment as the space between the third and fourth age calls into question how this syndrome is viewed in younger adults. Whilst the prevalence of cognitive impairment increases with age, there are some individuals who will experience cognitive impairment earlier in life. For these individuals, if cognitive impairment is viewed as a consequence of ageing, how does this fit with the identity and experiences of younger individuals affected? This is an area which warrants future research and exploration to understand how younger adults living with cognitive impairment perceive and experience this condition and how they are perceived by others.

In their discussions of cognitive impairment, many participants raised the notion of death and dying despite this not being something that was explicitly asked about. This suggests a view held by most participants that cognitive impairment was related to later life and therefore was closely associated with end of life either in terms of being directly viewed as a terminal illness or correlating with end of life due to the age at which it most frequently presents. There was also a suggestion of cognitive impairment being viewed as a living death or a death that leaves the body behind, similar to descriptions of dementia (George, 2010). This supports the findings of Sweeting & Gilhooly (1997) who suggested that people living with dementia were perceived by their relatives as "socially dead" (Sweeting & Gilhooly, 1997, p.94) and extends these findings to cognitive impairment, highlighting the pervasiveness of these views across a range of populations. Participants also discussed cognitive impairment as a threat to identity,

suggesting that cognition and cognitive abilities were viewed as central to an individual's core personhood. Future research should consider how this view of cognitive impairment as a threat to personal identity impacts upon stigma and help-seeking behaviour, and whether this perceived threat can be minimised in any way.

In the presented causation accounts, many participants discussed similar potential causes that were identified in phase one and phase two of the research, highlighting brain damage, ageing, stress, stroke and genetics as possible causes of cognitive impairment. Inherent in these discussions were ideas of whether cognitive impairment was something which could be controlled and prevented, and whether people could ever be blamed for their own situation with regards to cognitive impairment. Most participants posited causes they considered to be outside of an individual's personal control, suggesting an overall view that cognitive impairment was generally something which people could not be blamed for; something which people could attempt to mediate risk factors for but which could not always be prevented. Again whether cognitive impairment was preventable was reported to be dependent on the cause. Participants reported that some causes may have an element of avoidability, but that cognitive impairment was not generally something which someone could avoid or control. As such, it is likely that people living with cognitive impairment would be viewed with sympathy and supported by others according to the tenets of attribution theory (Weiner, 1993). This perception of cognitive impairment as something for which individuals are blameless reflects the views of individuals living with type 2 diabetes who reported contrasting perceptions about the underlying cause of their illness, with some individuals echoing this view that their current situation was the result of uncontrollable external influences (Lawton et al., 2008; Parry et al., 2006). The results reported here present an extension of the literature investigating illness causation accounts, by both exploring a syndrome which has not previously received interest around causation narratives previously, and also by exploring the views of a wide range of populations, not just the perceptions of people living with a particular illness and their care partners. Understanding the views of a wide range of people is beneficial to developing a detailed picture of the causes that are perceived to play a role in cognitive impairment.

One potential risk factor that participants stated was within an individual's control was a healthy lifestyle. The majority of participants reported that diet and exercise may play a role in cognitive health, echoing the often stated message of "what's good for the heart is good for the brain". As such, participants claimed that attempting to live healthily was important in order

to reduce one's risk of developing cognitive impairment, but that this was by no means the only factor which could contribute to cognitive impairment, therefore, even if someone had an exceptionally healthy lifestyle they may still develop cognitive impairment. This suggests an overall perception that living healthily should be encouraged but that a healthy lifestyle does not entirely negate the risk of developing cognitive impairment, implying that participants did not consider this to be a major cause of cognitive impairment. There is some evidence in support of physical activity being associated with a reduced risk of MCI (Geda et al., 2010), and a growing body of literature highlighting the potential role of dietary factors in cognitive decline (Plassman, Williams Jr, Burke, Holsinger, & Benjamin, 2010), but no specific recommendations are in place to date regarding the association between lifestyle factors and cognitive impairment.

6.7 Summary

The views of participants highlighted in these interviews suggest that most people have a perception of cognitive impairment and can explain this quite clearly. However, almost all of the participants suggested that more education and information was important in order to ensure that the general population had a better understanding of what cognitive impairment is. Nearly all participants, including those living with cognitive impairment highlighted that they did not know what cognitive impairment was at first and that it was only through personal experience that this knowledge was established. In the final chapter, I will discuss the results of the studies presented in this thesis in the context of the wider literature and research field and will consider how these studies have developed and informed the illness representation model of cognitive impairment. I will also outline limitations of the questionnaire and interview studies presented here and in Chapter 5, and summarise directions for future research based on the studies presented in this thesis.

Chapter 7: General Discussion

7.1 Overview

In this chapter, I will summarise the findings of this thesis and discuss how they relate and contribute to the broader literature. The implications of these findings will be outlined, particularly how this study can inform policy, media presentations, and public health campaigns in relation to cognitive impairment. I will also outline a theoretical model of cognitive impairment which draws on previous models of illness representation (Leventhal et al., 1980), labelling theory (Scheff, 1966) and attribution theory (Weiner, 1993) and incorporates the findings of this study. Finally, this chapter will document the limitations of this thesis and highlight areas and directions for future research.

7.2 Aim of the Thesis

The overarching aim of this thesis was to identify what people know and understand about cognitive impairment and what language and terms people employ when talking about this, including formal diagnostic labels that people may be familiar with. By including participants with a range of different experiences, this thesis also aimed to explore whether different groups of individuals have different understandings about cognitive impairment.

7.3 Main Findings

7.3.1 Definitions of Cognitive Impairment

Across the three studies, one of the core findings was the definitions of cognitive impairment proposed by participants. There were very few differences between population groups as to how cognitive impairment was defined, with participants highlighting similar symptoms. This suggests that, even where people were explicitly stating that they were unsure what cognitive impairment is, there is a core knowledge of cognitive impairment in society. Of particular note, the majority of participants highlighted memory problems as a fundamental symptom of cognitive impairment. This was the case for all participant groups, though in the interviews it was clear that, whilst all participants referenced memory difficulties in their discussions of cognitive impairment, several also stated that memory was not always implicated in cognitive impairment, and that a range of cognitive domains could be impacted. This supports the shift in criteria for cognitive impairment with the revised definition for MCI listing a

requirement for an impairment in any cognitive domain (Winblad et al., 2004). However, that participants still discussed memory most frequently suggests an implicit view that most people living with cognitive impairment will experience a memory deficit. This is further compounded by the fact that all participants living with cognitive impairment identified memory as one of their own symptoms and one which they found most noticeable and as impacting on their life.

This focus on memory is unsurprising given the higher prevalence of amnesic MCI (Pistacchi, Gioulis, Contin, Sanson, & Marsala, 2015) than non-amnesic variants and the associated focus in the literature on amnesic MCI. Looking at previous terms and labels which have been proposed to account for cognitive decline, the majority of these focus on a memory complaint (see section 1.1), so it is to be expected that the pervasive view of cognitive impairment would include memory problems. Similarly, given the current situation in the UK where assessment services for people with cognitive concerns are generally referred to as memory clinics and memory assessment services, the connecting feature always seems to be memory. If we are to move away from this focus on memory problems and deficits as a key indicator of cognitive impairment, then the language around these services has to change.

Whilst there was a particular set of symptoms that was agreed by most participants to be representative of cognitive impairment, there was also universal acknowledgement of cognitive impairment as a personal experience that will present differently for each individual. This provides further support to the notion of cognitive impairment as a syndrome, typified by Boyle (2002) as a particular pattern or clustering of signs and symptoms whereby most people with the syndrome will share at least one symptom. This also supports Kitwood's (1997) view that people living with dementia have a unique experience and extends this to consider the personal nature of living with cognitive impairment.

7.3.2 Social Isolation

Entangled with participants' explanations of cognitive impairment was the notion of social isolation and the importance of other people in the identification of cognitive impairment. Participants stated that other people noticing presenting symptoms was key to seeking help and assessment. This view supports the finding of a questionnaire study by Dale et al. (2008) who found that adults aged over 35 were most likely to seek help for a cognitive concern if a family member suggested that they do so rather than if they noticed the symptoms themselves.

Participants also reported that social isolation may be a risk factor for cognitive impairment and that those individuals who were less socially active and engaged would be at a higher risk of developing cognitive impairment, touting the use it or lose it philosophy. This view is also supported by empirical data from Wilson et al. (2007) suggesting that it is not just physical isolation, but loneliness or emotional isolation, which contributes to an increased risk of cognitive impairment. As such, it is important that older adults continue to be fully integrated into their communities, maintaining meaningful activities and relationships to prevent social and emotional isolation. In doing so, this may reduce the risk of cognitive impairment and dementia amongst the older adult population.

7.3.3 Conflation with Dementia

A key finding of this study is that participants conflated cognitive impairment with dementia, explaining their understanding of cognitive impairment in the context of dementia and expressing a difficulty in ascertaining differences between the two. A contributing factor to this amalgamation of cognitive impairment and dementia may be the language used when discussing dementia, whereby cognition is described as being impaired. Thus, for participants who may not have previously heard of cognitive impairment as a separate condition, it would be a logical step to conclude that dementia and cognitive impairment are terms for the same entity. Indeed, several participants identified cognitive impairment as an umbrella term which could include, amongst other ailments and conditions, dementia. However, even where participants explicitly acknowledged that cognitive impairment and dementia were essentially different conditions, even if this difference only existed in terms of the level of impairment, participants responded to questions about cognitive impairment by referencing dementia. This suggests that participants had a fundamental awareness of dementia, most likely the result of media presentation and personal experience. Most participants had a personal experience of a family member or friend who had been diagnosed with dementia, whereas very few knew anyone who had ever been diagnosed as cognitively impaired outside the context of dementia. There is also a high prevalence of media references to dementia, particularly emotive, negatively framed portrayals (Peel, 2014; Van Gorp & Vercruyse, 2012).

It has previously been suggested that MCI represents a transitional state between normal ageing and dementia (Brooks & Loewenstein, 2010; DeCarli, 2003; Petersen & Morris, 2005). Alongside the direct conflation of cognitive impairment and dementia, the results of the studies presented here suggest that some people do view cognitive impairment as a transitional

state, with many respondents identifying normal ageing as a risk factor for cognitive impairment and cognitive impairment as a risk factor for dementia. However, very few respondents in either the survey study or the interviews identified the statistical estimates around progression rates from cognitive impairment to dementia suggesting that participants were not familiar with the scientific evidence surrounding cognitive impairment as a possible “at risk state” for dementia.

7.3.4 Fear of Cognitive Impairment and Dementia

In their discussions of cognitive impairment, participants utilised a language of negativity and fear, using terms such as “nightmare”, “cruel”, “terrifying”. In this context, one interview participant who had been diagnosed with terminal lung cancer expressed her relief that she was going to die of this rather than live to experience a cognitive impairment or any other neurological condition. This sentiment was echoed by participants who stated they would rather experience an illness such as cancer than cognitive impairment. One possible reason for this may be the implied hope for effective treatment and cure for other illness and conditions, something which is lacking at present for cognitive impairment, and this lack of available treatments was something which participants were explicitly aware of. Amongst older adults, dementia is often the health condition feared the most (Corner & Bond, 2004; Schiff, Rajkumar, & Bulpitt, 2000). This fear was evidenced in the discussions of relief that people living with cognitive impairment felt about their diagnosis not being dementia, highlighting the level of perceived fear of dementia, which was considerably less for cognitive impairment. Perhaps this fear would be higher if people were aware of the increased risk of dementia for people living with cognitive impairment. As awareness raising initiatives continue, it is important to consider how education about conditions such as dementia and cognitive impairment may subsequently impact levels of fear (Draper, Peisah, Snowden, & Brodaty, 2010).

7.3.5 Stigma

Many interview participants explicitly stated a perception that there was a stigma around cognitive impairment, though several participants stated that this stigma was improving over time and there was a sense that things were better now than they had been in the past. It remains to be seen whether this perceived shift in stigmatised views of cognitive impairment is reflected in lived experiences.

In their talk about the symptoms of cognitive impairment, people discussed shame and embarrassment when these symptoms were noticed, and participants living with cognitive

impairment themselves stated that they were very aware of their own difficulties and of the reactions of others to their actions and behaviours. This supports the idea of self-stigma (Watson, Corrigan, Larson, & Sells, 2007) whereby an individual internalises the societal stereotypes surrounding a particular label. The stigmatising nature of cognitive impairment may lead people to try to hide their symptoms from others, sometimes resulting in the individual removing themselves from social activities to ensure that others will not notice their symptoms and judge them (Garand et al., 2009). The results of this thesis suggest that stigma is still prevalent in cognitive impairment and thus has implications for whether individuals are likely to engage in help-seeking behaviours for cognitive concerns.

7.3.6 Normality/Normal Ageing

Across the findings from the studies in this thesis, there is evidence to suggest that people perceived cognitive impairment as something which challenges normality. Many participants described cognitive impairment as something which was “abnormal”. However, participants also expressed a perception of cognitive impairment as an expected part of ageing. This view may stem from an underlying perception of old age as something which is intrinsically abnormal in itself.

Linked to this view of cognitive impairment as an artefact of normal ageing was the association of cognitive impairment and old age. Whilst several participants acknowledged that cognitive impairment could occur at any age, the language people used in their talk invoked images of older adults living with cognitive impairment; this was rarely discussed in the context of a younger adult. When talking about their experiences of cognitive impairment, it was evident from the age of the participant that when they referred to a particular relation that they were discussing an older adult. Two participants living with cognitive impairment had been diagnosed at a young age. These participants highlighted the difficulty they found in accessing appropriate services and support due to the focus on older adults prevalent in published information and support groups.

For some participants, ageing was viewed as a “cruel” process, suggesting a generally negative perception of ageing. This could be the result of the increased risk of a wide range of health conditions and illnesses, including cognitive impairment, in later life. The view of ageing as negative and the perception of normal ageing as resulting in a potentially abnormal cognitive

state suggests that older adults may be under-valued and stigmatised as being other to the general population, altered in some fundamental way.

The perception held by many participants of cognitive impairment and dementia as negative, unpleasant conditions which are to be feared places them on the cusp of the 'fourth age'. This is a stage of ageing representative of people whose later life is affected by ill health and incapacity (Higgs & Gilleard, 2015). The views about cognitive impairment held by participants position this as a form of unsuccessful ageing, limiting people's ability to live independently and to maintain social activities (Bowling & Dieppe, 2005).

7.3.7 Brain Disease

One of the key findings of this study was the identification of cognitive impairment as a disorder or disease of the brain. Nearly all participants claimed that cognitive impairment was fundamentally rooted in a change in or to the brain which subsequently resulted in the presenting symptoms. This is a particularly interesting result given the prevalent view of cognitive impairment as a normal aspect of ageing. This understanding of cognitive impairment as a disorder of the brain places it firmly as a physical health condition, an illness underpinned by a physiological basis. Despite this view of cognitive impairment as a disease or disorder of the brain, some participants stated that it might be possible for someone to control their own situation and to prevent an impairment from occurring.

7.3.8 Blame and Controllability

For the most part, participants stated that cognitive impairment was outside of an individual's personal sphere of control and that someone should not be viewed as responsible for their own cognitive impairment. Several participants reported that there was a blame culture surrounding illnesses as a whole, but that whilst this could include cognitive impairment, it was not as pronounced as in illnesses with more tangible associations with unhealthy lifestyle factors such as obesity and diabetes.

When asked whether cognitive impairment was preventable in the questionnaire study, the majority of participants were uncertain about this, and very few participants stated that it was possible to prevent cognitive impairment. The view that cognitive impairment was not preventable was particularly evident amongst people living with cognitive impairment suggesting that this group were distancing themselves from any notion of internal self-blame

for their circumstances, positing that it would not have been possible for them to prevent what they were now experiencing.

One factor that participants considered could play a role in cognitive impairment was a healthy lifestyle. There was a perception that diet and exercise could play a role in cognitive health and in the development of cognitive impairment. The message of “what’s good for the heart is good for the brain” was something which many participants were aware of. However, in the questionnaire study, diet was the least endorsed cause of cognitive impairment and when this was subsequently discussed in the interview study, most participants did not identify diet in their own discussions of the causes of cognitive impairment. It was only when I asked a question which specifically addressed whether diet may play a role in cognitive health that participants agreed this may indeed be a salient factor. This suggests that, whilst participants were aware of the potential role that diet may play in cognition, this was not something which was easily summoned to the forefront of their mind and therefore was probably not something many participants were considering on a day-to-day basis in their lives. This perception of a degree of controllability in cognitive impairment could be a self-protective strategy, with participants choosing to present cognitive impairment as something that could potentially be avoided or prevented and thus as something which they can prevent in themselves by adopting risk mediation and avoidance strategies.

7.3.9 Illness Causation

Throughout the studies included in this thesis, participants discussed the potential causes and risk factors for cognitive impairment. The causes suggested were the same across the three studies suggesting that there was a broadly unified perception of possible causes of cognitive impairment. The most cited cause was brain damage, which participants stated could result from a variety of factors including stroke, head injury via an accident, and genetic or biological aspects. However, despite this view of cognitive impairment as the result of a disorder or damage to the brain, many participants also viewed ageing as a likely cause of cognitive impairment. These seemingly conflicting views were often offered by the same participant, suggesting that there is an expectation that the brain will be damaged in some way as we age.

The causes most posited by participants were those outside of an individual’s personal control, providing further support to the notion of cognitive impairment as something which was not viewed in the blame culture of other illnesses. Many participants acknowledged

explicitly that people could try to live well and do everything “right” but could still experience a cognitive impairment as not all possible causes could be prevented and some people were “unfortunate” or had “hard luck” in getting cognitive impairment.

This adds new information to the growing body of literature investigating illness causation accounts, and positions cognitive impairment as separate to a variety of other conditions which are generally perceived as having more of a blame culture surrounding them such as diabetes (Lawton et al., 2007, 2008; Parry et al., 2006) and heart disease (Richards, Reid, & Watt, 2003). This perception of cognitive impairment as a condition for which an individual does not have personal responsibility is not surprising as there is little evidence to suggest that there are any strategies which have a significant impact on the risk of cognitive impairment.

7.3.10 “Them” versus “Us”

Throughout the discussions of cognitive impairment, interview participants employed a language of “them” for people living with cognitive impairment, extricating this group as separate and other from “us”. This distancing stance may be a protective mechanism employed to reduce the fear of cognitive impairment by positioning it as something which affects other people and which will not be experienced by oneself. People living with cognitive impairment were viewed as “weird” and were often perceived to be a danger to themselves, requiring supervision and intervention to live independently. In this vein, people may be choosing to distance themselves from these negative connotations by clearly stating membership of an alternative population group. However, in the language of everyday conversation, presenting different population groups in an “us” versus “them” manner is commonplace and it may simply be that participants are employing this common conversational mechanism in their descriptions of people living with cognitive impairment. Participants further employed a discourse of “them” and “us” by describing people living with cognitive impairment and dementia as “cognitively impaired” and “demented”, denying their personhood by referring to the individual solely in terms of the condition which they are experiencing. This is a mechanism which has been identified in research exploring stigma in mental illness (Rüsch, Angermeyer, & Corrigan, 2005). The results of this thesis suggest that there may be a view of people living with cognitive impairment as a distinct group of individuals who are no longer included in the “us” description; no longer the same functioning members of society and community that they once were.

7.3.11 Death and Dying

One of the key findings of the interview study was the frequent references to death and dying raised by participants in their talk despite there being no explicit questions relating to this. The references to death were often related to the perception of cognitive impairment as a condition of old age and therefore raised the idea that cognitive impairment was the “waiting room to death” entangled with the expectation that most people would experience a cognitive impairment in later life. Some participants even explicitly stated a view that cognitive impairment was a terminal illness.

For many participants, there was a view that it would be better to die than to live with cognitive impairment and people claimed a short life expectancy post-diagnosis would be “lucky”. This view may be an artefact of the emotional strain and burden felt by family members and carers of people living with cognitive impairment. Alternatively, this view may be a result of the perception of cognitive impairment and dementia as a “living death” with participants referring to the notion that whilst someone’s body might still be there, they, as a person, were gone. This suggests that cognition is intrinsically linked to personhood and identity and a view that once someone’s cognition is damaged, they are no longer the same person that they used to be. This adds to the notion of dementia as a condition whereby someone is perceived as less than a full person (Kitwood, 1997) or as Behuniak (2011) suggests of people living with Alzheimer’s disease “they are neither fully dead nor do they appear to be fully alive” (p.80).

7.3.12 Labelling and Diagnosis

Many participants viewed cognitive impairment as an umbrella term incorporating a wide range of illnesses and conditions which could affect someone’s cognition, including dementia. Participants also expressed views throughout the interviews that cognitive impairment was a technical term not used by a lay population. However, despite this, participants were able to suggest a definition of cognitive impairment which closely mapped to the proposed criteria for MCI (Winblad et al., 2004) suggesting that many participants had an idea of cognitive impairment as a condition with a specific set of symptoms and that people may be aware of the concept of MCI. However, when asked about the label of MCI specifically, several participants responded that they had not heard of this before and most participants showed a degree of uncertainty and hesitancy in offering a description of this. This suggests

that most participants were not fully aware of MCI but were aware of the symptoms which would commonly be ascribed this label.

The data presented here suggest that MCI may not be perceived as a beneficial or sufficient label; the “mild” had connotations of this being something which would not impact an individual’s life, but all participants living with cognitive impairment stated that this condition did have pronounced impacts on their life both in terms of symptoms and also their experiences of other people’s frustration towards them. This suggests that the diagnostic label of MCI may not be appropriate as it does not convey what the individual is experiencing therefore may result in a lack of understanding about what cognitive impairment is and the impact on an individual and their wider social network. There is a difficult balance to be struck in the labelling of cognitive impairment in order to explain the nature of what someone is experiencing without employing a term that conveys a message of fear about the condition. As such, the studies in this thesis also contribute to the debate surrounding whether MCI is an appropriate clinical diagnosis or should be viewed as a research construct (Garand et al., 2009). The findings presented here suggest that, under the current terminology, MCI is not a clinically appropriate label, as it is a term which many people are not familiar with and which some people living with cognitive impairment do not feel adequately describes their own situation. However, no participants were opposed to cognitive impairment being diagnosed, and as such, I do believe that people presenting with cognitive impairment should be given a diagnosis for their presenting symptoms, but the specific label applied to this needs to be further investigated to establish a more appropriate and accepted term.

7.4 Implications of Findings

7.4.1 Policy/Government

In recent years, dementia has increasingly become the focus of government policy with the release of the Prime Minister’s Challenge on Dementia (Department of Health, 2015) following the National Dementia Strategy (Department of Health, 2009). However, in the midst of the growing spotlight on dementia, cognitive impairment continues to be overlooked in policy. The findings of the studies presented here suggest that people are beginning to develop an understanding of this condition, but an increased awareness could be fostered and facilitated via its inclusion in future policy initiatives. Given the estimated prevalence of cognitive impairment, an increased awareness would enable people to recognise the symptoms of

cognitive impairment in themselves and others encouraging help-seeking behaviour and enabling timely assessment and diagnosis. This could in turn impact on the care pathway for people living with dementia, as, if people experiencing cognitive impairment are identified and monitored, this may reduce the number of people presenting with dementia at crisis stage, when healthcare interventions are resource and cost intensive.

Current policy initiatives target improving awareness of dementia such as the Dementia Friends initiative supported by the Alzheimer's Society which aims to raise awareness of dementia within the general public and aims to create four million Dementia Friends by 2020. However, this initiative, whilst valuable, may not be adequate to change societal and cultural perceptions as it is lacking information regarding cognitive impairment outside of dementia *per se*. In order to foster a widespread perceptual shift, there must be a better understanding regarding the factors that influence understandings of cognitive impairment. This thesis makes steps towards doing this, providing information about the current perceptions and understandings of cognitive impairment.

The results of this thesis also suggest that policy makers and healthcare professionals must focus on what we call cognitive impairment. Participants reported that the label "cognitive impairment" was too technical and too broad. "Mild cognitive impairment" was viewed to be inadequate due to the use of the word "mild" which implied a condition with a very low impact on an individual's life, something which was claimed to not be the case. This also calls into question the criteria for MCI which states that an individual should be able to function independently and that their activities of daily life should not be affected. However, for the participants living with cognitive impairment, it was clear that, even where their symptoms were not impacting their life *per se*, the coping strategies they employed required considerable effort on their part and that their daily life was impacted significantly.

The name ascribed to secondary specialist services designed to provide assessment, diagnosis and follow-up for people living with cognitive impairment and dementia also needs to be considered. At present, most of these services are called memory clinics or memory assessment services, suggesting that they help with memory complaints. However, given the nature of both cognitive impairment and dementia as conditions that can affect multiple areas of cognition, including, but not limited to, memory, this naming structure should be addressed. Framing these services in the context of memory may be confusing to people who are

experiencing cognitive problems outside of the realm of memory but who would still benefit from a thorough assessment of their cognitive abilities via a secondary specialist service.

7.4.2 Media

The results of this thesis unsurprisingly suggest that the media plays a significant role in the public's understanding of health and illness, including dementia and cognitive impairment. As such, it is important that media messages convey a realistic portrayal of cognitive impairment and dementia. Participants identified the current media representation of dementia and other neurological conditions to be one of negativity, presenting dementia in terms of suffering and death. If we are to change the cultural and societal perception of cognitive impairment and dementia, then it is essential the media portrayal offers a more balanced and realistic view of these conditions. It is important to strike a delicate balance, ensuring that positive stories of people living well with cognitive impairment are presented, but that the experiences of people who are living with cognitive impairment in difficult situations are not ignored. A realistic presentation should showcase both negative and positive experiences of people living with cognitive impairment, ensuring that people are informed about all angles of cognitive impairment and are able to develop views grounded in reality but which can offer a message of hope rather than the current bleak presentations of dementia and infrequent references to cognitive impairment.

From a personal perspective, I believe that moving away from the word "sufferer" would be a huge step along this path. At present, it appears that the default position of media reports around someone experiencing any health condition or illness, including dementia, positions them as someone who is suffering. This was reflected in the talk of participants who frequently referenced sufferers and suffering with regards to the experience of cognitive impairment. The use of the word "suffer" automatically positions cognitive impairment as a condition which is a negative experience and has connotations of someone who is in pain or distress. This is not the message which we want to present about cognitive impairment and does not present cognitive impairment as something which someone can live well with or which can be anything other than a fundamentally negative experience.

7.4.3 Public Health Campaigns

In considering public health campaigns which focus on potential risk factors for cognitive impairment, it is important to consider how this may impact the perception of the controllability

of cognitive impairment particularly with regards to stigma and blame. Presenting messages regarding lifestyle factors which may play a role in cognitive impairment could result in a view of cognitive impairment as a condition which is entirely within an individual's control. As such, risk factors for cognitive impairment should be framed within a wider discussion which considers both modifiable and non-modifiable risk factors, encouraging people to adopt a healthy lifestyle but acknowledging that not all occurrences of cognitive impairment could be prevented.

7.4.4 Cognitive Impairment Illness Representation Model

The results of this thesis inform and refine the MCI illness representation model proposed in Chapter 4. This model suggests the way in which people understand cognitive impairment is influenced by societal perceptions of what it means to experience this, together with media presentations and representations of cognitive impairment. These societal views and media representations are currently focused more around dementia than cognitive impairment and are predominantly negative, portraying this as a terrible condition which should be feared. These views relating to dementia are perceived to be relevant to cognitive impairment due to its situation as a potential precursor and risk factor for dementia. Participants' views and experiences of dementia played a key role in how they viewed cognitive impairment. As dementia is a concept people are more familiar with, this was often the reference point to accessing information and perceptions of cognitive impairment.

Within the representation of cognitive impairment itself, people ascribe a particular set of symptoms including memory difficulties, communication problems, repetitiveness, and a loss of previous skills and abilities. When asked about labels and terminology used to describe these symptoms, no universal answer was found. To date, it is not clear what the most adequate or acceptable label for cognitive impairment is, with participants electing to use a range of different terms and stating a view that both cognitive impairment and MCI were not appropriate labels.

The consequences of cognitive impairment were reported to be quite wide-ranging but predominantly included changed relationships, stigma and embarrassment, reduced activities and socialisation, and a reduction of freedom and independence. Cognitive impairment itself was not always viewed to be at the heart of these consequences, the role of societal and media perceptions was also integral to these perceived consequences. There was a suggestion that if a cultural shift of perspective around cognitive impairment could be achieved then these consequences could be entirely different.

Participants highlighted a number of core factors that they viewed as likely causes of cognitive impairment. The most cited cause was brain damage. Cognitive impairment was frequently referred to as a disease or disorder of the brain which could in turn be caused by a range of factors including a head injury or a stroke. Many participants stated that normal ageing could cause cognitive impairment and there was a general, but not universal, perspective that most older adults would experience cognitive impairment.

Linked to causation accounts offered by participants was the notion of whether cognitive impairment was something which an individual was able to control. The overwhelming majority of participants reported that it was not possible to control whether one would develop cognitive impairment or to control its subsequent impacts and effects. There was a view that there were no medical interventions which were able to help or treat cognitive impairment and that the best possible treatment available currently was social support; providing mental and physical activity and stimulation. Entangled with the view of cognitive impairment as outside of an individual's control was the perception of people living with cognitive impairment as blameless for their situation, suggesting that these individuals are generally viewed with sympathy and elicit understanding, sympathetic, helping behaviours from other people.

The timeline of cognitive impairment was viewed as chronic, permanent and generally progressive. The majority of participants stated that cognitive impairment was permanent, though there was a view that permanency depended on the underlying cause of cognitive impairment and that some causes may result in a more transient state of cognitive impairment, one which could potentially be resolved. For most participants, there was a view that cognitive impairment was associated with dementia, and that it was likely, but not guaranteed, that an individual living with cognitive impairment would develop dementia or at the very least that their cognition would decline over time.

The results of this thesis suggest that people do hold an illness representation for cognitive impairment, informed by experiences and media and societal views. The model of cognitive impairment illness representation shown in Figure 7.1 provides a framework under which we can explore how to change perceptions of cognitive impairment and structure information and health campaigns which can alter individual and societal views of what it means to have cognitive impairment. Utilising this model will enable future information campaigns to target each relevant component and also highlights areas where future research is warranted to clarify areas of confusion or gaps within the model.

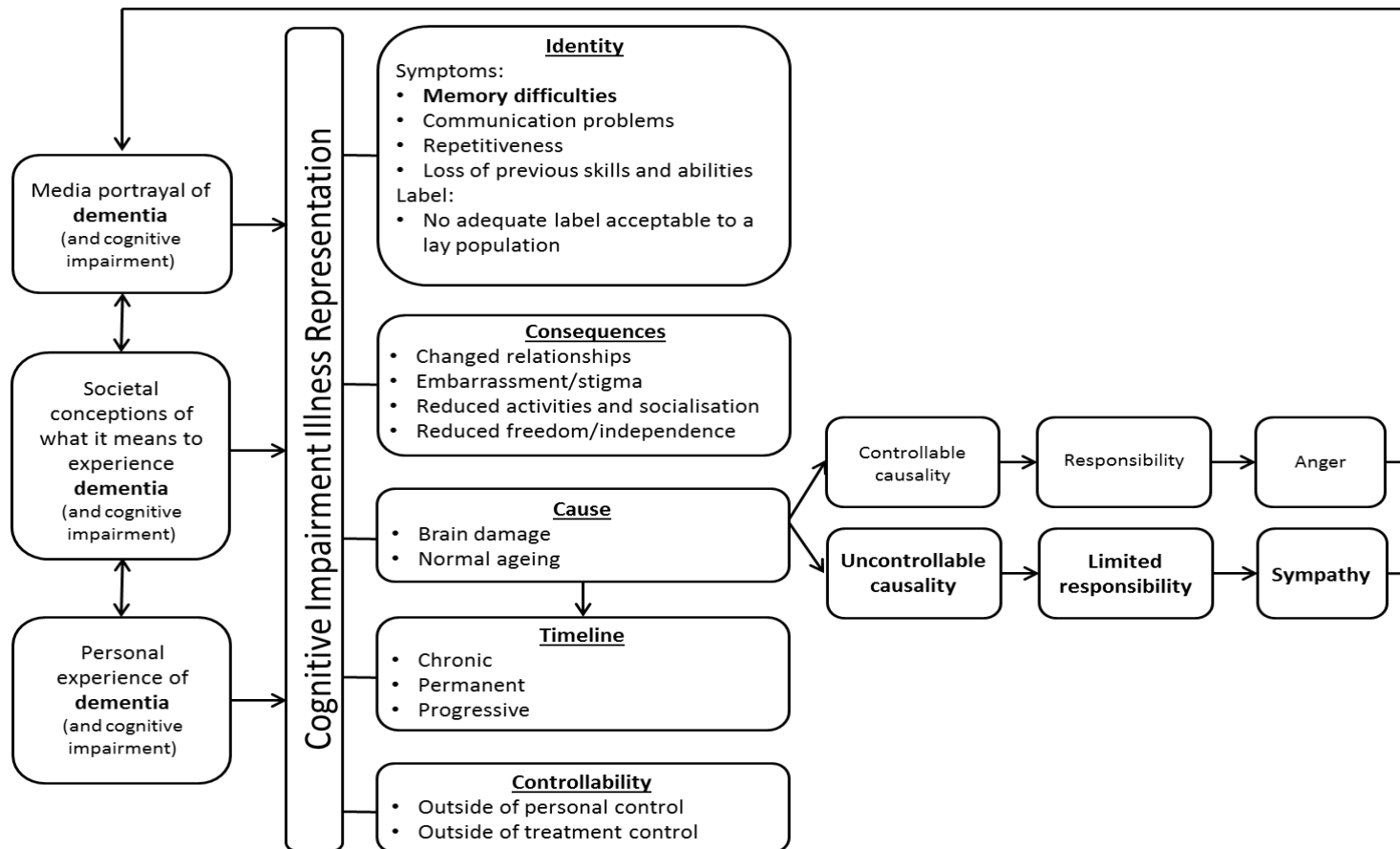


Figure 7.1: Diagrammatic representation of the cognitive impairment illness representation model. Societal conceptions and media portrayals of what it means to experience dementia directly influence the illness representation of cognitive impairment, together with personal experience(s) of dementia and, to a lesser extent, cognitive impairment. Smaller sized font represents a smaller contribution to the model, and bold font represents a larger contribution or focus.

7.5 Limitations

There were a number of key limitations of the research included in this thesis which it is important to acknowledge.

7.5.1 Design

This thesis employed a mixed methods design with three phases conducted sequentially, but with some overlap between the questionnaire study and interview study insofar as the questionnaire data analysis was still underway when the interviews commenced. This slightly blurred the boundaries between these two studies but still enabled the results of the questionnaire study to inform the design and conduct of the interview study. The overlap ensured that the data and results from the questionnaire were fresh in my mind as I was conducting the interviews, allowing this information to inform some of the questions that were asked. However, this is a two-edged sword as this overlap may have caused some bias to be introduced to the study as there was a danger that I could have focused too much on the questionnaire results in the interviews and not allowed participants views to speak for themselves in this study. As I was acutely aware of this risk, I ensured that the interview schedule was adhered to, but also allowed participants to guide the interview, asking probing questions to explore their views in more detail rather than allowing the questionnaire results to drive the interview structure more than the participants themselves.

The data collection for this study was detailed, but lacked some demographic information which could have added more depth to the analysis of the results. For example, for participants living with cognitive impairment, I did not ask explicitly when their diagnosis had been received or how long they had been living with their symptoms. This detail could have aided analysis of the results by enabling me to explore where views of people living with cognitive impairment may have varied depending on the length of time they had been living with their diagnosis.

A key limitation of the survey study (Chapter 5) is that it is not possible to identify from the questionnaire responses why a respondent chose to answer in the way they did, or whether they deliberated over any items or wanted more information about the questions in order to make a decision. It is also not clear whether respondents accessed information during questionnaire completion, or asked anyone else for help or advice in completing their responses.

As this study was cross sectional, it only captured the views of participants at one point in time. The research would have benefited from follow-up in a longitudinal study design to monitor whether perspectives and perceptions changed over time. This would have been particularly insightful if an interventional aspect was inserted providing education and awareness raising to see whether this may have affected perspectives.

This thesis aimed to explore participant's knowledge and understanding of cognitive impairment, in terms of the concept most often referred to as MCI. In order to identify language and terms participants utilised to talk about this condition, I elected to not explicitly use the term MCI in the study (with the exception of one or two specific questionnaire items and interview questions). However, this choice left the term cognitive impairment open to interpretation and it may be that some participants were thinking about and discussing something very distinct from MCI.

7.5.2 Sample

The sample for the questionnaire study asked participants to self-identify the participant group they belonged to. This self-selection may have resulted in groups which were not reflective of the populations I was aiming to access. For example, when asking participants if they had been diagnosed with memory and thinking difficulties, participants living with a range of illnesses and conditions could have responded meaning that the sample of people living with cognitive impairment may not have been representative of people living with "pure" cognitive impairment. Similarly, many participants selected multiple participant groups, making it difficult to assign these to any specific group as I did not feel that I, as the researcher, could select the most important or prominent grouping for these individuals. However, this self-selection also had a benefit in allowing participants to express their own view as to which participant group they felt they belonged to rather than being assigned to a group which they may not have identified with.

The sample included in this study is also not representative of the wider population due to respondents being predominantly female, white, and highly educated. The geographical spread of respondents in this study was also limited. Whilst the questionnaire study was open to a national (and even international) population, the majority of respondents were from the West Midlands. As such, the results of this study may not be generalizable to a wider population due to this geographical restriction. However, as there were a number of respondents from

other locations, the results were relatively widespread across England and captured the views of a range of participants. This study did not, however, capture the views of participants from other cultures and also did not consider factors which may be salient to participant's views such as socioeconomic status and religious beliefs. Therefore, it is not possible to generalise the results of this research to an international population, or indeed even to a culturally diverse national population.

7.5.3 Sample Size

The sample recruited to each participant group in the questionnaire and interview studies within this thesis were not balanced, with a differing number of participants in each group. Ideally, equal numbers within each group would have facilitated more balanced and powerful analyses, but this is representative of the difficulties inherent in accessing and identifying people living with cognitive impairment. When conducting research involving people living with dementia, there are a wide variety of support groups and charities where information can be distributed to reach a wide audience, alongside NHS recruitment avenues. However, for cognitive impairment this is not the case. Despite my best efforts, I could not identify any support groups for people living with cognitive impairment in the West Midlands, and the NHS services involved in study recruitment stated in advance of the study commencing that they were not seeing large numbers of people diagnosed with cognitive impairment. This was in part due to the changing nature of the care pathway with several services identifying that they were not using the label of MCI and were instead either choosing to not issue a diagnosis, instead keeping people in monitoring situations within the service, or diagnosing what would once have been labelled as MCI as early dementia.

7.5.4 Researcher Influence

I have my own personal experience of cognitive impairment and dementia as my grandfather was diagnosed with frontotemporal dementia at a late stage and died shortly after his diagnosis. I believe that this experience, which occurred during the questionnaire study, provided me with an insight into a family members experience when a loved one is diagnosed with a cognitive impairment, enabling me to be sympathetic and to relate to participants with similar experiences.

I conducted all of the interviews, and I was also responsible for the study design and therefore aware of the aims of the research, the questionnaire responses provided by

participants, and the participant group to which they identified. As such, I was careful to take efforts to ensure that I considered my own perspectives at every stage of the interview process, considering how my views may be impacting on the research. However, I found that rather than my views influencing the research, the research and views of the participants impacted my own perspectives. At the start of this research, I felt confident in my perspective of cognitive impairment as an illness, something which was distinct from normal ageing and was certainly not an inevitability. I also viewed cognitive impairment as a condition which would not impact an individual's life dramatically and something that could be managed relatively easily. Now, my views have significantly altered. I am no longer confident in framing cognitive impairment as an entity entirely removed from ageing and have begun to consider the role of ageing in cognitive impairment. This research has also caused me to think more about ageing and what it means to age well and to age normally as compared to atypical or abnormal occurrences in older age. Being aware of my own perspectives throughout the research process and considering how my views and the views of participants converged or differed enabled me to maintain my position as the researcher, sharing some of my views with participants but always focusing on their views and accounts.

7.6 Future Directions for Research

The results of the studies in this thesis suggest a number of questions which remain unanswered and identify issues and areas which future research should seek to address:

1. Labels and terminology

The results presented here suggest the language and terminology used to describe cognitive impairment are not acceptable to the general population. Future research should seek to explore what label could be applied to this state of cognitive impairment which would convey what it is in a manner which is succinct and acceptable to the wider population. This confusion regarding language use also extends to the description of specialist cognitive assessment services as memory clinics or memory assessment services, which may be contributing to the view of cognitive impairment as something which predominantly affects memory. As such, research is warranted to explore what these services should be named and to consider the impacts of renaming these services on public perceptions of cognitive impairment.

2. Raising awareness

One of the main policy statements around dementia is to raise public awareness of this condition. If we are to extend this to cognitive impairment, we should explore what information people feel they need about this condition and how they would prefer to receive such information. This thesis has gone some way towards informing the construction of awareness campaigns, offering a model upon which such campaigns can be based, but further research is needed. To explore whether public health and policy initiatives aimed at raising awareness of cognitive impairment are successful, pre and post educational research would be beneficial, monitoring perception changes following educational intervention.

3. Cross-cultural studies

This research presents a cross-sectional view of a small population, geographically limited to the UK, and predominantly to the West Midlands. In order to understand whether views of cognitive impairment are influenced by cultural perspectives, cross-cultural research would be valuable. Exploring the perceptions of cognitive impairment across cultures and diverse geographical regions would provide further information about the nature of understandings of cognitive impairment and the factors which influence individual perspectives.

4. Further analysis

Both the questionnaire dataset and the interview transcripts offer an opportunity for further analyses to be conducted, possibly scrutinising and interrogating the data in the context of similar datasets, including the possibility of a follow-up questionnaire to see if perceptions change over time. The data presented from the interviews represents a snapshot of the data which answers the research questions in this thesis. Subsequent analysis may open new avenues of interest which warrant further interrogation.

5. Perspective of people living with cognitive impairment

Whilst this research aimed to include the views of people living with cognitive impairment, only a very small sample of participants took part. Future research should seek to incorporate larger numbers of people living with cognitive impairment to obtain a representative view from this population.

Future research will enable further developments in this area, though this thesis has begun to address a key gap in the literature to date.

7.7 Conclusion

This thesis presents a mixed methods study exploring people's knowledge and understanding of cognitive impairment. The studies presented here have directly addressed a key gap in the literature around public knowledge and understanding of cognitive impairment. It offers timely and relevant information regarding the lay perception of cognitive impairment which could have significant impacts on policy and practice around dementia and cognitive impairment which could, in turn, provide substantial benefits for people living with cognitive impairment including improved quality of life and more timely assessments and diagnoses.

The language used to label and discuss cognitive impairment is viewed as too technical for a lay population. The label of MCI was something which many participants were not familiar with and those who were stated that it was not an adequate or appropriate label. I believe that we must consider what term is applied to this syndrome if we are to raise awareness of this and reduce stigma.

There is a pervasive association in the views of the population between cognitive impairment, normal ageing and dementia. Cognitive impairment is often conflated with dementia showing participants heightened understanding of dementia in comparison to cognitive impairment. The notion of cognitive impairment as an artefact of normal ageing also suggests an expectation that all older adults will experience cognitive impairment and frames old age as something which in itself confers a state of cognitive abnormality.

The public understanding of cognitive impairment reflects the complex and multi-faceted nature of this condition and highlights how much we still do not know about this syndrome. However, despite these continuing gaps in the literature on cognitive impairment, most people were able to assert what they thought cognitive impairment was and these views were broadly similar. This suggests that the public do have a core knowledge and understanding of cognitive impairment though this knowledge is predominantly the result of personal experiences rather than information obtained from independent sources.

The model of cognitive impairment illness representation provides a framework around which information and awareness campaigns can be based to address key components of individuals understanding of cognitive impairment. It is clear from the results of this thesis that, if we are to improve the experiences of people living with cognitive impairment and reduce the

associated stigma, information campaigns and media presentations must focus on a realistic and balanced view of what it means to live with cognitive impairment.

8. References

- Albert, M. S., DeKosky, S. T., Dickson, D., Dubois, B., Feldman, H. H., Fox, N. C., ... Phelps, C. H. (2011). The diagnosis of mild cognitive impairment due to Alzheimer's disease: Recommendations from the National Institute on Aging and Alzheimer's Association workgroup. *Alzheimer's & Dementia*, 7(3), 270–279. <http://doi.org/10.1016/j.jalz.2011.03.008>
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Arlington, VA.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA.
- Anderson, L. A., Day, K. L., Beard, R. L., Reed, P. S., & Wu, B. (2009). The public's perceptions about cognitive health and Alzheimer's disease among the U.S. population: A national review. *The Gerontologist*, 49(S1), S3–S11. <http://doi.org/10.1093/geront/gnp088>
- Aretouli, E., Tsilidis, K. K., & Brandt, J. (2013). Four-year outcome of mild cognitive impairment: The contribution of executive dysfunction. *Neuropsychology*, 27(1), 95–106. <http://doi.org/10.1037/a0030481>
- Artero, S., Ancelin, M.-L., Portet, F., Dupuy, A., Berr, C., Dartigues, J.-F., ... Ritchie, K. (2008). Risk profiles for mild cognitive impairment and progression to dementia are gender specific. *Journal of Neurology Neurosurgery & Psychiatry*, 79(9), 979–984. <http://doi.org/10.1136/jnnp.2007.136903>
- Banningh, L. J.-W., Vernooij-Dassen, M., Rikkert, M. O., & Teunisse, J.-P. (2008). Mild cognitive impairment: coping with an uncertain label. *International Journal of Geriatric Psychiatry*, 23, 148–154. <http://doi.org/10.1002/gps.1855>
- Beard, R. L., & Neary, T. M. (2013). Making sense of nonsense: experiences of mild cognitive impairment. *Sociology of Health & Illness*, 35(1), 130–146. <http://doi.org/10.1111/j.1467-9566.2012.01481.x>
- Behuniak, S. M. (2011). The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing and Society*, 31, 70–92. <http://doi.org/10.1017/S0144686X10000693>
- Berg, A. I., Wallin, A., Nordlund, A., & Johansson, B. (2013). Living with stable MCI: Experiences among 17 individuals evaluated at a memory clinic. *Ageing & Mental Health*, 17(3), 293–299. <http://doi.org/10.1080/13607863.2012.751582>
- Betts Adams, K. (2006). The transition to caregiving: The experience of family members embarking on the dementia caregiving career. *Journal of Gerontological Social Work*, 47(3–4), 3–29. <http://doi.org/10.1300/J083v47n03>
- Bischkopf, J., Busse, A., & Angermeyer, M. C. (2002). Mild cognitive impairment - a review of prevalence, incidence and outcome according to current approaches. *Acta Psychiatrica Scandinavica*, 106, 403–414. <http://doi.org/doi:10.1034/j.1600-0447.2002.01417.x>
- Blackford, R. C., & La Rue, A. (1989). Criteria for diagnosing age-associated memory impairment: Proposed improvements from the field. *Developmental Neuropsychology*, 5(4), 295–306. <http://doi.org/10.1080/87565648909540440>
- Blazer, D. (2013). Neurocognitive disorders in DSM-5. *The American Journal of Psychiatry*, 170(6), 585–587. <http://doi.org/10.1176/appi.ajp.2013.13020179>
- Blieszner, R., & Roberto, K. A. (2009). Care partner responses to the onset of mild cognitive

- impairment. *The Gerontologist*, 50(1), 11–22. <http://doi.org/10.1093/geront/gnp068>
- Blieszner, R., Roberto, K. A., Wilcox, K. L., Barham, E. J., & Winston, B. L. (2007). Dimensions of ambiguous loss in couples coping with mild cognitive impairment. *Family Relations*, 56, 196–209.
- Bondi, M. W., Jak, A. J., Delano-Wood, L., Jacobson, M. W., Delis, D. C., & Salmon, D. P. (2008). Neuropsychological contributions to the early identification of Alzheimer's disease. *Neuropsychology Review*, 18, 73–90. <http://doi.org/10.1007/s11065-008-9054-1>
- Bowling, A., & Dieppe, P. (2005). What is successful ageing and who should define it? *BMJ*, 331, 1548–1551. <http://doi.org/10.1136/bmj.331.7531.1548>
- Bown, M. J., & Sutton, A. J. (2010). Quality control in systematic reviews and meta-analyses. *European Journal of Vascular and Endovascular Surgery*, 40, 669–677. <http://doi.org/10.1016/j.ejvs.2010.07.011>
- Boyle, M. (2002). *Schizophrenia: A scientific delusion* (2nd ed.). London: Routledge.
- Brambati, S. M., Belleville, S., Kergoat, M.-J., Chayer, C., Gauthier, S., & Joubert, S. (2009). Single- and multiple-domain amnesic mild cognitive impairment: two sides of the same coin? *Dementia and Geriatric Cognitive Disorders*, 28, 541–549. <http://doi.org/10.1159/000255240>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. <http://doi.org/10.1191/1478088706qp063oa>
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: SAGE Publications Ltd.
- Brewer, N. T., Chapman, G. B., Gibbons, F. X., Gerrard, M., McCaul, K. D., & Weinstein, N. D. (2007). Meta-analysis of the relationship between risk perception and health behavior: The example of vaccination. *Health Psychology*, 26(2), 136–145. <http://doi.org/10.1037/0278-6133.26.2.136>
- Brooker, D., La Fontaine, J., Evans, S., Bray, J., & Saad, K. (2014). Public health guidance to facilitate timely diagnosis of dementia: Alzheimer's COoperative Valuation in Europe recommendations. *International Journal of Geriatric Psychiatry*, 29, 682–693. <http://doi.org/10.1002/gps.4066>
- Brooks, L. G., & Loewenstein, D. A. (2010). Assessing the progression of mild cognitive impairment to Alzheimer's disease: Current trends and future directions. *Alzheimer's Research & Therapy*, 2(5), 28–36. <http://doi.org/10.1186/alzrt52>
- Broome, M. R., Woolley, J. B., Johns, L. C., Valmaggia, L. R., Tabraham, P., Gafoor, R., ... McGuire, P. K. (2005). Outreach and support in south London (OASIS): Implementation of a clinical service for prodromal psychosis and the at risk mental state. *European Psychiatry*, 20, 372–378. <http://doi.org/10.1016/j.eurpsy.2005.03.001>
- Bruscoli, M., & Lovestone, S. (2004). Is MCI really just early dementia? A systematic review of conversion studies. *International Psychogeriatrics*, 16(2), 129–140. <http://doi.org/10.1017/S1041610204000092>
- Budson, A. E., & Solomon, P. R. (2012). New diagnostic criteria for Alzheimer's disease and mild cognitive impairment for the practical neurologist. *Practical Neurology*, 12, 88–96. <http://doi.org/10.1136/practneurol-2011-000145>
- Burgener, S. C., & Berger, B. (2008). Measuring perceived stigma in persons with progressive neurological disease: Alzheimer's dementia and Parkinson's disease. *Dementia*, 7(1), 31–

53. <http://doi.org/10.1177/1471301207085366>
- Cameron, L. D. (2003). *Conceptualizing and assessing risk perceptions: A self-regulatory perspective*. Washington DC.
- Carduff, E., Murray, S. A., & Kendall, M. (2015). Methodological developments in qualitative longitudinal research: the advantages and challenges of regular telephone contact with participants in a qualitative longitudinal interview study. *BMC Research Notes*, 8(142). <http://doi.org/10.1186/s13104-015-1107-y>
- Carpenter, B. D., Xiong, C., Porensky, E. K., Lee, M. M., Brown, P. J., Coats, M., ... Morris, J. C. (2008). Reaction to a dementia diagnosis in individuals with Alzheimer's disease and mild cognitive impairment. *Journal of the American Geriatrics Society*, 56, 405–412. <http://doi.org/10.1111/j.1532-5415.2007.01600.x>
- Carpenter, W. T. (2009). Anticipating DSM-V: Should psychosis risk become a diagnostic class? *Schizophrenia Bulletin*, 35(5), 841–843. <http://doi.org/10.1093/schbul/sbp071>
- Cheston, R., Bender, M., & Byatt, S. (2000). Involving people who have dementia in the evaluation of services: A review. *Journal of Mental Health*, 9(5), 471–479. <http://doi.org/10.1080/09638230020005200>
- Christensen, H., Leach, L. S., & Mackinnon, A. (2010). Cognition in pregnancy and motherhood: Prospective cohort study. *British Journal of Psychiatry*, 196, 126–132. <http://doi.org/10.1192/bjp.bp.109.068635>
- Christensen, K., Doblhammer, G., Rau, R., & Vaupel, J. W. (2009). Ageing populations: the challenges ahead. *Lancet*, 374, 1196–1208. [http://doi.org/10.1016/S0140-6736\(09\)61460-4](http://doi.org/10.1016/S0140-6736(09)61460-4)
- Clark, L. R., Delano-Wood, L., Libon, D. J., McDonald, C. R., Nation, D. A., Bangen, K. J., ... Bondi, M. W. (2013). Are empirically-derived subtypes of mild cognitive impairment consistent with conventional subtypes? *Journal of the International Neuropsychological Society*, 19, 635–645. <http://doi.org/10.1017/S1355617713000313>
- Collie, A., & Maruff, P. (2002). An analysis of systems of classifying mild cognitive impairment in older people. *Australian and New Zealand Journal of Psychiatry*, 36, 133–140. <http://doi.org/10.1046/j.1440-1614.2002.00972.x>
- Comas-Herrera, A., Wittenberg, R., Pickard, L., & Knapp, M. (2007). Cognitive impairment in older people: future demand for long-term care services and the associated costs. *International Journal of Geriatric Psychiatry*, 22, 1037–1045. <http://doi.org/10.1002/gps.1830>
- Corbin, J. M., & Strauss, A. (2008). *Basics of qualitative research* (3rd ed.). London: SAGE Publications Ltd.
- Corner, L., & Bond, J. (2004). Being at risk of dementia: Fears and anxieties of older adults. *Journal of Aging Studies*, 18, 143–155. <http://doi.org/10.1016/j.jaging.2004.01.007>
- Corner, L., & Bond, J. (2006). The impact of the label of mild cognitive impairment on the individual's sense of self. *Philosophy, Psychiatry, & Psychology*, 13(1), 3–12. <http://doi.org/10.1353/ppp.2006.0036>
- Creswell, J. W., & Plano Clark, V. L. (2004). *Designing and conducting mixed methods research* (2nd ed.). London: SAGE Publications Ltd.
- Critical Appraisal Skills Programme. (2013). *10 questions to help you make sense of qualitative research*. Retrieved from

- http://media.wix.com/ugd/dded87_951541699e9edc71ce66c9bac4734c69.pdf
- Crook, T., Bartus, R. T., Ferris, S. H., Whitehouse, P., Cohen, G. D., & Gershon, S. (1986). Age-associated memory impairment: Proposed diagnostic criteria and measures of clinical change - report of a national institute of mental health work group. *Developmental Neuropsychology*, 2(4), 261–276. <http://doi.org/10.1080/87565648609540348>
- Cullen, B., O’Neill, B., Evans, J. J., Coen, R. F., & Lawlor, B. A. (2007). A review of screening tests for cognitive impairment. *Journal of Neurology Neurosurgery & Psychiatry*, 78, 790–799. <http://doi.org/10.1136/jnnp.2006.095414>
- Dai, B., Mao, Z., Mei, J., Levkoff, S., Wang, H., Pacheco, M., & Wu, B. (2013). Caregivers in China: Knowledge of mild cognitive impairment. *PLoS ONE*, 8(1), e53928. <http://doi.org/10.1371/journal.pone.0053928>
- Dale, W., Hemmerich, J., Hill, E. K., Hougham, G. W., & Sachs, G. A. (2008). What correlates with the intention to be tested for mild cognitive impairment (MCI) in healthy older adults? *Alzheimer Disease and Associated Disorders*, 22(2), 144–152. <http://doi.org/10.1097/WAD.0b013e318161103c>
- Dale, W., Hougham, G. W., Hill, E. K., & Sachs, G. A. (2006). High interest in screening and treatment for mild cognitive impairment in older adults: A pilot study. *Journal of the American Geriatrics Society*, 54, 1388–1394. <http://doi.org/10.1111/j.1532-5415.2006.00852.x>
- Dean, K., & Wilcock, G. (2012). Living with mild cognitive impairment: The patient’s and carer’s experience. *International Psychogeriatrics*, 24(6), 871–881. <http://doi.org/10.1017/S104161021100264X>
- DeCarli, C. (2003). Mild cognitive impairment: prevalence, prognosis, aetiology, and treatment. *Lancet Neurology*, 2, 15–21. [http://doi.org/10.1016/S1474-4422\(03\)00262-X](http://doi.org/10.1016/S1474-4422(03)00262-X)
- Department of Health. (2009). *Living well with dementia: A National Dementia Strategy*.
- Department of Health. (2012). *Prime Minister’s challenge on dementia*.
- Department of Health. (2015). *Prime Minister’s challenge on dementia 2020*.
- Diefenbach, M. A., & Leventhal, H. (1996). The common-sense model of illness representation: Theoretical and practical considerations. *Journal of Social Distress and the Homeless*, 5(1), 11–38. <http://doi.org/10.1007/BF02090456>
- Dillman, D. A. (2000). *Mail and Internet Surveys: The tailored design method* (2nd ed.) Chichester: John Wiley & Sons.
- Dixon-Woods, M., Bonas, S., Booth, A., Jones, D. R., Miller, T., Sutton, A. J., ... Young, B. (2006). How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative Research*, 6(1), 27–44. <http://doi.org/10.1177/1468794106058867>
- Donoghue, P. J., & Siegel, M. E. (2000). *Sick and tired of feeling sick and tired: Living with invisible chronic illness*. London: W. W. Norton & Company Ltd.
- Draper, B., Peisah, C., Snowden, J., & Brodaty, H. (2010). Early dementia diagnosis and the risk of suicide and euthanasia. *Alzheimer’s and Dementia*, 6, 75–82. <http://doi.org/10.1016/j.jalz.2009.04.1229>
- Dubois, B., Feldman, H. H., Jacova, C., DeKosky, S. T., Barberger-Gateau, P., Cummings, J., ... Scheltens, P. (2007). Research criteria for the diagnosis of Alzheimer’s disease: revising the NINCDS-ADRDA criteria. *Lancet Neurology*, 6, 734–746. [http://doi.org/10.1016/S1474-4422\(07\)70178-3](http://doi.org/10.1016/S1474-4422(07)70178-3)

- Eckert, M. A., Keren, N. I., Roberts, D. R., Calhoun, V. D., & Harris, K. C. (2010). Age-related changes in processing speed: unique contributions of cerebellar and prefrontal cortex. *Frontiers in Human Neuroscience, 4*(10), 1–14. <http://doi.org/10.3389/neuro.09.010.2010>
- Elvish, R., Lever, S.-J., Johnstone, J., Cawley, R., & Keady, J. (2012). *Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence*. Lutterworth. <http://doi.org/10.1080/14733145.2012.739632>
- Erol, R., Brooker, D., & Peel, E. (2015). *Women and Dementia A global research review*. London.
- Farias, S. T., Mungas, D., Reed, B. R., Harvey, D., & DeCarli, C. (2009). Progression of mild cognitive impairment to dementia in clinic- vs community-based cohorts. *Archives of Neurology, 66*(9), 1151–1157. <http://doi.org/10.1001/archneurol.2009.106>
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). Mini-Mental State: a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*, 189–198.
- Forlenza, O. V., Diniz, B. S., Talib, L. L., Radanovic, M., Yassuda, M. S., Ojopi, E. B., & Gattaz, W. F. (2010). Clinical and biological predictors of Alzheimer's disease in patients with amnesic mild cognitive impairment. *Revista Brasileira de Psiquiatria, 32*(3), 216–222. <http://doi.org/10.1590/S1516-44462010005000002>
- Frank, A. R., & Petersen, R. C. (2008). Mild cognitive impairment. In C. Duyckaerts & I. Litvan (Eds.), *Handbook of Clinical Neurology: Dementias* (Vol. 89, pp. 217–221). Amsterdam: Elsevier.
- Frank, L., Lloyd, A., Flynn, J. A., Kleinman, L., Matza, L. S., Margolis, M. K., ... Bullock, R. (2006). Impact of cognitive impairment on mild dementia patients and mild cognitive impairment patients and their informants. *International Psychogeriatrics, 18*(1), 151–162. <http://doi.org/10.1017/S1041610205002450>
- Garand, L., Lingler, J. H., Conner, K. O., & Dew, M. A. (2009). Diagnostic labels, stigma, and participation in research related to dementia and mild cognitive impairment. *Research in Gerontological Nursing, 2*(2), 112–121. <http://doi.org/10.3928/19404921-20090401-04>
- Geda, Y. E., Roberts, R. O., Knopman, D. S., Christianson, T. J. H., Pankratz, V. S., Ivnik, R. J., ... Rocca, W. A. (2010). Physical exercise, aging, and mild cognitive impairment: a population-based study. *Archives of Neurology, 67*(1), 80–86. <http://doi.org/10.1001/archneurol.2009.297.Physical>
- George, D. R. (2010). Overcoming the social death of dementia through language. *Lancet, 376*, 586–587. [http://doi.org/10.1016/S0140-6736\(10\)61286-X](http://doi.org/10.1016/S0140-6736(10)61286-X)
- Gilleard, C., & Higgs, P. (2011). Ageing abjection and embodiment in the fourth age. *Journal of Aging Studies, 25*, 135–142. <http://doi.org/10.1016/j.jaging.2010.08.018>
- Gorelick, P. B., Scuteri, A., Black, S. E., DeCarli, C., Greenberg, S. M., Iadecola, C., ... Seshadri, S. (2011). Vascular contributions to cognitive impairment and dementia: A statement for healthcare professionals from the American heart association/American stroke association. *Stroke, 42*, 2672–2713. <http://doi.org/10.1161/STR.0b013e3182299496>
- Greco, V., & Roger, D. (2003). Uncertainty, stress, and health. *Personality and Individual Differences, 34*(6), 1057–1068. [http://doi.org/10.1016/S0191-8869\(02\)00091-0](http://doi.org/10.1016/S0191-8869(02)00091-0)
- Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a conceptual framework for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis, 11*(3),

- 255–274. <http://doi.org/10.3102/01623737011003255>
- Higgs, P., & Gilleard, C. (2015). *Rethinking old age: Theorising the fourth age*. London: Palgrave.
- Higher Education Statistics Agency. (2015). Data and Analysis. Retrieved from <http://www.hesa.ac.uk/data-and-analysis/staff/overviews?breakdown%5B%5D=583&year=2>
- Hodson, R., & Keady, J. (2008). Mild cognitive impairment: A review and nursing implications. *British Journal of Nursing*, 17(6), 368–373.
- Hurt, C. S. (2006). *Representations of Illness in People with Mild Cognitive Impairment*. University of Manchester, Manchester, UK.
- Irish Department of Health Social Services and Public Safety. (2011). *Improving Dementia Services in Northern Ireland: A Regional Strategy*.
- Jemmott, J. B., Ditto, P. H., & Croyle, R. T. (1986). Judging health status: Effects of perceived prevalence and personal relevance. *Journal of Personality and Social Psychology*, 50(5), 899–905. <http://doi.org/10.1037/0022-3514.50.5.899>
- Johnson, R. B., & Onwuegbuzie, A. J. (2015). Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, 33(7), 14–26.
- Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research*, 1(2), 112–133. <http://doi.org/10.1177/1558689806298224>
- Jones, R. W., Mackell, J., Berthet, K., & Knox, S. (2010). Assessing attitudes and behaviours surrounding Alzheimer's disease in Europe: Key findings of the important perspectives on Alzheimer's care and treatment (IMPACT) survey. *The Journal of Nutrition, Health & Aging*, 14(7), 525–530. <http://doi.org/10.1007/s12603-010-0263-y>
- Kaduszkiewicz, H., Zimmermann, T., van den Bussche, H., Bachmann, C., Wiese, B., Bickel, H., ... Pentzek, M. (2010). Do general practitioners recognize mild cognitive impairment in their patients? *The Journal of Nutrition, Health & Aging*, 14(8), 697–702. <http://doi.org/10.1007/s12603-010-0038-5>
- Katz, S., & Peters, K. R. (2015a). Interview with Dr Carol Brayne, 5 April 2013. *Dementia*, 14(3), 351–360. <http://doi.org/10.1177/1471301214562137>
- Katz, S., & Peters, K. R. (2015b). Interview with Dr Constantine Lyketsos, 14 May 2013. *Dementia*, 14(3), 318–327. <http://doi.org/10.1177/1471301214562138>
- Katz, S., & Peters, K. R. (2015c). Interview with Dr John Morris, 28 February 2013. *Dementia*, 14(3), 335–342. <http://doi.org/10.1177/1471301214562142>
- Katz, S., & Peters, K. R. (2015d). Interview with Dr Ronald Petersen, 7 February 2013. *Dementia*, 14(3), 298–306. <http://doi.org/10.1177/1471301214562142>
- Kitwood, T. (1997). The experience of dementia. *Aging & Mental Health*, 1(1), 13–22. <http://doi.org/10.1080/13607869757344>
- Kotrlik, J. W., Williams, H. A., & Jabor, M. K. (2011). Reporting and interpreting effect size in quantitative agricultural education research. *Journal of Agricultural Education*, 52(1), 132–142. <http://doi.org/10.5032/jae.2011.01132>
- Kral, V. A. (1962). Senescent forgetfulness: benign and malignant. *The Canadian Medical Association Journal*, 86(6), 257–260.
- Krinsky-McHale, S. J., & Silverman, W. (2013). Dementia and mild cognitive impairment in

- adults with intellectual disability: Issues of diagnosis. *Developmental Disabilities Research Reviews*, 18, 31–42. <http://doi.org/10.1002/ddrr.1126>
- Kundrat, A. L., & Nussbaum, J. F. (2003). The impact of invisible illness on identity and contextual age across the life span. *Health Communication*, 15(3), 331–347. http://doi.org/10.1207/S15327027HC1503_5
- Kuo, L.-M., & Shyu, Y.-I. L. (2010). Process of ambivalent normalisation: experience of family caregivers of elders with mild cognitive impairment in Taiwan. *Journal of Clinical Nursing*, 19, 3477–3484. <http://doi.org/10.1111/j.1365-2702.2010.03240.x>
- La Fontaine, J., & Oyeboode, J. R. (2014). Family relationships and dementia: a synthesis of qualitative research including the person with dementia. *Ageing and Society*, 34, 1243–1272. <http://doi.org/10.1017/S0144686X13000056>
- Laidlaw, K., Wang, D., Coelho, C., & Power, M. (2010). Attitudes to ageing and expectations for filial piety across Chinese and British cultures: A pilot exploratory evaluation. *Aging & Mental Health*, 14(3), 283–292. <http://doi.org/10.1080/13607860903483060>
- Lau, R. R., & Hartman, K. A. (1983). Common sense representations of common illnesses. *Health Psychology*, 2(2), 167–185.
- Lawrence, V., Fossey, J., Ballard, C., Moniz-Cook, E., & Murray, J. (2012). Improving quality of life for people with dementia in care homes: making psychosocial interventions work. *The British Journal of Psychiatry*, 201, 344–351. <http://doi.org/10.1192/bjp.bp.111.101402>
- Lawton, J., Ahmad, N., Peel, E., & Hallowell, N. (2007). Contextualising accounts of illness: notions of responsibility and blame in white and South Asian respondents' accounts of diabetes causation. *Sociology of Health and Illness*, 29(6), 891–906. <http://doi.org/10.1111/j.1467-9566.2007.01036.x>
- Lawton, J., Peel, E., Parry, O., & Douglas, M. (2008). Shifting accountability: A longitudinal qualitative study of diabetes causation accounts. *Social Science and Medicine*, 67, 47–56. <http://doi.org/10.1016/j.socscimed.2008.03.028>
- Leventhal, E. A., Leventhal, H., Schaefer, P., & Easterling, D. (1993). Conservation of energy, uncertainty reduction, and swift utilization of medical care among the elderly. *Journal of Gerontology*, 48(2), P78–P86. <http://doi.org/10.1097/00005650-199510000-00002>
- Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. In S. Rachman (Ed.), *Contributions to Medical Psychology, Volume II* (pp. 7–30). New York: Pergamon Press.
- Leventhal, H., Nerenz, D. R., & Steele, D. J. (1984). Illness representation and coping with health threats. In A. Baum, S. E. Taylor, & J. E. Singer (Eds.), *Handbook of Psychology and Health* (pp. 219–252). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Levey, A., Lah, J., Goldstein, F., Steenland, K., & Bliwise, D. (2006). Mild cognitive impairment: An opportunity to identify patients at high risk for progression to Alzheimer's disease. *Clinical Therapeutics*, 28(7), 991–1001. <http://doi.org/10.1016/j.clinthera.2006.07.006>
- Levine, R. M., & Reicher, S. D. (1996). Making sense of symptoms: Self-categorization and the meaning of illness and injury. *British Journal of Social Psychology*, 35, 245–256. <http://doi.org/10.1111/j.2044-8309.1996.tb01095.x>
- Levy, R. (1994). Aging-Associated Cognitive Decline. *International Psychogeriatrics*, 6(1), 63–68.
- Lin, F., Gleason, C. E., & Heidrich, S. M. (2012). Illness representations in older adults with mild cognitive impairment. *Research in Gerontological Nursing*, 5(3), 195–206.

<http://doi.org/10.3928/19404921-20120605-04>

- Lin, F., & Heidrich, S. M. (2012). Role of older adult's illness schemata in coping with Mild Cognitive Impairment. *Journal of Psychosomatic Research, 72*(5), 357–363.
<http://doi.org/10.1016/j.jpsychores.2012.01.008>
- Lineweaver, T. T., Berger, A. K., & Hertzog, C. (2009). Expectations about memory change across the life span are impacted by aging stereotypes. *Psychology and Aging, 24*(1), 169–176. <http://doi.org/10.1037/a0013577>. Expectations
- Lineweaver, T. T., & Hertzog, C. (1998). Adults' efficacy and control beliefs regarding memory and aging: Separating general from personal beliefs. *Aging, Neuropsychology, and Cognition: A Journal on Normal and Dysfunctional Development, 5*(4), 264–296.
<http://doi.org/10.1076/anec.5.4.264.771>
- Lingler, J. H., Nightingale, M. C., Erlen, J. A., Kane, A. L., Reynolds, C. F., Schulz, R., & DeKosky, S. T. (2006). Making sense of mild cognitive impairment: A qualitative exploration of the patient's experience. *The Gerontologist, 46*(6), 791–800.
<http://doi.org/10.1093/geront/46.6.791>
- Link, B. G., Cullen, F. T., Struening, E., Shrout, P. E., & Dohrenwend, B. P. (1989). A modified labeling theory approach to mental disorders: an empirical assessment. *American Sociological Review, 54*, 400–423. <http://doi.org/10.2307/2095613>
- Lins, S., Hayder-Beichel, D., Rücker, G., Motschall, E., Antes, G., Meyer, G., & Langer, G. (2014). Efficacy and experiences of telephone counselling for informal carers of people with dementia. *The Cochrane Library, (9)*. <http://doi.org/10.1002/14651858.CD009126.pub2>
- Litherland, R. (2008). Involving people with dementia in service development and evaluation. In M. Downs & B. Bowers (Eds.), *Excellence in Dementia Care: Research into Practice* (pp. 397–413). Maidenhead: Open University Press.
- Lonie, J. A., Herrmann, L. L., Donaghey, C. L., & Ebmeier, K. P. (2008). Clinical referral patterns and cognitive profile in mild cognitive impairment. *The British Journal of Psychiatry, 192*, 59–64. <http://doi.org/10.1192/bjp.bp.107.035642>
- Lonie, J. A., Parra-Rodriguez, M. A., Tierney, K. M., Herrmann, L. L., Donaghey, C., O'Carroll, R. E., & Ebmeier, K. P. (2010). Predicting outcome in mild cognitive impairment: 4-year follow-up study. *The British Journal of Psychiatry, 197*, 135–140.
<http://doi.org/10.1192/bjp.bp.110.077958>
- Lopez, O. L., Jagust, W. J., DeKosky, S. T., Becker, J. T., Fitzpatrick, A., Dulberg, C., ... Kuller, L. H. (2003). Prevalence and classification of mild cognitive impairment in the Cardiovascular Health Study Cognition Study: part 1. *Archives of Neurology, 60*(10), 1385–1389.
<http://doi.org/10.1001/archneur.60.10.1385>
- Lu, Y. F. Y., & Haase, J. E. (2009). Experience and perspectives of caregivers of spouse with mild cognitive impairment. *Current Alzheimer Research, 6*(4), 384–391. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2867606/>
- Lu, Y. F. Y., Haase, J. E., & Farran, C. J. (2007). Perspectives of persons with mild cognitive impairment: Sense of being able. *Alzheimer's Care Quarterly, 8*, 75–86.
- Mason, O., Startup, M., Halpin, S., Schall, U., Conrad, A., & Carr, V. (2004). Risk factors for transition to first episode psychosis among individuals with "at-risk mental states". *Schizophrenia Research, 71*, 227–237. <http://doi.org/10.1016/j.schres.2004.04.006>
- Matthews, F. E., Stephan, B. C. M., McKeith, I. G., Bond, J., Brayne, C., & Medical Research

- Council Cognitive Function and Aging Study. (2008). Two-year progression from mild cognitive impairment to dementia: To what extent do different definitions agree? *Journal of the American Geriatrics Society*, *56*, 1424–1433. <http://doi.org/10.1111/j.1532-5415.2008.01820.x>
- Mattsson, N., Brax, D., & Zetterberg, H. (2010). To know or not to know: Ethical issues related to early diagnosis of Alzheimer's disease. *International Journal of Alzheimer's Disease*, *2010*. <http://doi.org/10.4061/2010/841941>
- Maxwell, J. A. (2012). *A Realist Approach for Qualitative Research. A Realist Approach to Qualitative Research*. London: SAGE. <http://doi.org/10.1017/CBO9781107415324.004>
- McIlvane, J. M., Popa, M. A., Robinson, B., Houseweart, K., & Haley, W. E. (2008). Perceptions of illness, coping, and well-being in persons with mild cognitive impairment and their care partners. *Alzheimer Disease and Associated Disorders*, *22*(3), 284–292. <http://doi.org/10.1097/WAD.0b013e318169d714>
- McParland, P. (2014). *Dementia: What comes to mind? An exploration into how the general public understands and responds to dementia*. University of Stirling, Stirling, UK.
- McParland, P., Devine, P., Innes, A., & Gayle, V. (2012). Dementia knowledge and attitudes of the general public in Northern Ireland: an analysis of national survey data. *International Psychogeriatrics*, *24*(10), 1600-1613. <http://doi.org/10.1017/S1041610212000658>
- Mitchell, A. J., & Shiri-Feshki, M. (2009). Rate of progression of mild cognitive impairment to dementia - meta-analysis of 41 robust inception cohort studies. *Acta Psychiatrica Scandinavica*, *119*, 252–265. <http://doi.org/10.1111/j.1600-0447.2008.01326.x>
- Mitchell, T., Woodward, M., & Hirose, Y. (2008). A survey of attitudes of clinicians towards the diagnosis and treatment of mild cognitive impairment in Australia and New Zealand. *International Psychogeriatrics*, *20*(1), 77–85. <http://doi.org/10.1017/S1041610207005583>
- Modell, S. (2009). In defence of triangulation: A critical realist approach to mixed methods research in management accounting. *Management Accounting Research*, *20*, 208–221. <http://doi.org/10.1016/j.mar.2009.04.001>
- Moreira, T., Hughes, J. C., Kirkwood, T., May, C., McKeith, I., & Bond, J. (2008). What explains variations in the clinical use of mild cognitive impairment (MCI) as a diagnostic category? *International Psychogeriatrics*, *20*(4), 697–709. <http://doi.org/10.1017/S1041610208007126>
- Morris, J. C. (2012). Revised criteria for mild cognitive impairment may compromise the diagnosis of Alzheimer disease dementia. *Archives of Neurology*, *69*(6), 700–708. <http://doi.org/10.1001/archneurol.2011.3152>
- Morris, J. C., Storandt, M., Miller, J. P., McKeel, D. W., Price, J. L., Rubin, E. H., & Berg, L. (2001). Mild cognitive impairment represents early-stage Alzheimer disease. *Archives of Neurology*, *58*, 397–405. <http://doi.org/10.1001/archneur.58.3.397>
- Morrison, V., & Bennett, P. (2009). *An Introduction to Health Psychology* (2nd editio). Harlow: Pearson.
- Mukadam, N., Cooper, C., & Livingston, G. (2011). A systematic review of ethnicity and pathways to care in dementia. *International Journal of Geriatric Psychiatry*, *26*, 12–20. <http://doi.org/10.1002/gps.2484>
- Nakano, M., Sato, S., & Nakahara, J. (2012). Emotional experiences of the community-dwelling with mild cognitive impairment and their families. *Neuropsychological Trends*, *12*, 117–

124. <http://doi.org/10.7358/neur-2012-012-naka>
- National Institute for Health and Care Excellence. (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. Retrieved from <http://www.nice.org.uk/guidance/cg42>
- Nygård, L. (2006). How can we get access to the experiences of people with dementia? *Scandinavian Journal of Occupational Therapy*, 13(2), 101–112. <http://doi.org/10.1080/11038120600723190>
- O'Brien, J. T., & Levy, R. (1992). Age associated memory impairment. *BMJ*, 304, 5–6.
- Östlund, U., Kidd, L., Wengström, Y., & Rowa-Dewar, N. (2011). Combining qualitative and quantitative research within mixed method research designs: A methodological review. *International Journal of Nursing Studies*, 48, 369–383. <http://doi.org/10.1016/j.ijnurstu.2010.10.005>
- Palmer, K., Di Iulio, F., Varsi, A. E., Gianni, W., Sancesario, G., Caltagirone, C., & Spalletta, G. (2010). Neuropsychiatric predictors of progression from amnesic-mild cognitive impairment to Alzheimer's disease: The role of depression and apathy. *Journal of Alzheimer's Disease*, 20, 175–183. <http://doi.org/10.3233/JAD-2010-1352>
- Palmer, K., Musicco, M., & Caltagirone, C. (2010). Are guidelines needed for the diagnosis and management of incipient Alzheimer's disease and mild cognitive impairment? *International Journal of Alzheimer's Disease*, 2010. <http://doi.org/10.4061/2010/417615>
- Parry, O., Peel, E., Douglas, M., & Lawton, J. (2006). Issues of cause and control in patient accounts of Type 2 diabetes. *Health Education Research*, 21(1), 97–107. <http://doi.org/10.1093/her/cyh044>
- Parsons-Suhl, K., Johnson, M. E., McCann, J. J., & Solberg, S. (2008). Losing one's memory in early Alzheimer's disease. *Qualitative Health Research*, 18(1), 31–42. <http://doi.org/10.1177/1049732307308987>
- Pasymowski, S., Roberto, K. A., & Blieszner, R. (2013). Adjustment to mild cognitive impairment: Perspectives of male care partners and their spouses. *Journal of Couple & Relationship Therapy*, 12(3), 213–234. <http://doi.org/10.1080/15332691.2013.806703>
- Patel, B. B., & Holland, N. W. (2012). Mild cognitive impairment: Hope for stability, plan for progression. *Cleveland Clinic Journal of Medicine*, 79(12), 857–864. <http://doi.org/10.3949/ccjm.79a.11126>
- Peel, E. (2014). "The living death of Alzheimer's" versus "Take a walk to keep dementia at bay": representations of dementia in print media and carer discourse. *Sociology of Health & Illness*, 36(6), 885–901. <http://doi.org/10.1111/1467-9566.12122>
- Peel, E., Parry, O., Douglas, M., & Lawton, J. (2005). Taking the biscuit? A discursive approach to managing diet in Type 2 diabetes. *Journal of Health Psychology*, 10(6), 779–791. <http://doi.org/10.1177/1359105305057313>
- Peters, K. R., & Katz, S. (2015a). Interview with Dr Anne Davis Basting, 21 May 2013. *Dementia*, 14(3), 328–334. <http://doi.org/10.1177/1471301214562136>
- Peters, K. R., & Katz, S. (2015b). Interview with Professor John Bond, 30 April 2013. *Dementia*, 14(3), 343–350. <http://doi.org/10.1177/1471301214562141>
- Peters, K. R., & Katz, S. (2015c). Voices from the field: Expert reflections on mild cognitive impairment. *Dementia*, 14(3), 285–297. <http://doi.org/10.1177/1471301214562135>
- Petersen, R. C. (2004). Mild cognitive impairment as a diagnostic entity. *Journal of Internal*

- Medicine*, 256, 183–194. <http://doi.org/10.1111/j.1365-2796.2004.01388.x>
- Petersen, R. C., Knopman, D. S., Boeve, B. F., Geda, Y. E., Ivnik, R. J., Smith, G. E., ... Jack Jr, C. R. (2009). Mild cognitive impairment: Ten years later. *Archives of Neurology*, 66(12), 1447–1455. <http://doi.org/10.1001/archneur.2009.266.Mild>
- Petersen, R. C., & Morris, J. C. (2005). Mild cognitive impairment as a clinical entity and treatment target. *Archives of Neurology*, 62, 1160–1163. <http://doi.org/10.1001/archneur.62.7.1160>
- Petersen, R. C., & O'Brien, J. (2006). Mild cognitive impairment should be considered for DSM-V. *Journal of Geriatric Psychiatry and Neurology*, 19, 147–154. <http://doi.org/10.1177/0891988706291085>
- Petersen, R. C., Roberts, R. O., Knopman, D. S., Geda, Y. E., Cha, R. H., Pankratz, V. S., ... Rocca, W. A. (2010). Prevalence of mild cognitive impairment is higher in men. *Neurology*, 75, 889–897. <http://doi.org/10.1212/WNL.0b013e3181f11d85>
- Petersen, R. C., Smith, G. E., Waring, S. C., Ivnik, R. J., Tangalos, E. G., & Kokmen, E. (1999). Mild cognitive impairment: Clinical characterization and outcome. *Archives of Neurology*, 56(3), 303–308. <http://doi.org/10.1001/archneur.56.3.303>
- Petersen, R. C., Stevens, J. C., Ganguli, M., Tangalos, E. G., Cummings, J. L., & DeKosky, S. T. (2001). Practice parameter: Early detection of dementia: Mild cognitive impairment (an evidence-based review). *Neurology*, 56, 1133–1142. <http://doi.org/10.1212/WNL.56.9.1133>. 2001;56;1133
- Petersen, R. C., Thomas, R. G., Grundman, M., Bennett, D., Doody, R., Ferris, S., ... Thal, L. J. (2005). Vitamin E and donepezil for the treatment of mild cognitive impairment. *New England Journal of Medicine*, 352(23), 2379–2388. <http://doi.org/10.1056/NEJMoa050151>
- Pistacchi, M., Gioulis, M., Contin, F., Sanson, F., & Marsala, S. Z. (2015). Cognitive profiles in mild cognitive impairment (MCI) patients associated with Parkinson's disease and cognitive disorders. *Annals of Indian Academy of Neurology*, 18(2), 200–205. <http://doi.org/10.4103/0972>
- Plassman, B. L., Williams Jr, J. W., Burke, J. R., Holsinger, T., & Benjamin, S. (2010). Systematic review: Factors associated with risk for and possible prevention of cognitive decline in later life. *Annals of Internal Medicine*, 153(3), 182–193.
- Portet, F., Ousset, P. J., Visser, P. J., Frisoni, G. B., Nobili, F., Scheltens, P., ... Touchon, J. (2006). Mild cognitive impairment (MCI) in medical practice: A critical review of the concept and new diagnostic procedure. Report of the MCI Working Group of the European Consortium on Alzheimer's Disease. *Journal of Neurology, Neurosurgery & Psychiatry*, 77, 714–718. <http://doi.org/10.1136/jnnp.2005.085332>
- Raskin, J. D. (2001). On relativism in constructivist psychology. *Journal of Constructivist Psychology*, 14(4), 285–313. <http://doi.org/10.1080/10720530126044>
- Rattray, J., & Jones, M. C. (2007). Essential elements of questionnaire design and development. *Journal of Clinical Nursing*, 16, 234–243. <http://doi.org/10.1111/j.1365-2702.2006.01573.x>
- Richards, H., Reid, M., & Watt, G. (2003). Victim-blaming revisited: A qualitative study of beliefs about illness causation, and responses to chest pain. *Family Practice*, 20(6), 711–716. <http://doi.org/10.1093/fampra/cm615>

- Ringman, J. M., Medina, L. D., Rodriguez-Agudelo, Y., Chavez, M., Lu, P., & Cummings, J. L. (2009). Current concepts of mild cognitive impairment and their applicability to persons at-risk for familial Alzheimer's disease. *Current Alzheimer Research*, 6(4), 341–346. <http://doi.org/10.2174/10341>
- Roberto, K. A., Blieszner, R., McCann, B. R., & McPherson, M. C. (2011). Family triad perceptions of mild cognitive impairment. *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 66(6), 756–768. <http://doi.org/10.1093/geronb/gbr107>
- Roberto, K. A., McCann, B. R., & Blieszner, R. (2011). Trajectories of care: Spouses coping with changes related to mild cognitive impairment. *Dementia*, 12(1), 45–62. <http://doi.org/10.1177/1471301211421233>
- Roberts, J. L., & Clare, L. (2013). Meta-representational awareness in mild cognitive impairment: An interpretative phenomenological analysis. *Aging & Mental Health*, 17(3), 300–309. <http://doi.org/10.1080/13607863.2012.732033>
- Roberts, J. S., Karlawish, J. H., Uhlmann, W. R., Petersen, R. C., & Green, R. C. (2010). Mild cognitive impairment in clinical care: A survey of American Academy of Neurology members. *Neurology*, 75, 425–431. <http://doi.org/10.1212/WNL.0b013e3181eb5872>
- Robinson, E. (2002). Should people with Alzheimer's disease take part in research? In H. Wilkinson (Ed.), *The Perspectives of People with Dementia: Research Methods and Motivations* (pp. 101–108). London: Jessica Kingsley.
- Rodda, J., Gandhi, S. D., Mukadam, N., & Walker, Z. (2013). Attitudes of UK psychiatrists to the diagnosis of MCI in clinical practice. *International Psychogeriatrics*, 25(2), 286–291. <http://doi.org/10.1017/S1041610212001500>
- Rogalski, E. J., Murphy, C. M., DeToledo-Morrell, L., Shah, R. C., Moseley, M. E., Bammer, R., & Stebbins, G. T. (2009). Changes in parahippocampal white matter integrity in amnesic mild cognitive impairment: A diffusion tensor imaging study. *Behavioural Neurology*, 21, 51–61. <http://doi.org/10.3233/BEN-2009-0235>
- Rossi, R., Geroldi, C., Bresciani, L., Testa, C., Binetti, G., Zanetti, O., & Frisoni, G. B. (2007). Clinical and neuropsychological features associated with structural imaging patterns in patients with mild cognitive impairment. *Dementia and Geriatric Cognitive Disorders*, 23, 175–183. <http://doi.org/10.1159/000098543>
- Rüsch, N., Angermeyer, M. C., & Corrigan, P. W. (2005). Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma. *European Psychiatry*, 20, 529–539. <http://doi.org/10.1016/j.eurpsy.2005.04.004>
- Sachs-Ericsson, N., & Blazer, D. G. (2015). The new DSM-5 diagnosis of mild neurocognitive disorder and its relation to research in mild cognitive impairment. *Aging & Mental Health*, 19(1), 2–12. <http://doi.org/10.1080/13607863.2014.920303>
- Scheff, T. (1966). *Being Mentally Ill: A Sociological Theory*. Chicago: Aldine.
- Schiff, R., Rajkumar, C., & Bulpitt, C. (2000). Views of elderly people on living wills: interview study. *BMJ*, 320, 1640–1641. <http://doi.org/10.1136/bmj.320.7250.1640>
- Sechrest, L., & Sidani, S. (1995). Quantitative and qualitative methods: Is there an alternative? *Evaluation and Program Planning*, 18(1), 77–87. [http://doi.org/10.1016/0149-7189\(94\)00051-X](http://doi.org/10.1016/0149-7189(94)00051-X)
- Serrano, C., Rojas, G., & Allegri, R. (2011). Different risk of dementia in mild cognitive impairment subtypes. *Alzheimer's & Dementia*, 7(4), S534.

<http://doi.org/10.1016/j.jalz.2011.05.1504>

- Steenland, N. K., Auman, C. M., Patel, P. M., Bartell, S. M., Goldstein, F. C., Levey, A. I., & Lah, J. J. (2008). Development of a rapid screening instrument for mild cognitive impairment and undiagnosed dementia. *Journal of Alzheimer's Disease, 15*, 419–427. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2679370/pdf/nihms97803.pdf>
- Stephan, B. C. M., Matthews, F. E., McKeith, I. G., Bond, J., Brayne, C., & Medical Research Council Cognitive Function and Aging Study. (2007). Early cognitive change in the general population: How do different definitions work? *Journal of the American Geriatrics Society, 55*, 1534–1540. <http://doi.org/10.1111/j.1532-5415.2007.01386.x>
- Stephan, B. C. M., Minett, T., Pagett, E., Siervo, M., Brayne, C., & McKeith, I. G. (2013). Diagnosing mild cognitive impairment (MCI) in clinical trials: a systematic review. *BMJ Open, 3*. <http://doi.org/10.1136/bmjopen-2012-001909>
- Sullivan, G. M., & Artino Jr, A. R. (2013). Analyzing and interpreting data from Likert-type scales. *Journal of Graduate Medical Education, 5*(4), 541-542.
- Sweeting, H., & Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health & Illness, 19*(1), 93–117. <http://doi.org/10.1111/j.1467-9566.1997.tb00017.x>
- Teddlie, C., & Tashakkori, A. (2011). Mixed methods research: Contemporary issues in an emerging field. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (4th ed., pp. 285–300). London: SAGE Publications Ltd.
- Teng, E., Tingus, K. D., Lu, P. H., & Cummings, J. L. (2009). Persistence of neuropsychological testing deficits in mild cognitive impairment. *Dementia and Geriatric Cognitive Disorders, 28*, 168–178. <http://doi.org/10.1159/000235732>
- The Scottish Government. (2010). *Scotland's National Dementia Strategy*.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology, 8*(45). <http://doi.org/10.1186/1471-2288-8-45>
- van Baalen, A., Vingerhoets, A. J. J. M., Sixma, H. J., & de Lange, J. (2010). How to evaluate quality of care from the perspective of people with dementia: An overview of the literature. *Dementia, 10*(1), 112–137. <http://doi.org/10.1177/1471301210369320>
- Van Gorp, B., & Vercruyse, T. (2012). Frames and counter-frames giving meaning to dementia: A framing analysis of media content. *Social Science and Medicine, 74*, 1274–1281. <http://doi.org/10.1016/j.socscimed.2011.12.045>
- Vogel, A., Stokholm, J., Gade, A., Andersen, B. B., Hejl, A.-M., & Waldemar, G. (2004). Awareness of deficits in mild cognitive impairment and Alzheimer's disease: Do MCI patients have impaired insight? *Dementia and Geriatric Cognitive Disorders, 17*, 181–187. <http://doi.org/10.1159/000076354>
- Wadley, V. G., Crowe, M., Marsiske, M., Cook, S. E., Unverzagt, F. W., Rosenberg, A. L., & Rexroth, D. (2007). Changes in everyday function in individuals with psychometrically defined mild cognitive impairment in the Advanced Cognitive Training for Independent and Vital Elderly Study. *Journal of the American Geriatrics Society, 55*, 1192–1198. <http://doi.org/10.1111/j.1532-5415.2007.01245.x>
- Wadley, V. G., & Haley, W. E. (2001). Diagnostic attributions versus labeling: Impact of Alzheimer's disease and major depression diagnoses on emotions, beliefs, and helping intentions of family members. *Journal of Gerontology, 56B*(4), P244–P252.

<http://doi.org/10.1093/geronb/56.4.P244>

- Watson, A. C., Corrigan, P., Larson, J. E., & Sells, M. (2007). Self-stigma in people with mental illness. *Schizophrenia Bulletin*, *33*(6), 1312–1318. <http://doi.org/10.1093/schbul/sbl076>
- Weiner, B. (1993). On sin versus sickness: A theory of perceived responsibility and social motivation. *American Psychologist*, *48*(9), 957–965. <http://doi.org/10.1037/0003-066X.48.9.957>
- Weiner, B., Perry, R. P., & Magnusson, J. (1988). An attributional analysis of reactions to stigmas. *Journal of Personality and Social Psychology*, *55*(5), 738–748. <http://doi.org/10.1177/0146167295215004>
- Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health*, *11*, 431–445. <http://doi.org/10.1080/08870449608400270>
- Welsh Assembly Government. (2011). *National Dementia Vision for Wales: Dementia Supportive Communities*.
- Werner, P., Heinik, J., & Kitai, E. (2013). Familiarity, knowledge, and preferences of family physicians regarding mild cognitive impairment. *International Psychogeriatrics*, *25*(5), 805–813. <http://doi.org/10.1017/S1041610212002384>
- Wilkinson, S. (2000). Women with breast cancer talking causes: Comparing content, biographical and discursive analyses. *Feminism & Psychology*, *10*(4), 431–460. <http://doi.org/10.1177/0959353500010004003>
- Wilson, R. S., Krueger, K. R., Arnold, S. E., Schneider, J. A., Kelly, J. F., Barnes, L. L., ... Bennett, D. A. (2007). Loneliness and risk of Alzheimer disease. *Archives of General Psychiatry*, *64*, 234–240.
- Winblad, B., Palmer, K., Kivipelto, M., Jelic, V., Fratiglioni, L., Wahlund, L.-O., ... Petersen, R. C. (2004). Mild cognitive impairment - beyond controversies, towards a consensus: report of the International Working Group on Mild Cognitive Impairment. *Journal of Internal Medicine*, *256*, 240–246. <http://doi.org/10.1111/j.1365-2796.2004.01380.x>
- Wooffitt, R. (2001). Researching Psychic Practitioners: Conversation Analysis. In M. Wetherell, S. Taylor, & S. J. Yates (Eds.), *Discourse as Data: A Guide for Analysis* (pp. 49–92). London: SAGE Publications Ltd.
- Yang, L. H., Wonpat-Borja, A. J., Opler, M. G., & Corcoran, C. M. (2010). Potential stigma associated with inclusion of the psychosis risk syndrome in the DSM-V: An empirical question. *Schizophrenia Research*, *120*, 42–48. <http://doi.org/10.1016/j.schres.2010.03.012>
- Yar, M., Dix, D., & Bajekal, M. (2006). Socio-demographic characteristics of the healthcare workforce in England and Wales - results from the 2001 Census. *Health Statistics Quarterly*, *(32)*, 44–56.
- Yung, A. R., McGorry, P. D., McFarlane, C. A., Jackson, H. J., Patton, G. C., & Rakkar, A. (1996). Monitoring and care of young people at incipient risk of psychosis. *Schizophrenia Bulletin*, *22*(2), 283–303. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/8782287>
- Yung, A. R., Phillips, L. J., Yuen, H. P., Francey, S. M., McFarlane, C. A., Hallgren, M., & McGorry, P. D. (2003). Psychosis prediction: 12-month follow up of a high-risk (“prodromal”) group. *Schizophrenia Research*, *60*, 21–32. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12505135>

- Yung, A. R., Yuen, H. P., McGorry, P. D., Phillips, L. J., Kelly, D., Dell'Olio, M., ... Buckby, J. (2005). Mapping the onset of psychosis: The comprehensive assessment of at-risk mental states. *The Australian and New Zealand Journal of Psychiatry, 39*, 964–971. <http://doi.org/10.1111/j.1440-1614.2005.01714.x>
- Zachariadis, M., Scott, S., & Barrett, M. (2013). Methodological implications of critical realism for mixed-methods research. *MIS Quarterly, 37*(3), 855–879.

Appendix A: Critical Appraisal Skills Programme checklist (CASP, 2013) for qualitative studies

| CASP - 10 Questions to make sense of qualitative research | 1 = No 2 = Yes with restrictions 3 = Yes |
|---|---|
| Was there a clear statement of the aims of the research? | |
| o What was the goal of the research? | |
| o Why was it thought important? | |
| o Consider its relevance | |
| Is a qualitative methodology appropriate? | |
| o Consider if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants | |
| o Is qualitative research the right methodology for addressing the research goal? | |
| Was the research design appropriate to address the aims of the research? | |
| o Consider if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)? | |
| Was the recruitment strategy appropriate to the aims of the research? | |
| o Consider if the researcher has explained how the participants were selected | |
| o Consider if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study | |
| o Consider if there are any discussions around recruitment (e.g. why some people chose not to take part) | |
| Was the data collected in a way that addressed the research issue? | |
| o Consider if the setting for data collection was justified | |
| o Consider if it is clear how data were collected (e.g. focus group, semi-structured interview, etc.) | |
| o Consider if the researcher has justified the methods chosen? | |
| o Consider if the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)? | |
| o Consider if methods were modified during the study. If so, has the researcher explained how and why? | |
| o Consider if the form of data is clear (e.g. tape recordings, video materials, notes, etc.) | |
| o Consider if the researcher has discussed saturation of data | |
| Has the relationship between researcher and participants been adequately considered? | |
| o Consider if the researcher critically examined their own role, potential bias and influence during: | |

| | |
|--|--|
| • Formulation of the research questions | |
| • Data collection, including sample recruitment and choice of location | |
| o Consider how the researcher responded to events during the study and whether they considered the implications of any changes in the research design | |
| Have ethical issues been taken into consideration? | |
| o Consider if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained? | |
| o Consider if the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on participants during and after the study) | |
| o Consider if approval have been sought from the ethics committee | |
| Was the data analysis sufficiently rigorous? | |
| o Consider if there is an in-depth description of the analysis process | |
| o Consider if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? | |
| o Consider whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process | |
| o Consider if sufficient data are presented to support the findings | |
| o Consider to what extent contradictory data are taken into account | |
| o Consider whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation | |
| Is there a clear statement of findings? | |
| o Consider if the findings are explicit | |
| o Consider if there is adequate discussion of the evidence both for and against the researchers arguments | |
| o Consider if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst) | |
| o Consider if the findings are discussed in relation to the original research question | |
| How valuable is the research? | |
| o Consider if the researcher discussed the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature | |
| o Consider if they identify new areas where research is necessary | |
| o Consider if the researcher have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used | |
| TOTAL SCORE (out of 30) | |
| RELEVANCE (out of 3) | |

Appendix B: Modified Critical Appraisal Skills Programme checklist (CASP, 2013) for quantitative studies

| Modified CASP - 10 Questions to make sense of survey research | 1 = No 2 = Yes with restrictions 3 = Yes |
|--|---|
| Was there a clear statement of the aims of the research? | |
| o What was the goal of the research? | |
| o Why was it thought important? | |
| o Consider its relevance | |
| Is the methodology appropriate? | |
| o Consider what the research is seeking to investigate (to interpret or illuminate the actions and/or subjective experiences of research participants, to gain an overview of participants knowledge/opinions etc.) | |
| o Is questionnaire/survey design the right methodology for addressing the research goal? | |
| Was the research design appropriate to address the aims of the research? | |
| o Consider if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)? | |
| Was the recruitment strategy appropriate to the aims of the research? | |
| o Consider if the researcher has explained how the participants were selected | |
| o Consider if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study (clear eligibility criteria etc.) | |
| o Consider if there are any discussions around recruitment (e.g. why some people chose not to take part) | |
| Was the data collected in a way that addressed the research issue? | |
| o Consider if the setting for data collection was justified | |
| o Consider if it is clear how data were collected (e.g. postal questionnaire, email, telephone etc.) | |
| o Consider if the researcher has justified the methods chosen? | |
| o Consider if the researcher has made the methods explicit (e.g. is there an indication of how the survey was conducted, any instructions/information provided to participants, any of the items included in the questionnaire)? | |
| o Consider if multiple versions of the survey were utilised for different participant groups/populations? | |
| o Consider if the form of data is clear (e.g. Likert scale responses, yes/no dichotomy, etc.) | |
| Has the relationship between researcher and participants been adequately considered? | |

| | |
|--|--|
| o Consider if the researcher critically examined their own role, potential bias and influence during: | |
| • Formulation of the research questions | |
| • Data collection, including sample recruitment and choice of data collection tool | |
| o Consider how the researcher responded to events during the study and whether they considered the implications of any changes in the research design | |
| Have ethical issues been taken into consideration? | |
| o Consider if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained? | |
| o Consider if the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on participants during and after the study) | |
| o Consider if approval have been sought from the ethics committee | |
| Was the data analysis sufficiently rigorous? | |
| o Consider if there is an in-depth description of the analysis process | |
| o Consider if statistical analysis is used and if statistical methods are described, including those used to control for confounding variables. If so, is the analysis selected appropriate for the data collected? Was the statistical significance assessed (if this is possible/appropriate)? | |
| o Consider whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process | |
| o Consider if sufficient data are presented to support the findings | |
| o Consider to what extent contradictory data are taken into account | |
| o Consider if and how missing data were addressed | |
| o Consider whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation | |
| Is there a clear statement of findings? | |
| o Consider if the findings are explicit | |
| o Consider if there is adequate discussion of the evidence both for and against the researchers arguments | |
| o Consider if the researcher has discussed the credibility of their findings (e.g. validity, reliability etc.) | |
| o Consider if the findings are discussed in relation to the original research question | |
| How valuable is the research? | |
| o Consider if the researcher discussed the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature | |

| | |
|--|--|
| o Consider if they identify new areas where research is necessary | |
| o Consider if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used | |
| TOTAL SCORE (out of 30) | |
| RELEVANCE (out of 3) | |

Knowledge and understanding of cognitive impairment

What is the research about?

Cognitive impairment is a term used to describe mild but persistent memory and thinking difficulties that are not as severe as dementia. I'm interested in finding out what people know and understand about cognitive impairment.

The issue of investigating what people know about cognitive impairment is currently under researched. It is important that we explore what people know so that we can identify any gaps in knowledge and misunderstandings to ensure that we can develop and provide future information about cognitive impairment which can reduce any confusion or uncertainty about this. I would like to explore the knowledge of people who may or may not have heard about cognitive impairment, including healthcare professionals, specialists working with older adults, younger adults, older adults both with and without cognitive impairment, and supporters and care partners of people living with cognitive impairment.

In order to understand what people know about cognitive impairment, there are two key parts to this research:

1. Questionnaire – asking you what you know about cognitive impairment
2. Interview – some people who complete a questionnaire will be invited to meet with me to discuss in more detail what you know and understand about cognitive impairment

You can take part in just one or both parts of the study if you would like.

Do I have to take part?

No. Participation in this research is entirely voluntary. If you do choose to take part but then decide that you want to stop, you can do this without having to provide a reason. Your decision will not affect any help and support that you may receive now or in the future. You are free to withdraw your information from this study up to 4 weeks after returning your completed questionnaire by contacting the researcher.

What will taking part mean for me?

If you are happy to fill in a questionnaire about your knowledge in this area that would be very much appreciated. The questionnaire should take no more than 30 minutes to complete. You can either post this back to me in the freepost envelope provided or complete the questionnaire online at <https://www.surveymonkey.com/r/cognitive-impairment>. You do not have to complete this questionnaire if you don't want to. If you would like to speak to me before you decide whether to complete the questionnaire, please feel free to contact me.

Following the questionnaire, some people will be invited to take part in a follow-up interview about what you know and understand about cognitive impairment.

Completing the questionnaire does not mean that you have to take part in an interview if you do not want to.

Will the information I give stay confidential?

All information gathered for this research will be kept confidential. No names will be used in any reports about the research, and the information gathered in this study will be kept in a secure location at the University of Worcester. The only person who will have access to any of the research data is the researcher.

What will happen to the results of the research study?

Once the research is completed, a summary of the main findings will be available to everyone who has taken part. If you would like to receive a copy of the main findings of the study, please indicate how you would prefer to receive this information (by post or email) along with your contact details on the last page of the questionnaire booklet.

What happens next?

If you are happy to fill in a questionnaire then please either post this back to me or complete this online. If you would like to find out more about the second stage of the research, and potentially take part in an interview, please fill in your contact details on the last page of the questionnaire booklet and return this in the freepost envelope provided. Alternatively, you can contact me directly using the details below. **This does not commit you to taking part in an interview**

Who has reviewed the study?

This research has been reviewed and approved by North East – Tyne & Wear South NHS Research Ethics Committee (Ref: 15/NE/0227) and the University of Worcester Institute of Health & Society Ethics Committee.

Further information and contact details

If you have any questions or would like more information about the research at any time, please contact:

| | | |
|---|-----------|---|
| Heather Yemm (<i>PhD Researcher</i>) | or | Professor Dawn Brooker (<i>Supervisor</i>) |
| Graduate Research School (BB 173) | | Association for Dementia Studies |
| University of Worcester | | University of Worcester |
| Henwick Grove | | Henwick Grove |
| Worcester, WR2 6AJ | | Worcester, WR2 6AJ |
| Tel: 01905 54 2295 | | Tel: 01905 85 5250 |
| Email: h.yemm@worc.ac.uk | | Email: d.brooker@worc.ac.uk |

If you would like to speak to an independent person who is not a member of the research team, please contact:

Dr John-Paul Wilson

Graduate Research School, University of Worcester, Henwick Grove, Worcester, WR2 6AJ
Tel: 01905 54 2196
Email: j.wilson@worc.ac.uk

Thank you for taking the time to read this information

Appendix D: Introductory Letter

Version 1 (09.02.15)



Heather Yemm
Graduate Research School (BB 173)
University of Worcester
Henwick Grove
Worcester
WR2 6AJ
Tel: 01905 542295
Email: h.yemm@worc.ac.uk

Date

Dear Sir/Madam,

Research Study: Knowledge and understanding of cognitive impairment

I am writing to ask for your help with a research study that I am carrying out which aims to explore what people know and understand about cognitive impairment. Cognitive impairment is a term which is used to describe memory and thinking difficulties which are worse than would be expected as a result of ageing, but are not as bad as dementia. Research suggests that, at present, many people don't understand a lot about cognitive impairment, despite there being quite a high number of people who experience these difficulties. This lack of understanding means that some people do not seek or receive appropriate help and support.

The research that I am carrying out aims to explore what people currently know and understand about cognitive impairment. I am hoping to obtain the views of a range of different people, including healthcare professionals, specialists working with older adults, younger adults, older adults both with and without cognitive impairment and supporters and care partners of people living with cognitive impairment, as I would like to see if knowledge and understanding of cognitive impairment differs among these groups of individuals.

I would like to know what you have heard about cognitive impairment and see what you know and understand about this. There is an information leaflet with this letter which explains more about the research and what taking part in it involves. Part of the research involves completing a questionnaire, which asks questions about what, if anything, you currently know about cognitive

Version 1 (09.02.15)

impairment. A copy of this questionnaire is included and it would be very much appreciated if you could look at this and complete it if you are happy to do so. If you would like to speak to me about the questionnaire, or about the research project overall, please feel free to contact me on 01905 542295 or email me at h.yemm@worc.ac.uk.

If you are happy to complete the enclosed questionnaire, please return this to me in the freepost envelope which is included with this letter, or complete the questionnaire online following the web link provided on the information leaflet. If you would like to find out more about the second stage of this research and possibly take part in an interview, please complete the enclosed contact details form (on the back page of the questionnaire booklet) and also return this in the same envelope.

Agreeing to hear more about the research does not mean that you have to take part. You can choose not to take part at any point and this will not affect any care and support that you receive now or in the future.

Thank you for taking the time to read this and for your help with this important study.


Kind regards,

A handwritten signature in black ink, appearing to read 'H. Yemm', with a long horizontal stroke extending to the right.

Heather Yemm
PhD Student

Appendix E: Questionnaire

Version 2 (28.05.15)

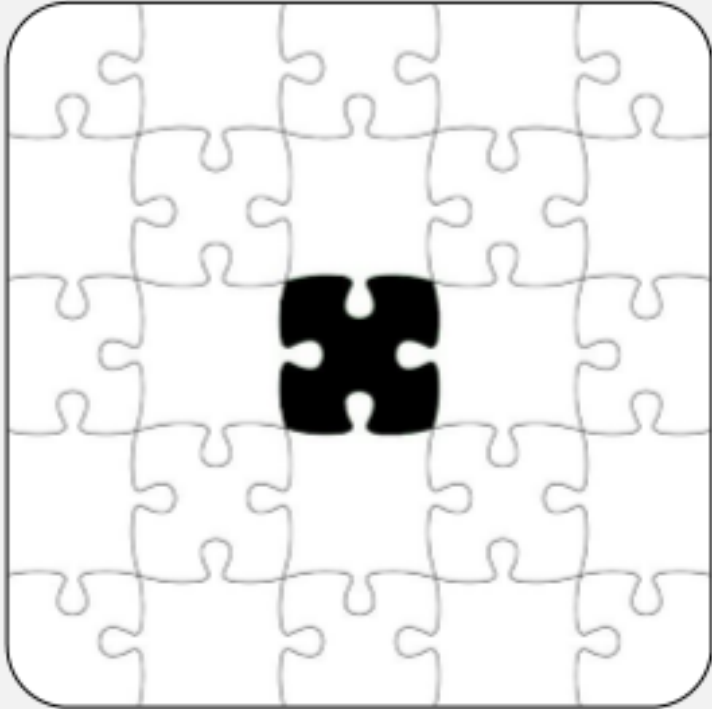


University of Worcester

Heather Yemm
Graduate Research School (BB 173)
University of Worcester
Henwick Grove
Worcester
WR2 6AJ
Tel: 01905 54 2295
Email: h.yemm@worc.ac.uk

**Knowledge and understanding of
cognitive impairment**

QUESTIONNAIRE



CONSENT FORM

Before filling in the questionnaire, please first read carefully and sign this consent form. This form must be returned with your completed questionnaire in order for your responses to be included in the study. Please tick the boxes if you agree to the following statements:

- I confirm that I have read and understood the information sheet about this research and have had the opportunity to ask questions.
- I confirm that I have had enough time to decide whether I want to complete this questionnaire.
- I understand that I do not have to complete this questionnaire.
- I understand that any information I give will be kept confidential and that the questionnaire will be coded to protect my identity.
- I agree to complete the questionnaire.
- I would like to be contacted to find out more about taking part in an interview and have completed the contact details form at the end of the questionnaire so that the researcher can get in touch with me.

(You do not have to agree to this – if you would prefer not to be contacted, please leave this box blank)

Signature:

Name (please print):

Date:

**THIS PAGE WILL BE REMOVED FROM THE QUESTIONNAIRE AND STORED
CONFIDENTIALLY SO THAT NO-ONE CAN IDENTIFY YOU**

Thank you for taking the time to complete this questionnaire. Please answer as many of the questions as you can, if you are not sure about an answer please skip the question and move on to the next one. Please try to complete the questionnaire on your own if you can. You do not have to answer all of the questions.

SECTION 1: WHAT IS COGNITIVE IMPAIRMENT?

1 Have you heard of cognitive impairment before?

Please tick one box

Yes

No

2 Do you know anybody personally who has ever been given a diagnosis of cognitive impairment (memory and thinking difficulties)?

Please tick all answers that apply

Yes – family member

Yes – friend

Yes – myself

Yes – other _____

No

3 Do you know anybody personally who has ever been given a diagnosis of dementia?

Please tick all answers that apply

Yes – family member

Yes – friend

Yes – myself

Yes – other _____

No

4 Have you ever read any information about cognitive impairment?
Please tick all answers that apply

- Yes – as part of my job role
- Yes – as part of my studies
- Yes – for personal or other reasons
- No

5 Have you ever read any information about dementia?
Please tick all answers that apply

- Yes – as part of my job role
- Yes – as part of my studies
- Yes – for personal or other reasons
- No

6 What do you think about the following statements?
Please circle one answer for each statement

| | | | | | |
|--|----------------|-------|---------|----------|-------------------|
| a. I have a good understanding of what cognitive impairment is | Strongly agree | Agree | Neither | Disagree | Strongly disagree |
| b. I want to know more about cognitive impairment | Strongly agree | Agree | Neither | Disagree | Strongly disagree |
| c. I have a good understanding of what dementia is | Strongly agree | Agree | Neither | Disagree | Strongly disagree |
| d. I want to know more about dementia | Strongly agree | Agree | Neither | Disagree | Strongly disagree |

7 Do you think the following statements are true or false?

Please circle one answer for each statement

| | | | |
|--|------|-------|------------|
| a. Cognitive impairment is a normal part of ageing | True | False | Don't know |
| b. Cognitive impairment is a form of dementia | True | False | Don't know |
| c. Cognitive impairment only affects people over the age of 65 | True | False | Don't know |
| d. People with cognitive impairment will definitely develop dementia | True | False | Don't know |
| e. There are treatments available which can help people with cognitive impairment | True | False | Don't know |
| f. Cognitive impairment is a mental illness | True | False | Don't know |
| g. People with cognitive impairment are no longer the same person that they used to be | True | False | Don't know |
| h. Memory and thinking problems are a normal part of getting older | True | False | Don't know |
| i. Cognitive impairment can be cured | True | False | Don't know |
| j. Cognitive impairment is permanent | True | False | Don't know |
| k. Cognitive impairment is easy to live with | True | False | Don't know |
| l. People with cognitive impairment lose their independence | True | False | Don't know |
| m. People with cognitive impairment lose their self-confidence | True | False | Don't know |
| n. Staying active can help to treat the symptoms of cognitive impairment | True | False | Don't know |
| o. Cognitive impairment is preventable | True | False | Don't know |
| p. People with cognitive impairment can still live a full and happy life | True | False | Don't know |

8 If a friend asked you what cognitive impairment was, how would you describe it?

Please write your answer in your own words in the box below. You can write as much or as little as you'd like. You do not have to fill the box.

9 If a friend asked you what dementia was, how would you describe it?

Please write your answer in your own words in the box below. You can write as much or as little as you'd like. You do not have to fill the box.

SECTION 2: TERMINOLOGY AND LABELS

- 10** 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 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?

Please tick all answers that apply

- | | |
|---|---|
| <input type="checkbox"/> Mild cognitive impairment | <input type="checkbox"/> Age associated memory impairment |
| <input type="checkbox"/> Mild neurocognitive disorder | <input type="checkbox"/> Benign senescent forgetfulness |
| <input type="checkbox"/> Early stage dementia | <input type="checkbox"/> Getting older |
| <input type="checkbox"/> Early stage Alzheimer's disease | <input type="checkbox"/> Stress |
| <input type="checkbox"/> Memory problems | <input type="checkbox"/> Depression |
| <input type="checkbox"/> Questionable dementia | <input type="checkbox"/> Physical health problems |
| <input type="checkbox"/> Age related cognitive decline | <input type="checkbox"/> Mental health problems |
| <input type="checkbox"/> Age associated cognitive decline | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Other _____ | |

- 11** Do you think the following can cause cognitive impairment?

Please circle one answer for each statement

| | | | |
|--|-----|----|------------|
| a. Getting older | Yes | No | Don't know |
| b. Genetics | Yes | No | Don't know |
| c. Abnormal brain changes | Yes | No | Don't know |
| d. Head injury (recently or in the past) | Yes | No | Don't know |
| e. Diet | Yes | No | Don't know |
| f. Stress or worry | Yes | No | Don't know |
| g. Personal behaviour (e.g. levels of physical and/or mental activity) | Yes | No | Don't know |
| h. Physical health problems | Yes | No | Don't know |

SECTION 3: ABOUT YOU

12 What is your gender?

Please tick one box

- Male
 Female
 Other

13 How old are you?

14 What county of the UK do you live in?

15 Which of the following best describes you?

Please tick all answers that apply

- I have been diagnosed with memory/thinking difficulties
 I am a care partner or supporter of someone living with memory/thinking difficulties
 I am a student
 I am a healthcare professional
 My work or study involves working with people living with cognitive impairment
 Other _____

16 Which of the following best describes your current marital status?

Please tick one box

- Single (never married)
 Married / Civil partnership
 Cohabiting
 Divorced
 Widowed

17 Which of the following best describes your ethnicity?

Please tick one box

- White
- Black
- Asian
- Mixed
- Other _____

18 Which of the following best describes your current employment status?

Please tick all answers that apply

- Employed
- Unemployed or looking for work
- Retired
- In full-time education
- Other _____

19 Do you have any of the following qualifications?

Please tick all answers that apply

- Higher degree (PhD, Masters)
- First degree (BSc, BA)
- A-Level or equivalent
- GCSE or equivalent (O-Level)
- Other _____

THANK YOU!

Thank you for taking the time to complete this questionnaire. Your answers are very important to us. Please use the following space to write any additional comments that you would like.

Any additional comments:

CONTACT DETAILS

Research: Knowledge and understanding of cognitive impairment

If you would like to receive a summary of the research findings, or if you are interested in hearing more about taking part in an interview, please fill in your contact details on this page so that a report can be sent to you once the study is complete, or so that the researcher can contact you with details of the interviews.

COMPLETING THIS FORM DOES NOT COMMIT YOU TO TAKING PART IN AN INTERVIEW

Name:

Address:

Telephone Number:

Email Address:

INTERVIEW

I would like to find out more about taking part in an interview: Yes
 No

Preferred method of contact about interviews: Email
 Telephone

RESEARCH REPORT

I would like to receive a copy of the main research findings: Yes
 No

Preferred method of contact for report: Post
 Email
 Both post and email

Thank you very much

THIS PAGE WILL BE REMOVED FROM THE QUESTIONNAIRE AND STORED CONFIDENTIALLY SO THAT NO-ONE CAN IDENTIFY YOU.

Please return the completed questionnaire to:

**Heather Yemm
Graduate Research School (BB 173)
University of Worcester
Henwick Grove
Worcester
WR2 6AJ**



Appendix F: Participant Study Report

Version 1 (05.03.17)



Heather Yemm
Graduate Research School
University of Worcester
Henwick Grove
Worcester
WR2 6AJ
Tel: 01905 542295

Email: heather.yemm@outlook.com

Knowledge and understanding of cognitive impairment

PARTICIPANT STUDY REPORT

Why am I receiving this report?

This report is being sent to people who participated in the study "Knowledge and understanding of cognitive impairment" and indicated that they would like to receive a summary of the key findings. Thank you for taking part in this research.

What was the purpose of the study?

Some people experience memory and thinking (cognitive) difficulties that are more severe than would be expected for their age, but are not as severe as would be expected with dementia. This is known as cognitive impairment. Whilst quite a lot of people experience cognitive impairment, research suggests that there is a lack of understanding about it. This results in people not getting help and support for their concerns, delaying visiting their GP and not knowing what help may be available for them. The aim of this study was to explore what people know about cognitive impairment to gain a better understanding of how people view this and what people have heard about this previously. Understanding what people know and do not know about cognitive impairment will allow us to develop information in the future which can better inform people about this. It also allows us to identify areas where research is lacking so that we can undertake more studies to address any gaps in knowledge.

What happened?

There were two studies involved in this research:

1) Questionnaire Study

The first study involved a questionnaire which asked people what they knew about cognitive impairment. This questionnaire was available as a paper copy or could be completed online.

2) Interview Study

Following the questionnaire, a small sample of people who had completed this were invited to take part in a follow-up interview about what they knew and understood about cognitive impairment.

Who took part?

417 people completed the questionnaire. In the questionnaire, people were asked to indicate which of several possible participant groups they identified with. The numbers of people responding from each group were:

- 10 people living with cognitive impairment
- 23 care partners and supporters of people living with cognitive impairment
- 83 younger adults (aged between 18 and 65)
- 83 older adults (aged over 65)
- 96 healthcare professionals
- 40 dementia specialists
- 48 dementia specialist healthcare professionals
- 34 other (undeclared and multiple groups)

Following the questionnaire, 46 people were invited to take part in an interview. Unfortunately, several people were not able to take part. In total, 22 people took part in an interview. The numbers of people interviewed from each participant group were:

- 4 people living with cognitive impairment
- 4 care partners and supporters of people living with cognitive impairment
- 2 younger adults (aged between 18 and 65)
- 6 older adults (aged over 65)
- 1 healthcare professional
- 5 dementia specialists

The interviews ranged in time from 30 minutes to 2 hours and 17 minutes. The average interview lasted 1 hour and 6 minutes.

What were the results?

Questionnaire Study

Overall, participant groups did not differ greatly in their knowledge and understanding though there were some differences in the responses that people gave in the questionnaire. For example:

- Healthcare professionals and dementia specialists had the most confidence in their own understanding about cognitive impairment and dementia.
- Younger adults were the most likely to report that memory and thinking problems were a normal part of getting older.

- Dementia specialists and older adults were the least likely to report that cognitive impairment is easy to live with.
- Care partners, older adults and younger adults were most likely to state that cognitive impairment leads to a loss of independence.
- Older adults were the most uncertain about whether people with cognitive impairment can still live a full and happy life.
- Dementia specialist healthcare professionals were the least likely to state that cognitive impairment was permanent.

Across all participants, most people stated that:

- Cognitive impairment was not a normal part of ageing nor a form of dementia
- People with cognitive impairment will not definitely develop dementia
- People with cognitive impairment are still the same person
- Cognitive impairment is not easy to live with
- People with cognitive impairment lose their self-confidence
- Staying active can help treat the symptoms of cognitive impairment
- There were a wide range of things which could cause cognitive impairment, including: getting older, genetics, abnormal brain changes, head injury, stress or worry, physical health problems, and personal behaviour.

There was uncertainty around:

- Whether memory and thinking problems are a normal part of getting older
- Whether cognitive impairment is preventable
- Whether diet could cause cognitive impairment

One of the questions asked what term would best describe the symptoms experienced by Beth who “has noticed that she is forgetful at work and has missed a couple of meetings and personal appointments. Beth has also been having trouble finding the right words to describe things at times.” The term selected by most participants was mild cognitive impairment, followed by memory problems and stress.

Interview Study

Most participants thought cognitive impairment involved memory and communication problems. People used a range of terms to talk about cognitive impairment. Some participants felt that the word “mild” in the term mild cognitive impairment was inappropriate as the impact of cognitive impairment was not mild for people living with this. People reported that cognitive impairment was a personal experience which varied between individuals.

Most participants stated that the permanency of cognitive impairment depended on the cause. Participants offered a range of possible causes of cognitive impairment, generally stating that cognitive impairment was not something that people could control. Participants suggested that lifestyle factors may increase or decrease

someone's risk of cognitive impairment but that it was not possible to entirely prevent cognitive impairment.

Participants talked about whether cognitive impairment was related to dementia and/or normal ageing and were unclear where to place the boundaries between these. People were fearful of cognitive impairment and dementia and a few participants suggested that they would not want to live with a cognitive impairment. People talked about cognitive impairment as an end of life or terminal condition.

What next?

The results of this study suggest that people have a clear view about what cognitive impairment is, but that they know more about dementia. People want more information about both cognitive impairment and dementia and this information should attempt to clarify where the boundaries are between normal ageing, cognitive impairment and dementia.

Future research should explore the labels and language people use when talking about cognitive impairment. Many different terms are currently used which may be confusing. Research should explore what specific information people want to know about cognitive impairment to develop information resources to address this. This study mainly involved highly educated, white female participants. Future research should explore the views of a more diverse population.

The results of this research provide a framework for information resources and awareness campaigns for cognitive impairment and highlight areas for future research. Providing better information may allow people to recognise symptoms of cognitive impairment and seek timely help and advice, as well as understanding how best to support people living with cognitive impairment.

Further information and contact details

If you would like to find out more about this study, or if you have any questions, please contact one of the research team:

Heather Yemm
PhD Researcher
Graduate Research School
University of Worcester
Henwick Grove
Worcester
WR2 6AJ
Tel: 01905 54 2295
Email: heather.yemm@outlook.com

Or

Professor Dawn Brooker
Supervisor
Association for Dementia Studies
University of Worcester
Henwick Grove
Worcester
WR2 6AJ
Tel: 01905 85 5250
Email: d.brooker@worc.ac.uk

Thank you for taking part in this study

Appendix G: Questionnaire Response Data

Table G.1: Respondents prior experience of cognitive impairment and dementia

| | Participant Groups - Responding "Yes": % (n) | | | | | | | | Total |
|--|---|---------------------|--------------------|----------------------|--------------------------------|-------------------|---|---|--------------|
| | Living with cognitive impairment | Care partner | Older adult | Younger adult | Healthcare professional | Specialist | Specialist healthcare professional | Other (undeclared and multiple groups) | |
| Have you heard of cognitive impairment before? | 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) |
| Do you know anybody personally who has ever 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) |
| Do you know anybody personally who has ever 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) |
| Have you ever read any information about cognitive impairment? | 70.0% (7) | 69.6% (16) | 39.8% (33) | 38.6% (32) | 93.8% (90) | 80% (32) | 95.8% (46) | 91.2% (31) | 68.8% (287) |
| Have you ever 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) |

Table G.2: Respondents knowledge of cognitive impairment and dementia

| | % (n) responding Agree or Strongly Agree | | | |
|----------------------------------|---|--|---|------------------------------------|
| | I have a good understanding of what cognitive impairment is | I want to know more about cognitive impairment | I have a good understanding of what dementia is | I want to know more about dementia |
| All | 61.4% (256) | 82.0% (342) | 82.3% (343) | 81.8% (341) |
| Gender | | | | |
| Male | 50.5% (46) | 73.6% (67) | 78.0% (71) | 73.6% (67) |
| Female | 64.4% (208) | 84.5% (273) | 83.6% (270) | 84.2% (272) |
| Undeclared | 66.7% (2) | 66.7% (2) | 66.7% (2) | 66.7% (2) |
| Age | V = 0.379*** | V = 0.244*** | V = 0.292*** | V = 0.231*** |
| <20 | 100.0% (2) | 50.0% (1) | 100.0% (2) | 50.0% (1) |
| 21-30 | 47.3% (26) | 80.0% (44) | 76.4% (42) | 87.3% (48) |
| 31-40 | 79.7% (51) | 85.9% (55) | 90.6% (58) | 89.1% (57) |
| 41-50 | 82.7% (62) | 84.0% (63) | 97.3% (73) | 82.7% (62) |
| 51-60 | 67.3% (68) | 83.2% (84) | 90.1% (91) | 81.2% (82) |
| 61-70 | 35.1% (20) | 75.4% (43) | 63.2% (36) | 71.9% (41) |
| 71-80 | 44.2% (19) | 79.1% (34) | 65.1% (28) | 76.7% (33) |
| 81-90 | 46.2% (6) | 100.0% (13) | 76.9% (10) | 92.3% (12) |
| 91-100 | 0.0% (0) | 50.0% (1) | 0.0% (0) | 50.0% (1) |
| Undeclared | 40.0% (2) | 80.0% (4) | 60.0% (3) | 80.0% (4) |
| Marital status | | | | |
| Single (never married) | 50.8% (32) | 84.1% (53) | 76.2% (48) | 79.4% (50) |
| Married / Civil partnership | 65.0% (147) | 78.8% (178) | 84.5% (191) | 79.2% (179) |
| Cohabiting | 63.8% (44) | 88.4% (61) | 84.1% (58) | 91.3% (63) |
| Divorced | 68.0% (17) | 88.0% (22) | 80.0% (20) | 92.0% (23) |
| Widowed | 41.4% (12) | 79.3% (23) | 72.4% (21) | 75.9% (22) |
| Undeclared | 80.0% (4) | 100.0% (5) | 100.0% (5) | 80.0% (4) |
| Educational qualification | V = 0.170** | | | |
| Higher degree (PhD, Masters) | 66.8% (125) | 81.8% (153) | 84.0% (157) | 81.3% (152) |

| | | | | |
|--|--------------|-------------|--------------|-------------|
| Post-graduate qualification | 57.1% (4) | 100.0% (7) | 71.4% (5) | 71.4% (5) |
| Professional qualification | 48.8% (20) | 87.8% (36) | 82.9% (34) | 90.2% (37) |
| First degree | 67.2% (82) | 79.5% (97) | 82.0% (100) | 82.0% (100) |
| A-Level or equivalent | 54.1% (20) | 78.4% (29) | 81.1% (30) | 75.7% (28) |
| GCSE or equivalent (O-Level) | 18.8% (3) | 87.5% (14) | 81.3% (13) | 87.5% (14) |
| Undeclared/None | 28.6% (2) | 85.7% (6) | 57.1% (4) | 71.4% (5) |
| Employment status | V = 0.208*** | | V = 0.194*** | |
| Employed | 73.1% (198) | 83.0% (225) | 90.4% (245) | 83.0% (225) |
| Unemployed | 33.3% (1) | 100.0% (3) | 66.7% (2) | 100.0% (3) |
| Retired | 36.4% (36) | 77.8% (77) | 63.6% (63) | 76.8% (76) |
| In full-time education | 47.1% (8) | 76.5% (13) | 76.5% (13) | 76.5% (13) |
| Other ("Other" and multiple groups) | 42.9% (9) | 90.5% (19) | 71.4% (15) | 90.5% (19) |
| Undeclared | 66.7% (4) | 83.3% (5) | 83.3% (5) | 83.3% (5) |
| Ethnicity | | | | |
| White | 61.9% (242) | 82.1% (321) | 83.1% (325) | 82.1% (321) |
| Black | 100.0% (2) | 100.0% (2) | 100.0% (2) | 100.0% (2) |
| Asian | 60.0% (3) | 80.0% (4) | 60.0% (3) | 60.0% (3) |
| Mixed | 20.0% (1) | 100.0% (5) | 60.0% (3) | 100.0% (5) |
| Other | 40.0% (4) | 60.0% (6) | 60.0% (6) | 60.0% (6) |
| Undeclared | 100.0% (4) | 100.0% (4) | 100.0% (4) | 100.0% (4) |
| Heard of cognitive impairment before | V = 0.299*** | | V = 0.147** | |
| Yes | 67.8% (249) | 81.2% (298) | 84.5% (310) | 81.2% (298) |
| No | 12.8% (6) | 89.4% (42) | 66.0% (31) | 87.2% (41) |
| Undeclared | 33.3% (1) | 66.7% (2) | 66.7% (2) | 66.7% (2) |
| Know somebody with cognitive impairment | V = 0.315*** | | V = 0.156** | |
| Yes | 78.7% (188) | 81.6% (195) | 88.3% (211) | 82.0% (196) |
| No | 37.7% (66) | 82.3% (144) | 74.3% (130) | 81.1% (142) |
| Undeclared | 66.7% (2) | 100.0% (3) | 66.7% (2) | 100.0% (3) |
| Know somebody with dementia | | | V = 0.161*** | |
| Yes | 64.2% (212) | 82.1% (271) | 86.1% (284) | 82.1% (271) |

| | | | | |
|--|--------------|-------------|--------------|-------------|
| No | 50.0% (43) | 81.4% (70) | 67.4% (58) | 80.2% (69) |
| Undeclared | 100.0% (1) | 100.0% (1) | 100.0% (1) | 100.0% (1) |
| Read about cognitive impairment | V = 0.450*** | | V = 0.208*** | |
| Yes | 80.8% (232) | 82.2% (236) | 89.2% (256) | 81.5% (234) |
| No | 16.7% (21) | 81.0% (102) | 65.9% (83) | 81.7% (103) |
| Undeclared | 75.0% (3) | 100.0% (4) | 100.0% (4) | 100.0% (4) |
| Read about dementia | V = 0.234*** | | V = 0.286*** | |
| Yes | 66.1% (251) | 82.4% (313) | 86.8% (330) | 82.4% (313) |
| No | 11.4% (4) | 80.0% (28) | 31.4% (11) | 77.1% (27) |
| Undeclared | 50.0% (1) | 50.0% (1) | 100.0% (2) | 50.0% (1) |

*p ≤ 0.05, **p ≤ 0.01, ***p ≤ 0.001

Table G.3: Responses to statements relating to identification and definition of cognitive impairment

| | % (n) responding True | | | | |
|----------------------------------|---|--|---|--|---|
| | Cognitive impairment is a normal part of ageing | Cognitive impairment is a form of dementia | Cognitive impairment only affects people over the age of 65 | Cognitive impairment is a mental illness | Memory and thinking problems are a normal part of getting older |
| All | 22.5% (94) | 18.9% (79) | 0.2% (1) | 17.7% (74) | 48.4% (202) |
| Gender | | | | V = 0.158** | V = 0.260*** |
| Male | 24.2% (22) | 23.1% (21) | 0.0% (0) | 33.0% (30) | 59.3% (54) |
| Female | 22.0% (71) | 17.6% (57) | 0.3% (1) | 13.6% (44) | 45.2% (146) |
| Undeclared | 33.3% (1) | 33.3% (1) | 0.0% (0) | 0.0% (0) | 66.7% (2) |
| Age | V = 0.207** | V = 0.237*** | V = 0.240*** | V = 0.223*** | V = 0.224*** |
| <20 | 0.0% (0) | 50.0% (1) | 0.0% (0) | 0.0% (0) | 50.0% (1) |
| 21-30 | 29.1% (16) | 23.6% (13) | 0.0% (0) | 27.3% (15) | 63.6% (35) |
| 31-40 | 32.8% (21) | 25.0% (16) | 1.6% (1) | 21.9% (14) | 53.1% (34) |
| 41-50 | 16.0% (12) | 12.0% (9) | 0.0% (0) | 6.7% (5) | 33.3% (25) |
| 51-60 | 17.8% (18) | 19.8% (20) | 0.0% (0) | 14.9% (15) | 34.7% (35) |
| 61-70 | 17.5% (10) | 19.3% (11) | 0.0% (0) | 15.8% (9) | 49.1% (28) |
| 71-80 | 23.3% (10) | 9.3% (4) | 0.0% (0) | 16.3% (7) | 67.4% (29) |
| 81-90 | 38.5% (5) | 15.4% (2) | 0.0% (0) | 30.8% (4) | 76.9% (10) |
| 91-100 | 50.0% (1) | 50.0% (1) | 0.0% (0) | 100% (2) | 50.0% (1) |
| Undeclared | 20.0% (1) | 40.0% (2) | 0.0% (0) | 60.0% (3) | 80.0% (4) |
| Marital status | | | | V = 0.178*** | |
| Single (never married) | 25.4% (16) | 17.5% (11) | 0.0% (0) | 25.4% (16) | 49.2% (31) |
| Married / Civil partnership | 21.2% (48) | 21.7% (49) | 0.0% (0) | 15.5% (35) | 44.7% (101) |
| Cohabiting | 26.1% (18) | 13.0% (9) | 1.4% (1) | 17.4% (12) | 58.0% (40) |
| Divorced | 16.0% (4) | 20.0% (5) | 0.0% (0) | 8.0% (2) | 52.0% (13) |
| Widowed | 20.7% (6) | 13.8% (4) | 0.0% (0) | 20.7% (6) | 48.3% (14) |
| Undeclared | 40.0% (2) | 20.0% (1) | 0.0% (0) | 60.0% (3) | 60.0% (3) |
| Educational qualification | V = 0.165* | V = 0.184*** | V = 0.237*** | V = 0.200*** | |

| | | | | | |
|--|---------------------|---------------------|---------------------|---------------------|-------------------|
| Higher degree (PhD, Masters) | 24.1% (45) | 13.9% (26) | 0.5% (1) | 13.9% (26) | 51.3% (96) |
| Post-graduate qualification | 14.3% (1) | 28.6% (2) | 0.0% (0) | 0.0% (0) | 28.6% (2) |
| Professional qualification | 14.6% (6) | 26.8% (11) | 0.0% (0) | 22.0% (9) | 41.5% (17) |
| First degree | 22.1% (27) | 23.0% (28) | 0.0% (0) | 23.0% (28) | 46.7% (57) |
| A-Level or equivalent | 18.9% (7) | 18.9% (7) | 0.0% (0) | 13.5% (5) | 48.6% (18) |
| GCSE or equivalent (O-Level) | 37.5% (6) | 25.0% (4) | 0.0% (0) | 18.8% (3) | 56.3% (9) |
| Undeclared/None | 28.6% (2) | 14.3% (1) | 0.0% (0) | 42.9% (3) | 42.9% (3) |
| Employment status | V = 0.172*** | V = 0.157** | V = 0.214*** | V = 0.184*** | V = 0.153* |
| Employed | 21.4% (58) | 17.3% (47) | 0.0% (0) | 14.4% (39) | 42.8% (116) |
| Unemployed | 0.0% (0) | 33.3% (1) | 0.0% (0) | 66.7% (2) | 66.7% (2) |
| Retired | 22.2% (22) | 17.2% (17) | 0.0% (0) | 22.2% (22) | 61.6% (61) |
| In full-time education | 41.2% (7) | 35.3% (6) | 5.9% (1) | 23.5% (4) | 76.5% (13) |
| Other ("Other" and multiple groups) | 28.6% (6) | 28.6% (6) | 0.0% (0) | 19.0% (4) | 38.1% (8) |
| Undeclared | 16.7% (1) | 33.3% (2) | 0.0% (0) | 50.0% (3) | 33.3% (2) |
| Ethnicity | | | | | |
| White | 23.0% (90) | 19.4% (76) | 0.3% (1) | 17.9% (70) | 48.3% (189) |
| Black | 0.0% (0) | 50.0% (1) | 0.0% (0) | 0.0% (0) | 0.0% (0) |
| Asian | 0.0% (0) | 20.0% (1) | 0.0% (0) | 0.0% (0) | 60.0% (3) |
| Mixed | 40.0% (2) | 20.0% (1) | 0.0% (0) | 20.0% (1) | 80.0% (4) |
| Other | 20.0% (2) | 0.0% (0) | 0.0% (0) | 30.0% (3) | 60.0% (6) |
| Undeclared | 0.0% (0) | 0.0% (0) | 0.0% (0) | 0.0% (0) | 0.0% (0) |
| Heard of cognitive impairment before | V = 0.208*** | V = 0.236*** | V = 0.253*** | V = 0.124* | |
| Yes | 21.5% (79) | 17.7% (65) | 0.3% (1) | 16.9% (62) | 46.6% (171) |
| No | 29.8% (14) | 29.8% (14) | 0.0% (0) | 23.4% (11) | 63.8% (30) |
| Undeclared | 33.3% (1) | 0.0% (0) | 0.0% (0) | 33.3% (1) | 33.3% (1) |
| Know somebody with cognitive impairment | V = 0.183*** | V = 0.168*** | V = 0.146** | | |
| Yes | 23.0% (55) | 20.1% (48) | 0.0% (0) | 15.5% (37) | 41.8% (100) |
| No | 22.3% (39) | 17.1% (30) | 0.6% (1) | 21.1% (37) | 57.7% (101) |
| Undeclared | 0.0% (0) | 33.3% (1) | 0.0% (0) | 0.0% (0) | 33.3% (1) |
| Know somebody with dementia | V = 0.132* | | | | |

| | | | | | |
|--|--------------|--------------|--------------|-------------|--------------|
| Yes | 23.0% (76) | 17.3% (57) | 0.0% (0) | 16.7% (55) | 45.8% (151) |
| No | 20.9% (18) | 24.4% (21) | 1.2% (1) | 22.1% (19) | 59.3% (51) |
| Undeclared | 0.0% (0) | 100.0% (1) | 0.0% (0) | 0.0% (0) | 0.0% (0) |
| Read about cognitive impairment | V = 0.291*** | V = 0.357*** | V = 0.214*** | V = 0.149** | V = 0.208*** |
| Yes | 17.8% (51) | 16.7% (48) | 0.3% (1) | 14.6% (42) | 38.7% (111) |
| No | 33.3% (42) | 24.6% (31) | 0.0% (0) | 24.6% (31) | 69.8% (88) |
| Undeclared | 25.0% (1) | 0.0% (0) | 0.0% (0) | 25.0% (1) | 75.0% (3) |
| Read about dementia | | V = 0.192*** | | | |
| Yes | 22.9% (87) | 17.9% (68) | 0.3% (1) | 17.1% (65) | 46.6% (177) |
| No | 20.0% (7) | 31.4% (11) | 0.0% (0) | 22.9% (8) | 71.4% (25) |
| Undeclared | 0.0% (0) | 0.0% (0) | 0.0% (0) | 50.0% (1) | 0.0% (0) |

*p ≤ 0.05, **p ≤ 0.01, ***p ≤ 0.001

Table G.4: Responses to statements relating to consequences of cognitive impairment

| | % (n) responding True | | | | | |
|-----------------------------|---|---|---|--|---|---|
| | People with cognitive impairment will definitely develop dementia | People with cognitive impairment are no longer the same person that they used to be | Cognitive impairment is easy to live with | People with cognitive impairment lose their independence | People with cognitive impairment lose their self-confidence | People with cognitive impairment can still live a full and happy life |
| All | 0.7% (3) | 9.1% (38) | 3.8% (16) | 19.7% (82) | 65.7% (274) | 89.4% (373) |
| Gender | V = 0.137* | | | | | |
| Male | 2.2% (2) | 13.2% (12) | 6.6% (6) | 23.1% (21) | 62.6% (57) | 82.4% (75) |
| Female | 0.3% (1) | 7.7% (25) | 2.8% (9) | 18.9% (61) | 66.9% (216) | 91.3% (295) |
| Undeclared | 0.0% (0) | 33.3% (1) | 33.3% (1) | 0.0% (0) | 33.3% (1) | 100.0% (3) |
| Age | V = 0.242*** | | V = 0.202** | V = 0.195** | V = 0.276*** | |
| <20 | 0.0% (0) | 0.0% (0) | 0.0% (0) | 0.0% (0) | 50.0% (1) | 100.0% (2) |
| 21-30 | 0.0% (0) | 1.8% (1) | 1.8% (1) | 16.4% (9) | 56.4% (31) | 89.1% (49) |
| 31-40 | 1.6% (1) | 4.7% (3) | 3.1% (2) | 26.6% (17) | 68.8% (44) | 98.4% (63) |
| 41-50 | 0.0% (0) | 2.7% (2) | 1.3% (1) | 12.0% (9) | 65.3% (49) | 97.3% (73) |
| 51-60 | 0.0% (0) | 15.8% (16) | 4.0% (4) | 22.8% (23) | 69.3% (70) | 92.1% (93) |
| 61-70 | 1.8% (1) | 17.5% (10) | 1.8% (1) | 22.8% (13) | 73.7% (42) | 77.2% (44) |
| 71-80 | 2.3% (1) | 4.7% (2) | 9.3% (4) | 9.3% (4) | 62.8% (27) | 88.4% (38) |
| 81-90 | 0.0% (0) | 7.7% (1) | 15.4% (2) | 23.1% (3) | 38.5% (5) | 53.8% (7) |
| 91-100 | 0.0% (0) | 100.0% (2) | 50.0% (1) | 100.0% (2) | 100.0% (2) | 50.0% (1) |
| Undeclared | 0.0% (0) | 20.0% (1) | 0.0% (0) | 40.0% (2) | 60.0% (3) | 60.0% (3) |
| Marital status | V = 0.143* | V = 0.165** | | | V = 0.151* | V=0.149* |
| Single (never married) | 0.0% (0) | 9.5% (6) | 3.2% (2) | 17.5% (11) | 49.2% (31) | 84.1% (53) |
| Married / Civil partnership | 0.9% (2) | 8.4% (19) | 2.2% (5) | 19.9% (45) | 72.1% (163) | 90.7% (205) |
| Cohabiting | 0.0% (0) | 2.9% (2) | 2.9% (2) | 20.3% (14) | 66.7% (46) | 94.2% (65) |

| | | | | | | |
|--|--------------|--------------|--------------|--------------|--------------|--------------|
| Divorced | 4.0% (1) | 8.0% (2) | 12.0% (3) | 16.0% (4) | 48.0% (12) | 92.0% (23) |
| Widowed | 0.0% (0) | 31.0% (9) | 13.8% (4) | 24.1% (7) | 69.0% (20) | 82.8% (24) |
| Undeclared | 0.0% (0) | 0.0% (0) | 0.0% (0) | 20.0% (1) | 40.0% (2) | 60.0% (3) |
| Educational qualification | V = 0.209*** | V = 0.192*** | | V = 0.164* | | V = 0.194*** |
| Higher degree (PhD, Masters) | 0.0% (0) | 5.9% (11) | 3.7% (7) | 18.7% (35) | 63.6% (119) | 93.6% (175) |
| Post-graduate qualification | 0.0% (0) | 14.3% (1) | 0.0% (0) | 14.3% (1) | 85.7% (6) | 71.4% (5) |
| Professional qualification | 0.0% (0) | 14.6% (6) | 7.3% (3) | 19.5% (8) | 63.4% (26) | 78.0% (32) |
| First degree | 2.5% (3) | 6.6% (8) | 4.9% (6) | 16.4% (20) | 67.2% (82) | 91.0% (111) |
| A-Level or equivalent | 0.0% (0) | 13.5% (5) | 0.0% (0) | 29.7% (11) | 75.7% (28) | 91.9% (34) |
| GCSE or equivalent (O-Level) | 0.0% (0) | 25.0% (4) | 0.0% (0) | 31.3% (5) | 68.8% (11) | 81.3% (13) |
| Undeclared/None | 0.0% (0) | 42.9% (3) | 0.0% (0) | 28.6% (2) | 28.6% (2) | 42.9% (3) |
| Employment status | V = 0.174*** | V = 0.174*** | V = 0.181*** | V = 0.161** | | V = 0.167** |
| Employed | 0.4% (1) | 7.0% (19) | 2.6% (7) | 16.6% (45) | 64.6% (175) | 95.2% (258) |
| Unemployed | 0.0% (0) | 0.0% (0) | 0.0% (0) | 33.3% (1) | 66.7% (2) | 100.0% (3) |
| Retired | 2.0% (2) | 14.1% (14) | 6.1% (6) | 20.2% (20) | 69.7% (69) | 77.8% (77) |
| In full-time education | 0.0% (0) | 0.0% (0) | 5.9% (1) | 23.5% (4) | 52.9% (9) | 82.4% (14) |
| Other (“Other” and multiple groups) | 0.0% (0) | 19.0% (4) | 9.5% (2) | 47.6% (10) | 71.4% (15) | 81.0% (17) |
| Undeclared | 0.0% (0) | 16.7% (1) | 0.0% (0) | 33.3% (2) | 66.7% (4) | 66.7% (4) |
| Ethnicity | V = 0.160** | | | | V = 0.145* | V = 0.160** |
| White | 0.5% (2) | 9.2% (36) | 3.8% (15) | 19.4% (76) | 66.2% (259) | 90.3% (353) |
| Black | 0.0% (0) | 0.0% (0) | 0.0% (0) | 0.0% (0) | 0.0% (0) | 100.0% (2) |
| Asian | 0.0% (0) | 0.0% (0) | 0.0% (0) | 40.0% (2) | 100.0% (5) | 80.0% (4) |
| Mixed | 20.0% (1) | 0.0% (0) | 0.0% (0) | 20.0% (1) | 60.0% (3) | 60.0% (3) |
| Other | 0.0% (0) | 20.0% (2) | 10.0% (1) | 20.0% (2) | 50.0% (5) | 70.0% (7) |
| Undeclared | 0.0% (0) | 0.0% (0) | 0.0% (0) | 25.0% (1) | 50.0% (2) | 100.0% (4) |
| Heard of cognitive impairment before | V = 0.259*** | V = 0.218*** | V = 0.211*** | V = 0.250*** | V = 0.215*** | V = 0.291*** |
| Yes | 0.5% (2) | 8.7% (32) | 3.5% (13) | 19.6% (72) | 66.2% (243) | 92.4% (339) |
| No | 2.1% (1) | 12.8% (6) | 6.4% (3) | 21.3% (10) | 63.8% (30) | 70.2% (33) |
| Undeclared | 0.0% (0) | 0.0% (0) | 0.0% (0) | 0.0% (0) | 33.3% (1) | 33.3% (1) |
| Know somebody with cognitive impairment | V = 0.168*** | | V = 0.164*** | | V = 0.135* | |

| | | | | | | |
|--|--------------|--------------|------------|--------------|--------------|--------------|
| Yes | 0.8% (2) | 8.8% (21) | 4.2% (10) | 20.1% (48) | 65.3% (156) | 93.3% (223) |
| No | 0.6% (1) | 9.7% (17) | 2.9% (5) | 19.4% (34) | 66.3% (116) | 84.6% (148) |
| Undeclared | 0.0% (0) | 0.0% (0) | 33.3% (1) | 0.0% (0) | 66.7% (2) | 66.7% (2) |
| Know somebody with dementia | V = 0.187*** | | | | | |
| Yes | 0.9% (3) | 9.7% (32) | 3.9% (13) | 21.2% (70) | 65.5% (216) | 89.4% (295) |
| No | 0.0% (0) | 7.0% (6) | 2.3% (2) | 14.0% (12) | 67.4% (58) | 89.5% (77) |
| Undeclared | 0.0% (0) | 0.0% (0) | 100.0% (1) | 0.0% (0) | 0.0% (0) | 100.0% (1) |
| Read about cognitive impairment | V = 0.297*** | V = 0.198*** | | V = 0.267*** | V = 0.213*** | V = 0.189*** |
| Yes | 0.7% (2) | 8.0% (23) | 3.8% (11) | 20.9% (60) | 65.5% (188) | 94.8% (272) |
| No | 0.8% (1) | 11.9% (15) | 4.0% (5) | 17.5% (22) | 65.9% (83) | 77.0% (97) |
| Undeclared | 0.0% (0) | 0.0% (0) | 0.0% (0) | 0.0% (0) | 75.0% (3) | 100.0% (4) |
| Read about dementia | V = 0.221*** | | | V = 0.127* | | V = 0.125* |
| Yes | 0.8% (3) | 8.4% (32) | 3.9% (15) | 19.5% (74) | 66.1% (251) | 90.8% (345) |
| No | 0.0% (0) | 17.1% (6) | 2.9% (1) | 22.9% (8) | 65.7% (23) | 74.3% (26) |
| Undeclared | 0.0% (0) | 0.0% (0) | 0.0% (0) | 0.0% (0) | 0.0% (0) | 100.0% (2) |

*p ≤ 0.05, **p ≤ 0.01, ***p ≤ 0.001

Table G.5: Responses to statements relating to permanency and controllability of cognitive impairment

| | % (n) responding True | | | | |
|-----------------------------|-----------------------------------|--|-----------------------------------|---|-------------------------------------|
| | Timeline | | Control | | |
| | Cognitive impairment is permanent | There are treatments available which can help people with cognitive impairment | Cognitive impairment can be cured | Staying active can help to treat the symptoms of cognitive impairment | Cognitive impairment is preventable |
| All | 26.1% (109) | 66.9% (279) | 11.3% (47) | 85.1% (355) | 18.0% (75) |
| Gender | V = 0.141* | | | | |
| Male | 26.4% (24) | 57.1% (52) | 12.1% (11) | 79.1% (72) | 11.0% (10) |
| Female | 26.0% (84) | 69.7% (225) | 11.1% (36) | 87.0% (281) | 20.1% (65) |
| Undeclared | 33.3% (1) | 66.7% (2) | 0.0% (0) | 66.7% (2) | 0.0% (0) |
| Age | V = 0.254*** | V = 0.271*** | V = 0.218*** | | V = 0.198** |
| <20 | 50.0% (1) | 100.0% (2) | 0.0% (0) | 100% (2) | 100% (2) |
| 21-30 | 23.6% (13) | 74.5% (41) | 10.9% (6) | 78.2% (43) | 25.5% (14) |
| 31-40 | 25.0% (16) | 82.8% (53) | 10.9% (7) | 82.8% (53) | 15.6% (10) |
| 41-50 | 26.7% (20) | 74.7% (56) | 16.0% (12) | 90.7% (68) | 24.0% (18) |
| 51-60 | 28.7% (29) | 66.3% (67) | 16.8% (17) | 85.1% (86) | 21.8% (22) |
| 61-70 | 31.6% (18) | 52.6% (30) | 3.5% (2) | 82.5% (47) | 10.5% (6) |
| 71-80 | 25.6% (11) | 48.8% (21) | 2.3% (1) | 93.0% (40) | 7.0% (3) |
| 81-90 | 0.0% (0) | 30.8% (4) | 0.0% (0) | 76.9% (10) | 0.0% (0) |
| 91-100 | 0.0% (0) | 100% (2) | 50.0% (1) | 100% (2) | 0.0% (0) |
| Undeclared | 20.0% (1) | 60.0% (3) | 20.0% (1) | 80.0% (4) | 0.0% (0) |
| Marital status | | | | | |
| Single (never married) | 22.2% (14) | 73.0% (46) | 9.5% (6) | 81.0% (51) | 30.2% (19) |
| Married / Civil partnership | 27.4% (62) | 69.0% (156) | 11.5% (26) | 87.2% (197) | 14.6% (33) |
| Cohabiting | 27.5% (19) | 60.9% (42) | 10.1% (7) | 82.6% (57) | 18.8% (13) |
| Divorced | 32.0% (8) | 64.0% (16) | 20.0% (5) | 80.0% (20) | 20.0% (5) |

| | | | | | |
|--|--------------|--------------|--------------|--------------|--------------|
| Widowed | 13.8% (4) | 55.2% (16) | 10.3% (3) | 89.7% (26) | 13.8% (4) |
| Undeclared | 40.0% (2) | 60.0% (3) | 0.0% (0) | 80.0% (4) | 20.0% (1) |
| Educational qualification | V = 0.174** | V = 0.162* | V = 0.178** | | |
| Higher degree (PhD, Masters) | 24.1% (45) | 70.6% (132) | 10.2% (19) | 86.6% (162) | 22.5% (42) |
| Post-graduate qualification | 57.1% (4) | 42.9% (3) | 0.0% (0) | 100% (7) | 14.3% (1) |
| Professional qualification | 31.7% (13) | 63.4% (26) | 9.8% (4) | 78.0% (32) | 4.9% (2) |
| First degree | 28.7% (35) | 71.3% (87) | 13.1% (16) | 87.7% (107) | 18.9% (23) |
| A-Level or equivalent | 27.0% (10) | 59.5% (22) | 8.1% (3) | 86.5% (32) | 16.2% (6) |
| GCSE or equivalent (O-Level) | 12.5% (2) | 43.8% (7) | 31.3% (5) | 62.5% (10) | 6.3% (1) |
| Undeclared/None | 0.0% (0) | 28.6% (2) | 0.0% (0) | 71.4% (5) | 0.0% (0) |
| Employment status | V = 0.181*** | V = 0.219*** | V = 0.199*** | V = 0.212*** | V = 0.164** |
| Employed | 25.1% (68) | 76.4% (207) | 15.1% (41) | 86.7% (235) | 23.2% (63) |
| Unemployed | 0.0% (0) | 33.3% (1) | 33.3% (1) | 100% (3) | 33.3% (1) |
| Retired | 28.3% (28) | 47.5% (47) | 2.0% (2) | 86.9% (86) | 4.0% (4) |
| In full-time education | 17.6% (3) | 70.6% (12) | 11.8% (2) | 64.7% (11) | 23.5% (4) |
| Other ("Other" and multiple groups) | 42.9% (9) | 47.6% (10) | 4.8% (1) | 76.2% (16) | 4.8% (1) |
| Undeclared | 16.7% (1) | 33.3% (2) | 0.0% (0) | 66.7% (4) | 33.3% (2) |
| Ethnicity | | | | V = 0.174*** | V=0.147* |
| White | 26.6% (104) | 67.8% (265) | 11.3% (44) | 86.2% (337) | 17.6% (69) |
| Black | 0.0% (0) | 100% (2) | 50.0% (1) | 50.0% (1) | 0.0% (0) |
| Asian | 0.0% (0) | 40.0% (2) | 0.0% (0) | 60.0% (3) | 0.0% (0) |
| Mixed | 20.0% (1) | 40.0% (2) | 20.0% (1) | 40.0% (2) | 20.0% (1) |
| Other | 20.0% (2) | 40.0% (4) | 10.0% (1) | 80.0% (8) | 10.0% (1) |
| Undeclared | 50.0% (2) | 100% (4) | 0.0% (0) | 100% (4) | 100% (4) |
| Heard of cognitive impairment before | V = 0.176*** | V = 0.190*** | V = 0.189*** | V = 0.297*** | V = 0.200*** |
| Yes | 26.7% (98) | 70.3% (258) | 12.3% (45) | 86.1% (316) | 19.3% (71) |
| No | 21.3% (10) | 40.4% (19) | 4.3% (2) | 78.7% (37) | 8.5% (4) |
| Undeclared | 33.3% (1) | 66.7% (2) | 0.0% (0) | 66.7% (2) | 0.0% (0) |
| Know somebody with cognitive impairment | V = 0.169*** | V = 0.243*** | V = 0.176*** | | V = 0.179*** |
| Yes | 28.0% (67) | 79.1% (189) | 15.5% (37) | 87.9% (210) | 23.0% (55) |

| | | | | | |
|--|--------------|--------------|--------------|--------------|--------------|
| No | 24.0% (42) | 51.4% (90) | 5.7% (10) | 81.7% (143) | 10.9% (19) |
| Undeclared | 0.0% (0) | 0.0% (0) | 0.0% (0) | 66.7% (2) | 33.3% (1) |
| Know somebody with dementia | | V = 0.140* | | | |
| Yes | 26.1% (86) | 69.1% (228) | 11.5% (38) | 85.5% (282) | 18.2% (60) |
| No | 26.7% (23) | 59.3% (51) | 10.5% (9) | 83.7% (72) | 17.4% (15) |
| Undeclared | 0.0% (0) | 0.0% (0) | 0.0% (0) | 100.0% (1) | 0.0% (0) |
| Read about cognitive impairment | V = 0.305*** | V = 0.339*** | V = 0.298*** | V = 0.214*** | V = 0.248*** |
| Yes | 27.9% (80) | 79.8% (229) | 14.6% (42) | 89.5% (257) | 22.3% (64) |
| No | 21.4% (27) | 38.1% (48) | 3.2% (4) | 75.4% (95) | 7.9% (10) |
| Undeclared | 50.0% (2) | 50.0% (2) | 25.0% (1) | 75.0% (3) | 25.0% (1) |
| Read about dementia | V = 0.162*** | V = 0.206*** | V = 0.189*** | | |
| Yes | 26.6% (101) | 70.0% (266) | 12.4% (47) | 85.3% (324) | 19.2% (73) |
| No | 20.0% (7) | 37.1% (13) | 0.0% (0) | 82.9% (29) | 2.9% (1) |
| Undeclared | 50.0% (1) | 0.0% (0) | 0.0% (0) | 100.0% (2) | 50.0% (1) |

*p ≤ 0.05, **p ≤ 0.01, ***p ≤ 0.001

Table G.6: Endorsements of causes of cognitive impairment

| | % (n) responding Yes | | | | | | | |
|-----------------------------|----------------------|-------------|------------------------|---------------------------------------|-------------|-----------------|---|--------------------------|
| | 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) | Physical health problems |
| All | 72.4% (302) | 73.1% (305) | 84.4% (352) | 90.4% (377) | 45.1% (188) | 82.7% (345) | 63.8% (266) | 72.4% (302) |
| Gender | | | V = 0.156** | V = 0.143** | | V = 0.135* | | V=0.166*** |
| Male | 70.3% (64) | 68.1% (62) | 78.0% (71) | 90.1% (82) | 38.5% (35) | 73.6% (67) | 58.2% (53) | 60.4% (55) |
| Female | 73.1% (236) | 74.3% (240) | 86.7% (280) | 91.0% (294) | 47.1% (152) | 85.8% (277) | 65.9% (213) | 76.5% (247) |
| Undeclared | 66.7% (2) | 100.0% (3) | 33.3% (1) | 33.3% (1) | 33.3% (1) | 33.3% (1) | 0.0% (0) | 60.4% (55) |
| Age | | V=0.212*** | V=0.314*** | V=0.330*** | V=0.240*** | V = 0.195** | V = 0.192* | V=0.383*** |
| <20 | 100.0% (2) | 100.0% (2) | 100.0% (2) | 100.0% (2) | 50.0% (1) | 100.0% (2) | 100.0% (2) | 100.0% (2) |
| 21-30 | 85.5% (47) | 78.2% (43) | 90.9% (50) | 98.2% (54) | 43.6% (24) | 89.1% (49) | 80.0% (44) | 63.6% (35) |
| 31-40 | 68.8% (44) | 85.9% (55) | 98.4% (63) | 95.3% (61) | 53.1% (34) | 92.2% (59) | 70.3% (45) | 89.1% (57) |
| 41-50 | 70.7% (53) | 74.7% (56) | 93.3% (70) | 94.7% (71) | 62.7% (47) | 92.0% (69) | 68.0% (51) | 88.0% (66) |
| 51-60 | 69.3% (70) | 77.2% (78) | 92.1% (93) | 96.0% (97) | 50.5% (51) | 78.2% (79) | 65.3% (66) | 84.2% (85) |
| 61-70 | 56.1% (32) | 59.6% (34) | 77.2% (44) | 78.9% (45) | 24.6% (14) | 71.9% (41) | 45.6% (26) | 57.9% (33) |
| 71-80 | 81.4% (35) | 48.8% (21) | 51.2% (22) | 76.7% (33) | 25.6% (11) | 74.4% (32) | 51.2% (22) | 41.9% (18) |
| 81-90 | 92.3% (12) | 84.6% (11) | 46.2% (6) | 76.9% (10) | 15.4% (2) | 53.8% (7) | 38.5% (5) | 30.8% (4) |
| 91-100 | 100.0% (2) | 50.0% (1) | 0.0% (0) | 0.0% (0) | 50.0% (1) | 100.0% (2) | 100.0% (2) | 0.0% (0) |
| Undeclared | 100.0% (5) | 80.0% (4) | 40.0% (2) | 80.0% (4) | 60.0% (3) | 100.0% (5) | 60.0% (3) | 40.0% (2) |
| Marital status | | | V = 0.153* | | V=0.190*** | | | V=0.178*** |
| Single (never married) | 77.8% (49) | 76.2% (48) | 88.9% (56) | 96.8% (61) | 46.0% (29) | 79.4% (50) | 66.7% (42) | 68.3% (43) |
| Married / Civil partnership | 72.1% (163) | 72.6% (164) | 85.0% (192) | 91.2% (206) | 43.4% (98) | 83.6% (189) | 63.3% (143) | 73.0% (165) |
| Cohabiting | 68.1% (47) | 78.3% (54) | 92.8% (64) | 94.2% (65) | 55.1% (38) | 89.9% (62) | 71.0% (49) | 81.2% (56) |
| Divorced | 76.0% (19) | 64.0% (16) | 72.0% (18) | 76.0% (19) | 56.0% (14) | 64.0% (16) | 60.0% (15) | 72.0% (18) |

| | | | | | | | | |
|---|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|
| Widowed | 69.0% (20) | 62.1% (18) | 62.1% (18) | 75.9% (22) | 27.6% (8) | 79.3% (23) | 51.7% (15) | 55.2% (16) |
| Undeclared | 80.0% (4) | 100.0% (5) | 80.0% (4) | 80.0% (4) | 20.0% (1) | 100.0% (5) | 40.0% (2) | 80.0% (4) |
| Educational qualification | | V=0.203*** | V=0.262*** | V=0.318*** | V=0.213*** | V=0.188*** | | V = 0.156* |
| Higher degree (PhD, Masters) | 67.9% (127) | 81.3% (152) | 89.9% (168) | 94.7% (177) | 51.9% (97) | 84.5% (158) | 63.6% (119) | 77.5% (145) |
| Post-graduate qualification | 57.1% (4) | 57.1% (4) | 71.4% (5) | 85.7% (6) | 14.3% (1) | 71.4% (5) | 57.1% (4) | 71.4% (5) |
| Professional qualification | 68.3% (28) | 58.5% (24) | 78.0% (32) | 90.2% (37) | 34.1% (14) | 70.7% (29) | 48.8% (20) | 63.4% (26) |
| First degree | 78.7% (96) | 70.5% (86) | 86.9% (106) | 91.0% (111) | 41.8% (51) | 86.9% (106) | 68.9% (84) | 72.1% (88) |
| A-Level or equivalent | 83.8% (31) | 64.9% (24) | 81.1% (30) | 89.2% (33) | 51.4% (19) | 78.4% (29) | 70.3% (26) | 75.7% (28) |
| GCSE or equivalent (O-Level) | 68.8% (11) | 75.0% (12) | 62.5% (10) | 68.8% (11) | 31.3% (5) | 81.3% (13) | 56.3% (9) | 56.3% (9) |
| Undeclared/None | 71.4% (5) | 42.9% (3) | 14.3% (1) | 28.6% (2) | 14.3% (1) | 71.4% (5) | 57.1% (4) | 14.3% (1) |
| Employment status | | V=0.158** | V=0.248*** | V=0.210*** | V=0.215*** | V=0.150* | V=0.151* | V=0.258*** |
| Employed | 71.6% (194) | 79.0% (214) | 93.7% (254) | 96.3% (261) | 54.6% (148) | 87.8% (238) | 69.4% (188) | 85.6% (232) |
| Unemployed | 66.7% (2) | 100.0% (3) | 100.0% (3) | 100.0% (3) | 33.3% (1) | 66.7% (2) | 100.0% (3) | 33.3% (1) |
| Retired | 71.7% (71) | 55.6% (55) | 57.6% (57) | 73.7% (73) | 21.2% (21) | 71.7% (71) | 48.5% (48) | 45.5% (45) |
| In full-time education | 88.2% (15) | 76.5% (13) | 88.2% (15) | 100.0% (17) | 35.3% (6) | 76.5% (13) | 70.6% (12) | 52.9% (9) |
| Other ("Other" and multiple groups) | 76.2% (16) | 71.4% (15) | 85.7% (18) | 85.7% (18) | 42.9% (9) | 71.4% (15) | 52.4% (11) | 52.4% (11) |
| Undeclared | 66.7% (4) | 83.3% (5) | 83.3% (5) | 83.3% (5) | 50.0% (3) | 100.0% (6) | 66.7% (4) | 66.7% (4) |
| Ethnicity | V = 0.143* | | | | | V = 0.149* | | |
| White | 72.6% (284) | 73.9% (289) | 84.4% (330) | 90.5% (354) | 45.5% (178) | 83.9% (328) | 64.7% (253) | 72.6% (284) |
| Black | 50.0% (1) | 50.0% (1) | 100.0% (2) | 100.0% (2) | 50.0% (1) | 50.0% (1) | 50.0% (1) | 100.0% (2) |
| Asian | 80.0% (4) | 80.0% (4) | 100.0% (5) | 100.0% (5) | 20.0% (1) | 80.0% (4) | 40.0% (2) | 80.0% (4) |
| Mixed | 80.0% (4) | 80.0% (4) | 60.0% (3) | 80.0% (4) | 20.0% (1) | 20.0% (1) | 40.0% (2) | 40.0% (2) |
| Other | 70.0% (7) | 40.0% (4) | 80.0% (8) | 80.0% (8) | 50.0% (5) | 80.0% (8) | 60.0% (6) | 60.0% (6) |
| Undeclared | 50.0% (2) | 75.0% (3) | 100.0% (4) | 100.0% (4) | 50.0% (2) | 75.0% (3) | 50.0% (2) | 100.0% (4) |
| Heard of cognitive impairment before | | | V=0.205*** | V = 0.157** | | V=0.150** | | V = 0.140* |
| Yes | 72.5% (266) | 74.1% (272) | 87.7% (322) | 92.1% (338) | 46.6% (171) | 83.9% (308) | 64.6% (237) | 75.2% (276) |
| No | 70.2% (33) | 63.8% (30) | 59.6% (28) | 76.6% (36) | 31.9% (15) | 76.6% (36) | 57.4% (27) | 51.1% (24) |
| Undeclared | 100.0% (3) | 100.0% (3) | 66.7% (2) | 100.0% (3) | 66.7% (2) | 33.3% (1) | 66.7% (2) | 66.7% (2) |

| | | | | | | | | | |
|--|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|--|
| Know somebody with cognitive impairment | V = 0.129* | | | | | | | V=0.198*** | |
| Yes | 71.5% (171) | 76.6% (183) | 89.1% (213) | 94.1% (225) | 51.5% (123) | 84.9% (203) | 64.0% (153) | 82.4% (197) | |
| No | 74.3% (130) | 68.6% (120) | 77.7% (136) | 85.1% (149) | 37.1% (65) | 79.4% (139) | 64.0% (112) | 58.9% (103) | |
| Undeclared | 33.3% (1) | 66.7% (2) | 100.0% (3) | 100.0% (3) | 0.0% (0) | 100.0% (3) | 33.3% (1) | 66.7% (2) | |
| Know somebody with dementia | | | | | | | | | |
| Yes | 70.6% (233) | 74.2% (245) | 85.8% (283) | 91.2% (301) | 43.3% (143) | 82.4% (272) | 60.0% (198) | 73.9% (244) | |
| No | 79.1% (68) | 68.6% (59) | 79.1% (68) | 87.2% (75) | 52.3% (45) | 83.7% (72) | 77.9% (67) | 66.3% (57) | |
| Undeclared | 100.0% (1) | 100.0% (1) | 100.0% (1) | 100.0% (1) | 0.0% (0) | 100.0% (1) | 100.0% (1) | 100.0% (1) | |
| Read about cognitive impairment | V=0.182*** | V = 0.142** | V=0.250*** | V=0.238*** | V=0.210*** | V=0.185*** | V=0.194*** | V=0.269*** | |
| Yes | 71.4% (205) | 78.7% (226) | 92.7% (266) | 96.5% (277) | 53.0% (152) | 86.4% (248) | 65.5% (188) | 82.9% (238) | |
| No | 75.4% (95) | 61.1% (77) | 65.9% (83) | 77.0% (97) | 27.8% (35) | 74.6% (94) | 59.5% (75) | 48.4% (61) | |
| Undeclared | 50.0% (2) | 50.0% (2) | 75.0% (3) | 75.0% (3) | 25.0% (1) | 75.0% (3) | 75.0% (3) | 75.0% (3) | |
| Read about dementia | V=0.173*** | | | V = 0.150** | | | | | |
| Yes | 71.3% (271) | 74.5% (283) | 86.6% (329) | 91.3% (347) | 46.6% (177) | 83.2% (316) | 64.2% (244) | 74.2% (282) | |
| No | 82.9% (29) | 57.1% (20) | 60.0% (21) | 80.0% (28) | 25.7% (9) | 77.1% (27) | 57.1% (20) | 51.4% (18) | |
| Undeclared | 100.0% (2) | 100.0% (2) | 100.0% (2) | 100.0% (2) | 100.0% (2) | 100.0% (2) | 100.0% (2) | 100.0% (2) | |

*p ≤ 0.05, **p ≤ 0.01, ***p ≤ 0.001

Table G.7: Respondent’s endorsements of labels and terminology for the presented vignette

| | % (n) | | | | | | | | |
|---|----------------------------------|---------------|---------------|---------------|-------------------------|---------------|------------------------------------|--|----------------|
| | Living with cognitive impairment | Care partner | Older adult | Younger adult | Healthcare professional | Specialist | Specialist healthcare professional | Other (undeclared and multiple groups) | 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 | 4.8 | 3.5 | 3.7 | 4.1 | 4.1 | 4.1 | 4.4 | 4.0 |
| Mean (SD) range | (3.5) 1-11 | (3.5) 1-14 | (2.4) 1-11 | (3.2) 1-17 | (3.5) 1-17 | (3.6) 1-16 | (3.5) 0-16 | (2.8) 1-11 | (3.2) 0-17 |

Appendix H: Interview Information Sheet (version for people living with cognitive impairment)

Version 2 (25.03.15)



Heather Yemm
Graduate Research School (BB 214)
University of Worcester
Henwick Grove
Worcester
WR2 6AJ
Tel: 01905 542295
Email: h.yemm@worc.ac.uk

Knowledge and understanding of cognitive impairment

PARTICIPANT INFORMATION SHEET

I would like to invite you to take part in a research study. Before you decide whether you would like to take part, it is important that you understand why this research is being done and what it will involve. Please take time to read this leaflet carefully and ask me if you have any questions. Please feel free to talk about this study with others if you wish to do so.

Why is the study being done?

Some people experience memory and thinking (cognitive) difficulties that are more severe than would be expected for their age, but are not as severe as would be expected with dementia. This is known as cognitive impairment. Whilst quite a lot of people experience cognitive impairment, research suggests that there is a lack of understanding about it. This results in people not getting help and support for their concerns, delaying visiting their GP and not knowing what help may be available for them. This research aims to explore what people know about cognitive impairment in order to develop guidelines for future information that addresses any knowledge gaps or misunderstandings about cognitive impairment. Producing information resources that cover areas where people are uncertain or confused about cognitive impairment may help cognitive impairment to be better understood and hopefully encourage people to seek help if they are concerned about their memory or thinking.

Why have I been invited?

You have been invited to take part because you have been assessed as having memory or thinking difficulties and I would like to understand what you know and have been told about cognitive impairment as you may have heard terms like this mentioned by the healthcare team who assessed your memory.

Do I have to take part?

No. Participation in this study is voluntary. It is up to you to decide whether you want to take part or not. Please take your time to decide. If you agree to take part, I will ask you to sign a consent form. You are free to withdraw from this study at any time, without giving a reason.

What will happen to me if I decide to take part?

If you choose to participate, the research will involve me (Heather Yemm) coming to a location which is convenient for you to meet with you for a short interview. The purpose of this interview is to ask you some questions about what you know and understand about cognitive impairment. This interview will last around 1 hour. You can have this meeting on your own or with a family member or friend present if you would prefer. If you feel that the interview is taking too long, we can arrange for the meeting to take place over 2 separate sessions. The interview will be tape recorded if you agree to this.

What are the possible disadvantages / risks of taking part?

Some people taking part in this study may find it difficult to discuss some of the topics that we talk about. If at any time you feel uncomfortable, or feel at all anxious or distressed by the study then I can discuss with you the support options available which might help you to deal with this distress. I can also provide appropriate contact numbers for services which you can contact should you wish. I will provide this information even if you withdraw from the research. You are free to leave the study at any time without having to give a reason for your decision.

What are the possible benefits of taking part?

Whilst there will be no direct or immediate benefits to you, it is hoped that the information from this research will help us to develop information resources to help people understand what cognitive impairment is and help to raise awareness of cognitive impairment.

Expenses and payments

No payments will be offered for taking part in this research. However, if you would like to meet at a location other than your home or workplace then reasonable travel expenses will be paid.

What will happen if I want to stop being involved in the study?

You can decide at any time that you no longer wish to take part in this research. This decision will not affect any care and support that you receive now or in the future. All of the information that you have provided will still be used in the study, unless you request to withdraw this. You have up to 4 weeks after the interview to withdraw your information from the study.

Will my participation in this study be kept confidential?

Ethical procedures will be strictly followed at all times during the course of the research and all information will be handled in complete confidence.

The only time when confidentiality might be broken is if I see something which suggests that you, or someone else, are at risk of harm. However, I would discuss this with you before speaking to anyone else about this.

All personal information will be kept in a paper file in a secure location at the University of Worcester, separately from all other information relating to the research, and will be destroyed within 12 months of the research ending. I am the only person that will have access to any personal information. All electronic files, such as the audio recordings, will be kept in a password protected electronic folder on a secure server and destroyed within 12 months of the research ending.

The information you give may be used in research reports and journal articles, but all of your personal information and any identifying data, such as names and addresses, will be changed to protect your identity.

Involvement of my General Practitioner (GP)

I would like to inform your GP that you are participating in this study so that you can discuss this with them should you want to. This is not something that you have to agree to, and if you don't agree then I will not contact them.

What will happen to the results of the research study?

The results of this research will be written up in my PhD thesis. They will also be presented at conferences and published in academic and professional journals.

A summary of the main findings of the research will be available to everyone who has taken part.

Who is organising and funding the research?

This research study is being carried out as part of my studies to achieve a PhD at the University of Worcester. Funding for this research has been provided in full by the University of Worcester.

Who has reviewed the study?

This study has been reviewed and approved by North East – Tyne & Wear South NHS Research Ethics Committee (Ref:15/NE/0227) and the University of Worcester Institute of Health & Society Ethics Committee.

Further information and contact details

If you have any questions, concerns or complaints about this study, please contact one of the research team:

Heather Yemm
PhD Researcher

Graduate Research School (BB 214)
University of Worcester
Henwick Grove
Worcester
WR2 6AJ
Tel: 01905 54 2295
Email: h.yemm@worc.ac.uk

Or

Professor Dawn Brooker
Supervisor

Association for Dementia Studies
University of Worcester
Henwick Grove
Worcester
WR2 6AJ
Tel: 01905 85 5250
Email: d.brooker@worc.ac.uk

If you would like to speak to an independent person who is not a member of the research team, please contact:

Dr John-Paul Wilson

Independent Sponsor

Graduate Research School
University of Worcester
Henwick Grove
Worcester
WR2 6AJ
Tel: 01905 54 2196
Email: j.wilson@worc.ac.uk

Thank you for taking the time to read this information leaflet

There were multiple versions of the information sheet available; one for each participant group.

Appendix I: Interview Consent Form (version for people living with cognitive impairment)

Version 1 (11.02.15) CI



PARTICIPANT CONSENT FORM

Research Study: Knowledge and understanding of cognitive impairment

Please tick the boxes if you agree to the following statements:

| | YES | NO |
|---|--------------------------|--------------------------|
| 1. I confirm that I have read the information sheet (version number 2, dated 25.03.15) for the above study and have had the opportunity to ask questions. | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I understand that I do not have to take part in this research and that I am free to withdraw from this study at any time without having to provide a reason. | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I understand that this research study has been reviewed and approved by the NHS Research Ethics Committee and the University of Worcester Institute of Health & Society Ethics Committee. | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of Worcester, from regulatory authorities or from the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. I understand that any information I give will be kept confidential unless there are any concerns about the safety or wellbeing of any individual, in which case this concern will be discussed with me before confidentiality is broken. | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I understand the data storage and access permissions for information and data that has been collected as part of the research. | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I consent to my GP being informed about my participation in this study. You do not have to agree to this. | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. I agree to the researcher audio taping the interview. | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. I agree to take part in this study. | <input type="checkbox"/> | <input type="checkbox"/> |

Name

Date

Signature

Version 1 (11.02.15) CI

Researcher Name

Date

Researcher Signature

Two versions of the consent form were available, one for people living with cognitive impairment and one for all other participant groups.

Knowledge and understanding of cognitive impairment

Topic Guide

- 1. Can you tell me a little bit about what you know about cognitive impairment?**
Prompts: Have you ever heard the term before? Have you ever looked for information about cognitive impairment? What does the term mean, do you think?
- 2. What experience, if any, have you had of cognitive impairment?**
Prompts: Have you ever had any friends or family members who have been diagnosed with cognitive impairment? Do you come across people with cognitive impairment as part of your work or socially? Have you ever talked to anyone about cognitive impairment?
- 3. What do you think causes cognitive impairment?**
Prompts: Is cognitive impairment just something that happens to everyone as they get older? Could a bad diet cause cognitive impairment? How about a head injury/stroke? Is it a permanent or a temporary condition? Or could it be both?
- 4. What do you think the difference is between cognitive impairment and dementia?**
Prompts: Is there any difference between them? Are they the same? Which is the most serious? What about the difference between normal ageing and cognitive impairment? Does one lead to the other?
- 5. If you were to explain to a friend what cognitive impairment is, how would you describe it?**
Prompts: What symptoms would someone with cognitive impairment display? What sorts of symptoms would worry you personally? What do you think are/might be the negative things about MCI? What do you think are/might be the positive things about MCI?
- 6. Do you think cognitive impairment is something that can be avoided or prevented? If so, how?**
Prompts: Improving your diet? Not smoking? Reducing or cutting out alcohol? Getting more exercise? Being more active – taking part in more physical exercise? Being more mentally active (doing crosswords etc.)? Are people who are more intellectual less likely to have cognitive impairment? Being less stressed?
- 7. How do you think we can treat or help people living with cognitive impairment?**
Prompts: Are there ways of slowing it down or reversing it once it starts? Do you think medication would help? Improving your diet? Giving up smoking? Reducing or cutting out alcohol? Getting more exercise? Being more mentally active? Stress management? Mindfulness? Cognitive Behavioural Therapy? Counselling?

8. What sort of information/support do you think people living with cognitive impairment might need?

Prompts: What about a support group to meet with other people living with cognitive impairment? Memory aids (calendars, diaries, medication reminders etc.)? Should information be available online? Via booklets? What about Admiral/Macmillan nurse provision for people living with cognitive impairment?

9. If someone came to you and said they were worried about their memory or thinking, what would you think was the matter?

Prompts: Would you think it was cognitive impairment? Dementia? Normal ageing? What would you advise them to do? See their GP? Look for advice or information online? Look on NHS website? Go to their pharmacist? Advise dietary supplements? Get more information from a charity that focussed on older people such as Age UK or the Alzheimer's Society or Dementia UK? Go on holiday? Look after themselves better? Tell them not to worry and see whether it got better or worse over time?

10.If someone told you they had been diagnosed with "mild cognitive impairment", what would that mean?

Prompts: Have you ever heard of MCI before? What do you think MCI is? Would it mean they were going to develop dementia? Is it just a way of saying they have mild dementia?

11.Is there anything else you'd like to tell me?

Appendix K: Transcription Symbols

| | |
|--------------|---|
| (1) | The number in brackets indicates a time gap in whole seconds |
| (.) | A dot enclosed in a bracket indicates a pause in the talk of less than one second |
| .hh | A dot before an 'h' indicates an in-breath. The more 'h's the longer the in-breath |
| hh | An 'h' indicates an out-breath. The more 'h's the longer the out-breath |
| (()) | A double bracket enclosing a description indicates a non-verbal activity, for example ((shuffling papers)), ((coughs)) or ((laughs)) |
| - | A dash indicates a sharp cut-off of the preceding word or sound |
| : | A colon indicates that the preceding sound has been stretched. The more colons, the more the sound was stretched |
| () | Empty brackets indicate an unclear fragment of speech |
| (guess) | Words contained within a single bracket indicate the transcriber's best guess at an unclear fragment |
| . | A full stop indicates a stopping fall in tone but does not necessarily indicate the end of a sentence |
| , | A comma indicates a continuing intonation |
| ? | A question mark indicates a rising inflection but does not necessarily indicate a question |
| <u>Under</u> | Underlined fragments indicate speaker emphasis |
| ↑↓ | Pointed arrows indicate a marked falling (↓) or rising (↑) intonational shift – placed immediately before the onset of the shift in intonation |
| CAPITALS | Capital letters indicate a section of speech noticeably louder than the surrounding talk (with the exception of the capitalisation of proper nouns) |
| °° | Degree signs are used to indicate that the talk they encompass is noticeably quieter than the surrounding talk |
| = | The equals sign indicates contiguous utterances |
| [] | Text contained within square brackets indicates an anonymised portion of speech |

Adapted from Wooffitt, R. (2001). *Researching Psychic Practitioners: Conversation Analysis*. In M. Wetherell, S. Taylor, & S. J. Yates (Eds.), *Discourse as Data: A Guide for Analysis* (pp. 49-92). London, UK: Sage Publications Ltd.