How does active ageing policy and practice reconfigure the experience of cognitive impairment? A study of an active ageing intervention.

Christine Carter

Division of Psychiatry

University College London (UCL)

A thesis submitted for the degree of Doctor of Philosophy (PhD).

April 2024

Declaration

I, Christine Carter confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Date: April 11th 2024.

Abstract

This thesis explores the interface between active ageing policy, practice and people with memory problems and mild cognitive impairment (MCI), which are not dementia. The complexity of this interface is influenced by an increased medicalisation around memory difficulties. This thesis is set within the context of an active ageing intervention, APPLE-tree (Active Prevention in People at risk of dementia through Lifestyle, bEhaviour change and Technology to build REsiliEnce), based upon modifiable risk factors surrounding dementia. I apply a social science lens, drawing upon sociological theory, with three interrelated studies forming the core of the thesis.

1. Scoping review and meta-synthesis: exploring subjective experiences of cognitive impairment and MCI through literature and synthesis.
2. Secondary data analysis: analysis of consultations from the APPLE-tree intervention.
3. Ethnographic study: provides an ethnographic view of APPLE-tree as an example of active ageing practice, using focused ethnography and reflexive thematic analysis to explore experiences of engaging an active ageing aimed at modifying dementia risk.

A recurring theme throughout the thesis is one of absence, evident in a number of ways. This includes the lack of acknowledgement of individual subjective experiences of memory difficulties which are not dementia. Ambiguity surrounded cognitive impairment and the uncertain trajectory of an MCI diagnoses created expectations and responsibilities for individuals with memory issues to engage in active ageing interventions.

Motivation to participate in APPLE-tree often stemmed from a fear of developing dementia and a desire to prevent cognitive decline. Participation is framed by personal responsibility for health and societal expectations of healthy and successful ageing elevated through public health policy. Engagement in active ageing was complicated by an unclear definition of success with interventions differing from those targeting physical health. Ultimately this led to a tension between participation in an active ageing intervention and achieving desired outcomes, which remains unresolved.

Impact statement

During my PhD I explored the complexity of active ageing practice and policy for cognitive health, including the impact of an MCI diagnosis. I have developed expertise in understanding active ageing policy and practice and its impact upon notions of normal ageing, cognitive health, and impairment, and found this to be an under researched area.

I have successfully disseminated my research in diverse settings, directly impacting upon different policy and academic settings. This includes publishing my scoping review in the journal Dementia (2022). I presented my findings within the Department of Psychiatry at UCL and received feedback I integrated into my wider PhD research plans.

Nationally, I gave oral presentations online (due to Covid-19) at the British Society of Gerontology conference in 2020 and 2021. I participated in a theoretical symposium about the concept of liminality following an MCI diagnosis. I received a bursary to attend the second conference and presented methodological challenges of conducting ethnography online. Both received positive feedback. I received a bursary to attend the British Sociological Association conference (2022) in Lancaster and presented in person, expanding my findings through the application of sociological theory.

Internationally, I have presented my work in Europe and established academic links in Denmark and Norway. I was awarded competitive funding from the ESRC and spent two weeks at Copenhagen University in the Centre for Healthy Ageing. I collaborated with an Associate Professor whose work on ageing and enablement influenced my PhD study. I had the opportunity to present different aspects of my PhD study and connected with other academics in this area and early career researchers. I also presented my findings to a social enterprise group developing a digital support platform for older people.

I connected with a Professor of Nursing from Agdar University, Norway who was on a scholarly visit to UCL, we explored the differences between countries in relation to cognitive health, dementia, and active ageing strategies. Agdar

University offered to fund me for a week's visit within the nursing & research school to further develop this collaboration. I presented findings from my PhD to a range of professionals and visited a dementia friendly living village. I also connected with academics from Oslo University, I have established ongoing links with them to explore future research opportunities. I have maintained links with both universities and plan to develop joint working with them. The Associate Professor from Copenhagen University has provided mentoring support to me throughout my PhD, enhancing my academic development.

I have disseminated my research findings through poster presentations at both Alzheimer's Association International Conference, Amsterdam and at the International Psychogeriatric Association Congress in Lisbon, both in 2023.

Future wider policy implications from my PhD include:

- Making active ageing interventions more inclusive and sustainable
- Understanding the importance of actionable personalised lifestyle goals
- Acknowledging subjective experiences with a MCI diagnosis

I have applied for a career development grant and plan to develop these points into a post-doc application to explore further planning for active ageing policy and practice.

UCL Research Paper Declaration Form

referencing the doctoral candidate's own published work(s)

1. **For a research manuscript that has already been published**

   a) **What is the title of the manuscript?** Understanding the subjective experiences of memory concern and MCI diagnosis: A scoping review.

   b) **Please include a link to or doi for the work:** doi:10.1177/14713012221147710

   c) **Where was the work published?** Dementia

   d) **Who published the work?** Sage

   e) **When was the work published?** 2023

   f) **List the manuscript's authors in the order they appear on the publication:** Carter C, James T, Higgs P, Cooper C, & Rapaport, P.

   g) **Was the work peer reviewed?** Yes

   h) **Have you retained the copyright?** No

   i) **Was an earlier form of the manuscript uploaded to a preprint server?** No

   If 'No', please seek permission from the relevant publisher and check the box next to the below statement:

   ☒ *I acknowledge permission of the publisher named under **1d** to include in this thesis portions of the publication named as included in **1c**.*

2. **For multi-authored work, please give a statement of contribution covering all authors** (if single-author, please skip to section 4)

   Conceptualisation and project coordination: CC devised the concept for the scoping review together with PR, PH and CCb.

   Specifying search terms and searching the literature: CCa created the search terms; PH, PR and TJ contributed to their refinement. CCa conducted the literature searches.

Screening abstracts and/or full-texts: CC, PR and TJ screened abstracts and full-texts.

Data extraction: CCa created the data extraction form with input from PR and TJ.

Analysis: CCa completed the qualitative synthesis of findings and interpreted the results with input from PR, PH, TJ and CCb

Writing: CCa wrote the first draft of the manuscript which formed the basis of this chapter. The manuscript was reviewed by all co-authors prior to submission. Following peer review, CCa revised the manuscript and responded to the reviewers. CC also updated the review for inclusion in this thesis with drafts commented on by PR and PH

3. **In which chapter(s) of your thesis can this material be found?**
   Chapter 2
4. **e-Signatures confirming that the information above is accurate** (this form should be co-signed by the supervisor/ senior author unless this is not appropriate, e.g., if the paper was a single-author work)

   Candidate: Christine Carter

   Date: 03 April 2024

   Supervisor/ Senior Author (where appropriate)

   Click or tap here to enter text.

   Date: 04 April 2024

My PhD thesis is dedicated to Julie Anne Attenborough

July 1960 – January 2024

the most inspirational woman I have ever known

Acknowledgements

I want to acknowledge my parents who despite never really understanding what I have been doing, have given me unquestionable support and encouragement and are both inspirational examples of how to enjoy life in old age.

A special mention to my brilliant friends from Cheltenham 'the nanas' Julia, Tanya, Jules, Niki and Sophie, for their constant support, encouragement, patience and belief that I could complete this.

My wonderful ex-nursing colleagues Sally and Izzi for their encouragement, coffee, cakes and keeping me calm and just listening.

A big thank you to Alison and to Bobby, the best PhD support dog ever. Thank you for the many walks and runs we have had together during this process which have been invaluable, especially through covid.

I could not have done this without the practical support from my beautiful friends Julie and Steve who welcomed me into their home in London whilst studying, and sharing some wonderful time together, although Julie will not see me complete this, I am inspired by her every day. Thank you, Steve, for your continued support and friendship.

My PhD buddies Harriet, Tash and in particular my wonderful friend Tiff, not only for their support, advice, and practical help but their unequivocal friendship.

I would like to thank my supervisors Paul Higgs and Penny Rapaport who believed in me enough to give me an opportunity to do this PhD and have supported my ups and down on this journey, giving steady advice and support along the way and helping me get to the finish line.

Finally, I need to acknowledge my family, my sons Lewis and Elliot who I am so proud of, and I hope I have made them proud. I could not have done this without my husband Pete for his quiet calmness, all the proof reading, listening to me through my highs and lows, running the house and providing coffee, chocolate and alcohol without me asking, I'm looking forward to our life beyond the PhD.

Abbreviations

AA	Active Ageing
AT	APPLE-tree Intervention
DSM	Diagnostical Statistical Manual
ESRC	Economic Social Research Council
FCD	Functional Cognitive Decline
HRA	Health Research Authority
MCI	Mild Cognitive Impairment
NICE	National Institute of Clinical Guidelines
NIHR	National Institute of Health Research
PIS	Patient Information Sheet
PPI	Public and Patient Information
RCT	Randomised Controlled Trial
RTA	Reflexive Thematic Analysis
SCD	Subjective Cognitive Decline
WHO	World Health Organisation

Contents

Table of tables

Table of appendices

Chapter 1 The ‘culture’ of active ageing: an introduction through policy and practice.

1.1 Aims and introduction

This research explores the interface between active ageing policy and practice concerning cognitive impairment and memory difficulties which are not dementia. I explore how active ageing policy and practice reconfigure mild cognitive impairment (MCI) and memory difficulties which are not dementia.

Throughout this thesis I use the terms cognitive impairment, memory concerns and memory difficulties interchangeably to refer to any cognitive impairment where individuals experience this subjectively and objectively. I use MCI to refer to people with a diagnostic label of MCI, and those who self-identify with symptoms which fits the criteria for an MCI diagnosis. My choice of term at different points throughout the thesis is determined by how individuals with cognitive impairment describe themselves or how it is described in the literature.

This thesis reflects my interest in the concept of active ageing and associated strategies for people who have memory problems. This is of particular interest due to my background as a mental health nurse working with older people with memory problems in the community and in outreach services. The traditional ethos of ‘caring for’ within mental health nursing has moved to ‘engaging with’ people, along with expectations of patients being ‘expert’ in their own conditions with the aim to empower individuals. Aspects of this appear to have transferred into active ageing policy and practice for older people with memory problems and this is an under researched area. I wanted to approach this topic through a social science perspective rather than a medical or nursing one, which I was familiar with. I was interested in understanding a broader social perspective and consider how these aspects translated into the experiences for those engaging with such programmes.

This PhD is embedded within, but distinct from, the NIHR/ESRC APPLE-tree programme. APPLE-tree is an active ageing intervention and stands for Active Prevention in People at risk of dementia through Lifestyle, bEhaviour change and Technology to build REsiliEnce (Cooper et al., 2020). As such, APPLE-tree acts as a portal through which to answer my research questions. A descriptive account of this intervention, including how the content was structured and how it was delivered is provided in Appendix 1. Further explanation of my role within this program as a researcher is covered within my methods section in chapter 4. This health and lifestyle intervention provides a lens with which to focus upon active ageing, both as a concept and an experience for people with a range of mild cognitive concerns.

1.2 Chapter outline

In this chapter I describe the context within which I developed my research questions. I begin by describing the demographics of age, dementia, and the subsequent focus on cognitive health in society. I introduce active ageing as a concept and consider a definition through a UK and European focus. I discuss age and ageing and the paradox of normalising memory loss as part of getting older yet identifying age and memory loss as a risk factor for dementia through a diagnosis of mild cognitive impairment (MCI). This normalisation means that experiences of memory loss in old age are not regarded as a problem, so no action is required, yet equally the same memory loss, labelled as MCI, becomes an identifier of potential dementia with subsequent expectation of a response. I describe MCI and the diagnostic complexity surrounding this construct. I then introduce modifiable risk factors, along with the development of dementia prevention strategies and the relationship of active ageing policies to practice. I consider the construct of active ageing more broadly through other terms, such as ‘successful’ and ‘healthy ageing’. I outline key sociological gerontological theory and key concepts of citizenship, life course, responsibilisation and positioning before finally, moving to consider how these inform my research questions. In summarising this, I include my rationale, outline how my research studies inter-relate and describe the structure of my thesis.

1.3 The demographics of old age, dementia and the rise of a cognitively vigilant society

By 2025 over half of adults in the UK are expected to be 50 or over, however increases in longevity have not been matched with an increase in health expectancy (Office for Health Improvement & Disparities, 2022). Although life expectancy has increased over time, the disparity with healthy life expectancy, means that more years are spent in poor health (Raleigh, 2022). Health Expectancy refers to the measure of the average number of years a person would expect to live in good health based on contemporary mortality rates and prevalence of self-reported good health (Office for Health Improvement & Disparities, 2022). However, this term has been contested due to the subjective nature of health and good health.

Dementia is rising as a public health concern both globally and in the United Kingdom. Dementia affects one in 14 people over the age of 65 and one in six over the age of 80 (Prince et al., 2015). Dementia is a chronic condition, most commonly in older people, with incidence doubling with every 5.9-year increase in age, (WHO, 2015). In addition to its effects at a personal and individual level, dementia is a leading cause of morbidity, increased health and social care costs, and mortality at a population level (Prince et al., 2015).

Knapp & Wong (2023) demonstrate how economics and dementia are interconnected and how an individual's economic status can affect their risk of dementia and their ability to respond to it. There is accumulating evidence of the ways in which dementia impacts on the economic status of individuals and families, on health and social care system budgets, and on national economies (Knapp & Wong, 2023). Inevitably economic status will impact an individual's ability to adopt a healthy lifestyle, and consequently it may not be viewed as a priority concern.

Dementia is characterised by progressive cognitive impairment, affecting a person's daily life beyond what would normally be expected from biological ageing. It is an umbrella term for a set of syndromes characterised by acquired, and usually progressive cognitive and social or functional decline, WHO (Santé & Organization, 1993). In 2009 the first Dementia Strategy was launched in the UK and saw the term 'living well with dementia' become part of a 'new' discourse surrounding dementia care (Burns & Robert, 2009). Exploring this concept involves recognising a dichotomy between a 'tragedy' discourse surrounding dementia versus the contemporary 'living well' with dementia discourse

(McParland et al., 2017). Neither position is a desirable one for older people with memory difficulties which are not dementia. The 'tragedy' discourse reflects an inevitability of helpless decline, where nothing can be done, and ‘living well’ with dementia carries with it an obligation to not only accept this chronic incurable condition, but to be obliged to ‘live well’ with it, regardless of what ‘well’ looks like. This foregrounds any understanding of cognitive health and the avoidance of dementia through active ageing.

Although the risk of developing dementia is connected to ageing, for many it is synonymous with old age. Despite organisations such as the Alzheimer’s Society having addressed this through educational campaigns, there remains a level of tension in social attitudes around this relationship in UK society. This reflects media accounts of dementia which regard it as a looming burden linked to the increased longevity of the population, yet simultaneously this population has opportunities to be consumers of healthy lifestyles, with increasing expectations to work to prevent or avoid dementia. This contradictory framing of later life has been represented by a consumer orientated ‘third’ age versus a ‘fourth’ age imaginary of decline, reflecting the fracturing of old age as a social category in contemporary society (Higgs & Gilleard, 2022), these concepts will be discussed fully later in this chapter. This binary distinction creates a level of fear and uncertainty in older people who are concerned about their memory. In 2021, Alzheimer’s Research UK found that 49% of those surveyed said dementia was the health condition they most feared. Subsequently in 2023, 21% still believed that dementia is an inevitable part of ageing. However, as stated in this report; ‘more positively, awareness of dementia risks is now 36% (up from 33%

in 2021), recognising that it's possible to reduce dementia risk' (Alzheimers Research UK, n.d.) in 2021 and 2023. This highlights a juxtaposition between dementia being viewed as an inevitable part of ageing and old age yet at the same time, an increased emphasis on the potential for an individual to reverse and reduce their dementia risk (Katz et al., 2020; Lock, 2013).

The term 'hyper-cognitive' has been used to describe the cultural separation of dementia from normal loss of capacities that comes with ageing (Post, 2000). This has been seen as reflecting a societal expectation of cognitive ability and function as being infallible, and 'anti-age-able' cognitive skills which affects cultural narratives about ageing, mind, body, and personhood' (Katz & Peters, 2008). Katz and Peters point to the social expectations for 'hyper-cognitive' performance, which, combined with anti-ageing formulations and biosocial research about the treatability of the ageing brain, mean that forgetting and ageing are equated with dementia and dysfunction (Katz & Peters, 2008). However, the opposite is also present, with an increased focus upon cognitive health and subsequent identification of conditions such as mild cognitive impairment (MCI) as a prodromal stage to dementia, indicating that this is, "not just your age", including an expectation that something can be done about it.

All the above exist within a context of fear of the condition itself. This fear has been described through two common perceptions, the progressive loss of one's cognitive capacity and the lack of any effective treatment to halt or reverse the condition (Gilleard & Higgs, 2023). Individuals who have dementia or who live in fear of the diagnosis, are concerned not only about the medical meaning of the disease, but also about social responses to it (Behuniak, 2011). Behuniak argues that dementia stigma is of a specific sort, a dehumanisation based on disgust and terror, and she cites references to people with Alzheimer's disease as representing 'the living dead': zombies. Although extreme, other research has shown how depictions of dementia in popular culture are associated with negative images and feelings, and importantly, social distance between people with dementia and those without (Low & Purwaningrum, 2020). This distance characterises UK society's perceptions of dementia and dementia risk, with a desire for distance from these stereotypes driving the need to avoid and prevent dementia.

Despite a lack of any curative treatment for dementia, the drive to increase dementia diagnosis remains a priority. The rationale being that providing 'timely' diagnoses through earlier detection helps people plan for their future, achieve a better quality of life, and access clinical trials and possible future disease modifying treatments (Ford et al., 2023). Inevitably this move to identify cognitive concerns earlier, means that many older people are living with an awareness of having a memory difficulty which is not diagnosed as being dementia (Peters & Katz, 2015). In this context, and in what has been regarded as a 'neuro- culture' (Williams et al., 2012), the impetus to act through dementia prevention within active ageing practice has emerged.

The concept of active ageing and its relationship to cognitive health in old age is under researched, thus it shapes and centres my study. I expand upon this in the next sections, initially describing active ageing and its relationship with age then discussing the identification of modifiable risk factors for dementia, and the impact of biomarkers, along with the diagnosis of other cognitive conditions such as MCI.

1.4 Active ageing: European and UK perspectives, policy, and practice.

In this thesis I will refer to Europe and the UK when considering active ageing policy and practice whilst recognising that globally there are shared understandings of active ageing as a concept which focuses upon optimal achievements for the individual. However, policy analysis has illustrated the contrast between the primarily European discourse on active ageing, which emphasizes health, participation, and well-being, and a U.S. discourse that prioritizes productivity (Walker, 2008). This distinction was supported by (Principi et al., 2018) in their study of active ageing in Europe, UK and the USA. They identified that USA respondents focused more on productivity and working for financial security, whereas UK respondents embraced retirement as a form of leisure and independence, in part this may reflect cultural and health care differences (Principi et al., 2018).

In the World Health Organisation (WHO) 2002 ‘Active Ageing: A Policy Framework, active ageing is defined as ‘the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age’ (Kalache & Gatti, 2003). In adopting this definition, I recognise that there are others, which reflects the many debates around what ‘active’ ageing is and whether there are more appropriate terms.

Understanding the concept of active ageing begins with recognising how policies situated within a European context influence the UK, despite it no longer being part of the EU. Active ageing is a central principle of current European policy making (e.g., ‘Green paper on Active Ageing’, European Commission, 2021). This has influenced national policies of most member states (e.g., Department for Work and Pensions, 2015) and as the UK is now outside the European Union, local polices such as Understanding the Drivers of Healthy Life Expectancy (Office for Health Improvement & Disparities, 2023). This continues to be monitored across Europe through the ‘Active Ageing Index’ (AAI) policy tool which measures active and healthy ageing indicators (Principi et al., 2018). Currently in its third iteration and looking to extend to non-EU countries, the AAI measures several domains, allowing identification of the domains most in need of public policy interventions (De São José et al., 2017). However, this review criticized the AAI for its paradoxical aim; trying to derive ‘solutions’ from the perceived ‘problems’ of an ageing population, it also conveys a certain model of ageing which measures achievements and not capabilities (De São José et al., 2017).

This has arisen within a background of policies such as the influential United Nations (UN) ‘Principles for Older Persons’ policy, adopted by the UN General Assembly in 1991, (United Nations,1991.). The UN introduced five themes; Independence, Participation, Care, Self-fulfilment, and Dignity with governments encouraged to incorporate these into their national programmes. The themes characterise the developing discourse around active ageing as they underline a focus towards individual responsibility. This reflects a more general move in the conceptualisations of healthy age and ageing within Europe from workforce productivity to personal responsibility.

The term ‘active ageing’ as a policy to promote health independence and productivity for citizens was adopted in 2002 to encompass the wider dimensions of participation, including social, cultural, and civic domains alongside physical activity and economic contribution (Kalache & Gatti, 2003). The connection between remaining active and healthy in later life and an extended life expectancy through the conception of ‘active ageing’ is attributable to (Kalache & Keller, 1999). In their WHO perspective on active ageing these authors described how quality of life and the ‘slope of decline’ could be influenced by individual and policy measures throughout the life course. Examples include maintaining functional capacity through policies such as smoking cessation, and they also raise the matter of the individual and their responsibility to eat healthily (Kalache & Keller, 1999). This notion of responsibility reflects a fundamental part of health and illness prevention, inherent within active ageing which I will explore more fully throughout my thesis. My focus on how older people with cognitive impairment engage with active ageing practice and how policy and practice influence cognitive impairment requires an understanding of the concept of age and old age in relation to health. This will be addressed in the next section.

1.5 Age, old age, ageing and connections with health and lifestyle

Old age and ageing are viewed as a period of inevitable decline, yet increasingly this period has also become regarded as an opportunity to avoid cognitive and physical decline. Active ageing and its application to cognitive health has emerged within a background characterised by this juxtaposition. The relationship between activity and age, coupled with an increasing focus upon cognitive health warrants further exploration.

In the policy document *Active Ageing in the UK- Issues and Barriers*; active ageing is defined as, “allowing people to remain independent and achieve their potential regardless of age” (Mayhew, 2005 pg.455). Age is described as a “device used widely in society for assigning or taking away responsibilities, allocating resources, or determining access to services on age grounds, or as a proxy for mental and physical wellbeing” (Mayhew, 2005 pg. 455). Assigning a health status to old age yet assuming a direct relationship between age and mental and physical wellbeing, Mayhew identifies a potential conflict and therefore barriers to actively ageing. This reflects a fundamental dichotomy inherent within the concept of active ageing as both an experience and a concept.

As a universal phenomenon, old age is like other dimensions of the human condition, a social construct (Achenbaum in Johnson et al., 2005). Achenbaum describes a juxtaposition between several positive and negative contradictory images, ideas, attitudes, and behaviours in ageing related constructs and how this correlates with the process, problems, and opportunities of growing older. However, he points out that international perspectives on ageing do not mirror this reality but rather arise from political, social, economic, cultural, and demographic factors which shape a particular society (Achenbaum in Johnson et al., 2005).

Green & Hillersdal, (2021) highlight that the reframing of ageing as risk has social and ethical implications, as it is generative of normative notions of what constitutes successful ageing and good citizenship (Green & Hillersdal, 2021). Dementia is intrinsically linked to the sociocultural and temporal context of what ageing means to a population (Walsh et al., 2022a). Leibing and Schicktanz draw attention to the broader ‘epistemic, ethical, and socio-political issues’ of what they term the contested ‘new dementia’ and consider this effect on rethinking individual and societal perceptions of ageing (Leibing & Schicktanz, 2022).

The various discussions concerning age mirror those found within active ageing, both are characterised by imprecise terminology. Uncertainty exists over the meanings of, and interpretations placed upon the terms ‘old age’ and ‘ageing’. Johnson & Thane, (1998) describe how these terms are used interchangeably to define both conditions and processes which can be either individual or societal. Rooted in a division with age, ageing has primarily been understood through biology whereas old age has been typically understood as a status or social location (Higgs, 2022). Higgs and Gilleard state that ageing’s inextricable connection to health has resulted in it having been previously overlooked within social sciences discourse (Gilleard & Higgs, 2023). This has subsequently altered through social gerontology moving the discussion from one of universal ageing to understanding the effects of circumstances created by society. Health, illness, and deterioration remain prominent themes in any discussion of old age. However, contemporary discourse includes the role of culture and a recognition that there are multiple ways of being old and acknowledging the personal nature of health in old age.

Increasingly external health and lifestyle factors influencing and affecting cognitive health in older people are considered, in relation to their role alongside cognitive ageing theories of compensation and cognitive reserve (Oosterhuis et al., 2023). Sociology and psychology have contributed to broadening the medical and biomedical discourse around age, ageing and cognitive health. Katz (2020) points to the value of sociology in understanding subjective and narrative practice of individuals, families and communities in the shared experiences of cognitive impairment, (Katz et al., 2020).

Alongside this is a medical and physiological focus which has conventionally dominated discussions about age, particularly in relation to health and well-being. Age has been seen as leading to diminishing physical ability and regarded as a category of need and an entry point to the provision of benefits, with concepts such as frailty replacing older notions of infirmity (Gilleard & Higgs, 2011). While physical and cognitive frailties do increase with age, stereotypes around age and ageing often define old age purely by reference to these co-morbidities. The physical changes of getting older and their associated common co-morbidities, such as arthritis, seem to be regarded as less threatening than those of reduced cognitive function and ability, reflecting a new ‘hyper-cognitive society’ (Gilleard & Higgs, 2023). Active ageing has been regarded as offering a move away from this medicalised model (Featherstone et al., 1990; Gilleard & Higgs, 2011). In Western societies, the rise of neoliberalism since the 1990s has resulted in a greater emphasis on the market productivity, and individual responsibility in economic and social policy. Clotworthy argues in her work on the Danish ‘re-ablement system’ that a new type of post-retirement citizen has been constructed in the 21st century – specifically an older person who may suffer from certain physical health limitations but who still has unlimited potential to engage as an active, contributing member of society (Clotworthy, 2020). This sub-group of ‘the elderly’ has been constituted in terms of what Clotworthy describes as ‘limited yet limitless’ ageing consumers. In describing policy in this way she captures a positive paradigm of active ageing along with the imputed desire that individuals would want to achieve ‘limitless’ ageing as they grow older rather than be defined by their limitations. This approach acts as a conceptual starting point for my research which examines how such assumptions affect participation in an active ageing intervention. Clotworthy draws attention to a complexity inherent within active ageing regarding an individual’s willingness, desire, and responsibility to engage in such practice; something that is further complicated when thinking about people with MCI and memory difficulties. Identifying people who are at risk of developing dementia reveals a somewhat incoherent situation pertaining to the role and meaning of a diagnosis and the labels of MCI and SCD which I consider below.

1.6 Ascribing the label of MCI: diagnosis and prodromal factors

Understanding the culture of active ageing requires consideration of the categories of MCI and subjective cognitive decline (SCD) which have been ascribed formally and informally as a way of identifying people without dementia but who may be at risk of getting dementia. Mild Cognitive Impairment (MCI) and Subjective Cognitive Decline (SCD) are diagnostic categories which describe respectively, objective, and subjective cognitive concerns judged to be inconsistent with age, but not indicative of dementia. There is a growing debate concerning the most appropriate approach for an early diagnosis of dementia in those individuals identified as having MCI. However, (Rossini et al., 2022) rightly questioned the feasibility of screening individuals at risk of developing dementia if MCI used as a diagnostic tool from a public health perspective.

Identifying and diagnosing MCI is fundamentally problematic as its diagnostic criteria have been contested (Schweda et al., 2018). Despite its inclusion in the Diagnostic Statistical Manual-5 (DSM-5) under cognitive neurological conditions, ambiguity remains, with research highlighting a lack of standardised criteria (Schweda et al., 2018). Doubts regarding the value and utility of the diagnosis create dilemmas for those conferring, and in receipt of this diagnostic ‘label’. SCD is regarded as a precursor to MCI and has similarly been questioned as a diagnostic category in its own right (Gifford et al., 2015). Opdebeeck et al., (2019) found limited associations between SCD and objective cognition, querying the worth of this label.

MCI affects between 5 – 20% of the UK population over 65 (Alzheimers Society, 2022). The reported conversion rate from MCI to dementia varies greatly (Dunne et al., 2021; McGrattan et al., 2022). McGrattan et al. (2022) found a conversion range of 6.0%–44.8%; with an average follow-up check for dementia of 3.7years. People diagnosed with MCI may show further cognitive decline, stabilise, or even improve, adding to the questions surrounding the utility of it as a diagnosis. Research studies document the resultant uncertainty and confusion for those seeking help for memory concerns and receiving a diagnosis (Gerstenecker & Mast, 2015; Joosten-Weyn Banningh et al., 2008; Pickersgill, 2014; Schweda et al., 2018).

Some people experiencing memory loss in later life perceive it as just normal ageing, or they seek help and want to know whether they are going to develop Alzheimer's disease or not (Corner & Bond, 2006). More recently the term functional cognitive disorder (FCD) has been used by the UK Alzheimer's society to identify memory concerns which are temporary and not related to dementia (Ball et al., 2020). This reflects an evolving discourse in medical and scientific terminology, diagnostic criteria, and categories of memory impairment. Although memory loss is a significant symptom of these conditions, daily functional ability has been regarded by some as a more important indicator of MCI than cognitive decline (Gerstenecker & Mast, 2015). This reflects a broader ambiguity not just in diagnostic criteria, but also in categories of cognitive impairment and terminology around memory concerns and difficulties which are not diagnosed as dementia.

Concerns about cognitive function generate uncertainty and confusion with some older people who consult health care professionals, going on to receive a diagnostic label. However, it is worth noting that most individuals who meet the criteria for MCI are undiagnosed, so these labels are ascribed to the minority who seek early help for memory concerns. Diagnosis serves to enable individuals to distance and distinguish themselves with the MCI label, thereby psychologically distancing themselves from 'the others' who are in the 'dementia group'.

As MCI and SCD are now commonly associated with a prodromal stage of dementia, individuals identified with these labels are perceived as not currently having dementia 'yet' but are considered at risk of developing it. However, the timeline for this development remains uncertain.

MCI and SCD are frequently considered within dementia literature, despite the impact and prognosis of each being very different, this distinction is not made explicit. Research which has specifically considered MCI and dementia suggest that those ascribed this label expressed considerable uncertainty of what MCI is and how it differs from dementia and are unsure what their diagnosis means (Beard & Neary, 2013). Other studies have indicated a sense of not knowing and not wanting to know (Pierce et al., 2016). All conclude that more research is needed to consider the subjective experiences of those ascribed a diagnosis of MCI and those who are not diagnosed with MCI, but who self-identify as having symptoms of cognitive impairment and could be categorised as having SCD but have not been ascribed this label.

These terms have been used liberally within the scientific and medical arena, but with little attention to their impact upon the subjective experiences of people ascribed such labels. As the mean age of the global world population increases rapidly and dementia becomes more prevalent in society, it is regarded as of paramount importance to develop understanding of the mechanisms which allow for healthy cognitive ageing (Oosterhuis et al., 2023). In the absence of any disease modifying treatments for dementia and its recognised long pre-clinical phase, prevention has been regarded as the most effective form of intervention (Sabayan et al., 2023). The arrival of modifiable risk factors in dementia brings another layer of complexity to the subjective experiences of MCI and SCD, including the increased role of active ageing in dementia prevention, which I discuss next.

1.7 The science of modifiable risk factors and the rise of dementia prevention and bio-markers

Public health approaches to dementia risk were transformed by the identification of modifiable risk factors and have promoted the prospect of dementia becoming regarded as a preventable condition through two significant reports from the Lancet Commission (Livingston et al., 2017, 2020). The most recent identifies 12 risk factors; hearing impairment, low education, smoking, depression, low social contact, traumatic brain injury, air pollution, hypertension, physical inactivity, diabetes, alcohol consumption and obesity – purportedly accounting for 40% of dementias (Livingston et al., 2020). This has led to increased public health initiatives and policy developments such as the current UK governments, ‘Prevention is better than cure' policy regarding health promotion (The Department for Health and Social Care, 2018). However, the claim that 40% of dementias are preventable has been received cautiously by several researchers and considered as optimistic, with establishing causality and relationships with risk factors being difficult, (Kivimäki & Singh-Manoux, 2018; Leibing & Schicktanz, 2022; Warren & Bamiou, 2018).

In the absence of effective treatments for dementia, this means that risk reduction is one of the key public health challenges of our time (Walsh et al., 2022b). The arrival of the drug ‘Lecanenab’ with its positive results on cognitive performance in early Alzheimer’s has raised public awareness and hope of a pharmaceutical disease modifying intervention (Walsh et al., 2022b). However, the short trial period of eighteen months provides limited insight into the drug’s effectiveness in relation to the overall disease course of Alzheimer’s disease, thus illustrating the complexity of translating very early clinical trial results into clinical practice (Planche & Villain, 2023). Dementia prevention has become a term which has developed into a feasible reality for those considered to be at risk of developing dementia. However, this is a contentious area, the nature of 'risk' is not a universal entity and the poor accuracy of risk assessments and diagnostic technologies in predicting future outcomes has been documented (Fahey et al., 2023). Fahey's study considers the future of dementia prevention through interviews with clinicians in the area, they predicted a shift in terminology from 'dementia prevention' to 'brain health', more accurately reflecting the reality that interventions postpone rather than prevent dementia (Fahey et al., 2023). Respondents from Fahey's study make the point that dementia risk-assessment is meaningfully distinct from diagnosis and raise concern over how having 'at risk statuses' could adversely impact people's lives (Fahey et al., 2023). The potential to reverse or reduce dementia risk through active health interventions has become both an opportunity for individuals but also a responsibility, raising the significance of active ageing policy and practice's role in this.

Prevention strategies within the UK, Europe and the US tend to place the responsibility for change upon the individual with few resources being given to population wide approaches. Clinical Randomised controlled trials (RCTs) provide little evidence supporting the efficacy of preventative interventions (Richard et al., 2019; Whitty et al., 2020). However, strengthening the social dimension of prevention programmes and lifestyle changes represent key elements in improving quality of life and reducing the risk of loss of physical autonomy, especially among those aged over-75 (Liotta et al., 2018). The idea of a ‘responsibilised’ citizen has been discussed through a Foucauldian theory of Governmentality; ‘government at a distance;’ (Conway & Crawshaw, 2009). Conway and Crawshaw discuss how through the notion of ‘healthy senior citizenship 'older people are increasingly being directed to live their lives in an active and entrepreneurial way. They go on to state that older people are expected to see their everyday decisions in terms of a personal assessment of risks and benefits (Conway & Crawshaw, 2009). Within active ageing policy this is illustrated by an unequal distribution between population and individual approaches to prevention, with an increasing focus upon individual approaches inherent within most public health policies and educational campaigns around brain health.

The inclusion of mild cognitive impairment (MCI) in the DSM-5 identifies it as a diagnostic category of memory impairment which is not dementia (Pickersgill, 2014), however, as previously noted this is contested and most people who have symptoms fitting this category are not diagnosed. Contemporary conceptualization of dementia in medicine and science has explored the role of blood-based biomarkers in predicting early dementia conditions, with the category of mild cognitive impairment gaining increasing importance in this context (Leibing, 2018). The most influential aspects of the Lancet Commission Reports (Livingston et al., 2017, 2020) have been stratifications of discrete risk factor contributions as percentages. This represents an increased clinical and epidemiological approach to dementia prevention with the development of bio-marker research which has pushed earlier identification of dementia diseases such as Alzheimer’s to a pre-clinical phase. Potentially, this means that people may be diagnosed before observable and measurable symptoms are present.

A legacy of clinical trial failures to find effective treatments for dementia, shifting aetiological hypotheses and epidemiological observations contribute to forming a discourse around modifiable risk and dementia prevention. Additionally, Katz and Marshall (2003) describe how the intensified focus on prevention of ageing let us believe that we can “grow older without ageing”, by providing possibilities of action to counteract the ageing process (Katz & Marshall, 2003). Science not only offers solutions to a predefined societal problem, but also contributes to the framing of ageing as a health problem (Green & Hillersdal, 2021). The dominance of a bio-medical focus on dementia, along with prodromal factors such as MCI for earlier diagnostic opportunities and recognition of modifiable risk factors have all contributed to an increased clinical focus on dementia prevention and subsequent policy. This has emerged in the context of a cultural shift from a traditional regard of old age as a period of deficits and limitations to one that has been replaced by an active ageing discourse which stimulates ongoing participation in later life (Boudiny, 2013). Boudiny discusses the idea of ‘competence thinking,’ referring to societies increased focus on older people’s competence and knowledge to participate in activities. This implies a cognitive ability which may be compromised in older people with MCI and memory difficulties. Dementia prevention brings with it an added sense of responsibility or moral imperative with implications for how participants engage within active ageing practices such as the APPLE-Tree intervention. I will now explore the relationship between active ageing policy and practice.

1.8 Active ageing policy and its relationship with active ageing practice

The World Health Organisation report on active ageing promotes healthy and active ageing by advocating strategies for encouraging everyone to age as well as they can, recognising diverse needs in policy and practice in a non-coercive and inclusive fashion (WHO, 2015; Zaidi & Howse, 2017). Active ageing policy aims to combine with active ageing practice in the promotion of individual well-being with the achievement of benefits to the wider society (Zaidi & Howse, 2017). However, active ageing policy has been criticised for its preoccupation with employment and productivity without providing adequate resources to enable it and active ageing practice has equally been criticised for overly ambitious formulations, and an unrealistic focus upon 'youthful' activities that emphasise health and independence (Foster & Walker, 2015).

Two central themes emerge from this discussion around active ageing policy and active ageing practice; one is that physical health is privileged over cognitive health and the second is the adoption of simplified and reductive models which overlook subjective experience. Throughout Europe and the UK active ageing policy has tended to focus upon improving and managing long term physical health conditions, known as co-morbidities (Walker, 2008). However, less attention has been given to cognitive conditions which are not dementia such as mild cognitive impairments, including the consideration of this as a co-morbidity. The emphasis on the physicality of health in age and ageing is reflected in National Institute of Clinical Excellence (NICE) pathways advising on the management and reduction of long-term conditions in older people (NICE, 2015).

However, these chronic disease management systems often provide simplified models to tackle complex processes and practices (Fudge & Swinglehurst, 2022). Replication of this is evident within active ageing practices, as prevention interventions tend to focus upon one or two health determinants and do not account for an individual’s wider social and economic position and biography.

Lived experiences of active ageing practice have been explored in relation to technologies such as brain training (Libert et al., 2020a). However, there is a paucity of literature relating to active ageing practices with people who have MCI and memory difficulties with the intention of preventing or delaying the onset of dementia. Research on the lived experience of MCI focuses upon the impact and meaning of a diagnosis. For example, (Lingler et al., 2006) found that people displayed a range of interrelated emotions when conceptualising a diagnosis of MCI. Joosten-Weyn Banningh et al (2008) found that individuals with a diagnosis of MCI encounter stress-inducing practical, social, and psychological difficulties. More recently (Johansson et al., 2015) described the large variations in individual experiences of having memory difficulties or an MCI label which were not regarded as dementia and the need for health professionals increased awareness of the emotional complexities surrounding this. As previously stated, ‘early signs’, such as different biomarkers, and the prodromal nature of mild cognitive impairment is contested by researchers and not reliable as clear indicators of future disease. Along with research on the subjective experiences of memory difficulties and MCI, this suggests a context characterised by uncertainty and instability. Consequently, active ageing practices, specifically those focused on dementia prevention interventions, have emerged within this complex context. It is crucial to recognise and understand subjective experiences within the framework of active ageing policy and practice. Simultaneously, there is a lack of clarity regarding the specific actions that individuals should take.

Stenner (2011) critiques the prevalent deterministic ‘cause and effect’ frameworks used by social scientists, using the example of the WHO model which refers exclusively to determinants of active ageing. Whether economic, social, physical, behavioural or personal in nature, these frameworks lack understanding of the subjective and agentic while assuming determinism, (Stenner et al., 2011). It has therefore been suggested that preventive measures need to be evaluated not only regarding their effects, but also regarding how they weigh on people’s everyday lives (Leibing & Schicktanz, 2022). This is at the centre of my thesis, exploring how people with a cognitive impairment which is not dementia engage with the health and lifestyle intervention APPLE-tree. The APPLE-tree intervention as an example of active ageing practice will be discussed in the next section.

1.9 Active ageing practice: APPLE - tree as dementia health and lifestyle intervention

The APPLE-tree programme stands for Active Prevention in People at risk of dementia through Lifestyle, Behaviour change and Technology to build Resilience (Cooper et al., 2020), and is an example of active ageing practice for people with MCI and memory difficulties which are not dementia. In the next section I briefly introduce the APPLE-tree intervention as an example of active ageing practice and how it developed from a previous multi-modal study.

The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) is one of the few prevention trials recognising the multifactorial nature of Alzheimer's disease and dementia, from which a focus upon multi-domain interventions emerged (Rosenberg et al., 2018). The prominence of the FINGER trial as a cognitive impairment prevention programme, along with an increased interest in the role of modifiable risk factors, biomarkers, and early diagnosis, led to the development of dementia prevention programmes such as APPLE-tree. The APPLE-tree programme is a multi-domain lifestyle intervention, delivered through workshops with people aged 60+ who have memory difficulties to which no diagnostic label has been ascribed, as well as those diagnosed with MCI or subjective cognitive decline (Cooper et al., 2020). More detailed information of how APPLE-tree operated as an intervention is found in Appendix 1.

This programme became a lens through which I was able to study active ageing as a concept through the experience of people undertaking the intervention, by exploring how participants engaged and situated themselves within a dementia prevention programme. The APPLE-tree programme is one of the few examples of active ageing interventions for people with MCI and memory difficulties. Participants enter the intervention through different routes, and this will be discussed further in my methods chapter (Chapter 4). However, my focus of interest was not how people were recruited to the study, but how they engaged and participated within it and what this particular active ageing approach meant to them. It provided me with a unique opportunity to consider the concepts of active ageing policy and practice through the experiences of people participating in such an intervention.

The APPLE-tree intervention provides an opportunity to understand this previously neglected area. I apply a social science dimension to consider healthy ageing policy and practice, which reflects and recognises the varied meanings ascribed to the term ‘active ageing’. In the following section I outline the differences and similarities of these terms, providing a context and rationale for the adoption of ‘active ageing’ within my thesis.

1.10 Understanding the terminology: successful active and healthy ageing

The terms successful ageing, active ageing and healthy ageing are often used interchangeably and are synonymous with both illness prevention and health intervention. The similarities and differences between them reflect the complex and complicated context which interventions such as APPLE–tree have developed within and from. These terms are not distinct concepts, but have developed iteratively, as policy responses shaped by a demographic, political, old age and ageing landscape previously outlined, with inevitable overlap between them. Therefore, for clarity I introduce these chronologically, starting from successful ageing, moving to discussions about active ageing and most recently healthy ageing.

1.10.1 Successful ageing

Rowe & Kahn's (1997) initial definition of successful ageing included three components: the low probability of disease, high cognitive functional capacity, and active engagement in life. The notion of ‘active ageing’ dates back to discussions from the 1960s around the concept of successful ageing (Havighurst, 1963). The overlap with ‘successful ageing’ (Rowe & Kahn, 1997) exemplifies the range of terms and definitions which exist, where the semantics reflect a changing political, social, and medical landscape through usage of words such as optimal, productive, and healthy. One problem is that old age may be regarded as a terminal destination in itself and not part of a re-ordered life course (Higgs, 2018). Fernández-Ballesteros et al., (2019) argue that this mix of variables is rooted in the purpose of the definitions; that is, the promotion of policies at a population level, whilst conversely promoting responsibility through an individual perspective. Rowe and Kahn make a distinction between what they term as ‘non-diseased older people’ as being ‘usual; non-pathological but high risk’ and the people who are ‘successful; low risk and high function’ (Rowe & Kahn, 1997), This reflects a tension between Rowe & Kahn’s version of successful ageing as individualistic, whereas critical gerontologists take a more systemic view.

The definition of ‘successful ageing’ through health and functionality, physical and cognitive competence, and life involvement, has been criticised for not considering overlapping social issues (Calasanti, 2016). Toni Calasanti suggests that the unintended consequence of successful ageing is intensifying a burden on older people to be responsible for fixing the problem of old age and the associated decline. This has implications for the terms and conditions of engagement with cognitive health prevention programmes, where the very word ‘successful’ may not be comprehendible for an older person with a cognitive impairment. Potentially this could create feelings of exclusion and social devaluation (Calasanti, 2016), particularly for those who can't achieve success. However, studies which have considered broader formulations of 'successful' through measures of wellbeing, found that by using ''wellbeing in adversity' scores, mental health and social relationships were important predictors of successful ageing (Livingston et al., 2008). This illustrates the importance of recognising the broader aspect of people's lives when considering what successful ageing might look like, by capturing the subjective wellbeing experiences of people living with mild dementia and memory difficulties.

1.10.2 Healthy ageing

In the 2015-2030 strategy the World Health Organisation (WHO) changed 'active ageing' to 'healthy ageing', bringing a greater focus on diversity and inequity (WHO, 2015). This was a reversion back to an original term of healthy ageing which had at that time been considered to be the most important factor in discussions around age, followed by independence (ability to manage oneself). (Paúl et al., 2012). Paúl et al point out that at the same time ability to learn new things, work after retirement, feel able to influence others and stay involved with the world and people was considered less important until the adoption of the term 'active ageing' in 2002. The WHO's 're-adoption' of the term healthy ageing is defined as a process that includes outcomes such as 'health' and 'participation', as well as determinants of active ageing such as 'security'.

The WHO advocate that everybody is potentially able to experience healthy ageing and that being free of disease or infirmity is not a requirement for healthy ageing, as many older people have multiple health conditions or co-morbidities.

They believe that healthy ageing is about creating the environments and opportunities that enable people to be and do what they value throughout their lives. Abyad points out that ‘active and healthy ageing’ helps reduce the pressure on health care and social services, as older people who stay healthy, active, and independent can continue to contribute their skills, knowledge, and experience to society (Abyad, 2018). WHO’s (2021 – 2030) ‘Decade of Healthy Ageing’ is a global collaborative approach designed to bring communities together to improve the lives of older people, in line with a life course approach (WHO, 2015)

1.10.3 Summary of successful, active, and healthy ageing

Active ageing and healthy ageing are most closely aligned and are used interchangeably. Despite the WHO reversion back to the term ‘healthy ageing’, the term ‘active ageing’ as a definition and a concept remains relevant and present in the discourse surrounding illness prevention strategies and health and wellbeing interventions for older people. Although there were attempts to shift the location of success and failure upon the APPLE-tree intervention, I found that in practice, the connotations of ‘active ageing’ remained dominant. Therefore, adopting active ageing as a focus for my thesis reflects the coalescence between healthy and active ageing, whilst successful ageing remains desired by many older people as the optimum, as yet it is not easily identifiable.

Essentially the terms successful, active, and healthy ageing all describe the function of active ageing practices. Any differences between these definitions reflect specific temporal changes in a political and social context, however all refer to a sense of activity and participation. ‘Healthy ageing’ and ‘active ageing’ share the belief that keeping active equates to keeping healthy, which ultimately leads to maintaining independence, with both incorporating social, cultural, and economic considerations. Successful ageing focuses upon the absence or presence of disease along with an individual's functional ability as being a deciding factor in how successfully older people age. This has attracted criticism for not considering overlapping social issues and producing a burden of individual responsibility (WHO, 2015). As previously documented, notions of ability and responsibility are paramount in any discussion of active ageing practice and has specific implications for participants with cognitive impairment.

In the following section I consider citizenship and life course, distinction, and positioning to contextualise active ageing for people with memory difficulties and MCI. This includes an overview of the concept of 'responsibilisation' and its impact before moving into a discussion of sociological theories.

1.11 Shaping active ageing policy through concepts of citizenship, life course and positionality

Active ageing policies are shaped by the political and economic context of the countries within which they develop, taking a social science perspective allows for a broader exploration of this context. Walker, (2002) pointed out that the policy challenge for any active and healthy ageing strategy is to join several policies in society around employment, health, social inclusion, transport, and education; he notes that an effective strategy on active ageing will be based on a partnership between the citizen and society. Increasingly the terms 'active citizen and citizenship' have become prominent reflecting the politics of citizenship in the UK and the changing direction towards concepts of ‘responsibilisation’, which have shaped the current idea of citizenship (Lister, 2011). Historically, the emphasis of citizenship has moved from the collective to the individual, as people are encouraged to take on more responsibility (Higgs, 1995). Citizenship approaches have been critiqued as being homogenous and assuming that older people embrace old age and will therefore embrace citizenship (Gilleard & Higgs, 2014). Any discussion of active ageing policy therefore needs to include and acknowledge notions of citizenship as inherent to its discourse and as shaping its practice.

Lister draws attention to the politics of citizenship in the UK, with notions of responsibility and obligation producing a shift in direction towards the processes of “responsibilisation”’ which have in turn increasingly shaped the ideal citizen of today (Lister, 2011). Trnka & Trundle discuss how ‘neoliberal responsibilisation’ promotes forms of public presentation and display that fall in line with much wider moral principles (Trnka & Trundle, 2014). They point to a multiplicity of responsibilities, where individuals deal with competing responsibilities within a matrix of relationships, dependencies, reciprocities, and obligations. I will discuss this interplay of responsibilities from the participants I observed and interviewed within the APPLE-tree intervention.

Increasingly age and ageing have been conceptualised through a life course approach to health (Higgs, 2022). Unlike a disease-oriented approach, which focuses on interventions for a single condition at a single life stage, a life course approach considers the critical stages, transitions, and settings where large differences can be made in promoting or restoring health and wellbeing

(Public Health England, 2019). Walker suggests that adopting this approach means that active ageing strategies should be considered “ageless” (Walker, 2002). By this he means covering the whole of the life course and therefore operationalised at different stages of the life cycle.

Jones, (2006) has explored how older people talk about old age and use language to ‘position’ themselves within their life course. Positions are theorised to be a more variable, multiple, and shifting version of ‘role’, which may be contradictory and be part of an ongoing process of interaction, (R. L. Jones, 2006). The notion of old age as one of decline has historically underpinned the status of old age, which has led to a static understanding of the nature of old age, (Higgs & Gilleard in Pescosolido et al., 2010). Memory difficulties can disrupt ‘normal’ ageing, but MCI places individuals in a liminal position. Poppe, (2020) refer to liminality as an experience of “lostness” among people with memory concerns who find themselves in a transitional state betwixt-and-between the normal age-related decline in memory and the pathological, dementia. Birt et al., (2017) have described liminality in relation to dementia as a progressive disease with marked landmarks and transitions. MCI does not readily fit this definition, although considered part of a pre-clinical phase of dementia, as previously stated, this is not definitive. Not all people with MCI go on to develop dementia and a diagnosis of MCI is not crucial in an individual’s desire to avoid developing dementia.

However, rather than identifying at-risk individuals, whole population approaches to risk reduction have been proposed as a way of affecting the contexts and environments in which people live, work, and play (Walsh et al., 2022a). Unlike a life course approach which takes a temporal perspective on the individual and their health determinants, a whole-population-based approach requires engagement from a much broader range of stakeholders, including national and local governments, industry, the education sector, town planners, and workplaces (Walsh et al., 2022a). Assertions about a person's ability to transform their cognitive future have been criticised as creating a potential to misattribute blame to individuals (Schweda & Pfaller, 2020). Fahey's study of people in active ageing interventions found that participants desired greater collectivisation of prevention to counter overly individualistic approaches (Fahey et al., 2023). They also suggested that personalised risk identification could become a clinically useful routine health check. However, Fahey warned that individualised approaches may attribute blame to people for cognitive impairment which is beyond personal control. This reflects wider critiques of 'responsibilisation' theories that appeal to individual behaviour and assume unrealistic agency regarding lifestyle and obscure structural determinants (Schweda & Pfaller, 2020). I will consider responsibilisation in relation to active ageing in the next section.

1.12 Conceptualising active ageing through responsibilisation

The advocation of successful ageing regimes in public discourse along with the shift in accountability for 'achieving' a successful older age to the individual has resulted in the 'responsibilisation of ageing' (Chelberg, 2023; Latimer, 2018). As previously stated responsibilisation, has been regarded as a form of 'governmentality' identified by Foucault, described as "the process whereby individuals and communities are simultaneously liberated, and accountable, to define and achieve their own future and wellbeing” (Chelberg, 2023 pg.4). Responsibilisation guides individuals’ conduct in the management of their own good health.

Within sociology and critical gerontology, the concept of ‘responsibilisation’ in health prevention can be considered through a deliberation of responsibility on ‘the fair distribution of roles and claims between individuals, communities, and the state’ (Schweda & Pfaller, 2020). In Chelberg’s recent study of ‘brainwork practices’, she discussed the moral obligation and responsibilisation of brain health through successful ageing. She describes how self-responsibility and dementia can be seen as ‘failed citizenship obligations’ and thus reinforce stigma surrounding the condition, whilst equally promoting a sense of responsibility and effort to become ‘good agers’ (Chelberg, 2023).

Embedded within ‘responsibilisation’ discourse, MCI may be regarded as a call to galvanise older people into action, to do something to stave off a future with dementia. Thus, potentially placing a moral burden on individuals to act with the knowledge that they can (and should) do so. An MCI diagnosis becomes an impetus to act and engage in active ageing strategies to prevent cognitive deterioration. Paradoxically the MCI label also distinguishes people as not having ‘too much’ dementia and therefore gives people agency to affirm their location in a ‘consumer’ orientated third age through engaging in what Libert describes as, ‘active cognitive health promotion’ (Libert et al., 2020a). The active ageing narrative also aims to shift perceptions and associated prejudices, towards a more positive, dynamic view of old age (Walker, 2002). Active ageing sits within both the re-negotiation of ageing, and fitting with neoliberal ideals, with the shift of responsibility from states to the individual, (Stenner et al., 2011; Walker, 2008). Continuing to draw upon sociological theory in the next section, I consider their application to cognitive health.

1.13 Sociological theories and concepts to frame understanding

A range of sociological theories have been put forward to explain the position of older people in contemporary society and I will briefly outline these. Given that most of the population reaching old age is a modern phenomenon dating to the 20th century, ideas about the roles and expectations relate to the novelty of ageing populations. They can be divided into negative and positive approaches (Higgs and Nazroo in Fillit et al., 2016). Disengagement theory sees old age as inevitable, natural with old people unable to negotiate new roles, and within this context the concept of 'successful ageing' developed (Cumming & Henry, 1962). Structured dependency theory emerged as support for disengagement theory declined, this stressed social policy and retirement with the dependency of older people structured by society and state responsibility (Townsend, 1981). The third age challenged structural dependency theory as Laslett raised the prospect of older people fulfilling good health and therefore having new opportunities through retirement and a subsequent increase in 'self-enriching' activities (Laslett, 1991). These preceded theories around the culture of ageing which considers the idea of a life course where age and stages blur and a linear life course becomes problematic. In conclusion, old age is not regarded as a stable phenomenon but one which is constantly changing, and each cohort is different (Higgs, 2018).

Conceptualising the commonality of age as a shared experience of discrimination and marginality to a position of recognising the increased individuality of experience of age and ageing, including stages of personal choice and an individualised lifestyle. The latter reflect a division of later life into stages through ideas of a third and fourth age (Laslett, 1991), a concept which became established in contemporary gerontology. However, this has developed as more of a division than a distinct stage with the concept of the third age regarded as a cultural field encompassing choice and consumerism and which shapes the 'social imaginary' of the fourth age (Gilleard & Higgs, 2010). The social imaginary of the fourth age according to Higgs and Gilleard creates a representation of a life with restricted choice and little agency and a set of socially organised assumptions about society. Dementia alongside frailty, abjection, and the need for care project a 'feared' old age irrespective of attempts to de-stigmatise it.

The contrast between the third and fourth age provides a way of thinking about the role of MCI and memory difficulties as components of a metaphorical 'event horizon' (Gilleard & Higgs, 2010), creating a pull of a negative fourth age from the agency associated with the third. Certainly receiving an MCI diagnosis has been reported as producing a 'new and fearful presence' marked by contradictions between the known and the unknown (Katz et al., 2020). Within this context fear is something which has multiple dimensions, unclear causality and can lead to stigma, avoidance, and uncertainty.

The culture of active ageing policy and practice has shifted conceptualisations of older people from one of dependence and decline to one of being capable consumers, who have been described as 'limited but limitless' in their ability (Clotworthy,2020). Biographical disruption can help to consider subjective experiences of illness and its impact through an individual's life course, with a chronic condition not just regarded as a medical category (Bury, 1982). Bury describes chronic illness as a major disruptive event disabling one's relationships and ability to get resources, with the reconfiguration of narratives as people integrate the condition of being ill into their understanding of themselves and their life trajectories (Engman, 2019). Although MCI may be regarded as less 'biographically disruptive' there is an implication of individual responsibility for memory deterioration which may lead to being asked to accept the idea of memory loss at an earlier stage.

People with MCI and memory difficulties which are not labelled dementia do not have a clear trajectory, and although this may be regarded as a liminal space this is not a static position. This idea of movement and transition characterises the concept of status passage which has been used to consider older peoples experiences of dementia. Conceiving the experience of dementia as a passage rather than taking its disruptive elements as a focal point offers greater conceptual breadth, focusing upon interactions between the 'passagee and related agents' (Tolhurst & Kingston, 2013). Both biographical disruption and status transition offer different ways of understanding active ageing practices, and how and why people with memory difficulties and MCI engage with and participate in dementia prevention interventions. These are considered further through my discussion in chapter 5.

Libert (2020) uses Bourdieu's theories of distinction to discuss how individuals within an active ageing intervention, position themselves away from dementia and allows them to demonstrate to themselves and others their cognitive health (Libert et al., 2020a). They argue that as people progress into later life, they are continually called to engage with the ideal of active ageing whether it be through brain training or health and lifestyle initiatives, with a distinction being made between notions of activity and passivity. Libert et al (2020) have used the concept of technologies of distinction in his work to studying brain training and healthy ageing discourses.

All the above theories and concepts share a common sense of movement, alluding to the idea of transition from locations and positions. However, they predominately focus upon dementia as a chronic illness or physical health problems, with less consideration given to individuals with memory difficulties which are not dementia. The complexity of these subjective experiences suggests that they are all characterised by uncertainty and disturbance, as individuals perceive growing older and developing dementia. In this research I aim to explore this multi-faceted concept and consider how active ageing plays out for individuals through a dementia prevention programme. I am interested in how these people position and locate themselves within an active ageing practice (APPLE-tree intervention) and particularly how this might be different for people with memory difficulties.

My research question: how does active ageing policy and practice reconfigure experiences of cognitive impairment? flows from the policy shift in which active ageing practice moves from the collective to the individual. This includes notions of responsibility, as people appear to negotiate a terrain which is unknown and unclear and position themselves accordingly. A desire to maintain cognitive health as third age active consumers is in juxtaposition to the uncertainty of what is happening to them and knowing what they should do. They don't know what to expect but are willing to engage in actively modifying their risks though active ageing interventions. My focus is consequently on what an active ageing approach means to the participants in the APPLE-tree programme.

1.14 Providing a rationale and focus

The focus of this thesis is to understand how active ageing policy and practice reconfigures mild cognitive impairment. In this chapter I have described the context of this question and have introduced the culture of active ageing as a multi-faceted phenomenon, responsive to temporal, political, economic, social, and scientific developments in the concept of age and ageing. One of the most significant developments is the identification of modifiable risk factors for dementia and through biomedical advances in the early diagnosis of dementia. Both have elevated the importance in MCI as it is considered a prodromal element of dementia, and this has subsequently increased the recognition of self-identified memory difficulties. The diagnostic status of these conditions is complicated and has been questioned, however this recognition has raised their importance within the public health arena of dementia prevention. This has resulted in active ageing policies and practices being considered and applied to people with MCI and self-identified memory difficulties.

I have introduced a definition of active ageing as one of participation, optimising health and maintaining independence (WHO, 2015) whilst recognising 'healthy' and 'successful' ageing are terms which have come from specific contexts and theoretical positions. Theoretical discussions drawn from the sociology of age and active ageing provide a focus for exploration and frame critical discussion throughout my thesis. It is from this diverse and complex background that the APPLE-tree programme has developed as a health and lifestyle intervention as well as a dementia prevention strategy.

My focus is to examine the complex and overlapping nature of active ageing as a concept through policy and as a subjective experience through practice, both of which are under researched areas in people who have memory difficulties and MCI which is not dementia. Studying the participants in the APPLE-tree intervention provides an opportunity to understand both aspects with subsequent research questions around understanding how people situate themselves within the APPLE-tree intervention and how they adopt this into their lives. I wished to explore the subjective experience of active ageing practice and do this through ethnographic methods and draw upon theoretical constructs outlined here. This study aims to capture the authentic experiences of individuals taking part in this innovative health and lifestyle dementia prevention programme.

In the following chapters I present results from a scoping review of the subjective experiences of diagnosis of MCI and a secondary data analysis of consultation interviews from the APPLE-tree programme. This is followed by a chapter outlining my methods and methodology, and an ethnographic findings chapter focusing on participants' experiences of the APPLE-tree dementia prevention programme viewed as an example of active ageing practice in dementia prevention. This study describes more than just the experiences of individuals participating in a dementia prevention programme. It includes an analysis of the various strategies employed by participants as they negotiated this domain. This includes examples of how individuals become participants within an active ageing intervention and come to terms with the uncertainty of their condition, their fears for themselves, their comparison with others, and the way that they make social distinctions about themselves and others. The studies within this research reveal the lack of clarity associated with the unknown and suggest constant negotiation of the terms of reference required by individuals as they position themselves to demonstrate their taking of individual responsibility for their own cognitive health. In this way they seek to avoid developing dementia through their engagement with an intervention that minimises their risk of developing dementia. Finally, the discussion in chapter 7 applies theoretical concepts from sociology outlined here, to critically explore how policy and practice reconfigures this experience. It suggests implications for active ageing as a concept and an experience increasingly motivating dementia prevention as a public health activity.

1.15 Overall aims and objectives

My overall aim is to understand how active ageing policy and practice reconfigures the experiences of cognitive impairment. I want to consider the interface between active ageing policy and practice, and to explore it both as a concept and an experience through an active ageing intervention. The following questions are considered through my **scoping review** and **secondary data analysis**.

- What meaning do individuals give to their memory concerns, including those with or without a diagnosis of MCI and SCD?

- How do they understand this in the context of cognitive impairment and ageing?

My scoping review in chapter two explores accounts of receiving a diagnosis of MCI and having memory difficulties which are not dementia. This aims to identify any gaps in understanding these subjective experiences which have an implication for active ageing policy and practice. The secondary data analysis in chapter 3 explores how individuals navigate the management of their own memory. In chapters 4 and 5 I use an **ethnographic** approach to explore active ageing policy in practice through the APPLE-tree intervention and address the following questions:

- How do participants situate themselves within the APPLE-tree intervention?
- How do participants adopt this into their lives?

The novel contribution of this study is to move beyond the individual experience to look at the collective experience and the interconnections within active ageing policy and practice.

Finally, in chapter six I **discuss** how active ageing as both a concept and an experience increasingly motivate dementia prevention as a public health activity through a critical application of theoretical concepts from sociology.

Chapter 2 Exploring the literature to understand the subjective experiences of memory concern and MCI diagnosis: a scoping review.

2.1 Introduction

In chapter one I introduced the concept of active ageing as multifaceted. Active ageing practice and policy is shaped by a historical political and economic landscape which has seen old age and health move into a responsbilised activity. Additional linkage with memory difficulties and mild cognitive impairment, adds another layer of complexity. The possibility of preventing dementia through the identification of modifiable risk factors has pushed dementia prevention into the realms of what might be considered normal forgetfulness in old age. Increased significance attached to memory difficulties in later life has been solidified through categories such MCI. These have become identifiers of risk and triggers to act, respond and ultimately engage with dementia prevention interventions.

My focus here is exploring how active ageing practice changes notions of cognitive impairment by studying individual participation in an intervention, such as the APPLE-tree programme. However, as illustrated in chapter one this area is characterised by a general lack of clarity and recognition around the subjective experiences of older people who have memory difficulties which are not dementia. In this chapter I explore this gap in the research through the analysis of existing literature to understand how this might influence and shape active ageing policy and practice for cognitive health. Using a systematic search method through a scoping review I explored a range of primary sources from psychology, health, and social science literature to explore the meaning individuals give to their memory difficulties and subsequent labels of cognitive impairment, MCI or SCD and analysed these findings to provide more in-depth insight. Beard & Neary, (2013) describe how an increased medicalisation of cognitive impairment through the diagnosis of MCI fails to fully acknowledge subjective experiences. In exploring this further through a review of the literature, I recognise that this is a significant part of the background from which people will present and engage with active ageing practice and contributes to understanding of active ageing policy.

MCI and SCD do not have homogeneous underlying pathologies or a predictable disease course and the capacity of a diagnosis to reassure and help people has been questioned (Gifford et al., 2015; Howard, 2020; Pickersgill, 2014). This contributes to the feelings of uncertainty expressed within the literature. The concept of ‘manufactured uncertainty’ (Giddens,1999) has resonance here where more knowledge does not lead to clarity but its opposite; consequently, the diagnostic process surrounding MCI rarely appears to produce certainty and understanding (Linden et al., 2024). Despite its significance in the prodromal phase of dementia, MCI remains problematic due to a lack of standardised criteria (Schweda et al., 2018). The contested nature of MCI is not only about clinical nosology but rather is about how people’s lives are not reducible to stages of a predefined disease progression. The lack of an explicit patient career creates not only uncertainty but also a sense of a void or vacuum (Pinner, 2000). Individuals are forced to navigate a range of unclear meanings without any prospect of clarity or resolution.

Scoping\ reviews explore and understand knowledge in an emerging field and discuss characteristics in that field (Peters et al., 2020). This was therefore a suitable method to use to start to address the lack of clarity identified in the introduction and establish how individuals give meaning to memory difficulties and MCI. In the following section I will outline the methods and methodological process I used to undertake this, followed by a presentation of the findings before summarising these and considering them in relation to my research focus and how this links with research within the thesis. This work has been published in a separate form as a paper in Dementia see (Appendix 2).

2.2 Methods and methodology

This scoping review was guided by (Arksey & O'Malley, 2005) 6 Stage Framework for scoping reviews and Levac and colleagues, (2010) paper on advancing scoping review methodology. It also incorporates contemporary guidance from the Joanna Briggs Institute (JBI) which points to scoping reviews as being mostly descriptive, with authors having the flexibility to undertake more in-depth analyses to inform research questions (Khalil et al., 2021). I used thematic analysis to conduct a qualitative meta-synthesis of the findings and report the methods using headings from Arksey & O'Malley, (2005) framework.

<u>Stage 1) Identifying the research questions</u>

To capture the individuality of lived experience, I included subjective terminology in my research questions:

- What meaning do individuals give to their memory concerns, including those with or without a diagnosis of MCI and SCD?
- How do they understand this in the context of cognitive impairment and ageing?

Stage 2) Identifying relevant studies

I searched CINAHL, PsycINFO and MEDLINE on 12/3/2020 for words relating to three concepts. Concept 1 included search terms around cognitive impairment, MCI, SCD, memory concerns and related terms used within a public domain. Concept 2 included words relating to older people, age, and later life. Concept 3 included words for subjective experiences such as feelings and meaning. I also hand searched reference lists of relevant articles and re-ran searches in September 2021.

Stage 3) Study selection: Inclusion criteria

I included primary qualitative or mixed methods research studies, published in English in peer reviewed journals, reporting the experiences of populations, all of whom were aged 55 and over and living with a cognitive impairment which was not dementia e.g., MCI, SCD or other memory concerns. I excluded review articles but individual papers on review reference lists were considered for inclusion. Following de-duplication, search results were screened via title by myself, (CC), excluding any that were irrelevant. The remaining were screened by abstract with a second researcher (PR) double screening 20% to standardise the screening process. We resolved any disagreements through discussion. This process resulted in 92 articles for full text screening. Papers were critically discussed with reviewer (PR) and a second blinded reviewer (TJ) reviewed a sample of six selected papers in depth. The PRISMA flow diagram in figure 1 shows the screening process.

Stage 4) Charting the data

I produced a data extraction table and extracted for each paper: country of publication, research aims, sample population, data collection method, data analytic approach, and key themes identified. I used the Critical Appraisal Skills Programme tool for qualitative studies (CASP 2019). Studies were not excluded on the grounds of quality, in line with qualitative review practice (Thomas & Harden, 2008). The data extraction and quality assessment tables can be seen in the published paper in Appendix 2.

Stage 5) Collating, summarising, and reporting the results

Full papers were imported into NVivo 11 for thematic synthesis (Clarke & Braun, 2021). Where papers were mixed methods only qualitative results were used. Guided by Thomas & Harden (2008b) approach to thematic synthesis, primary qualitative data was included within the published papers, the reported themes and supporting quotes were coded. Using NVivo I organised and categorised papers themes as codes. I coded data guided by my research questions; additionally other researchers also reviewed this data. Quotations from participants were used to preserve their voice and retain the integrity of the original studies, recommended in scoping reviews (Peters et al., 2020). I re-read papers and developed overarching themes; further synthesis of themes was achieved through discussion within my supervisory team.

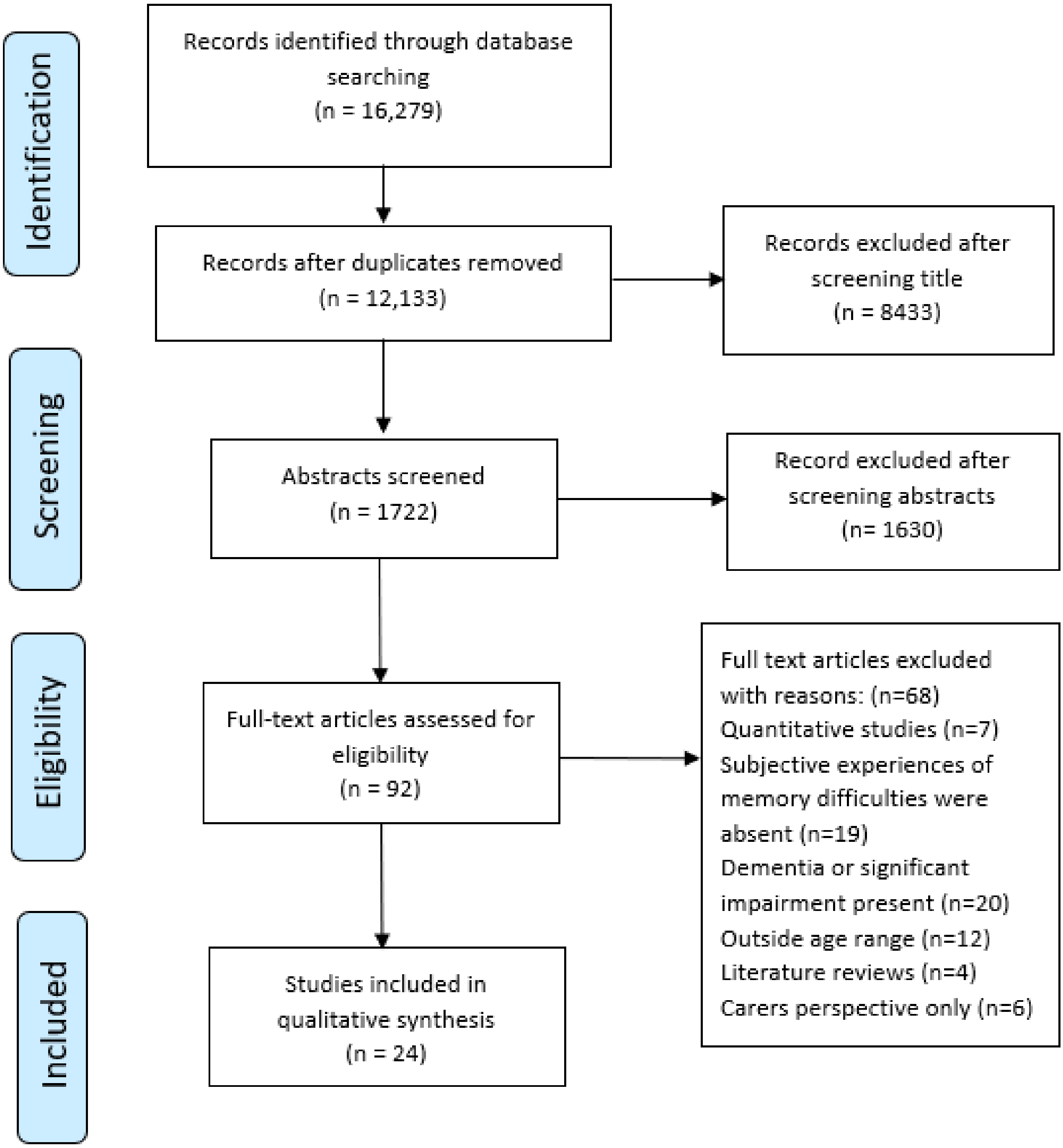
Stage 6) Consultation stage

Consultation is a recommended part of the scoping review process. (Arksey & O'Malley 2006). I consulted on my findings with a Patient Participation Involvement (PPI) group from the APPLE-tree multi-domain health and lifestyle intervention for people aged 60+ who have memory difficulties with or without a diagnosis of MCI (Cooper et al., 2020). I held the session on zoom with 3 people. All participants were female, one described herself as having 'early-stage Alzheimer', the second cared for parents with memory problems and the third was the APPLE-tree programme manager. Using my two themes I presented quotes from selected studies within the literature to facilitate a discussion. Participants felt the quotes reflected their own personal experiences, describing them as 'accurate and valid' and another saying they were 'spot on'. Although this was an optional stage of the methods, I felt that this was an important step to facilitate and include when the overall aim of my thesis is about people, or participants, and their voice in their relationship with active ageing.

2.3 Findings

My search yielded 16,279 studies, from which I included 24 papers (see Figure 1 for PRISMA flow diagram).

Figure 1 - PRISMA flow diagram of the screening process



2.3.1 Country of origin

Seven studies took place in the UK (Corner & Bond, 2004; Dean et al., 2014; Giebel et al., 2016; Gomersall et al., 2017; Meilak et al., 2016; Pierce et al., 2016; Poppe, 2020), followed by five papers from the USA (Beard & Neary, 2013; Hill et al., 2018; Kruger TM, 2014; Lingler et al., 2006; Renn et al., 2021). Two papers were from Israel (Rotenberg et al., 2020; Werner, 2004) and two were from Canada (Parikh et al., 2016; Vandermorris et al., 2017). The remaining papers were from Belgium, Sweden, Holland, New Zealand, South Korea, and Japan.

2.3.2 Participant characteristics

The 24 papers included a total of 211 male participants and 242 female participants with ages ranging from 55– 93 years. Participants in 15 papers had a diagnosis of MCI, ranging from within the last six months (Rotenberg et al., 2020), to over seven years ago (Berg et al., 2013). Seven papers included participants described as having memory concerns (subjective or objective), whilst in two papers participants were screened as having SCD.

Within this chapter I use the term ‘memory concerns’ to refer to people with varying degrees of cognitive impairment who experience this subjectively and objectively and which includes people with a diagnosis of MCI or screened for SCD and those without. When I just use the term ‘MCI’ I refer to papers where participants specifically have a diagnosis of MCI.

Out of the 24 papers selected only 15 reported on the ethnicity of the participants. Where ethnicity was documented, the majority were reported as being Caucasian and White British, only 3 participants described themselves as

African Caribbean British (Meilak et al., 2016; Poppe, 2020). One UK study focus was on South Asian participants described as Indian British and Pakistani British (Giebel et al., 2016). Studies from New Zealand described participants who identified as native New Zealand and the South Pacific Islands, (Collier et al., 2020) two papers were from Japan and Korea respectively (Choi & Kim, 2020; Nakano et al., 2012) and one paper from Israel described European and Asian participants but didn't specify further, (Werner, 2004). The majority of participants were reported as having moderate to high levels of education.

2.3.3 Population and settings

Ten studies recruited from memory clinics (Begum et al., 2013; Dean et al., 2014; Gomersall et al., 2017; Imhof et al., 2006; Joosten-Weyn Banningh et al., 2008; Lingler et al., 2006; Meilak et al., 2016; Pierce et al., 2016; Poppe, 2020) seven recruited sub-samples from larger studies, (Beard & Neary, 2013; Berg et al., 2013; Collier et al., 2020; Corner & Bond, 2004; Kruger TM, 2014; Rotenberg et al., 2020; Vandermorris et al., 2017). Five papers recruited from community settings (Begum et al., 2013; Hill et al., 2018; Nakano et al., 2012; Poppe, 2020; Werner, 2004) defined as rural, urban, community dwelling and third sector community organisations, four papers purposively recruited from Geriatric Day/Hospitals settings (Choi & Kim, 2020; De Vriendt et al., 2012; Parikh et al., 2016; Renn et al., 2021).

In order to fully utilise my findings from scoping the literature I undertook a thematic analysis. This gathered the findings through analysis to generate a depth of meaning rather than them simply being a descriptive account of the literature. This was an important part of understanding what the individual experience of memory difficulties and an MCI diagnosis are and exploring the lack of clarity surrounding this experience, contributing to my research focus, and understanding active ageing.

2.3.4 Thematic analysis

The thematic analysis generated two themes; 1) Making a diagnosis personal and 2) Remembering not to forget. Themes and subthemes reflect both the breadth of the literature an\d commonalities within it.

<u>Theme 1: Making a diagnosis personal.</u>

This theme describes how individuals respond to MCI and how a lack of clear knowledge surrounding memory concerns creates feelings of uncertainty. I identified 3 sub-themes. These explore; (1) the uncertainty and reactions surrounding a diagnosis of MCI due to a lack of knowledge, (2) the normalisation of the experience of memory concern with others of a similar age and (3) coming to terms with accepting MCI. People either appear to accept these experiences, some that feel frightened by the uncertainty and others need to fill in the gaps by learning more.

Sub-theme 1: Responding to uncertainty and certainty of a diagnosis.

The lack of clarity around a diagnosis of MCI results in feelings of uncertainty, (Beard & Neary, 2013; Gomersall et al., 2017; Poppe, 2020). The impact of this is exemplified by a participant diagnosed with MCI, who expressed uncertainty and questioned the diagnosis several times during an interview.

“I don’t know how important [an MCI diagnosis] is, or not important. Is it very important? Seriously important? Or not very important? I don’t know.”
(Collier et al., 2020 p.306)

In attempting to gain clarity participants sought knowledge around the physical nature of memory impairment (Choi & Kim, 2020; Collier et al., 2020; Giebel et al., 2016; Imhof et al., 2006; Renn et al., 2021). Collier et al., (2020) describes how following a diagnosis of MCI, a participant learnt about the physical structure and function of the brain. Reactions and responses to MCI include, relief, acceptance, distance, and fear (Beard & Neary, 2013; Begum et al., 2013; Berg et al., 2013; Corner & Bond, 2004; Gomersall et al., 2017; Kruger TM, 2014; Lingler et al., 2006; Pierce et al., 2016; Rotenberg et al., 2020). Relief was expressed when finding out the diagnosis was MCI and not Alzheimer’s disease. A participant who was 7 years post MCI diagnosis comments.

“When I spoke to the doctor after the 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)

However, ‘a new’ diagnosis of MCI, ‘downgraded’ from Alzheimer’s may fail to assuage worry. In the following example a participant who had been given a diagnosis of MCI after previously being told that she had Alzheimer’s said the following after reading a leaflet about MCI.

“I thought: I haven’t got it, well, what have I got then? And I were reading that, and I thought: what’s this? This is more or less saying a similar thing to er... dementia.” (Gomersall et al., 2017 p.793)

These experiences illustrate how in practice, the concept of MCI lacks clarity. Being given a diagnosis of MCI allowed individuals to distance themselves from dementia yet the uncertainty of developing dementia is not eliminated (Beard & Neary, 2013; Begum et al., 2013; Lingler et al., 2006). A participant with memory concern who had a close relative with Alzheimer's describes the fear this induced.

> *"And this is one thing I do just dread, and that is Alzheimer's, very much so, because my father had it...the mere thought of dementia terrifies me... more than any other thing [disease] to die from... like cancer."*
>
> (Corner & Bond, 2004 p.147)

Corner (2004) interviewed people categorised 'at risk' of memory impairment, finding concerns about dementia increased where a relative had developed it, and the perception was that little could be done by contacting health professionals.

> *"There's not much point going to your doctor, really is there, I mean it's not like they can cure it or anything."* (Corner & Bond, 2004 p.149)

Linglers (*et al* 2006) study supports this and reports that participants preferred to construct personal narratives about their diagnosis with only sporadic references to health care professionals as a source of information. Giebel (2016) found that those who had not consulted a GP about their memory concerns were more likely to describe themselves as leaving things to fate.

Sub-theme 2: Normalising memory concerns through age and shared experiences.

Normalising memory concerns through age and ageing is well documented in the literature, with uncertainty and disagreement among experts how best to characterize the relationship between ageing and dementia (Beard & Neary, 2013; Begum et al., 2013; Corner & Bond, 2004; Giebel et al., 2016; Kruger TM, 2014; Parikh et al., 2016; Renn et al., 2021; Vandermorris et al., 2017). Within this context, individuals must navigate the meanings around MCI, diagnosis, and their relationship to age. Imhof (2008) and Renn (2021) both discuss how age is presented as an explanation of memory concerns which can be reassuring and how disclosure of this to others is a source of support, illustrated here from a participant diagnosed with MCI.

> *"… and* we *all talk to each other because we're all more or less in the same boat"*
>
> (Begum et al., 2013 p.468)

Expectations about age could distance individuals from services, limiting support or invalidating concerns, (Dean et al., 2014; Gomersall et al., 2017; Imhof et al., 2006; Renn et al., 2021). Illustrated by a female participant diagnosed with MCI who, on seeing her GP about memory concerns was asked.

> *"Have you considered your age Mrs…? [She describes being furious, saying] 'absolute rubbish we go to church with elderly people in their mid and late nineties, maybe wobbly on their feet but as alert as anything."*
>
> (Dean et al., 2014 p.477)

Positioning herself in relation to older peers resulted in feeling this was not normal for her age. Individuals' lack of clarity of how MCI differed from 'normal' ageing and dementia mirrors uncertainty within professional diagnosis; illustrated by a participant with MCI.

> *"I don't know what [MCI] means […] I want to know; I sort of need to know. I mean, with other people who are my age and my activity […] how does that fit alongside people of similar circumstances? I don't know."*
>
> (Collier et al., 2020 p.307)

Shared activities and settings served to normalise changes in memory. For example, being in a senior living community made it easier to talk about memory decline as *'people accept it because it's not uncommon here'*, (Renn et al., 2021). In Renn's study a participant with a diagnosis of MCI talked about giving up driving.

> *"It's not a premature thing a lot of 80 years old I know don't drive."*
> (Renn et al., 2021 p.1102)

Vandermosis (2017) and Beards (2013) studies suggest that normalising cognitive decline through age allows individuals to view memory concerns as evidence they don't have a serious problem, such as Alzheimer disease.

> *"It's not early-stage Alzheimer's. It's not MCI. I have a situation where I can't remember something. But I don't think that is different than other people my age"* (Beard & Neary, 2013)

Individuals re-frame the MCI label as part of normalising their memory problem, evident in the above quote by a participant diagnosed with MCI within the last 3 years.

<u>Sub-theme 3: Coming to terms with accepting MCI.</u>

Time-based or temporal factors shape understandings of MCI. A study participant on receiving a diagnosis of MCI perceived a friend's experience of memory decline as rapid and used this to position himself.

> *"I know one guy who went from six months ago MCI to losing it all in 6 months so I'm aware how serious it is."* (Kruger, 2011 p.120)

Corner & Bond, (2004) highlight a complex picture due to unknown trajectories of MCI raising questions for individuals. When asked about future expectations one participant with MCI said they didn't feel there was any future, and at the same time reconciled this to themselves.

> *"The future? Oh, the future is behind me*! (laughs) *You know, I have had a great life, I have had a good job and kids, and... all that is behind me you know. I just hope I will have some good and healthy years now."*
>
> (Berg et al., 2013 p.297)

Renn et al (2021) describes how people with MCI can 'seek a sense of calmness', suggesting a more positive acceptance about their future life, One participant, for example described it as '*taking stock of life'*. The confusion about length of progression from MCI to something 'worse' is illustrated by this quote from a person living with MCI.

> *"Well, I do worry if it gets worse. I don't want to end up like a cabbage. You need your faculties don't you in life."* (Pierce et al., 2016 p.8)

Although not using the term Alzheimer's, perceptions of progression reflect a fear of losing control and an ability to function independently. The belief that 'it could be worse', means it could have been a diagnosis of dementia. An extract below from a participant with MCI demonstrates this.

> *"I have to resign myself to it''* and '*'I have to convince myself that they couldn't find anything and accept that it's not dementia I'm suffering from."*
>
> (Joosten-Weyn Banningh et al., 2008 p.152)

Many researchers suggest that individuals normalise their forgetfulness rather than actively fight it (Beard & Neary, 2013; Joosten-Weyn Banningh et al., 2008; Parikh et al., 2016; Pierce et al., 2016). This is, illustrated in the following from a participant with an MCI diagnosis.

"If I can't do anything about it, I accept it, and that's the way it is. That's life"

(Parikh et al., 2016 p.881)

In the absence of clear information, it could be argued that MCI generates both acceptance and inevitability.

Theme 2: Remembering not to forget.

This theme describes actions individuals undertake adapting and responding to memory concerns, highlighting the emotional effort this involves. We identified 3 sub-themes, 1) attempts to make sense of memory concerns, 2) using everyday compensatory strategies, 3) how individuals navigate relationships with friends and family.

Sub-theme 1: The effort and impact of adapting actions and to stay active

Individuals respond to memory concerns by adapting which sometimes includes failing, with responses requiring tremendous effort (Corner & Bond, 2004; Hill et al., 2018; Meilak et al., 2016; Renn et al., 2021). Imhof (2006) described participants as, *'trying to manage failure and reorganizing tasks to reduce complexity'*. This is illustrated in the following extract which indicates how exhausting the conscious effort of remembering can be, this participant did not have a diagnosis of MCI but had concerns about their memory.

"I need to think and keep my attention on what I am doing, and I am tired of thinking… In earlier days, I managed to do a thousand things at the same time." (Imhof et al., 2006 p.350)

Adapting to the disruption caused by memory concerns, affirms ability to continue that activity, exemplified by the following participant who had memory problems for more than 6 months but no MCI diagnosis.

"I started reading a book, and only about halfway through I realized that I had already read it. For a while I almost stopped reading because of this. Eventually I got back to reading books, because it's entertainment, and as long as it's fun while I read, that's enough for me"

(Rotenberg et al., 2020 p.6)

Individuals try to avoid fixating on the process of remembering, as illustrated in the following extract from a participant who has been screened has having SCD.

"I try to make the things I need to remember less important" (Hill et al., 2018 p.5)

This suggests a pressure to perform, linked to the concept of a *'use it or lose it'* belief described by Meilak (2016). Pressure to compensate through writing everything down also acts as a reminder of individual limitations in people concerned about their memory, illustrated in the following.

"I have a diary there and I write everything down that I've got to do—all my appointments, dentist, everything. I think Oh God! I'm losing my marbles." (Corner & Bond, 2004 p.5)

Renn (2016) describes how 'helpful' strategies imposed by others could produce feelings of shame. A participant described how using a whiteboard calendar set up by his wife to plan his week left him feeling embarrassed. Thus, the intervention response inadvertently positions the individual as feeling they are the problem. There appears to be juxtaposition of creating and maintaining strategies to compensate for the impact of memory loss, yet simultaneously these serve as a constant reminder of that loss. Feelings of stupidity amongst participants in relation to MCI or memory concerns have been documented (Berg et al., 2013; Collier et al., 2020; Gomersall et al., 2017; Nakano et al., 2012; Parikh et al., 2016). Emotional reactions ranged from bewilderment to feeling stupid over memory mistakes, as exemplified by a participant with a diagnosis of MCI.

> *"If I say something and [my son] says, "Oh, you've said that before…." That destroys you when they say, "you've said that before."*
>
> (Parikh et al., 2016 p.881)

Feeling "destroyed" when memory mistakes are brought to his attention highlights the impact that this may have on self-esteem and confidence for some individuals, (Parikh et al., 2016).

<u>Sub-theme 2: Using compensatory strategies every day.</u>

Compensatory strategies minimise the disruption memory concerns create, such as writing lists, using diaries, creating routines, visualising travel routes and repetition of information (Corner & Bond, 2004; Hill et al., 2018; Imhof et al., 2006; Joosten-Weyn Banningh et al., 2008; Meilak et al., 2016; Parikh et al., 2016; Renn et al., 2021). 'Self–management strategies' were undertaken as a way of compensating for memory concerns (Begum et al., 2013; Gomersall et al., 2017). Parikh et al., (2016) study describes this as '*reliably remembering'*, a process of helping with "self-esteem" and "coping", expressed by the following participant with MCI.

"It's just a matter of compensating, learning how to compensate…. I think we've adjusted so we can continue doing what we've done for years and years." (Parikh et al., 2016 p.882)

However, studies describe individual's inability to remember to use the external compensatory strategies they develop, exemplified in the following extract from a participant screened as having SCD.

"Well, I try to associate other names or other ideas with it and sometimes it works, then other times, I figure I have an association, and then I can't figure the association." (Hill et al.,2018 p.7)

Individual's previous careers supported compensatory strategies, such as using appointment books (Berg et al., 2013; Hill et al., 2018; Parikh et al., 2016; Poppe, 2020).

Sub-theme 3: Relationships and connections with others.

Poppe's (2020) study found that maintaining a job and socialising were deemed important ways of staying connected, affecting views of retirement and activity. Personal relationships, such as spousal relationships frequently provided sources of practical and emotional support (Begum et al., 2013; Dean et al., 2014). Partner relationships are significant in how individuals live and cope with memory concerns, a female participant with MCI illustrated this after being asked about support from publicly funded services.

"*Without my husband I wouldn't have managed this well"*

(Dean et al., 2014 p.481)

The importance of relational support through family and friends is well documented (Collier et al., 2020; Dean et al., 2014; Parikh et al., 2016; Pierce et al., 2016; Renn et al., 2021). Research describes how friendships help participants with MCI cope with stress, as illustrated below.

> *"I've got good friends and sometimes you just got to let it out, then I can calm down then I carry on."* (Dean et al., 2014 p.481)

Literature suggests relationships need to be adaptable to be supportive, examples of friends adjusting to an individual's memory concerns when participants choose to share their MCI diagnosis, as illustrated below.

> "*All my friends know about it (MCI diagnosis) and they* are making *allowances for me, they're very good like that."* (Pierce et al., 2016 p.5)

This also infers a tolerability, allowing others to be accepting of the situation but may not mean acceptance. Several authors found the consequences of revealing memory concerns to others was invariably negative, leaving people irritated or angry with family and friend's reactions, (Begum et al., 2013; Joosten-Weyn Banningh et al., 2008; Meilak et al., 2016; Nakano et al., 2012; Vandermorris et al., 2017). This is exemplified in the following statement from a female participant who had revealed her MCI diagnosis to her family.

> "*I'm sorry I told them now, I'm not an invalid."* (Meilak et al., 2016 p.5)

This was in response to a family perceived as being overbearing in their offers of help. Reactions from friends can also invalidate experiences of memory concerns. (Gomersall et al., 2017). This is illustrated by Gommersall who describes an 84-year-old participant recounting how her friend ‘roared with laughter’ at hearing that she had attended the memory clinic for MCI diagnosis.

2.4 Interpretation of findings

This scoping review identified that individuals normalise memory loss through comparison with peers of a similar age. As such individuals seek to gauge their own individual journey, in the absence of any clear ‘external’ trajectory following memory concerns and MCI. Unlike the more established concept of ‘biographical disruption’ where the diagnosis creates a new understandable narrative for the patient (Bury, 1982) conditions such as MCI do not lead to the same permanence. As Llewelyn points out, diagnosis should make a disease more navigable, ‘‘fixing the terrain over which care can be mapped’’ (Llewelyn H, 2017). However, in the case of memory concerns the terrain is not easily read and its status as a disease is questionable. These findings reflect the features of a diagnosis of dementia noted by others; it rarely happens at a single point in time but, rather across time and is situated in the physical and social changes realised by the individual and others (Birt et al., 2017).

Regardless of whether an individual has a formal diagnosis of MCI or SCD, self-identified memory difficulties which are not dementia require that an individual do something. The prodromal significance of MCI in dementia increases this impetus to act, potentially creating an intense experience.

The first theme ‘making a diagnosis personal’ captures the uncertainty surrounding reactions and responses to a diagnosis of MCI. It supports the notion of a liminal experience for those living with MCI and reflects its contested nature.

Birt et al (2017) describes liminality as relating to people being pushed into an in-between state through a diagnosis which results in uncertainty and confusion. This indicates that as familiar roles altered through retirement and familial roles were compromised through cognitive changes, an individual's sense of place and position in society was disrupted. Birt et al., (2017) points out that cognitive changes also mark a sociological event, as planned trajectories, roles, and statuses are threatened. Unclear trajectories mean individuals find themselves in a sustained liminal state which (Kelly, 2010) describes as 'learning to live with liminality'. However, contemporary descriptions challenge this focus on liminality, with notions of active or successful ageing challenging discourses of decline and deficit, (Birt et al., 2017). Birt et al talks about a post-liminal state as people reposition themselves through agentic actions which support social citizenship such as active ageing (Birt et al., 2017). These findings suggest that participants put a considerable amount of effort into actively responding to their memory concerns through prevention strategies.

The second theme 'remembering not to forget' describes compensatory strategies people adopt in the face of memory concerns and how individuals navigate relationships with others (Pierce et al., 2016) highlight that when people 'make allowances' for friends with memory concerns they are treated differently, drawing attention to notions of self-acceptance, and seeking acceptance. Relationships can also be sources of stress and anxiety especially when familial roles change. Role transformation and re-negotiation of long-standing roles within dementia has been considered by (Fletcher, 2020) as the 'dyadic career' and relates to spousal dyads. With MCI distinct caring roles in relationships are not as defined as where an individual has dementia, however the relational aspect remains significant. Tanner, (2016) describes ‘relational agency’ as a way of preserving identity. Cognitive concerns are not simply a negation of agency but involve taking on new forms of agency, exercised in new ways (Tanner 2016). This showed that individuals navigated relationships with family and others as a way of exercising agency. How people place and position themselves in relation to others is significant and these relationships can create supportive or stressful encounters.

This suggests that the absence of knowing what to do after a diagnosis of MCI can create an urge to act. Within the culture of active ageing or ‘successful ageing’, this implies an expectation to undertake healthy interventions to slow cognitive deterioration following confirmation of memory impairment, with or without a diagnosis (Jones & Higgs, 2010). The notions of distinction identified in healthy ageing discourse describe how individuals prove they are actively resisting cognitive decline and as such distancing themselves from others (Libert et al., 2020a). Within this context societal expectations about age and ageing are predominately negative. Colliers (2020) study discovered that concern around cognitive changes were secondary to the social and emotional changes associated with ageing in general. Understanding this through the concepts of the third and fourth age draws attention to the networks of social, material, and cultural resources which support ‘normative differences’ and away from ‘life stage identifiers’ in later life (Gilleard & Higgs, 2014). For these authors, the cultures of the third age are characterised by discourses of agency, choice, consumerism, and the motivating desire to not be seen as old. In contradiction, the fourth age is conceived as a ‘social imaginary’ which projects the most negative aspects of decline in ageing onto society (Gilleard and Higgs 2014). Within this social imaginary events such as ‘falling’ act as social markers of the pull of being defined by the fourth age. A diagnosis of MCI or concerns about one’s memory fall into this category and can be conceived as warnings of what may lie ahead.

MCI is accompanied by temporal factors with people using timelines to position themselves in relation to others establishing their own trajectory. Trajectories don’t follow a linear progression but exist as a range of individual experiences defined by liminality but characterised through anxiety and unknowing. Individuals adopt a range of strategies in attempts to cope and stave off dementia. Sometimes this is an inaction, a desire to do nothing which appears at odds with current rhetoric about active ageing. Romaioli & Contarello, (2019) argue that although considered ‘defeatist’ within contemporary successful or active ageing discourses, the absence of activism can be viewed as an active choice and offers another perspective to the fatalistic or acceptance attitudes documented in this scoping review. This raises questions when considering active ageing practice and potential interventions; how agency equates to activity for individuals engaging within active ageing practices including examples of the opposite, what could be termed, ‘disengagement’. Romaioli & Contarello (2019) suggest that there is a risk that the idea of agency is defined as the capacity for active commitment and in this sense deprives the individual of the possibility of constructing a different relationship with time. Temporal factors in how individuals with memory difficulties and MCI situate themselves within active ageing practice interventions and its relationship to policy begins with understanding the background context. My scoping review has helped to elucidate this perspective, understanding this as a ‘living’ rather than ‘lived experience’, which reflects and acknowledges individual’s attempts to navigate memory concerns and MCI which affirms self-esteem and agency, however that is exercised.

2.5 Implications for this research

The findings from my scoping review contribute to understanding the lived experiences of people with mild cognitive impairment and memory difficulties and highlight the context in which a culture of active ageing has developed. Literature focuses upon prognostic implications of MCI and SCD, with less attention given to the subjective experiences of diagnosis, and memory concerns (Gerstenecker & Mast, 2015). I have explored individual subjective experiences of memory concern, with or without a diagnosis of MCI, and more broadly how this interacts with the notion of cognitive impairment and age. The findings have illustrated the individuality of this experience yet at the same time identified themes reflecting a normative comparison with others of the same age which has implications for active ageing interventions. Responses including fear, relief, and acceptance, but culminating in uncertainty. Individuals must navigate their own narrative and trajectory through memory impairment in the hope of creating certainty and maintaining agency. This experience is one of potential anxiety and the unknown, which informs thinking about MCI as a diagnostic category and more readily encompasses the emotional and psychological impact of this on people’s lives. This indicates that there was an uncertainty surrounding an MCI diagnosis and associated disconnect with a sense of self and agency. It is difficult to know how this compares to the experiences of most people who live with memory concerns who have not sought help and the question requires future investigation, with the relationship between those seeking help for problems with their memory and subsequently engaging in an active ageing practice being unclear.

The findings imply that the adoption of active ageing practices through health and lifestyle interventions may facilitate a way of ‘being’ in what is an unclear trajectory. In a desire to navigate a trajectory, active ageing practice may offer individuals a direction in the absence of certainty and clarity. However, this is clearly complicated, with individual’s expectations of information and knowledge to inform and empower them not fulfilled, characterised by a sense of absence. Individuals gauge and measure their individual memory difficulties and MCI in relation to others, and this acts as a focal point for direction in the desire to move from a sense of the unknown to the known. These factors informed my research focus and question by illustrating the importance of self-identified memory difficulties and ascribed labels of MCI which are not dementia and by understanding the subjective experiences surrounding this helps to foreground exploring active ageing as a concept and a practice. My focus is upon how individuals reconfigure these experiences of memory difficulties and MCI through active ageing interventions and how this affects their engagement with the interventions.

In this chapter I have provided an exploration of the subjective experiences of older people with memory difficulties and MCI through a scoping review. This has demonstrated the critical neglect of the subjective experiences of older people with memory difficulties and MCI. The culture of active ageing for people with memory difficulties and MCI has developed within this context. How this development influences individuals and interacts with their lack of clarity and absence surrounding their position, as identified through the scoping review is a question I aim to address in this thesis.

Further investigation of the subjective experiences was provided by an opportunity to study the consultation stage interviews for the APPLE-tree intervention. I undertook a secondary data analysis of the interviews from people who self-identified as experiencing memory difficulties and/or MCI applying the same questions used within the scoping review. This provided an opportunity to build upon and expand the understanding from the literature through empirical data which was connected to the APPLE-tree programme. In the next chapter I present this work, which includes a thematic analysis of this secondary data followed by an interpretation of the findings, and finally a summary pulling implications of both chapters together.

Chapter 3 Secondary data analysis of the APPLE-tree intervention consultation interviews

3.1 Introduction

In the previous chapter I presented the findings of my scoping review which explored the meaning individuals give to their memory concerns and subsequent diagnosis of MCI or SCD. I identified a gap between the intended purpose of diagnostic labels to bring understanding and certainty and the lived experiences of those ascribed them, highlighting this context as one of uncertainty and liminality. This context will affect those participating in a dementia prevention intervention such as APPLE-tree, who may be starting from a position of a lack of clarity and knowing. This knowledge has informed my research, understanding more about how this gap affects individual experiences of cognitive impairment and its relationship with active ageing policy and practice felt essential when considering the culture of active ageing.

The lack of clarity around diagnosis and the poor consideration of subjective experiences of cognitive health identified in my scoping review, reflects a general sense of 'absence' that individuals who have memory difficulties and MCI often experience. This absence reflects a series of 'unknowns' which I have previously described, around diagnosis, trajectory, progression, and what individuals should do, which characterises the experience of MCI and memory difficulties. My aim in this thesis is to understand how such active ageing policy and practice reconfigure cognitive impairment, and it was therefore important to consider this sense of absence further through individual accounts. The APPLE-tree consultation interviews provided an opportunity for me to explore first-hand accounts of memory difficulties and individual perceptions of these building upon my scoping review findings.

In this chapter I present a secondary data analysis of the qualitative interviews which were conducted as part of a consultation period for the APPLE-tree intervention. The interviews were primarily focused upon active ageing practice, to inform the content of the APPLE-tree intervention. Through individual accounts of MCI and memory difficulties, my secondary data analysis provides insight into the experiences of the absence identified in the scoping review. I focused upon eighteen interviews conducted with people who had self-identified as having memory difficulties or MCI and who were interviewed as part of this consultation stage. This study builds on the findings from my scoping review and adds additional depth through the analysis of empirical data. Inevitably undertaking secondary data analysis has limitations, data is not collected with the intended focus that a secondary analysis will apply, however mitigating steps were taken to reduce this which will be outlined in this chapter.

I will describe the rationale and focus for undertaking secondary data analysis of the consultation interviews, outlining the methods used to do this. Followed by a discussion of findings. Finally, I discuss how my scoping review and secondary data analysis add to an overall understanding of the culture of active ageing for people with memory problems and MCI, how this contributes to my overall research focus and questions and how this work influences my ethnographic study.

The medicalisation of MCI and memory impairment fails to account for subjective experiences of the condition, including fear and a desire to distance indicators of dementia (Beard & Neary, 2013; Dooley et al., 2020; Leibing, 2018; Poppe, 2020). Additionally, it results in certain positions or responses being available to people, which includes an impetus to act or engage in activity to prevent dementia. These are influenced by a culture of active ageing practice and formalised through active ageing policy, such as dementia prevention programmes. Here I consider this by exploring first-hand accounts via the APPLE-tree consultation interviews. These became a valuable resource, informing my research focus and approach to my ethnographic study of participants in the APPLE–tree programme.

In this study I consider individual memory concerns and experiences of MCI expressed as part of the consultation interviews. I explore how participants sought to navigate the challenges memory concerns and MCI bring to their expectations of later life, including those around identity. The following questions from the scoping review are the focus for this exploration of the empirical data:

- What meaning do individuals give to their memory concerns including a diagnosis of MCI and SCD
- How do they understand this in the context of cognitive impairment and ageing

3.2 Methods

3.2.1 The consultation study – procedure and settings.

This secondary analysis uses data collected for a qualitative study designed to inform consultation, development, and co-production of the APPLE-tree intervention. The purpose of the primary qualitative study was to explore how the APPLE-tree dementia prevention programme should be designed and delivered (Poppe, 2020). It involved semi-structured, face-to-face qualitative interviews with 45 participants including NHS staff, third sector staff, people living with memory concerns or MCI and family carers between July and September 2019. The methods of the primary study and topic guides are described in full by Poppe, (2020). From this sample of 45 I focused upon 18 interviews, the 18 selected were all interviews undertaken with people with self-identified memory concerns and difficulties, some of whom had been diagnosed with MCI. The 18 participants' interviews included one in which a spouse was present during the interview.

As part of the consultation stage for the APPLE-tree intervention, participants were recruited purposively for MCI or memory concerns from NHS memory services, Improving Access to Psychological Therapies (IAPT) services for common mental health problems, University College London (UCL), and third sector organisations across London, South, and North-West England. Interviews explored how people with memory concerns are motivated and supported to make targeted behavioural changes, and the potential barriers and facilitators to participating in, and delivering an active dementia prevention programme. Research Ethics Committee (Reference: 19/LO/0260) and UK Health Research Authority (HRA) approved this study in April 2019. Ethics included approval of consent forms which contained an optional agreement for data to be reused in further research studies as shown below:

> *I agree that the information collected about me can be used to support other research in the future, and may be shared anonymously with other researchers (optional)*

3.2.2 Considerations when using secondary data analysis.

The consultation interviews did not directly address my research questions aims, and this is a limitation of secondary data analysis. However, the area of study and method of analysis aligned with the primary data set. Hinds et al (1997) identifies different approaches to justify using secondary data analysis, one of which supports our study where the focus is on a different unit of analysis from that of the parent study. Sharing data is a legitimate way to use the consultation data effectively and lead to a generation of new knowledge whilst addressing a sensitive area of research (Long-Sutehall et al., 2011). My findings provided insight into the complexity of participants' experiences of memory concerns and MCI diagnosis illustrating the interviewee's experiences, thus extending knowledge from the data, and illustrating the need for further direct research in this area.

Requirements for using secondary data state that the researchers 'authentically account for the nature of the original data set and have knowledge of the original data set' (Thorne, 2013). One of my supervisors, Penny Rapaport was an original interviewer from the consultation phase of the APPLE-tree programme which enhanced my familiarisation with the data. Questions contained within the interview schedule focused on experiences of memory problems in individuals' lives. As the nature of the data set align with my research questions, I avoided any additional burden of re-interviewing this group. I focused upon the answers participants gave when they were asked specifically about their memory concerns and in relation to thinking about a potential active ageing intervention.

3.2.3 Analysis and context of the data.

I used thematic analysis to analyse the interviews (Clarke & Braun, 2017) in line with my specific research question. I repeatedly read all transcripts and listened to a sample of interview recordings, and adopted a reflexive approach, using a diary to record reflections during the analysis, and then systematically coded all transcripts into meaningful fragments and created initial codes. Codes were discussed with my supervisors and then developed into clusters of codes and then themes. Themes were discussed through a reflexive process involving my supervisors and the results were written and re-written as part of the analysis. I extracted information from participants' interviews of their own accounts of memory concerns and diagnosis of MCI to provide me with a fuller sense of the characteristics of the sample I was exploring.

3.3 Findings

3.3.1 Sample characteristics

The sample contained 18 participants, including four women and 14 men. Five people reported that they had a formal diagnosis of MCI. Nine people described themselves as having memory concerns and had sought professional advice but had not received a diagnosis, and four described having memory concerns but had not sought professional advice. Table 1 outlines the sample characteristics including the types of memory concern identified by the participant.

I use the term ‘professional’ to refer to a range of health staff from Primary Care, these were GPs, psychiatrists, community teams, and IAPT. Participants who had sought professional advice or received a diagnosis of MCI described repeated contacts with services involving single to multiple cognitive tests, some were unclear about what testing they had received, if any.

Table 1: Sample characteristics from secondary data analysis

Type of memory concern	Number	Gender	Age range
MCI diagnosis	5	2 female 3 male	61 - 92 72 - 78
Memory concerns and professional advice	9	2 female 7 male	61 – 68 62 - 83
Memory concerns with no professional advice	4	4 male	73 - 87

I explored how people sought help, what follow up they described was available to them, and what advice they received after a consultation with a professional and/or receiving a diagnosis of MCI and categorised these into 1) Raising concern 2) Follow up support and 3) Available advice. These categories reflect the individual accounts of the consultation and diagnostic process surrounding MCI and cognitive impairment and I will describe these in more detail below. In some categories participants’ responses covered more than one option, therefore not all categories add up to 18.

Raising concern; how and why individuals sought help.

In this sample of eighteen people, in seventeen cases some form of help was discussed with family, friends or professionals. This would follow family and friends noticing changes in everyday functioning and expressing concern about an individual's memory and possible safety. The remaining person did not instigate help either formally or informally, but they self-identified as a person with memory problems. Table 2 shows how the different types of raising concern is broken down.

Table 2: Raising concern; how and why individuals sought help.

Raising concern	Number
Self-instigating help	7
By a Spouse and jointly	5
Discussion with family (children)	5
Discussion with friends	1
Did not to want to instigate help	1

Follow-up support

This category describes what follow up was available after consultation, how this was accessed and in what form this was offered. Table 3 shows the types of follow up support against the number of participants.

Table 3: Follow up offered after consultation.

Types of follow-up support after consultation	Number
No formal follow-up offered	10
Did not approach formal services so no follow up	4

Advised to self-monitor memory function	2
Referred to a specialist memory service	2
Unclear about what had been offered	2

Advice offered and available.

This category describes advice offered, what was adopted including any practical advice. Those who engaged in health and exercise activities which predated memory problems or MCI did so because they considered it to be important for health generally. These activities were not considered specifically in relation to cognitive health, but there was a growing recognition of their potential impact upon memory problems. Table 4 shows the types of advice offered to people following consultation for memory difficulties.

Table 4: Advice offered after consultation for memory difficulties.

Types of advice and actions offered	**Number**
No advice given but self-strategies adopted involving physical exercise and coping strategies (including new activities and existing ones)	10
Advised to do activities such as physical exercise, puzzles and reading	6
Advice given through leaflet	2

3.3.2 Thematic analysis

Within the sample studied it was generally the case that individuals were sufficiently concerned about their own memory difficulties to instigate a consultation with a ‘professional’. This was closely followed by individuals acting in response to the concerns of family and/or friends. These two drivers were not mutually exclusive and suggest that concerns are reinforced by the concern of others close to them. There was a lack of clarity post-consultation with individuals not receiving formal follow-up. Where this did occur, individuals were advised to monitor their own cognitive changes. Most people continued with their existing activities and adopted self-strategies, such as keeping a diary or writing lists, with some citing new activities such as exercises or dietary changes after a consultation about their memory. Any advice which was offered by professionals appeared to be done on an ad-hoc basis with little detail about what was involved or what was expected. These categories describe a picture of consultation and diagnosis which includes unclear information and support, coupled with increasing expectations of responsibility placed upon individuals to monitor their own memory function.

The data includes some common experiences around diagnosis and consultation, but also reflects the individual experience of memory impairment and MCI, this will be explored further through a thematic analysis of the data. The description of categories provides insight into my two research questions; '*What meaning and what understanding do individuals give to a diagnosis of MCI and SCD*'. Themes generated from the data add to this and respond to my second question ''*how do individuals make sense of this in the context of ageing.'*

Three key themes with sub-themes were generated (outlines in table 5), giving insight into the individual experiences of memory concerns. Quotes from interviews are used to illustrate the complexity of this experience.

Table 5: Themes and subthemes of secondary data analysis

Themes	Subthemes
1) Situating memory concern	1a. Navigating language and understanding knowledge 1b. Expectation and age
2) Affirming self in the face of memory loss	2a. Sustaining an identity 2b. Expressions of health and anxiety
3) Identity and relationships	3a. Concealing memory difficulties 3b. Maintaining relationships 3c. Navigating a place - where I am in relation to others

<u>Theme 1: situating memory concern</u>

This theme refers to how memory concerns were situated in terms of people's experiences, commonly this was through their distinction from dementia. For those who received a diagnosis of MCI, this was experienced as a relief but also a threat, as participants were aware of the future risk of dementia and felt ill informed by services about how to manage this risk.

Sub-theme 1a: navigating the language and understanding the knowledge.

Most individuals had not received a formal diagnosis of MCI. Health service professionals and participants appeared to use a range of terms to describe memory concerns. Frequently this meant that participants had to navigate varied and often contradictory discourses. The resultant anxiety is captured in the extract below between the researcher and husband and wife.

> *"The main thing I would say is just more information, a lot more information. We don't get enough. You were in there, like, ten minutes, weren't you? They didn't really tell you much, and then you were out. That was it. One leaflet."* (Husband of person with MCI)

> *"One leaflet."* (Female participant 2 diagnosed with MCI)

"It might turn into dementia, and then you're thinking all this; checking online." (Husband of person with MCI)

I know. They don't tell you really a lot online, do they? They tell you bits of things, don't they? (Female participant 2 diagnosed with MCI)

Regardless of whether a diagnosis of MCI was made, participants described common experiences of how information about causes, prognosis and possible remedies for memory loss was delivered, received, and understood. Some individuals with a diagnosis of MCI appeared to find the diagnosis reassuring as the extract below illustrates.

Participant: *"Now that I have been diagnosed, I feel okay*

Interviewer: *"And before that? Before you had the diagnosis?"*

Participant: *"Where I was always thinking, what is wrong, what is wrong with me, and then this is very mild compared to what I could be looking at in ten years"* *(Male participant 2 diagnosed with MCI)*

The above quote reflects participant's difficulty in predicting future progression of memory impairment following a diagnosis of MCI. The relief at the absence of dementia may be tempered by the presence of the unknown.

Subtheme 1b: expectation and age.

Expectations around age were significant factors in recalled clinical consultations, affecting how individuals situated and made sense of impairment. The exchange below was framed within the context of normal ageing and physical health with phrases such as 'nothing to worry about'. The intended reassurance or confirmation that an individual's memory concern is 'just' related to age often left several unanswered questions as the extract below demonstrates. This 77-year-old man was asked about an exchange with his GP when he sought help regarding his memory concerns.

Participant: *"Yes, he (GP) understood, but he said you haven't got a problem. It's an age-related thing."*
Interviewer: *"Okay, so it's age rather than anything more serious?"*
Participant*: "No, nothing medical."*
Interviewer: *"Did he give you any kind of information about what you can do?"*
Participant: *"No, No. and I don't think it was taken that seriously. I don't think he saw it as a problem. I saw it as a problem, but I don't think he did"*

(Male participant 15 with memory concerns)

In attempting to distance memory problems from a medical explanation, the GP gives an explanation that it is normal and 'age related'. The significance of 'age' in a consultation provides evidence of not having 'other' problems, i.e., dementia. Alternatively, locating the responsibility with individuals to self-monitor memory function and any deterioration was also evident, as the following exchange illustrates.

Husband: *"They [the GP] basically said she had the mild cognitive impairment, and just gave her a little leaflet about doing exercises and stuff*
Wife with MCI*: But they didn't even tell me really what it was or anything.*
Husband: *No, she [GP] didn't explain*
Wife: *She [GP] said if it gets worse come back*"

(Female participant 1 diagnosed with MCI)

Although empowering for some individuals, judging if or when things become worse involves self-awareness, an ability to seek help and when, all of which may become harder to instigate as memory deteriorates.

Theme 2: affirming self in the face of memory loss.

People described reaffirming their self-identity, agency, and control over their lives through participation in activities. Advice about health promotion may help to re-frame memory impairment from a marker of deterioration to a potentially treatable condition, raising expectations. Individuals utilised existing social and physical activities to minimise effects of impairment, often in the face of adversity. They frequently drew upon previous roles and activities to affirm who they are, as shown in the extract below.

> *"Because I was very busy as a businessman before I retired, and I was very conscious before I retired that I had to have the plan in place to do things. The only plan I didn't have in place was to keep my memory, so there we go, that's where it is."* (Male participant 7)

As illustrated here, individuals were confronted by the reality that previous roles and experience may not help to manage memory impairment, comparing their current self negatively to their past self.

Sub-theme 2a: sustaining an identity.

Individuals frequently related their identity to what they did, who they are and who they were in context of their memory concerns. This is illustrated in this extract below, in which a female participant talked about activities she did.

> *"I am trying, yes, because I am that sort of person. I am interested. Obviously, as a university graduate. I am a book person. An Arts graduate. I am a word person, yes"* (Male participant 5)

Avoiding dementia through retaining one's identity was a key motivator and keeping physically active helped individuals to re-position themselves and reinforce their identity. One male participant talked about how he viewed undertaking and maintaining such activities as *'stopping him disappearing'*.

> *"Well, I think being physically active and getting fit, must increase the blood flow through the system and stops you from… What's the word? Disappearing, or you know, just sitting down and not doing anything."* (Male participant 10)

Additionally, there was a pressure not to 'give in' to memory failings with individuals using language such as '*carrying on'* and *'just doing it'* when they were describing their memory concerns.

Sub-theme 2b; expressions of health and anxiety.

Although individuals did not directly equate memory impairment to well-being, on closer analysis expressions of anxiety and fear were voiced. Lack of control and knowledge about dementia produces feelings of uncertainty and anxiety as described in the extract below.

> *"I do worry about my memory because it's getting worse, I know it's getting worse. And I don't want to get dementia. That's the last thing I want to get because I've seen people with it, and I know what it's like."*
>
> *(*Female participant 2)

Physical and mental health concerns combine and can affect well-being through an individual's ability and motivation to take part in activities such as exercise. This is illustrated below after this female participant was asked about food and diet as part of the consultation study.

> *"Well, if you had a proper diet and you had proper exercise, and you had something to get up for in the mornings, you know, I've got nothing to get up for really. When I get up in the morning, it's the same thing every day,*

nothing ever changes. And I think it gets you down, and I suffer from anxiety as well." (Female participant 3)

There are wider issues around mental health and well-being here. Discussions around health and lifestyle which may be motivating may also trigger feelings of anxiety if the person feels they should be doing something which they are not.

Theme 3: identity and relationships.

This theme refers to the impact of memory impairment upon relationships with family and friends. Individuals described times of feeling harassed by family members who they felt were irritated and exasperated by their behaviour. Getting a diagnosis of MCI may be regarded as a solution by relatives who want external validation. However, without resultant support this can feel exposing for individuals. This is highlighted by a male participant who was speaking about a situation where his wife accompanied him to the GP.

> *"What's annoying me slightly about it, because we went to the doctors about it and she insisted on coming…. She said, "I wanted you to know what you're really like."* (Male participant 10)

The impact of memory impairment had a profound effect on relationships with others. Avoiding having difficulties reflected back is hard when memory impairments are overt. This can create stress resulting in individuals avoiding contacts. This is captured by the participant below when asked who else had noticed her memory impairment.

> *"People that I know that I've forgotten to meet them at a particular place. And they're angry or I've forgotten to call them when I should*

have or... that kind of thing…I prefer not to go, I prefer not to socialise actually. I prefer to stay at home and not to go out somewhere.”

(Male participant 9)

How individuals relate to others is to some extent affected by how other people relate to them and their memory difficulties and how this view is reflected back to them.

Sub-theme 3a: concealing memory difficulties.

The experience of memory impairment involves strategies to manage deficits in memory which range from those which can be regarded as ‘acceptable’ to those which require concealment. Concealing memory concerns and impairment was key to participating in everyday life. A female participant decided not to tell family and friends about her MCI diagnosis and described in detail a situation of not remembering where she had parked her car,

> *“Whenever I would park to do an exercise class or visit a friend, my car, I would not be able to see it. Even remember the colour or where I parked it. So, then I have the embarrassment of pretending from a mile away that I am bleeping my car. I changed my car to get over this.”*
>
> (Female participant 2)

She concealed this by changing her car to one where the lights flashed when pressing the key remotely, allowing her to locate the car after being out with friends or visiting family. When asked at what point she might tell her family she replied she would *‘bat it back for a long a possible’* and *‘just get on with it’*. This illustrates the range of strategies adopted from everyday problem solving to complex decisions to retain autonomy, control, and agency. It also highlights the pressure some individuals feel to conceal memory difficulties for as long as possible.

Sub-theme 3b: maintaining relationships.

Memory concerns can impact upon couples' relationships. The extract below is from a married couple who were interviewed together, where the husband has memory impairment. This exchange came up at the end of the interview and it was clear listening to the audio that it was a difficult thing for his wife to talk about.

> *"We think … if you could talk about these conversational difficulties and perhaps give us a clue as to what to do. Probably the answer is you can't. But I did talk to somebody here last week and he was really nice and said, the partners can contact ... but we've never had a chance, have we, to talk to somebody about how [unclear] impacts around the relationships."*
>
> (Wife of male participant 1)

Understanding the impact of memory impairment on an individual within a family system is essential to begin to fully understand their lived experience, including recognising the potential burden of knowing when and how to return to services if things change.

3.4 Interpretation of findings

The findings illustrate the complex experiences of people with memory concerns, with or without MCI diagnoses. Individuals find diagnosis difficult to understand. This makes the utility of a formal diagnosis uncertain (Dooley et al., 2020; Gerstenecker & Mast, 2015; Schweda et al., 2018). However, I also found individuals embraced a 'diagnosis' of 'age related problems' as evidence of not having 'other' problems, i.e., dementia. Paradoxically, this diagnosis also indicates a risk of developing dementia, both to individuals and professionals.

I identified three themes with several subthemes. Themes are situated within a context of expectations surrounding age and normal ageing. Knowledge and information received from clinicians was described by participants as being limited and unclear producing confusion. I found that the affirmation of identity is sought and navigated in multiple ways, including negotiating strategies to avoid and conceal memory impairment. These serve to distance individuals from the 'fear' of developing dementia. Relationships are complicated by memory impairment and appear to affirm and support identity.

The themes around identity and relationships suggest that reaffirmation of self-identity can be a strategy employed to keep memory problems "at bay". However, there is also a sense in participants accounts that despite reassurances that memory problems are not dementia, they can powerfully affect relationships, impacting on self-identity. Relationships can challenge how people respond to memory concerns, forcing people to see how they are in other people eyes. Retaining strategies to conceal memory impairment, mitigate this and maintain identity and relationships require 'extra cognitive work' (Chaudoir et al., 2013). The study revealed examples of concealment, we found that the experience of memory concerns appears to pose challenges to relationships which the diagnosis of MCI does not seem to allay, at least for the person with memory concerns. Themes describe experiences which are tempered by societal responses to cognitive decline which includes assumptions about health, age, and individual responsibility.

The majority of those studied had not received a formal diagnosis of MCI. Their experiences suggest a broader understanding of liminality, rather than the static or transitional state of illness progression previously considered. Pervasive liminality considers how individuals encounter discrete experiences which overlap and fluctuate over time, rather than in-between experiences associated with a liminal space (Bruce et al., 2014). This reflects the findings, where the experiences of MCI and memory impairment are layered with broader social and individual responses to age and ageing, encompassing negotiating relationships and identity. Experiences of forgetfulness and age-related memory loss, shift toward being re-defined as examples of cognitive ill health and impairment. Higgs & Gilleard (2020) adopt a reflexive approach concentrating on the interplay between the culture of the third age and the social imaginary of the fourth age.

Findings suggest that individuals are expected to navigate the management of their own memory with an explicit assumption they have the capacity to recognise when their memory is declining, and to respond to such changes through adaptive strategies (Berg et al., 2013). This relates to the discourses of both active ageing and 'responsibilisation' in the arena of health and ageing (Varey et al., 2021). Existing research describes experiences of liminality for people with MCI and memory impairment as conferring a sense of responsibility (Birt et al., 2017; Poppe, 2020) and includes the idea that dementia now has 'modifiable' risks which can be incorporated into everyday life. Active ageing has expanded notions of active cognitive ageing along with the corresponding normative expectations and assumptions for the older population (Libert et al., 2020a), examples of which were within my findings and themes.

Through the analysis of interview transcripts from the Apple-tree consultation phase, I sought to expand upon the knowledge gained from the scoping review and better understand the subjective experiences of people living with memory concerns and those diagnosed with MCI. This includes understanding the sense of absence associated with this experience. Individuals with MCI and memory impairment feel the need to create meaning, exercise control and avoid cognitive deterioration. Active ageing practices, through a health and lifestyle intervention to prevent cognitive deterioration may enable this. However, highlighted through my themes, any engagement in such practice will be complicated by issues around the affirmation of identity, expectations and age, relationships with others, and the navigation of unclear information. The evidence within the data of the creation of strategies to mask and live with the effects of memory impairment and age 'normally' or 'successfully,' is important to recognise and requires consideration. Understanding how identity is affirmed, constructed, and maintained is an important part of exploring the subjective nature of memory impairments and MCI, expanding the knowledge in this area.

3.5 Drawing together the scoping review and the secondary data analysis

The scoping review and secondary data analysis provided me with a deeper understanding of individual's subjective experiences of memory difficulties, and /or receiving or having a diagnosis of MCI. Applying the same research questions to both my scoping review and secondary data analysis allowed for a richer and broader understanding of the 'lived', or as I have referred to it, the 'living experience' of having memory difficulties and a diagnosis of MCI.

My findings capture the multi-faceted nature of this experience, evident in both studies. Their shared focus highlighting how factors both relate and contribute to a culture of active ageing. This is illustrated through concepts of liminality and the idea of liminal spaces which feature in experiences of having a contested diagnosis. Responsibility is placed upon individuals from a societal expectation of old age and cognitive health. This is complicated by the juxtaposition of the assumption of memory difficulties in old age, whilst simultaneously the realisation of this as a prodromal risk. A temporal aspect to this experience was identified, with the absence of certainty extending to needing to know when and how things would change, creating an impetus to act which was inherent within this narrative and indicates how a developing 'active ageing culture' influences individuals around their cognitive health. However, as noted through the scoping review there is a danger that an individual's agency could be defined through capacity for active commitment. The concept of distinction was prominent in how people considered or reflected upon their position as individuals with memory difficulties and MCI. An increasing pressure to recognise their 'markers of decline', or 'life stage indicators' was evident within both studies.

The experiences of active ageing practice for cognitive health are a relatively under-researched area and as illustrated through both studies, individuals with memory difficulties and MCI have to negotiate and contend with complex factors. This influences engagement with active ageing practice, with a sense of absence dominating this experience. Active ageing culture may create a potential for people with memory difficulties and MCI to move beyond the absence identified throughout these studies. My interest is in exploring this further, by understanding how people situate themselves within active ageing practice and adopt an intervention for cognitive health into their lives. The findings from my scoping review and secondary data analysis illuminate the complicated context from which individuals arrive at such an intervention and engage with active ageing. As previously outlined in the Chapter 1, APPLE-tree (Appendix 1) is as dementia prevention intervention for people with MCI and memory difficulties. As such it provides an opportunity to consider active ageing as a both a concept and a practice and its relationship with active ageing policy. The findings from both the scoping review and secondary data analysis have helped to shape my ethnographic research, incorporating the concepts of absence, responsibility, distinction, and agency as areas of emphasis and focus.

In the following chapters I present the results of my ethnographic study, firstly in chapter 4, I outline my methods used for the ethnographic study of APPLE-tree including the methodological approach, which is based on focused ethnography. I outline my decision to adopt this approach and the methodology including how I approached studying the APPLE-tree interventions before I move on to describe my method of analysis using Reflexive Thematic Analysis (RTA). I then present the qualitative findings of this study in chapter 5 before my discussion in chapter 6 where I critically consider the study findings through a sociological lens. Finally, I provide a conclusion in chapter 7.

Chapter 4 Documenting the methods of my ethnographic study.

4.1 Introduction: working ethnographically and reflexively with the APPLE-tree intervention.

The previous chapters have drawn attention to the multi-faceted nature of active ageing, with my scoping review and secondary data analysis evidencing this complex culture. It is out of this context that individuals with memory difficulties and MCI enter active ageing interventions such as APPLE-tree. Taking an ethnographic approach to explore how participants engage with the APPLE-tree intervention allows me to consider more broadly how active ageing policy and practice reconfigures cognitive impairment. In this chapter I outline the methodological approach and methods for my ethnographic study.

As previously stated, APPLE-tree is a multi-domain health and lifestyle intervention which aims to respond to the modifiable risk factors associated with dementia and promote active ageing in people aged over 60 (Cooper et al., 2020) (Appendix 1). Originally intended to be delivered through face-to-face workshops, the intervention was moved online and delivered through Zoom due to the Covid-19 pandemic. I will describe the methodological approach I have taken towards my research through ethnography and discuss my reasons for adopting a focused ethnographic approach. I outline my methodology, describing the methods I used to gather and manage my data and analysis. I reflexively consider my own positionality in relation to my background as a mental health nurse working with older people and consider how this has shaped my identity as a researcher in this study.

My study sits within the social sciences and draws upon sociological theories, influencing my positionality as a researcher and my adoption of ethnography, where data is collected through observations and interviews. Definitions of ethnography range from viewing it as an approach to research to regarding it as a method in research (Hammersley & Atkinson, 2019; Scott, 2009). Scott uses a broad definition of ethnography as an approach which aims to reach an "in-depth, interpretative understanding of the way of life found in a particular cultural or subcultural context from the perspective of the people within it" (Scott 2009: p193). This approach best fits the context of my research as it involves the researcher being immersed in the field of study. It aligns with my aim to understand the concept of active ageing in relation to older people with memory difficulties and MCI, and to gain an authentic account of their experience.

Achieving credibility by including a discussion of the philosophical foundations of a particular ethnographic practice, is regarded as a way to achieve 'data transparency' in ethnographic research (Madden, 2017). With this in mind I have adopted a flexible reflexive approach throughout the writing of this chapter to capture my intention to stay connected with the data and throughout the research process, thus acknowledging reflexivity as an integral part of an ethnographic approach (Atkinson, 2007).

I will account for my use of Reflexive Thematic Analysis (RTA), which is structured around the premise of an active and reflexive researcher (Clarke & Braun, 2021). Trainor & Bundon, (2021) argue for researchers to take a more reflexive and transparent stance in reporting their methodology and this reflects how my methods chapter will now proceed. I begin this chapter by outlining my theoretical position through a consideration of critical realism, its relationship with ethnography and move into my rational for adopting focused ethnography.

4.2 Adopting a critical realist approach

My ethnographic study is influenced by critical realism. Critical realism seeks to overcome the traditional dichotomy between the positivist and structuralist paradigms through its adoption of a 'modified naturalism' (Fletcher, 2017). According to Alderson, critical realism clearly separates our thinking (epistemology) from the independent world of being and doing (ontology), which we can discover but not invent (Alderson, 2021 pg42). Roy Bhaskar's (1978) ‘modified naturalist’ approach to critical realism provides a suitable lens to view the complexities of active ageing practices with people with memory difficulties and MCI. Bhaskar’s philosophical and sociological considerations regard human behaviour as fallible or changeable under the contexts in which it is observed (Archer, 1995). The commonality between the natural and social sciences lies in the connection between empirical investigation and theory construction, which in both cases involves the move from observing phenomena to seeking a generative structure (Bhaskar, 2010). Critical realism treats the world as theory-laden, but not theory-determined (Fletcher, 2017), and as such allows flexibility for acknowledging sociological theories and concepts such as active ageing and engages in providing explanation and causal analysis (Fletcher, 2017). This search for causation helps researchers to explain social events and suggest practical policy recommendations to address social problems (Fletcher, 2017). May, (2002) points out there is a need for the qualitative testing of theories about the nature and effects of social structures upon social actions and visa- versa. As the subject matter of social science is conceptual as well as empirical, ethnographic methods have a role to play in critical realist social science.

4.2.1 Ethnography and critical realism

The ability to engage in explanation and causal analysis (rather than solely engaging in thick empirical description of a given context) makes critical realism useful for analysing social problems and suggesting solutions for social change (Fletcher, 2017). Geertz (1973) notion of the ‘thick description’ in qualitative research and ethnography has resonance here, a central component being the interpretation of what is being observed rather than just description, as well as interpreting participant intentions in their behaviours and actions (Geertz, 1973). Rees & Gatenby (2014) have considered the relationship and value of ethnography and critical realism, describing it as well placed to provide this ‘connective tissue’ to ethnographic enquiry. They point out that it is not merely a method of data collection but a sociological practice of linking observed accounts to context and explaining rather than merely describing social phenomena (Rees & Gatenby, 2014). Adopting a critical realist stance provides a grounded and contextual understanding of how the ‘social world works’ (Alderson, 2021). In my research this refers to understanding how participants with cognitive impairment engage in an active ageing practice, the relationship with active ageing policy and sociological theory, therefore critical realism complements my ethnographic approach. As Madden (2017) points outs, ethnographic research should contain theoretical and methodological discussion rather than simply listing a process of techniques and regarding this as an ‘unqualified good', a critical realist approach supports this. I provide a descriptive account of the APPLE-tree intervention in

Appendix 1, however, my role involved more than simply amassing details from observations but involved what Ponterotto (2006) describes as “the researcher’s task of describing and interpreting observed social action (and behaviour) within its context” (Ponterrotto 2006 pg543).

Critical realism allows for the consideration of the relationship between agency and structure accepting that the social structures in which individuals are located pre-exist those individuals’ participation in them and do not exist independently of social actors’ conceptions of what they are doing when they act (May, 2002). I chose to adopt a focused ethnographic approach (Chapter 3) with the aim of not only illuminating the understandings and actions of individuals within an active ageing intervention, but to use examination of those understandings and actions to help to uncover the relationship between agency and structure (May 2002).

Studying the APPLE-tree programme required flexible research methods to capture the multi-faceted nature of the online intervention sessions. Focused ethnography is rooted in sociology and is concerned with actions, interactions and social situations and is useful for short term, time limited and intensive research (Knoblauch, 2005). Traditional ethnography is a branch of anthropology and the systematic study of individual cultures. Ethnography explores cultural phenomena from the point of view of the subject of the study. Focused ethnography shares many common features, both require similar techniques to ensure quality data and analysis, in contrast to traditional ethnography, focused ethnography explores a specific problem within sub-cultures and among small groups of people (Rashid et al., 2019).

Focused ethnography is appropriate for well-defined social episodes, interactions, and time specific events. It has also been regarded as valuable in observations which use supported technologies (Woermann, 2018). These characteristics make it a suitable methodological approach with which to study the online APPLE-tree programme. Its focus upon specific contexts includes acknowledging situations where participants may not know each other but there is a focus on their common behaviours and shared experiences (Wall, 2015). Focused ethnography works from a backdrop of familiarity as (Knoblauch, 2005) describes an element of otherness or 'alterity' rather than the 'strangeness' expected in traditional ethnographic research. This affirmed and validated my role as a researcher with previous experience and knowledge of working with older people with memory difficulties and MCI (Knoblauch, 2005).

Focused ethnography provides the researcher with a position in the social sciences yet allows freedom to shift focus which is both iterative and inductive and in line with the ethos of traditional ethnography. It enabled me to define my focus on the APPLE-tree intervention to the areas pertaining to my research questions and overall aim of the thesis. My focus was to understand active ageing as a concept through practices and exploring the gaps identified in chapters 2 and 3 around absence of clarity and people's subjective experiences of memory difficulties. Being immersed within the APPLE-tree intervention sessions provided this opportunity as I considered how people situated themselves within active ageing practice and how they adopt such practices in their lives. Firstly, through participant observation during the intervention sessions and later, building on this through semi-structured interviews with participants. My observations and subsequent field notes were subject to both deductive, theory driven analysis, and inductive, exploratory, and interpretive processes. This has been characterised as abductive analysis, this process is regarded as neither data-driven nor hypothesis-driven but conducts parallel and equal engagement with empirical data and extant theoretical understanding (Thompson, 2022). Brinkmann (2014) states that abduction is a form of reasoning that is concerned with the relationship between a situation and inquiry. This fits with my adoption of a focused ethnographic approach as way to consider theory through the study of the APPLE-tree intervention, as an example of active ageing practice. Abductive analysis provides a 'double engagement' with existing theory and methodological steps, this includes an emphasis upon the positionality of the researcher, their biography, affinity, and familiarity with broader theoretical fields and is regarded it as a 'creative inferential process' (Earl Rinehart, 2021; Timmermans & Tavory, 2012). Inherent within a critical realist perspective is the fundamental role of reflexivity in forming knowledge through recognising the researcher as 'part of their own field of inquiry' (Fletcher, 2017). My positionality reflects my background as a mental health nurse which is influenced by a clinical and care orientated culture whilst embracing a social science perspective of health and illness.

My PhD is embedded within the APPLE-tree programme, but my research is sufficiently removed by undertaking an ethnographic study as part of my studentship.

4.3 Study design: process and methods

Based upon the decisions outlined above and in line with a critical realist approach I am taking a focused ethnographic approach using reflexive thematic analysis to explore the social actions of an active ageing intervention within the structure of active ageing as a concept and culture. In this section I will outline and discuss the following methodological processes:

1. Ethics and consent
2. Recruitment and sample
3. Familiarisation; the pilot study and development of a dual role
4. Methods; Undertaking participant observation and interviews
5. Working with the data; storage, management, and familiarisation
6. Analysis of the field notes and interviews

4.3.1 Ethics and consent

Ethical approval and consent were obtained through a non-substantial amendment to existing APPLE-tree approval and was endorsed through statutory regulators including the Health Research Authority (HRA). London (Camden and Kings Cross) Research Ethics Committee (Reference: 19/ LO/0260) and UK Health Research Authority (HRA) approved this study in April 2019. The HRA's protocol on qualitative studies considers ethnographic observations (2016:5), and consent in research settings however this guidance does not extend to observing people online. People who wished to take part in the APPLE-tree study needed to have capacity to consent, which was one of the inclusion criteria for participation. Individuals were consented as part of an overall consent process to the APPLE-tree programme, this was done with a research assistant. I was not involved in this process, but consent included agreeing to being observed by me in their sessions, thus avoiding an additional consent process and overloading individuals. However, I was aware that my ease of access into the intervention was due in part to this consent process so before observing the intervention I checked that participants fully understood my role in their group and that they were still happy to have me observe their sessions. The understanding being that if one participant changed their mind and did not what me to observe them then I would not be able to attend that group. I include examples of the consent form (Appendix 3) and participant information sheet (PIS – Appendix 4) from the APPLE-tree study in the appendix.

Ethical ethnography involves awareness of your effect as a researcher on participants and on the data, (Madden, 2017). This statement supports my aim to be reflexive throughout my study. Despite these considerations and the guidance from HRA, ethical conundrums emerged during field work. Confidentiality, participants remembering information and understanding my role within the sessions are three issues which are considered in the next sections.

4.3.2 Recruitment and sampling

Purposive sampling is commonly used in focused ethnography and reflects the APPLE-tree recruitment strategy. That is 'to select respondents most likely to yield appropriate and useful information' by better matching the sample to the aims and objectives of the research, thereby improving rigour and trustworthiness of the data and results (Campbell et al., 2020). Individuals who self-identified with memory difficulties and/or had a diagnosis of MCI either volunteered by responding to adverts about the programme or their names had been put forward by GPs and a letter was sent by the study team to ask if they would like to take part. Researchers from the study team undertook baseline cognitive functioning assessment with inclusion dependent upon a predesignated score. I chose not to document specific baseline measures for recruitment into the APPLE-tree study as my research was not an evaluation of this programme. The APPLE-tree research team recruited participants to the study, and I was not involved in this process. I did not want the way people were designated a place in APPLE-tree to determine or overshadow discussions of the empirical data, I was more interested in what they do and how they engaged with this active ageing practice once they were in the programme.

Participants were recruited from two locations: one coastal town near London and one urban area in North London. Two groups were recruited from each location making a total of four. Participants from the coastal town were recruited through a health and well-being service via the GP surgery. Participants in London were recruited through the NHS memory assessment service, Improving Access to Psychological Therapies (IAPT) services, and GPs. I briefly provide an overview of the participants involved below in table 6, however, for more detailed demographics see Appendix 5.

In in January 2021, I joined the first group who were recruited from the coastal town outside London, and in April 2021 I joined the second group who were recruited from London. At each location there were two groups who met for 10 sessions and was interspersed with a ‘tea’ group every other week, so a complete intervention programme ran for a total of 20 weeks each.

Table 6 – APPLE-tree participant demographic information

	Coastal town		Urban area in London	
	Group A n = 6	**Group B** n = 5	**Group A** n = 5	**Group B** n= 6
Age (years)				
Mean	76.0	76.8	73.2	76.6
Range	68 - 79	68 - 89	69 - 77	70 - 87
Gender (n)				
Female	4	3	4	3
Male	2	2	1	3

Recruiting participants for interviews following the intervention sessions was made easier given the amount of time we had spent together as a group, albeit on Zoom. I believe individuals felt comfortable in my presence as we had got to know each other. Participants regarded me as a 'participant' in the intervention delivery team and at times this overshadowed my role as a researcher, particularly in the context of online delivery and the participants' memory impairment. I drew upon my engagement skills as a health professional to accommodate this position and build rapport. However, I was conscious not to use this sense of confidence unfairly, becoming complacent or cajoling people into interviews. Participants had previously also consented to follow-up interviews; however, I was careful to check this consent again, giving individuals the option to not take part if they had changed their mind.

4.3.3 Familiarisation: the pilot study and the development of a dual role

The APPLE-tree study team undertook a pilot study to test the online intervention over 10 weeks in summer 2020. This provided me with an essential familiarisation (and introduction) period to doing ‘ethnography online.’ Familiarisation is a way of increasing transparency within ethnography (Davies, 2012). During the pilot study I attended all the online intervention sessions, approaching them in an unstructured way. Participation in the pilot study enhanced my focus on what to observe and consider during the main intervention sessions, in line with a focused ethnographic approach.

The pilot study also allowed me to experience and reflect upon my position and role as observer and researcher with participants within the actual intervention sessions. Participating in a group for people with MCI or being a co-facilitator was inappropriate, whilst simultaneously observing sessions online without contributing or interacting in them also felt uncomfortable. Drawing upon these reflections and following in-depth discussions with the APPLE-tree project team, as well as with my supervisors, it was agreed that I would take on a role as an assistant to the two facilitators running the group. This resolved the difficulty of undertaking observations over Zoom and meant that I had a legitimate role as an assistant, helping with IT issues when participants disconnected or couldn’t connect to the session, and this worked well. The pilot study allowed me to orientate myself within the intervention and establish how my dual role of researcher and assistant would work.

Dilemmas with my dual role: “being ethnographic”.

Although consistent with ethnographic research, undertaking a dual role as a participant observer and assistant with individuals who have fluctuating memory loss meant re-clarifying my role and indirectly re-establishing consent when asked why I was there. Initially I introduced myself and my role at the start of each session, however, early into the intervention I reflected upon this and decided against doing this. Consent had been given, and most participants remembered why I was there, or were quick to remember my role with a small prompt. I felt uncomfortable reintroducing my dual role as it felt patronising, and my decision was influenced by the fact that the facilitators did not do that. Instead, I responded to queries as and when they arose, in this way I was responsive to the emergence of any queries and could address any consent queries within the sessions. Madden refers to this as ‘being ethnographic’; that is ‘thinking’ and ‘doing’ ethnography in the moment (Madden 2017).

A ‘blurring’ of roles has been embraced within research as the researcher has been considered both part of the situation studied and an instrument of research activity, deeply embedded within the account (Richards, 2020). Inevitably some participants’ memory deficits were exposed online, and any lack of ability.

Applying theory: insider/outsider role

As previously stated, I adopted what may be described as an’ observer participant’ role rather than the traditional ethnographic ‘participant observer’ role. Taking a critical realist viewpoint behaviour is considered as changeable within the context it is observed, therefore the impact of the observers’ participation is an important dimension to acknowledge. This ‘observer-participant’ role is not dissimilar to what Adler & Adler (1987) described as the ‘peripheral’ observer, where first-hand insider perspective is gained without functionally participating in the scenario observed. The ‘observer-as-participant’ role conceptualised by Gold, in 1958 has resonance here, where observations are more formal, and contact with participants is considered brief (Uldam & McCurdy, 2013). However, Gold pointed out that there is potential for the observer to misunderstand their participants due to the brief nature of their contact in the field, (Uldam & McCurdy, 2013). A key characteristic of ethnography is that it attempts to find a relationship between the 'insider', that of the participants point of view, with the 'outsider' that of the researcher's point of view. I was aware of the importance of me developing a relationship with participants in APPLE-tree in order to support their experience in the intervention in my role as an assistant inside the sessions. However, at the same time I needed to remain external to their experience and retain a sense of an outsider to enhance my role as a researcher. Utilising discussions with my academic supervisors and debriefing discussions with the session facilitators provided both reflexivity and perspective. Awareness of what Madden describes as a cultural translation involves the researcher never losing sight of their own perspective (Madden, 2017). Madden goes on to state that 'proper' reflexivity requires that researchers do not forget that they will in some sense always be 'outsiders' despite becoming very familiar with the people they study and how reflexivity has a central role in resolving this. The 'outsider' role was important to retain and be aware of as it allowed for creating distance when approaching the interviews with participants from the sessions.

4.3.4 Methods: undertaking participant observations and interviews

Ethnographic methods such as participant observation and interviews may be regarded as complementary as both provide different perspectives and narratives to my data rather than a singular interpretation. The combination of participant observation and interviews sets ethnography apart from other forms of qualitative research, and these methods have become synonymous with ethnographic methodology. Atkinson & Coffey (2023) draw attention to a false dichotomy existing between interviews and observations; however, they suggest that distinctions between talk and action are erroneous and irrelevant and recognise that talk is action. In my study I regarded both methods as complementary ways to explore active ageing practice and to develop iterative ways of developing my areas of focus, providing rich data. In the next sections I describe my use of participant observation and follow-up interviews, including online challenges.

Participant observations

Used alongside a transparent research design, participant observation has been regarded as providing an accurate account of what is happening at a given time in a phenomenon, resulting in an extensive description of that event (DeWalt & DeWalt, 2011). Participant observation is regarded as fundamental to ethnography (Madden, 2017), albeit possessing an inherent tension, as ‘participant’ meaning joining in whereas ‘observation’ refers to being objective (O’Reilly, 2012). However, O’Reilly notes that this tension does not need to be resolved, and that balancing detachment and involvement as both an insider and outsider can be a strength. As previously outlined, I positioned my research role as more of an ‘observer participant’.

First and foremost, I observed the intervention sessions and took notes, with participation as an assistant to the facilitators a secondary role. In observing the APPLE-tree intervention I was able to get a detailed description of sessions which provided the basis of further interpretation through analysis. When observational techniques are combined with other methods such as interviews a wider exploration was achieved. Interviews combined with participant observation can result in being told different things at different times (O'Reilly, 2012).

<u>"Doing" ethnography online.</u>

Undertaking ethnography through an online platform presented unfamiliar challenges to me. Although unable to share a physical space, I was part of the participant's virtual space as a researcher and as an assistant present virtually inside their rooms, home, and location. Using the term 'ethnographic space' I refer to the space around and behind people, which is visible through the Zoom camera, and I regarded this space as equally worthy of observation (Watson & Lupton, 2022). Privacy and space were a bonus for some participants whereas for other people spaces were small and shared with multiple family members, particularly apparent during lockdown. I observed this range of backgrounds, and I was conscious of my assumptions and reflected upon any judgements I was making about these. The Zoom platform acted as a mirror, but I was aware that I had a very different perspective than that of the facilitators, who were inevitably occupied and engaged with delivering the session topic. I used reflexivity to evaluate my interaction with participants online during the sessions and adjusted my research design accordingly, and I cover this in more detail during the next section on interviewing.

<u>Interviews.</u>

In ethnography semi-structured interviews should be designed to flow whilst avoiding ambiguity in questions, giving participants enough 'conversational space' to explore the answer as an act of discussion (Madden, 2017). I used open ended questions to elicit information about areas from the topic guide related to my research questions. These loosely centred around the following areas; how people came to the intervention, how they engaged with it and why, and their thoughts about the intervention in relation to dementia and getting older. I iteratively revised the topic guide throughout the process as an essential part of ethnography and reflects a more active approach to interviewing which occurs as an ethnographic approach progresses, (O'Reilly, 2012).

My topic guide reflected my research questions around understanding how people situated themselves within active ageing practice and how they adopted it into their lives (Appendix 6). I asked questions about their arrival into the programme, their thoughts on the intervention, and the connection between cognitive impairment and age. The nature of these questions aligned with critical realism's endeavour to explain and critique social conditions, such as active ageing practice. Taking a focused ethnographic approach considers the action and interactions within such a social situation. Consequently, exploring how participants engaged with the APPLE-tree intervention as a dementia prevention strategy was central to the endeavour. This relationship went beyond that of thick description of the empirical entities, and in adopting a process of abduction provided an additional 'level of theoretical engagement' (Fletcher, 2017). DeWalt & DeWalt (2011) argue that a phase of research based upon participant observation is necessary before formulating appropriate questions for an interview schedule. With this in mind, I responded to the observations made during the intervention and recorded in my field notes to further revise topic guides for interviews. This resulted in the inclusion of a question on the topic of personal biography which was significant and will be discussed later in this chapter.

Interviewing people with memory difficulties and MCI and asking them to remember details from and about an intervention they had attended could be problematic. Characteristically people might experience short term memory problems, making recalling events harder. I allowed for this by conducting interviews as soon as possible after both programmes finished and I believe that, overall, participants were able to recollect their experiences in quite a lot of detail. However, being sensitive to participants' needs and abilities, at times I didn't feel that I could go further in the interviews in order to be able to ascertain accuracy. Forgetting is part of this story and provided confirmation to people of their need to engage with an active ageing intervention. This will be explored further through the findings chapter.

I allowed for what (Madden, 2017) called 'pauses, lags and tangents' throughout the interview recognising that these can provide opportunities for people to elaborate on difficult areas. This was pertinent as I was asking people about their memory difficulties, which is a sensitive and potentially emotive area. Madden also talks about how the 'peripheral' information which accompanies longer responses to open ended questions is relevant in the larger scheme of things (Madden, 2017). Examples of such 'peripheral' information emerged early on during observations from the intervention sessions as participants spoke about their background or history. I incorporated questions asking about biography within the interview schedule structure, however, participants often chose to recount their life history and biography to me without a prompt. The significance of these are discussed further in my findings in chapter 5. Frank, (2000) makes the point that in reducing an individual's life story to a narrative, data for analysis (or in my case biography) reduces or risks losing the purpose for which people engage in storytelling, which he describes as being about relationship building and reaffirming relationships (Frank, 2000). I felt individual biographies were important to my research, they worked to establish a rapport, allowing people to feel comfortable and have some control with the interview agenda. I believe this an important reflection of their experience of having memory difficulties and MCI and their subsequent lack of control in this situation; wanting to be heard was essential to their story living with memory difficulties and MCI.

I became aware of a juxtaposition of getting to know participants lives through the 20-week online sessions and not knowing them outside the intervention. This felt less apparent when interviewing participants through Zoom. However, entering people's homes and meeting participants in person was a more significant experience than I had anticipated. Participants were incredibly welcoming and greeted me as someone they knew and were familiar with. This smoothed the interview process for both them and me, but I was conscious that this should not become too informal. I reflected upon the fact that my data collection was within the time of the covid-19 pandemic with its subsequent impact on social relationships and acknowledged that this may well have affected participants' responses towards me and their willingness to engage with an interview.

4.3.5 Working with the data: storage, management, and familiarisation.

The quality of field notes is not simply about transcribing events, but it is part of being transparent in the process of ethnography. Transparency includes being open and clear about the process of data collection, the different between types of data and how extracts of data and quotes are used (Richards, 2020). Field notes, whether quoted or summarised in the final thesis, facilitate thick description and permit the reader to vicariously experience the research setting (Geertz, 1973).

Writing the field notes.

When writing ethnographic notes in the field getting descriptive information down is key, followed by more effective consolidated notes later after the event (Madden, 2017). I sought to get descriptive information down through jottings during the intervention sessions, these needed to be inconspicuous on Zoom as I became aware of my eye contact and looking down too much. My field notes became a combination of participatory note taking during the intervention and recall. These were always done on the day of the event, usually straight after the interventions so that I could remember as much detail as possible, reducing the writing I had to do during the sessions. Madden (2017) points out the immediacy of note taking is greatly enhanced by a daily schedule.

I critically reflected upon the quality of my field notes and their structure and depth in fortnightly reflexive discussion with a member of my thesis committee (Henry Llewelyn). These discussions were invaluable in enabling me to refine the structure of the field notes to capture the level of detail I wanted. As the group sessions progressed my field notes developed and were organized around the session's structure and significant events within the content of the intervention, an example is found in Appendix 7. I used an Excel spreadsheet to hold and manage the large amounts of field note data I was generating from the two interventions groups; an example is provided in Appendix 8.

Interviews were conducted through Zoom or face to face in people's homes during a period of the lifting of covid-19 social distancing restrictions in the UK. In all instances, interviews took a semi-structured form and with the consent of participants all interviews were audio-recorded using a Dictaphone or recorded through Zoom and subsequently transcribed verbatim.

Keeping a log of changes in design can be seen as a significant source of data, documenting reflections of the data making process as well as account changes and discoveries is at the core of validity and reliability (Richards, 2020). I kept a coding notebook to record how methods and changes in design developed at all stages of data collection, an example of which is in Appendix 9.

Getting familiar with my data.

I actively and critically immersed myself in the data, detailing field notes and conducting initial analyses in tandem as notes were read and re-read making initial observations through memos. Memos allowed early ideas about what was happening in the data to be documented and reflected upon. It is recommended that distance between collection and immersion enhances this critical process (Madden, 2017). The process of participating in two groups a week, (at one point this was four a week) writing field notes after each and keeping a reflective diary was a sufficient commitment, until the whole programme was complete. This created a natural distance between me as a researcher and the data, which was helpful.

4.3.6 Analysis of the field notes and interviews

Using reflexive thematic analysis.

As an analytical approach, reflexive thematic analysis is a natural ontological position within a critical realist approach, as it takes account of the participants version of reality (Clarke & Braun, 2021 pg171). Clarke and Braun point out that participants bring the researcher, “a located interpreted reality (the data) which you interpret thought reflexive thematic analysis” (pg171). This ‘fits’ with my focused ethnographic approach, as interpreting the data from the reflective standpoints of the researcher and the researcher’s role in knowledge production is a key dimension of this approach (Braun & Clarke, 2021). Adopting a critical realist approach acknowledges that social meanings, ideas, and decisions can have causal impacts in the world, yet these social objects do not follow a conception of causal law (Fletcher, 2017).

I used reflexive thematic analysis (RTA) to categorise the data before drawing it together through RTA in order to develop themes and theory. I followed the guidance of Braun and Clarkes (Clarke & Braun, 2021) articulation of the ‘six-phase process’ for reflexive thematic analysis. This involved: (1) becoming familiarised with the data, (2) systematic coding of data, (3) generating initial themes from the coded data, (4) developing and reviewing themes, (5) refining and defining themes, and (6) producing the written report. Braun and Clarke emphasize the flexibility in their method which sometimes gets overlooked in application (Braun & Clarke, 2021).

Triangulation.

Triangulation of data is a way of integrating data from qualitative interviews and participant observations to reduce bias and enhance validation across different methods of data collection (DeWalt & DeWalt, 2011). This was done reflexively, keeping awareness of my different type of data through field notes and interview transcripts and I worked iteratively. My iterative approach to analysis required a constant conversation between theory and data, rather than an early formulation of codes which might limit subsequent analysis. Despite drawing upon a theoretical framing of my research questions I was conscious of the temptation to formulate analytical conclusions too early and sorting my data into these hastily created categories. Commitment to delaying the formulation of premises is crucial to the ethnographer's 'analytic mentality' (Hammersley & Atkinson, 2019). Keeping a reflexive diary helped me to avoid this (see Appendix 10 for an example). Treating ideas and reflections as more data which can be read and revisited and linked and written about (Richards, 2020).

Categorizing, coding, and analysing the data.

In line with focused ethnography, I approached the data with areas of interest and focus on the positioning and situation of participants within the sessions, their interactions and engagement, and their beliefs about age, memory, and active ageing. These areas developed from my research questions, my findings from the scoping review and secondary data analysis as well as my experiences within the pilot study. In line with critical realism these weren't predefined entities but were fluid and evolving areas constructed as I responded to the continued collection and analysis of data.

For clarity the stages of my process of analysis are listed below:

1. Recognising that a level of interpretation took place during my writing field notes, I began with general descriptive categories, which were assigned as columns with headings on the excel spread sheet, this allowed for a visual presentation of the large amount of data.

2. Categories included extracts from the sessions which occurred frequently and/or which appeared to be significant to my areas of my interest and focus. Initial categories included the following: Activities from the session/Memory/Age/Zoom & IT /Online Setting/Space & environment /Food and nutrition /Co-morbidity /Covid-19 & lockdown /Narrative or life story/ Miscellaneous.

3. After coding data from the field notes into related categories, I then went through each category to produce more analytical coding. Coding is a process of analysis rather than description, sorting and categorising create familiarisation with the data allowing patterns themes and anomalies to become apparent (Richards, 2020). This was an iterative process where I was fully immersed within the data, with movement backwards and forward between the field notes. Additionally, I anonymised and checked interview transcripts for accuracy whilst also listening to corresponding audio-recordings.

4. I used NVivo 12 software (QSR International, 2018) to organise the interview data and began by re-reading all the interview transcripts and transcribing interviews from Zoom myself, meant that I was fully immersed in the data.
5. Initially I managed data from the 16 individual interviews through NVivo, with coding and linking data to ideas and from ideas back to supporting data, 'codes may link to codes as patterns or associations become clear' (Bazeley, 2009).
6. I moved off Nvivo to write accounts around codes and the clustering of codes which enabled me to consider patterns, interpretations and understanding of the APPLE-tree intervention, focusing specifically upon the participants experiences, questioning, and being informed by the field note and interview data.
7. I worked iteratively, developing, discarding, and generating codes in relation to the research questions and theoretical focus of my research, whilst frequently returning to my field note categories and the interview transcripts,
8. I kept a coding notebook and wrote memos, making it visual through colour coding of notes and emerging themes (Appendix 7). Developing and refining definitions of codes in this way contains the essence of the naming of themes and as such is regarded as a critical part of the analysis (DeWalt & DeWalt, 2011).
9. Overlapping themes were evident and I wrote accounts of these to help consolidate them, producing numerous iterations. Analysis and data collection are not discreet processes, even when data is sorted or categorised

the final analysis is through writing and as such should be considered an integral part of the analytical process (Waller et al., 2015).

10. I drew upon sociological theory to help identify and explore a deeper level of interpretation within my theoretical framework, the findings of which are presented in chapter 5.

4.3.1 Pulling the picture together and making the data meaningful

My field notes and subsequent categories and themes were revisited as part of expanding and understanding thematic development from the interview data. Context specific extracts and quotes were used in their entirety from field notes in order to identify and illustrate themes, as Madden (2017) warns that these must not be divorced from their context to retain the full meaning. The final process of analysis involved drawing examples and text from both sets of data to illustrate different concepts and interpretations.

In the next chapter I present the analysis of the findings through three themes which reflect the empirical data through a focused ethnographic approach of enquiry, influenced by sociology. Connected themes and sub-themes were generated and these are presented through chapter 5, drawing upon sociological theories for critical discussion in chapter 7.

Chapter 5 Exploring active ageing practice through the dementia prevention intervention APPLE-tree

5.1 Introduction

In the previous chapter I outlined my ethnographic methods and methodological approach to exploring the APPLE-tree intervention as an example of active ageing practice for older people who have cognitive impairment which is not dementia. Adopting a focused ethnographic approach allowed me to apply sociological theory to my empirical study.

Active ageing as applied to the prevention of dementia draws upon notions of hope and the anticipation of maintaining cognitive functioning and avoiding cognitive decline. As previously noted, individuals who self-identify as having memory difficulties or are ascribed a label of MCI are increasingly subject to discourses around modifiable risk factors, prevention, diagnosis, and the potential prodromal factors associated with dementia. Navigating this is complicated, as illustrated in chapter 1 and explored through my scoping review and secondary data analysis in chapters 2 and 3. In these chapters I identified issues around the consideration of MCI as a contested term, and the potential liminality of this status once ascribed. I also drew attention to contemporary discourse and societal expectations surrounding successful, active, and healthy ageing.

In this chapter I build upon chapters 2 and 3 through the application of an ethnographic lens using examples from empirical data to illustrate three identified themes. I describe how individuals with memory difficulties and MCI participate and engage in active ageing practices, using the APPLE-tree programme as a portal to explore this under researched area. Finally, I summarise the ethnographic findings through my two research questions:

- How do people situate themselves in an active ageing intervention
- How do people adopt active ageing into their lives

I use these questions to frame a critical discussion of the interpretations of this empirical data.

As previously outlined in chapter 1, the culture of active ageing reflects a context which is shaped by economic, political, social, and scientific attitudes and developments within age and ageing. The APPLE-tree intervention provides a focus with which to understand the culture of active ageing through the concept of cognitive active ageing practice in action. The concept of active ageing has been used alongside the idea of neuro-culture as a way of examining expectations of later life (cognitive) health. It captures the personal and the collective experience of active ageing practice and impact of policy and will be discussed further through my discussion in chapter 6.

5.2 Rationale for combining data sources

This chapter presents a combination of the analysis from the ethnographic observational data, through extensive field notes, along with data from the interviews. Combining these two forms of data captures the depth of the context in which it occurs, providing more robust research (Phillippi & Lauderdale, 2018). My intention was to provide a comprehensive and rich account of participants' experiences of active ageing practice, capturing both what people did during the APPLE-tree sessions and how they talked and felt about it post intervention. In total 65 field notes were made and these interpretations of participants' engagements in the sessions were important in providing a grounding in understanding participation in an active ageing intervention. This helped to shape the interviews in two ways. Firstly, directly through adjustment of the topic guide, such as adding a question asking about biography. This was something which appeared to be significant for participants during the sessions. Secondly, specific activities observed and described within the field notes from the sessions were referenced during the interviews. Thus allowing a context in which participants could readily draw upon their experiences. The themes presented here represent analysis from the observational and interview data with extracts from the field notes supporting interview extracts and quotations.

5.3 Themes

5.3.1 Overview of themes

I present three interrelating themes with sub-themes (table 7) which describe much more than the operations of APPLE-tree as an example of active ageing practice, but speak to broader concepts of identity, ageing and self-determination inherent within a culture of active ageing in society. Below I briefly outline my themes, following this with a fuller exploration and discussion of their meaning. I include anonymised extracts using pseudonyms from my field notes and from my interview transcripts. These extracts illustrate how people engaged with the intervention sessions and assimilate active ageing practice into their lives through three interconnecting themes:

1. Becoming an ‘active ager’
2. The responsibilisation of active ageing; accountability and obligation
3. Positionality in active ageing; individuals in a collective experience

The overview of each theme below including theoretical correlates which will be expanded on further in my discussion in chapter 6.

Table 7: Themes and subthemes of my ethnographic study

Themes	**Subthemes**
1. Becoming an ‘active ager’	1a. Great expectations - motivations to engage in an active ageing intervention. 1b. Terms of engagement - ‘being active’ 1c. Addressing the ‘elephant in the room’- exposing memory difficulties and MCI
2. The responsibilisation of active ageing; accountability and obligation	2a. Showing accountability by making an effort - ‘*doing something is better than nothing’* 2b. Making it meaningful to me - individual meanings and responsibility
3. Positionality in active ageing; individuals in a collective experience	3a. Retaining identity and agency in active ageing practice – sharing biographies 3b. Locating myself through an online platform - affirming my position with others

Theme 1: Becoming an ‘active ager’.

This theme explores how and why participants came to active ageing practice. It illustrates the expectations individuals placed upon themselves and the intervention and how participants become ‘active agers’ to engage ‘successfully’ with the activities from the sessions. This theme considers the context in which this engagement occurs and how becoming an ‘active ager’ requires not only ‘doing’ actions and undertaking activities, but individual adjustment to the context within which active ageing practice occurs through a dementia prevention intervention. I draw upon theories of individualisation of health and the construction of self-narratives to explore this.

Theme 2: The responsibilisation of active ageing; accountability and obligation.

This theme explores how becoming a participant in an active ageing practice, ‘dementia prevention programme’ requires individuals to engage with activities that are undertaken to prevent further decline and to take personal responsibility for making the ‘correct’ decisions and choices, with an obligation to demonstrate personal accountability within the intervention. This is framed through theories of responsibilisation and citizenship.

Theme 3: Positionality in active ageing; individuals situated in collective experience.

This theme provides examples of participants seeking to retain control and affirm their identity, through participation in the intervention activities which as individualised and collective experience, were highly personal and complex. People positioned themselves within the sessions with regard to others, influenced by internal and external expectations. Also, virtually through the online platform, by controlling their Zoom background and what they chose to display to the group. In this theme positionality in active ageing is considered through concepts of distinction, difference, and stigma.

5.3.2 Theme 1: becoming an “active ager”.

“Just knowing that I’m sort of doing everything I can towards sort of preventing.”

Bill, Group 2, Coastal town outside London.

In this theme I illustrate how participants with memory difficulties and MCI engaged with active ageing practice through the APPLE-tree programme. I describe the context in which participants engaged with the intervention and became 'active agers' as one of negotiating and navigating their own memory difficulties and highlights the exposure of those difficulties through the intervention sessions. I begin by exploring how and why they arrived at the APPLE-tree programme, their motivations to take part and consider this through their role of becoming 'active agers'. Expectations surrounding the intention of the APPLE-tree intervention were wide ranging. This included the desire to avoid dementia through a perceived opportunity to change their cognitive trajectory, as well as individuals seeking reassurance and emotional support. However, discussions about the experience of memory difficulties and MCI were not always overtly addressed and this will be explored through a sub-theme. Societal expectations of active ageing influenced decisions and recommendations for participation in the APPLE-tree intervention with motivations illustrated through the following sub-theme.

<u>Sub-theme 1a: Great expectations - motivations to engage in an active ageing intervention.</u>

Motivations to take part in the APPLE-tree intervention were diverse and varied. Participants couldn't always recollect why they had been recommended to the programme. However, this conceals the fact that all those attending had made an 'active' choice to do so. They responded to a letter or agreed to a referral to do something, so this process was not entirely passive. June describes her expectations of the intervention:

> *“Well, its meeting other people you we always learn from other people. yeah. Hopefully, some new ideas, or new research will improve our knowledge on how to prevent dementia.”* June, Group 1, North London

June’s main motivation was around preventing dementia and a desire to actively engage with the intervention as a means to avoid this. However, interestingly June doesn’t mention her own memory difficulties as a motivation. Individuals were often unsure as to whether they had consulted their GP about their memory or not. This sense of not knowing is indicative of the generalised lack of clarity in their lives around memory difficulties and cognitive impairment. Particularly around the diagnosis of MCI, including whether they were offered or received one. The quote below illustrates how Hillary was happy to take part in the intervention after receiving an invitation, but was unclear about its purpose, thinking it might be diagnostic.

Christine: “W*hat did you hope to get from the groups, what was your motivation*.”

Hillary*:* *“To be honest I’m not even sure what I expected to get from it is just my only thing is I’m thinking oh, ‘maybe there’s something I can do that if I do develop this thing, they'll pick it up quickly’. That was on my mind, but I realised that it's nothing like that... well it’s not a diagnosis process.”*

Christine*:* *“Okay so did you think it was going to be a diagnosis process.”*

Hillary: *“I don’t know what it was going to be that why I wasn’t sure, yeah”.*

Hillary, Group 2, Coastal town near London

In this extract, Hillary's confusion reflects the broader complexity surrounding diagnosis and its role within MCI. Hillary's statement, "*maybe there's something I can do"* reflects the desire to take part in the APPLE-tree intervention yet she was unable to fully articulate what she hoped to get out of taking part. Hope is significant here, participants described attending the APPLE-tree intervention as an opportunity they were grateful to have been given to prevent their memory getting worse. Therefore, when asked, recollecting their entry to the intervention was less prominent than articulating the hope it offered them.

Within the confines of the intervention sessions, participants engaged with activities and group tasks, however these sat within the wider social context of the participant's communities and families. For example, during one of the APPLE-tree sessions Vera talked about her belief that by taking part in the intervention she would *'stave off dementia'* and compared herself to her parents' experience of having dementia.

> *"At least I am staving off dementia, my parents had it before 80 so at least I haven't got it now."* Vera, Group 2, Coastal town near London

Vera reassured herself that this was less likely to happen through her participation in the intervention and because she was older than her parents were when first diagnosed. This highlights how individuals used participation in the programme to gauge their memory difficulties in relation to an endpoint of developing dementia. By participating in active ageing practices such as the APPLE-tree sessions individuals were working to actively distance themselves from a perceived dementia risk, by 'doing' something about their memory difficulties rather than just 'being' someone with memory difficulties. Risk of dementia was a motivator in wanting to engage within the intervention and the notion of becoming an ‘active ager’ describes the opportunity to move or transition and adapt one’s own narrative, as ‘doing ‘means that you cannot also be a person with dementia.

Families of participants were important in how they approached the intervention and engaged with it. Participants recalled their families’ approval and encouragement about their attendance in the APPLE-tree programme. Tessa spoke about how her family were pleased she was “doing something about her memory”, this resonated with others who then recounted similar experiences.

> *“My daughter…, she's so happy about it (participating in AT) so she kept asking me for feedback.”* Tessa, Group 1, North London

Tessa described her daughter’s relief at her decision to join the programme and in the extract above describes how she wanted regular updates on progress. Ultimately a fear of dementia was present in both participants and family member’s motivation for engagement in the intervention. Becoming an ‘active ager’ involved navigating different and sometime conflicting expectations. Although family members focus was on their relatives “doing something about their memory” participants described these expectations as being both supportive and creating a sense of pressure. This links to my second theme about responsibilisation which is in the next section.

Participants’ expectations of the intervention went beyond improving their memory and also included personal and emotional well-being. Judy embraced the opportunity to gain knowledge and understanding through the APPLE-tree session content. However, improving her emotional health and feeling more reassured was part of her decision to take part, in particular being reassured that she was 'doing something' about her memory difficulties was significant.

> *"The main thing was the reassurance, you know, I'm not on my own here with this problem, so the main thing was the reassurance, then, obviously, going through the booklet in the sessions it was, well, we can do that, can we, that might help me a little bit, I never thought about that, that sort of thing, all this stuff came out that I didn't know anything about that I could have been doing".* Judy, Group 2, North London

The quotation from the above extract ***"****I'm not on my own here with this problem"* captures the sense of isolation many expressed around understanding what was happening with their memory and cognitive changes. This emotional investment in the intervention not only influenced decisions to participate but encapsulates the expectations placed upon active ageing interventions which extended beyond it as a practice, but into participants' lives.

Active ageing practice operates through older people adopting certain behaviour and actions to instil a change, reflecting in part societal expectations around age and activity in dementia prevention. How participants looked to engage in the APPLE-tree intervention and develop as 'active agers' is explored in the next sub-theme with the notions of being active rather than passive being significant.

Sub-theme 1b: Terms of engagement - 'being active'.

This sub-theme describes how participants engaged with the intervention sessions and how demonstrations of 'being active' and 'doing activities' contributed to them becoming active agers. Individuals engaged in the intervention in ways which were meaningful to them, thus addressing some of the uncertainty surrounding their experiences. This uncertainty is complex and multi-layered, indicating the unique and personal experiences of participants with MCI and memory difficulties who engage in an active ageing practice. This is evident below when Bill is asked about the sessions and his memory. He describes feeling a range of uncertainties and how he attempts to mitigate these by taking part in the intervention, positioning himself as doing and being an active ager.

Bill*:* *"I think it was slightly reassuring really and it made me feel perhaps less slightly less worried about it overall."*

Christine: *"What was it about the session that made you feel like that?"*

Bill: "*I think just knowing that I'm doing everything I can towards sort of preventative. You know, just trying to avoid it getting worse, as far as one can, and just waiting for somebody to come up with a proper cure for dementia (laughing). But just yeah just understanding that what I'm doing is not too far off, you know, being as positive as you can about you know."* Bill, Group 2, Coastal town outside London

This extract and in particular the statement I *think 'Just knowing that I'm sort of doing everything I can towards sort of preventative',* illustrates the personal investment individuals have in active ageing practice. It indicates their desire to do something by taking part in the intervention and actively engaging with session activities and group tasks. Individuals became 'active', in their wish to improve memory difficulties and prevent a decline towards dementia. The APPLE-tree sessions provided content and activities which were tangible and measurable and helped to create and define an active ageing role for participants to adopt. Becoming an 'active ager' was a role which was both adopted by individuals and ascribed to them by the group facilitators' attitudes and expectations about their engagement in the intervention. Always done supportively, facilitators ensured participants' adopted the activities, as the following example illustrates, for example Clive said "*oh yes and I've started a diary' it not what I have done but writing down tasks to do then I can tick them off as I go ....Lizzy made me do it"* ...laughing, facilitator Lizzy said, "*I think I helped you do it"*, Colin said it was working well as he forgets what task he has to do at what times "*so this is perfect for me"*.

Participating in the intervention meant that individuals actively engaged with the content, and it was also a way of doing something to avoid the sense of absence created by an unclear trajectory and establish certainty in their experiences of memory difficulties and MCI. Participants engaged in displays of effort within the group of 'doing something', which was demonstrated through showing and sharing achievements from session activities. The group acted as witness to these activities, thus confirming participants as 'being active' and engaged. This was enhanced through the immediacy offered by the online platform as participants sent in pictures via their phone or device, for example recipes made from the nutrition topic and session on healthy eating. This 'real time' interactivity between home and the virtual setting provided participants with opportunities to demonstrate to themselves and the group that they were 'doing' the activities, in this case making the recipes. Being 'active' and engaging rather than just passively 'being' in the sessions.

Topic content delivered within the intervention was intentionally interactive, encouraging participants to actively participate in sessions, thereby affirming their role as ‘active agers’. Inevitably this generated questions, yet these questions appeared to be almost incidental to their purpose. For example, questions around the benefits of dietary change on memory. Participants asked questions of the intervention such as, “*would it work”, “will my memory change or improve”* and “*when may this happen?* These were raised in a reflective and rhetorical way and rarely answered fully. Questions appeared to be a starting point with which individuals considered their memory difficulties and MCI, yet which were never fully addressed. An extract from my field notes illustrates this:

> *During a discussion around the health benefits of cooking with olive oil and brain health, participants raised questions around how much they should use every day to get maximum benefit to memory and when it might have an effect... but what I felt wasn’t discussed was an apparent underlying anxiety about the course of their memory decline.* Field note

It was as if the questions not being asked were the ones which are important here. Their absence characteristic of a border absence of knowledge, ‘knowing’ and clarity for people with memory difficulties and MCI in active ageing practice. It is within this context of absence that individuals engage with active ageing interventions and navigate ‘being active’.

Absence is a unique feature of active ageing practice for people with cognitive impairment and sets their experience apart from active ageing initiatives around physical health conditions. This indicates an observable absence within the session activities to address participant’s experiences of memory difficulties and cognitive impairment, and this is discussed through the next sub-theme.

Sub-theme 1c: Addressing the ‘elephant in the room’- exposing memory difficulties and MCI.

Participants with memory difficulties and MCI engaged in the intervention with the intention of improving or maintaining cognitive health and ultimately preventing dementia. However, I observed a lack of direct questions from participants about their dementia risk or memory difficulties within the sessions and this was rarely addressed directly within the content or by the facilitator. Paradoxically, within the APPLE-tree intervention (aimed at addressing memory difficulties and MCI), sessions didn’t overtly include discussions about experiences of those self-same memory problems. Instead, discussions arose incidentally, following participants engagement with session tasks which were difficult and required recollection, such as remembering to complete activity diaries or sharing scores from completed nutrition quizzes. These activities and tasks would precipitate a discussion about memory difficulties and MCI within the group.

Inevitably, experiencing memory difficulties and MCI affected participant’s actions and decisions during the sessions and served to raise self-awareness of their own memory difficulties. Participants forgot personal events they wanted to share with the group or couldn’t remember activities or health advice. All of which then triggered discussion about these personal experiences of cognitive impairment in an informal way. Experiences were met with humour, permitting acknowledgement of difficulties in a non-emotive way, and diffusing these incidents through a shared experience. For example, when the group facilitator couldn’t remember which activity video we had previously watched and asked the group, this became a shared source of humour.

Facilitator: *"Can you remember?"*

Robert: *"You're asking a man who has a bad memory to remember" [laughing] "we've all got memory problems so don't ask us."*

Robert, Group 1, Coastal town near London

The use of humour became key to how participants dealt with their own cognitive impairment and how they engaged with the intervention. Humour was used in a supportive way within the groups, diffusing and minimising participant's cognitive difficulties.

Discussions about memory and cognitive impairment often only occurred after participants overtly experienced frustration with their memory during an actual session. Competence and cognitive ability were not only on display to others in the group but mirrored through Zoom. An example of this is shown below when Philippa was asked to recall her score from the nutritional quiz which everyone had completed during the first session.

Philippa: "*I vaguely remember doing something like this"*

Facilitator: *"If you can roughly remember what number you had?"*

Philippa: "*Don't ask me to remember things, that's my one area that's why I wanted to join this, it don't work my memory."*

Philippa, Group 2, North London

The unintentional exposure of memory deficits within sessions became common place and was juxtaposed with sharing of activity accomplishments online. However, in both examples' participants used humour to deflect from overt memory lapses, which they also used to justify participation in the intervention. This is illustrated in the extract below when Clive was trying to recollect how he arrived at the intervention and joked to me that this confirmed to him he needed to be in the APPLE-tree programme. This was echoed by others in both the interviews and during the sessions when remembering information became difficult.

> *“My problem is I don't know who recommended me I know it was a medical person, so I’m assuming yeah it was either the GP or what it could well be is that because you're at [name] that's where I went to the memory clinic.*” Clive, Group 1, North London

The absence of participants openly discussing individual experiences of memory difficulties and MCI contrasted with experiences around physical health, ability, and inability, which were readily discussed by participants during sessions. I observed this in the activities participants engaged with; where their physical health, through monitoring nutrition, exercise and co-morbidities are tangible to individuals, as opposed to cognitive health and the fear of dementia which is not. This points to a more straightforward relationship between active ageing practices and physical illness, through treatment and intervention, which is not reflected when active ageing is associated with memory difficulties and MCI. In becoming an ‘active ager’ and engaging within the intervention, participants attempted to challenge the absence of any clear trajectory of memory decline which is not dementia. The next theme explores the concept of responsibilisation and responsibility as being part of the active ‘ager’ role and engagement within active ageing practice.

5.3.3 Theme 2: the responsibilisation in active ageing - obligation and accountability

"I'm disciplining myself from this study.''

Marion, Group 1, Coastal town near London

Responsibilisation, as introduced in chapter 1, is inherent within active ageing. It promotes a sense of individual responsibility and self-regulation for one's cognitive health, characterised by participation as active agers. This theme and its associated sub-themes conceptualise active ageing practice through an agenda of responsibilisation. This is exemplified by the ways individuals engaged and responded with the intervention content and activities. Participants navigated individual concerns about what they should do in relation to their memory difficulties and MCI. I found that individuals appeared to have internalised a sense of responsibility, blaming themselves for their own memory difficulties and therefore prompting a personal need to 'actively age'; the intervention gave them a way to do this in concrete terms. Both an external and internal sense of responsibility were evident, reflecting the developing responsibilisation agenda around cognitive health, and subsequent culture of active ageing. This leads to increased societal expectations of individuals, who once identified 'at risk' of dementia through a diagnosis of MCI, are expected to become responsible for their cognitive health and engage with prevention opportunities.

All the above, contributes to understanding the impact of active ageing practice interventions for prevention and the relationship to cognitive health as one with competing notions of responsibility and accountability. A sense of responsibility was instilled through the APPLE-tree intervention session content, which ranged from activities with tangible everyday goals, such as around diet and exercise, but also extended to broader life changing aspirations and expectations. For example, in the extract below, Sally's aspirations go beyond the remit of the intervention and illustrate the impact of perceptions of responsibility.

> *"It's made me examine, re-examine and doing this course, yes, has made me realize that the responsibility lies with me to become engaged in life, you know in a much broader sense."* Sally, Group 2, North London

Sally's comment implies that she had been disengaged from life but will now take 'responsibility for engaging with it', thereby illustrating how active ageing practice permeates different aspects of an individual's life. The context is important here, Sally's best friend died from Covid-19 which she also developed at the same time and subsequently experienced long-Covid symptoms. Although the Covid-19 pandemic reflects a specific period, understanding this extract within this context illustrates the impact of active ageing culture into participant's lives beyond the intervention. It highlights how engaging in active ageing practices, such as APPLE-tree, infiltrates other areas of participants' lives, stimulating a broader self-reflection of their lives and their responsibilities. Additionally, this raises a question about the responsibility which active ageing practice has for participant's wider aspirations. What is a realistic and achievable expectation, given that individuals are affected by cognitive impairment.

The belief that an individual is responsible for their own health choices is central to the concept of active ageing, with participants questioning their own sense of responsibility in how and why they arrived at the intervention. Tessa wondered if her GP had put her name forward for the intervention after her recent appendectomy and her perceived delay in seeking help for this.

> *"I had to have appendectomy and shortly after that I got a letter sent to me, so I don't know if the interview I probably gives me an indication that I'm not completely focused, we didn't know."*
>
> Tessa, Group 1, North London

Later in my interview Tessa talked about wanting to try and '*make an effort with the activities*' in reference to the above belief. This is indicative of people feeling they must 'take part' to do something, but at the same time are not sure what that is. There is an element of blame within this example, in the sense of being at fault and captured in the expressions of self-doubt. This was evident throughout the themes, possibly reflecting participant's experiences of the broader insecurity and uncertainty surrounding active ageing practice and cognitive health. This extended to knowing and doing the right thing, participants engaged with the sessions on an individual basis and talked about their desire to participate with the intervention 'successfully' and *"to do the right thing"*. The following sub-theme expresses how participants made an effort to 'do the right thing' and why they wanted to do so.

Sub-theme 2a: Showing accountability by making an effort - '*doing something is better than nothing'.*

Displays of personal accountability in engaging with the group sessions correctly were evident in the intervention and are inherent to active ageing practice. Showing that you were 'making an effort' was discussed as a way for participants to 'be' in the sessions, successfully becoming an 'active ager'. Although difficult to specify what ‘unsuccessful’ would look like, the aspiration to avoid it was a key feature in how people thought about and engaged with the intervention. This revealed a sense of personal responsibility which characterised participant’s experience. This was also reinforced by collective responsibility, with demonstrations of engagement and effort. For example, when Marion was asked what she wanted or was getting from the intervention, she talked about preventing dementia by *‘doing the best they can and making an effort’* which indicates a moral self-judgement and a need to respond.

> *“You know, do the best we can to prevent that, yeah that and be healthy, yes, I know it's made me more conscious of I don't exercise I’m, I’m very lazy I don’t believe in going to the gym. I drive, but if I do walk, I’m a bit more aware if I do walk and make sure I walk briskly. I make a bit more effort to, to walk as much as I can, yeah.”*
>
> Marion, Group 1, Coastal town near London

The competitive nature of active ageing was also evident during the sharing of recipe pictures online with increasingly elaborate pictures of food and meals produced and shared. Measuring and monitoring health related activities was fundamental to the intervention, weekly topics included one-to-one goal setting with facilitators via the phone, recording activity through a step-meter and completion of activity diaries. The expectation of a responsibility to achieve these tasks and activities within the group reflects the competitive basis of active ageing practice, with activities influencing how participants engaged with the session content at an individual level, for example:

> *“I’ve increased my fruit intake, but I missed a couple of days and only had 2 portions instead of 3 simply because I forgot.”*
>
> Clive Group 1, North London

This also included more specific examples of measuring personal ability and recording personal progress.

"*If I write it down then I have to follow it through and do it, the first 10,000 steps."*

Marion Group 1, Coastal town near London

These measuring and monitoring activities may be regarded as forms of self-surveillance, characterised by responsibility or accountability to the intervention, the facilitator, other members of the group, but importantly to themselves. However, this was also moderated by individuals, as Marjorie's statement below reflects.

''I've been walking but activity diaries don't like lazy people and I was born lazy.''

Marjorie, Group 2, Coastal town near London

Marjorie's statement suggests the diaries and self-monitoring mean that you can't hide or conceal because '*activity diaries don't like lazy people'*. This illustrates how active ageing practice is based upon self-monitoring and self-surveillance as a way of participants 'being active agers', taking part and doing the right thing. The problem is that it wasn't always clear to individuals what the right thing was, illustrated though the rhetorical questions previously outlined. Self-monitoring included examples of participants realisation, whether accurate or not, that they weren't doing enough. Edna shared the following comments during a session, after participants were asked to complete a nutrition questionnaire at the beginning of the programme and then report back on it. After the questionnaire Edna said:

> *"I thought I was doing good but now I know I'm not so good" she was reassured by the facilitator, and Edna replied saying that "it was opening up her mind." (referring to the intervention*)."

Edna, Group 2, North London

Edna described the intervention positively as an opportunity to expand her knowledge, this knowledge included gaining awareness of her own abilities to improve her health, lifestyle, and cognitive health. However, paradoxically, the knowledge gained from the sessions also served to draw Edna's attention and cast doubt on her abilities. Although these uncertainties were acknowledged by the facilitators, it was difficult for them to explore this within the intervention given the time frame of the session, resulting in this doubt being left with the participant.

As a competitive practice active ageing requires that participants show and share that they are being active in several ways, yet this was more complex than simply recounting achievements. Confessional statements were apparent when individuals shared personal examples of 'deviation' from the advice on health within the sessions, reflecting different aspects of responsibility. These '*slip ups',* as one participant termed them, were generally treated supportively by the group, and frequently deflected through humour, as the example below illustrates.

Bruce: *"Well I do have the occasional Mr Kipling apple pie and digestive biscuit."*
To some laughter and reassurance from the facilitator
Facilitator: *'I think that is allowed!"*
Lots of smiling and laughter about this from Bruce and the rest of the group.

Bruce, Group 2, North London

Humour appeared to be used when people transgress active ageing practice. As each group got to know each other and became established this occurred frequently. Additionally, examples of self-chastisement occurred, particularly through certain activities. The most common being the 'apples in the jar exercise', participants embraced the inter-activity of this exercise which became a regular feature at the beginning of each session.

The ‘apples in the jar’ exercise was done at the beginning of each session; plastic apples were put into a glass jar after each participant shared a’ positive development’ of the week. This was loosely defined as undertaking health advice from the sessions, such as adoption of dietary changes or increased activity through an exercise. As a regular opening exercise, it prompted a lot of humour, discussion, and interaction, with the apples coming to symbolise several things. Apples were a visual way of representing or counting achievements, however sometimes their use reminded participants of what they had failed to achieve. In the extract Andrea uses the apples in the jar exercise to chastise herself about a lapse in healthy eating.

> *“You might want to remove an apple from the jar as I haven’t been very good this week, I was hungry, and I ate a whole bag of nuts.”*
>
> Andrea, Group 1, Coastal town near London

The apples assumed an added significance, becoming a form of currency with which individuals would ascribe values of being deserving and undeserving as the statement above illustrates.

Individual measures of progress through the exercises and activities by presenting achievements and sharing perceived failures to the group became features of the APPLE-tree sessions. This presents active ageing practice as a ‘responsibilised’ activity, with individuals displaying responsibility through demonstrations of accountability and effort. This activity involved participants navigating active ageing practice in order to make activities meaningful to them and their lives.

Sub-theme 2b: Making it meaningful to me - individual meanings and responsibility.

This sub-theme relates to how participants affirmed their individuality within the intervention. Participants made activity tasks meaningful by situating the intervention within their existing lives. However, it also illustrates how people pushed back and rejected aspects of the responsibility it placed upon them.

The activity diary became a benchmark of participant's engagement with the intervention advice, but also revealed how participants related to this advice both as individuals and within a group. This is illustrated through my field notes when Rita described what the activity diary meant to her.

> *"I think it's good to use it as part of a normal routine, the activity diary makes you think about what I can do and reflects a commitment .I know I need to walk more and I feel quite guilty if I don't go, before I was part of this group it didn't matter but now it does matter, it's becoming a routine and if you miss that you feel guilty"* Rita, Group 1, North London

The activity diary may be regarded as another form of self-surveillance where individuals were encouraged to monitor and measure what they were doing and when. Inevitably this captured and highlighted examples of an absence of activity. Within the culture of active ageing this could be perceived as failure, yet it reflected a reality which is important to acknowledge. This sense of an absence of something is indicative of the lack of presence, by which I am referring to the documented sense of liminality participants living with a cognitive impairment experience. It illustrates the absence or gap previously identified in the literature and secondary data analysis in chapters 2 and 3 which reflects a more generic uncertainty about what to do when experiencing memory difficulties which are not regarded as dementia. Participants discussed how completing the activity diary showed them how little they did in everyday life.

The notion of ‘not doing anything’ in active ageing culture and practice implies passivity and not being a successful active ager. However, participants decisions not to undertake a particular activity within the sessions also reflects broader aspects around ability (capacity) and choice and provide examples of how individuals interpreted session tasks in their own way. Subversive examples were evident which initially appeared to be at odds with the intention of the task. Robert filled in the activity diary consistently, describing it as an ‘enjoyable part of his day’. In this way the activity of completing the diary became his activity, as illustrated in the extract below.

> *‘‘I’ve been filling it in and it’s so full I don’t know where I have the time to do everything.’’*

Robert then said that he also scheduled in time to fill in the activity diary:

> *“I like it, I like filling it in.” “I realised that my biggest entry is, I am bored.”*
>
> Robert, Group 1, Coastal town near London

Although Robert’s actions subvert the intention of the activity diary, conversely, he engages with the diary in a way which has meaning to him, his entry, *‘I am bored’* possibly reflected the then lockdown restrictions due to the covid-19 pandemic. However, Robert’s example also suggests his ability to share how he felt about his current situation in the group, which may be regarded as more meaningful than listing events in the diary.

This illustrates how messages about health-related activities from active ageing practice were conceptualised and personalised in a way which is meaningful to the individual. Participants were very positive about being in the APPLE-tree intervention as long as it accommodated individual preferences, backgrounds, and motivations. Patrick describes this during his interview when asked about some of the tasks from the AT sessions.

Christine*: "But did it help you sort of keep focused?"*

Patrick: *"Well, yes, I realised not only the correct things I was doing but I realised my limitations and what I was prepared to do, and I'm not prepared to do anything that makes my life harder, my life isn't hard at all, but I've got my limitations."* Patrick, Group 1, North London

This extract illustrates expressions of agency and individualism, participants talked about the choices they had, underlining the belief that doing something is better than nothing with expressions such as *"I know I am doing the best I can"* which sits alongside notions of 'making an effort'. This demonstration of agency reflects how individuals positioned themselves in order to affirm their ability and identity which is reflected in the next theme.

5.3.4 Theme 3: positioning in active ageing - individuals in a collective experience.

"Just understanding that what I'm doing is not too far off."

Bill, Group 2, Coastal town outside London

This theme considers the positionality of participants and the concepts of distinction and status. It refers to how the social and cultural concept of active ageing places expectations upon participant's ability and actions to become 'active agers'; in contrast to how older people with memory difficulties are frequently positioned in society, as being in a state of inevitable decline. By actively engaging with sessions participants moved or, ‘re-positioned’ themselves into an active ageing role. By doing so they distinguished themselves from others not participating in an active ageing intervention. Becoming an ‘active ager’ rather than simply ‘being’ an individual with memory difficulties and MCI. The following sub-theme characterises this and draws attention to the significance of identity, as found in my secondary data analysis in chapter 3. I found examples of how individuals strived to affirm their identity through their participation in the APPLE-tree interventions and as an opportunity to re- position themselves away from the decline narrative associated with dementia. The following subtheme describes examples and how participants used their biographies.

<u>Sub-theme 3a: Retaining identity and agency in active ageing practice – sharing biographies.</u>

This sub-theme illustrates how individuals consider their identity through active ageing practice by reflecting upon their engagement in the intervention and use of their personal biographies to support or reframe this. The example below illustrates how Trevor relates to his identity and location, and where he is on his trajectory of living with a cognitive impairment, contemplating this position in the broadest sense. Trevor’s statement was made during one of the last APPLE-tree sessions and he was reflecting upon the intervention.

> *“Well, I’ve been taking stock of everything from the course and where I am and where have I gone, as I knew that this was number 10, I was having a think about it.”* Trevor, Group 1, North London

In a longer discussion, Trevor went on to describe how the sessions had made him reflect on his own situation and although they hadn’t provided any answers, helped him consider what he could do and should do regarding his memory difficulties. This example typifies the wider impact of active ageing practice and how participants sought to establish meaning and certainty through practices such as APPLE-tree. Trevor's reference to himself and '*where I am and where have I gone*' indicates his contemplations around identity and draws upon notions of liminality. As previously documented this concept refers to an 'in-between' status that people with memory difficulties, which are not dementia, find themselves in. Within the context of active ageing practice and the APPLE-tree intervention the desire for change by becoming an 'active ager' reveals a liminal space also characterised by a desire for movement and transition.

The intervention was embraced by individuals as an opportunity to change and improve their situation as well as actively doing something to avoid dementia and provided an opportunity of conceiving a change in their future trajectory of potential decline, as the example below from one of the interviews indicates.

Christine: *"And what would you be hoping for, what are you ultimately hoping for?*
Trevor: *"Well if I don't improve memory definitely not for my memory, to go downhill, yeah, I really don't want it to go downhill, I'm really hot on exercise."* Trevor, Group 1, North London

Taking part in the APPLE-tree sessions appeared to be reassuring for many individuals, as they placed themselves within the intervention to feel active, reassured and grounded in the absence of external clarity.

Individuality was maintained and affirmed by participants drawing upon their biographies to determine how they approached and engaged with the intervention topics. Examples occurred during the intervention sessions and in the interviews, with participants recounting their biography or life history becoming an important feature. The following example occurred during a facilitated group discussion about how participants felt they were engaging with the session activities. Reg drew on his background in the army, positioning himself as being ‘responsible’ through, as he said, it was *‘who he was’* in the British army. The senior position he held was replicated in the group as he liked to lead discussions and followed the advice offered methodically, for example:

> “*Yes. I like to think of myself as a bit streetwise, with 40 years serving in the British army all over the world you do tend to focus on things, and I think you get to be very disciplined in what you do. Even today, I’m 72 years old nearly, and today things that I did in the army I use in my life every day.”* Reg, Group 2, Coastal town near London

In the example above Reg describes himself as being aware, focused and disciplined from his army background and in the longer interview he describes drawing upon these factors as a means by which he approached the APPLE-tree intervention sessions.

Participants also shared their biographies as way of countering feelings of being disconnected and justifying their health choices or lifestyle and drew upon these to retain a sense of self. This applied to specific topic areas covered in the sessions and is illustrated by Nina during the session on healthy drinking and alcohol use. The example below from Nina demonstrates how the groups knowledge of a participants biography re-situates what may be regarded as a seemingly ‘confessional statement’ to one within a different context and meaning.

> *“I know I drink too much, its part who I am, its more social I think, living abroad in Italy they all drink all day but only small amounts, I have to limit*

what I have but I like to have wine with a meal."

Nina, Group 2, Coastal town near London

Nina might be making this statement because she felt the need to be doing something contrary to the inherent virtue within active ageing and health promotion, equally asserting her identity. Nina uses her biography to reframe actions which don't fit with the active ageing narrative and the health messages contained within the session.

Participant's use of their life story or biography was significant, and these featured throughout the intervention in various ways. Participants shared memories of their health-related behaviours and that of family members (e.g., smoking & drinking behaviour). Distancing themselves from unhealthy behaviour as a way of affirming their current relationship with health and their identity within an active ageing intervention. Participants like Nina and Reg shared their previous jobs, work roles and where they lived as a way of explaining current health decisions and behaviours. Participants also reminisced about family members lost as a result of dementia, and the impact this had on their health and lifestyle choices.

Sharing personal biographies appeared to enable participants to retain their identity within the trajectory of their life living with cognitive impairment. This is important within active ageing practices for cognitive health, where identity is threatened by memory difficulties. Understanding how participants draw upon their personal biographies to position themselves within the intervention and retain their identity is crucial to the planning of active ageing policy which will provide meaningful prevention strategies to individuals with memory difficulties and MCI. The online delivery of the APPLE-tree intervention allowed participants to control and protect their personal space through Zoom. This enabled positionality to be evident both metaphorically, but also literally using the Zoom platform, and will be discussed in the next sub-theme.

Sub-theme 3b: Locating myself through an online platform - affirming my position with others.

This sub- theme depicts how participants engaged with an online platform to present and position themselves within the intervention sessions. Although these aspects are specific to the online delivery of the APPLE-tree intervention, they apply to more generic themes within active ageing, which recognises that participants need to affirm individual identity and agency whilst engaging in group active ageing practice. The artificiality of negotiating active ageing virtually through the online platform Zoom added a unique dimension to the intervention sessions. This is captured through unique discourse and language evoked by this virtual space and are particularly significant to participants with memory difficulties and MCI. Mirroring uncertainties about position and identity, words commonly used on Zoom such as *'lost'* and *'dropped off',* '*gone*' or '*left'* were used in the sessions to describe occasions when participants had become dis-connected from the session or screens had frozen and proved to be emotive. In the opening sessions participants were concerned by others perceived absence and some needed verbal reassurance from the facilitator about where that person had '*gone*'. The absence of a virtual stability mirrors the real-life instability of mild cognitive impairment. Disorientating for participants, their visual location and clues would change through the Zoom gallery display, exemplified in participant's comments below:

"We keep disappearing." *"Where am I"* *"What am I doing"*

These comments illustrate participant's investment in the sessions to the extent that Zoom peculiarities became substantial to them. This sense of checking in on each other reflected a collective sense of responsibility inherent within the groups. The broader sense of absence associated with these examples reflects the lack of clarity previously identified, which was intensified by the online context making it even more intangible.

The online platform also created unique opportunities for participants to retain control within the intervention. Examples include participants purposefully moving their camera to display their location as a way of affirming their individuality and possibly status. An example of this came when Alma shared the attractive coastal view from her flat with the rest of the group, described from my field notes extract below,

> *Alma physically turning the camera around so that we could see the sea, she wanted us to know where she was (by the coast) and what she could see, with others in the group quick to point out that 'this is the Hove Sea and not Brighton Sea.* Field note

This appeared to be a way of Alma displaying her status to others in the group, and other participants responded to myself and the facilitators by confirming she was correct. The exceptional context of the covid-19 restrictions and lockdown meant that participant's external environment and community was reduced. This potentially mirrors the experiences of increasing cognitive impairment and the disconnection with their wider community, all of which may contribute to the effect upon participants' identity, a sense of location, and position.

The online platform was also significant in concealing individual physicality to the group. Participants experienced physical co-morbidities alongside their cognitive impairment. The embodiment of physical health on ability and motivation to undertake certain activities would be freely discussed by participants within sessions. Andrea revealed to the group she was in a wheelchair, choosing to share this in the third session. Unnecessary in a face-to-face group, the online platform enabled Andrea to decide when to share this information to the group, meaning that her physical disability didn't define her and allowed her to affirm her own identity. The next sub-theme, navigating a place, refers to how people positioned themselves in relation to others in this group and how active ageing functioned in a way which fostered that.

Sub-theme 3c: Navigating a place - where I am in relation to others.

Active ageing policy and practice requires individuals to change certain health behaviours. However, interventions tend to be delivered in groups, characterised by people participating individually but sharing a collective group experience with shared aims. The APPLE-tree intervention was no exception and although it was a dementia prevention intervention, participants shared aims were less apparent, as the individuality of their experiences of memory difficulties were varied and emotive. The extract below from an interview with Clive illustrates the emotional impact of being in a group with other people with memory difficulties and MCI:

Christine: *"And how has it changed how you see yourself".*

Clive: (long pause) *"Yes, it has to degree that I should not be blaming myself as much as. I know it's something which I've done before, but I'm not blaming myself and I now know there are others, and now I noticed that the group is very small area, there's obviously tens of thousands in the same situation as I am, and they are coping and they're coping far better than I was so therefore I'm going to do my upmost to become far more positive"*

Clive, Group 1, North London

The issue of blame in this extract, '*but I'm not blaming myself and I now know there are others'* signifies how active ageing practice for people with memory difficulties and MCI carries with it wider expectations than just improving measures and scores around diet and exercise. Clive suggests that being in the group has been liberating for him and that having shared experiences has allowed him to reconsider how he deals with his memory problems in relation to others and become less self-critical. In my interviews with participants after completion of the intervention, very few felt that the intervention would change anything in relation to their memory. However, they were keen to point out that the collective shared experience of the sessions was invaluable and engaging in the task and activities enhanced this. This finding is significant in highlighting the complex relationship people with memory difficulties and MCI have with active ageing interventions such as APPLE-tree. Suggesting active ageing interventions need to be considered more than just healthy activities and tasks when considering active ageing practice and policy for cognitive health.

Participants used active ageing practice to distance themselves from old age and cognitive impairment, which inevitably means other participants, therefore it may be considered as both an isolating and a connecting experience.

In the following example from Patrick's interview, he reflects upon his participation in the group to measure his own ageing experience, ability, and situation.

> *"Well, it was nice to talk to other people and see, you know, where they're coming from. But I do think most of the people on the course, I think, were older than me. Because some of them seemed a bit sort of vague"*
>
> Patrick, Group 1, North London

This extract reflects a sense of the collective and the individual, suggesting a juxtaposition where participants positioned themselves in relation to their sense of self and others in the group. This could be through their own individual 'achievement' or 'failure' of tasks within the intervention. This draws attention to the external societal stigma associated with memory decline and dementia which although not directly voiced by participants may have influenced the internalisation of the intervention.

5.4 Summarising the ethnographic findings

In summarising my ethnographic findings, the APPLE-tree intervention, as an example of an active ageing practice for people with memory difficulties and MCI, held multiple meanings for participants. It provided tangible activities of doing, taking part and being an 'active ager', which functioned to create greater certainty and held the potential to create a trajectory of risk reduction around developing dementia. Crucially it enabled individuals to ground themselves through the responsibility attached to becoming an 'active ager' and to engage in ways which displayed effort and accountability. This was both an enabling experience and a pressured one, but provided a way to 'be' which was missing in the context within which APPLE-tree participants resided. Participants used active ageing practices to position themselves in ways which reinforced and enabled them to affirm their identity and agency within the confines of the sessions, and more broadly in other areas of their lives. Participants drew upon their biography to provide a social, family and community context.

I conclude this chapter by summarising my ethnographic findings through my research questions, identified, and outlined in the introduction chapter: how people situate themselves within the interventions and how they adopt it into their lives.

5.4.1 How do people situate themselves in an active ageing intervention

Individuals situated themselves within the active ageing intervention, APPLE-tree, by negotiating both external and internal pressures, hopes and anticipations. Negotiating a position as an 'active ager' occurred through both the confines of the intervention and more broadly through the external context of their lives. This highlights how active ageing practice includes expectations from participant's wider community, immediate families and from themselves about what the intervention would offer them. Individuals responded to both internal expectations of personal responsibility and wider external societal beliefs about active ageing, and its relationship to cognitive impairment. This infers that once labelled as having MCI people should react in ways which demonstrate an active response and effort to maintain their cognitive health, and ultimately prevent dementia.

The diverse background of participants before they began to participate in an active ageing intervention contributed to how individuals situated themselves within it. For active ageing practice to be active it requires activities and actions to occur and individuals to adopt these. Therefore, any consideration of how individuals 'situate' themselves within such an intervention, needs to recognise that this is not a static action but instead involves negotiation, movement, and a transition towards becoming an 'active ager'.

The APPLE-tree intervention is just one example of an active ageing intervention for people with memory difficulties and MCI, but it is indicative of a broader culture of active ageing practice regarding cognitive health. It reflects the discussions about expectations, responsibility and seeking clarity which corresponds with the literature discussed in chapters 2 and 3. The intervention illustrates how session topics and their associated tasks provided participants with an opportunity to undertake tangible activities of 'doing', taking part and being an 'active ager'. The elements within the group activities and tasks mirror the broader societal context of active ageing. Displays of competition, self-chastisement, and confessional statements which are evidenced through the findings, reflect a culture of active ageing which is based upon an individualised sense of accountability. However additionally this sits within a collective or societal notion of the responsibilisation of welfare practices in old age. This meant that individuals sought to situate themselves through the responsibility attached to becoming an 'active ager' as well as engaging in 'approved' ways to display effort and accountability.

Active ageing culture includes judgements which are absorbed into the intervention. For instance, through the monitoring and measuring of activities, around nutrition and exercise. Individuals often sought confirmation from within the group by showing and sharing their achievements. Positioning oneself as an active ager displaced any judgements made from their peers within the group about their cognition, as they were ‘doing something’. In other words, taking part in the APPLE-tree intervention affirmed their status as ‘active agers.’ Self-affirmation of this status or position created perceptions of control in a situation which was in essence uncontrollable. Participating in an active ageing intervention such as APPLE-tree instilled feelings of hope and certainty. It enabled individuals to attempt to change or control the sense of uncertainly associated with memory difficulties and MCI, legitimising their position.

5.4.2 How do people adopt active ageing in their lives?

My findings reveal that participants adapt active ageing into their lives rather than adopt it and do so as a way of dealing with the uncertainly surrounding their cognitive health. Participants utilise the APPLE-tree programme by changing the content and messages within the intervention to inform and affirm their actions. Essentially this was driven by a fear of dementia, which although not overtly articulated was present in motivations to take part in the intervention. Fundamentally decisions to adopt active ageing practice were perceived as opportunities to distance themselves from dementia and move forward. The temporal element to this experience revealed how individual entry into the intervention raised participants’ awareness of what might be approaching them in terms of their cognitive health. The sense of uncertainty and the unknown is within active ageing culture, and it inevitably raises the question about what happens next:

"Yeah, it didn't make me more worried or less worried, I guess, overall, it made me feel that it, I wasn't doing too badly and if, by following some of the things that were suggested, I can things off into the distance a bit more being healthier, this was what came out of it for me that might be a positive thing." Judy Group 2, North London

The statement '*push things into the distance a bit more'* reflects how the intervention offered possibilities of movement and change from an anticipated course or outcome of having MCI and memory difficulties.

Participants enter a paradoxical situation regarding how individuals engage in a dementia prevention intervention which centres upon knowing what it means, what they should do about it and how they should do it, whilst their memory of how to do this and skills in engagement may be diminished by the very memory concerns which have brought them to this situation. The effectiveness of such active ageing practice is uncertain, potentially adding to feelings of instability, mirroring their experiences of cognitive impairment as the quotation below allude to.

"Yeah, I did find it useful, but again also slightly worried that you know might be, I might be going that way in five or ten years myself, but time will tell" Clive Group 1, North London

Participation reveals both the individualised nature of undertaking active ageing practices through an intervention and the impact of the collective experiences of other individuals with MCI and memory difficulties. This experience is shaped by a broader generic sense of absence, to which participation in the APPLE-tree intervention is a response.

Participation in active ageing practice also provides hope with the adoption of the ‘active ager’ role providing a way of ‘being’, a position to adopt and aspire to. Whilst participants within the APPLE-tree intervention felt obligated to adhere to an ‘active ageing lifestyle’ they also expressed agency in negotiating their position in this, choosing what they wanted to adopt and what they didn’t’.

Expectations from the intervention sessions varied. Participants believed that by taking part it would either improve their cognitive health: *“I can sort of push things off into the distance a bit more” (*Bill) or hoped it would: “*I’m just trying to avoid it getting worse”* (Judy), or they were not sure: *“I’m not even sure what I expected to get from it”* (Hillary). Some felt that it wouldn’t do anything, but all were happy to attend, with the shared group experiences being a highlight. My follow-up interviews revealed that very few people actually felt that the intervention would change anything in relation to their memory, but they recounted a collective sense of camaraderie amongst group members in the sessions**.** This relational aspect, present throughout the sessions, also refers to the sense of a commonality participants expressed about experiencing cognitive impairment.

All viewed it as being beneficial to their lives, and in particular the activities and information about nutrition and exercise. Participants chose to take part in activities which created a culture in which measuring and monitoring of their lifestyle and behaviour became the norm. For others participating in the intervention provided confirmation that what they were already doing was ‘correct’, as the extract below indicates:

> *“I’m more aware of exercise and nutrition than I was, especially the olive oil and less fluid at bedtimes as always need the loo in the night but think my way of life was quite good anyway but it’s made me realise that it’s more important it is as you get older….and that’s it.”*
>
> Philippa, Group 2, North London

The above quotation sums up the conceptualisation of active ageing culture and practice and its influence upon approaching old age and getting older throughout one’s life course, with the aim of avoiding or preventing dementia. Participants appear to both adopt and adapt to active ageing practice, citing resilience as part of this story. As Clive said when asked about the interventions and what it had taught him, he replied with *‘perseverance,’* this characterises the sense of keeping going regardless of the absence which surrounds their future trajectory.

5.4.3 In conclusion

Active ageing practice is not a linear and passive exchange of knowledge leading to activity but involves a complex interplay of individual actions and interactions with others. This was significant in individuals’ decision to take part and continue attending the intervention. A culture of active ageing for people with memory difficulties and MCI works on the premise that these ‘individuals do not have dementia but are at risk of developing dementia’ and there is an opportunity to become and position oneself as an ‘active ager’ as a response to this. The APPLE-tree intervention was perceived as providing opportunities for older people to engage in meaningful and potentially health and life changing activities through practice and interventions. Yet simultaneously this was also perceived by some as not being possible by people participating, some who didn’t expect it would help but who wanted to take part to be able ‘to do something’ about their memory and came to benefit from engaging in a group with others with similar problems.

The discussion chapter which follows explores this complexity, building upon the empirical data and three interconnected themes presented here. I also draw upon the scoping review and secondary data analysis and utilise theoretical framing from sociology to illustrate and explore this further.

Chapter 6 Discussion

6.1 Overview

In this chapter I consider my research in its entirety, relating it to my overall thesis aim and research question(s). I will draw upon theoretical constructs to explore this in relation to wider concepts about later life, physical and cognitive health as well as active ageing interventions and dementia prevention, and I will consider the implications for policy and practice.

My PhD area of study is complex and multi-faceted, as outlined in my introduction in chapter 1. Complicated and contradictory factors characterise the active ageing as applied to older people with memory difficulties and MCI, which is not dementia. This includes the contested nature of MCI, which is regarded as a prodromal feature of dementia, with the MCI label distinguishing recipients from dementia yet conversely moving their proximity closer to a diagnosis of dementia. Contemporary focus upon the arrival of modifiable risk factors around dementia moves experiences of memory difficulties which are not dementia into the realms of active ageing policy and practice, with accompanying expectations of appropriate engagement. Throughout my thesis chapters, I have illustrated this complexity with examples of competing concerns and contradictions about how older people with memory problems and MCI should behave. These factors reflect both macro and micro expectations as well as agendas around active ageing policy and practice which I will discuss in this chapter.

6.1.1 Chapter outline

I begin by discussing the common themes present in the different parts of the study, these centre on notions of absence and uncertainty. The sense of absence creates a context in which individuals feel the need to engage and respond, therefore moving into positions of actively ageing with the aim of navigating a trajectory, which excludes dementia. I revisit sociological constructs to consider the concept of active ageing practice through aspects of positioning, responsibility, identity, agency, and distinction.

In previous chapters I have described the diagnostic uncertainty surrounding MCI and memory difficulties which are not dementia. In my scoping review I documented a neglect of subjective experiences. I use the concept of biographic disruption (Bury, 1982), to explore these understandings. Finally, I apply the concept of status transition as an explanatory framework with which to consider my findings in more detail, interweaving the results from my three studies together.

6.1.2 Overview of findings

In drawing together the three elements within my thesis of my scoping review, secondary data analysis and ethnography key themes were identified. The scoping review and secondary data analysis provided an understanding of individuals' subjective experiences of memory difficulties and receiving or having a diagnosis of MCI. Their shared focus highlighted the multi-faceted nature of this experience and societal expectations about age and cognitive decline, along with concepts such as liminality and responsibility. The findings from both the scoping review and secondary data analysis shaped my ethnographic research, incorporating the concepts of responsibility, distinction, and agency as areas of emphasis whilst observations captured an exploration of people's first-hand experiences within the active ageing intervention, APPLE-tree.

The theme of absence ran throughout all three elements. Initially from a literal absence of information and clarity surrounding MCI and diagnosis, identified through the scoping review. To an uncertainty of how to respond and what to do, identified in the secondary data analysis. Finally, this sense of absence was observed during the intervention through participants not knowing how best to engage, and what was 'good enough' engagement in order to avoid dementia, and an existential sense of how to be verbalised through the interviews.

In the following discussion, these key concepts are critically considered through literature and sociological theory is applied to explore and understand the complexities.

6.1.3 Absence as a narrative

The narrative around this research is structured by one of absence, gaps in knowledge, navigation of the potentially unknown meaning of what constitutes 'actively ageing' in the prevention and avoidance of dementia, and / or cognitive decline. Uncertainty as to the effectiveness of active ageing practice interventions, including the belief that it may not prevent dementia along with a sense of an inevitable cognitive decline regulates participants mixed response to an active ageing practice such as APPLE-tree. Gaps and uncertainties in participants' knowledge resonate with a broader sense of absence, for example the absence of consideration for individual's subjective experiences of a diagnosis of MCI. Individuals are unsure how to negotiate this void, what to do next and how to 'be', and search for a way to navigate what is happening to them. My secondary data analysis draws attention to this dilemma. Individuals felt unsure about what their memory difficulties and MCI meant, and what they should do next but welcomed discussions about active ageing interventions.

The contradictory nature of the presence of 'an absence' as a constant, was both literal and experiential for individuals. The literal absence of knowledge and information as people sought understanding about their cognitive impairment, was coupled with existential experiences of absence, around identity, agency, status, and their position as older people with a cognitive impairment. This absence was viewed through the lens of the concept and culture of active ageing as individuals sought to fill this gap through their engagement with a dementia prevention program.

My ethnographic study of the APPLE-tree intervention provided a methodology with which to explore participants' beliefs, behaviours, motivations, and expectations of active ageing as it was practiced in the intervention. The findings of this study identified three interconnecting themes: becoming an 'active ager'; responsibilisation; and positioning. Individuals become 'active agers' by engaging in active ageing practice through an intervention, thus demonstrating their responsibility to age healthily and positioning themselves as being distinct from others at risk of dementia. This approach also indicated the uniqueness of active ageing when applied to cognitive impairment and dementia prevention and highlighted the differences between this and active ageing strategies and interventions for physical health and illnesses.

6.2 Active ageing as a concept and practice: applying theoretical constructs.

6.2.1 Third and fourth age

Despite a documented variability in conversion rate from MCI to dementia, the risk of such a progression instils a 'generalised' fear of dementia which participants referred to as a motivating factor for their participation in the dementia intervention. The idea of the social imaginary of the fourth age, as an ageing without agency represented by feared decline in old age recognises this. Conversely it also illustrates how individuals work to retain their status as participants in the cultural field of the third age, one which is validated by choice and social engagement. Active ageing mediates between these two representations of later life allowing those who choose to participate an active ageing intervention for preventing dementia an opportunity to engage in the cultures of the third age. The fourth age is important as a symbolic terminus of ageing but it is not constructed around the same co-ordinates as those of the third age (Gilleard & Higgs, 2010). Fear of being construed as being defined by the fourth age has been considered 'a new line of fracture' in later life (Libert et al., 2020b). Participants who chose to engage in the APPLE-tree dementia prevention program affirmed their desire to stay within the cultures of the third age, through acquiring a status as 'active agers'. Inevitably most people came to the intervention as existing consumers of healthy lifestyles choices, through diet and exercise choices. An ethnographic study embraces this varied recruitment background, as encapsulating the complexity of the social world within which human agents operate, capturing both phenomenological and hermeneutic interpretations (O'Reilly, 2012).

6.2.2 Distinction

The desirability of active ageing in this context of cognitive health is shaped by individuals needing to position themselves as being distinct from others with MCI and memory difficulties. Active ageing practices which aim to enhance cognitive health and prevent dementia serve to differentiate individuals from others, whilst also allowing for a distancing from dementia. Distinction has been regarded as asserting the boundaries of the third age and keeping the 'feared' form of old age, or in this case dementia, at bay (Gilleard & Higgs, 2010). Libert et al have considered the concept of distinction and applied it to dementia and brain training, which he describes as operating within these tensions between the third and fourth ages (Libert et al., 2020a). Libert et al draws upon Bourdieu's concept of distinction to describe this process of social positioning and argues that as people progress into later life they are continually called to engage with the ideal of active again. This perception of differentiating and being distinct shapes active ageing practice into a virtuous activity, which 'others' those who are not participating. However, this is further complicated when related to cognitive health. Individuals with MCI and memory difficulties are invested in avoiding a path of decline and dementia. The pathway between active ageing practices, such as the APPLE-tree intervention and its relationship to avoiding dementia is not a straightforward one. Findings from my studies supported this, with evidence of individuals wanting to be responsible through displays of accountability exhibited throughout the intervention being common, to affirm their position and identity as ‘active agers’, as opposed to being perceived as ‘passive agers’. Participants within the intervention voiced an absence of certainty, which was apparent in their expressions about knowing what to do, and questions about whether they were doing enough and doing it correctly. This anxiety regarding engaging in health practices correctly has been discussed by Higgs (2012) in his account of Bauman’s contribution to the understanding of the difference between health and fitness in later life. Active ageing practices may create structures, methods, and a route with which to proceed through this uncertainty, which appeared to provide a temporary anchor of stability, but not one that is capable of permanence.

6.2.3 Active citizenship

Living as an active citizen has been described as a post-liminal way of shifting dementia discourse from deficit to discourses of active citizenship (Birt et al., 2017). This shapes the context in which the culture of active ageing has developed and how people with MCI and memory difficulties position themselves. This was apparent as many of the individuals who chose to participate in the active ageing intervention already engaged with health-related behaviour and wanted to extend this by moving into a role as an ‘active ager’. In an active ageing culture this health-related behaviour is not enough, and it is something that needs to be seen and validated by others through active ageing practices, such as the APPLE-tree intervention. In their ‘will’ to maintain cognitive health they affirmed this status through the tasks and activities of the intervention, retaining their position within third age. Responses of participants reflect a desire to age 'successfully' yet measures of that success were difficult to gauge. This may be regarded as a response or desire to avoid the fourth age, associated with decline and dementia. This is considered as a terminal destination rather than as an exact location for older people; only being able to be viewed from the outside, framed as it is through social imaginaries which have their routes in frailty, abjection, loss of the self and the moral imperative to care (Higgs & Gilleard, 2017).

6.2.4 Self-help and "limited but limitless" ageing.

The enabling of self-help has been considered in relation to the positive discourse of healthy ageing in the third age. Higgs et al. (2009) state that health is central to the pursuit of an agentic third-age lifestyle and that the 'will to health' emerges as a powerful discourse in later life. The positive paradigm of active ageing which suggests that older people should want to achieve the fulfilling, limitless promises of the Third Age, has been termed as 'limited and limitless' ageing (Clotworthy, 2020). Clotworthy studied the Danish re-enablement scheme promoting physical health in older people, she found it created a pressure and perception to remain physically fit, socially active, cognitively sharp consumers who take responsibility for their own lives, even when they had limitations caused by their health and disabilities. Clotworthy goes on to state that by articulating this desire and making the 'correct' choices regarding their health, this consumer-citizen becomes positioned as an active subject of the state, and these citizens are expected to behave as such (Clotworthy, 2020). My findings support this, with older people with MCI and memory difficulties regarded by the third age as consumer citizens in an arena of lifestyle choices. APPLE-tree participants were not only consumers of the programme; but also subject to surveillance regarding making the correct lifestyle choices at both a micro level, individually within the intervention, and at a broader macro and societal level.

6.3 It's not dementia yet – diagnostic uncertainty.

6.3.1 Contested terms and subjective experiences.

I have previously documented how the labels ascribed to older adults with memory difficulties such as 'subjective cognitive decline' or 'mild cognitive impairment' reflect an increasing medicalisation of memory difficulties and old age. This is complicated by the precarious position individuals ascribed these labels hold, the questionable status of having MCI or memory difficulties and a subsequent conversion rate to dementia being variable illustrates the contested label of MCI. Individuals' subjective experiences are minimised in favour of diagnosis, prodromal features and later, the influence of modifiable risk factors. These contested terms, within social science and medical literature highlight the somewhat neglected area around individuals' subjective experiences, characterised by a lack of clarity. It has been pointed out that diagnostic labels are powerful entities shaping society and individual subjectivities, therefore justifying having concern about what they are and with what they do (Pickersgill, 2014).

6.3.2 Liminal space

Fundamental to the experience of MCI and memory difficulties is uncertainty, with gaps in the knowledge available of what these labels or terms mean to the individuals ascribed them. This gap in 'knowing' reflects the sense of absence inherent throughout all parts of my PhD study, which is evident in the form of liminality. The concept of a liminal space in relation to memory difficulties and MCI which is not dementia has been well documented in the literature, with authors such as (Birt et al., 2017; Swallow, 2020), drawing attention to this predicament of the 'betwixt and between' status of mild cognitive impairment (Farwell, 1976). Despite a diagnosis of MCI placing older people with memory difficulties into a medicalised position, this is not clearly defined. MCI has been regarded as providing a convenient space in which individuals come to terms with the strong possibility of approaching dementia, while making allowances for the inevitable uncertainties involved, including the fact that some people diagnosed will not progress to dementia (Lock, 2013). The ambiguity surrounding this location in part creates the experience and conception of it as a liminal space, induced by a lack of 'knowing' how and what to be, and reinforced by its apparent role as a diagnostic 'place holder' within the medical arena.

6.3.3 Movement towards dementia

Importantly, as the term liminality suggests, this is not a static position. As referred to in chapter 3, the concept of 'pervasive liminality' considers how individual experiences overlap and fluctuate over time, rather than in-between experiences associated with a liminal space (Bruce et al., 2014). This may better capture APPLE-tree participants' experiences and their desire for movement and change.

It has been argued that the MCI diagnosis shifts individuals toward a social and experiential pathway towards Alzheimer's (Rose, 2006). More recently it has been pointed out that the acceptance of memory difficulties and MCI as a pre-dementia phase means that it has become part of a continuum, or what may be regarded as a spectrum disorder (Beard & Neary, 2013). However, this idea of a spectrum disorder does not hold with my findings which indicate that this phase is more characteristic of a non-linear trajectory. This has been exacerbated by the disproportionate focus on dementia in society and by the media, specifically on Alzheimer's and has resulted in what has been described as an 'Alzheimerisation of ageing' (Adelman,1995). However, concern about the limitations in applying this concept to MCI and the implications of this exist. Gomersall argues that by doing so it fails to recognise the social psychosocial and occupational needs of people with MCI and SCD (Gomersall et al., 2017). The impact of this is evidenced throughout my scoping review and the secondary data analysis, both revealed an emotional complexity apparent in receiving and seeking out a diagnosis of MCI and the inevitable uncertainties of those who don't. The juxtaposition of not having dementia but being at risk of developing it looms over people. Individuals work to navigate being in-between these states. I refer to this as a 'living experience', rather than the more commonly regarded term, 'lived experience', with 'living' capturing the sense of movement evident throughout my findings.

6.4 Not knowing what to do: biographical disruption and the impact of MCI.

6.4.1 Chronic illness and MCI: applying biographical disruption theory.

Biographical disruption theory describes chronic illness as a fundamental rupture of everyday life, resulting in disruption of future narratives people use to understand themselves and their trajectories (Bury, 1982). I found that people's subjective experiences of memory difficulties, being diagnosed with MCI, or not, disrupted personal relationships, self-concept and compromised their sense of identity and agency. All these aspects are addressed by Burys' concept of biographical disruption, which draws attention to the more subjective experiences of people through their understanding of personal narratives of illness. This concept helps to draw attention to the disruptive nature and impact of MCI and memory difficulties on individuals ascribed with these labels, highlighting their subjective experiences. The question as to whether MCI and memory difficulties may be regarded as a chronic illness is debatable and indicates the continued lack of clarity and confusion around the MCI diagnosis. Research found that a diagnosis of MCI did result in the belief that it was a chronic condition, despite people with MCI and health care professionals being uncertain as to symptoms and progression (Harnett & Jönson, 2017). Harnett and Jonson found that this 'perception of chronicity was related to believing one has little personal control over the illness, worse consequences, and greater emotional distress'. This finding would affect how people approach an active ageing practice, and in particular their engagement in a dementia prevention intervention, such as the APPLE-tree, which requires a belief in control and in positive outcomes.

Regarded as inconsistent with age and a prodromal feature of dementia means that MCI could fall under the category of a chronic illness. However, the liminality surrounding this label, identified in previous chapters, may minimise consideration of potential disturbance, due to the 'in-between-ness' associated with this term and therefore the comparability with a chronic illness is less apparent. Both my scoping review and secondary data analysis provide evidence of the disturbance to individual perceptions of their normal ageing, coupled with the uncertainties associated with their trajectories. Supported and evidenced through my ethnographic study, participant's engaging with the active ageing intervention recounted examples of interruption's that memory difficulties have on their daily lives, including emotional disruption.

6.4.2 Limitations of biographical disruption as a critical context

Applying the concept of biographical disruption has allowed me to discover aspects of my research which challenge some of the formulations of biographical disruption in relation to memory difficulties and MCI. Firstly, the sense of absence and its complication of knowing what to do, this condition is not characteristic of a chronic illness trajectory or biographical narrative. It requires that individuals must reconfigure personal narratives and navigate uncertain trajectories. However, with no definable 'disease state' the liminal position of having memory difficulties, MCI, but not dementia, [yet] makes navigating this challenging. Secondly, less attention has been given to understanding the impact of age and ageing within biographical disruption and criticism levied at Burys work is applicable when considering older people with memory difficulties and MCI. Williams and others have pointed out that older people may not experience distinct ruptures in their identity as they already anticipate increasing physical limitations, and take this into account when considering the trajectory of their lives, (Cluley et al., 2021; Engman, 2019; S. Williams, 2000). This expectation was apparent in my studies, with an anticipation that memory difficulties were part of old age. Within the social arena these experiences were normalised as forgetfulness and seen as part of ageing, this contrasted with the medical arena which defined this differently. Here memory difficulties were considered within a pre-dementia phase, with MCI being a prodromal feature of dementia. Thirdly, biographical disruption is limited in its ability to explain the more nuanced complexity of these experiences, which I have evidenced throughout my findings. (Williams et al., 2012).

6.4.3 Embodiment, frailty, and MCI

Engman (2019) broadens the concept of biographical disruption to consider embodiment, arguing that 'biographical disruption is a result of the ways illness impinges on physical ability to engage with everyday life' (Engman, 2019). When conceptualising MCI and memory difficulties within this version of biographical disruption, unlike other chronic conditions which may have a visible physicality, importantly MCI does not. The embodied nature of this experience is a cognitive one, but with both an internal and external impact to the individual.

More recently biographical disruption has been applied to frailty, this extension of the concept allows parallels to be drawn with the experiences of memory difficulties and MCI. Frailty and MCI are not regarded as a disease, but both have social and clinical implications. Cluley regards frailty as being more disruptive than chronic conditions whose effects are narrower and more readily contained within a diagnosis (Cluley et al., 2021). Equally, this is the same for memory difficulties and MCI, where a sense of 'subjective disruption' is more apparent and wide ranging. Yet at the same time this disruption is difficult to anticipate and articulate, with the MCI label being disregarded by many. Both include a juxtaposition of having something undesirable, yet also anticipated with ageing and old age. Biographical disruption draws attention to the ‘static’ stages of frailty assessment including its physicality, neither of which are duplicated in MCI and memory difficulties. The label of ‘frail’ has been linked to moral weakness and in an era of ‘healthy ageing’ messages designed to counter prevailing ageism, frailty may represent a personal failure (Mudge & Hubbard, 2018). Examples of the attribution of personal failure were present within my findings with participants describing activities and tasks which they felt they had been unable to engage as expected, evident by Marjorie’s comment, “I’m very lazy and activity diaries don’t like lazy people”. The moral status of frailty is in contrast to Tom Kitwood's (2007) concept of personhood in dementia, which positions it as a ‘bestowed status based upon shared relational exchanges’ and which is changed but not lost in people with dementia (Chapman et al., 2022). However, both concepts of frailty and personhood have been accused of de-contextualising understandings from the broader social, relational, and situational nature of these experiences. The unpredictability of MCI and memory difficulties sets it apart from frailty and a chronic illness trajectory.

6.4.4 From biographical disruption to status transition

Both my scoping review and secondary data analysis highlighted an absence of clarity, knowledge and understanding when older people are ascribed a diagnostic label of MCI. Individuals do not reside in a context devoid of agency and are positioned through a diagnosis of MCI as being at increased risk of developing dementia. They are left in what Birt describes as a post-liminal state, as people then reposition themselves through agentic actions (Birt et al., 2017). In this apparent absence or void individuals look to navigate and anchor themselves into a trajectory which is not available to them. Active ageing practice around dementia prevention offers up that possibility for change, filling the experienced void. This is based upon a sense of movement and a desire for understanding yet restricted by a lack of clarity.

The resonance of the concept of biographical disruption to MCI and memory difficulties only applies so far. The limitations, outlined previously, include the lack of consideration of temporal factors through the unpredictability of its trajectory, how older people may normalise disruption of memory difficulties within later life, and the lack of nuanced detail which neglects subjective experiences of memory loss. Status transition provides an alternative to biographical disruption, providing an opportunity to consider the transition and movement inherent within the experience of having MCI and memory difficulties, whilst engaging within active ageing. In the next section I will discuss this concept and relate it to my findings and the broad areas of MCI, memory difficulties and active ageing practice.

The theoretical concept of status transition helps to capture the sense of movement I found to be fundamental to individual's experiences of MCI and memory difficulties within active ageing. Glaser & Strauss (1971) formalised a theory of status passage as part of a universal phenomenon of passage through social statuses. Passages entail movement into different parts of a social structure, such as moving from being single to married or moving from childhood to adolescence to adulthood. Status transition suggests that individuals move from different stages or passages throughout their life course (Tolhurst & Kingston, 2013). In its application to long-term conditions, status transition has provided different dimensions through which to consider dementia. Tolhurst and Kingston have applied it to dementia and found that as status transition conceptualises experiences as a passage, it offers greater conceptual breadth than biographical disruption, which takes its disruptive elements as a focal point (Tolhurst & Kingston, 2013). Similarly, to dementia, MCI is not a static construct, and it is difficult to identify a focal point of disruption. However, unlike dementia, which is a long-term cognitive condition, for individuals with MCI their status is uncertain and may vary considerably.

I applied dimensions from status transition to frame an understanding of how people with memory difficulties and MCI navigate this precarious trajectory, including their arrival into active ageing practice. I consider dimensions from status transition as a way to consider the interconnected stages or 'status passages' of individual experiences. These include 'temporal' and 'reversibility' dimensions, 'desirability', 'shaping' and the 'multiple' passages or stages people adopt and move through (Glaser & Strauss, 2011). This sense of movement and navigation is captured in the following examples from participants, Trevor said of the sessions, "*I'm just trying to figure out what it is they are trying to get at, and you know what we're trying to do here".* When asked about her participation in the intervention Gina said that *"I'm hoping I can sort of push things off into the distance"* and Philippa said of the whole APPLE-tree intervention *"I want to renew life".* In the following sections I combine dimensions from the status transition approach with my findings, allowing me to illustrate the movement and the navigation inherent within individual's experience.

6.4.5 Temporal dimension

Unlike biographical disruption, in status transition the temporal dimension as a stage or passage is significant. Status transition offers a temporal framing of a passage and is regarded as conceptually attentive of an inter-relation of factors linked to age (Tolhurst & Kingston, 2013). Interrelated factors for people with MCI experiences and memory difficulties include age and ageing, cognitive health, stigma, fear of dementia and the potential that active ageing practices offer. A temporal dimension highlights these unique aspects as passages, with individuals experiencing these at different times, but which also overlap and interconnect. It includes examples where memory difficulties were either overtly medicalised and regarded as problematic or conversely, trivialised and normalised as part of ageing. In an example from the secondary data analysis a man who has seen a GP about his memory difficulties recounts how this was normalised and dismissed, "*he said you haven't got a problem. It's an age-related thing, nothing medical. I don't think it was taken that seriously. I don't think he saw it as a problem. I saw it as a problem, but I don't think he did".* This example disregards both a temporal aspect of memory changes and his subjective experiences of this change.

6.4.6 Shaping dimension

The dimension of shaping from status transition refers to the external and internal conflicts individuals responded to, characterised by a constant perception of navigation and change (Glaser & Strauss, 1971). It draws attention to roles and responsibilities within active ageing practice, of who is in control, and of what. In the absence of a clear trajectory surrounding MCI and memory difficulties the concept of active ageing practice offered the potential for individuals to clarify and affirm their roles and responsibilities, through an active ageing intervention. I found that individuals moved through a variety of roles which were both comforting and contradictory. Adopting an 'active ager' role saw individuals positively engage with the health information and activities in the intervention APPLE-tree, providing a purpose which was both comforting and encouraging. As one participant said: "*the programme has eased my mind quite a bit*". However contrary to that reassurance there were examples where engagement with the intervention content as unsettling, potentially raising more uncertainties for individuals, exemplified in this quotation, "*I thought I was doing good but now I know I'm not so good"*, expressed after completion of a nutrition questionnaire during the session.

MCI and memory difficulties distinguish individuals from having dementia whilst simultaneously being at risk of developing dementia, reflecting the dimension of desirability. Status transition includes the idea of desirable or undesirable 'passages'. Having MCI and memory difficulties can be desirable, as the status of having MCI offers a relief at not having dementia but is undesirable as it indicates an increased risk of getting dementia. All my studies hold examples of this paradox; however this is not dichotomous. Individuals with MCI and memory difficulties are relieved not to have dementia yet are aware of the transient nature of this status or passage. An example from the secondary data analysis illustrates this: "*Where I was always thinking, what is wrong with me, and then this is very mild compared to what I could be looking at in ten years"*, for this individual desirability is conditional on a temporal aspect. This reflects the tenuous nature of this status, captured through the following statement from the scoping review: *“I have to resign myself to it*, *I have to convince myself that they couldn’t find anything and accept that it’s not dementia I’m suffering from”,* demonstrating this as being both desirable and undesirable simultaneously.

Moving into a role of participation and becoming an ‘active ager’ is complicated by multiple external and internal factors. Roles are assigned and adopted as individuals position themselves into active stages or ‘passages’ as they engage with and move through an active ageing intervention. Participation is characterised by both hope and uncertainty of whether you are ‘doing enough’ through the intervention. I found that conceptualising this as positions rather than roles provides a more accurate understanding of how people situated themselves within the active ageing practice.

Positions are theorised to be variable, multiple and shifting and may well be contradictory (Jones, 2006). Jones points out that positioning theory offers a more dynamic and flexible idea of ‘role’ and importantly positioning occurs as part of an ongoing process of interaction with others (Jones, 2006). This was evident from my ethnographic study and findings in how people engaged with active ageing practice through positioning themselves as ‘active agers’. Applying the concept of status transition exemplifies the movement inherent in this process and is indicative of active ageing as a culture.

6.4.7 Collective dimensions: aggregate, sole, and collective

The dimensions of ‘collective’, ‘aggregate’ and ‘sole’ provide insight into the interconnecting ways individuals participate in active ageing practice through the multiple ‘status passages’ which operate. Participants moved into the intervention as individuals with their own narrative of memory difficulties yet were part of a collective experience of cognitive health. The collective sense of the group cohesion within active ageing practice was summed up by a participant in APPLE-tree as, *“we are all in this together”.* This demonstrates the shared sense of purpose which was frequently referred to by participants. The phrase *‘all in this’* raises the question of what ‘this is’ and may be regarded as an existential expression of group experiences of active ageing practice. This experience includes the ‘correct’ undertaking of the intervention session activities and tasks, it also captures the inherent sense of uncertainty and absence of clarity.

Individuals move to interact and engage in relationships within the requirements of the intervention, whilst influenced by the groups in which they situate. Simultaneously there is a sense of individual responsibility which active ageing practice instils in participants. Individuals negotiate with others as they position themselves as ‘active agers’ and navigate a narrative which is distinct from passive ageing but in which developing dementia is a constant concern, characterised by uncertainty. The individualisation apparent represents a sense of the autonomous self and as previously outlined in chapter one, reflects a broader societal move from notions of collective to individual responsibility around one’s health. The notion of ‘will to health’ ascribes a discourse in later life which reflects a distinction between natural and normal ageing (Higgs et al., 2009). The dimension of shaping highlights this as a transient stage, capturing a context of shifting concerns around individuals increased or decreased dementia risk, inherent within active ageing practices for cognitive health.

6.4.8 ‘Open and ‘Closed’ awareness dimensions.

The dimensions of ‘open’ and ‘closed awareness’ contexts highlight the interaction of stages or passages which have internal and external factors, (Glaser & Strauss, 1971). These are shaped and influenced by individual experiences of MCI, memory difficulties and active ageing practice. This is reflected throughout my scoping review and secondary data analysis through individual’s self-awareness and the impact of other people. The APPLE-tree intervention fostered an open context of awareness through information, tasks, and activities, which reflects the ethos of active ageing practice. Examples from the findings illustrated participants increased awareness of their own memory difficulties either through each sessions informational content or being unable to remember tasks, goals, and activities. This served to remind individuals why they were there in a dementia prevention intervention, and affirmed to them that their participation was necessary and appropriate. Importantly Tolhurst and Kingston makes the point that an open context of awareness does not always mean an enhanced experience (Tolhurst & Kingston, 2013). Raising awareness through open discussion of one’s cognitive ability, health and dementia risk is fundamental to dementia prevention programmes, I found this proved to be both empowering and unsettling for individuals.

This reflects the moral imperative attached to becoming an ‘active ager’. Becoming an active ager dictates that individuals accept responsibility for their cognitive health and are obliged to engage ‘successfully’ with a dementia prevention intervention. However, the clarity over what this involves, how it manifests and what you do to achieve this is less apparent. I identified examples of feelings of responsibility which were simultaneously interconnected with individuals moving themselves into a position of ‘active agers’ as they navigated a trajectory of not only ‘doing’ dementia prevention through active ageing practice but being seen to do so within a group. This moral imperative was evident in active ageing and enacted though participation in the APPLE-tree intervention, with examples of obligation and a responsibility to follow the rules of engagement. Active ageing’s ’purveyance of a moral message’ as Tanner (2016) puts it, describes how older people should behave, highlighting responsibility, but neglects social and economic influences, marginalising those who cannot aspire to age well (Tanner, 2016). This was evident through the ethnographic study which highlighted how expectations of dietary and nutritional changes were outside some individuals comfort zone, for example, guidance towards eating avocados was un-relatable and intangible for some participants. This touches upon the cultural and social class differences between the two groups studied, and the different geographical and social locations between them. Simple inferences to post-working lifestyles and consumption in relation class identities are contested in older age (Jones & Higgs, 2013), thus adding to the complexity surrounding understanding the position of ‘active ager.’

Active ageing practice applied to cognitive impairment sits in contrast to physical health and illness, where there is a clearer and more transparent trajectory of actions to achieve a recognisable state of health and wellbeing. Additionally physical health is not subject to the same stigma surrounding cognitive health and impairment, illustrated through the findings from my ethnographic study in two ways. Firstly, there was a general fear of dementia, which although often unintentionally expressed through the intervention, was evident and cited as a motivator to participate. Secondly, individuals were reluctant to voice experiences of their own memory difficulties and MCI within the intervention. However, this was revealed to me during the interviews, and may therefore reflect the societal stigma around openly discussing memory loss and cognitive impairment, ironically the very thing people were there to address within the sessions. The awareness dimension encapsulates these different levels of awareness and open and closed contexts. ‘Closed’ awareness contexts included examples of how stigma and feelings of self-consciousness associated with cognitive health, resulted in signs of memory difficulties being hidden, concealed, or denied. Individuals engaging in active ageing practice through an intervention, positioned themselves through self-awareness of where they were in relation to other participants within the intervention. This comparison or ’othering’ with individuals is a fundamental part of active ageing both internally as a practice and externally as a concept or culture.

6.5 Implications for policy, practice, education and research

Active ageing policies which target ‘at risk’ individuals who have MCI or memory difficulties, which are not dementia, need to recognise that this is characterised by a number of interchangeable definitions of cognitive impairment. These varying descriptions of cognitive decline which people can associate themselves with somewhat inhibits the notion of identifying people ‘at risk’ of developing dementia, fundamental to any effective active ageing policy. The dilemma between individual and collective active ageing policy needs to be considered more fully during active ageing policy development. This includes how notions of individual responsibility and expectation placed upon older people, evident from my research, work with, or are in contrast to a focus in public health policy upon desired collective outcomes.

In the absence of treatment options for dementia, policy and practice has focused upon active ageing prevention programmes as intervention models for dementia. Consequently this may result in a medicalisation of intervention programmes in active ageing practice. This may subsequently fail to recognise the importance of the subjective experiences of individual participants in any prevention programme. Understanding the different ways participants engage within an active ageing practice are vital in order to be meaningful to individuals' lives. This includes careful planning around the programmes measures of success and what this means to each individual participation. Active ageing practice needs to consider prevention in a broader sense and its relationship to intervention.

Training and recognising the difference and similarities between dementia intervention and dementia prevention and where possible treatment models fit within this is essential when developing both active ageing policy and practice. Educate staff who deliver active ageing interventions to recognise the difficulties people face in agency, due to the external societal expectations placed upon them regarding active aging and cognition. Additionally, being aware of additional constraints due to social-economics, gender, ethnicity and culture, these are all areas which deserve further research.

6.6 Limitations

My PhD was embedded within the APPLE-tree research programme which resulted in dilemmas and potential limitations which emerged from being part of a large, existing research study. For example, as a result of being funded from within the APPLE-tree study, the power I had to fully critique how the operations and experiences for those engaged with the intervention, may have been compromised. Inevitably my role was layered with levels of authority within this context which meant that striking a balance between not criticising the intervention but critiquing it was a genuine dilemma which I had to struggle with and reflect upon through supervision and my reflexive diary.

The APPLE-tree study included a process evaluation of the intervention. Initially there was some blurring over expectations of role between this and my study which was resolved through my decision to adopt an ethnographic approach to the intervention and locating my PhD within a social science perspective. I was therefore able to maintain impartiality from the main study and data collection. However, inevitably there were times when independence from the impact of being within a large study was a limitation. For example, although I was able to use APPLE-tree ethics approval and get my study approved through an ethics amendment. This did mean being restricted to their timeline and consent approval, so any option to re-interview participants was not feasible.

6.5.1 COVID-19

My thesis was inevitably affected and shaped by the covid-19 pandemic. The first UK national lockdown was announced on 23rd of March 2020 and extended by 3 weeks in April 2020, but from the 10th of May 2020 there was an easing of some restrictions, coinciding with the summer period. As a result of these restrictions the APPLE-tree intervention was delayed by 3 months from April 2020 until July 2020, during this time delivery was adapted from in-person sessions and moved to online sessions. The third national lockdown commenced on the 6th of January 2021 and was one of the most restrictive with all sectors of public life, not fully reopening until the 19th of July 2021. Both of the APPLE-tree programmes I studied were delivered during this third lockdown.

My methods were affected by covid-19 as the intervention had to move online which required a rethinking of adopting an ethnographic approach and limited the extent to which I could immerse myself within a traditional ethnography with its roots in anthropology. However, my decision to adopt focused ethnography was a strength as it provided emphasis with which to approach the complexities of active ageing practice, as well as being particularly suitable for online study. Undertaking ethnographic observations online required some thought, including the dilemma around my role as a researcher and an assistant within the intervention, which I have documented in my methods chapter. The practicalities of field work through participant observation online were challenging. Observing and writing field notes needed to be re-considered, with unforeseen issues such as ensuring eye contact with participants during the zoom sessions whilst simultaneously making notes.

The intention and aims of some of the content of the active ageing intervention, APPLE-tree was compromised due to the third national lockdown.

Activities based upon modifiable risk factors, such as increasing exercise and activity were very difficult to complete. The intervention content was adjusted to provide activities which were achievable to participants in lockdown, however this was a challenge and limited to participants watching NHS exercise clips for future reference. Therefore, my observations were also limited to watching participants watching videos.

Motivations to participate within the intervention may have been affected by the lockdowns, for those who lived alone the sessions became their only source of contact during the lockdown restrictions. Conversely families were expected to stay at home, resulting in a number of people being in the house during the participant's online sessions. I have noted the potential ethical concerns which arose from this around confidentiality and privacy which I had not anticipated and have considered in my methods chapter.

A societal sense of fear during the most severe lockdown restrictions in the UK was not uncommon. Within the field notes and interview data participant's perceptions about their memory loss and their fear of developing dementia included expressions of a sense of foreboding in response to the uncertainties surrounding the existence of covid-19. It is difficult to separate these concerns and fears from each other, with the impact possibly shaping participants motivation and engagement within the intervention, and I reflected upon this through my reflexive journal.

6.7 Summary

Ideas of agency generally centre around being active in old age. Tom Kitwood argued that the “malignant social psychology” of the framing of dementia leads to a loss of selfhood for the person with dementia through interactions among those surrounding them. In other words, the experience of dementia is in large part shaped by the expectations and behaviour of others (Dewing, 2008). However cognitive impairment, MCI and memory difficulties are subject to ideas of agency which focus upon the methods older individuals adopt to delay growing old and address the decline ‘ideology’ linked to age (Romaioli & Contarello, 2019). This paradox is evident in the concept and culture of active ageing, reflecting notions of ‘successful’ and ‘healthy’ ageing, and their subsequent pressures. Older people with memory difficulties and MCI are subject to these stresses, but also need to negotiate a broader paradox. The normalisation of memory decline within the intervention and age minimises individual’s subjective experiences of cognitive health whilst conversely a neuro-culture medical model conceives MCI and SCD as prodromal. Neuro-culture reflects the increasing prominence of a relationship between science, ageing and treatment and enhancement in old age which regards memory decline as problematic (Williams et al., 2012). Individuals responded to the external and internal sense of responsibility through positioning themselves as ‘active agers’, exemplified through the active ageing intervention under study. Rather than being stationary within a liminal space, direction was provided by a dementia prevention intervention, providing a post-liminal context. Active ageing addresses the presence of absence inherent within this experience. The concept of biographical disruption draws attention to this complexity, whilst status transition provides an explanatory framework which captures the movement and shifting entities inherent in this experience.

Active ageing practices provide a way of ‘being,’ in an otherwise empty space. The efficacy of active ageing interventions for dementia prevention is contentious and is not considered here. However, with the potential of a trajectory to follow, active ageing practices create opportunities to reaffirm identity and agency through a shared experience, which provides hope and meaning to individuals without dementia. To this extent it fills a gap or absence providing a tangibility to an intangible experience and providing positives as opposed to deficits. The difficulty lies in what happens when people cannot achieve the required health changes and or their memory changes, and declines. How do they proceed with and incorporate active ageing practices into their life, staying within the realms of an agentic and consumer third age, and what happens when they don’t. In the next chapter I conclude my findings and consider these in relation to active ageing policy and implications, future direction, and the culture of Active Ageing.

Chapter 7 Conclusion

In this thesis I explored how active ageing policy and practice reconfigure the experience of cognitive impairment. I used the dementia prevention programme APPLE-tree as a portal through which to consider how people situate themselves in such an intervention and how participation in this programme then translates into practices of active ageing focused on cognitive health.

7.1 Summary of my thesis

Historically the terms healthy, active, and successful ageing have often been used interchangeably to refer to practices which promote a more engaged and less illness defined later life. This has connected with discourses of empowerment in health care where individuals are encouraged to manage their own physical and mental health as a personal responsibility. Much has been written about how this reflects the shift from ideas of a state orientated collective responsibility for health to a generalised expectation of citizens having increased individual responsibilities for their health and well-being. In relation to ageing and old age this individualisation includes the juxtaposition of a normalisation of physical co-morbidities and cognitive health but at the same time, the problematising of cognitive decline. Definitions of old age have centred on physical health and associated co-morbidities. Normalisation of memory difficulties in older age and perceptions of inevitable decline have been replaced by expectations of avoidance and the maintenance of cognitive function. This carries with it a moral imperative to actively engage with prevention interventions which is articulated and reinforced by cultural and social expectations of 'successful' ageing objectives.

Cognitive impairment which is not dementia has been defined through terms such as, subjective cognitive decline, early-stage dementia, prodromal and MCI. This range of definitions demonstrates the lack of clarity surrounding the condition and captures the generic sense of uncertainty attached to this experience. This means that individuals choosing to engage with a dementia prevention programme may associate themselves with all or with none of these definitions. Inevitably this lack of a clarity inhibits the identification of individuals 'at risk' of developing dementia by the health care system. This has ramifications for planning active ageing policy and practice. Individual motivations to engage will be influenced by the label that individuals most readily identify with, yet, as I have previously noted, there is a general absence of consideration of subjective experiences in active ageing. This is part of what could be seen as the generic absence of knowing and understanding what is happening in this arena; something which translates into practice around what to do and how to do it.

The increasing acceptance of MCI as a prodromal risk factor in dementia has increased the importance of identifying modifiable risk factors. It is generally assumed that if these can be pursued at the population level, they may create potential for improved cognitive function and a reduced risk of developing dementia for larger numbers of people who would have gone on to develop different forms of age-associated cognitive deficits. At a social and cultural level this has led to an emphasis for people with memory difficulties and MCI to act and actively do something to avoid dementia. This ‘activation’ is, however, set against a context where the diagnostic nature of MCI is contested, where there is a general lack of a clear clinical disease trajectory, and where the knowledge base available to individuals is patchy and sometimes inconclusive. This has the overall effect of creating a sense of uncertainty and ‘absence’ for individuals caught up in this situation. For many, active ageing practices provide a potential way of dealing with this sense of uncertainty and help navigate this sense of absence.

7.1.1 Active ageing practice through dementia prevention

Researchers in recent years have made major advances in blood tests so that they can predict a person’s risk of developing dementia more than a decade before the condition is formally diagnosed using other techniques. When combined with more conventional risk factors such as age, sex, education, genetic susceptibility and protein profiles, researchers now claim to be able to predict dementia with an estimated 90% accuracy nearly 15 years before people received clinical confirmation of the disease (Naddaf, 2024).

The implications of this have been widely welcomed throughout the scientific community and by health care professionals as providing opportunities for intervention given the emergence of potential treatments. This points to a tension between the discourses of prevention and intervention which are both prominent within the scientific and medical dementia landscape. Prevention as an intervention focuses on the long-term objective of avoiding the need for treatment, however media attention often equates intervention with treatment.

Consequently, the arrival of drugs such as Lecanembab to ‘treat’ symptoms of dementia, has increased optimism and this has extended into mainstream society through media exposure. This is despite concern surrounding side effects and the highly medicalised route of delivery to patients and questions have been raised surrounding the low numbers in the trials and the extent of actual cognitive improvement on testing. Additionally social scientists have pointed to the economic cost to the NHS if Lecanembab is approved for use in the UK (Burke et al., 2023). Preventative dementia measures are considered to be a feasible way to reduce the ‘burden of predicted increasing costs of dementia’ (Braun et al., 2024). With the limitations highlighted from drugs such as Lecanembab, active ageing practices such as dementia prevention interventions are filling the gap in the absence of any effective treatment for dementia.

Noticeably absent in these discussions is any recognition of the subjective experiences of a diagnosis of MCI upon individuals affected by memory difficulties, which are not dementia. As I identified in the scoping review and the secondary data analysis in chapters 2 and 3, these experiences are characterised by a lack of clarity and uncertainty, producing a liminal space for them to inhabit. This sense of liminality is not a static one and I have identified how individuals move and transition from a status of someone with a diagnosis of MCI and memory difficulties, to becoming part of an ‘at risk group’ and a prodromal category of dementia. Once identified as such, this subsequently fosters an impetus to act to reduce identified or ‘modifiable’ risks. Individuals are allocated this status by the medical and scientific community and within a growing culture of active ageing policy focused upon cognitive health, and with this, an inherent expectation to adopt active ageing practices, such as the APPLE-tree intervention. Research has highlighted the benefit of multi–domain prevention interventions such as the APPLE-tree programme, which address a number of the modifiable risk factors identified by the Lancet report, as opposed to a single domain prevention addressing one factor, such as nutrition. In a recent systematic review two thirds of studies using multi-domain lifestyle interventions reported improvements in cognitive function, however researchers have stressed the importance of longer term follow up (Castro et al., 2023).

An ‘at risk’ status is not a (formal) diagnosis, yet increasingly it is reducing people to a set of clinical features, cognitive symptoms and/or scores, separating people who are ‘at risk’ from those who are not. The likely implication being that this identification will gradually broaden out to a wider section of older people in society and produce a new understanding around older people’s levels of health and personal responsibility regarding cognitive health. This may lead to the production of anxieties at an individual level reshaping the co-ordinates of old age, memory loss and forgetfulness, and ultimately contributing to an increasing responsibilisation of old age. For many individuals not only are the actions associated with this responsibility for cognitive health unrealistic and hard to achieve, but they are also unclear. The blurring between population based and individualistic responsibility, means navigating a path through active ageing practices which simultaneously involves negotiating an absence of direction and expectation.

Contemporary media reports have highlighted research which often pushes an agenda that the earlier point that health and lifestyle modifications occur the better the outcome. The prime time is assumed to be mid-life where the risk of dementia can be decreased the most (Livingston et al., 2020). Such research was disconcerting for older participants in the APPLE-tree study as it inevitably drew attention to the tenuous temporal nature of their own situation. This created an added urgency and a responsibility to engage in active ageing practice effectively so as to be able to be able to position themselves as active agers before it's too late. A frequently referred to absence of clarity about what to do, and the subsequent engagement with the APPLE-tree intervention was voiced by participants, with quotations such as, 'doing something is better than doing nothing'.

Using the concept of an 'event horizon' as a representation of issues at a meeting point of the social imaginary of the fourth age with its associated narrative of cognitive decline. It was apparent that individuals exhibited a sense of fear of what lay beyond, which was openly voiced or alluded to by the participants in APPLE-tree. This helps to explain participants' willingness to take part in something they didn't always understand or which they didn't always know how to engage with. The following section describes key features of that engagement.

7.1.2 Active ageing practice in the APPLE-tree dementia prevention programme: 'being an active ager'.

Understanding the notion of 'at risk' for people with memory difficulties and MCI, has illustrated how active ageing practices applied to cognitive health and dementia risks are different to those applied to physical health, highlighting a unique complexity which needs consideration. One of my key observations was participating in the APPLE-tree programme involved becoming an ‘active ager’. This captured the sense of ‘doing’ and ‘being’ part of something, through inhabiting an identifiable role, positioning oneself as an ‘active ager’. This role is conferred upon those on entry and participation into the APPLE-tree intervention and was accompanied by broad expectations. These not only revolved around participants undertaking the tasks and activities of the sessions, but also involved wider societal expectations once individuals were designated an ‘at risk status’ of developing dementia through an MCI label. Having MCI and memory difficulties attests to not having dementia yet at the same time moves individuals into an ‘at risk’ status of developing dementia. The opportunity to respond to an ascribed ‘at risk status’ by participating in an active ageing intervention for dementia, addresses the liminality associated with this experience by creating a potential direction or trajectory of cognitive health.

Positioning oneself as an ‘active ager’ revealed how individuals engaged with active ageing and create a sense of role and location within an intervention for dementia prevention. The role encompassed more than participation but captures their affirmation of identity and status, which may be compromised through memory difficulties and MCI diagnosis. Participants also shared and drew upon their own biographies as ways of reaffirming their position beyond that of just an ‘active ager,’ in order to retain their identity. This was a way of grounding themselves and creating a stability within an unstable situation. Although circumstantial, the delivery of the intervention online drew attention to the instability surrounding MCI and memory difficulties which was mirrored through the Zoom online platform.

Active ageing practice separated participants from those ‘others’ who may be regarded as ‘at risk’ but are not participating in an intervention for dementia prevention. These examples of distinction and distance characterised how people were motivated and engaged in active ageing interventions such as APPLE-tree. Being active in an active ageing practice meant engaging in an intervention such as APPLE-tree, and works to distinguish participants from being passive, which was not desirable. Once in the intervention there was an expectation to be and stay active and be able to demonstrate this through the carrying out of tasks and self-monitoring activities, examples included the activity diary and the filling out of nutritional questionnaires. Progress and achievements were shared within the groups, with examples described within my findings of participants apologising or chastising themselves for not achieving set goal or targets. This illustrated the importance participants attached to engaging in ways which they considered ‘correct’ within the intervention. In this way they adhere to the moral imperative of personal responsibility in maintaining their own cognitive health in old age. An alternative to this narrative, involves individuals with MCI and memory difficulties, outside the intervention group, being unable or unwilling to navigate the landscape of active ageing practice and therefore being viewed by society as disregarding identified modifiable risks. Measures of success in this process were difficult for individuals to ascertain and are unclear and generally unknown. Numerous contributing external factors such as cultural, socio-economic and gender issues affect engagement are not fully acknowledged in active ageing practice. This creates a tension in cognitive health in old age between those people who are ‘modifying’ their risk factors through active ageing interventions, such as APPLE-tree, and those who are seemingly not ‘engaged’. Consequently, examples of those choosing to opt out of specific tasks and activities within the intervention were present within my data, showing the distinction between active and passive forms of active ageing, where choosing to do nothing is considered not active ageing.

The collective nature of the intervention was cited by many participants as being key to their involvement and commitment to the programme. Sharing the awareness of absence of ‘not knowing’ was invaluable, not only as a mutual experience but as an opportunity for individuals to position and place themselves in relation to others, creating a sense of all being in it together. However, this sometimes-created further uncertainty as people compared themselves with others and it made them more aware of the ‘unknowns’ in their own cognitive health journey. The tasks within the intervention became secondary to this shared comparison experience, and there appears to be a contradiction of the positivity of a being part of a group alongside the pressure of comparison with others, including the sense of competition that this could evoke. The majority of dementia prevention interventions and active ageing practices are based upon group activities, but personal orientations are not always considered. These orientations centre around the individual responsibilities placed upon the participant as an ‘active ager’, while at the same time being expected to contribute to a collective group experience of active ageing practice. Achievement of tasks within the APPLE-tree intervention was a shared group activity, but how people engaged with those tasks was shaped by participants’ background experiences and individuals’ biographies.

7.1.3 Active ageing policy and its implications

The neglect of individual subjective experiences of MCI and memory difficulties influences the nature of active ageing policies which focus upon collective outcomes rather than the individualism inherent in active ageing practice. The promotion of active ageing policy at a whole population level supposedly requires engagement from a broad range of local and national stakeholders. However, in practice it takes on more of an individualistic approach in the APPLE-tree intervention. The responsibilisation agenda runs throughout the topic and features strongly in my thesis, in chapter 5 the responsibilising of cognitive health through engagement in active ageing practice includes examples of personal, collective, and societal expectations of responsibility. This is explored further in chapter 6, through the sense of responsibilities to age healthily and position oneself as distinct from others at risk of dementia.

Responsibilisation orientates active ageing policy and practice, producing and reinforcing a personal sense of responsibility around being old and an individual's cognitive health. There is a tension between the individualistic versus collective notions of health and responsibility, which appeared to increase rather than decrease the sense of uncertainty among participants. The increased and targeted awareness or personal risk operates in contrast to some of the recommended population level approaches, such as longitudinal, lifelong learning and intergenerational collaboration, proposed in the European Commission Green Paper (2021). This tension may also be understood through the concept of governmentality, with 'government at a distance' through 'active citizenship' evident within active ageing policy and the 'governing of the self', inherent within active ageing practice (Conway & Crawshaw, 2009). As an active ageing practice, the APPLE-tree intervention operates at both a personal and a professional level and aims to fill a treatment gap. However, in the absence of knowing how and when in relation to their cognitive health, participants negotiate a position as 'active agers' so as to be able to navigate this unknown.

The content of the APPLE-tree programme sessions reflected the research on the benefit of multi-modal health and lifestyle interventions, with many sessions focused on physical health measures around exercise and healthy eating. However, I found that at times there was a lack of clarity around the meaning of cognitive health as well as an absence of acknowledgement regarding the purpose of the intervention. Within the intervention, cognitive impairment, MCI, and memory difficulties were addressed more incidentally as they arose within the content of the sessions, rather than in any specific fashion. This is a key finding and suggests two things, firstly the difficulty in addressing forms of mild cognitive impairment which is not dementia as well as being aware of participant's potential embarrassment in sharing their experiences often meant that facilitators were reluctant to address it and may themselves felt uncomfortable in doing so. Secondly, it points to a fundamental concern regarding the debilitating experiences which MCI and memory difficulties can take, and the barriers which may inhibit participant's cognitive ability to engage in an active ageing practice intervention for memory difficulties. Both these points need to be considered in any policy and practice development and indicate the importance of supportive training for staff facilitating active ageing practice interventions around dementia prevention.

Active ageing policy and practice has prioritised physical health with cognitive health receiving less attention. Intervention models which have borrowed or adapted from physical health practices may not fit with cognitive health and impairment. These pervade a wider set of issues which relate to mental health, dementia and felt stigma which are not fully addressed. Active ageing policy should also consider social and economic factors and think through how these can filter into active ageing practices. My ethnographic study drew attention to cultural and social class differences between the two groups studied. The different geographical and social locations of an affluent coastal town outside London and urban area of North London was associated in this difference between the two groups. This was indicated through the variations surrounding the nutritional changes which were required within the intervention, and what was regarded as realistic to adopt as 'healthy' food items (e.g., avocados), or the choice of available activity options for participants. Jones points out that 'social class identities may have an important role to play in individual responses both the experience and the conceptualisation of dementia (Jones & Higgs, 2013). Within my findings in chapter 5, I describe a participant sharing their location to the group on Zoom as an expression of a 'social class identity' and an expression of agency, and this may be regarded as a response to the compromising nature of memory difficulties and MCI on cognitive function which affects self-esteem.

The increased responsibilisation of cognitive health in old age creates a moral impetus to act, and active ageing practice provides a structure and means to do this through interventions, such as APPLE-tree. As I previously discussed in chapter 6, a positive paradigm of active ageing suggests that older citizens may be ‘limited’ but should want to achieve the ‘limitless’ promises of the Third or consumer age, and need to take responsibility in doing this (Clotworthy, 2020). However, I found that the complexity surrounding responsibilisation as a concept is not fully acknowledged by active ageing policy and practice. The translation of this into personal responsibility to engage in dementia prevention carries with it an assumption that older people with MCI are in some way complicit in their own cognitive decline and requires them to adapt and improve their health and lifestyle choices. The moral imperative of responding to an ‘at risk’ status and being seen to respond correctly is paramount. Doing the right things when it matters yet still not knowing when these things will and should matter reflects the absence inherent within this experience. Ultimately the opportunity to undertake and engage with a dementia prevention intervention can be motivating and empowering but it also potentially creates an anxiety around expectations of achievement which for many individuals will be unachievable.

The active ageing intervention may fill a policy void for this growing population of people identified as having memory problems but does not address the overall sense of absence regarding its actual practices identified from my studies. A sense of absence was present throughout my research and represents an issue which is not discussed within the literature on MCI and memory difficulties. It is subsequently under researched and under explored. Absence is not something which sits comfortably within a medical model of diagnosis or within a culture of active ageing, which has a focus on activities that change outcomes. The enormity of the ‘presence of an absence’ as part of a subjective experience has also been overlooked in the literature. Public health policies which are based upon an intervention-based model which overly medicalises the condition need to acknowledge this sense of the unknown and consider the impact of this upon participants within active ageing practice.

Evidence of the ability of programmes such as APPLE-tree to delay the onset of dementia is currently lacking, but this was of less importance for participants taking part than the hope and expectation they provide; in effect an ‘economy of hope’ (Novas, 2006). The sense of structure, activity and outcome replace the lack of clarity and uncertainly, however the presence of a sense of absence remains. Participants feel a responsibility to fill this gap through engaging in the content of the intervention and positioning themselves as active agers. This role provides a status, counteracting the impact of cognitive impairment, and in the attempts to avoid cognitive decline, provided participants with what many regarded as a’ moral identity’. In this way dementia prevention interventions are different from other active ageing policy and practices. This moral identity associated with an active ageing interventions such as APPLE-tree justifies spending money on prevention interventions even through the results are far from clear. However, Braun points out that current health economic literature has focused solely on risk factors and clinical disease stages and pointed to the gap around cost effectiveness of primary prevention for people at risk (Braun et al., 2024).

7.2 Finally

My overall focus in this thesis was to explore how active ageing policy and practice reconfigures experiences of cognitive impairment. This is multi-faceted and influenced by the extension of active ageing's application to the field of cognitive health and dementia risk in Western society.

Active ageing practice fills the absence of unclear trajectories and the lack of an effective treatment. It allows for the construction of a new pathway for personal engagement regarding memory concerns moving from a liminal state flanked by more consequential diagnoses of dementia into a more active status which is perceived as empowering and enabling. However, there are added challenges in relation to cognitive health which do not fit the model of active ageing practice more commonly applied to physical health. These include the invalidating nature of memory difficulties and MCI, which creates uncertainties around self-identity and the inability to retain new information or engage with others. Active ageing policy does not appear to fully address this with expectations of a moral responsibility to do something to prevent or avoid dementia being paramount. Active ageing policy and practice changes notions of cognitive impairment into something which is considered avoidable if individuals undertake certain health and lifestyle changes.

My findings suggest that this is an under researched area which has traditionally been overshadowed by a medical and interventionist focus. A range of research approaches to study this area including various social science-based methods such as ethnography are required, exploring the cultural, socioeconomic and gender aspects, personal motivations, and the sustainability of such interventions in participant's lives. Focus for my ethnographic study was provided through my scoping review literature in chapter 2 and the secondary data analysis in chapter 3. This was a valuable starting point as they identified the complexity of this area and lack of clear knowledge or evidence which was reflected in the absence felt by participants.

Finally, my personal background as a mental health nurse provided additional weight and familiarity with this area, including the participants' challenges with memory difficulties and cognitive impairment, which provided an invaluable connection with them. However, thinking reflexively this may also have been a problem. I questioned whether at times I was too comfortable with being in the group intervention with participants, as it was similar to experiences from my work as a nurse. I needed to remind myself of my researcher role and avoid engaging in pathologising and responding to people's conditions. I made every attempt through reflexive diaries and supervision to counteract this, most importantly I am grateful to all the participants who I connected with through the intervention and interviews, they constantly grounded me in the reality of the phenomenon which is active ageing through their honest exchanges with the APPLE-tree intervention and with me. This point reflects the deduction that understanding and listening to the subjective and personal experiences of participants in any active ageing practice for dementia prevention is fundamental to producing policies which are applicable to people lives and active ageing practices which are realistic and achievable.

References

Abyad, A. (2018). From active ageing to health ageing. *QJM: An International Journal of Medicine*, *111*(suppl_1), hcy200. 067.

Adelman, R. C. (1995). The Alzheimerization of aging. *The Gerontologist*, *35*(4), 526–532.

Adler, P. A., & Adler, P. (1987). *Membership roles in field research* (Vol. 6). Sage.

Alderson, P. (2021). *Critical realism for health and illness research: A practical introduction*. Policy Press.

Alzheimers Research UK. (n.d.). *Public perceptions of dementia*. Dementia Statistics Hub. Retrieved 27 December 2023, from https://dementiastatistics.org/perceptions-and-inequalities/public-perceptions-2/

Alzheimers Society. (2022). *What is mild cognitive impairment (MCI)?* 10.

Archer, M. S. (1995). *Realist social theory: The morphogenetic approach*. Cambridge university press.

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, *8*(1), 19–32.

Atkinson, P. (2007). *Ethnography: Principles in practice*. Routledge.

Atkinson, P., & Coffey, A. (2023). *Handbook of Interview Research* (By pages 801-814). SAGE Publications, Inc. https://doi.org/10.4135/9781412973588

Ball, H. A., McWhirter, L., Ballard, C., Bhome, R., Blackburn, D. J., Edwards, M. J., Fleming, S. M., Fox, N. C., Howard, R., & Huntley, J. (2020). Functional cognitive disorder: Dementia's blind spot. *Brain*, *143*(10), 2895–2903.

Bazeley, P. (2009). Analysing qualitative data: More than 'identifying themes'. *Malaysian Journal of Qualitative Research*, *2*(2), 6–22.

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

Begum, A., Whitley, R., Banerjee, S., Matthews, D., Stewart, R., & Morgan, C. (2013). Help-seeking Response to Subjective Memory Complaints in Older Adults: Toward a Conceptual Model. *The Gerontologist*, *53*(3), 462–473. https://doi.org/10.1093/geront/gns083

Behuniak, S. M. (2011). The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing & Society*, *31*(1), 70–92.

Berg, A. I., Wallin, A., Nordlund, A., & Johansson, B. (2013). Living with stable MCI: Experiences among 17 individuals evaluated at a memory clinic. *Aging & Mental Health*, *17*(3), 293–299. https://doi.org/10.1080/13607863.2012.751582

Bhaskar, R. (2010). *Reclaiming reality: A critical introduction to contemporary philosophy*. Routledge.

Birt, L., Poland, F., Csipke, E., & Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health & Illness*, *39*(2), 199–211.

Boudiny, K. (2013). ‘Active ageing’: From empty rhetoric to effective policy tool. *Ageing & Society*, *33*(6), 1077–1098.

Braun, A., Höfler, M., & Auer, S. (2024). Cost-Effectiveness of Prevention for People at Risk for Dementia: A Scoping Review and Qualitative Synthesis. *The Journal of Prevention of Alzheimer’s Disease*, 1–12.

Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, *18*(3), 328–352.

Brinkmann, S. (2014). Doing without data. *Qualitative Inquiry*, *20*(6), 720–725.

Bruce, A., Sheilds, L., Molzahn, A., Beuthin, R., Schick-Makaroff, K., & Shermak, S. (2014). Stories of liminality: Living with life-threatening illness. *Journal of Holistic Nursing*, *32*(1), 35–43.

Burke, J. F., Kerber, K. A., Langa, K. M., Albin, R. L., & Kotagal, V. (2023). Lecanemab: Looking before we leap. *Neurology*, *101*(15), 661–665.

Burns, A., & Robert, P. (2009). The national dementia strategy in England. In *Bmj* (Vol. 338). British Medical Journal Publishing Group.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, *4*(2), 167–182.

Calasanti, T. (2016). Combating ageism: How successful is successful aging? *The Gerontologist*, *56*(6), 1093–1101.

Campbell, S., Greenwood, M., Prior, S., Shearer, T., Walkem, K., Young, S., Bywaters, D., & Walker, K. (2020). Purposive sampling: Complex or simple? Research case examples. *Journal of Research in Nursing*, *25*(8), 652–661. https://doi.org/10.1177/1744987120927206

Castro, C. B., Costa, L. M., Dias, C. B., Chen, J., Hillebrandt, H., Gardener, S. L., Brown, B. M., Loo, R. L., Garg, M. L., Rainey-Smith, S. R., Martins, R. N., & Sohrabi, H. R. (2023). Multi-Domain Interventions for Dementia Prevention–A Systematic Review. *The Journal of Nutrition, Health and Aging*, *27*(12), 1271–1280. https://doi.org/10.1007/s12603-023-2046-2

Chapman, M., Philip, J., & Komesaroff, P. (2022). A person-centred problem. *Humanities and Social Sciences Communications*, *9*(1), 1–11. https://doi.org/10.1057/s41599-022-01166-9

Chaudoir, S. R., Earnshaw, V. A., & Andel, S. (2013). “Discredited” versus “discreditable”: Understanding how shared and unique stigma mechanisms affect psychological and physical health disparities. *Basic and Applied Social Psychology*, *35*(1), 75–87.

Chelberg, K. (2023). ‘Brainwork practices’: Responsibilisation of dementia prevention in Australian aged care discourse. *Ageing & Society*, 1–26.

Choi, M., & Kim, M. (2020). Living a Daily Life With Self-Awareness Among Older Adults With Mild Cognitive Impairment. *Research in Gerontological Nursing*, *13*(1), 41–48. https://doi.org/10.3928/19404921-20191025-01

Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology*, *12*(3), 297–298.

Clarke, V., & Braun, V. (2021). Thematic analysis: A practical guide. *Thematic Analysis*, 1–100.

Clotworthy, A. (2020). Empowering the Elderly? In *Empowering the Elderly?* transcript Verlag.

Cluley, V., Martin, G., Radnor, Z., & Banerjee, J. (2021). Frailty as biographical disruption. *Sociology of Health & Illness*, *43*(4), 948–965.

Collier, G., Kayes, N., Reay, S., Hayes, N., & Bill, A. (2020). Designing a diagnosis? Reflections on design, medicalization, and mild cognitive impairment (MCI). *Design for Health*, *4*(3), 296–312. https://doi.org/10.1080/24735132.2020.1837507

Conway, S., & Crawshaw, P. (2009). 'Healthy Senior Citizenship'in voluntary and community organisations: A study in governmentality. *Health Sociology Review*, *18*(4), 387–398.

Cooper, C., Aguirre, E., Barber, J. A., Bass, N., Brodaty, H., Burton, A., Higgs, P., Hunter, R., Huntley, J., & Lang, I. (2020). APPLE-Tree (Active Prevention in People at risk of dementia: Lifestyle, bEhaviour change and Technology to REducE cognitive and functional decline) programme: Protocol. *International Journal of Geriatric Psychiatry*, *35*(8), 811–819.

Corner, L., & Bond, J. (2004). Being at risk of dementia: Fears and anxieties of older adults. *Journal of Aging Studies*, *18*(2), 143–155. https://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.

Cumming, E., & Henry, W. E. (1962). *The process of disengagement*. LWW.

Davies, C. A. (2012). *Reflexive ethnography: A guide to researching selves and others*. Routledge.

The Department for Health and Social Care (2018). Prevention is better than cure. https://www.gov.uk/government/publications/prevention-is-better-than-cure-our-vision-to-help-you-live-well-for-longer

De São José, J. M., Timonen, V., Amado, C. A. F., & Santos, S. P. (2017). A critique of the Active Ageing Index. *Journal of Aging Studies*, *40*, 49–56.

De Vriendt, P., Gorus, E., Cornelis, E., Velghe, A., Petrovic, M., & Mets, T. (2012). The process of decline in advanced activities of daily living: A qualitative explorative study in mild cognitive impairment. *International Psychogeriatrics*, *24*(6), 974–986. https://doi.org/10.1017/S1041610211002766

Dean, K., Jenkinson, C., Wilcock, G., & Walker, Z. (2014). Exploring the experiences of people with mild cognitive impairment and their caregivers with particular reference to healthcare – a qualitative study. *International Psychogeriatrics*, *26*(3), 475–485. https://doi.org/10.1017/S104161021300207X

DeWalt, K., & DeWalt, B. R. (2011). *Participant observation: A guide for fieldworkers*. Rowman Altamira.

Dewing, J. (2008). Personhood and dementia: Revisiting Tom Kitwood's ideas. *International Journal of Older People Nursing*, *3*(1), 3–13.

Dooley, J., Bailey, C., Xanthopoulou, P., Bass, N., & McCabe, R. (2020). Communication and understanding of mild cognitive impairment diagnoses. *International Journal of Geriatric Psychiatry*, *35*(6), 662–670. https://doi.org/10.1002/gps.5284

Dunne, R. A., Aarsland, D., O'Brien, J. T., Ballard, C., Banerjee, S., Fox, N. C., Isaacs, J. D., Underwood, B. R., Perry, R. J., & Chan, D. (2021). Mild cognitive impairment: The Manchester consensus. *Age and Ageing*, *50*(1), 72–80.

Earl Rinehart, K. (2021). Abductive analysis in qualitative inquiry. *Qualitative Inquiry*, *27*(2), 303–311.

Engman, A. (2019). Embodiment and the foundation of biographical disruption. *Social Science & Medicine*, *225*, 120–127.

Fahey, M., Tinker, A., & Fletcher, J. R. (2023). Dementia's preventative futures: Researcher perspectives on prospective developments in the UK. *Working with Older People*.

Farwell, L. J. (1976). *Betwixt and between: The anthopological contributions of Mary Douglas and Victor Turner towards a renewal of Roman Catholic ritual*. The Claremont Graduate University.

Featherstone, M., Turner, B. S., & Hepworth, M. (1990). The body: Social process and cultural theory. *The Body*, 1–352.

Fernández-Ballesteros, R., Benetos, A., & Robine, J.-M. (2019). *The Cambridge handbook of successful aging*. Cambridge University Press.

Fillit, H. M., Rockwood, K., & Young, J. B. (2016). *Brocklehurst's textbook of geriatric medicine and gerontology E-book*. Elsevier Health Sciences.

Fletcher, A. J. (2017). Applying critical realism in qualitative research: Methodology meets method. *International Journal of Social Research Methodology*, *20*(2), 181–194.

Fletcher, J. R. (2020). Renegotiating relationships: Theorising shared experiences of dementia within the dyadic career. *Dementia*, *19*(3), 708–720. https://doi.org/10.1177/1471301218785511

Ford, E., Milne, R., & Curlewis, K. (2023). Ethical issues when using digital biomarkers and artificial intelligence for the early detection of dementia. *Wiley Interdisciplinary Reviews: Data Mining and Knowledge Discovery*, e1492.

Foster, L., & Walker, A. (2015). Active and Successful Aging: A European Policy Perspective. *The Gerontologist*, *55*(1), 83–90. https://doi.org/10.1093/geront/gnu028

Frank, A. W. (2000). The standpoint of storyteller. *Qualitative Health Research*, *10*(3), 354–365.

Fudge, N., & Swinglehurst, D. (2022). Keeping in balance on the multimorbidity tightrope: A narrative analysis of older patients' experiences of living with and managing multimorbidity. *Social Science & Medicine*, *292*, 114532. https://doi.org/10.1016/j.socscimed.2021.114532

Geertz, C. (1973). Chapter 1/Thick Description: Toward an interpretive theory of culture. *The Interpretation of Cultures: Selected Essays, New York, Basic Books*.

Gerstenecker, A., & Mast, B. (2015). Mild cognitive impairment: A history and the state of current diagnostic criteria. *International Psychogeriatrics*, *27*(2), 199–211.

Giddens, A. (1999). Risk and responsibility. *Mod. L. Rev.*, *62*, 1.

Giebel, C., Challis, D., Worden, A., Jolley, D., Bhui, K. S., Lambat, A., & Purandare, N. (2016). Perceptions of self-defined memory problems vary in south Asian minority older people who consult a GP and those who do not: A mixed-method pilot study: Consultation for memory problems in south Asian elders. *International Journal of Geriatric Psychiatry*, *31*(4), 375–383. https://doi.org/10.1002/gps.4337

Gifford, K. A., Liu, D., Romano, R. R., Jones, R. N., & Jefferson, A. L. (2015). Development of a subjective cognitive decline questionnaire using item response theory: A pilot study. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, *1*(4), 429–439.

Gilleard, C., & Higgs, P. (2010). Aging without agency: Theorizing the fourth age. *Aging & Mental Health*, *14*(2), 121–128.

Gilleard, C., & Higgs, P. (2011). Frailty, disability and old age: A re-appraisal. *Health:*, *15*(5), 475–490.

Gilleard, C., & Higgs, P. (2014). *Cultures of ageing: Self, citizen and the body*. Routledge.

Gilleard, C., & Higgs, P. (2023). Ageing without senescence: A critical absence in social gerontology? *Journal of Aging Studies*, *66*, 101166.

Glaser, B. G., & Strauss, A. L. (1971). *Status Passage*. Transaction Publishers.

Glaser, B. G., & Strauss, A. L. (2011). *Status Passage*. Transaction Publishers.

Gold, R. L. (1958). *Roles in sociological field observation in social forces*.

Gomersall, T., Smith, S. K., Blewett, C., & Astell, A. (2017). 'It's definitely *not* Alzheimer's': Perceived benefits and drawbacks of a mild cognitive impairment diagnosis. *British Journal of Health Psychology*, *22*(4), 786–804. https://doi.org/10.1111/bjhp.12255

Green, S., & Hillersdal, L. (2021). Aging biomarkers and the measurement of health and risk. *History and Philosophy of the Life Sciences*, *43*, 1–23.

Hammersley, M., & Atkinson, P. (2019). *Ethnography: Principles in practice*. Routledge.

Harnett, T., & Jönson, H. (2017). "They are different now" – Biographical continuity and disruption in nursing home settings. *Journal of Aging Studies*, *42*, 1–8. https://doi.org/10.1016/j.jaging.2017.05.003

Havighurst, R. J. (1963). Successful aging. *Processes of Aging: Social and Psychological Perspectives*, *1*, 299–320.

Higgs, P. (1995). Citizenship and old age: The end of the road? *Ageing & Society*, *15*(4), 535–550.

Higgs, P. (2012). Consuming bodies: Zygmunt Bauman on the difference between fitness and health. In *Contemporary Theorists for Medical Sociology* (pp. 20–32). Routledge.

Higgs, P. (2018). Later life, health and society. *Sociology as Applied to Health and Medicine*, 203–224.

Higgs, P. (2022). Ageing and the Lifecourse. *Key Concepts in Medical Sociology*, 77–83.

Higgs, P., & Gilleard, C. (2017). *Rethinking old age: Theorising the fourth age*. Bloomsbury Publishing.

Higgs, P., & Gilleard, C. (2020). The ideology of ageism versus the social imaginary of the fourth age: Two differing approaches to the negative contexts of old age. *Ageing & Society*, *40*(8), 1617–1630.

Higgs, P., & Gilleard, C. (2022). 'Apocalyptic demography'versus the 'reckless generation': Framing the third and fourth ages in the media. In *Ageing and the Media* (pp. 15–29). Policy Press.

Higgs, P., Leontowitsch, M., Stevenson, F., & Jones, I. R. (2009). Not just old and sick–the 'will to health'in later life. *Ageing & Society*, *29*(5), 687–707.

Hill, N., Mogle, J., Kitko, L., Gilmore-Bykovskyi, A., Wion, R., Kitt-Lewis, E., & Kolanowski, A. (2018). Incongruence of subjective memory impairment ratings and the experience of memory problems in older adults without dementia: A mixed methods study. *Aging & Mental Health*, *22*(8), 978–985. https://doi.org/10.1080/13607863.2017.1337715

Hinds, P. S., Vogel, R. J., & Clarke-Steffen, L. (1997). The possibilities and pitfalls of doing a secondary analysis of a qualitative data set. *Qualitative Health Research*, *7*(3), 408–424.

Howard, R. (2020). Subjective cognitive decline: What is it good for? *The Lancet. Neurology*, *19*(3), 203–204.

Imhof, L., Wallhagen, M. I., Mahrer-Imhof, R., & Monsch, A. U. (2006). Becoming Forgetful: How Elderly People Deal With Forgetfulness in Everyday Life. *American Journal of Alzheimer's Disease & Other Dementiasr*, *21*(5), 347–353. https://doi.org/10.1177/1533317506292499

Johansson, M. M., Marcusson, J., & Wressle, E. (2015). Cognitive impairment and its consequences in everyday life: Experiences of people with mild cognitive impairment or mild dementia and their relatives. *International Psychogeriatrics*, *27*(6), 949–958.

Johnson, M. L., Bengtson, V. L., Coleman, P. G., & Kirkwood, T. B. (2005). *The Cambridge handbook of age and ageing*. Cambridge University Press.

Johnson, P., & Thane, P. (1998). *Old age from antiquity to post-modernity*. Routledge London.

Jones, I. R., & Higgs, P. (2013). Class and health inequalities in later life. In *Social Class in Later Life* (pp. 113–132). Policy Press.

Jones, I. R., & Higgs, P. F. (2010). The natural, the normal and the normative: Contested terrains in ageing and old age. *Social Science & Medicine*, *71*(8), 1513–1519.

Jones, R. L. (2006). 'Older people'talking as if they are not older people: Positioning theory as an explanation. *Journal of Aging Studies*, *20*(1), 79–91.

Joosten-Weyn Banningh, L., Vernooij-Dassen, M., Rikkert, M. O., & Teunisse, J.-P. (2008). Mild cognitive impairment: Coping with an uncertain label. *International Journal of Geriatric Psychiatry*, *23*(2), 148–154. https://doi.org/10.1002/gps.1855

Kalache, A., & Gatti, A. (2003). Active ageing: A policy framework. *Advances in Gerontology= Uspekhi Gerontologii*, *11*, 7–18.

Kalache, A., & Keller, I. (1999). The WHO perspective on active ageing. *Promotion & Education*, *6*(4), 20–23.

Katz, S., & Marshall, B. (2003). New sex for old: Lifestyle, consumerism, and the ethics of aging well. *Journal of Aging Studies*, *17*(1), 3–16.

Katz, S., & Peters, K. R. (2008). Enhancing the mind? Memory medicine, dementia, and the aging brain. *Journal of Aging Studies*, *22*(4), 348–355.

Katz, S., Peters, K. R., & Ballantyne, P. J. (2020). The preventative uncertainty of mild cognitive impairment (MCI). In A. Leibing & S. Schicktanz (Eds.), *Preventing dementia?* 151-176. Berghan books.

Kelly, A. (2010). Lost the feel for the game: Meanings of onset and diagnosis of AIDS dementia for significant others. *Qualitative Health Research*, *20*(4), 531–540.

Khalil, H., McInerney, P., Pollock, D., Alexander, L., Munn, Z., Tricco, A. C., Godfrey, C. M., & Peters, M. D. (2021). Practical guide to undertaking scoping reviews for pharmacy clinicians, researchers and policymakers. *Journal of Clinical Pharmacy and Therapeutics*.

Kitwood, T. M., Baldwin, C., & Capstick, A. (2007). Tom Kitwood on dementia: A reader and critical commentary.

Kivimäki, M., & Singh-Manoux, A. (2018). Prevention of dementia by targeting risk factors. *The Lancet*, *391*(10130), 1574–1575.

Knapp, M., & Wong, G. (2023). Economics and dementia: Challenges and responses. *Dementia*, 14713012231193141.

Knoblauch, H. (2005). Focused ethnography. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, *6*(3).

Kruger TM. (2014). *Affective and Behavioural Responses to a diagnosis of mild cognitive impairment*.

Laslett, P. (1991). *A fresh map of life: The emergence of the third age*. Harvard University Press.

Latimer, J. (2018). Repelling neoliberal world-making? How the ageing–dementia relation is reassembling the social. *The Sociological Review*, *66*(4), 832–856.

Leibing, A. (2018). Situated prevention: Framing the “new dementia”. *Journal of Law, Medicine & Ethics*, *46*(3), 704–716.

Leibing, A., & Schicktanz, S. (2022). *Preventing dementia? Critical perspectives on a new paradigm of preparing for old age*. Berghahn Books.

Levac, D., Colquhoun, H., & O’Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, *5*(1), 1–9.

Libert, S., Charlesworth, G., & Higgs, P. (2020a). Cognitive decline and distinction: A new line of fracture in later life? *Ageing & Society*, *40*(12), 2574–2592.

Libert, S., Charlesworth, G., & Higgs, P. (2020b). Cognitive decline and distinction: A new line of fracture in later life? *Ageing & Society*, *40*(12), 2574–2592.

Linden, I., Wolfs, C., Hevink, M., Dirksen, C., Ponds, R., & Perry, M. (2024). Why to test for dementia: Perspectives of patients, significant others and general practitioners. *Age and Ageing*, *53*(1), afad251. https://doi.org/10.1093/ageing/afad251

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. https://doi.org/10.1093/geront/46.6.791

Liotta, G., Canhao, H., Cenko, F., Cutini, R., Vellone, E., Illario, M., Kardas, P., Poscia, A., Sousa, R. D., & Palombi, L. (2018). Active ageing in Europe: Adding healthy life to years. *Frontiers in Medicine*, *5*, 123.

Lister, R. (2011). The age of responsibility: Social policy and citizenship in the early 21st century. In *Social Policy Review 23* (pp. 63–84). Policy Press.

Livingston, G., Cooper, C., Woods, J., Milne, A., & Katona, C. (2008). Successful ageing in adversity: The LASER–AD longitudinal study. *Journal of Neurology, Neurosurgery & Psychiatry*, *79*(6), 641–645.

Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., & Cooper, C. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, *396*(10248), 413–446.

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., Ballard, C., Banerjee, S., Burns, A., & Cohen-Mansfield, J. (2017). Dementia prevention, intervention, and care. *The Lancet*, *390*(10113), 2673–2734.

Llewelyn H. (2017). *Navigating brain tumours: Uncertainty, fixing and the production of possibility*.

Lock, M. (2013). The Alzheimer Conundrum: Entanglements of Dementia and Aging. In *The Alzheimer Conundrum*. Princeton University Press. https://doi.org/10.1515/9781400848461

Long-Sutehall, T., Sque, M., & Addington-Hall, J. (2011). Secondary analysis of qualitative data: A valuable method for exploring sensitive issues with an elusive population? *Journal of Research in Nursing*, *16*(4), 335–344.

Low, L.-F., & Purwaningrum, F. (2020). Negative stereotypes, fear and social distance: A systematic review of depictions of dementia in popular culture in the context of stigma. *BMC Geriatrics*, *20*(1), 1–16.

Madden, R. (2017). *Being ethnographic: A guide to the theory and practice of ethnography*. Sage.

May, T. (2002). *Qualitative Research in Action*. SAGE Publications Ltd. https://doi.org/10.4135/9781849209656

Mayhew, L. (2005). Active ageing in the UK-issues, barriers, policy directions. *Innovation*, *18*(4), 455–477.

McGrattan, A. M., Pakpahan, E., Siervo, M., Mohan, D., Reidpath, D. D., Prina, M., Allotey, P., Zhu, Y., Shulin, C., Yates, J., Paddick, S.-M., Robinson, L., Stephan, B. C. M., & Team, the D. (2022). Risk of conversion from mild cognitive impairment to dementia in low- and middle-income countries: A systematic review and meta-analysis. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, *8*(1), e12267. https://doi.org/10.1002/trc2.12267

McParland, P., Kelly, F., & Innes, A. (2017). Dichotomising dementia: Is there another way? *Sociology of Health & Illness*, *39*(2), 258–269. https://doi.org/10.1111/1467-9566.12438

Meilak, C., Partridge, J., Willis, R., & Dhesi, J. (2016). Mild Cognitive Impairment: A qualitative exploration of older adults' understanding, concerns and expectations. *Annals of Psychiatry and Mental Health*, *4*(1), 1–8.

Mudge, A. M., & Hubbard, R. E. (2018). Frailty: Mind the gap. *Age and Ageing*, *47*(4), 508–511.

Naddaf, M. (2024). Early dementia diagnosis: Blood proteins reveal at-risk people. *Nature*. https://doi.org/10.1038/d41586-024-00418-9

Nakano, M., Sato, S., & Nakahara, J. (2012). Emotional experiences of the community-dwelling with mild cognitive impairment and their families. *Neuropsychological Trends*, *12,* 6. https://doi.org/10.7358/neur-2012-012-naka

Nations, U. (n.d.). *Ageing*. United Nations; United Nations. Retrieved 2 May 2023, from https://www.un.org/en/global-issues/ageing

NICE. (2015). *Older people with social care needs and multiple long-term conditions | Search results*. NICE. https://www.nice.org.uk/search

Novas, C. (2006). The political economy of hope: Patients' organizations, science and biovalue. *BioSocieties*, *1*(3), 289–305.

Office for Health Improvement & Disparities. (2022). Healthy ageing: Applying all our health. https://www.gov.uk/government/publications/healthy-ageing/healthy-ageing-applying-all-our-health

Office for Health Improvement & Disparities. (2023). Understanding the drivers of healthy life expectancy: report.

https://www.gov.uk/government/publications/understanding-the-drivers-of-healthy-life-expectancy/understanding-the-drivers-of-healthy-life-expectancy-report

Oosterhuis, E. J., Slade, K., May, P. J. C., & Nuttall, H. E. (2023). Toward an Understanding of Healthy Cognitive Aging: The Importance of Lifestyle in Cognitive Reserve and the Scaffolding Theory of Aging and Cognition. *The Journals of Gerontology: Series B*, *78*(5), 777–788.

Opdebeeck, C., Yates, J. A., Kudlicka, A., & Martyr, A. (2019). What are subjective cognitive difficulties and do they matter? *Age and Ageing*, *48*(1), 122–127.

O'Reilly, K. (2012). *Ethnographic methods*. Routledge.

Parikh, P. K., Troyer, A. K., Maione, A. M., & Murphy, K. J. (2016). The Impact of Memory Change on Daily Life in Normal Aging and Mild Cognitive Impairment. *The Gerontologist*, *56*(5), 877–885. https://doi.org/10.1093/geront/gnv030

Paúl, C., Ribeiro, O., & Teixeira, L. (2012). Active ageing: An empirical approach to the WHO model. *Current Gerontology and Geriatrics Research*, *2012*.

Pescosolido, B. A., Martin, J. K., McLeod, J. D., & Rogers, A. (2010). *Handbook of the sociology of health, illness, and healing: A blueprint for the 21st century*. Springer Science & Business Media.

Peters, K. R., & Katz, S. (2015). Voices from the field: Expert reflections on mild cognitive impairment. In *Dementia* (Vol. 14, Issue 3, pp. 285–297). SAGE Publications Sage UK: London, England.

Peters, M. D., Marnie, C., Tricco, A. C., Pollock, D., Munn, Z., Alexander, L., McInerney, P., Godfrey, C. M., & Khalil, H. (2020). Updated methodological guidance for the conduct of scoping reviews. *JBI Evidence Synthesis*, *18*(10), 2119–2126.

Phillippi, J., & Lauderdale, J. (2018). A guide to field notes for qualitative research: Context and conversation. *Qualitative health research*, *28*(3), 381-388.

Pickersgill, M. D. (2014). Debating DSM-5: Diagnosis and the sociology of critique. *Journal of Medical Ethics*, *40*(8), 521–525.

Pierce, S., Lamers, C., & Salisbury, K. (2016). Knowingly not wanting to know: Discourses of people diagnosed with mild cognitive impairment. *Dementia*, *15*(5), 1246–1259. https://doi.org/10.1177/1471301215600895

Pinner, G. (2000). Truth-telling and the diagnosis of dementia. *The British Journal of Psychiatry*, *176*(6), 514–515. https://doi.org/10.1192/bjp.176.6.514

Planche, V., & Villain, N. (2023). Advocating for Demonstration of Disease Modification—Have We Been Approaching Clinical Trials in Early Alzheimer Disease Incorrectly? *JAMA Neurology*, *80*(7), 659–660. https://doi.org/10.1001/jamaneurol.2023.0815

Ponterotto, J. G. (2006). Brief note on the origins, evolution, and meaning of the qualitative research concept thick description. *The Qualitative Report*, *11*(3), 538–549.

Poppe, M. (2020). “ *Falling through the cracks* ”; Stakeholders’ views around the concept and diagnosis of mild cognitive impairment and their understanding of dementia prevention. *International Journal of Geriatric Psychiatry*, *35*(11), 1349–1357. https://doi.org/10.1002/gps.5373

Post, S. G. (2000). The concept of Alzheimer disease in a hypercognitive society. *Concepts of Alzheimer Disease: Biological, Clinical and Cultural Perspectives*, 245–256.

Prince, M., Guerchet, M., & Prina, M. (2015). *The epidemiology and impact of dementia-current state and future trends. WHO Thematic Briefing*.

Principi, A., Santini, S., Socci, M., Smeaton, D., Cahill, K. E., Vegeris, S., & Barnes, H. (2018). Retirement plans and active ageing: Perspectives in three countries. *Ageing & Society*, *38*(1), 56–82.

Public Health England. (2019). *Health matters: Prevention - a life course approach*. https://www.gov.uk/government/publications/health-matters-life-course-approach-to-prevention/health-matters-prevention-a-life-course-approach

Raleigh .V. (2022, August 10). *What is happening to life expectancy in England?* The King's Fund. https://www.kingsfund.org.uk/publications/whats-happening-life-expectancy-england

Rashid, M., Hodgson, C. S., & Luig, T. (2019). Ten tips for conducting focused ethnography in medical education research. *Medical Education Online*, *24*(1), 1624133.

Rees, C., & Gatenby, M. (2014). Critical Realism and Ethnography. In P. K. Edwards, J. O'Mahoney, & S. Vincent (Eds.), *Studying Organizations Using Critical Realism: A Practical Guide* (p. 0). Oxford University Press. https://doi.org/10.1093/acprof:oso/9780199665525.003.0007

Renn, B. N., Wool, J. L., & Belza, B. (2021). A typical week with mild cognitive impairment. *The Gerontologist*, *61*(7), 1095–1106.

Richard, E., van Charante, E. P. M., Hoevenaar-Blom, M. P., Coley, N., Barbera, M., van der Groep, A., Meiller, Y., Mangialasche, F., Beishuizen, C. B., & Jongstra, S. (2019). Healthy ageing through internet counselling in the elderly (HATICE): A multinational, randomised controlled trial. *The Lancet Digital Health*, *1*(8), e424–e434.

Richards, L. (2020). Handling qualitative data: A practical guide. *Handling Qualitative Data*, 1–336.

Romaioli, D., & Contarello, A. (2019). Redefining agency in late life: The concept of 'disponibility'. *Ageing and Society*, *39*(1), 194–216. https://doi.org/10.1017/S0144686X17000897

Rose, N. (2006). Disorders Without Borders? The Expanding Scope of Psychiatric Practice. *BioSocieties*, *1*(4), 465–484. https://doi.org/10.1017/S1745855206004078

Rosenberg, A., Ngandu, T., Rusanen, M., Antikainen, R., Bäckman, L., Havulinna, S., Hänninen, T., Laatikainen, T., Lehtisalo, J., & Levälahti, E. (2018). Multidomain lifestyle intervention benefits a large elderly population at risk for cognitive decline and dementia regardless of baseline characteristics: The FINGER trial. *Alzheimer's & Dementia*, *14*(3), 263–270.

Rossini, P. M., Miraglia, F., & Vecchio, F. (2022). Early dementia diagnosis, MCI-to-dementia risk prediction, and the role of machine learning methods for feature extraction from integrated biomarkers, in particular for EEG signal analysis. *Alzheimer's & Dementia*, *18*(12), 2699–2706.

Rotenberg, S., Sternberg, S., & Maeir, A. (2020). Where did I put my glasses? The lived experience of older adults seeking medical help for perceived memory problems. *Disability and Rehabilitation*, *42*(25), 3606–3613. https://doi.org/10.1080/09638288.2019.1602849

Rowe, J. W., & Kahn, R. L. (1997). Successful aging. *The Gerontologist*, *37*(4), 433–440.

Sabayan, B., Doyle, S., Rost, N. S., Sorond, F. A., Lakshminarayan, K., & Launer, L. J. (2023). The role of population-level preventive care for brain health in ageing. *The Lancet Healthy Longevity*, *4*(6), e274–e283.

santé, O. mondiale de la, & Organization, W. H. (1993). *The ICD-10 classification of mental and behavioural disorders: Diagnostic criteria for research* (Vol. 2). World Health Organization.

Schweda, M., Kögel, A., Bartels, C., Wiltfang, J., Schneider, A., & Schicktanz, S. (2018). Prediction and early detection of Alzheimer's dementia: Professional disclosure practices and ethical attitudes. *Journal of Alzheimer's Disease*, *62*(1), 145–155.

Schweda, M., & Pfaller, L. (2020). 9 RESPONSIBILIZATION OF AGING? *PREVENTING DEMENTIA?*, 192.

Scott, S. (2009). *Making sense of everyday life*. Polity.

Stenner, P., McFarquhar, T., & Bowling, A. (2011). Older people and 'active ageing': Subjective aspects of ageing actively. *Journal of Health Psychology*, *16*(3), 467–477.

Swallow, J. (2020). Constructing classification boundaries in the memory clinic: Negotiating risk and uncertainty in constituting mild cognitive impairment. *Sociology of Health & Illness*, *42*, 99–113.

Tanner, D. (2016). Sustaining the self in the "fourth age": A case study. *Quality in Ageing and Older Adults*.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(1), 45. https://doi.org/10.1186/1471-2288-8-45

Thompson, J. (2022). *A guide to abductive thematic analysis*.

Thorne, S. (2013). Secondary qualitative data analysis. In *Routledge international handbook of qualitative nursing research* (pp. 423–434). Routledge.

Timmermans, S., & Tavory, I. (2012). Theory construction in qualitative research: From grounded theory to abductive analysis. *Sociological Theory*, *30*(3), 167–186.

Tolhurst, E., & Kingston, P. (2013). Understanding the experience of dementia: Utilising the theoretical insights of 'status passage'. *Social Theory & Health*, *11*, 175–193.

Townsend, P. (1981). The structured dependency of the elderly: A creation of social policy in the twentieth century. *Ageing & Society*, *1*(1), 5–28.

Trainor, L. R., & Bundon, A. (2021). Developing the craft: Reflexive accounts of doing reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *13*(5), 705–726.

Trnka, S., & Trundle, C. (2014). Competing responsibilities: Moving beyond neoliberal responsibilisation. *Anthropological Forum*, *24*(2), 136–153.

Uldam, J., & McCurdy, P. (2013). Studying social movements: Challenges and opportunities for participant observation. *Sociology Compass*, *7*(11), 941–951.

Vandermorris, S., Davidson, S., Au, A., Sue, J., Fallah, S., & Troyer, A. K. (2017). 'Accepting where I'm at' – a qualitative study of the mechanisms, benefits, and impact of a behavioral memory intervention for community-dwelling older adults. *Aging & Mental Health*, *21*(9), 895–901. https://doi.org/10.1080/13607863.2016.1181709

Varey, S., Dixon, M., Hernández, A., Mateus, C., Palmer, T. M., & Milligan, C. (2021). The role of combinatorial health technologies in supporting older people with long-term conditions: Responsibilisation or co-management of healthcare? *Social Science & Medicine*, *269*, 113545.

Walker, A. (2002). A strategy for active ageing. *International Social Security Review*, *55*(1), 121–139. https://doi.org/10.1111/1468-246X.00118

Walker, A. (2008). Commentary: The emergence and application of active aging in Europe. *Journal of Aging & Social Policy*, *21*(1), 75–93.

Wall, S. S. (2015). Focused ethnography: A methodological adaptation for social research in emerging contexts. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, *16*(1).

Waller, V., Farquharson, K., & Dempsey, D. (2015). *Qualitative social research: Contemporary methods for the digital age*. Sage.

Walsh, S., Govia, I., Wallace, L., Richard, E., Peters, R., Anstey, K. J., & Brayne, C. (2022a). A whole-population approach is required for dementia risk reduction. *The Lancet Healthy Longevity*, *3*(1), e6–e8.

Walsh, S., Merrick, R., Richard, E., Nurock, S., & Brayne, C. (2022b). Lecanemab for Alzheimer's disease. In *Bmj* (Vol. 379). British Medical Journal Publishing Group.

Warren, J. D., & Bamiou, D.-E. (2018). Prevention of dementia by targeting risk factors. *The Lancet*, *391*(10130), 1575.

Watson, A., & Lupton, D. (2022). Remote Fieldwork in Homes During the COVID-19 Pandemic: Video-Call Ethnography and Map Drawing Methods. *International Journal of Qualitative Methods*, *21*, 16094069221078376. https://doi.org/10.1177/16094069221078376

Werner, P. (2004). Beliefs About Memory Problems and Help Seeking in Elderly Persons. *Clinical Gerontologist*, *27*(4), 19–30. https://doi.org/10.1300/J018v27n04_03

Whitty, E., Mansour, H., Aguirre, E., Palomo, M., Charlesworth, G., Ramjee, S., Poppe, M., Brodaty, H., Kales, H. C., & Morgan-Trimmer, S. (2020). Efficacy of lifestyle and psychosocial interventions in reducing cognitive decline in older people: Systematic review. *Ageing Research Reviews*, *62*, 101113.

WHO, W. H. (2015). *World report on ageing and health*. World Health Organization.

Williams, S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health & Illness*, *22*(1), 40–67.

Williams, S. J., Higgs, P., & Katz, S. (2012). Neuroculture, active ageing and the 'older brain': Problems, promises and prospects. *Sociology of Health & Illness*, *34*(1), 64–78.

Woermann, N. (2018). Focusing ethnography: Theory and recommendations for effectively combining video and ethnographic research. *Journal of Marketing Management*, *34*(5–6), 459–483.

Zaidi, A., & Howse, K. (2017). The Policy Discourse of Active Ageing: Some Reflections. *Journal of Population Ageing*, *10*(1), 1–10. https://doi.org/10.1007/s12062-017-9174-6

Appendices

Appendix 1 – Description of the APPLE-tree intervention as an example of active ageing practice.

Background and context of the intervention

The APPLE-tree programme stands for Active Prevention in People at risk of dementia through Lifestyle, Behaviour change and Technology to build Resilience (Cooper et al., 2020). It aims to apply and test an active dementia prevention model which seeks to facilitate active ageing in people who are limited by cognitive and other impairments.

- The hypothesis that dementia incidence can be reduced by targeting modifiable dementia risk factors is increasingly accepted (Cooper 2019).
- Content was devised in response to and influenced by modifiable risk factors of dementia, identified from the Lancet Commission on Dementia Prevention, Intervention, and Care.
- APPLE-tree developed within a background of few multi-modal health interventions and is unique as it specifically targets older people (60+) with mild cognitive impairment which is not dementia.
- Co- production workshops shaped the structure of the sessions.

Recruitment and participants

Recruitment was through NHS primary and secondary care services, using the Dementia Research register, and third-sector partners. Recruitment ranged from memory services to well-being centres where posters were responded to as well as GPs identifying people who may benefit from the intervention.

Content of the workshops

Mix of taught information, power point, white board exercise, sharing experiences through questions and answer of ‘myth busting’ on health topics.

1. Nutrition

2. Physical Activity
3. Cognitive stimulation
4. Social isolation
5. Physical health and illness

Delivery

Intended to be face-to-face the intervention moved to a 1 hour online session due to the covid-19 pandemic. One intervention group ran for 20 weeks and included the following:

- 10 facilitated sessions on healthy lifestyle topics interspersed with 'tea-groups'.
- 10 'tea-groups' or social sessions which ran every other week.

These were delivered by two facilitators, trained, and supervised by a clinical/health psychologist, to groups of approx. 10 to 12 participants, with catch-up sessions for participants unable to attend groups.

Resources

Participants received a manual containing both text and pictures relating to the five health session topics and was to be used in conjunction with the online sessions.

Participants also received a one-off delivery of food items linked to the recipes and a Fitbit watch to measure their steps whilst walking. They also received weekly individual goal setting phone calls from the facilitator in their groups and a goal setting booklet/record.

Example of structure and content of an average session:

Arrival stage

Entry into the session through zoom was significant and was always accompanied by a comment about who was first and usually there would be IT difficulties and camera and sound problems which would need attention and allowed and introductory opening for people to establish themselves

Apple in the jar exercise as weekly opening exercise:
Inter-active activity participants were encouraged to share individual achievements and a plastic apple was placed symbolically in the jar, intended to be lighthearted.

Introduction of the two health related topics to be covered,
Information and clips with a question-and-answer discussion, often using a white board. Participants encouraged to refer to their manual throughout.

Exercise clips
Collection of clips from NHS health website and participant asked to pick one to watch and discussion followed around the likelihood of trying the activity shown. Practicalities of accessing it locally with links shared when available.

Activity diary
Introduced as an ongoing exercise from about week 3-4 onwards and then referred to during different sessions with participants asked about their progress and entries, option to share.

Weekly recipe/nutrition
Introduced through a short clip made by the research team demonstrating cooking the recipe video. Also, a nutritional questionnaire was completed at the beginning and the end of the programme.

Takeaways
Always finished with participants being asked what their ‘take away’ piece of information of advice was from the session.

Appendix 2 – Published paper of my scoping review

UK/Europe and the rest of the world

Dementia
2022, Vol. 0(0) 1–36

Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/14713012221147710
journals.sagepub.com/home/dem
SAGE

Understanding the subjective experiences of memory concern and MCI diagnosis: A scoping review

Christine Carter
Division of Psychiatry, University College London, London, UK

Tiffeny James
Division of Psychiatry, University College London, London, UK

Paul Higgs
Division of Psychiatry, University College London, London, UK

Claudia Cooper
Division of Psychiatry, University College London, London, UK

Penny Rapaport
Division of Psychiatry, University College London, London, UK

Abstract

Introduction: Many older people experience memory concerns; a minority receive a diagnosis of Mild Cognitive Impairment (MCI) or Subjective Cognitive decline (SCD). There are concerns that medicalisation of MCI and memory concern may fail to acknowledge subjective experiences.

Aim: We explore the meaning individuals give to their memory concerns, with or without a diagnosis of MCI and SCD.

Method: We scoped literature exploring subjective experiences of memory concern, with or without a diagnosis of MCI or SCD. We searched CINAHL, PsycINFO and MEDLINE in March 2020, and updated in Sept 2021.We used (Arksey & O'Malley, 2005) framework to guide our scoping review method and thematic analysis to analyse our findings.

Corresponding author:
Christine Carter, Division of Psychiatry, University College London, Maple House, 149 Tottenham Court Road, Bloomsbury, London W1T7NF, UK.
Email: christine.carter.19@ucl.ac.uk

Results: We screened 12,033 search results reviewing the full texts of 92 papers. We included 24 papers, including a total of 453 participants, the majority of whom were female, from White ethnic majority populations (or from studies where ethnicity was not identified) with high levels of education. In 15 out of 24 studies, 272 participants were diagnosed with MCI. We identified two themes; *Making a diagnosis personal* and *Remembering not to forget*. We found that subjective experiences include normative comparison with others of the same age and responses including fear, relief, and acceptance, but culminating in uncertainty.
Conclusion: Drawing upon sociology, we highlight the subjective experiences of living with memory concerns, SCD and an MCI diagnosis. We identify a gap between the intended purpose of diagnostic labels to bring understanding and certainty and the lived experiences of those ascribed them.

Keywords
Memory concerns, mild cognitive impairment, liminality, subjective experiences, diagnosis, age, agency, active ageing, relationships, roles

Introduction

Many older people have concerns about their cognitive function, which generate uncertainty and confusion. Some seek help and receive a diagnostic label. Mild Cognitive Impairment (MCI) and Subjective Cognitive Decline (SCD) are diagnostic categories which describe respectively, objective, and subjective cognitive concerns judged by the diagnostician to be inconsistent with age, but not indicative of dementia.

There is ambiguity around the diagnosis of MCI (Schweda et al., 2018) despite its inclusion in the Diagnostical Statistical Manual-5 (DSM-5). Doubts regarding the value and utility of the diagnosis create dilemmas for those conferring, and in receipt of, this diagnostic 'label'. The conversion rate from MCI to dementia varies. McGrattan et al., (2022) study found a range of 6.0%–44.8%; with an average follow-up 3.7 years. SCD is sometimes a precursor to MCI. Opdebeeck et al., (2019) found limited associations between SCD and objective cognition, querying the worth of this term as a category (Gifford et al., 2015). Most individuals meeting the criteria for MCI and SCD are undiagnosed, so these labels are descriptors of the minority of people who seek help for mild memory concerns.

Literature focuses upon prognostic implications of MCI/SCD, with less attention given to the subjective experiences of diagnosis, and memory concerns (Gerstenecker and Mast (2015)). (Beard & Neary, 2013) describe how the medicalisation of MCI and memory concern does not account for the subjective accounts of lived experiences of the condition. Our scoping review is the first, to our knowledge, to explore literature on individual experiences of living with memory concern that is not dementia. Scoping reviews explore and understand knowledge in an emerging field and discuss characteristics in that field (Peters et al., 2020). We draw upon notions of liminality, agency, and sociological concepts of age through the third and fourth age to explore our review findings.

Methods

Our review was guided by (Arksey & O'Malley, 2005) 6 stage framework for scoping reviews and Levac and colleagues (2010) paper on advancing scoping review methodology. We also incorporated contemporary guidance from the Joanna Brigg Institute (JBI) which points to scoping reviews as being mostly descriptive, with authors having the flexibility to undertake more in-depth analyses to inform research questions. We used thematic analysis techniques to conduct a qualitative meta-synthesis of our findings. We report our methods using headings from Arksey and O'Malley's (2005) framework,

Stage 1) Identifying the research questions

To capture the individuality of lived experience, we included subjective terminology in our research questions

- What meaning do individuals give to their memory concerns, including those with or without a diagnosis of MCI and SCD.
- How do they understand this in context of cognitive impairment and ageing

Stage 2) Identifying relevant studies

We searched CINAHL, PsycINFO and MEDLINE on 12/3/2020 for words relating to three concepts. Concept 1 included search terms around MCI, subjective cognitive decline, memory concerns and related terms used within a public domain. Concept 2 included words relating to older people, age and later life. Concept 3 included words for subjective experiences such as feelings, and meaning. A full search example is included in Appendix 1. We also hand searched reference lists of relevant articles. We re-ran searches in September 2021.

Stage 3) Study selection: Inclusion criteria

We included primary qualitative or mixed methods research studies, published in English in peer reviewed journals, reporting the experiences of populations, all of whom were aged 55 and over and living with a cognitive impairment which was not dementia e.g., MCI, SCD or other memory concerns. We excluded review articles but individual papers on review reference lists were considered for inclusion. Following de-duplication, search results were screened via title by one researcher (CC), excluding any that were irrelevant. The remaining were screened by abstract with a second researcher (PR) double screening 20% to standardise the screening process. We resolved any disagreements through discussion. This process resulted in 92 articles for full text screening. Papers were critically discussed with reviewer (PR) and a second blinded reviewer (TJ) reviewed a sample of six selected papers in depth. The PRISMA flow diagram in Figure 1 shows the screening process.

Stage 4) Charting the data

We (CC, PR & TJ) produced a data extraction table (Appendix 2) and extracted, for each paper: country of publication, research aims, sample population, data collection method, data analytic approach, and key themes identified. We used the Critical Appraisal Skills Programme tool for qualitative studies (CASP 2019). Studies were not excluded on the grounds of quality, in line with qualitative review practice (Thomas & Harden, 2008). The quality assessment table is in Appendix 3.

Stage 5) Collating, summarising, and reporting the results

Full papers were imported into NVivo 11 for thematic synthesis (Braun & Clarke, 2021). Where papers were mixed methods only qualitative results were used. We were guided by Thomas and Harden's (2008)

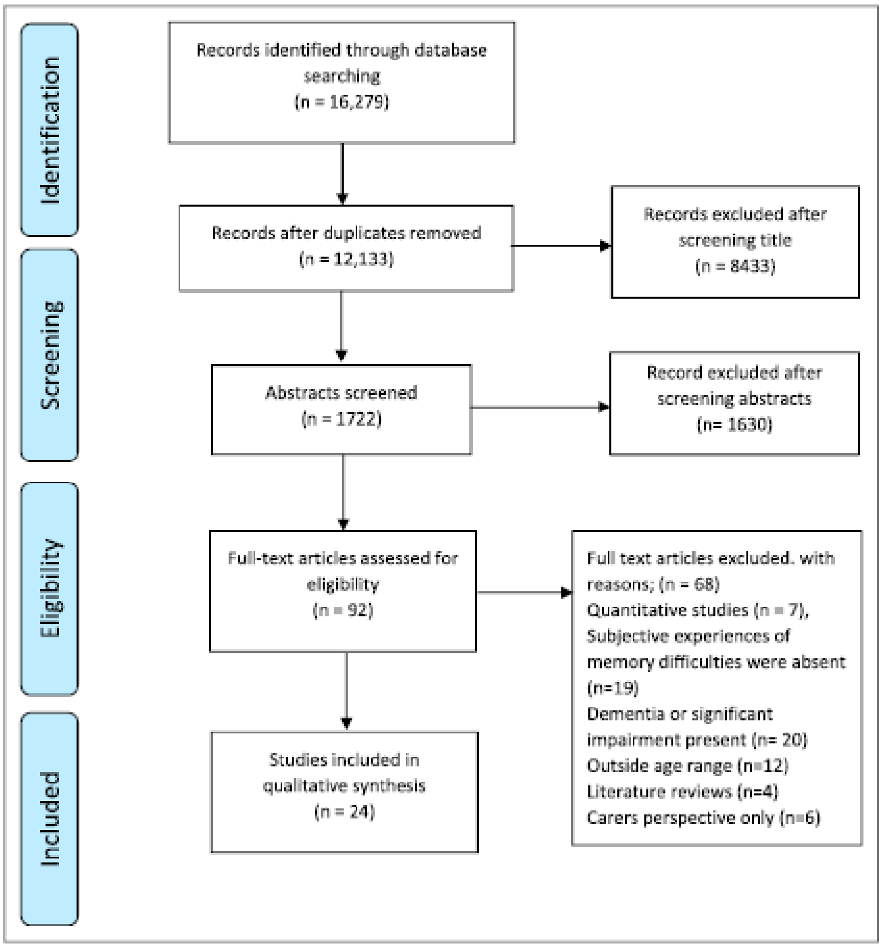


Figure 1. PRISMA flow diagram of screening process.

approach to thematic synthesis. Primary qualitative data included within the published papers, the reported themes and supporting quotes were coded. Using Nvivo we organised and categorised papers themes as codes. (CC) coded data guided by our research questions and (PR) and (PH) reviewed this data. Quotes from participants were used to preserve their voice and retain the integrity of the original studies, recommended in scoping reviews (Peters et al, 2020). CC re-read papers and developed overarching themes, further synthesis of themes was achieved through discussion within the co-author group.

Stage 6) Consultation stage

Consultation is a recommended part of the scoping review process. (Arksey & O' Malley 2006) We consulted on our findings with a Patient Participation Involvement (PPI) group from the APPLE-tree multi-domain health and lifestyle intervention for people aged 60 + who have memory concerns with or without a diagnosis of MCI (Cooper et al., 2020). We held the session on zoom with 3 people. All participants were female, one described herself as having 'early stage Alzheimer' the second cared for parents with memory problems and the third was the APPLE-tree programme manager. Using our two themes we presented quotes from selected studies within the literature to facilitate a discussion. Participants felt the quotes reflected their own personal experiences, describing them as 'accurate and valid' and another saying they were 'spot on'.

Findings

Study selection

Our search yielded 16,279 studies, from which we included 24 papers (see Figure 1 for PRISMA).

Country of origin

Seven studies took place in the UK (Corner & Bond, 2004; Dean et al., 2014; Giebel et al., 2016; Gomersall et al., 2017; Meilak et al., 2016; Pierce et al., 2016; Poppe et al., 2020), followed by five papers from the USA (Beard & Neary, 2013; Hill et al., 2018; Kruger TM, 2014; Lingler et al., 2006; Renn et al., 2021). Two papers were from Israel (Rotenberg et al., 2020; Werner, 2004) and two were from Canada (Parikh et al., 2016; Vandermorris et al., 2017). The remaining papers were from Belgium, Sweden, Holland, New Zealand, South Korea, and Japan.

Participant characteristics

The 24 papers included a total of 211 male participants and 242 female participants with ages ranging from 55 to 93 years. Participants in 15 papers had a diagnosis of MCI, ranging from within the last 6 months (Rotenberg et al., 2020), to over 7 years ago (Berg et al., 2013). Seven papers included participants described as having memory concerns (subjective or objective), whilst in two papers participants were screened as having SCD.

From this point forward when we use the term 'memory concerns' we refer to people with varying degrees of cognitive impairment who experience this subjectively and objectively and which includes people with a diagnosis of MCI or screened for SCD and those without. When we just use the term 'MCI' we refer to papers where participants specifically have a diagnosis of MCI.

Out of the 24 papers selected only 15 reported on the ethnicity of the participants. Where ethnicity was documented the majority were reported as being Caucasian and white British, only 3 participants described themselves as African Caribbean British (Meilak et al., 2016; Poppe, 2020). One UK study focus was on South Asian participants described as Indian British and Pakistani British (Giebel et al., 2016). Studies from New Zealand described participants who identified as native New Zealand and the South Pacific Islands,(Collier et al., 2020) two papers were from Japan and Korea respectively, (Choi & Kim, 2020; Nakano et al., 2012) and one paper from Israel described European and Asian participants but didn't specify further, (Werner, 2004). The majority of participants were reported as having moderate to high levels of education.

Population and settings

Ten studies recruited from memory clinics,(Begum et al., 2013; Dean et al., 2014; Giebel et al., 2016; Gomersall et al., 2017; Imhof et al., 2006; Joosten-Weyn Banningh et al., 2008; Lingler et al., 2006;

Meilak et al., 2016; Pierce et al., 2016; Poppe et al., 2020); seven recruited sub-samples from larger studies, (Beard & Neary, 2013; Berg et al., 2013; Collier et al., 2020; Corner & Bond, 2004; Kruger TM, 2014; Rotenberg et al., 2020; Vandermorris et al., 2017). Five papers recruited from community settings (Begum et al., 2013; Hill et al., 2018; Nakano et al., 2012; Poppe et al., 2020; Werner, 2004), defined as rural, urban, community dwelling and third sector community organisations, four papers purposively recruited from Geriatric Day/Hospitals settings (Choi & Kim, 2020; De Vriendt et al., 2012; Parikh et al., 2016; Renn et al., 2021).

Thematic analysis

Thematic analysis generated two themes; *Making a diagnosis personal* and *Remembering not to forget*. Themes and subthemes reflect both the breadth of the literature and commonalities within in.

Making a diagnosis personal

This theme describes how individuals respond to MCI and how a lack of clear knowledge surrounding memory concerns creates feelings of uncertainty. We identified 3 sub-themes. These explore; (1) the uncertainty and reactions surrounding a diagnosis of MCI due to a lack of knowledge, (2) the normalisation of the experience of memory concern with others of a similar age and (3) Coming to terms with accepting MCI . People either appear to accept these experiences, some that feel frightened by the uncertainty and others need to fill in the gaps by learning more.

Sub-theme 1: Responding to uncertainty and certainty of a diagnosis. The lack of clarity around a diagnosis of MCI results in feelings of uncertainty, (Beard & Neary, 2013; Gomersall et al., 2017; Poppe, 2020). The impact of this is exemplified by a participant diagnosed with MCI, who expressed uncertainty and questioned the diagnosis several times during an interview,

> *"I don't know how important [an MCI diagnosis] is, or not important. Is it very important? Seriously important? Or not very important? I don't know"* (Collier et al., 2020 p.306)

In attempting to gain clarity participants sought knowledge around the physical nature of memory impairment (Choi & Kim, 2020; Collier et al., 2020; Giebel et al., 2016; Imhof et al., 2006; Renn et al., 2021). Collier et al., (2020) describes how following a diagnosis of MCI, a participant learnt about the physical structure and function of the brain. Reactions and responses to MCI include, relief, acceptance, distance and fear. (Beard & Neary, 2013; Begum et al., 2013; Berg et al., 2013; Corner & Bond, 2004; Gomersall et al., 2017; Kruger TM, 2014; Lingler et al., 2006; Pierce et al., 2016; Rotenberg et al., 2020). Relief was expressed when finding out the diagnosis was MCI and not Alzheimer's disease. A participant who was 7 years post MCI diagnosis comments,

> *"when I spoke to the doctor after the 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)

However, 'a new' diagnosis of MCI, 'downgraded' from Alzheimer's may fail to assuage worry. In the following example a participant who had been given a diagnosis of MCI after previously being told that she had Alzheimer's said the following after reading a leaflet about MCI,

> *"I thought: I haven't got it, well, what have I got then? And I were reading that and I thought: what's this? This is more or less saying a similar thing to er ... dementia"* (Gomersall et al., 2017 p.793)

These experiences illustrate how in practice, the concept of MCI lacks clarity. Being given a diagnosis of MCI allowed individuals to distance themselves from dementia yet the uncertainty of developing dementia is not eliminated., (Beard & Neary, 2013; Begum et al., 2013; Lingler et al., 2006). A participant with memory concern who had a close relative with Alzheimer's describes the fear this induced,

> *"and this is one thing I do just dread, and that is Alzheimer's, very much so, because my father had it...the mere thought of dementia terrifies me...more than any other thing [disease] to die from ... like cancer"* (Corner & Bond, 2004 p.147)

Corner & Bond, (2004) interviewed people categorised 'at risk' of memory impairment, finding concerns about dementia increased where a relative had developed it, and the perception was that little could be done by contacting health professionals,

> *"There's not much point going to your doctor, really is there, I mean it's not like they can cure it or anything"* (Corner & Bond, 2004 p.149)

Linglers (et al. 2006) study supports this and reports that participants preferred to construct personal narratives about their diagnosis with only sporadic references to health care professionals as a source of information. Giebel et al (2016) found that those who had not consulted a GP about their memory concerns were more likely to describe themselves as leaving things to fate.

Sub-theme 2: Normalising memory concerns through age and shared experiences. Normalising memory concerns through age and ageing is well documented in the literature, with uncertainty and disagreement among experts how best to characterize the relationship between ageing and dementia (Beard & Neary, 2013; Begum et al., 2013; Corner & Bond, 2004; Giebel et al., 2016; Kruger TM, 2014; Parikh et al., 2016; Renn et al., 2021; Vandemorris et al., 2017). Within this context, individuals must navigate the meanings around MCI, diagnosis and their relationship to age. Imhof, (2006) and Renn, (2021) both discuss how age is presented as an explanation of memory concerns which can be reassuring and how disclosure of this to others is a source of support, illustrated here from a participant diagnosed with MCI;

> *"and we talk to each other because we're all more or less in the same boat"* (Begum et al., 2013 p.468)

Expectations about age could distance individuals from services, limiting support or invalidating concerns, (Dean et al., 2014; Gomersall et al., 2017; Imhof et al., 2006; Renn et al., 2021). Illustrated by a female participant diagnosed with MCI who, on seeing her GP about memory concerns was asked;

> *"have you considered your age Mrs? [She describes being furious, saying]; 'absolute rubbish we go to church with elderly people in their mid and late nineties, maybe wobbly on their feet but as alert as anything"* (Dean et al., 2014 p.477)

Positioning herself in relation to older peers resulted in feeling this was not normal for her age. Individuals' lack of clarity of how MCI differed from 'normal' ageing and dementia mirrors uncertainty within professional diagnosis; illustrated by a participant with MCI, *"I don't know what [MCI] means [...] I want to know, I sort of need to know. I mean, with other people who are my age and my activity [...] how does that fit alongside people of similar circumstances? I don't know"* (Collier et al., 2020 p.307)

Shared activities and settings served to normalise changes in memory. For example, being in a senior living community made it easier to talk about memory decline as *'people accept it because it's not uncommon here'*, (Renn et al., 2021). In Renn's study a participant with a diagnosis of MCI talked about giving up driving,

"it's not a premature thing a lot of 80 years old I know don't drive" (Renn et al., 2021 p.1102)

Vandermosis et al. (2017) and Beards (2013) studies suggest that normalising cognitive decline through age allows individuals to view memory concerns as evidence they don't have a serious problem, such as Alzheimer disease

"It's not early stage Alzheimer's. It's not MCI. I have a situation where I can't remember something. But, I don't think that is different than other people my age" (Beard & Neary, 2013 p.137)

Individuals re-frame the MCI label as part of normalising their memory problem, evident in the above quote by a participant diagnosed with MCI within the last 3 years,

Sub-theme 3: Coming to terms with accepting MCI. Time-based or temporal factors shape understandings of MCI. A study participant on receiving a diagnosis of MCI perceived a friend's experience of memory decline as rapid and used this to position himself.

"I know one guy who went from six months ago MCI to losing it all in 6 months so I'm aware how serious it is" (Kruger, 2014 p.120)

Corner and Bond (2004) highlight a complex picture due to unknown trajectories of MCI raising questions for individuals. When asked about future expectations one participant with MCI said they didn't feel there was any future, and at the same time reconciled this to themselves;

"the future? Oh, the future is behind me! (laughs) You know, I have had a great life, I have had a good job and kids, and... all that is behind me you know. I just hope I will have some good and healthy years now" (Berg et al., 2013 p.297)

Renn et al., (2021) describes how people with MCI can 'seek a sense of calmness', suggesting a more positive acceptance about their future life, One participant, for example described it as '*taking stock of life*'. The confusion about length of progression from MCI to something 'worse' is illustrated by this quote from a person living with MCI,

"Well I do worry if it gets worse, 'I don't want to end up like a cabbage. You need your faculties don't you in life" (Pierce et al., 2016 p.8)

Although not using the term Alzheimer's, perceptions of progression reflect a fear of losing control and an ability to function independently. The belief that 'it could be worse', means it could have been a diagnosis of dementia. An extract below from a participant with MCI demonstrates this,

> *"I have to resign myself to it" and "I have to convince myself that they couldn't find anything and accept that it's not dementia I'm suffering from"* (Joosten-Weyn Banningh et al., 2008 p.152)

Many researchers suggest that individuals normalise their forgetfulness rather than actively fight it, (Beard & Neary, 2013; Joosten-Weyn Banningh et al., 2008; Parikh et al., 2016; Pierce et al., 2016). This is, illustrated in the following from a participant with an MCI diagnosis;

> *"If I can't do anything about it, I accept it, and that's the way it is. That's life"* (Parikh et al., 2016 p.881)

In the absence of clear information, it could be argued that MCI generates both acceptance and inevitability.

Remembering not to forget

This theme describes actions individuals undertake adapting and responding to memory concerns, highlighting the emotional effort this involves. We identified 3 sub-themes, 1) attempts to make sense of memory concerns, 2) using everyday compensatory strategies, 3) how individuals navigate relationships with friends and family.

Sub-theme 1: The effort and impact of adapting actions and to stay active. Individuals respond to memory concerns by adapting which sometimes includes failing, with responses requiring tremendous effort (Corner & Bond, 2004; Hill et al., 2018; Meilak et al., 2016; Renn et al., 2021). Imhof et al. (2006) described participants as, *'trying to manage failure and reorganizing tasks to reduce complexity'*. This is illustrated in the following extract which indicates how exhausting the conscious effort of remembering can be, this participant did not have a diagnosis of MCI but had concerns about their memory;

> *"I need to think and keep my attention on what I am doing, and I am tired of thinking... In earlier days, I managed to do a thousand things at the same time"* (Imhof et al., 2006 p.350)

Adapting to the disruption caused by memory concerns, affirms ability to continue that activity, exemplified by the following participant who had memory problems for more than 6 months but no MCI diagnosis;

> *"I started reading a book, and only about half way though I realized that I had already read it. For a while I almost stopped reading because of this. Eventually I got back to reading books, because it's entertainment, and as long as it's fun while I read, that's enough for me"* (Rotenberg et al., 2020 p.6)

Individuals try to avoid fixating on the process of remembering, as illustrated in the following extract from a participant who has been screened has having SCD,

> *"I try to make the things I need to remember less important"* (Hill et al., 2018 p.5)

This suggests a pressure to perform, linked to the concept of a *'use it or lose it'* belief described by Meilak et al. (2016). Pressure to compensate through writing everything down also acts as a reminder of individual limitations in people concerned about their memory, illustrated in the following;

> *"I have a diary there and I write everything down that I've got to do—all my appointments, dentist, everything. I think Oh God! I'm losing my marbles"* (Corner & Bond, 2004 p.5)

Renn, (2021) describes how 'helpful' strategies imposed by others could produce feelings of shame. A participant described how using a whiteboard calendar set up by his wife to plan his week left him feeling embarrassed. Thus, the intervention response inadvertently positions the individual as feeling they are the problem. There appears to be juxtaposition of creating and maintaining strategies to compensate for the impact of memory loss, yet simultaneously these serve as a constant reminder of that loss. Feelings of stupidity amongst participants in relation to MCI or memory concerns have been documented, (Berg et al., 2013; Collier et al., 2020; Gomersall et al., 2017; Nakano et al., 2012; Parikh et al., 2016). Emotional reactions ranged from bewilderment to feeling stupid over memory mistakes, as exemplified by a participant with a diagnosis of MCI,

> *"If I say something and [my son] says, "Oh, you've said that before…." That destroys you when they say, "you've said that before"* (Parikh et al., 2016 p.881)

Feeling "destroyed" when memory mistakes are brought to his attention highlights the impact that this may have on self-esteem and confidence for some individuals, (Parikh et al., 2016).

Sub-theme 2: Using compensatory strategies everyday. Compensatory strategies minimise the disruption memory concerns create, such as writing lists, using diaries, creating routines, visualising travel routes and repetition of information, (Corner & Bond, 2004; Hill et al., 2018; Imhof et al., 2006; Joosten-Weyn Banningh et al., 2008; Meilak et al., 2016; Parikh et al., 2016; Renn et al., 2021). 'Self–management strategies' were undertaken as a way of compensating for memory concerns, (Begum et al., 2013; Gomersall et al., 2017). Parikh et al., (2016) study describes this as '*reliably remembering*', a process of helping with "self-esteem" and "coping", expressed by the following participant with MCI;

> *"It's just a matter of compensating, learning how to compensate…. I think we've adjusted so we can continue doing what we've done for years and years"* (Parikh et al., 2016 p.882)

However, studies describe individual's inability to remember to use the external compensatory strategies they develop, exemplified in the following extract from a participant screened as having SCD;

> *"Well, I try to associate other names or other ideas with it and sometimes it works, then other times, I figure I have an association, and then I can't* figure *the association"* (Hill et al., 2018 p.7)

Individual's previous careers supported compensatory strategies, such as using appointment books. (Berg et al., 2013; Hill et al., 2018; Parikh et al., 2016; Poppe, 2020).

Sub-theme 3: Relationships and connections with others. Poppe's (2020) study found that maintaining a job and socialising were deemed important ways of staying connected, affecting views of retirement and activity. Personal relationships, such as spousal relationships frequently provided sources of practical and emotional support, (Begum et al., 2013; Dean et al., 2014). Partner relationships are significant in how individuals live and cope with memory concerns, a female participant with MCI illustrated this after being asked about support from publicly funded services "*without my husband I wouldn't have managed this well*" (Dean et al., 2014 p.481)

The importance of relational support through family and friends is well documented, (Collier et al., 2020; Dean et al., 2014; Parikh et al., 2016; Pierce et al., 2016; Renn et al., 2021). Research describes how friendships help participants with MCI cope with stress, as illustrated below;

"*I've got good friends and sometimes you just got to let it out, then I can calm down then I carry on*" (Dean et al., 2014 p.481)

Literature suggests relationships need to be adaptable to be supportive, examples of friends adjusting to an individual's memory concerns when participants choose to share their MCI diagnosis, as illustrated below,

"*all my friends know about it (MCI diagnosis) and they are making allowances for me, they're very good like that*" (Pierce et al., 2016 p.5)

This also infers a tolerability, allowing others to be accepting of the situation but may not mean acceptance. Several authors found the consequences of revealing memory concerns to others was invariably negative, leaving people irritated or angry with family and friends reactions, (Begum et al., 2013; Joosten-Weyn Banningh et al., 2008; Meilak et al., 2016; Nakano et al., 2012; Vandermorris et al., 2017). This is exemplified in the following statement from a female participant who had revealed her MCI diagnosis to her family.

"*I'm sorry I told them now, I'm not an invalid*" (Meilak et al., 2016 p.5)

This was in response to a family perceived as being overbearing in their offers of help. Reactions from friends can also, invalidate experiences of memory concerns. (Gomersall et al., 2017). This is illustrated by Gommersall who describes an 84-year-old participant recounting how her friend 'roared with laughter' at hearing that she had attended the memory clinic for MCI diagnosis.

Discussion

In this scoping review we selected 24 papers which included the experiences of 453 people either diagnosed with MCI or subjective cognitive decline (SCD), and others who self-identified with concerns about their memory. The majority of participants living with memory concerns with or without a diagnosis of MCI/SCD were female, from White ethnic majority populations (or from studies where ethnicity was not identified) and with high levels of education. We identified two themes; *Making a diagnosis personal* and *Remembering not to forget*. We found that individuals understand cognitive concerns through normative comparison with others of the same age and this is associated with a range of responses including fear, relief, and acceptance but culminating in uncertainty.

Mild cognitive impairment and SCD do not have homogeneous underlying pathologies or a predictable disease course and the ability of a diagnosis to reassure and help people has been questioned, (Gifford et al., 2015; Howard, 2020; Pickersgill, 2014). This contributes to the feelings of uncertainty expressed within the literature. The concept of 'manufactured uncertainty', (Giddens, 1999) has resonance here where more knowledge does not lead to clarity but its opposite; consequently, the diagnostic process surrounding MCI rarely appears to produce certainly and understanding. Despite its significance in the prodromal phase of dementia, MCI remains problematic due to a lack of standardised criteria (Schweda et al., 2018). The contested nature of MCI is not only about clinical nosology but rather is about how people's lives are not reducible to stages of a predefined disease progression. The lack of an explicit patient career creates not only uncertainty but also an existential vacuum. We found seemingly fatalistic responses with participants talking about 'resigning' to MCI. Individuals are forced to navigate a range of unclear meanings without any prospect of clarity or resolution.

Our scoping review identified that individuals normalise memory loss through comparison with peers of a similar age. As such individuals seek to gauge their own individual journey, in the absence of any clear 'external' trajectory following memory concerns and MCI. Unlike the more established concept of 'biographical disruption' where the diagnosis creates a new understandable narrative for the patient (Bury, 1982) conditions such as MCI do not lead to the same permanence. As Llewelyn points out, diagnosis should make a disease more navigable, "fixing the terrain over which care can be mapped" (Llewelyn H, 2017). However, in the case of memory concerns the terrain is not easily read and its status as a disease is questionable. Our findings reflect the features of a diagnosis of dementia noted by others; it rarely happens at a single point in time but, rather across time and is situated in the physical and social changes realised by the individual and others (Birt et al., 2017).

Our first theme 'making a diagnosis personal' captures the uncertainty surrounding reactions and responses to a diagnosis of MCI. Its supports the notion of a liminal experience for those living with MCI and reflects its contested nature. Birt et al., (2017) describes liminality as relating to people being pushed into an in-between state through a diagnosis which results in uncertainty and confusion. We found that as familiar roles altered through retirement and familial roles were compromised through cognitive changes, an individual's sense of place and position in society was disrupted. Birt et al., (2017) points out that cognitive changes also mark a sociological event, as planned trajectories, roles and statuses are threatened. Unclear trajectories mean individuals find themselves in a sustained liminal state which Kelly (2010) describes as 'learning to live with liminality'. However, contemporary descriptions challenge this focus on liminality, with notions of active or successful ageing challenging discourses of decline and deficit, (Birt et al., 2017). Birt et al talks about a post-liminal state as people reposition themselves through agentic actions which support social citizenship such as active ageing. (Birt et al., 2017). We can see from our findings that participants put a considerable amount of effort into actively responding to their memory concerns through prevention strategies.

Our second theme 'remembering not to forget' describes compensatory strategies people adopt in the face of memory concerns and how individuals navigate relationships with others. (Pierce et al., 2016) highlight that when people 'make allowances' for friends with memory concerns they are treated differently, drawing attention to notions of self-acceptance and seeking acceptance. Relationships can also be sources of stress and anxiety especially when familial roles change. Role transformation and re-negotiation of long-standing roles within dementia has been considered by (Fletcher, 2020) as the 'dyadic career' and relates to spousal dyads. Distinct caring roles in relationships MCI are not as defined as where an individual has dementia, however the relational aspect remains significant. Tanner, (2016) describes 'relational agency', as a way of preserving identity. Cognitive concerns is not simply a negation of agency but involves taking on of new forms of agency, exercised in new ways Tanner (2016). We found individuals navigated relationships with family and others as a way of exercising agency. How people place and position themselves in relation to others is significant and these relationships can create supportive or stressful encounters.

We found that the absence of knowing what to do after a diagnosis of MCI can create an urge to act. Within the culture of active ageing or 'successful ageing', this implies an expectation to undertake healthy interventions to slow cognitive deterioration following confirmation of memory impairment, with or without a diagnosis (Jones & Higgs, 2010). The notions of distinction identified in healthy ageing discourse describe how individuals prove they are actively resisting cognitive decline and as such distancing themselves from others, (Libert et al., 2020). Within this context societal expectations about age and ageing are predominately negative. Colliers et al. (2020) study discovered that concern around cognitive changes were secondary to the social and emotional changes associated with ageing in general. Understanding this through the concepts of the third and fourth age draws attention to the networks of social, material, and cultural resources which support 'normative differences' and away from 'life stage identifiers' in later life (Gilleard & Higgs, 2014). For these authors, the cultures of the third age are characterised by discourses of agency, choice, consumerism and the motivating desire to not be seen as old. In contradiction, the fourth age is conceived as a 'social imaginary' which projects the most negative aspects of decline in ageing onto society (Gilleard & Higgs, 2014). Within this social imaginary events such as 'falling' act as social markers of the pull of being defined by the fourth age. A diagnosis of MCI or concerns about one's memory fall into this category and can be conceived as warnings of what may lie ahead.

MCI is accompanied by temporal factors. We found that people use timelines to position themselves in relation to others establishing their own trajectory. Trajectories don't follow a linear progression but exist as a range of individual experiences defined by liminality but characterised through anxiety and unknowing. Individuals adopt a range of strategies in attempts to cope and stave off dementia. Sometimes this is an inaction, a desire to do nothing which appears at odds with current rhetoric about active ageing. Romaioli and Contarello (2019) argue that although considered 'defeatist' within contemporary successful or active ageing discourses, the absence of activism can be viewed as an active choice and offers another perspective to the fatalistic or acceptance attitudes we saw within our results, Romaioli and Contarello (2019) suggest that there is a risk that the idea of agency is defined as the capacity for active commitment and in this sense deprives the individual of the possibility of constructing a different relationship with time. Understanding this as a 'living' rather than 'lived experience', reflects and acknowledges individual's attempts to navigate memory concerns and MCI which affirms self-esteem and agency, however that is exercised.

Strengths and limitations

Multiple terms synonymous with memory problems exist, including various diagnostic terminology surrounding SCD and MCI. Therefore, decisions were made to include some search terms at the exclusion of others and as such may have restricted our breadth of search in this area. However, that aside, our search terms brought together a broad range of areas within a complex topic.

Our research questions included people with both a diagnosis of either MCI or SCD alongside those concerned about memory. We noted these distinctions but did not attempt to compare groups according to labels, given our conceptual understanding that the labels often reflected help-seeking rather than underlying pathology. Gaps in the literature reflect the subjective nuanced differences in people ascribed a diagnosis of MCI diagnosis and those who are not, including culturally diverse experiences which need to be considered in future research.

Conclusion

We have explored individual subjective experiences of memory concern, with or without a diagnosis of MCI, and more broadly how this interacts with the notion of cognitive impairment and age. Normalised and understood through age, societal expectations around active ageing adds to the complexity of these experiences. Individuals must navigate their own narrative and trajectory through memory impairment in the hope of creating certainty and maintaining agency. While a minority of people living with memory concerns are ascribed a diagnostic label of SCD/MCI. Acknowledging this as experience of potential anxiety and unknowing informs thinking about MCI as a diagnostic a category and more readily encompasses the emotional and psychological impact of this on people lives. The uncertainty surrounding an MCI diagnosis and associated disconnect with a sense of self and agency is still concerning. It is difficult to know how this compares to the experiences of most people who live with memory concerns who have not sought help. These questions require future exploratory research and increased understanding of the emotional and lived experiences of people with MCI to be taken into account when delivering public services.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: ESRC/NIHR dementia programme grant, Grant/Award Number: ES/S010408/1; NIHR/ESRC APPLE-Tree dementia programme, Grant/Award Number: ES/S010408/1 ESRC PhD grant number is ES/P000592/1.

Ethical approval

This is a review article based on publicly available published data, thus no ethical approval was sought, as no primary data were collected.

ORCID iDs

Christine Carter https://orcid.org/0000-0001-7650-8108
Tiffeny James https://orcid.org/0000-0002-5706-1467
Claudia Cooper https://orcid.org/0000-0002-2777-7616
Penny Rapaport https://orcid.org/0000-0003-0479-6950

References

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, *8*(1), 19–32, DOI: 10.1080/1364557032000119616

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

Begum, A., Whitley, R., Banerjee, S., Matthews, D., Stewart, R., & Morgan, C. (2013). Help-seeking response to subjective memory complaints in older adults: Toward a conceptual model. *The Gerontologist*, *53*(3), 462–473. DOI: https://doi.org/10.1093/geront/gns083

Berg, A. I., Wallin, A., Nordlund, A., & Johansson, B. (2013). Living with stable MCI: Experiences among 17 individuals evaluated at a memory clinic. *Aging & Mental Health*, *17*(3), 293–299. DOI: https://doi.org/10.1080/13607863.2012.751582

Birt, L., Poland, F., Csipke, E., & Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health & Illness*, *39*(2), 199–211, DOI: 10.1111/1467-9566.12530

Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, *18*(3), 328–352, DOI: 10.1080/14780887.2020.1769238

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, *4*(2), 167–182, DOI: 10.1111/1467-9566.ep11339939

Choi, M., & Kim, M. (2020). Living a daily life with self-awareness among older adults with mild cognitive impairment. *Research in Gerontological Nursing*, *13*(1), 41–48. DOI: https://doi.org/10.3928/19404921-20191025-01

Collier, G., Kayes, N., Reay, S., Hayes, N., & Bill, A. (2020). Designing a diagnosis? Reflections on design, medicalization, and mild cognitive impairment (MCI). *Design for Health*, *4*(3), 296–312. DOI: https://doi.org/10.1080/24735132.2020.1837507

Cooper, C., Aguirre, E., Barber, J. A., Bass, N., Brodaty, H., Burton, A., Higgs, P., Hunter, R., Huntley, J., Lang, I., Kales, H. C., Marchant, N. L., Minihane, A. M., Ritchie, K., Morgan-Trimmer, S., Walker, Z., Walters, K., Wenborn, J., & Rapaport, P. (2020). APPLE-Tree (active prevention in people at risk of dementia: Lifestyle, bEhaviour change and technology to REducE cognitive and functional decline) programme: Protocol. *International Journal of Geriatric Psychiatry*, *35*(8), 811–819, DOI: 10.1002/gps.5249

Corner, L., & Bond, J. (2004). Being at risk of dementia: Fears and anxieties of older adults. *Journal of Aging Studies*, *18*(2), 143–155. DOI: https://doi.org/10.1016/j.jaging.2004.01.007

Dean, K., Jenkinson, C., Wilcock, G., & Walker, Z. (2014). Exploring the experiences of people with mild cognitive impairment and their caregivers with particular reference to healthcare – A qualitative study. *International Psychogeriatrics*, *26*(3), 475–485. DOI: https://doi.org/10.1017/S104161021300207X

De Vriendt, P., Gorus, E., Cornelis, E., Velghe, A., Petrovic, M., & Mets, T. (2012). The process of decline in advanced activities of daily living: A qualitative explorative study in mild cognitive impairment. *International Psychogeriatrics*, *24*(6), 974–986. DOI: https://doi.org/10.1017/S1041610211002766

Dooley, J., Bailey, C., Xanthopoulou, P., Bass, N., & McCabe, R. (2020). Communication and understanding of mild cognitive impairment diagnoses. *International Journal of Geriatric Psychiatry*, *35*(6), 662–670. DOI: https://doi.org/10.1002/gps.5284

Fletcher, J. R. (2020). Renegotiating relationships: Theorising shared experiences of dementia within the dyadic career. *Dementia*, *19*(3), 708–720. DOI: https://doi.org/10.1177/1471301218785511

Gerstenecker, A., & Mast, B. (2015). Mild cognitive impairment: A history and the state of current diagnostic criteria. *International Psychogeriatrics*, *27*(2), 199–211. https://doi.org/10.1017/S1041610214002270

Giddens, A. (1999). Risk and responsibility. *Mod. L. Rev*, *62*, 1–10, DOI: 10.1111/1468-2230.00188

Giebel, C., Challis, D., Worden, A., Jolley, D., Bhui, K. S., Lambat, A., & Purandare, N. (2016). Perceptions of self-defined memory problems vary in South Asian minority older people who consult a GP and those who do not: A mixed-method pilot study: Consultation for memory problems in South Asian elders. *International Journal of Geriatric Psychiatry*, *31*(4), 375–383. DOI: https://doi.org/10.1002/gps.4337

Gifford, K. A., Liu, D., Romano, R. R., Jones, R. N., & Jefferson, A. L. (2015). Development of a subjective cognitive decline questionnaire using item response theory: A pilot study. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, *1*(4), 429–439, DOI: 10.1016/j.dadm.2015.09.004

Gilleard, C., & Higgs, P. (2014). *Cultures of ageing: Self, citizen and the body*. Routledge.

Gomersall, T., Smith, S. K., Blewett, C., & Astell, A. (2017). 'It's definitely *not* Alzheimer's': Perceived benefits and drawbacks of a mild cognitive impairment diagnosis. *British Journal of Health Psychology*, *22*(4), 786–804. DOI: https://doi.org/10.1111/bjhp.12255

Henley, J., Hillman, A., Jones, I. R., Woods, B., MacLeod, C. A., Pentecost, C., & Clare, L. (2021). 'We're happy as we are': The experience of living with possible undiagnosed dementia. *Ageing and Society*, *1–26*, 1–26, DOI: https://doi.org/10.1017/S0144686X21001495

Higgs, P., & Gilleard, C. (2021). Techno-fixes for an ageing society. *Aging & Mental Health*, *0*(0), 1–3. DOI: https://doi.org/10.1080/13607863.2021.2008308

Hill, N., Mogle, J., Kitko, L., Gilmore-Bykovskyi, A., Wion, R., Kitt-Lewis, E., & Kolanowski, A. (2018). Incongruence of subjective memory impairment ratings and the experience of memory problems in older adults without dementia: A mixed methods study. *Aging & Mental Health*, *22*(8), 978–985. DOI: https://doi.org/10.1080/13607863.2017.1337715

Howard, R. (2020). Subjective cognitive decline: What is it good for? *The Lancet. Neurology*, *19*(3), 203–204, DOI: 10.1016/s1474-4422(20)30002-8

Imhof, L., Wallhagen, M. I., Mahrer-Imhof, R., & Monsch, A. U. (2006). Becoming forgetful: How elderly people deal with forgetfulness in everyday life. *American Journal of Alzheimer's Disease & Other Dementiasr*, *21*(5), 347–353. DOI: https://doi.org/10.1177/1533317506292499

Jones, I. R., & Higgs, P. F. (2010). The natural, the normal and the normative: Contested terrains in ageing and old age. *Social Science & Medicine*, *71*(8), 1513–1519, DOI: 10.1016/j.socscimed.2010.07.022

Joosten-Weyn Banningh, L., Vernooij-Dassen, M., Rikkert, M. O., & Teunisse, J.-P. (2008). Mild cognitive impairment: Coping with an uncertain label. *International Journal of Geriatric Psychiatry*, *23*(2), 148–154. DOI: https://doi.org/10.1002/gps.1855

Kelly, A. (2010). Lost the Feel for the Game: Meanings of Onset and Diagnosis of AIDS Dementia for Significant Others. *Qualitative Health Research*, *20*(4), 531–540. https://doi.org/10.1177/1049732309360537

Kruger, T. M. (2014). *Affective and behavioral responses to a diagnosis of mild cognitive impairment*: University of Kentucky. (Publication No. UMI 3579470) [Doctoral dissertation], Published by ProQuest LLC.

Libert, S., Charlesworth, G., & Higgs, P. (2020). Cognitive decline and distinction: A new line of fracture in later life? *Ageing & Society*, *40*(12), 2574–2592. DOI: 10.1017/s0144686x19000734

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. DOI: https://doi.org/10.1093/geront/46.6.791

Llewelyn, H. (2017). *Navigating brain tumours: Uncertainty, fixing and the production of possibility*.

McGrattan, A. M., Pakpahan, E., Siervo, M., Mohan, D., Reidpath, D. D., Prina, M., Allotey, P., Zhu, Y., Shulin, C., Yates, J., Paddick, S.-M., Robinson, L., & Stephan, B. C. M.Team, the D. (2022). Risk of conversion from mild cognitive impairment to dementia in low- and middle-income countries: A systematic review and meta-analysis. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, *8*(1), Article e12267. DOI: https://doi.org/10.1002/trc2.12267

Meilak, C., Partridge, J., Willis, R., & Dhesi, J. (2016). Mild cognitive impairment: A qualitative exploration of older adults' understanding, concerns and expectations. *Annals of Psychiatry and Mental Health*, *4*(1), 1–8. https://eprints.soton.ac.uk/388679/1/psychiatry-4-1054.pdf

Nakano, M., Sato, S., & Nakahara, J. (2012). Emotional experiences of the community-dwelling with mild cognitive impairment and their families. *Neuropsychological Trends*, *12*, 6. DOI: https://doi.org/10.7358/neur-2012-012-naka

Opdebeeck, C., Yates, J. A., Kudlicka, A., & Martyr, A. (2019). What are subjective cognitive difficulties and do they matter? *Age and Ageing*, *48*(1), 122–127. DOI: 10.1093/ageing/afy148

Parikh, P. K., Troyer, A. K., Maione, A. M., & Murphy, K. J. (2016). The impact of memory change on daily life in normal aging and mild cognitive impairment. *The Gerontologist*, *56*(5), 877–885. DOI: https://doi.org/10.1093/geront/gnv030

Peters, M. D., Marnie, C., Tricco, A. C., Pollock, D., Munn, Z., Alexander, L., McInerney, P., Godfrey, C. M., & Khalil, H. (2020). Updated methodological guidance for the conduct of scoping reviews. *JBI Evidence Synthesis*, *18*(10), 2119–2126, DOI: 10.11124/jbies-20-00167

Pickersgill, M. D. (2014). Debating DSM-5: Diagnosis and the sociology of critique. *Journal of Medical Ethics*, *40*(8), 521–525, DOI: 10.1136/medethics-2013-101762

Pierce, S., Lamers, C., & Salisbury, K. (2016). Knowingly not wanting to know: Discourses of people diagnosed with mild cognitive impairment. *Dementia*, *15*(5), 1246–1259. DOI: https://doi.org/10.1177/1471301215600895

Poppe, M., Mansour, H., Rapaport, P., Palomo, M., Burton, A., Morgan-Trimmer, S., Carter, C., Roche, M., Higgs, P., Walker, Z., Aguirre, E., Bass, N., Huntley, J., Wenborn, J., & Cooper, C. (2020). " Falling through the cracks "; Stakeholders' views around the concept and diagnosis of mild cognitive impairment and their understanding of dementia prevention. *International Journal of Geriatric Psychiatry*, *35*(11), 1349–1357. DOI: https://doi.org/10.1002/gps.5373

Renn, B. N., Wool, J. L., & Belza, B. (2021). A typical week with mild cognitive impairment. *The Gerontologist*, *61*(7), 1095–1106, DOI: 10.1093/geront/gnab008

Romaioli, D., & Contarello, A. (2019). Redefining agency in late life: The concept of 'disponibility'. *Ageing and Society*, *39*(1), 194–216. DOI: https://doi.org/10.1017/S0144686X17000897
Rotenberg, S., Sternberg, S., & Maeir, A. (2020). Where did I put my glasses? The lived experience of older adults seeking medical help for perceived memory problems. *Disability and Rehabilitation*, *42*(25), 3606–3613. DOI: https://doi.org/10.1080/09638288.2019.1602849
Schweda, M., Kögel, A., Bartels, C., Wiltfang, J., Schneider, A., & Schicktanz, S. (2018). Prediction and early detection of Alzheimer's dementia: Professional disclosure practices and ethical attitudes. *Journal of Alzheimer's Disease*, *62*(1), 145–155. DOI: 10.3233/jad-170443
Tanner, D. (2016). Sustaining the self in the "fourth age": A case study. *Quality in Ageing and Older Adults*.
Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(1), 45. DOI: https://doi.org/10.1186/1471-2288-8-45
Vandermorris, S., Davidson, S., Au, A., Sue, J., Fallah, S., & Troyer, A. K. (2017). 'Accepting where I'm at' – A qualitative study of the mechanisms, benefits, and impact of a behavioral memory intervention for community-dwelling older adults. *Aging & Mental Health*, *21*(9), 895–901. DOI: https://doi.org/10.1080/13607863.2016.1181709
Werner, P. (2004). Beliefs about memory problems and help seeking in elderly persons. *Clinical Gerontologist*, *27*(4), 19–30. DOI: https://doi.org/10.1300/J018v27n04_03

Appendix 1

1 mild cognitive impairment.mp. (21,418)
2 MCI.mp. (20,925)
3 (mild cognitive impairment adj20 diagnos*).mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (3237)
4 subjective cognitive decline.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (954)
5 SCD.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (14,392)
6 pre dementia.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (308)
7 memory concern*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (164)
8 memory complaint*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (1664)

9 memory loss.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (5181)
10 cognitive decline.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (28,324)
11 cognitive impairment.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (72,318)
12 senior moment*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (17)
13 (ageing or aging).mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (420,018)
14 older people.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (35,544)
15 elder*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (300,630)
16 older adult*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (103,399)
17 later life.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (12,852)
18 old age.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (31,872)
19 geriatric*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (114,100)
20 senior*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word,

protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (47,495)
21 experience*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (1,240,016)
22 feel*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (109,766)
23 understand*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (1,396,650)
24 (perceive or perception*).mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (508,288)
25 attitude*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (462,207)
26 meaning*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (159,712)
27 perspective*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (394,061)
28 belief*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (95,944)
29 view*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (521,025)
30 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 (118,963)
31 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 (856,109)
32 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 (3,999,165)
33 30 and 31 and 32 (7134)

Appendix 2

Author/Year/ Country	Research aims	Sample population	Data collection	Data analysis	Key themes
Kruger TM, (2014) USA	To develop a framework for understanding how and why older adults respond to a diagnosis of MCI.	Purposively selected subsample n = 15 of older people diagnosed with MCI from a longitudinal study on aging at the National Institute on aging-funded Alzheimer's disease centre, Sanders-Brown centre on aging, University of Kentucky Age range 64–91	In depth interviews and two survey.	Grounded theory	Three overlying themes. 1. Uncertainty 2. Temporal framing and 3. Interaction & role with others. Six influencing processes: 1. Beliefs about the cause of MCI, 2. Role of significant others, knowledge of MCI/dementia. 3. Knowledge of others with MCI/dementia, 4. Personality 5. Uncertainty associated with MCI.

(continued)

(continued)

Author/Year/Country	Research aims	Sample population	Data collection	Data analysis	Key themes
Beard and Neary (2013) USA	To explore the subjective experiences of individuals diagnosed with MCI, how individuals make sense of this diagnosis and its potential psychosocial impact.	Sub sample n = 18 diagnosed with MCI taken from larger study, ACCESS (assessing the cultural characteristics of elders and the support Systems) Average age n = 76	In-depth interview & two focus groups,	Grounded theory and thematic analysis	Overarching themes; 1. Uncertainty concerning definitions of memory loss, MCI, and AD 2. Uncertainty around distinctions between normal ageing and dementia Four common themes; 1. Questions around whether their condition was a disease or not. 2. Struggling to define MCI 3. Distancing themselves from Alzheimer's. 4. Grappling with the social implications of the diagnosis vis a vis Alzheimer's.
Imhof et al., (2006) Switzerland	To explore everyday experience of healthy elderly people worried about forgetfulness	Sample n = 32 from memory clinic, diagnostic screening to rule out dementia, only criteria for inclusion was that participants self-identified as forgetful, mean age 73.7	In depth interviews approach, coding and thematic development SPPSS used.	Grounded theory	Forgetfulness in daily life conceptualized as 'doing forgetfulness' three themes 1. Reducing complexity; 2. Creating and maintaining routines. 3. Dealing with feelings of embarrassment and shame

(continued)

(continued)

Author/Year/ Country	Research aims	Sample population	Data collection	Data analysis	Key themes
Begum et al., (2013) UK	To explore beliefs, attitudes, and help-seeking behaviours in subjective cognitive decline and compare and contrast experiences.	Purposively selected sample n = 18 all-female; from a memory assessment service and a community survey; following MMSE all within a 'conventional non-impaired' range. n = 9 who sought formal help mean age 78 n = 9 who did not seek formal help mean age 74	Semi structured interviews	Thematic framework	Three themes identified as facilitators and barriers to formal health service use: 1. Concern, 2. Causation, 3. Perception of general practitioner. Two further areas shaping responses: 1. Informal help seeking and 2. Alternative pathways to care
Corner and Bond (2004) UK	To explore and further understand the perceptions of older people, who, because age are at risk of developing dementia.	Purposively selected sub-sample n = 15, from a wider study of quality of life from the perspective of older people with dementia and of their caregivers. Age range 62–93	Interviews using a topic guide based on literature and acting as a memory aid and refined as progressed.	Thematic framework.	Results found that participants felt; 1. Fear of dementia 2. Uncomfortable with friends or relatives with dementia. 3. Reluctance to contact health professionals about memory problems. 4. Uncertainty about the causes of dementia, 5. Anxieties about loss of self-identity and dignity, and long-term care. Key theme; older people without dementia avoid talking & thinking about dementia and do not plan for it.

(continued)

(continued)

Author/Year/ Country	Research aims	Sample population	Data collection	Data analysis	Key themes
Werner (2004) Israel	To explore elderly persons' perceptions regarding their intentions to seek medical help.	A convenience sample n = 79 Taken from 'community dwelling setting' screened for subjective memory concern using CAMDEX (1988) Mean age 67.6	Semi-structured interviewing. Interview schedule developed to cover the health belief model (HBM) components.	Thematic analysis, HBM used as a conceptual framework	Results found participant beliefs and several influences act on willingness to seek memory assessment; 1. Memory problems inevitable part of aging, psychological consequences the main impact of these problems. 2. Seeking care presented as a result of fatalistic beliefs, 'nothing can be done'.
Berg et al., (2013) Sweden	To explore experiences among individuals who have lived with MCI over 7 years without converting to dementia.	Sub-sample n = 17 recruited from the longitudinal Gothenburg MCI-study starting in 1999, mean age 72	Interviews at one single occasion.	Thematic analysis of the transcripts	Themes around life situations. Experiences of living with MCI status resulting in four themes: 1. At that time, when I came to the memory Clinic. 2. Adjusting to reduced capacity; 3. Worries about what is to come. 4. I have a good life.

(continued)

(continued)

Author/Year/ Country	Research aims	Sample population	Data collection	Data analysis	Key themes
De Vriendt et al., (2012) Belgium	To gain a deeper understanding of the functional decline in the process of MCI, they hypothesized that patients with MCI show subtle functional deficits in a-ADL and explored which a-ADL were impaired and to what extent	Purposive sampling n = 37 from geriatric day hospitals all meeting MCI criteria. Age range 66–87	Semi-structured, in-depth interviews covered experiences of daily activities and changes in performance occurring over time.	Constant comparative analysis International classification of functioning, disability & health (ICF) (WHO, 2001), used to cluster activities	Results show participants diagnosed with MCI do not have performance problems in b-ADL and i-ADL. 1. Participants reported subtle problems in performance concerned with more complex a-ADL leisure, self-development. 2. Cyclic process of adaptation and coping mechanisms interacting with reduced skills can lead to emotional and functional consequences. 3. ADL important concept in the diagnosis of MCI.

(continued)

(continued)

Author/Year/ Country	Research aims	Sample population	Data collection	Data analysis	Key themes
Collier et al., (2020) New Zealand	To provoke discussion about how design processes and practices are embroiled in the construction of new medical diagnoses, through a web design project called 'living well with MCI' (2015)	Sub-sample n = 26 recruited from web design project and ethnographic study in memory clinics, n = 11 with MCI and n = 8 memory complaints An additional n = 7 family members Mean age 73.6.	Case study using interview data and recordings of discussions with anthropologist and web designer	Exploration of relationship between social, cultural, political and economic, contexts in which design processes unfold.	Results indicate that; 1. The website helped legitimize the MCI diagnosis by giving it form, despite ongoing debates about MCIs use and validity in clinical practice. 2. Older people (or 'users') internalized biomedical ideas as they negotiated what it meant to age 'normally' vs 'abnormally'.
Dean et al., (2014) UK	To investigate the experiences of people with mild cognitive impairment and their advocates. People with mild cognitive impairment (PWMCI)	Sample; n = 23 all diagnosed with MCI, recruited from research databases and memory clinics Age range 63–86 n = 20 advocates recruited Age range 42–84	Semi-structured interviews.	Qualitative analysis using methods based on grounded theory.	Results found that, 1. PWMCI rarely reported negative impressions of their GP. Positive impressions = finding the service to be "well run" Negative ones = assessment process or perceived lack of feedback. 2. Most PWMCI had no suggestions for improvements to their healthcare. 3. A variety of information was aimed at PWMCI.

(continued)

(continued)

Author/Year/ Country	Research aims	Sample population	Data collection	Data analysis	Key themes
Giebel et al., (2016) UK	To investigate how south asians with self-defined memory problems, with and without GP consultation, construe the symptoms, causes, consequences and treatment of the condition. It hypothesised that perceptions could vary depending upon consulting behaviour	Sample n = 33 recruited through community centres, networks & memory clinics all with self- defined memory problems. Group 1 n = 15 consulted GP Group 2 n = 18 no GP consultation Age 65+	Mixed methods study using the BEMI-D (Bart's explanatory model inventory for dementia) and MMSE & GDS	Analysis through statistical tests chi square & t-test of the answers to BEMI-D but perceptions also recorded and noted.	Results; differences in perceptions linked to consulting practice, Group 1 non-consultation 1. Memory difficulties in terms of spiritual 2. Non active let thigs run, normalised 3. Increased co-morbidities and high depression rating using GDS but no formal diagnosis Group 2 consultation with GP 1. More proactive in action, 2. Invest in relationships, hearing & vision support access hospital treatment. 3. Increased diagnosis and treatment of depression. Understanding dementia depended upon whether a GP had been consulted.

(continued)

(continued)

Author/Year/ Country	Research aims	Sample population	Data collection	Data analysis	Key themes
Gomersall et al., (2017) UK	To understand the perceived benefits and drawbacks of a mild cognitive impairment (MCI) diagnosis and the drawbacks this diagnosis confers on individuals and their families.	Total sample n = 42 recruited from a memory service, (clinician identified people coded as having MCI in last 6 months) family members recruited for their perspective, MCI sample n = 18 Age range 60–93	Semi structured interviews using a topic guide.	Grounded theory approach was used.	Results found diagnosis benefits and draw backs. 1. Emotional impact of the diagnosis. 2. Practical benefits and limitations of the diagnosis, understanding symptoms, accessing clinical support. Participants glad of clinical support but frustrated at lack of clarity & lack of available treatments. Living with MCI is an ambivalent experience.
Hill et al., (2018) USA	To describe experiences of older adults living with subjective memory impairment (SMI) and examine the extent to which SMI severity was associated with impact of SMI on daily life	Sample n = 19 screened as having subjective memory impairment (SMI) Recruited from community setting in rural and urban Pennsylvania, mean age 80.7	A mixed methods convergent design. Semi-structured interviews	Thematic analysis.	Results found that; 1. Impact of SMI varied depending meanings individuals attributed to their experience. 2. The impact of memory problems ranged from frustration, embarrassment to avoidance of social activities. 3. Degree of emotional impact was not reflected in SMI severity or cognitive status.

(continued)

(continued)

Author/Year/ Country	Research aims	Sample population	Data collection	Data analysis	Key themes
Joosten-Weyn Banningh et al., (2008) Dutch	To investigate how patients fulfilling MCI criteria experience and cope with their cognitive decline. Secondary aim to derive key themes for MCI support group.	Purposive sample n = 8 patients with diagnosis of MCI recruited from the memory clinic of the Nijmegen University medical Centre. Age range 58–83	Qualitative approach using interviews and topic guide.	Grounded theory approach	Results found four themes: 1. Changes to cognitive abilities, mobility, affect, and somatic complaints. 2. Numerous attributions concerned aetiologies such as personality traits and overload of information. 3. Consequences all negative and concerned patients, such as anxiety, loss of self-confidence, feelings of anger towards others. 4. Patients applied emotion-oriented, problem-focused and avoidant coping strategies

(continued)

(continued)

Author/Year/ Country	Research aims	Sample population	Data collection	Data analysis	Key themes
Lingler et al., (2006) USA	To describe the subjective experience of living with and making sense of the diagnosis of mild cognitive impairment.	Sample n = 12 recruited patients amnestic MCI (n = 6) non-amnestic MCI (n = 6) from a university-based memory disorders clinic. Age range 65–86	Semi-structured interviews with people within 3–6 months of them receiving a diagnosis of the syndrome.	Grounded theory used to analyse the data,	Results; adjusting to a diagnosis of MCI, or assigning meaning, fundamental aspect of living. 1. This process comprised interrelated emotional and cognitive dimensions. 2. Expectations of normal aging, personal experience with dementia, and concurrent health problems were used to assign meaning to MCI diagnosis.
Nakano et al., (2012) Japan	To explore the subjective and emotional experiences of MCI of community dwelling older people and their family	Sample n = 2, recruited from 'community dwelling' both diagnosed with mild cognitive impairment (MCI) Ages 74 & 80	Semi structured interviews, asking the question "please talk about the things that are troubling you"	Qualitative inductive method	Results showed four categories. 1. Bewilderment regarding memory decline, 2. Avoidance of neighbourly relations, 3. Desire to maintain a healthy life 4. Psychological impact of familial relationship in constant fluctuation

(continued)

(continued)

Author/Year/ Country	Research aims	Sample population	Data collection	Data analysis	Key themes
Parikh et al., (2016) Canada	To explore the impact that mild memory changes can have on everyday lives. Older adults with age-normal memory changes and those with amnestic (aMCI).	Purposive sample n = 37 recruited and screened from Baycrest health Sciences Centre. Two groups; n = 23 'age-normal memory ability' Age range 64–82 n = 14 aMCI (amnesic MCI) Age range 73–89	Qualitative research design, data collected from three focus groups	A thematic analysis using the constant comparative method.	Results found mild memory changes have a meaningful impact on several aspects of daily life; 1. Changes in feelings and views of the self, 2. Changes in relationships and social interactions, 3. Changes in work and leisure activities. 4. Deliberate increases in compensatory behaviours. These were more substantial and more adverse for individuals with aMCI than for those with age-normal memory changes.
Pierce et al., (2016) UK	To identify how people with a diagnosis of mild cognitive impairment used language in order to reveal the societal views and shared meanings of the diagnosis, and the positions taken by people.	Purposive sample n = 7 diagnosed with MCI recruited from memory clinics in North Wales, age range 60–78,	Interviews were conducted using a schedule.	Discourse analysis	Results revealed discourses around 'Not knowing' about MCI. Participants positioned themselves between two more familiar discourses; 1. 'Knowing about ageing and dying' and 'Not wanting to know' about dementia. 2. Consideration of where MCI is positioned in respect to normal ageing and dementia.

(continued)

(continued)

Author/Year/ Country	Research aims	Sample population	Data collection	Data analysis	Key themes
Choi and Kim (2020) South Korea	To understand how older adults with (MCI) perceived their condition following diagnosis and to explain the process of coping with concomitant changes in their lives.	Purposive sample n = 20 inclusion 1 year post diagnosis of MCI recruited through the head of a dementia support centre Age range 69–75	Theoretical sampling methods and in-depth interviews.	Grounded theory	Results; core category of living a daily life with self-awareness. Four stages; 1. Accepting their diagnosis 2. Strengthening their volition, 3. Taking care of their health 4. Maintaining a daily life with self-awareness, avoiding causing inconvenience to others
Rotenberg et al., (2020) Israel	To examine the lived experience of older adults who seek medical help for perceived memory problems,	Sub-sample n = 12 of larger quantitative study characterising 'help-seekers' from 4 geriatric clinics, n = 12 out of n = 51 recruited for qualitative study Inclusion; memory problems for at least 6 months. Age 65 upwards	Semi structured interviews.	Interpretative phenomenological analysis. Dedoose software	Results; three types of coping responses related to age context and social environment context: 1. Active problem solving, 2. Reframing perceptions of the problem 3. Avoidant behaviours, strategies to deal with memory problems and impact include four mechanisms; a) minimization, b) Normalization, c) rationalisation d) sense of control. Cognitive training alone will not make a meaningful change in lived experience.

(continued)

(continued)

Author/Year/ Country	Research aims	Sample population	Data collection	Data analysis	Key themes
Vandermorris et al., (2017) Canada	To gain in-depth insight into therapeutic mechanisms, benefits, and impact of a multimodal behavioural memory intervention for older adults concerned about memory.	Sub sample n = 11 of n = 53 recruited from memory and ageing programme all categorised as having 'normal age memory decline' Age range 63–88	Semi-structured interviews post-intervention.	Qualitative content analysis	Results; themes, normalization, benefit of participation, 'accepting where I'm at'. 1. Both specific intervention content and process of participating with others. 2. A positive impact; emotional; (feelings of reassurance, hope, and confidence). Functional (increasing motivation for lifestyle change)
Meilak et al., (2016) UK	Examine older people's understanding of MCI, explore attitudes towards disclosure of a hypothetical diagnosis of MCI and the experience of receiving a diagnosis of MCI.	Purposive sample n = 10 recruited from two memory clinics in London Two groups; n = 7 'cognitively intact' n = 6 MCI diagnosis Age 65 upwards	Semi structure interviews Group one; with hypothetical vignette of MCI Group two; exploring thoughts around diagnosis	Thematic analysis using Nvivo 10	Results; MCI group themes; • Understanding of MCI • Concerns regarding memory loss • Consequences of getting a diagnosis • Coping strategies

(continued)

(continued)

Author/Year/ Country	Research aims	Sample population	Data collection	Data analysis	Key themes
Renn et al., (2021) USA	To explore subjective experience of a "typical week" living with MCI to document (a) important activities, (b) barriers to usual activities, and (c) facilitators and supports	Sample n = 11 recruited from a University of Washington Harborview medical centre memory & brain Wellness centre research register & self through flyers Included if diagnosis of MCI Age range 57–79	Interviews and use of photographs	Thematic analysis and photo elicitation	Three themes: (a) important activities in a typical week, (b) disruptions to a typical week, (c) facilitators or compensatory supports. Two unexpected themes; (d) disclosure of diagnosis (e) reflections about the future.
Poppe, et al., (2020) London UK	To explore how people with MCI or SCD and other stakeholders consider how future dementia prevention (AT programme) should be designed for and delivered to this group.	Purposive sample n = 18 with memory concerns recruited from NHS memory clinics, primary care, IAPT; UCL/third sector organisations age 60 upwards	Qualitative interviews	Thematic analysis Nvivo 12	Three themes: (1) acknowledging the liminal state, (2) enabling change in challenging contexts, (3) building on existing values, cultures, and routines

Appendix 3

Key—— = This was unclear x = Not apparent + = Yes was evident	Clear statement of research aims	Qualitative methodology appropriate	Appropriate research design	Appropriate recruitment strategy	Appropriate data collection	Researcher and participant relationship considered	Ethical issues considered	Sufficiently rigorous data analysis	Finding clearly stated	Valuable research
(Kruger TM, 2014)	+	+	+	+	+	——	+	+	+	+
(Beard & Neary, 2013)	+	+	+	+	+	——	x	+	+	+
(Imhof et al., 2006)	+	+	+	+	+	x	+	+	+	+
(Begum et al., 2013)	+	+	+	+	+	+	+	+	+	+
(Corner & Bond, 2004)	+	+	+	+	+	x	x	——	+	+
(Werner, 2004)	+	+	——	+	+	——	x	——	+	——
(Berg et al., 2013)	+	+	+	+	+	+	+	+	+	+
(De Vriendt et al., 2012)	+	+	+	+	+	——	+	+	+	+
(Collier et al., 2020)	+	+	+	+	+	+	+	——	+	+
(Dean et al., 2014)	+	+	+	+	+	x	+	+	+	+
(Giebel et al., 2016)	+	+	+	+	+	——	——	+	+	+
(Gomersall et al., 2017)	+	+	+	+	+	+	+	+	+	+
(Hill et al., 2018)	+	+	+	+	+	+	——	+	+	+
(Joosten-Weyn Banningh et al., 2008)	+	+	+	+	+	x	——	+	+	+
(Lingler et al., 2006)	+	+	+	+	+	+	+	+	+	+
(Nakano et al., 2012)	+	+	——	——	x	+	+	——	+	+
(Parikh et al., 2016)	+	+	+	+	+	+	+	+	+	+
(Pierce et al., 2016)	+	+	+	+	+	x	+	+	+	+
(Choi & Kim, 2020)	+	+	+	+	+	x	+	+	——	——

(continued)

(continued)

Key——— = This was unclear x = Not apparent + = Yes was evident	Clear statement of research aims	Qualitative methodology appropriate	Appropriate research design	Appropriate recruitment strategy	Appropriate data collection	Researcher and participant relationship considered	Ethical issues considered	Sufficiently rigorous data analysis	Finding clearly stated	Valuable research
(Rotenberg et al., 2020)	+	+	+	+	+	——	+	+	+	+
(Vandermorris et al., 2017)	+	+	+	+	+	+	——	+	+	+
(Meilak et al., 2016)	+	+	+	+	+	——	x	+	+	+
(Renn et al., 2021)	+	+	+	+	+	+	——	+	+	+
(Poppe et al., 2020)	+	+	+	+	+	——	——	+	+	+

Key ——— = This was unclear **x** = This was not apparent **+** = Yes this was evident.

Appendix 3 – APPLE-tree consent form

UCL | ESRC Economic & Social Research Council | UK Research and Innovation | FUNDED BY NIHR | National Institute for Health Research

Centre Number:

Participant Identification Number:

CONSENT FORM – Participant

Title: APPLE-Tree Study; Active prevention of risk factors in people with memory problems.

PhD study exploring how people with memory concerns engage with active prevention sessions

Principal Investigator: Prof Claudia Cooper

	Please initial box
1. I have read the information sheet dated XX/XX/XX (version X) for the above study and understand the purpose of the research	☐
2. I have considered the information, been able to ask questions and have had these answered to my satisfaction	☐
3. I understand that my participation is voluntary and that I am free to withdraw from the research study at any time without my legal rights or medical care being affected.	☐
4. I understand that that my personal information will be processed only for the purposes of Research and that all material and personal information will be kept in accordance with General Data Protection Regulation (GDPR) and the Data Protection Act 2018.	☐
5. I understand that relevant data collected during the study may be looked at by individuals from UCL, regulatory authorities or from an NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.	☐
6. I agree that any of my group sessions can be observed.	☐
7. I understand that at the end of these sessions notes will be made which may include some of the interactions taking place, however no identifiable information will be recorded.	☐
8. I am happy to take part in an interview at the end of my group sessions *(optional)*	☐
9. I agree that I am happy for the interview to be audiotaped and I understand that an external transcription company will have temporary access to the information I provide in the audio recording. *(optional)*	☐
10. I agree that the information collected about me can be used to support other research in the future, and may be shared anonymously with other researchers *(optional)*	☐
11. I would like to receive a summary of the PhD research findings *(optional)*	☐
12. I agree to take part in the above study	☐

______________________	______________	______________
Name of Participant	Date	Signature
______________________	______________	______________
Name of Person taking consent	Date	Signature

Consent form PhD study: person with MCI or SCD. Version 1. Date 02/03/2020
IRAS ID: 274277

Appendix 4 – APPLE-tree participant information sheet

University College London,

Division of Psychiatry,

Maple House, 6th Floor Wing A,

London W1T 7BN.

Tel: 0207 6799031

Participant Information Sheet

Title of the study

A qualitative study exploring how people with mild cognitive impairment or memory concerns take part in health prevention sessions in the APPLE-tree project; using observation and interviews.

We are inviting you to take part in a research project which is part of a PhD exploring active ageing interventions and memory problems. We would like to understand how the health intervention sessions within the APPLE-tree study are delivered and how health advice is given out.

Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with others if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the study.

Please ask me if anything is not clear or you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Part 1

What is the purpose of the study?

We want to learn more about how and why people with memory concerns or cognitive impairment take part in health intervention sessions. The researcher would like to understand how people use and understand the information delivered in the future. Finally we would also like to explore how attending the health intervention sessions affects peoples thoughts about memory impairment.

Why have I been invited?

You have been approached as you have agreed to take part in the APPLE-tree project from UCL and you have been allocated to receive the intervention.

Do I have to take part?

No. It is up to you to decide whether to take part. You are free to withdraw consent at any time without giving a reason. If you do not want to take part in this PhD project it will not affect your inclusion in the group sessions in the APPLE-tree project.

What will happen to me if I take part?

A researcher would like to observe one or more of the group sessions you attend as part of the APPLE-tree project. The researcher will observe all aspects of the group including the facilitators and other members in the sessions. This will include the researcher being in the room and observing before the health intervention session begins and after the session ends. As part of the observations the researcher may talk to you from time to time about the session. Information from these conversations and observations will be completely anonymised and any identifiable information removed. Observations will be recorded in handwritten notes after the sessions have ended. These will be later typed up and stored electronically.

A researcher would like to interview you about your experiences in taking part in the health intervention sessions. It is up to you if you agree to take part in this additional interview. We want to ask you your views about making and keeping some of the lifestyle changes suggested in the sessions. We would like to understand how you feel about this in relation to your own memory concerns and wellbeing.

What do I have to do?

You will be asked to sign a consent form which will include an option for taking part in an interview.

If you agree to participate in an interview, you will be invited to talk to a researcher in a place you choose (we can come to your home or meet you at our centre). The researcher will take a few minutes to ask questions about your age, ethnicity, education and where you were born. These questions are because we want opinions from people from different backgrounds.

The discussion itself will last up to an hour, but we will be flexible and you are welcome to take breaks. It will be audio-recorded so we make sure that we do not miss anything you say. We will type up the discussion and send it to you. You can make comments and corrections or add things if you wish but you do not have to. We will provide a stamped addressed envelope for you to return your comments to us if you wish to. We will also ask if we can contact you in the future to ask you to comment on what we have found out together from the discussions with everyone and our ideas about it.

What are the possible disadvantages and risks of taking part?

We do not foresee there being risks associated with the study.

- During the health intervention sessions the researcher will seek to observe as unobtrusively as possible.
- The interviews will be semi-structured and there are no right or wrong answers to the questions and you can talk about anything that you feel is relevant. It is possible that some topics discussed may be upsetting. If at any time during the interview you find a topic sensitive or upsetting you can ask the interviewer to move on or stop the session altogether. If you feel upset by the interview you can speak to the researcher afterwards

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get might help us develop ways to improve health intervention sessions for people with memory concerns.

What if I do not want to carry on with the study?

You are free to withdraw your consent at any time, without giving a reason. If you withdraw from the study, you can also request that we do not use any of the information you may have already given us. Stored data that can still be identified as yours will be destroyed if you wish.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

We respect confidentiality but cannot keep it a secret if anyone is being harmed or is at risk of any harm. If this arises, you will be informed that confidentiality cannot be maintained in that particular regard, and the appropriate personnel will be informed.

Your anonymity will be maintained in the data analysis as you will be assigned an anonymised code which will be used throughout the analysis. You will not be identified in any reports or academic papers coming from the work. The information that you give will be stored securely, to enable researchers to continue analysis of the study data in future projects.

You can find out more about how we use your information by contacting data-protection@ucl.ac.uk or by going online and accessing the UCL research privacy notice: https://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice.

Contact

Please contact Dr Claudia Cooper, Principal Investigator or Michaela Poppe, APPLE-tree Trial Manager on 0207 679 9311 or Christine Carter PhD student carrying out this research (phone number) for further information. This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please read Part 2 before making any decision.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the Programme Manager, Michaela Poppe: Tel: 020 7679 9311. Email: m.poppe@ucl.ac.uk.If you remain unhappy or wish to make a complaint about any aspect of this study, you should ask to speak with Dr Claudia Cooper (APPLE-tree Study Principal Investigator on 0207 6799031) who will do her best to answer your questions.

You can also contact [local independent site contact] for support if you would like to complain about the study.

What will happen to the results of the research study?

We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. You will not be identified in any report/publication.

Who is organising and funding the research?

The Economic and Social Research Council and National Institute of Health Research are funding it, and University College London are sponsoring it.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by London – Camden and Kings Cross Research Ethics Committee. You will be given a copy of the information sheet and a signed consent form to keep.

Thank you for taking time to read this sheet.

Consent form PhD study: person with MCI or SCD. Version 1. Date 02/03/2020
IRAS ID: 274277

Appendix 5 – APPLE-tree participant demographic information.

	Coastal town		Urban area in London	
	Group A n = 6	**Group B** n = 5	**Group A** n = 5	**Group B** n= 6
Age (years)				
Mean	76.0	76.8	73.2	76.6
Range	68 - 79	68 - 89	69 - 77	70 - 87
Gender (n)				
Female	4	3	4	3
Male	2	2	1	3
Ethnicity				
White British	4	5	2	5
Other white background	1	0	0	0
Indian	1	0	0	1
Chinese	0	0	1	0
African	0	0	1	0
African Caribbean	0	0	1	0
Employment				
Part time	0	3	1	0
Retired	5	2	4	6
Unable to work	1	0	0	0
Education level				
Secondary	1	1	2	0
BTEC	2	2	2	1
Degree	3	1	1	3
Postgraduate	0	1	0	2
Living arrangements				
Living alone	4	2	0	2
Living with relatives	2	3	5	4
Living with friends	0	0	0	0
Accommodation				
Own home	4	5	5	6
Private rented	2	0	0	0
Marital status				
Single	1	1	0	1
Married	2	3	4	4
Divorced	0	1	1	1
Widowed	3	0	0	0

Appendix 6 – Interview topic guide

Topic Guide

Thank you for agreeing to talk with me. You are helping us understand more about how and why people with memory concerns or cognitive impairment take part in health intervention sessions. I would like to ask you about the intervention sessions which you attended in the APPLE-tree project. I want to ask you your views about making and keeping some of the lifestyle changes suggested in these sessions. I would also like to understand how you feel about this in relation to your own memory concerns and wellbeing.

To make sure that I don't miss anything, I will record our conversation on a digital recorder and then it will be professionally transcribed. Once the interview has been transcribed, I will ensure that everything will be anonymous so you can't be identified. Everything you tell me will be treated with complete confidence

I am interested in hearing about your thoughts and experiences so I'd like for you to give me long answers rather than or one word answers, there are no right or wrong answers to the questions and you can talk about anything that you feel is relevant.

Can you start by telling me bit about you, your back ground and history? (Sharing whatever you feel comfortable to do)

What concerns/difficulties do you have about your memory?

(a) How do you feel about these concerns?
(b) When did they start and when did you identify as someone who has memory problems?

Can you tell me about your motivation to attend the group and how did you arrive at the group ?

How do you feel about getting older and the changes associated with that?

(a) Specifically in relation to you memory
(b) How do you feel physical illness or physical changes have effected your memory?

Has attending the health intervention sessions affected your own thoughts about memory impairment and prevention? (if yes in what way)

What have you told other people about the group and how have you explained/described the sessions to other people (Eg; family/friends)

How has attending the group changed how you see yourself, your future and how other people see you?

Questions will be loosely based around the research questions but results from the observations of the intervention sessions will define and shape these further.

PhD study interview Topic Guide; IRAS number 274277; version 1 (04.03.2020)

Appendix 7 – Example of field notes

Group A session 7 30/04/21

Arrivals

was the first on connecting to audio always the same that either blank and no audio or usually we can seep people, but the audio is delayed. [Name] waved hello took his glasses of then said 'I cant see you' and put them back on and did a pretend scary face at seeing us all, joined blank initially followed by....lot of hellos and some chat about haircuts, mine had been cut and she said how nice it felt .. thinks she will keep it long and pulled it back to show her tying it up, lots of complements from the group.... said 'I cant do a thing with mine' to which everybody was laughing. Facilitator moved into the session explained that there was a lot of content and it would be good to get started

> **Carter, Christine**
> Always the same for nearly every group thinking about how different this would be if entering a room for the session
>
> @mention or reply

Starting

introduced session 7 about Health consultations smoking and alcohol and healthy flavours, People were looking down at the booklet to....she asked if anyone smoked or was supporting someone who wanted to give up smoking...
(this was a bit on the spot but not sure how else it could have been done) there was no one in the group who did either.

Apples in the Jar

got the jar out and said we have the apple jar again (she seemed more relaxed about it that other weeks) anyone tried anything new big or small any new developments? said that she had lost 51b which everyone acknowledged was good, said well I think that deserves 5 apples then which brought a lot of laughter and found very funny.... said well I'm am going to start my new bowling today ...Facilitator said well that deserves an apple ... 'just the one?' 'ok I will put another one in for you' Again some laughter about this ....
said that reminded her about asking to share the detail so they could meet up if everyone was happy which they were... said that she had done a spin class at the gym and asked what that was so she explained it....

> **Carter, Christine**
> The AITJ exercise allows a trivial but 'fun' way to reward and engage people and somewhat surprisingly works but with an element of competition as here although done with humour.
>
> @mention or reply

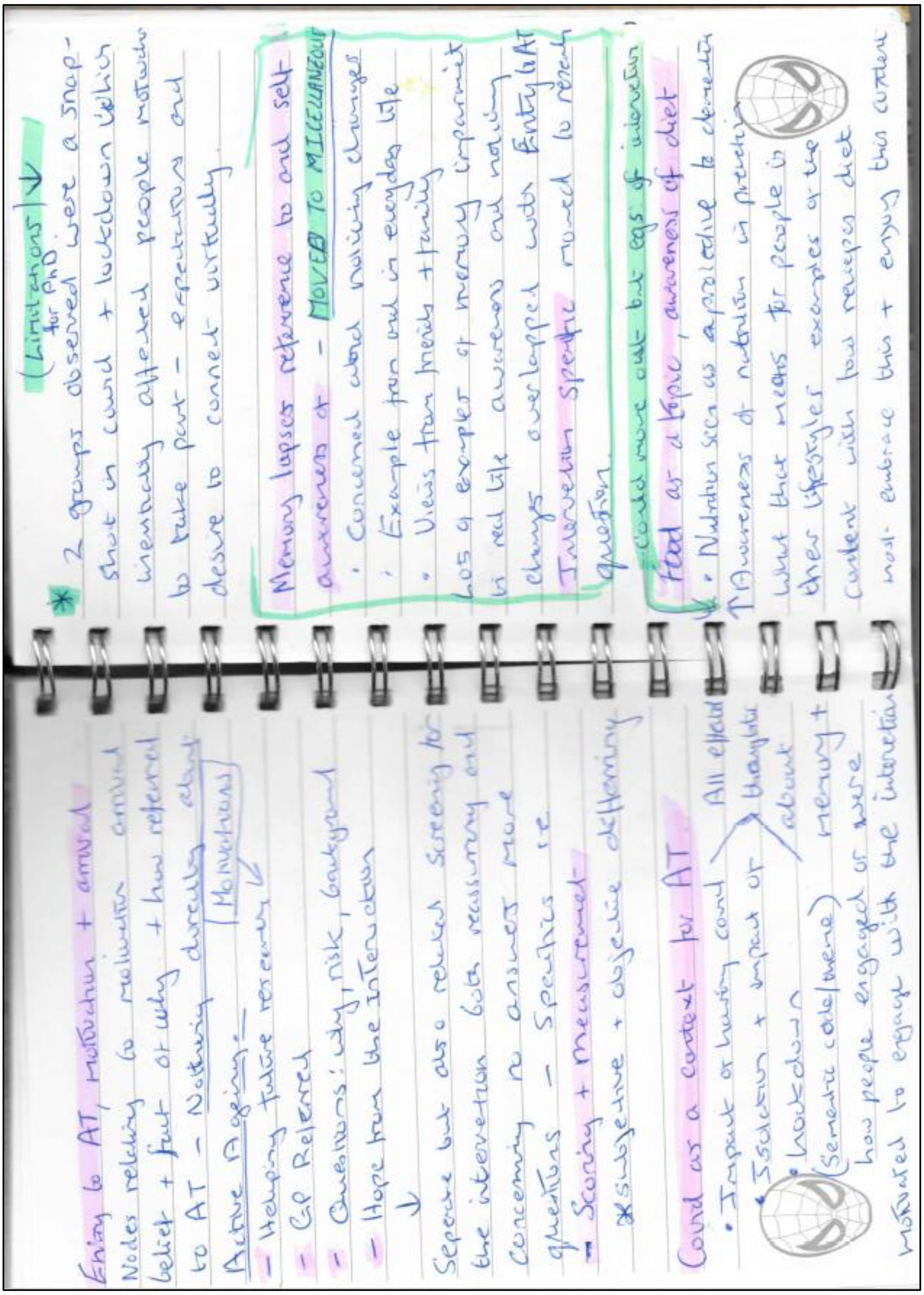
Said oh yes and I've started a diary' it's not what I have done but tasks to do then I can tick them off as I go ....[Name] made me do it ...laughing protested and said I think I helped you do it .. said it was working well as he forgets what task he has to do at what times 'so this is perfect for me
....Facilitator said that's great finding something which works for you, the jar is getting quite full now considering there is three of you, (holding the jar up) lots of smiling about this, asked if anything else new [Name] didn't say anything and we moved on but it felt very comfortable...

> **Carter, Christine**
> 'I need to do tasks and know I have done them'...interesting how he initially jokes the facilitator has got him to do it !
>
> @mention or reply

Appendix 8 – Example of field notes analysis

Session 1	Gender and exchanges and familalirity, group cohension making it work remember **' we are all in it together'.** First or opening exercises were about getting to know each other, interestingly the men in the group who were in the minority, did this through talking about themselves in relation to their spouses, some of this illustrated but the support they clearly recieved, [redacted] and the note) and there were also examples of expressing their identity as a mand [redacted] and their role as a father and gandfather this included their involvement in their lives which did not appear to emerge as much with the women in the group. Missing people frined and connections and social outings, straying from manual ....dicussion aroudn things which were not as intended ground rules but still valid. Voicing dislikes and asking questions. Checking out the facts how does this help me ...food and my memory ? [redacted]	Identity Gender Support creating a group Sharing who I am Fact checking
Session 2	References to being lazy and working, doing and engageing in things First topics introduced and the Apple in the jar exercise* (AITJ), lots of jokes about the plastic apples, pretending they were real, increasing fruit again mainly by the male menbers of both groups Hopes **renew life (P) we are trying to achieve a whole new diet or remould what we eat** [redacted] **am now having 3 portions of fish a week on allotted days so that I can remember but I skipped Saturday but I'm not going to give myself a hard time about it and thought I will just have it on Sunday. Also I have been having healthy snacks (she's laughing at this as it sounds like this is clearly a struggle for her). I was really good for a whole week then I went bonkers with crisps** (which brought some laughter to the group) I ate quite a lot too .. [redacted] said it's easy to slip but I will still put an AIT. Food and eating is clarly quickly domianting the sessions and the AITF is a way of rewarding....what at times feels like complaiance. The apples in the jar strangely works as a connection one of the only shared visual interaction activities .Although I felt this may be patronising and I know that that Ras thought that too it hasn't felt as if it is. The refences to apples are funny and seem trivial but maybe allow a connection and a method of engaging which is easier....metaphor (an apple a day keeps the Dr away) ?? References to the apples again a trival aspect with humour but tolerated and allowing people to interact with P and developments which is not too confrontational.This man was quite cynical last week and vocal about his dislike for a lot of the food and recipe's but he came back and engaged here with something positive through the AIT. Juxtapositions of being told to do something , not wanting to do something but knowing its healthy ...links to age and ageing and the age of the RA possibly .....an exchange to assert identity. **'I have a timer and I set it for every hour to go off and remind me to move and walk around'** [redacted]	Gender Defining a 'new' me. Identity AITJ as an activity and a interaction Measurement & restriction, control Getting things right (Chris). Self- montioring
Session 3	Hope, family and friends and mental health (P)Instructions were read out how to complete the diary and look next week with the statement **'living your life the most fulfilling way you can'** Goals; decsions not to do them, [redacted] **agreed saying that 'I feel a bit more comfortable with it and I don't have to do them if I don't want to'** [redacted] **agreed but gently said that it might be good to try writing some goals down as there were only 10 sessions and Pat agreed.** I don't have to if I don't want too, exercsiing choice but there is a right was which is implied . Writng goals down the act of writng them down and what to put. AITJ;a way of measuring, attoning, rewarding, connecting, trivalising and yet revealing flaws- self chastising [redacted] – **'You might want to remove an apple from the jar as I haven't been very good this week' 'I got hungry and ate a whole bag of nuts I couldn't stop I was terrible'** [redacted] **'a nothing week for me'** [redacted] said that the step counter had helped him get out **'I'm quite competitive I like to compete I need figures'.** [redacted] **aid similar u**pping his steps, men appear to favour the numbers and counting .Again something sthat seem to be common amongst the men about measurng technical aspects counting Gender - mens repsonces and enagement does appear to be different to the womens. A lot of banter from the men in Enfield group about their spouse all light hearted but maybe a way of bonding required more than from the womet (reflecting men experiences of being in groups and sharing detials of their lives) Rewards and meanings [redacted] **Also I got a star from my fitbit as I had done over 10,000 steps but I don't know what that means, the star, but I suppose its good, didn't know it would do that....**using technology and external stimuli and materials to, brief refence to well being (stress) one particapnt was not picked up but this was pursued in the goal	Exercising choice and/but choosing the correct way. Gender -mens responces differ from the women. Type of conversation that's that they have. (look at group , men,health messages, prevention) Self -chastising & as above Counting and accountability of the unknown. Humour Recording

Appendix 9 – Example of research coding notebook



Entry to AT, motivation + arrival
Nodes relating to motivation arrival belief + fact or why + how referred to AT – Nothing directly about Active Ageing:– (Motivations)
- Helping future researchers
- GP Referred
- Questions: why, risk, background
- Hope from the Interaction

↓

Separate but also related screening for the intervention both reassuring and concerning no answers more questions – Specifics i.e.
- Scoring + Measurement
  * subjective + objective differing

Covid as a context for AT
- Impact of having covid
- Isolation + impact of
- lockdown

All affected thoughts about

(Semantic code/theme) memory + how people engaged or were motivated to engage with the interaction

(Limitations for PhD) ↓

* 2 groups observed were a snap-shot in covid + lockdown which inevitably affected people motivation to take part – expectations and desire to connect virtually.

Memory lapses reference to and self awareness of – MOVED TO MISCELLANEOUS
- Concerned about noticing changes
- Example from and in everyday life
- Views from friends + family

Lots of examples of memory impairment in real life awareness and noticing changes overlapped with Entry to AT Intervention specific moved to research question.

Could move out but egs of intervention
Food as a topic, awareness of diet
- Nutrition seen as a protective to dementia
↑ Awareness of nutrition in practice what that means for people in their lifestyles examples of the content with food recipes diet most embrace this + enjoy this content

Appendix 10 – Example of reflexive diary notes

sharing stories and listening to others
— Not Always In The Content!!
Need a balance as the informal c
becomes the substantial content!
↓
In the de-brief afterwards N complained
about V going off on a tangent
about the scan experience (started
from limitations around hearing) she
said "I don't know where that
came from" - "why was V talking
about that!" "I'm glad she stopped herself
as I didn't know what to do"
- I felt frustrated by this and mildly
irritated - I was aware of my role
as researcher but also 'assistant' as
part of the participation - I struggled
with this for a little while but then
decided to speak - raising the
issue in defense of V as maybe
just wanting to share to warn the
group - feeling vulnerable on her
own - this is a wellbeing group
we cant contain what [illegible]