"Where Did I Park My Car?"

A Mixed Methods Investigation on Mild Cognitive Impairment Diagnosis in New Zealand

A thesis submitted in partial fulfilment of the requirements for the degree of a Doctor of Philosophy in Psychology

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2015

Abstract

Mild cognitive impairment (MCI) is defined as an objective impairment in cognitive function which spares everyday functional ability. The syndrome is shrouded in controversy regarding definition, cut-off criteria, and clinical utility. Consequently, it is an uncertain label for the client being diagnosed by their healthcare practitioner. To date, minimal research in New Zealand has focused on MCI within specialist assessment services. Reasons for this paucity of literature will be discussed throughout this thesis. The current research aimed to identify how practitioners deliver and perceive cognitive impairment diagnosis, and examine how clients respond to receiving this diagnosis. Client experiences were framed within the common sense model (CSM). This theory originates from health psychology, where coping behaviour is said to be influenced by the cognitive representations that a person has about their condition. Although the framework is previously discussed in relation to chronic illness, international researchers have started to examine the utility of the model in explaining MCI diagnosis response. Given this context, the CSM framework guided the client-focused components of this thesis. In Study One, 57 practitioners who diagnose cognitive impairment completed a questionnaire on labels applied to MCI and beliefs about the value of diagnosis delivery. Responses were analysed using content analysis to gain an impression of professional practice. Cognitive disorder - not otherwise specified (CD-NOS), early dementia, and normal ageing were reported to additionally label the symptoms of MCI in clinical practice. In Study Two, client responses were examined in a small clinical sample ($N = 9$) diagnosed with MCI and CD-NOS. Participants were interviewed twice within six months of initial diagnosis. Interpretative phenomenological analysis was used to gain insight into how people cope and make sense of their diagnosis over time. Descriptive analyses were also undertaken with a subset of Study Two data to examine changes and differences in coping strategies over time. Findings suggest that participants may not see their diagnosis as an illness or significant health threat in the first six months following diagnosis. This prompts a question on the suitability of an illness model with

reference to diagnosis response. Findings from this research add to the literature by highlighting

practice associated with an evolving form of clinical diagnosis in NZ.

Thesis Dedication

For Joy, my kind and thoughtful nanny who started this all. And for Bert, my friend who encouraged me in the early days.

Acknowledgements

Mrs Melanie Robertson for organising travel, and Mr Harvey Jones who constructed the online

component of the practitioner questionnaire.

Publications and Presentations

The following are publications and presentations authored while completing this PhD, as of September, 2015.

McKinlay, AR., Leathem, J., & Merrick, P. (submitted). Coping and Illness Representations in a Clinical Sample Diagnosed with Mild Cognitive Impairment and Cognitive Disorder Not Otherwise Specified.

McKinlay, AR., Leathem, J., & Merrick, P. (2014). Diagnostic processes and disclosure: A survey of practitioners diagnosing cognitive impairment. *New Zealand Journal of Psychology,* 43(2), pp. 20-31.

McKinlay, AR., Leathem, J., & Merrick, P. (2014). Practitioners' processes and attitudes in the diagnosis of cognitive impairment. Presented at *New Zealand Psychological Society Conference: Psychology in a Changing World.* Nelson, New Zealand.

McKinlay, AR., Leathem, J., & Merrick, P. (2012). PeArLS: 'Where did I park my car?': How do older adults cope with a diagnosis of mild cognitive impairment. Presented at *New Zealand Psychological Society and New Zealand College of Clinical Psychologists Joint Conference: Standing Together as One*. Wellington, New Zealand.

McKinlay, AR., Leathem, JM., & Merrick, PL. (2011). "Where did I park my car?" How do older adults cope with a diagnosis of mild cognitive impairment? Poster presented at the meeting *of New Zealand Inaugural Stroke and Applied Neurosciences Conference (NZSANC).* Auckland, New Zealand.

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ACh	Acetylcholine
AChE	Acetylcholinesterase
AChEI	Acetylcholinesterase Inhibitor
ADL	Activities of daily living
aMCI	Amnestic mild cognitive impairment
APOE	Apolipoprotein E
CR	Cognitive reserve
CSM-IR	Common sense model of illness representations
CT	Computed tomography
DHB	District healthboard
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders - IV - Text revision
DSM-V	Diagnostic and Statistical Manual of Mental Disorders - V
fMRI	Functional magnetic resonance imaging
GP	General practitioner (primary healthcare physician)
IADL	Instrumental activities of daily living
ICD	International Classification of Diseases
IPA	Interpretative phenomenological analysis
IPQ	Illness Perception Questionnaire
IR	Illness representations
MCI	Mild cognitive impairment
MMSE	Mini-Mental State Examination
mNCD	Mild neurocognitive Disorder
MOH	Ministry of Health
MRI	Magnetic resonance imaging
naMCI	non-amnestic mild cognitive impairment
NIA AA	National Institute on Ageing – Alzheimer's Association
PET	Positron emission tomography
SMC	Subjective memory complaints
WHO	World Health Organization

Important Terms

A number of terms are used in this thesis which will describe processes within healthcare services that are unique to New Zealand (NZ).

Client. The term "client" is favoured in many health settings by some as it is considered to portray an individual as autonomous and empowered. Reconstructing power relations using language is important with respect to vulnerable populations, such as those who are ill or considered old. Historically, some medical texts have equated terms such as "patient" with powerlessness and passivity, meaning healthcare provision is something *done to* a person with an absence of choice. In NZ, both of the terms patient and client are used across healthcare settings.

Diagnostic and Statistical Manual of Mental Disorders (DSM). The *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-V*; American Psychiatric Association [APA], 2013) is the primary manual for diagnosing psychiatric and cognitive disorders in NZ. The fourth edition (*DSM-IV-TR;* APA, 2000) was in circulation from 2000 – 2013 and replaced with the fifth edition in May 2013 (APA, 2013). One of the key changes relevant to this thesis was the addition of mild and major neurocognitive disorder, in place of terms such as dementia. The impact of these changes will be discussed in later chapters.

District Health Board (DHB). This acronym refers to healthcare services in NZ who are funded by the Ministry of Health. Currently 20 DHBs across NZ provide regional services to New Zealanders.

International Classification of Disease (ICD). This manual is diagnostic classification system commonly used in the United States (ICD 10; World Health Organisation, 1994). It is not widely used as the DSM is in NZ.

Ministry of Health (MOH). MOH refers to an organisation funded by the government of New Zealand.

Primary Care Organisation (PHO). PHO refers to primary healthcare services in NZ. Practitioners within these settings include general practitioners (GPs), practice nurses, and other general health professionals.

In addition to these important terms, it should be noted that language and labels can be a tool for reinforcing disempowering stereotypes about people who are considered to be "old". Specific phrases used to discuss older adults seem to have been phased in and out of gerontology literature. In considering the literature on ageism reviewed throughout the course of conducting this thesis, the term "older adults" is used here to refer to individuals who are aged 65 years and over. The acceptability of this term may evolve over the years to come. Care has been taken throughout this thesis to use language in attempt to avoid reinforcing negative stereotypes.

Preface

In the five years leading up to enrolment in my PhD, I had worked as a research assistant on a number of studies on healthcare in New Zealand (NZ). These investigations were based on quantitative methods, hypothesis testing, and positivist or post-positivist epistemologies. The decision to pursue an ageing-focused doctorate came from completing my honour's dissertation on data from the longitudinal Health, Work and Retirement (HWR) study. This project followed a community dwelling cohort of older adults in NZ. I had also previously completed my postgraduate level papers in clinical neuropsychology and human cognition. The culmination of these experiences lead to an interest in age-related memory impairment.

Initially, a research topic on suicidal ideation and dementia was considered. Dementia diagnosis has been associated with feelings of grief, uncertainty, and shock (Aminzadeh, Byszewski, Molnar, & Eisner, 2007), and some have highlighted an increased prevalence of suicide in the dementia population (Erlangsen, Zarit, & Conwell, 2008). It was unclear whether suicidal ideation develops in response to dementia diagnosis, or perhaps due to changes in the brain. Clearly, this is a complex topic where few published studies exist (Draper, Peisah, Snowdon, & Brodaty, 2010). A review of the literature revealed heavy emphasis on dementia, but less discussion on mild cognitive impairment (MCI). MCI is defined as an objective impairment in cognition (e.g., memory, attention, and executive function), not severe enough to interfere with daily functioning. A diagnosis of MCI is associated with an elevated chance of developing dementia; however, it is not inevitable, as some revert to normal function and others remain stable over time. By contrast, MCI is not linked with suicide in the published literature.

Literature searches on early dementia and MCI also revealed a paucity of empirical research in NZ healthcare services. This is an important gap that requires addressing. Research in this area will help stimulate an ongoing conversation on the importance of recognising and talking about early-stage memory impairment in this country. Creating awareness about changes in cognitive ageing may help reduce some of the fear associated with this category of diagnosis. Coupled with an interested in clinical neuropsychology and older adult healthcare, and a noted gap in the "evidence base" of age-related cognitive impairment literature in NZ, it was decided that MCI diagnosis represented a significant gap that could be addressed via a doctoral research project.

Over the course of conducting this PhD, developments in NZ have taken place which reinforce the need to conduct research on age-related cognitive impairment. A recent ageing and dementia compendium (Prasadarao, 2014) was the first of its kind published in NZ. The document highlights increasing frequency of academic interest in the field of memory decline in older adults. With developments in public policy such as the *New Zealand Framework for Dementia Care* (Ministry of Health, 2013), there is urgent need for evidence which blends empirical research and local practice (Patrick, 2014). Empirical research is required to assist healthcare services in caring for the growing older adult population. It is hoped that this PhD on MCI diagnosis (specifically within specialist healthcare services) will contribute towards an emerging body of knowledge on the subject of early-stage cognitive decline in NZ.

1.1 Research Rationale and Importance

In 2011, the first wave of children born following world war two (WW2), referred to as the "baby boomers", began turning 65. Due to changes in life expectancy, birth patterns, and improvements in healthcare, there are increasing numbers of adults in the 65 years and over age category. This phenomenon is referred to as "population ageing". The number of people living longer has prompted concern for some healthcare providers and policy makers. It is uncertain how healthcare services will cope with the increasing numbers of ageing clients. Although dementia is

not caused by older age, it is associated with increasing age; therefore, older adult healthcare services are likely to see more clients with cognitive decline than ever before.

In sum, numbers of dementia diagnoses are likely to increase as communities around the world experience population ageing. Although there are many causes of dementia (i.e., Lewy body dementia, frontotemporal dementia), this thesis is primarily concerned with dementia and memory symptoms caused by Alzheimer's disease (AD). Due to a lack of published studies on psychological responses to proposed dementia prodromes, this thesis will focus on MCI. The *research problems* to be addressed are: a) there is a lack of published literature on MCI in NZ, and b) not enough is known about the complex responses people have once diagnosed with MCI. Once more is known about the experiences of those receiving this diagnosis, healthcare services and policy makers may be better placed to appropriately tailor psychological support services.

1.2 Overview of the Thesis

Existing research on MCI is predominantly quantitative. As of November 2014, a keyword search with "mild cognitive impairment" and "qualitative" in PsycINFO[1] returned 121 results. Replacing this word with "quantitative" returned 215 results. During the design stages of this research, no published studies appeared to have utilised a mixed methods framework. A mixed methods design seemed to offer a detailed and novel approach for examining MCI diagnosis in NZ. This thesis (presented by manuscript) will contain two central focus points: (1) the experience of the client following diagnosis (primary focus), and (2) the role of the specialist practitioner in clinical diagnosis (secondary focus). Although many healthcare professionals are involved in the care of older adults, the scope of this thesis extends to diagnosis as it occurs within specialist older adult healthcare services.

Main research question. Throughout the process of conducting the literature search and thinking about the issues raised, one over-arching question came to mind: *What is like to receive a*

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[1] PsycINFO is an academic database used to access peer reviewed publications.

diagnosis that might develop into one of the most feared diseases of older age? If a clearer understanding could be gained on this question, it might help the practitioners who are faced with imparting this diagnosis to their clients. In the past, MCI has been treated as a research rather than clinical diagnosis; however, this has begun to change (Kaduszkiewicz et al., 2014; Petersen et al., 2014). In answering the above question and those which will be outlined in Chapter Seven, an examination of clients' reactions to diagnosis was required.

Secondary research question. The role of clinical judgement and decision-making is also important when a diagnosis is being delivered to a client (Bamford et al., 2004; Gerstenecker, 2014). Prior to conducting this thesis, no figures existed on the frequency of MCI diagnosis in NZ clinical services, so little was known about how practitioners approached this category of cognitive impairment. Thus, a secondary research question in this thesis was: *How do practitioners diagnose MCI in clinical settings?* In considering that so little research exists on this topic in NZ, it seemed prudent to include a study with practitioners who deliver MCI diagnosis, in order to gain contextual understanding.

Studies included with thesis. Two separate studies were conducted over the course of this thesis (refer Table 1).

Table. 1
Studies in Current Thesis by Publication

Sample	Time Frame	Region	Method
Practitioners	Cross sectional	Nationwide	Questionnaire
Clients	Longitudinal	North Island	Questionnaire
			Semi-structured interview

Study One was a practitioner-focused project, which included practitioners in NZ who diagnose MCI and dementia. Participants completed an anonymous online survey on their diagnostic practices, and answered questions on their approach to cognitive impairment diagnosis.

This study served as a preliminary investigation into MCI diagnosis across NZ, given so little research existed at that time. Findings from this study were used to aid the design and implementation of a second client-focused study.

Study Two involved a series of client-focused interviews, whereby participants were asked about their experiences of diagnosis, how they coped, and how they made sense of their condition. The utility of an illness representation model was examined within this study (model to be discussed).

In conducting preliminary research for this thesis, an expert in the health psychology field warned that coping is a "fluffy" concept to investigate. This was taken to mean that coping is difficult to define and objectively measure, which is a fair point (see Folkman & Moskowitz, 2004). Findings may be difficult to generalise on a concept which is highly personal and subjective. Despite the warning about the difficulty with defining this concept, the discussion of coping processes appears continuously in research on health and illness in older age (for systematic review, see Bjørkløf, Engedal, Selbæk, Kouwenhoven, & Helvik, 2013). For the individual, the idea of coping with changes in health status is clearly important. Given that this research is client-focused, a decision was made to pursue the subject of coping. Objective (quantitative) and subjective (qualitative) data were collected on what it means to cope with MCI.

Theoretical model of interest. At the time of deciding on this research topic, minimal research had referenced an explicit model in explaining coping responses following diagnosis. One framework which may explain the responses that people have following MCI diagnosis is the common sense model of illness representation (CSM; Cameron, Leventhal, & Leventhal, 1995; Leventhal, Meyer, & Nerenz, 1980). Under the model, coping strategies are influenced by 'illness perceptions' or representations generated following a diagnosis (Leventhal, Leventhal, & Contrada, 1998). Emerging research has examined the utility of this model to explain how people cope with early dementia (Harman & Clare, 2006) and MCI (Lin & Heidrich, 2012; Lingler et al., 2006;

Morgan, Garand, & Lingler, 2013). As research on this model is emerging, further detailed examination of the theory is warranted.

1.3 Thesis Organisation

The thesis is structured with an introduction, literature review, two studies written up as individual papers, and an overall discussion. The thesis will finish with an overall discussion chapter. Due to presentation style, there will be overlap in some aspects of the literature review chapters and introduction sections of the manuscripts. Indications have been made where possible to signpost sections in the manuscripts which have been discussed in the literature review. See the preface before each manuscript for further information.

Literature review. Chapter Two contains a discussion on the ageing population and need for increased focus on age-related healthcare research. This chapter will highlight the experience of "growing old" according to several philosophical frameworks. Chapter Three will discuss cognitive ageing. This concept is important because it has implications in how older adults make sense of their memory loss (i.e., as a normal part of ageing). Chapter Four will examine the controversies associated with MCI, a distinct form of cognitive impairment associated with an elevated risk of dementia. The label MCI was originally used in research settings, or for the purposes of clinician-to-clinician communication. Increasingly, MCI is being given as a clinical diagnosis, yet the impact of receiving such news is currently unclear. Chapter Five contains a discussion on MCI diagnosis and assessment. Identifying and diagnosing MCI is fraught with many unique challenges. The chapter deals with how practitioners approach disclosing a diagnosis associated with considerable contention. Chapter Six focuses on how clients feel about receiving a diagnosis associated with uncertainty. Chapter Seven summarises the literature presented in Chapter Two to Chapter Six. This chapter contains the specific research questions and methodological considerations for this thesis.

Study results. Study One and Study Two are presented as individual results chapters: (1) a survey of practitioners who diagnose cognitive impairment in NZ, (2) a mixed methods account of the experience of cognitive impairment diagnosis.

Discussion. The final chapter of the thesis contains an overall discussion on the research findings, and suggests recommendations for research going forward.

This chapter will focus on the older adult population and impact of population ageing. Older adulthood is associated with considerable transformation, such as change in marital status, living arrangement, working life, and health. Theories on the experience of these changes will be discussed in this chapter. Though the focus of this thesis is on MCI, it is important to discuss characteristics of the older adult population that MCI is most likely to affect.

2.1 Ageing Definitions: A Need for Change

Historically, many texts use a chronological age of 65 to define who is young and who is old. Today, many reject this dichotomous cut-off and instead, adopt a continuum approach to understanding the transition from middle age to older adulthood.

In the past, there has also been a lack of acknowledgement of the diversity within the older adult population; however, many gerontology publications now categorise cohorts of adults over 60 as either "young-old", or "old-old" (Lloyd-Sherlock, 2010). Some refer to the 100 and above age group as the "elite-old" (Meiner, 2011). The function of this distinction is to acknowledge that not all adults aged over 60 have the same experiences, abilities, or needs. People in other age groups do not have homogenous characteristics, lifestyles, and levels of functioning (Bludau, 2010; Victor, 2010); therefore, older adults should not be viewed any differently (Kart & Kinney, 2001). These changes in definition reflect a recognition of the diversity of experiences in older adulthood.

2.2 Trends in Population Ageing

The number of older adults is increasing dramatically as countries around the world experience population ageing. Population ageing characterises the higher numbers of adults in the 65 years and over age bracket. It is defined as an increased proportion of older adults and decreased

proportion of younger people. In the *World Population Ageing Report* (United Nations, 2013), authors note that many developed countries already have aged populations, and effects of this trend impact almost every country in the world.

By the year 2050, the international population of older adults is estimated to reach over 22%, or approximately one and a quarter billion people (Lloyd-Sherlock, 2010). Such demographic changes have been referred to as a "silver tsunami", "graying of the population", or an age of social transformation. Although such phrases have gained popularity in some areas of the literature, terms such as silver tsunami can have pejorative connotations when used to portray population ageing as a phenomenon associated with dread or fear.

Magnitude and upward trend of population ageing. Internationally, the number of people 65 years and over has tripled since 1950 and is expected to triple again in the coming 50 years (United Nations, 2001). Estimates suggest that by 2030, the older adult population will increase 3.5 times more rapidly than the total population (United Nations, 2001). Furthermore, not all regions of the world will experience population ageing in the same way (Lloyd-Sherlock, 2010). For instance, countries such as Japan are experiencing "hyper-ageing" where one fifth of their population is already 65 years and over (Hewitt, 2003).

The older adult population in NZ is increasing (refer Figure 1; United Nations, 2001). There are already more people in the 65 years and over category in NZ than any other point in time (Statistics New Zealand, 2009a), with these figures predicted to rise over the next 50 years (Families Commission, 2008). In addition, the 85+ age bracket is currently the fastest growing age group in the country (Hayman et al., 2012).
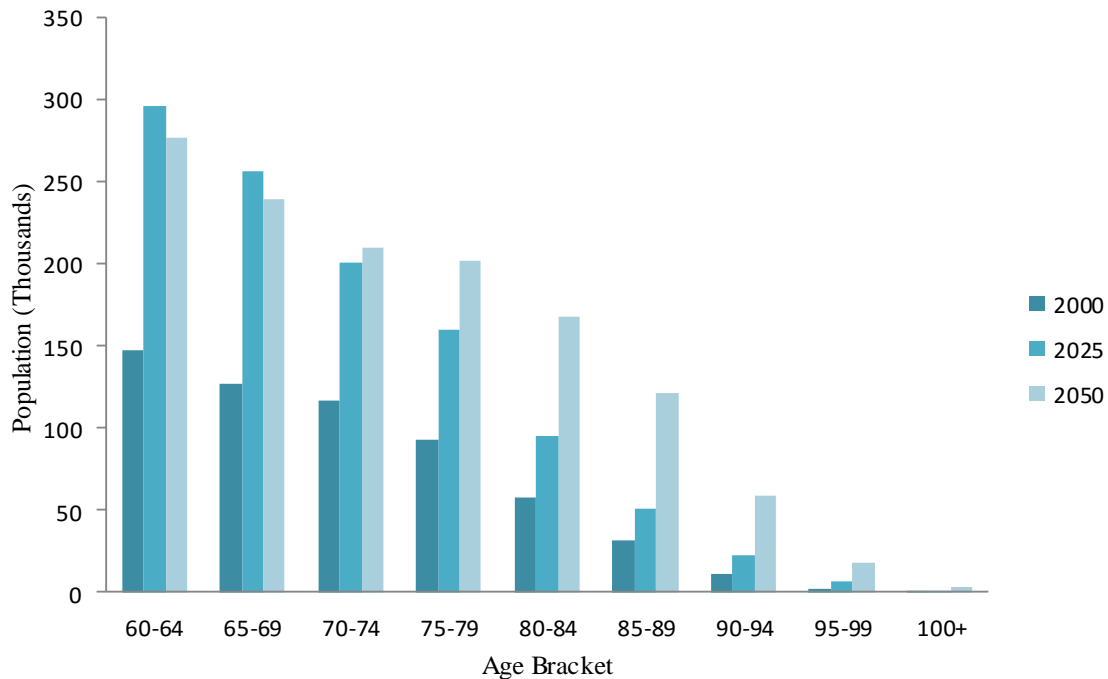
Figure 1. Projected Increase in Numbers of Older Adults in New Zealand. Adapted from United Nations. (2001). *World Population Ageing Report: 1950 – 2050.* New York: United Nations.

Significance and drivers of population ageing. The characteristics and needs of people living into older adulthood are different to what they were 50 years ago. This is a result of the socio-political milieu that many older adults today have matured in, but also due to life expectancy of the population having increased. One of the key drivers of population ageing is the arrival of the baby boomers reaching retirement age.

Editor-in-chief of ageing journal *The Gerontologist*, Professor Pruchno, describes the significance of this social change:

Baby Boomers redefined each stage of life as they experienced it, modifying fashion design and hair length as well as key societal institutions. They questioned the underlying values and attitudes of society. They influenced education, music, race relations, sex roles, and child rearing. They are about to change what we know about old age (Pruchno, 2012, p. 2).

The baby boom phenomenon is one of the key factors behind population ageing in NZ. Other factors include: declining fertility rates, increased life expectancy, higher standards of living, changes in lifestyle, and advances in medical knowledge (Davey, 2007). Indirect influences include changes in female education and employment, which can delay childbirth (Lloyd-Sherlock, 2010). Field (2012) notes how developed countries are spending more money on leisure activities, as well as goods and services which provide material comfort. This can impact on longevity indirectly by reducing stress and promoting health (Field, 2012). The culmination of these factors have meant societies around the world are ageing at rates never seen before (Kalula, 2010; Victor, 2010).

Population ageing has numerous implications for the healthcare system and public policy (Lloyd-Sherlock, 2010). Many researchers, academics, and policy makers debate whether population ageing will produce a crisis or manageable shift in the healthcare system (Cornwall & Davey, 2004). Irrespective of the impact, there will be a change in demand for healthcare services in the coming years (Ai & MacKenzie, 2006). As such, it is essential for societal infrastructures to be resourced for this population shift.

2.3 Important Concepts in Gerontology

Developments in healthcare provision, medical knowledge, and lifestyle factors have changed the way that individuals experience older adulthood today. A number of new phrases have emerged which accompany such socio-political change. Terms such as "optimal ageing", "productive ageing", and "healthy ageing" are often used to describe the process of being well in older age (Fernández-Ballesteros, 2011). In the gerontology literature, there is an increasingly common ideology that healthy lifestyle and health promotion equate to higher quality of life in older adulthood. Several new terms have been incorporated into public policy initiatives which acknowledge the need to "age well" in order to avoid or reduce the impact of age-related disease. Terms include: "successful ageing", "active ageing", and "positive ageing". Each concept is aimed at slightly different aspects of age-related quality of life (Chong, Ng, Woo, & Kwan, 2006). One

unifying theme in these concepts is the shift *away* from the negative aspects of ageing, to focusing on the positive elements of this life stage.

Successful ageing. This is term used to describe a shift in perspective, from older adulthood being a life stage synonymous with illness, to one of vitality and improved quality of life. The theory holds that to live "successfully", a person must be socially engaged, enhance their own wellbeing, and minimise their chances of acquiring disease or disability (Kahn, 2004). The term is prevalent in gerontology literature; although, the definition has undergone revision. One recent systematic review found 105 operational definitions on successful ageing (Cosco, Prina, Perales, Stephan, & Brayne, 2014). At present, successful ageing is widely understood as a process through which adults cope and accept age-related changes in their lives (Bagheri-Nesami, Rafii, & Oskouie, 2010). Overall, introduction of concepts like successful ageing embody an emphasis on quality of life for older adults and encouraging less reliance on aged care services (Hughes & Heycox, 2010).

Active ageing. Active ageing is a framework utilised by international organisations with a goal of optimising older adult health, participation, and quality of life (World Health Organisation, 2008). When the World Health Organisation (WHO) adopted this concept, they called for equal rights, healthcare, and treatment options for all older adults (Chong et al., 2006). The active ageing framework embodies an understanding that adults can live healthier lives for longer when environmental and lifestyle factors are modified.

Positive ageing. Sometimes confused with successful ageing, positive ageing is another component of older adult quality of life (Bowling, 1993). The concept has been used to develop public policy regarding welfare of older adults. Positive ageing is relevant within a NZ context because it formed a foundation for key healthcare policies in the late 1990s (Davey & Glasgow, 2006). These developments paved the way for further prioritisation of older adult healthcare in NZ. The *New Zealand Positive Ageing Strategy* (Ministry of Social Development, 2001) was established with the aim of creating of a society where adults in NZ could age well. This working document has

been updated almost annually until 2010 as per their website. Positive ageing is a concept that continues to underpin public policy in NZ today.

2.4 Theories of Ageing in Gerontology

The following theories are important to consider in the current thesis because many have relevance in how individuals experience older adulthood. Although there are many theories on the biopsychosocial processes of ageing, the following theories were selected for their relevance to NZ healthcare settings.

Biological theories. Many theories have attempted to explain the biological processes that occur in older adulthood. Such theories are linked with a growing emphasis on the importance of maintaining health and wellbeing over the lifespan (Touhy & Jett, 2016).

Past hypotheses on biological ageing. Many traditional biological theories on ageing have been criticised for being pessimistic and dated (Rattan, 2006). For instance, programmed theories of ageing propose that ageing and death occur by predetermined internal processes (Maguire & Slater, 2010), unamenable to intervention. Under this approach, cell death is programmed and unavoidable (Touhy & Jett, 2016). Evolutionary theories focus on how genetic factors influence the rate of ageing (Partridge & Gems, 2006). This theory has been critiqued for lack of acknowledgement on the role of the environment in ageing processes (Kirkwood & Austad, 2000).

Past biological theories of ageing are significant as they may shape an individual's understanding of what it means to grow old. For instance, some may expect to develop age-related illnesses as they get older due to the process of ageing, which they have no control over.

Current hypotheses on biological ageing. Current theories of ageing reflect an increased focus on modifiable lifestyle factors which may change the course of ageing. Ageing is now defined as a non-pathological process that varies according to individual differences (Bludau, 2010). Though it can make one susceptible to age-related disease, it is not a disease itself (Bludau, 2010; de Magalhaes, 2011).

Contemporary frameworks for conceptualising biological ageing focus on oxidative stress and free radicals (see Finkel & Holbrook, 2000, for review). Free radical theory attributes ageing to the body's natural metabolic processes (Steinberg, Vandell, & Bornstein, 2011). Under this approach, oxidative stress is proposed to cause cellular changes which manifest as ageing (Touhy & Jett, 2016). Biological theories such as this tend to focus on lifestyle habits, diet, and socioeconomic status (Kirkwood, 2002), particularly as they are postulated to modify the ageing process.

Psychosocial theories. There are many psychosocial theories on ageing (e.g., socioemotional selectivity theory, continuity theory); however, the following theories have been chosen for their relevance to thesis topic and New Zealand healthcare context. Although established some time ago, psychosocial theories of ageing have informed numerous healthcare policies, studies, and initiatives involving the older adult population.

Disengagement theory. Originally coined by Cumming and Henry (1961), this model holds that adults moving into older adulthood will normally discontinue or reduce involvement with usual life activities (Kahn, 2004). This model has been met with significant contention as it is associated with older adults being disenfranchised from the rest of society.

Activity theory. This theory was established in response to dissatisfaction with disengagement theory (Neugarten, Havighurst, & Tobin, 1961). This approach holds that ageing successfully and achieving wellbeing relies on remaining active throughout the lifespan (Dowd, 1975). Activity theory is linked with the concept of positive ageing (see Davey & Glasgow, 2006), which underpins the *New Zealand Positive Ageing Strategy* (Ministry of Health, 2001).

Continuity theory. This approach was developed by Atchley (1989) in response to disengagement and activity theory. Continuity theory suggests an individual will respond to ageing in similar ways to which they responded to previous life events (Atchley, 1989). An individual's identity is rooted in their sense of stability (Brandstadter & Greve, 1994), which is acknowledged in this framework. One of the key criticisms of continuity theory has been that the influence of society

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and the environment in ageing is overlooked or downplayed (Achenbaum, 2010). In the discussion of illness, continuity theory may be of value when trying to make sense of how an individual adapts to age-related challenges. Past research has employed continuity theory in explaining how people with dementia cope with their illness (Menne, Kinney, & Morhardt, 2002).

Life course theory. The life course perspective was developed initially in the 1920s following a University of California longitudinal study; however, it did not become well known until the 1960s (Elder, 1998). The theory acknowledges that life trajectories are influenced by environmental events, culture, and social structure (Elder, 1998). Cohorts of adults may experience life course stages similarly due to their shared experience of social and cultural events (Backett & Davison, 1995). It implicates sociocultural context and personal history as deeply relevant for an older adults' values, expectations, and behaviour (Hareven, 1994). This perspective is relevant in the discussion of older adults and age-related illness, as it acknowledges the importance of biographical history, society, and cultural factors which shape experiences of illness events.

Summary of theories of ageing. Ageing theories have moved away from emphasis on senescence and decline, to focusing on development and adaptation during older adulthood (Coleman & O'Hanlon, 2004). Theories about ageing can be used to explain trends in healthcare behaviours at individual and societal level. Aforementioned theories may also have links to experiences of age-related memory decline, and will be discussed in subsequent chapters of this thesis.

2.5 Age-Related Illness

Advancing age has been associated with increased levels of illness and disability. As the world experiences population ageing, incidences of age-related diseases are predicted to rise (Dyer & Ostwald, 2011). It is uncertain whether population ageing will mean there are higher numbers of older adults living longer, healthier lives, or whether this change will prompt a "compression of morbidity" (Lloyd-Sherlock, 2010). This phrase is used used in the gerontology field to refer to

James Fries' (1980) hypothesis that changes in lifestyle merely postpone chronic illness until later in life. Although there is uncertainty regarding the impact of population ageing, it is widely known that the chance of developing certain diseases increases with age (De Magalhaes, 2011; Hughes & Heycox, 2010; Ostwald & Dyer, 2011).

One of the most feared diseases associated with older age is dementia (Draper, 2013). Dementia is an umbrella term used to label a collection of symptoms, usually relating to memory, which cause significant difficulty with occupational and social functioning (Draper, 2013). AD is a type of dementia discovered by Alois Alzheimer in the early 1900s. To warrant diagnosis, deficits are observed in memory, language, visuospatial function, or executive function (Knopman, Boeve, & Petersen, 2003). Symptoms include impaired activities of daily living (ADL), such as showering, bathing, and eating. The experience of dementia results in restricted quality of life. In 2006, it was estimated 26.6 million people worldwide were living with AD and this figure is predicted to increase exponentially by 2050 (Brookmeyer, Johnson, Ziegler-Graham, & Arrighi, 2007). Countries with larger populations such as China and Japan are experiencing rapid population ageing and thus, AD prevalence figures are likely to be much higher.

2.6 Policy Regarding Age-Related Illness

Trends in age-related illness will impact demand for healthcare and disability services in the future (Cornwall & Davey, 2004). Of particular concern, is how to care for increasing numbers of adults who will be diagnosed with dementia. Global organisations such as Alzheimer's Disease International (2014) warn that dementia is a global phenomenon, and that dramatic increases of dementia diagnoses will affect infrastructures all over the world. As such, dementia is at the forefront of numerous global initiatives.

Global initiatives to combat dementia. As highlighted by the WHO (2012) in their *Dementia: A Public Healthcare Priority* report, many countries have developed public policy to address the growing numbers of adults diagnosed with dementia. Table 2 contains a brief summary

of international public policy. Strategies from a number of countries (i.e., China, India, parts of the

US) are still in development (WHO, 2012).

Table 2

Summary of International Policy Addressing Dementia in Healthcare

Country	Policy Name
Australia	The Dementia Initiative: Making Dementia a National Healthcare Priority
Canada	Alzheimer Strategy: Preparing for our Future
England	Living Well with Dementia: A National Dementia Strategy
Japan	Emergency Project for Improvement of Medical Care and Quality of Life for People with Dementia
Korea	War on Dementia
United States	(Individualised plans per state)

Note. Adapted from World Health Organisation. (2012*). Dementia: A public health priority*. Geneva, Switzerland: World Health Organisation.

National initiatives to combat dementia. In NZ, the most recent development in response

to population ageing has been the *New Zealand Framework for Dementia Care* report (Ministry of

Health, 2013). This framework aims to guide healthcare services that care for adults with dementia.

The system was based on a model for *Living well with Dementia* (Department of Health, 2009),

implemented in the UK as part of their *National Dementia Strategy* (Department of Health, 2011).

This strategy focused on dementia, with no mention of possible dementia prodromes, such as MCI

(Dean, 2013).

Key elements of the NZ-based strategy include: set processes for referrals, assessment,

follow-up, and ongoing care for people with dementia (Counties Manukau District Healthboard,

2013). Under the proposed NZ pathway, people with MCI will also be given follow-up, as well as

access to education, and support (Counties Manukau District Healthboard, 2013). Following the

release of the *New Zealand Framework for Dementia Care*, the Ministry of Health also published

an action plan to increase timely diagnosis of dementia, information on dementia, and improve support services (see Ministry of Health, 2014).

In summary, dementia is a global healthcare priority as populations' age around the world. NZ policymakers have reacted to population ageing by implementing strategies such as the *New Zealand Positive Ageing Strategy* (Ministry of Social Development, 2001) and *New Zealand Framework for Dementia Care* (Ministry of Health, 2013).

2.7 Experiences of Older Adulthood in the 21st Century

The experience of growing older in the 21st century will be different to previous generations, because of advances in medical knowledge, as well as changes in the way health and ageing are socially constructed.

Ageing, illness, and western culture. Adherence to a bio-medical view of older adult health and illness began in the 20th century, and is still prevalent in Western attitudes today (Phelan, 2011). Such views on health and illness are important, because they can influence how people negotiate their perceptions of illness (Hodgetts, 2000). A belief that "doctor knows best" can account for a tendency to unconditionally accept treatment and diagnostic advice delivered by a physician (Haug, 1979).

Will this belief hold true for older adults today? Coupled with a rise in consumerism, doctor-patient relationships are proposed to have become *less* biomedical and more support-based (Haug, 1994). Responsibility increasingly lies with the individual to take a proactive approach to their own health (Hodgetts, 2000).

Health-seeking and promotion. Historically, the process of ageing has been constructed in Western culture as a life-stage of frailty and physical deterioration (Cruikshank, 2013; Estes & Binney, 1989). Older adults' bodies have been portrayed as being prone to illness, and presumed incapable of contributing to society (Hareven, 1995). However, these depictions are inaccurate and do not represent experiences of *all* adults aged 65 years and over.

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Health promotion throughout the lifespan is a subject receiving increased attention from researchers and policy makers (Dannefer & Setterson, 2010). This is because prevention and intervention are viewed as means of prolonging healthy living and improving quality of life (Ostwald & Dyer, 2011). Health promotion and education could help off-set economic costs tied to population ageing (Boulton-Lewis, 2012); therefore, it seems likely that health promotion and prevention will become increasingly prevalent in age-related research and care in the future.

With the availability of the internet and increased access to technology (e.g., smartphones), the baby boomer generation will likely engage with health-seeking behaviour *differently* to previous generations of older adults (see Macias & McMillan, 2008, for discussion). In the US, internet and cellphone use has increased steadily in the older adult population over the past 15 years (Zickuhr & Madden, 2012). Increased engagement with technology in the older adult population has been referred to as "the rise of the silver surfer" (Selwyn, 2004). Although older adults tend to use the internet less than younger age groups (Choi, 2011), frequency of use compared to previous generations will likely be higher. In addition to accessing health-related information on the internet, computers and cellphones can now be used to access health-promoting activities. Reports on efficacy are tentative and the scientific literature is in its infancy; however, "brain training" applications are a rapidly expanding area in cognitive neuroscience literature (Nouchi et al., 2012).

Acknowledging the benefits of an ageing population. It is anticipated population that ageing *will* equate to social, economic, and political cost over the coming years (Vettori, 2010; Victor, 2010). One of the difficulties in addressing population ageing is that there is no historical record of any similar occurrence; thus, adapting public policy is unfamiliar territory (Bloom, Canning, & Fink, 2010). Knowing where to focus attention in healthcare provision and research is difficult to foresee. That said, not all literature on the cost of population ageing is pessimistic. There are those who argue healthcare spending is unrelated to population ageing (Zweifel, Felder, & Meiers, 1999), and may not be as dramatic as some are predicting (Bloom et al., 2010; Field, 2012).

Discussions focusing on overwhelming healthcare costs overlook the value that older adults have in society (Healy, 2004).

In NZ, the number of older adults is set to double in the next 25 years, but the cost and burden may not (Statistics New Zealand, 2009a). An ageing population may initiate a *shift* in healthcare spending, rather than a significant drain on the economy (Lloyd-Sherlock, 2010). Thus, the "silver tsunami" may only require a shift in focus, rather than preparation for catastrophe. Discussions on population ageing should reflect a need for change, rather than a need for fear!

There are a number of factors which may offset the cost of having an older population. Due to the need for supplemented income or mere stimulation, older adults' participation in the work force today is unprecedented (Achenbaum, 2010). In NZ, approximately 82,000 adults aged 65 years and over were in the workforce in 2006, compared with 21,000 in 1986 (Statistics New Zealand, 2009b). Organisations and older employees can mutually benefit from involvement with paid or unpaid work. The change in workforce which accompanies population ageing fits with 'active ageing' concept, whereby older adults are encouraged to retire later and remain active for longer.

Future directions. During a keynote presentation at the recent NZ Association for Gerontology conference, an expert on age-related care highlighted how education and prevention are *essential* in caring for an ageing population (Millar, 2014). This discussion point is timely given the wider context of international ageing literature. A report released one month later, by Alzheimer's Disease International (2014), reinforced such sentiments by describing the importance of focusing on brain health, activity, and modifiable risk factors for age-related memory decline. This focus on *prevention* of poor health and extension of reasonable health, is the embodiment of active ageing. It also illustrates the shift of focus from pessimism to optimism regarding population ageing.

2.8 Concluding Comments

The number of adults moving into the older age bracket is higher than it has ever been before; therefore, it is important that attention is paid to issues affecting adults as they reach older adulthood. AD is one of the most feared illnesses of older age, and it is no wonder, with previous generations seeing older adults segregated from society. In the past, ageing was seen as a life stage of disconnectedness and illness. Today, public policy has prioritized older adult health and dementia care, and it is hoped that these shifts in focus will facilitate better quality of life for people as they age. To achieve this goal, it is vital that research is carried out to highlight areas where public health can be improved to accommodate the growing numbers of older adults.

Healthcare services will undoubtedly experience an increase in demand as the older adult population increases. It is important that such services are equipped with information and resources to support a growing, diverse population of clients. Healthcare systems have a role in shaping the way that people experience age-related changes to health, which is why evidence is needed to support future policy development. The following chapter will outline how age affects the brain, and how these come to impact human memory.

Of the abilities people hope will remain intact as they get older, perhaps the most treasured

is to 'stay sharp' – to think clearly, remember accurately, and make decisions with careful

thought. Yet the brain ages… (Blazer, Yaffe, & Liverman, 2015, p. *ix*)

Sections of this chapter have been deliberately framed to highlight the contextual factors

relevant to MCI. First, several key terms require definition in relation to the older adult client and

their memory. Second, the concept of the cognitive continuum will be explained. Third, the biology

of ageing and the brain will be discussed. This topic is important in a thesis on MCI because

cognitive ageing, MCI, and AD might have similar underlying mechanisms according to some of

the current literature. Finally, this chapter will conclude with a review on the theories of cognitive

ageing, and future directions with research in this area. There are many categories and causes of

cognitive impairment; however, the following discussion highlights the complexity of memory loss

in older age.

3.1 Cognition in Later Life

Natural changes in cognition occur as people grow older. Typically, it is normal to forget an

acquaintance's name after an introduction, or occasionally misplace a set of car keys. Indicators of

cognitive ageing are not necessarily indicative of underlying neuropathology. However, the

experience of fleeting memory loss can be concerning for the individual and their family. On the

other hand, others may not notice when memory loss has progressed to a point where everyday

function is impaired. Symptoms of dementia may be rationalised with phrases such as "having a

senior moment", which normalise occurrences of memory loss. Others may deny or hide their

memory symptoms. As the following sections illustrate, the relationship between normal cognitive ageing and neuropathology is complex.

3.2 Key Terms on Age-Related Memory Impairment

A number of key terms will be used throughout the chapters of this thesis, and require brief explanation. What follows is an attempt to delineate normal cognitive ageing, MCI, and dementia. Despite this attempt at categorization, "it is far from straightforward to separate non-pathological from pathological cognitive decline" (Deary et al., 2009, p. 136). With careful consideration, points of difference can be observed between the features of normal cognition in later life and AD (Leifer, 2003).

Normal cognitive ageing. This phrase refers to a state whereby an individual's cognitive ability fits within the range expected for someone of a particular age. The definition of 'normal' has proved elusive, because individual differences significantly influence cognitive ability (Golomb, Kluger, & Ferris, 2004). Some individuals live well into their 90s, with only minor delays in processing speed and changes in attention (Buckner, 2004). Thus, the presentation of normal cognitive ageing can differ according to the individual.

Cognitive ageing is typically associated with changes in processing speed, executive function, inductive reasoning, and certain aspects of memory (Bondi, Salmon, & Kasniak, 2009; Deary et al., 2009; Harada, Natelson, Love, & Triebel, 2013). One meta-analysis suggests older adults are less able to perform a dynamic range of cognitive tasks (e.g., relating to perception, memory encoding, memory retrieval, and executive function) compared with younger adults (Spreng et al., 2010). Though the phrase might seem to indicate changes that occur in late adulthood, this process begins in adults as young as 20 to 30 (Salthouse, 2009).

It is difficult to distinguish normal ageing from pathology, particularly as these states may appear to be similar. Failure of episodic memory (i.e., memory for events) can occur in people who fall within normal limits of cognition; however, declines are also evident in people with MCI and

AD (Koen & Yonelinas, 2014). On the other hand, certain aspects of cognitive function (such as semantic memory, vocabulary, and cognitive priming) are not as affected by advancing age as others (Bondi et al., 2009). Processing of emotional stimuli and autobiographical events appear unaffected in many individuals (Hedden & Gabrieli, 2004).

Subjective memory complaints (SMC). These are self-identified difficulties with memory that cause individual concern (Mitchell, 2008). Early literature suggested that SMCs may predict dementia (Schmand, Jonker, Hooijer, & Lindboom, 1996), or serve as a red flag for future cognitive decline (Dik et al., 2001). Subsequent research challenged these statements, as many healthy older adults report innocuous SMCs (Gauthier et al., 2006). Current studies report controversy over the significance of SMCs in preclinical dementia (Laske et al., 2015). Although some working groups have recommended including SMCs in MCI diagnostic criteria (e.g., Winblad et al., 2004; Portet et al., 2006), few have employed this suggestion in their research (see Mitchell, 2008, for discussion). Agreement has not yet been reached over whether SMCs are necessary in MCI diagnosis (Yates, Clare, & Woods, 2015a).

One of the reasons for doubt over the prognostic utility of SMCs is due to a relationship with other variables. For instance, there is an association between SMCs, personality traits (Reid & MacLullich, 2006), and psychiatric symptoms (Yates, Clare, Woods, Matthews, & Wales, 2015b). Depression can predict SMCs (Schmand, Jonker, Geerlings, & Lindeboom, 1997), suggesting SMCs may exist *outside* of the normal ageing - dementia continuum. Current literature suggests SMCs may mediate the relationship between psychosocial status and cognitive decline (Yates et al., 2015a).

Summary on key terms. In response to population ageing, where higher numbers of adults are predicted to experience AD, growing interest has focused on diagnosing AD early, hence increased attention on concepts such as cognitive ageing, SMCs, and MCI. The tendency for individuals to progress through stages of normal ageing, to MCI, to dementia, provides basis for a

concept whereby cognition is thought to exist on a continuum. Factors affecting this continuum will be discussed in the following section.

3.3 The Cognitive Continuum

Cognition is now conceptualised as a series of stages between normal ageing, MCI, and dementia (Dubois, 2000; Jack et al., 2000; Portet et al., 2006), which form a continuum. In 1982, a clinical staging model was first introduced whereby a person could be classified as having either normal cognitive functioning or dementia (Gauthier et al., 2006). Not long after, the cognitive continuum concept was established (Brayne & Calloway, 1988). It is now thought that a person progresses through cognitive stages before transitioning into dementia (Petersen et al., 1997), and that boundaries between normal cognition, MCI, and dementia can overlap (Petersen, 2004). The cognitive continuum concept is important as it highlights the fluidity of cognition, which fluctuates in response to numerous outside sources such as stress, hormonal activity, and medication.

One proposed pathway along the continuum begins with an older adult presenting with depression (a risk factor or early manifestation of MCI), which can then eventually lead to dementia (Panza et al., 2010). Others suggest the continuum begins with normal ageing on the one side, MCI in the middle, and AD on the opposite side (Cha et al., 2013; Marshall et al., 2009). SMCs typically fall within the normal ageing to MCI range. Cognitive measures assess stages in cognition, which are often identified to indicate severity of decline (e.g., the Global Deterioration Scale; Reisberg, Ferris, de Leon, & Cook, 1982, refer to Table 3).

In summary, the continuum concept has been useful as it highlights the differences between states of cognition; however, it must be interpreted with caution because symptoms may appear to overlap. Despite the obvious utility of this concept, some have cautioned against continuum theory. Ganguli et al. (2015) argues an assumption is developing where once a diagnosis of MCI is given, a dementia diagnosis is perceived as inevitable. Only a subset of those diagnosed with MCI will

develop AD (Petersen, 2004), so not all individuals will "slide" from one end of the continuum to the other.

Table 3

GDS Score and Associated Symptoms of Cognitive Impairment

GDS score	Level of impairment
Stage one	Cognitively normal, free of SMC, some mild memory problems not noted by others
Stage two	Experience SMC though still cognitively normal, mild to moderate memory complaint
Stage three	SMC complaints increase to highest level and MCI generally identified or present
Stage four	Mild dementia, moderate memory problems
Stage five	Moderate dementia, memory complaints match those of a person in stage one, insight deficits are prevalent
Stage six	Moderate to severe dementia

Note. GDS = Global Deterioration Scale for Ageing and Dementia. MCI = Mild cognitive impairment. SMC = Subjective memory complaints. Adapted from B. Reisberg, & S. Gauthier, (2008). Current evidence for subjective cognitive impairment (SCI) as the pre-mild cognitive impairment (MCI) stage of subsequently manifest Alzheimer's disease. *International Psychogeriatrics* 20(1): 1-16.

3.4 Biological Changes in Cognitive Ageing

Developments in the neuroimaging literature have allowed researchers to investigate the complexities associated with cognitive ageing (Flynn & Ryan, 2013; Reuter-Lorenz & Park, 2010). As a person ages, a number of brain changes are proposed to take place. First of all, reduction in brain volume may occur (Raz et al., 2005). Reductions in white matter and grey matter may explain some cognitive changes in later life (Cabeza et al., 2002; Harada et al., 2013; Turner & Spreng, 2012). Thinning of the cerebral cortex (involved with higher thought processes) is also associated with cognitive ageing (Salat et al., 2004).

Brain regions are selectively affected as a result of cognitive ageing (see Hedden and Gabrieli, 2004, for review). Resnick and colleagues (2003) used magnetic resonance imaging (MRI)

methods in a sample of 92 healthy adults and found reductions in grey matter in the parietal (inferior), cingulate, insular, and frontal (orbital and inferior) regions of cognitively healthy brains. Past research also implicates selective degeneration in the frontal and prefrontal regions compared with other brain areas (Kramer et al., 1999; West, 1996). Furthermore, activation of certain brain regions involved with cognition change with age (Spreng et al., 2010; Turner & Spreng, 2012). Reduced plasticity can compromise the ability to recuperate function efficiently (Riddle, Sonntag, & Lichtenwalner, 2003), and as a result, different regions of the brain activate to perform the same task (Reuter-Lorenz, 2002).

With advances in neuroimaging technology, methods such as functional magnetic resonance imaging (fMRI) have shed light on many of the changes occurring in older adulthood (Reuter-Lorenz & Park, 2010; Spreng et al., 2010). However, certain biological aspects of cognitive ageing and AD may appear similar. For instance, oxidative stress (e.g., isoprostanes) and inflammation (e.g., cytokines) are present in normal cognitive ageing (Floyd & Hensley, 2002), but can also underlie AD pathology (Albert et al., 2011). Differentiation between cognitive ageing and AD poses an ongoing challenge for practitioners involved with assessment.

3.5 Neuroscientific Theories of Cognitive Ageing

A number of conceptual theories have been developed to explain some of the structural and functional changes associated with cognitive decline and ageing (for discussion, see Reuter-Lorenz & Park, 2010). The following theories have been selected due to their relevance in understanding the complexities practitioners face when assessing and diagnosing mild forms of cognitive impairment.

Overactivation. The Hemispheric Asymmetry Reduction in Older Adults model (HAROLD) is a framework proposed to explain the effects of cognitive ageing (Cabeza et al., 2002). Symmetry of brain hemispheres decline with advancing age, leading to symptoms of cognitive decline (Cabeza et al., 2002). As a result, a group of older adults performing a memory

task (e.g., spatial memory, verbal working memory) will show increased activation in additional regions of the brain than is necessary to complete the task, compared with younger adults (Reuter-Lorenz, 2002). Though the legitimacy of overactivation in the cerebral cortex of older adults has been examined in past research, the significance of this process of cognitive ageing is not yet agreed on (Reuter-Lorenz & Park, 2010).

Compensation. Neurobiological literature suggests some age-related differences in cognitive ability might be accounted for by compensatory brain activity (Cabeza, 2001; Spreng et al., 2010). Researchers argue that overactivation evidence provides validation for a separate compensatory hypotheses (Reuter-Lorenz & Park, 2010). Several terms have been proposed to capture aspects of this complex process, including: the compensation-related utilization of neural circuit hypothesis (CRUNCH; Reuter-Lorenz & Cappell, 2008) and posterior to anterior shift (PASA; Davis, Dennis, Daselaar, Fleck, & Cabeza, 2008). As with other neuroscientific theories on cognitive ageing, legitimacy of compensation-related theory is also contested (Hillary et al., 2006).

Scaffolding theory of ageing and cognition (STAC). This model highlights how the brain attempts to cope with the challenges of ageing by building protective "scaffolds" as the brain undergoes structural and functional change (Goh & Park, 2010, p. 394). Neural challenges precipitating these changes include amyloid deposition, atrophy, reductions in white matter, and changes in neurotransmitter activity (Reuter-Lorenz & Park, 2010).

Dedifferentiation. This theory has been discussed in relation to other cognitive abilities (e.g., intelligence); however, in the context of neural networks, the model is associated with a reduction in neural plasticity in specific regions of the brain, resulting in over-compensatory recruitment (Reuter-Lorenz & Park, 2010). Despite considerable investigation into these processes, conclusive evidence on the dedifferentiation hypothesis is scarce (de Frias, Lövdén, Lindenberger, & Nilsson, 2007).

Cognitive reserve. Cognitive reserve (CR) refers to the brain's proposed attempt to compensate for the effect of neuropathology (Stern, 2002). By comparison, CR theory has been used a great deal in the neurology and neuropsychology fields with reference to brain injury, dementia, and cognitive ageing. CR theory is used to explain how intelligence, education, and occupational level act as a protective factor against cognitive decline (Whalley et al., 2004). Increased CR is hypothesised to protect against eventual dementia diagnosis (Bozzali et al., 2015; Stern, 2006; Whalley et al., 2004). Enhanced CR may even slow down progressive AD-associated cognitive decline (Scarmeas & Stern, 2003).

3.6 Concluding Comments

Changes in cognition with normal ageing do not cause functional impairment. For an individual experiencing minor change in memory ability, this may come with fear and anxiety over the implications of subjective memory loss. Distinguishing normative from non-normative cognitive ageing is important, as both have very different outcomes. The former is considered innocuous, while the latter can indicate fatal neuropathological decline.

The literature is constantly evolving in attempt to understand MCI as: (a) a prodromal form of AD, and (b) an intervention point to ward off AD diagnosis (Brookmeyer et al., 2011). Much of the literature focuses on amnestic MCI as a pre-cursor to AD, rather than non-amnestic MCI. It has been difficult to gain a coherent understanding of MCI due to academic debate on the significance of this syndrome. The following chapter will contain a discussion on the concept of MCI, including definitions, criteria, and many of the current controversies regarding this diagnosis.

4.1 What is Mild Cognitive Impairment?

MCI represents a transitional phase between normal ageing and dementia. An individual receiving the diagnosis will have deficits in cognition, though everyday functioning remains preserved (Leszcz, 2011). MCI is a heterogeneous condition characterized by an objective memory complaint assessed by clinical interview, neuropsychological tests, biomarkers, and neuroimaging methods (Dubois & Albert, 2004; Moreira et al., 2008).

MCI is a challenging construct to operationalise and investigate. Research on etiology, prognosis, and incidence may be inaccurate due to varying MCI definitions and criteria (Mariani, Monastero, & Mecocci, 2007). In comparison with Alzheimer's disease, which was coined in the early 1900s, MCI is a construct which has been around for less than 30 years, though the research on this condition has been gathering momentum since the late 1990s (McKhann, 2011).

Controversies exist in the literature around MCI (Gauthier et al., 2006; Moretti et al., 2013; Roberto, McKhann, & Blieszner, 2011); however, despite these contentions, MCI has been indicated as a precursor or even prodromal form of dementia (Mitchell & Shiri-Feshki, 2008; Reisburg & Gauthier, 2008). Kaduszkiewicz et al. (2014) highlights highly variable courses of

MCI, such as: remitting, fluctuating, persistent, or stable. Reported annual conversion rates from MCI to dementia typically range from 10 – 15% (Busse et al., 2006). Though there is considerable debate over these percentages, the ostensibly low conversion rate from MCI to dementia is likely due to the ongoing difficulties with definition, diagnosis, and identification.

Historical background of MCI. Prior to the 1980s, cognitive decline was viewed as part of normal ageing (Bartlett & O'Connor, 2010). This belief is still prevalent in how many people perceive memory impairment today. In the early 1980s, the first systems were developed, allowing practitioners to assess stages on the cognitive continuum other than normal ageing versus dementia (Gauthier et al., 2006).

A Mayo Clinic working group was formed in 1986 to investigate incidences of cognitive decline, and is now widely known in the literature on MCI and dementia (Petersen, 2005). The remainder of the 1980s saw an acknowledgement of a prodromal form of AD, later known as MCI (Rosenberg, Johnston, & Lyketsos, 2006). Despite this development, it would be some time before the label of MCI would be formally accepted as a medical term. The concept was supported officially by the American Academy of Neurology for the first time in 2001 (Petersen et al., 2001).

As a diagnostic category, MCI was introduced through a number of key papers by Flicker, Ferris, and Reisburg (1991), Smith and colleagues (1996), and then most notably Petersen et al. (1999). This pioneering paper by Petersen and associates has been cited more than 6000 times as of December 2014. From 2000 to 2004, the frequency of MCI in scientific journals tripled from the previous ten year period (Petersen, 2005). This indicates an increasing interest in MCI as a definitive construct.

In the early 2000s, Dubois and Albert (2004, p. 248) suggested introducing clinical subtypes of MCI such as "MCI of the Alzheimer type". It was proposed that this would improve the value of MCI diagnosis. Ten years later, the term mild neurocognitive disorder (mNCD) has now been introduced which builds on this suggestion, whereby mNCD can be specified to communicate

underlying etiology (e.g., suspected AD). In this sense, the label is of value when it indicates likely progression to AD. The broader label of MCI is considered more heterogeneous with multiple underlying etiologies (Portet at al. 2006).

Caution has been advised with regard to the MCI diagnostic label. Dubois et al. (2007) recommended MCI be removed from research based dementia criteria due to problems associated with reliability of the construct. Ritchie, Artero, and Touchon (2001) found that MCI criteria was not predictive of eventual dementia diagnosis in the general population (although objective formal impairment should not be ignored). Other papers have been published in the years that followed, highlighting heterogeneity of the syndrome, and a need for consensus:

> …MCI is a concept that is more meaningful to clinicians and neuroscientists than it would
> be to a lay person. It does not tell the person receiving this diagnosis whether they have
> dementia or whether what they are experiencing is normal; nor does it say whether the
> person will go on to develop dementia, nor what type of dementia this might be. We simply
> do not know what the effects of being given a diagnosis of MCI are; they have not been
> fully explored for the person's perspective (Corner & Bond, 2006, p. 6).

National context: MCI in NZ. Research on dementia related conditions in NZ is scarce (Prasaradao, 2014). As a research construct, MCI themed discussions began appearing at national conferences from 2009 (e.g., Livingston et al., 2009). Publications from Otago and Canterbury contained discussions on MCI, though in the context of Parkinson's disease (PD-MCI; Dalrymple-Alford et al., 2011). Petra Hoggarth from the University of Canterbury notably published her PhD thesis on driving safety, MCI, and AD (Hoggarth, 2011; Hoggarth et al., 2011), which resulted in formal discussions on cognitive impairment and driver safety on NZ roads (e.g., Hoggarth, 2013).

As of 2014, several projects on MCI were in progress at several key tertiary institutions, DHBs, and research centres in NZ. Following the release of the *New Zealand Framework for Dementia Care* (Ministry of Health, 2013), research is currently underway on the effectiveness of

identifying and managing symptoms of cognitive decline in everyday practice (i.e., primary care). Until more of this research is published and disseminated, the field is likely to continue to vary in its approach to the diagnosis and treatment of early-stage cognitive impairment.

In sum, there is minimal information about MCI in NZ. Although research efforts are underway with DHB centres, working groups, and academic institutions, it remains unclear how MCI is approached in clinical practice *now*.

4.2 Defining and Characterising MCI

MCI definitions and research criteria have been subject to variation and inconsistency. Matthews, Stephan, Bond, & McKeith, (2007) identified 18 definitions of early cognitive impairment in a systematic review of the scientific literature. Examples of variable terminology include: age-associated cognitive decline (Busse, Bishhkopf, Riedel-Heller, & Angermeyer, 2003), mild memory impairment (Davies et al., 2010), benign senescent forgetfulness (Heinik, 2010; Rosenberg et al., 2006), possible dementia prodrome (Knopman et al., 2003), cognitively mildly impaired, and age-associated cognitive impairment (Luck, Luppa, Briel, & Riedel-Heller, 2009).

In addition to the varying nomenclature of cognitive impairment, research examining MCI has tended to employ variable cut-off scores to diagnose this condition. A research diagnosis of MCI is defined as an overall memory score lying 1.5 *SD* below the normative mean (Brooks, Iverson, & White, 2007). Although, a key paper published by Albert et al. (2011) suggested cut-off scores of 1-1.5 *SD* below the mean should only be used as a guideline. Some argue that varying cut-offs can influence the frequency of MCI diagnosis (for discussion, see Schinka et al., 2010), which limit the applicability of study findings.

Clinical information can also be problematic when diagnosis is based on cognitive screening measure or singular measure alone. Use of the Clinical Dementia Rating scale (CDR; Morris, 1993) results in a cognitive score ranging from zero (worst) to three (best). A score of 0.5 may indicate AD but could also indicate MCI (Hänninen, Hallikainen, Tuomainen, Vanhanen, & Soininen,

2002); therefore, using this source of information alone may spuriously inflate numbers of individuals with MCI or AD. In the past, studies have used just one screening measure to evaluate the presence of MCI (Petersen, 2004). However, using a singular score to indicate MCI is futile because clients have such varied premorbid levels of functioning (Knopman et al., 2003).

As described in Chapter Three, it can be difficult to differentiate cognitive impairment from normal ageing. An overlap often exists between the score of someone with normal cognitive functioning and someone with MCI (Brooks, Iverson, Holdnack, & Feldman, 2008; Portet et al., 2006). Brooks et al. (2008) found a number of cognitively healthy older adults performed 1.5 SD below the mean in their study, which by some criteria would indicate MCI. However, these scores could also be reached because *too many* measures are being considered simultaneously (Brooks et al., 2008). There is propensity for an individual to score poorly on at least one measure (Brooks et al., 2008), which is why a combination of supporting information is essential for diagnosis.

Subtypes of MCI. Four subtypes have been introduced in attempt to improve the clarity of MCI diagnosis. Subtypes are used to indicate which cognitive domains are affected (e.g., memory or non-memory) allowing the practitioner to gain an impression on the client's future prognosis (Han et al., 2012; Nordlund et al., 2007).

Amnestic mild cognitive impairment (aMCI) refers to objective memory impairment where other cognitive abilities remain unaffected (Petersen et al., 2006). Much of the literature on MCI focuses on this subtype as it is most likely to progress to AD (Golomb, Kluger, & Ferris, 2004; Petersen, 2003). Of those diagnosed with aMCI, up to 80% could be diagnosed with AD within six years (Petersen, 1995, cited in Petersen, 2005). Non-amnestic mild cognitive impairment (naMCI) is proposed to affect non-memory domains of cognition, such as attention and executive function.

Each subtype can be specified further depending on whether impairment is observed in single, or multiple domains. Identifying the domains affected is beneficial to clinicians as it may indicate their client's future prognosis. For instance, single domain aMCI is associated with AD,

single domain naMCI may progress to other dementias (e.g., frontotemporal dementia, Lewy body dementia), and multiple domain memory impairment may progress to AD or vascular dementia (see Petersen, 2003).

Though the intention of developing MCI subtypes was to improve diagnostic clarity and indicate possible prognosis, many argue these efforts have been in vain. The validity of MCI subtypes has been disputed (Han et al., 2012; Klekociuk & Summers, 2014). Particularly as aMCI may serve to identify those at risk for progression to AD, there is urgent need for clarification of this syndrome (Stephan et al., 2013).

Diagnosis criteria for MCI. Multiple sets of clinical and research based criteria exist for MCI. In a recent systematic review, Stephan and colleagues (2013) highlighted variable MCI criteria used in clinical research. They argue that varied operationalisation of MCI will continue to obscure tangible benefits from clinical research until consistency is reached.

In the 1980s, McKhann et al. (1984) published a set of clinical criteria for AD which paved the way for eventual MCI diagnostic information. Original AD criteria have since been modified in response to developments in the literature on dementia, MCI, neuroimaging, and biomarkers. At the turn of the 21st century, no consensus existed with respect to MCI diagnosis (Ritchie et al., 2001); however, a number of diagnostic guidelines have since been published in order to operationalize MCI (refer to Table 4). Most recently, an international working group published a key paper that redefined several key criteria for MCI diagnosis (i.e., MCI due to AD; Albert et al., 2011). This is now commonly used in research settings and is often referred to as the National Institute on Ageing and the Alzheimer's Association criteria (NIA AA; Albert et al., 2011).

Other labels are relevant in a discussion on MCI criteria as some of the symptoms may overlap. Cognitive disorder not otherwise specified (CD-NOS; refer Table 5), was published in the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV;* American Psychiatric

Association [APA], 2000). It is a diagnostic label which refers to impairment in cognition on formal testing.

Moreover, mNCD is a newer diagnostic label introduced in the *DSM-V* (APA, 2013). With the release of the *DSM-V*, terms such as dementia and MCI replaced with major NCD and mNCD (Breitner, 2014). Mild NCD is identified as a form of cognitive disorder which may or may not progress to dementia (Sachs-Ericsson & Blazer, 2015). Some argue inclusion of mNCD will cause more confusion about the differences between normal ageing and the emergence of a neuropathological syndrome (Rodriquez-Testal, Senín-Calderón, & Perona-Garcelán, 2014). Release of the *DSM-V* and formal introduction of mNCD are burgeoning discussion topics in the literature on MCI. No doubt, further publications on the impact of the new formal NCD diagnoses will emerge in the coming years.

Table 4
Research and Clinical Criteria for Establishing MCI Diagnosis

Authors	Criteria
Albert et al. (2011) criteria	Concern regarding change in cognition
	Impairment in one or more cognitive domains
	Preserved IADL
	No dementia
	Also known as National Institute on Ageing – Alzheimer's Association (NIA AA) criteria or "mild cognitive impairment due to AD"
Petersen et al. (2001) criteria	Memory complaint
	Normal ADL
	Normal general cognitive function
	Abnormal memory for age
	No dementia
Winblad et al. (2004) criteria	Not normal, no dementia (does not meet DSM-IV TR/ICD 10 criteria for a dementia syndrome)
	Cognitive decline
	Self/informant report and impairment on objective cognitive tasks
	Evidence of decline over time on objective cognitive tasks
	Preserved basic ADL/minimal impairment in complex instrumental functions

Note. ADL: Activities of Daily Living. DSM-IV-TR: Diagnostic and Statistical Manual 4th edition text revision. IADL: Instrumental Activities of Daily Living. ICD: International Classification of Diseases.

Consistent aspects across the different sets of criteria include: the absence of dementia, and the ruling out of any psychiatric disorder responsible for symptoms of cognitive decline (Collie & Maruff, 2002). In order for MCI to be diagnosed, possible underlying illness should be ruled out. Failure to account for these considerations may explain why many people with MCI do not go on to develop AD after diagnosis (Collie & Maruff, 2002).

Table 5

Additional Clinical Criteria for Diagnoses Relating to MCI

Authors	Clinical Label	Criteria
American Psychiatric Association (2000), DSM-IV-TR criteria	Cognitive Disorder Not Otherwise Specified	Impairment in cognitive functioning found in formal testing
American Psychiatric Association (2013), DSM-V criteria	Mild Neurocognitive Disorder	Deficits in complex attention, executive function, learning and memory, language, perceptual motor abilities, social cognition. Based on subjective and objective observation. Preserved complex IADL No delirium Absence of other organic disorder

One final point with regard to diagnosing MCI concerns activities of daily living (ADL) and instrumental activities of daily living (IADL). In addition to having multiple classification systems for MCI, many criteria differ on the presence of impairment in ADL (Collie & Maruff, 2002). One issue with this criteria is that research has shown ADL *are* impacted by changes associated with MCI (Mariani et al., 2007). Other studies suggest impaired ADL is indicative of more serious cognitive decline that has progressed beyond MCI (see Collie & Maruff, 2002, for discussion). It is possible this aspect of the diagnostic criteria will be revised in the future.

In sum, MCI has conjured up much controversy in the research literature (McIlvane et al., 2008). The exact criteria of MCI diagnosis has been a notorious grey area (Winblad et al., 2004), making it difficult to make conclusive statements about the findings of MCI-focused research (DeCarli, 2003). Consequently, this creates a challenge in deriving clinical benefits from research

on this category of syndrome. Improving consistency in definition, cut-off, and assessment can help improve clarity in research designed to help those affected by cognitive impairment.

4.3 Prevalence

It is difficult to determine accuracy of existing MCI prevalence rates. Existing figures contain high variation, depending on whether the sample is clinically-based or community-based (Lin, Vance, Gleason, & Heidrich, 2012). Furthermore, differing diagnostic criteria is likely to contribute to variable prevalence rates (DeCarli, 2003; Patel & Holland, 2012; Portet et al., 2006; Ward, Arrighi, Michels, & Cedarbaum, 2012). In one population-based sample ($n = 4803$), MCI prevalence was determined using the Petersen et al. (2001) criteria at 7.93% in the population, while "DSM-V MCI" (i.e., mNCD) criteria in the same sample returned a 3.72% prevalence rate (Lopez-Anton et al., 2015). One recent review by Langa and Levine (2014) reported rates of MCI in the 65 years and over population to be approximately 10% to 20%. Another US study published an annual incidence rate of 5.6% using aMCI criteria with a community-based cohort (Gao et al., 2014). No MCI prevalence figures are currently available in NZ.

Research suggests MCI is more prevalent among men than women (Langa & Levine, 2014; Petersen et al., 2010); however, women are more frequently diagnosed with dementia compared with men (Saava & Arthur, 2015). The relationship between cognitive impairment and gender is complex, and likely influenced by a multitude of factors. Proposed gender explanations could be due to differences in brain structure, cognitive reserve, social behaviour, and hormone activity (see Mielke, Vemuri, & Rocca, 2014, for discussion).

The typical candidate for dementia and MCI diagnosis is usually an individual over 65 years of age. However, there is a growing recognition that young-onset dementia and cognitive impairment can affect those under 65. One community-based prevalence study estimates around 10% of the adult population in their 60s have some form of mild cognitive disorder (Anstey et al.,

2013). In order to identify those with young-onset, it will be important to increase awareness of early signs of memory-related decline in middle age.

4.4 Etiology

In comparison to dementia, the literature on MCI etiology is sparse. This is not surprising, given MCI is continuing to be refined into further categories with differing labels (e.g., aMCI vs naMCI, mNCD). Etiology sources such as CA1 atrophy (a region of the hippocampus) and ApoE 4 genotype are frequently identified in literature on MCI and AD (Collie & Maruff, 2002). This means that some of the sources of MCI and AD etiology appear to overlap. Given the scope of the current thesis, the following section is written with a focus on aMCI and AD, due to their current proposed etiological links in the literature. Despite this focus, current literature reports considerable biological heterogeneity in the etiology MCI (Nettiksimmons, DeCarli, Landau, & Beckett, 2014).

Neurofibrillary tangles. One of the main areas of research on AD neuropathology is the presence of abnormally phosphorylated tau proteins, comprising of intracellular neurofibrillary tangles (Karran et al., 2011; Kovacs, 2012). The presence of neurofibrillary tangles in the entorhinal cortex, hippocampus, and amygdala, have also been implicated in the neuropathology of aMCI (Markesbery, 2010). Researchers' hypothesise that atrophy and neuronal loss in the CA1 regions of the hippocampus could be responsible for many of the impairments exhibited by individuals with aMCI (Fouquet et al., 2012). Some studies have found the presence of tangles to be more strongly correlated with clinical symptoms of AD than plagues (Kerchner et al., 2012; Kovari, Herrmann, Bouras, & Gold, 2014; Verdile et al., 2004). Investigations in this area are ongoing.

Apolipoprotein E (ApoE). ApoE is a genetic subtype associated with increased risk for late-onset AD (Strittmatter et al., 1993; Reitz et al., 2011). APoE is also hypothesised to play a role in the etiology of MCI, though less is known about the relationship between these alleles and MCI. ApoE4 is known to increase the likelihood of AD development, though not as a direct cause, rather in influencing progression (Itzhaki et al., 1997). Hence, individuals meeting the full criteria for MCI

diagnosis with ApoE e4 are most likely to progress to AD (Albert et al., 2011; Winblad et al., 2004). The role of ApoE alleles continues to be investigated in research in order to more thoroughly understand the precipitative role of this genotype.

Beta amyloid plaques (Amyloid cascade theory). Beta amyloid plaques are an extension of amyloid precursor proteins (APP) and are the product of abnormal of β-amyloid peptides in the brain (Delrieu et al., 2011; Karran et al., 2011). These biomarkers have previously been implicated in MCI pathology (Forsberg et al., 2008); although, progression in this area is hampered due to challenges in accessing and analyzing cerebral spinal fluid in patients with MCI (Portet et al., 2006). Nevertheless, the amyloid cascade theory has been one of the most influential in AD pathology literature for the past 20 years (Karran et al., 2011), and is therefore relevant in the context of MCI which progresses to AD. One problematic factor associated with this hypothesis is the presence of β-amyloid plaques have been observed in the brains of older adults without AD (Albert et al., 2011).

Acetylcholine (AChE) and cholinergic hypothesis. Coined in the 1970's, the cholinergic hypothesis is typically discussed in the context of AD and to a lesser extent MCI. It states that cholinergic dysfunction results in cognitive impairment in older adulthood and AD (Terry & Buccafusco, 2003). Support for this hypothesis arose from improvements in cognitive ability following courses of acetylcholinesterase inhibitors (AChEI; Terry & Buccafusco, 2003). The role of acetylcholinesterase (AChE) in cases of MCI has challenged the cholinergic hypothesis pervading AD etiology literature (Terry & Buccafusco, 2003). AChEIs is recommended for therapeutic use in AD cases, rather than mild AD or MCI (Terry & Buccafusco, 2003). Petersen et al. (2005) conducted a three year RCT ($N = 769$) to evaluate the efficacy of vitamin E supplements, Donepezil[2] (a cholinesterase inhibitor), or placebo. Donepezil had only a modest impact in lowering the progression rate from aMCI to AD over a 12 month period.

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[2] Donepezil (Aricept) is a type of acetylcholinesterase inhibitor (AChEI) which reportedly slows down the progression of decline in MCI (Petersen, 2005).

Risk factors. Though unconfirmed, there are various proposed risk factors for developing MCI. Medical conditions such as hypertension have documented effects on cognitive function, and may be involved with MCI etiology (DeCarli, 2003; Oveisgharan & Hachinski, 2010). It has been suggested that diet (Edman, 2006) and polypharmacy (Langa & Levine, 2014) can impact cognition. Increasing age and lower levels of education are also reported risk factors (Luck et al., 2010), relating back to the concept of cognitive reserve discussed in Chapter Three. Moreover, age, gender, and environment may interact with genetic subtype to increase the likelihood of developing MCI (Winblad et al., 2004). Researchers have tentatively suggested neuropsychiatric symptoms may herald future AD diagnosis in those with MCI (Geda et al., 2004). The relationship between neuropsychiatric symptoms and cognitive impairment is complex and a burgeoning topic in the scientific literature.

Summary on etiology. To conclude this section on etiology, MCI is presently a heterogeneous condition with differing manifestations and underlying causes. Research is needed to establish conclusive statements about causes of MCI. It may be that more conclusive statements about MCI etiology will appear as contentions over definitions and criteria are resolved. Further, with advancements in genetic testing and neuroimaging, it is likely more will come to light about the origin of cognitive impairment in years to come.

4.5 Prognosis

Individuals diagnosed with MCI face a prognosis of uncertainty (Joosten-Weyn Banningh et al., 2011). MCI symptoms may fluctuate over time, with some progressing from MCI to dementia, but also those who revert back to 'normal' function (Luck et al., 2010). Up to 50% of those diagnosed with MCI will eventually regain 'normal' cognitive function (Gauthier et al., 2006). This may be due to the underlying cause of impairment being removed after diagnosis, such as medication use or resolution of underlying medical condition, rather than impairment due to a neurodegenerative diagnosis. Despite the possibility of reverting back to normal cognitive function

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from MCI, one key Mayo Clinic taskforce report published in *Neurology* (Roberts et al., 2014) indicated that all those with MCI had an increased risk of dementia development, regardless of reversion rates back to normal functioning.

Uncertainty regarding the clinical course of MCI makes it a considerably different form of diagnosis compared with other illnesses where progression is inevitable. Petersen and colleagues (1997) notably cite conversion rates from 10% to 15% in their early longitudinal investigation on MCI outcome and the development of AD. This means that up to 85 to 90% of those diagnosed with MCI would not convert to AD. Past research has indicated conversion rates of 10% (Tuokko & McDowell, 2006) to 25% (Nordlund et al., 2010). It is likely variable diagnostic criteria, diagnostic setting, assessment procedures, and knowledge of MCI can account for such variable figures. More refined criteria for the syndrome are required to establish more accurate conversion rates.

The uncertainties associated with MCI make it difficult to predict the clinical prognosis of any client diagnosed with this condition (Dubois & Albert, 2004). Some may believe that they will fall into the 10 to 15% category who go on to develop AD. Based on this uncertainty, receiving a diagnosis of MCI might be experientially comparable to receiving a diagnosis of dementia. To date, a large proportion of the research has looked at the psychological experience of a diagnosis of dementia, but not MCI. There are several key reasons for this, which will be discussed in Chapter Five.

4.6 Treatment

Treatment is another elusive subject in the context of MCI. Treatment options for MCI are controversial due to the lack of conclusive evidence (Cooper, Li, Lyketsos, & Livingston, 2013; Simon, Yokomizo, & Bottino, 2013).

Pharmacological intervention. Pharmacological intervention in cases of MCI have been associated with controversy in the past (Simon et al., 2013). Some evidence suggests the nootropic drug Piracetam may be beneficial when combined with a vitamin E supplement (Winblad et al.,

2004). However, one recent Cochrane review advised further research is warranted before recommending for widespread clinical use (see Flicker & Grimley-Evans, 2012). Anti-inflammatory medication and antioxidants have showed some promise in the literature (Jelic, Kivipelto, & Winblad, 2006), although AChEIs appear to have gained the most recognition by comparison.

Donepezil (Aricept) reportedly slows down the progression of decline in MCI (Petersen, 2005). Some studies have shown enhanced brain activation during memory processing with AChEIs (Petrella et al., 2009); although, other studies report no efficacy of Donepezil treatment (Delrieu et al., 2011; Patel & Holland, 2012). A systematic review of the literature on MCI treatment found mixed results on Donepezil efficacy (Cooper et al., 2013). Donepezil side effects include diarrhea, nausea, vomiting, leg cramps, and nightmares (Birks & Flicker, 2006); although, these may be more severe in cases of AD rather than MCI (Amanzio, Benedetti, & Vase, 2012). In NZ, no published literature existed on the treatment of MCI using AChEI at the time of writing the literature for this thesis. The decision to prescribe cholinesterase inhibitors in NZ healthcare settings appears to be considered on a case-by-case basis when the risk of progression to dementia is present.

Cognitive intervention. A systematic review of 20 cognitive intervention studies (see Simon, Yokomizo, & Bottino, 2012) found many intervention programmes effectively targeted episodic memory impairment in aMCI. Simon et al. (2013) define intervention strategies as either: (a) cognitive stimulation, such as group strategies targeted at social and cognitive skills, (b) rehabilitation, including individualised programmes aimed at improving ADL, or (c) training methods that target specific cognitive function. In addition to improvements with cognition, other benefits have been observed in response to cognitive intervention. For instance, Clare et al. (2009) found major changes in cognition as well as positive behavioural changes (e.g., adopting practical coping skills) following cognitive intervention. Kurz, Pohl, Ramsenthaler, & Sorg, (2009) found clients benefited in ADL and mood, as well as memory performance (verbal and non-verbal

episodic memory), following this treatment approach. Cognitive intervention is becoming more thoroughly investigated as a therapeutic option, due to its relative safety in comparison with pharmacologic treatment approaches (Simon et al., 2012).

4.7 Current Revisions in the MCI Literature

New terms continue to appear in the literature describing cognitive impairment. Dysexecutive MCI (dMCI) has appeared in numerous peer reviewed publications, though does not appear to have been formally accepted as an MCI subtype. Pa and colleagues (2009) published a paper further refining understandings of naMCI as a syndrome solely involving executive dysfunction (e.g., dMCI). They propose single domain dMCI might be more likely to convert to other kinds of neurological illness, such as Parkinson's disease (PD) and vascular dementia. More recently, other papers have proposed an "executive impairment subtype of MCI" (Reinvang, Grambaite, & Espeseth, 2012), with similar definitions. A subcategory of Parkinson's disease-related MCI (PD-MCI) has also been introduced (for discussion, see Jellinger, 2013).

Primary age-related tauopathy (PART) has been discussed as a possible clinical diagnosis, following a consensus paper publication from the US, UK, and Europe (Crary et al., 2014). "Symptoms in persons with PART usually range from normal to amnestic cognitive changes, with only a minority exhibiting profound impairment" (Crary et al., 2014, p. 755). Confirming the presence of impairment is partly based on tau analysis. The focus on biomarkers as an objective measure of cognitive decline reflects many of the developments in the literature over the past 30 years, particularly with respect to the neurobiology of AD and cognitive impairment.

In sum, the introduction of new branches of MCI highlights how concepts regarding cognitive impairment are rapidly developing. It is likely that the label of MCI will continue to evolve as developments are made in this field of research.

4.9 Concluding Comments

Despite increased attention focusing on the subject of cognitive impairment, there is a need to have more concrete criteria, as well as more comprehensive understanding of cognitive decline in the context of ageing. In order for the healthcare field to benefit from MCI in clinical practice, a reduction in the heterogeneity of this concept must occur (Dubois & Albert, 2004; Werner & Korczyn, 2008). By reducing inconsistency, MCI may help clinicians to identify those at risk of progressing to dementia. The following chapter will provide discussion on assessment and diagnosis of cognitive impairment.

"'If the map differs from the terrain, believe the terrain'. Norse Proverb" (Looi &

Velakoulis, 2014, p. 284).

During the course of this thesis, it became clear that very little evidence had been published on 'what to do' about MCI in NZ clinical practice. In presenting the initial research topic and ideas at two conferences, it seemed that MCI was being diagnosed, at least in some centres. In order to facilitate timely identification of early cognitive decline, research on this very subject is valuable. The following chapter will outline how a diagnosis of MCI is assessed in clinical practice, as well as the challenges that practitioners face when dealing with early stage cognitive impairment.

5.1 Introduction

The quote at the start of this chapter was recently included in a paper about mNCD. Authors were pointing to unresolved tensions regarding terminology used to define cognitive impairment and the language used to diagnose it. With the introduction of mNCD to the *DSM-V* (APA, 2013), and the DSM being the basis for clinical diagnoses in NZ, it is likely more adults will be diagnosed with mNCD in the future.

5.2 Overview of MCI Diagnosis and Identification

The identification of MCI in clinical practice is complicated due to the primary symptoms sharing various other pathological sources (Dubois & Albert, 2004). MCI-like symptoms can also occur due to alcohol abuse, neurological disorders, and vascular conditions (Kornhuber et al., 2009). Health conditions such as depression can also present similarly to MCI or dementia. Medications causing or exacerbating cognitive impairment include: psychotropics, analgesics,

antidiabetics, antihistamines, beta-blockers, and dopamine agonists (National Health Committee, 1997). The practitioner will rule out the presence of potential reversible or treatable sources of cognitive decline throughout the process of care and diagnosis.

MCI in Primary Care. Diagnosis of MCI is a variable process and often occurs in stages (refer Figure 2). Following the release of policy documents such as the *New Zealand Framework for Dementia Care* (Ministry of Health, 2013)*,* which encourages early identification of cognitive impairment, a discussion on MCI in primary care is timely and warrants further consideration. GPs should be aware of possible dementia prodromes such as MCI, as clients with this condition require regular follow-up in case of further cognitive decline (Ghetu, Bordelon, & Langan, 2010). Despite recognizing this important area of practice, this thesis is primarily concerned with diagnosis in specialist older adult services. Thus, the following sections have been written with this focus in mind.
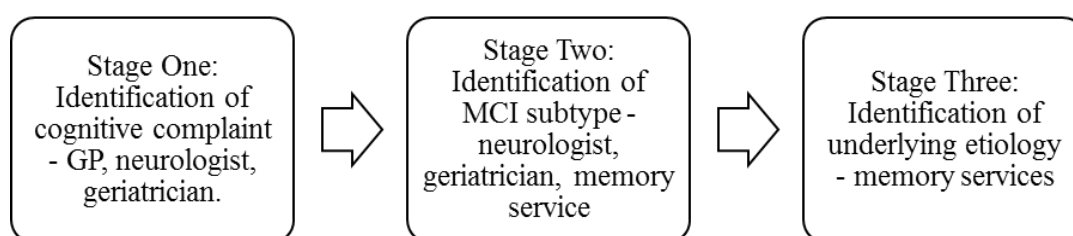
Figure 2. Possible Diagnostic Trajectory from Primary Care to Specialist Memory Services. Adapted from "Mild cognitive impairment (MCI) in medical practice: A critical review of the concept and new diagnostic procedure. Report of the MCI working group of the European Consortium on Alzheimer's Disease" by F. Portet et al. (2006), *Journal of Neurology, Neurosurgery, and Psychiatry,* 77, pp. 714 - 718. Adapted with permission from BMJ Publishing Group Limited.

5.3 Practitioners' Role in MCI Diagnosis

Internationally, there is no set process for reaching a diagnosis of MCI (Schinka et al., 2010). In NZ, diagnosis typically takes place in specialist care settings dedicated to older adult

mental health. Once a practitioner receives a referral for further testing, they will use a variety of information sources before determining a diagnosis.

Tools used to assess MCI. Specialist diagnosis is made on the basis of information from neuropsychological tests, brain imaging information, interviews with clients/family, informant reports, and additional information from other healthcare professionals (e.g., medical records from GP). There is no definitive test for MCI, nor are there any recommended instruments for reaching a diagnosis (Winblad et al., 2004). Typically, a practitioner will use instruments that are available and preferred in their practice (Portet et al., 2006). Practitioners use a combination of evidence as a way of building an overall clinical picture which provides basis for diagnosis. The next section will outline key sources of information used in reaching clinical MCI diagnosis.

Cognitive screening measures. In order to establish the presence of an objective cognitive impairment, a practitioner may initially use a cognitive screening measure. In a recent systematic review, Lonie, Tierney, and Ebmeier (2009) identified 15 cognitive screening tests for MCI. Based on previous cognitive impairment research (Strauss, Leathem, Humphries, & Podd, 2012), many of these tests are currently used in NZ. These include the AB Cognitive Screen (Molloy, Standish, & Lewis, 2005), Alzheimer's Disease Assessment Scale (ADAS-cog; Mohs, Rosen, & Davis, 1983), Cambridge Examination for Mental Disorders of the Elderly (CAMCOG; de Koning et al., 1998), Clock Drawing Test (CDT; Sunderland et al., 1989), Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005) and Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). Further testing is pursued when a client obtains a score that sits outside the established norms for their age group.

Neuropsychological testing. Observable deficits in executive function and attention are a hallmark of MCI and AD; therefore, a specific neuropsychological test might be employed if AD is suspected (Albert et al., 2010; Bondi et al., 2009). Episodic memory is impaired in people with MCI who are likely to progress to AD (Albert et al., 2010), so this element of memory may be assessed

specifically. Tests for episodic memory include the Logical Memory and Visual Reproduction sections of the *Wechsler Memory Scale Revised* (Albert et al., 2010). Delayed recall ability suffers greatly in people with AD too, due to difficulties with memory consolidation (Bondi et al., 2009). Therefore, this domain may be assessed using the Rey Auditory Verbal Learning Test and California Verbal Learning test (Albert et al., 2010).

Clients with MCI may experience deficits in other cognitive domains such as language, visuospatial awareness, and attention. Tests for such domains include: the Trail Making Test (executive function), the Boston Naming Test (language), figure copying (spatial skills), and testing of digit span (attention; Albert et al., 2010). Despite the breadth of clinical information supplied by neuropsychological testing, these scores in isolation are not sufficient to distinguish between normal ageing, MCI, and dementia (Corner & Bond, 2006).

Biomarkers. One rapidly growing area of the research is the use of biomarkers in the early identification and diagnosis of MCI and dementia. Ten years ago, Winblad and colleagues (2004) suggested there was limited evidence in using biomarkers in the identification of MCI. However, subsequent reports later emphasise that biomarkers *are* valuable. Specific biomarkers (CSF β42, T-tau, and P-tau) enable identification of those with MCI who will likely develop AD (Diniz, Pinto, & Forlenza, 2008; Mattsson et al., 2009; Portet et al., 2006). This is currently a developing area of neurobiological research.

Brain imaging information. Brain imaging techniques are routinely used in dementia diagnosis, though not yet with MCI (Portet et al., 2006). However, as highlighted in Figure 3, brain imaging information can provide valuable information on pre-clinical stages of cognitive decline, long before dementia symptoms present (Jack et al., 2012). Scans of individuals with MCI have previously shown atrophy in regions of the brain associated with memory formation (e.g., hippocampus; Winblad et al., 2004), also identified in those with AD. Moreover, neuroimaging methods (e.g., MRI, positron emission tomography) are essential in ruling out other possible causes

of cognitive decline (e.g., vascular injury, tumour; Winblad et al., 2004). Scans may also indicate

hypo-metabolism, a hallmark of pre-AD (Portet at al., 2006). Thus, neuroimaging can be beneficial

in diagnosis of MCI but also early identification of AD.
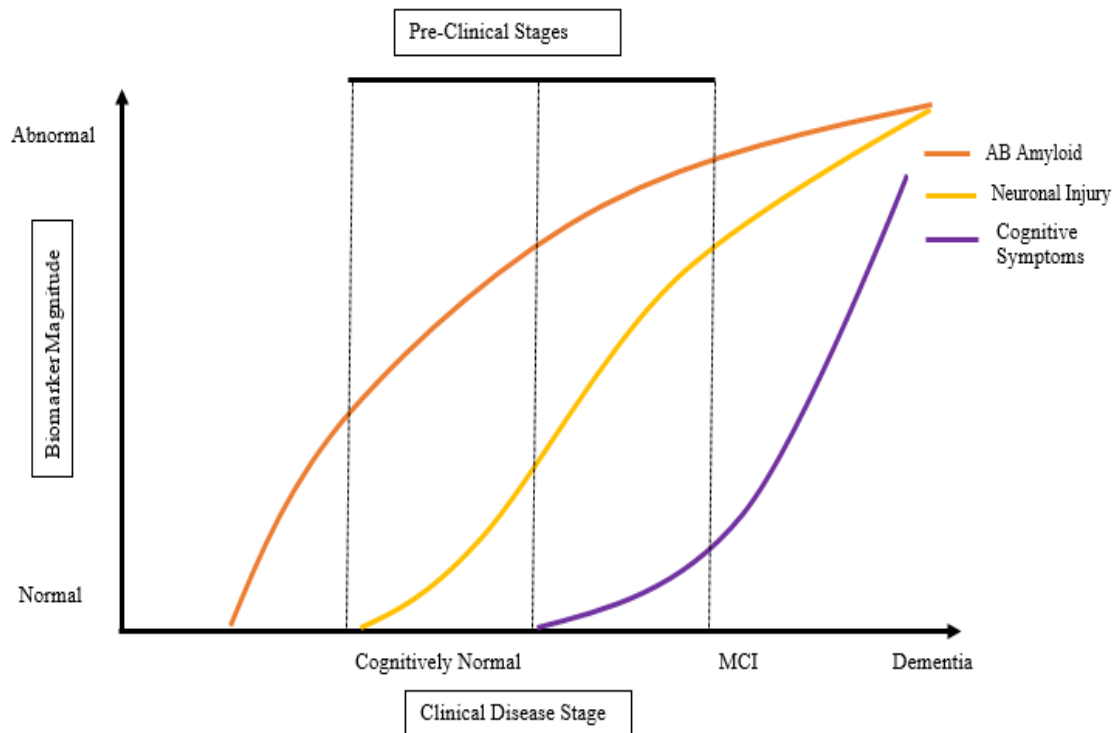
Figure 3. Hypothesised Preclinical Stages before AD Development. AB Amyloid identified through positron emission tomography (PET) and neuronal injury identified via PET or magnetic resonance imaging. Cognitive symptoms assessed via cognitive assessment measures. Adapted from "An operational approach to National Institute on Aging-Alzheimer's Association Criteria for Preclinical Alzheimer Disease" by C. R Jack et al. (2012), *Annals of Neurology,* 71, pp. 765 - 775. Adapted with permission from John Wiley and Sons Limited.

Interviews and informant reports. Client interviews and informant information (i.e., from

friends or family) are a vital source of information for practitioners assessing for MCI. Informant

report is essential, as the client may not be aware of the frequency of their memory symptoms.

Clinical judgement. In combining information sources such as screening measure score,

comprehensive neuropsychological evaluation, informant information, and medical history, an

additional aspect of diagnosis is clinical judgement. Some question the reliance on clinical

judgement in the assessment of cognitive impairment, but acknowledge access to other methods of

assessment (e.g., biomarker testing) is restricted in many healthcare services (Looi & Velakoulis, 2014).

5.4 The Ethics of Early Diagnosis

The value of early dementia diagnosis is increasingly recognized by policymakers and academics (e.g., Department of Health, 2009); although, it is unclear whether early diagnosis of MCI holds the same benefit. One the one hand, MCI diagnosis may be helpful for clients and their families, as it may facilitate preparation for the future (Werner & Korczyn, 2008). On the other hand, it is unclear whether use of this label is beneficial or whether it causes fear and distress (Werner & Korczyn, 2008).

The proposed benefit of early identification of cognitive decline may rest on diagnosis confirmation. Unfortunately, accurate diagnosis of MCI can be obscured by individual differences. Factors such as education level, psychological functioning, and hormone levels can account for performance on neuropsychological tests (Gauthier et al., 2006). These factors may present a false impression of MCI symptoms (Gauthier et al., 2006); thus, the practitioner must proceed with caution.

Numerous international working groups have formed in attempt to provide consensus on intervention at the earliest signs of cognitive impairment (e.g., Albert et al., 2011; Sperling et al., 2011). After diagnostic categories such as "MCI due to AD" were established (i.e., NIA AA; Albert et al., 2011), issues were raised with regard to this category of diagnosis:

> The ethical issues associated with earlier diagnosis of AD using the [International Working Group] and NIA AA criteria are (1) the disclosure of a diagnosis of AD in asymptomatic or minimally symptomatic persons with full insight, (2) the uncertainty of a diagnosis based on biomarkers without full validation, (3) the social stigma of very mild AD (Gauthier et al., 2013, p. 108).

In sum, while some propose benefits of early identification, others argue that this may cause unnecessary concern. Numerous issues have been highlighted with respect to the diagnosis of MCI, and these concerns require clarification. It is unclear how such issues highlighted in academic literature impact on everyday clinical practice, particularly for the practitioner who is tasked with assessing someone with memory complaints.

5.5 Diagnostic Disclosure of MCI

Considerable literature on the topic of cognitive impairment and disclosure is in relation to dementia (e.g., Carpenter et al., 2008; Derksen, Vernooij-Dassen, Gillissen, Rikkert, & Scheltens, 2006; Fisk, Beattie, Donnelly, Byszewski, & Molnar, 2007; Pinner & Bouman, 2002), rather than MCI (Dean & Wilcock, 2012; Joosten-Weyn Banningh, et al., 2008). Academic interest on diagnostic disclosure of dementia has increased in recent years due to growing emphasis on early detection of dementia (O'Reilly, Lavin, & Coughlan, 2011); although, minimal research has included a discussion on MCI.

Practitioners' attitudes on MCI diagnosis. Physicians have been dubious of giving a dementia diagnosis in the past, due to the negative responses associated with the news, and loss of hope and motivation seen in many individuals (Milne, 2010; Pinner & Bouman, 2002). Intuitively, such reluctance could also extend to less established diagnoses such as MCI. Robinson and colleagues (2008) carried out a study which looked at uncertainties of dementia diagnosis amongst GPs, community nurses, caregivers, and residential facility staff in Australia. Findings suggest a reluctance to diagnose and an avoidance of the term 'dementia' with clients. For those with severe cognitive impairment, the practitioner must weigh up the benefit of receiving a diagnosis and the ability for the client to comprehend, react, and recall this information (Cornett & Hall, 2008).

5.6 Summary and Suggestions for Future Research

The subject of MCI diagnosis has received increased attention in academic literature, particularly due to progressions in biomarker and genotype research. Practitioners have numerous tools available to assist in the diagnosis of MCI, yet in the absence of clear evidence, the diagnosis itself seems to be a 'placeholder' of sorts until evidence of further decline presents. How practitioners convey the complex issues associated with MCI is unknown.

To our knowledge, only one NZ based study has been conducted on MCI diagnosis in NZ. Mitchell, Woodward, and Hirose (2008) examined practitioner attitudes regarding MCI and early dementia, in a sample of NZ and Australian geriatric practitioners. Mitchell et al. found 82% of NZ based practitioners labelled MCI, but 44% of practitioners used words other than 'MCI' or 'early dementia' when delivering a diagnosis to a client. This study is beneficial in providing a starting point for further investigation into why such variation exists.

5.7 Concluding Comments

There is a growing emphasis on identifying cognitive decline at a pre-dementia stage, in order to introduce potentially disease modifying intervention. MCI may be a suitable intervention point; however, many have raised issues with use of this label in the absence of confirmed diagnosis or indicators of future cognitive decline. This chapter focused on the processes that practitioners go through when reaching a diagnosis of MCI, as well as the issues they are faced with when a client presents with mild memory complaints. The following chapter will discuss how clients *feel* about this diagnosis.

Despite academic debate on nomenclature, prognosis, and identification in clinical practice, MCI is a label used in some settings in NZ. Chapter Five highlighted the tools that practitioners use in assessing cognitive impairment, as well as the issues they face when indicators of MCI are present. Chapter Six will highlight international literature on the psychosocial benefits and consequences of MCI diagnosis, including models which have been used to explain reactions that clients have after being diagnosed.

6.1 Introduction: Literature Search Strategy

A literature review was conducted on the topic of coping with MCI. Key search terms included: MCI, coping/cope, reaction, diagnosis, experience. For the purposes of summarising available literature that was reviewed, the following information was extracted from each article: population, study aim, models used, analysis method, study limitations, and main conclusions. Table 6 contains a summary of the key studies on MCI diagnosis and subsequent coping behaviour. Some researchers have tended to group experiences of individuals with MCI, AD, and other forms of cognitive impairment in the same study – these papers were included with the literature review, though interpreted with caution. Studies were selected based on some discussion of individual experience of diagnosis, as opposed to a combined relationship triad (e.g., Blieszner et al., 2007; Roberto, Blieszner, McCann, & McPherson, 2011) between caregiver or spouse, and person with MCI.

Table. 6
Overview of Studies on Coping with MCI Diagnosis

Author (Year)	Population	Study aim	Model/ theory	Analysis method	Limitations	Conclusions
Beard and Neary (2013)	People with MCI (*n* = 18)	None explicitly stated.	Courtesy stigma (Goffman, 1963)	Grounded theory	More research needed on experience of uncertainty.	Vital to investigate impact of medical labels on social lives.
Berg, Wallin, Nordlund, and Johansson (2013)	People with MCI (*n* = 17)	Explore experiences of individuals with MCI for over 7 years. Gain understanding of how people cope with stressors associated with impaired cognitive status.	None specifically	Thematic analysis	Some participants declined to participate which may represent a group of participants not captured by the analysis.	More research needed on understanding how psychosocial factors influence cognitive health.
Carpenter et al. (2008)	People with AD, MCI (*n* = 90), and companions (*n* = 90)	To determine changes in depression and anxiety following diagnosis of MCI and AD.	None specifically	General liner effects model, descriptive statistics	Further research needed on doctor-patient interactions during diagnosis.	How diagnosis is delivered may have impact on psychosocial response.
Frank et al. (2006)	People with MCI (*n* = 20) and AD (*n* = 20) and informants (*n* = 26)	To identify the impact of cognitive impairment on clients with MCI, and mild probable AD.	None specifically	Qualitative analysis (not specifically recorded)	None discussed.	Responses to memory problems included diminished social confidence, concern about changes in social role, anxiety about prognosis. Noted differences in anecdote sharing between mild AD and MCI groups.
Joosten-Weyn Banningh et al. (2008)	People with amnestic MCI (*n* = 8)	Investigate how people with MCI cope with cognitive decline.	None specifically	Grounded theory	Small sample size. Informant information not collected. Direct information on diagnosis experience not collected.	People with MCI encounter stress. People with MCI need clear information in order to cope with MCI. Themes in reaction following MCI diagnosis included: change, attributions, consequences, coping. Many different perceptions on causes of memory decline.
Lin and Heidrich (2012)	People with MCI (*n* = 63)	Describe illness representations of people with MCI, explore relationship between illness representations and coping.	Common sense model	ANOVA, ANOCOVA, cluster analysis	Prospective design needed. Objective measures of health needed. Small sample size.	Illness representations might be useful in understanding clients' reactions and adjustment following MCI diagnosis.
Lingler et al. (2006)	People with MCI (*n* = 12)	To examine lived experience of diagnosis of MCI.	Common sense model	Grounded theory	Need to examine experiences of MCI over a longer time period.	Illness representation theory has applications with regard to explaining people's responses to MCI. Illness representations important in understanding how people conceptualise

						and cope with MCI.
Lu et al. (2007)	People with MCI (*n* = 11)	Describe experiences of being diagnosed and living with MCI.	None specifically	Phenomenological analysis	Small sample size.	Themes found in responses included: finding ways of holding on to being "able" and sense of self.
McIlvane et al. (2008)	People with MCI (*n* = 46) and their care partners (*n* = 29)	To describe daily experiences and coping strategies of people diagnosed with MCI.	Illness perception theory	T test, descriptive statistics	Small sample size. Demographically homogeneous (e.g., Caucasian, high education). Participation bias.	People with MCI generally cope well with their diagnosis. People with MCI minimise the threat of developing AD eventually. People with MCI and their care partners experience little stress relating to memory problems.
Morgan, Garand, and Lingler (2013)	People with MCI (*n* = 53)	To determine health-related activities that clients undertake following their recent diagnosis of MCI	Common sense model	Thematic analysis	Sample demographically homogeneous. Limited data gathered on factors which may mediate response to diagnosis.	Common sense model is valuable in understanding diagnosis experience of MCI. Lazarus and Folkman (1984) model of stress may also be relevant.
Roberts and Clare (2013)	People with MCI (*n* = 25)	Examine impact of living with MCI, and impact of symptom awareness on experience of MCI. Determine how people describe their challenges.	Newly developed model suggested based on level of awareness framework (Clare et al., 2011) – context specific coping responses are influenced by fear, uncertainty	Interpretative phenomenological analysis	Interview length considered short (11-30 minutes). Absence of direct questions about MCI (arguably a limitation).	Coping responses shaped by awareness of symptoms, and psychosocial response to cognitive decline.
Rodakowski, Schulz, Gentry, Garand, and Lingler (2014)	People with MCI (*n* = 60)	Examine participants' beliefs about MCI etiology.	Illness perception theory	Descriptive statistics, chi square analysis, ANOVA	Demographically homogenous sample. Formal diagnosis protocol might not have been standardised.	Participants felt MCI due to uncontrollable factors such as hereditary factors or ageing.

6.2 MCI Diagnosis Experience

Although a number of studies have examined coping responses following MCI diagnosis, comparatively few have queried actual MCI diagnosis experience. Samsi et al., (2013) examined diagnosis experience of those with cognitive impairment, but not subsequent coping strategies. Authors conducted qualitative interviews with 27 individuals with cognitive impairment (i.e., AD, MCI) with an aim of understanding assessment experience. They found that participants experienced uncertainty and concern over wait-times and diagnosis process. Given the aims of the study, it is difficult to isolate experiences of those with dementia diagnosis, compared to those with MCI or SMCs. Likely due to difficulties in terminology, many studies on dementia diagnosis experience have blended participant groups with dementia and MCI, making it difficult to tease out responses to each individual diagnosis.

6.3 MCI Illness Representations

MCI 'illness representations'[3] are complex because this syndrome is not strictly an illness by definition. Some people *do* go on to develop dementia, but many remain stable over time, or revert back to normal function. Thus, MCI may not necessarily be interpreted as a health threat by all individuals who receive this diagnosis. On the other hand, individuals may interpret their MCI diagnosis as if it were one of AD (Morgan et al., 2013). These differences in perception are important because they determine coping behaviour, such as help seeking after diagnosis. If an individual perceives their deteriorating memory as a natural part of ageing (as opposed to dementia prodrome), this could lead to not seeking medical intervention if they experience further cognitive decline.

Several key studies have examined beliefs about causes of MCI. Some authors have found many people believe that MCI is part of normal ageing and genetics (Lin & Heidrich,

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[3] "Illness representations" are associated with the CSM discussed in Chapter One.

2012). Others attribute their memory symptoms to personality or other life events (Joosten-Weyn Banningh et al., 2008). Rodakowski, Schulz, Gentry, Garand, and Lingler (2014) examined beliefs on causes of MCI in a sample of 60 client-spousal dyads using an Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne, 1996). They found that more participants believed their condition was caused by uncontrollable factors such as ageing (26.7%) and genetics (40%), while few perceived MCI as a medical condition (13.3%). A perception that cognitive decline is part of normal ageing could be why research has found reasonable levels of wellbeing following MCI diagnosis (e.g., McIlvane et al., 2008; Joosten-Weyn Banningh et al., 2008).

6.4 Literature on Coping after Diagnosis

Several international studies have documented psychosocial responses to MCI diagnosis. One of the key findings from past research is that overall, many people manage negative psychosocial responses well following diagnosis. For example, McIlvane et al. (2008) examined perceptions of illness and coping in 46 individuals within six months of being diagnosed. Participants minimised the likelihood of converting from MCI to Alzheimer's disease (AD). They also felt their condition could be controlled by health promotion strategies. Participants displayed average levels of wellbeing, and were optimistic about the future.

Lingler et al. (2006) interviewed 12 people with amnestic and non-amnestic MCI within three to six months of their initial diagnosis. Participant response to diagnosis was typically influenced by personal experience of dementia. Those who coped well were more likely to expect memory decline being part of normal ageing.

Joosten-Weyn Banningh et al. (2008) conducted interviews with eight people within one to three weeks of being diagnosed with aMCI. They found some reported psychosocial distress, but many managed fear of dementia by implementing health promotion strategies.

Others used avoidance behaviour such as denying or hiding symptoms. Joosten-Weyn Banningh et al. (2008) concluded that, although some participants cope reasonably well with diagnosis, the label itself warrants further investigation.

Notable experiences of struggle have also been reported in the literature following MCI diagnosis. For instance, Frank et al. (2006) conducted focus groups with 20 people diagnosed with MCI. Study authors highlighted uncertainty around meaning of MCI diagnosis, embarrassment, anger, and loss of emotional control.

Beard and Neary (2013) investigated the experiences of ten individuals and eight subgroups diagnosed with MCI, within the past three years. They found participants were relieved that MCI was not AD; although, many expressed uncertainty about their diagnosis and considered their memory loss to be associated with normal ageing.

In order to assist the practitioners who deliver this category of diagnosis, it is useful to identify elements of the label that clients struggle with. Given the likelihood of more frequent MCI diagnoses in the future, increased understanding on the psychosocial component to receiving a diagnosis of MCI is an important avenue of enquiry.

6.5 Psychosocial Theories of Coping

The first studies on coping with MCI were published 2006 – 2008 (i.e., Frank et al., 2006; Joosten-Weyn Banningh et al., 2008; McIlvane et al., 2008), but few provided theoretical explanation for behavior and beliefs following diagnosis. Lingler et al. (2006) suggested that illness representation theory may be useful in explaining the underlying mechanisms of coping behavior observed. Renewed interested in coping with MCI surfaced in 2012 – 2014 (e.g., Lin & Heidrich, 2012; Morgan et al., 2013; Rodakowski et al., 2014) where illness representation theory was explicitly examined. These researchers also used an objective measure of illness perceptions (e.g., IPQ).

Illness representation theory. The CSM (Cameron et al., 1995; Leventhal et al., 1980; Leventhal, Nerenz, & Steele, 1984) *may* offer an explanation on coping strategies exhibited following MCI diagnosis. Originally coined in the 1970s, CSM-associated theory has gone by numerous labels in the past, including: parallel process model, self-regulation model, as well as perception/representation theory (Reynolds, Martin, Nanyonga, & Alonzo, 2012). The model holds that individuals respond to their illness based on illness representations or 'schemata' generated about their diagnosis (Leventhal et al., 1998). As depicted in Figure 4, following the experience of a health threat (step 1), this leads to schemata development (step 2), which interact with coping responses and self-appraisal processes (step 3 to 4).
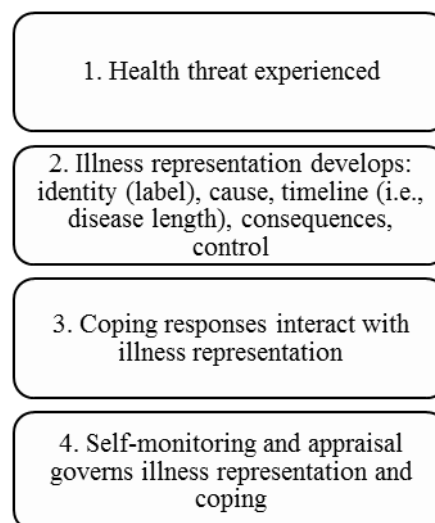
Figure 4. Basic Schematic of the Common Sense Model of Illness Representation. Adapted from N. R Reynolds, F. Martin, R. C Nanyonga, and A. A Alonzo. (2012). "Self-regulation" (pp. 465 – 483). In V. Hill Rice (Ed.). *Handbook of stress, coping, and health* (2nd ed). California: Sage Publications.

These initial schematic illness representations contain: normative social constructs about the illness, past experience of illness, and information from external sources (e.g., friends, healthcare practitioners; Hurt, Burns, Brown, & Barrowclough, 2011). Each

individual has their own beliefs and expectations about the cause, duration, and chronicity of their own healthcare condition (Weinman et al., 1996). This in turn can account for the kinds of healthcare behaviour they subsequently engage in, such as medication adherence and help-seeking. Illness perceptions then interact with coping behaviour, then simultaneously monitored by an individual's self-appraisal processes (Leventhal, Diefenbach, & Leventhal, 1992).

Research has examined the utility of this model to explain how people cope with early dementia (Harman & Clare, 2006) and MCI (Lin & Heidrich, 2012; Lingler et al., 2006; Morgan, Garand, & Lingler, 2013). Past unpublished doctoral research has also examined the CSM in relation to clients with early dementia (McNeill, 2013). In 2014, a research group in France published intent to conduct a prospective study on illness perceptions and memory complaints (Besozzi, Montel, Perret-Guillaume, & Spitz, 2014). This was published in an advance online issue of *International Psychogeriatrics*. Thus, it is likely the CSM will appear in future publications on MCI diagnosis.

Theory on coping with dementia. As discussed, contemporary research on coping with MCI has attributed diagnosis reaction to illness representation theory. Prior to this, considerable literature had discussed coping with dementia diagnosis. Although dementia and MCI are different, existing literature undertaken in this area may provide another perspective than the CSM offers. One reoccurring concept in research on coping with dementia is the importance of self-concept (Clemerson, Walsh, & Isaac, 2014). Charmaz (1995) described chronic illness as a phenomenon which compromises identity, where a person tries to ignore or minimise their illness, by holding onto their former sense of self. A new identity is eventually developed over time (Pearce, Clare, & Pistrang, 2002) as one comes to accept their diagnosis. Harre's (1998) social constructionist theory of the single-self has also been used to interpret changes in identity in those with mild to moderate AD (e.g., Hedman,

Hansebo, Ternestedt, Hellstrom, & Norberg, 2012). This framework emphasises the uniqueness of individual personhood in their experiences of the world (Harre, 1998). Given the frequency of self-concept in the literature on coping with dementia, individual identity is also likely to be important following MCI diagnosis.

6.6 Summary and Suggestions for Future Research

The studies outlined in Table 6 demonstrate several key findings: symptoms of MCI are often attributed to age, uncertainty/fear is associated with MCI, and the condition causes burden for clients and families. Many believe health promotion strategies can be used to avoid dementia.

Strengths of past research include: participants are interviewed reasonably soon after diagnosis, where one would assume psychosocial responses to diagnosis would develop (although, little is known about how these feelings change over time). Recommendations from past studies include: longitudinal research design (Lingler et al., 2006) and detailed examination of coping responses (Lin & Heidrich, 2012).

6.7 Concluding Comments

With the exception of Carpenter et al. (2008), whose sample mainly included clients with AD, many studies have reported mixed reactions to MCI. All past studies have examined client responses at one point in time (e.g., Joosten-Weyn Banningh et al., 2008; Lingler et al., 2006; McIlvane et al., 2008); however, linear processes such as coping may be better investigated over multiple time points. This may shed more light on how perceptions and coping change following diagnosis. Some studies have investigated the impact of MCI diagnosis, and many have made recommendations for future research in this area, as discussed throughout this chapter. To date, many studies have been atheoretical, cross sectional, and informed by hypothesis-testing philosophy, when it may be that a different

philosophical approach can shed more light on the processes a person experiences following diagnosis. It is hoped that with careful consideration of these suggestions, a study investigating these experiences might produce a clearer picture of the thoughts and feelings clients have after being clinically diagnosed with MCI.

This chapter will summarise the literature review conducted for this thesis, and outline the subsequent research plan which resulted. The methods and results for the studies included with this thesis will be presented as two separate manuscripts in Chapter Eight and Chapter Nine. The overall objective of this thesis is to examine the experience and response to a diagnosis of MCI within a NZ context. Due to the paucity of literature on MCI diagnosis in NZ, a preliminary study on practitioners' processes during diagnosis took place before a study on clients' responses. This preliminary study provided important contextual information for the main client-focused research. Investigations in Study One were cross sectional, involving specialist geriatric services. Investigations in Study Two were undertaken in a series of qualitative interviews with healthcare service users. Data were collected in qualitative and quantitative form through a series of questionnaires and face-to-face interviews.

7.1 Literature Review Summary

While researching dementia and suicidal ideation, MCI was clearly a developing subject in the literature on cognitive impairment. Though definitions and criteria for this condition are still developing, the psychological impact of this diagnosis is clearly being felt. This is evidenced by international literature reporting fear, distress, and uncertainty.

In initially setting out to do this thesis, it seemed the population of interest would be adults aged 65 years and over. However, over the course of reviewing literature on the older adult population, attending gerontology conferences, and meeting study participants, it

became evident that the process of growing older begins much younger than 65, such as in the case of cognitive ageing. In addition, not all adults over 65 consider themselves to be old!

MCI is a new form of cognitive impairment diagnosis in comparison with more established diseases such as dementia. The definition of MCI is constantly changing, as reflected in the literature and changes to the *DSM-V,* where terms such as mNCD have been introduced to label MCI symptoms. It is likely the label of MCI will undergo further revisions as more comes to light about this syndrome.

At the time of deciding on this thesis topic, MCI diagnosis response had received much less attention compared with dementia diagnosis reaction. This seemed puzzling, given MCI is a clinical label being delivered to clients following memory testing.

A small number of studies have investigated cognitive impairment diagnosis in NZ and Australia (e.g., Mitchell et al., 2008). This research provided a rationale for further investigation on the processes that practitioners follow when delivering MCI diagnosis in NZ. It is currently unclear how NZ practitioners feel about cognitive impairment diagnosis delivery.

Though MCI is not a disease entity in itself at this stage, it appears to have taken on this dimension in the literature on illness perceptions, and by the way some participants appear interpret this diagnosis as a healthcare threat. It was unclear how to best approach caring for those who do struggle with this diagnosis. It was uncertain whether MCI would be viewed similarly to dementia when diagnosed clinically.

Models on responses to dementia diagnosis are comparatively plentiful, with concepts such as management of identity being salient in an individual's coping trajectory. Current literature on diagnosis reaction compares MCI with the CSM more frequently than other health psychology models (e.g., Lazarus and Folkman stress model). Knowledge on underlying mechanisms in diagnosis response is limited, and requires further investigation.

Limitations of the literature. At the time of conducting the literature review for this thesis, there was no published research on the process by which a practitioner diagnosed cognitive impairment in NZ. A decision was made to focus on the specialist services most likely to conduct in-depth assessments and subsequently deliver cognitive impairment diagnosis to their clients.

In existing evidence on coping with MCI diagnosis, clients have expressed relief (e.g., McIlvane et al., 2008), but also stress (e.g., Joosten-Weyn Banningh, 2008). Theoretical research (e.g., Linger et al., 2006; Lin & Heidrich, 2012) has identified the illness perception model as a useful framework for understanding MCI diagnosis reaction. No research in NZ had investigated the clinical diagnosis of MCI, or subsequent reaction within a client-based sample before. It may be that individuals respond differently in NZ, not currently explained by the CSM.

Conducting research on MCI has provided many challenges for past researchers. Studies on coping with MCI have suffered methodological issues, such as small sample size (e.g., Joosten-Weyn Banningh et al., 2008), cross sectional study design (e.g., Lingler et al., 2006), and potential participation bias (e.g., McIlvane et al., 2008). Researchers have suggested examining clients' experiences of MCI diagnosis further (Dean & Wilcock, 2012).

7.2 Research Aims and Objectives

In acknowledging the paucity of literature on MCI in NZ, this thesis aimed to present an in-depth investigation of this condition in specialist healthcare settings. Overall, the present research aims to provide a starting point for further research in NZ on the subject of early stage cognitive impairment. This was achieved via several objectives:

1. Examine practitioner perspectives on the process of diagnosing cognitive impairment.

2. Examine client perspectives on experiencing a diagnosis of cognitive impairment, including how they respond and cope.

3. Build on previous international research which identifies a lack of longitudinal, exploratory studies on coping with MCI.

4. Contribute to international theory on models of coping with MCI.

7.3 Research Questions

After reviewing the national and international literature on the subject of MCI diagnosis, the following research questions were developed to guide the design of the practitioner-focused study:

1. How do practitioners reach a diagnosis of cognitive impairment?

2. What terms are used when diagnosing MCI?

3. What do practitioners believe is helpful for their clients during cognitive impairment diagnosis delivery?

After reviewing the national and international literature on the subject of MCI and coping, the following research questions were developed to guide the design of the client-focused study:

1. How do clients respond following a diagnosis of MCI?

2. How does this reaction change over time?

3. What theoretical framework best explains MCI diagnosis response?

4. What do clients find helpful during cognitive impairment diagnosis delivery?

In order to answer the above questions, two individual studies were undertaken, using several key philosophical and methodological underpinnings.

7.4 Philosophical Framework and Methodology

Crotty (1998) proposes a four tier framework in presenting the philosophical and theoretical assumptions that underlie a research project. These include epistemology, theoretical perspective, methodology, and method. The beliefs that a researcher holds about the nature of knowledge and reality are important because they shape how the researcher interprets and acts within their social world (Denzin & Lincoln, 2008).

The client-focused study in this thesis was undertaken primarily with an acknowledgement of the subjective nature of reality. Social Constructivism[4] is an orientation that proposes: reality is shaped by social processes, and an individual assigns meaning to experience through interactions with other people and their environment (Kim, 2001). With regard to coping and making sense of a new diagnosis, it is likely that reality and truth can change; and therefore, to rely on a fixed assumption of reality does not "fit" with this research topic. Moreover, the nature of knowledge around MCI is constantly changing. It seems likely that experiences of this diagnosis would be rich with the influence of interpersonal context, social climate, and geographic location, making social constructivism an appropriate epistemological position.

In addition, pragmatism is an approach whereby a researcher utilises multiple world views in order to understand a research problem (Rossman & Wilson, 1985). It is a non-reductionist approach that considers all points of view with regard to categorising reality (Pihlstrom, 2011). Pragmatists hold the research methodology and methods are less important than the research questions guiding the nature of an investigation (see Tashakkori & Teddlie, 2003). The method and methodology for each of the studies included with this thesis were chosen carefully to investigate the phenomenon of interest: MCI. The focus was on the nature

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[4] Social Constructivism here is distinguished from constructivism, or constructionism for that matter. In some texts, these terms are used interchangeably, erroneously. Both social constructivist and constructivist world views have similarities and convergences. For the purposes of this thesis, a social constructivist focus is attributed to social processes influenced by culture, environment and language.

of the research problem, which in turn, influenced the study design, not vice versa. Researchers adopting a pragmatist approach are able to utilise qualitative and quantitative assumptions as they conduct their research (Creswell, 2014). Pragmatism provides a theoretical base which guides mixed methods research (Johnson & Onwuegbuzie, 2004; Johnson, Onwuegbuzie, & Turner, 2007). The focus for this thesis was on the qualitative experiences of participants' diagnosed with MCI, which is conceptually suited to pragmatically-informed mixed methods research (Onwuegbuzie, Johnson, & Collins, 2010).

Regarding the theoretical perspective adopted throughout the thesis, a purely positivist approach is inappropriate due to the highly personal and subjective nature of illness experience. Post-positivism, is a theoretical perspective that knowledge is based on an objective reality where effects have definitive causes (Cresswell, 2014). Experimental enquiry often falls under this rubric, where events are constructed by an outsider, who is guided by a set of empirical assumptions (Rossman & Wilson, 1985). Post-positivist research typically seeks to test hypotheses based on empirical observations. Strands of post-positivism informed a small portion of the design of this thesis, but emphasis was made on the phenomenological accounts of individuals who have faced diagnosis, and the interpretative analysis of those narratives.

Interpretivism "looks for culturally derived and historically situated interpretations of the social life-world" (Crotty, 1998, p.67). Interpretivist researchers are interested in the way a participant comes to understand their world within their own subjective frames of reference (Williams, 2000). Cresswell, Plano-Clark, Gutmann, and Hanson (2003) suggest that interpretivism is an appropriate framework when conducting mixed methods research, with an emphasis on qualitative data. One of the defining features that links social constructivism and interpretivism is the focus on empathy within the researcher-participant dynamic (Kim, 2014). Given the research aim of understanding how a person makes sense of their diagnosis

on an individual level, it was essential to embody absolute empathy towards the participants' stories at all stages of the research.

Within an interpretivist lens, phenomenology is linked. Phenomenology is the theoretical position that as researchers, our gaze is drawn towards a person's perceptions of phenomena in their world, rather than the phenomena itself (Smith, Flowers, & Larkin, 2009). The philosophy of phenomenology has evolved considerably since inception, with German philosophers such as Edmund Husserl and Martin Heidegger proposing differing views of phenomenological enquiry. Husserl proposed descriptive phenomenology, while Heidegger was mentored by Husserl and later proposed interpretive hermeneutic phenomenology (von Hermann, 2013). To incorporate one without acknowledgement of the other would be to miss important methodological foundations of phenomenology itself (von Hermann, 2013). Thus, both theoretical positions were reviewed in preparation for carrying out the client-focused study of this thesis. Research that adopts a phenomenological perspective results in rich descriptions of individuals' experiences of a shared phenomenon, object, or event (Cresswell, 2014). In order to understand clients' experiences of diagnosis and ability to cope with this information, a phenomenological approach was adopted when interpreting the qualitative data obtained from clients.

"Looking at a phenomenon from only one perspective can constrain our understanding of it" (Plano-Clark, Creswell, Green, & Shope, 2013, p. 365). Therefore, involving multiple participant groups and studies is one way of achieving a more complete picture of diagnosis, coping, and cognitive impairment. The framework for this research was informed by an acknowledgement that elements of nomothetic and idiographic investigations can be used to investigate emerging phenomena. The quantitative data obtained in the current research were intended to enhance the qualitative accounts of client's experiences of MCI. Quantitative research is often positioned as an objective truth, and qualitative investigation is

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side-lined as a subjective narrative (Wilkins, 2011). This tendency to dichotomise quantitative versus qualitative prevents these approaches from being understood as complimentary, but rather mutually exclusive (Hoppe-Graff & Lamm-Hanel, 2006). Mixed methods research rejects this notion of incompatibility, and recognises that a researcher can elect the most suitable approach, in order to answer an overall set of research questions.

Mixed methodology. Mixed methods research (MMR) is defined as research where the researcher collects and analyses both forms of data, in a singular phase or multiple phases (Creswell, 2011). Greene, Caracelli, and Graham (1989) provide an early definition of MMR as any study where data is collected in the form of numbers and words. However, contemporary techniques in MMR are more complex than simply mixing methods. Research protocols should be guided by philosophies and techniques, thoughtfully combined in a synergistic manner (Creswell, 2015; Teddlie & Tashakkori, 2011).

MMR is an emerging research approach which has historical controversy and uncertainty, but a comparative degree of contemporary acceptance. Guided by a plethora of peer reviewed methodology papers (Johnson et al., 2007; Kettles, Creswell, & Zhang, 2011; Klassen, Creswell, Plano-Clark, Smith, & Meissner, 2012), and a call from dementia researchers to adopt a MMR framework to examine this complex condition (Robinson et al., 2011), the decision was made to conduct a mixed methods PhD.

7.5 Research Design

Study One was a qualitative study undertaken to gain an impression of clinical practice among NZ practitioners. The aim was not to generalise, but to provide an impression of the beliefs a sample of NZ practitioners have about the value of diagnosis delivery. Data were collected from multiple regions of NZ on processes involved with diagnosis of cognitive impairment. Descriptive data were collected on practitioners' attitudes towards the

diagnosis of cognitive impairment. Results from this practitioner-focused study are presented as a single research report (Chapter Eight).

Study Two was a concurrent mixed methods design where qualitative and quantitative data were collected in a single phase (Creswell & Plano-Clark, 2011). In order to build on previous cross sectional studies (e.g., McIlvane et al., 2008; Joosten-Weyn Banningh et al., 2008; Lin & Heidrich, 2012), and those who have recommended in-depth, longitudinal analysis (Lingler et al., 2006), data were collected at two time-points: within three and six months of diagnosis.

On an epistemological level, the mixing of some methods together does not make sense (Padgett, 2012). Therefore, care was taken to ensure that the quantitative analysis complemented the qualitative focus (i.e., QUAL+quan; Morse, 1991, 2003). As such, the qualitative analysis took place before the quantitative analysis.

The aim of Study Two was to examine clients' experiences of diagnosis (qualitative) and explore changes in coping over time (quantitative). The CSM was used as a guiding framework for the client-focused research on coping with MCI.

7.6 Concluding Comments

There is urgent need for research seeking to assist healthcare services in caring for older adults. Although the topic of MCI is subject to contention, it *is* clinically diagnosed in NZ. This means there is value in exploring the experiences of those who have received this form of diagnosis. In the process of conducting a PhD on this topic, several preliminary activities were undertaken: a literature review (i.e., Chapter Two to Six), a research plan was presented at two professional conferences, and consultation was undertaken with several practitioners working in the geriatrics field. Results from the studies of this thesis will now be presented in chronological order.

CHAPTER EIGHT

A Survey of Practitioners Diagnosing Cognitive Impairment

Preface

This chapter contains the findings of the first study for this thesis. The article was published in *New Zealand Journal of Psychology* and was presented in a platform session at the New Zealand Psychological Society annual conference held in Nelson, New Zealand, in August 2014. As the article stands alone, some material already presented in the introductory chapters is repeated. Reference entries for published and presented materials are as follows:

McKinlay, AR., Leathem, J., & Merrick, P. (2014). Diagnostic processes and disclosure: A survey of practitioners diagnosing cognitive impairment. *New Zealand Journal of Psychology,* 43(2), pp. 20 - 31.

McKinlay, AR., Leathem, J., & Merrick, P. (2014). Practitioners' processes and attitudes in the diagnosis of cognitive impairment. Presented at *New Zealand Psychological Society Conference: Psychology in a Changing World.* Nelson, New Zealand.

Please note: Additional documents pertaining to this study can be found in the Appendix section. These documents include ethics approval (Appendix 1) and online study questionnaire (Appendix 2).

Chapter Eight: A Survey of Practitioners Diagnosing Cognitive Impairment

Abstract

Minimal research has been conducted on how practitioners diagnosis mild cognitive impairment (MCI) in New Zealand. Fifty-seven New Zealand-based practitioners completed an online questionnaire relating to how they reach a diagnosis of cognitive impairment, and what labels are used to diagnose MCI. All qualitative responses were analysed using conventional content analysis. Findings indicate MCI is diagnosed using a number of different labels, including: cognitive disorder not otherwise specified, normal ageing, and early dementia. Practitioners noted more positive consequences associated with disclosing a diagnosis to their clients, which suggests providing a diagnosis is perceived by practitioners as helpful for people experiencing cognitive impairment. Ongoing research on the subject of diagnosis is needed, as the number of adults who will experience cognitive impairment is predicted to rise.

Keywords: cognitive impairment, diagnosis, attitudes

Introduction

Rapid ageing of the population in the Western world (De Meijer, Wouterse, Polder, & Koopmanschap, 2013) is associated with increased rates of age-related pathology such as dementia (Alzheimers New Zealand, 2010; Ministry of Health, 2013). The development of effective healthcare policies to meet the future needs of this age group poses a considerable challenge (Naaldenberg, Vaadrager, Koelen, & Leeuwis, 2011). In consideration of the upward trend observed in national epidemiology reports (Statistics New Zealand, 2000), the need for research focusing on older adult healthcare in New Zealand (NZ) is essential.

The issue of declining memory is an area that has received increased attention in academic literature to date. Dementia is defined as a group of symptoms which affect memory and cognitive ability, as well as everyday functional ability (Ihl et al., 2011). Although dementia-related pathology is not a normal part of the ageing process (Nelson et al., 2011), often an association is drawn between declining cognition and normal ageing (Schneider & Yvon, 2013).

As the number of those diagnosed with dementia increases (Portacolone, Berridge, Johnson, & Schicktanz, 2014), this disease has become significantly more feared than any other age-related health condition (Batsch & Mittelman, 2012). These reactions are fueled, not only by the emotional impact of a dementia diagnosis (Aminzadeh et al., 2007; Nicholson, 2013), but also pragmatic implications, such as loss of independence (e.g., revoked driver's license; Byszewski et al., 2013).

Mild cognitive impairment (MCI) is a related concept in the dementia field which is fraught with contention, both in academic literature and diagnostic practice. MCI is defined as a condition whereby a decline in ability is observed across one or more cognitive domains, though everyday functional ability remains intact (Albert et al., 2011). As a term, MCI was originally used by Reisburg and associates in the 1980s but later defined as a diagnostic

entity by Peterson et al. (1999). There has since been an ongoing debate regarding the definition and diagnostic utility of MCI, which shows no sign of remittance some 20 years later (see Peterson et al., 2014).

The release of the *Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition (*DSM-V*; American Psychiatric Association [APA], 2013) has arguably added to the controversy, with terms such as dementia and MCI replaced with major and mild neurocognitive disorder (Breitner, 2014). Mild neurocognitive disorder (mNCD) is identified as a form of cognitive disorder which may or may not progress to dementia (Sachs-Ericsson & Blazer, 2014). Given the *DSM-V* is a commonly used source for basing clinical diagnosis in NZ, it is likely clients will receive diagnoses such as mNCD in the future.

Despite these dissensions and changes in terminology, the presence of MCI as a clinical entity has remained a relatively stable prognostic indicator for an increased risk of a dementia pathology over time (Breitner, 2014). Due to the evolving nature of MCI (Gordon & Martin, 2013; Petersen et al., 2014) and the lack of peer reviewed literature in NZ relating to diagnostic issues around cognitive impairment, this study will use the term "cognitive impairment" to refer to a diagnosis of dementia and MCI.

In NZ, specialist service professionals such as geriatricians, clinical psychologists, and neuropsychologists, are often responsible for providing healthcare service users with a diagnosis of dementia (Ministry of Health, 2013). The process by which a diagnosis is reached and delivered can be variable according to the unique needs and circumstances of the client, available resources for testing, and preferred assessment measures in District Health Board (DHB) regions.

In addition to these differences in assessment practices, international literature reports varying levels of depth regarding the disclosure of a dementia diagnosis by practitioners (Bamford et al., 2004; Lecouturier et al., 2008), highlighting no "one size fits all", with

regard to diagnosis delivery. It is likely that a variation in practices of assigning diagnoses exists amongst NZ-based practitioners. Conducting research in this area may initiate ongoing discussions as to what constitutes best practice regarding diagnosis delivery in NZ.

There are a multitude of factors a practitioner must weigh up when considering how to relay a diagnosis of cognitive impairment to their client. Patient capacity, anosognosia, and the potential for self-harm can influence a practitioner's approach to disclosing a diagnosis (Cornett & Hall, 2008). Client insight levels may be impacted with more severe levels of cognitive decline; thus, rendering diagnostic disclosure unhelpful (Iliffe et al., 2009).

Suicide rates can also be higher in the elderly population (Cipriani, Vedovello, Lucetti, Di Fiorino, & Nuti, 2013; Haw, Harwood, & Hawton, 2009; Van Orden & Conwell, 2011), with slightly increased prevalence of suicide in the dementia population (Erlangsen, Zarit, & Conwell, 2008), particularly after a recent diagnosis (Seyfried, Kales, Ignacio, Conwell, & Valenstein, 2011). Practitioner reluctance to relay a timely diagnosis can also be due to the negative reactions observed in some individuals (Milne, Woolford, Mason, & Hatzidimitriadou, 2000), such as shock or denial (Aminzadeh et al., 2007).

Minimal research to date has looked specifically at practitioners' attitudes regarding diagnostic disclosure within the context of MCI, or asked whether issues applicable to dementia diagnoses are relevant to relaying the presence of MCI to clients. To our knowledge, only one NZ based study has been conducted on this topic. Mitchell, Woodward, and Hirose (2008) examined practitioner attitudes regarding MCI and early dementia in a sample of NZ and Australian geriatric practitioners. Mitchell et al. found 82% of NZ based practitioners labelled MCI, but 44% of practitioners used words other than 'MCI' or 'early dementia' when delivering a diagnosis to a client. This study is beneficial in providing a starting point for further investigation into why this variation in practice and terminology exists.

The current research will seek to extend the findings of Mitchell et al. (2008) by determining the rationale used when practitioners choose what labels to apply when disclosing an MCI diagnosis. Due to the lack of published research on attitudes regarding the delivery of any cognitive impairment diagnosis in NZ, practitioners were recruited based on having diagnosed dementia or MCI in the previous 12 months.

Objectives of this research were to shed light on how diagnosis of cognitive impairment is delivered in NZ, and to illustrate how practitioners feel about diagnosis delivery. Results are presented in a practical manner to show trends in current practice, and to clarify what the literature points out as gaps in understanding around the process of diagnosis disclosure.

Method

Research Design

The aim of this research was to examine the processes that practitioners follow when they reach a diagnosis of cognitive impairment. Attitudes regarding delivery of diagnosis were also examined. The research protocol for this study was reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 12/07 (refer Appendix 1).

Cross sectional information was gathered through an online, self-report questionnaire (refer Appendix 2). Participants were asked about issues highlighted in international literature around disclosure of a diagnosis of dementia (Bamford et al., 2004; Cornett & Hall, 2008; Fisk et al., 2007; Karnieli- Miller et al., 2007; Karnieli-Miller, Werner, Aharon-Peretz, Sinoff, & Eidelman, 2012; Mitchell et al., 2008; Werner, Karnieli-Miller, & Eidelman, 2013), as it is unknown if the same issues apply to practitioners in NZ, or with MCI.

Recruitment

The process of recruitment was guided in part by a recently published NZ study which targeted a similar practitioner population (Strauss, Leathem, Humphries, & Podd, 2012). The Australia and New Zealand Society for Geriatric Medicine (ANZSGM), the College of New Zealand Clinical Psychologists (NZCCP) and New Zealand Psychologists for Older Peoples (NZPOPs) were contacted during the process of ethics approval, requesting permission for an email invitation to be sent to members requesting participation in an online survey.

Organisations were selected as their members had a higher likelihood of direct involvement in assigning diagnoses of dementia and MCI. Members of the professional networks selected included geriatricians, clinical psychologists, psychiatrists, and neurologists. Although other healthcare services are involved with the diagnosis of cognitive impairment in NZ (e.g., general practitioners), complex assessment methods are generally employed at tertiary level services (BPAC[NZ], 2009; Ministry of Health, 2013). Hence, recruitment was focused on practitioners directly involved with cognitive testing and subsequent results delivery.

All organisations agreed to send out an email to active members on the researchers' behalf. After ethical approval was granted, the primary researcher sent an email to a representative of each professional body, who forwarded it to all active members: ANZSGM (135), NZCCP (510), and NZPOPs (79). Given the multidisciplinary nature of these organisations (e.g., psychologists, clinical psychologists), it is unclear how many practitioners are solely responsible for cognitive impairment diagnosis.

Inclusion criteria were that practitioners: (a) were currently practicing in NZ, and (b) had diagnosed dementia or MCI within the previous 12 months. Participants were not required to disclose which professional body they belonged to, as it is possible that the population of diagnosing practitioners in NZ is small enough for their identities to be

determined. By not providing any potentially identifying information, it was hoped participants would respond about issues in practice that they had experienced.

Participants

Of the 57 practitioners who completed the online survey, participants were mostly from Auckland, Wellington, and Canterbury. Participants worked in geriatrics (36.5%), followed by clinical psychology (25%), neuropsychology (13.5%), and psychiatry (11.5%). Although such professions were not specifically targeted during recruitment, several participants identified as nurse and medical practitioners ($n = 3$).

Participants varied in levels of experience with diagnosing cognitive impairment: 32% had more than 15 years of experience, 24% had 1 to 5 years, 22% had 5 to 10 years, 18% had 10 to 15 years, and 4% had less than one year of experience.

The Questionnaire

A questionnaire was developed for the purposes of this study and included three sections. In section A, broad information was collected on participant demographics. In section B, participants were asked questions regarding their diagnostic practices. Response options included: *never, sometimes, usually*, and *always*. The content of items in sections A and B were based on content from a recent questionnaire published by Strauss et al. (2012), which has been used with a similar population of practitioners in the past. The remainder of section B included questions regarding diagnosis of cognitive impairment. For example, "What terms are used with the client and their family when relaying a diagnosis of MCI?" Four questions in section C were constructed after reviewing available literature on the subject of diagnostic disclosure in dementia and MCI (Bamford et al., 2004; Cornett & Hall, 2008; Fisk et al., 2007; Karnieli- Miller et al., 2007; Mitchell et al., 2008). Participants were

given the opportunity to add further information not already captured by the style of the preceding questions in comment boxes throughout the questionnaire.

The questionnaire was piloted with several practitioners who currently practice clinical psychology. Amendments were made following their feedback to ensure that questions were relevant to the intended population.

Data Analysis

Study data was managed by the Massey University Information Technology system, then forwarded to the researcher at the completion of the study for analysis using SPSS statistics software version 21 (IBM Corporation, 2012).

The intention of the analysis was to describe any patterns that appeared, rather than using predetermined theory to guide the coding process (Hsieh & Shannon, 2005). The process of qualitative analysis was informed by Krippendorff (2013) and Neuendorf (2002). Responses were coded inductively according to the identified concepts in each response. They were then grouped according to a distinctively named primary code. For example, with the question "In your opinion, what do clients and their family find helpful during the process of diagnosis?" semantic units such as "empathy" and "clear language" were assigned to the primary code of practitioner approach.

Once the initial primary codes were developed, secondary codes were devised to further classify each subject found in the responses. Due to the length of some participants' responses, some entries were assigned multiple codes to capture each theme within the response. Refer to Table 7 for an example of how this was approached.

Table 7

Example of Participant Responses with more than one Sub-theme

Question	Participant response	Primary code	Sub-theme
In your opinion, what do clients and their family find helpful during the process of diagnosis?	"Chance to go away and think and come back for a second discussion with further questions"	Information and Support	Follow-up. Chance to have a discussion with a professional
	"Person is not alone when given the diagnosis. Face to face discussion with a clinician who is seen to care"	Information and Support	Support. Chance to have a discussion with a professional

The data was primarily coded by the lead researcher and checked by the study supervisors. Intercoder reliability was verified by cross checking a sample of codes. One rater agreed with 100% of the codes assigned, the second rater agreed with 97% of the codes assigned.

Results

Diagnosis Process

Results indicate that in the past year 84% ($n = 48$) reported diagnosing MCI, 75% ($n = 43$) had diagnosed vascular dementia, 74% ($n = 42$) Alzheimer's disease, 56% ($n = 32$) age-related cognitive decline, 56% ($n = 32$) frontotemporal dementia, and 54% ($n = 31$) had diagnosed cognitive impairment due to an acquired brain injury.

Diagnosis of cognitive impairment *always* included a client interview (97%), client healthcare records (84%), and informant information (76%). Participants used computed tomography (CT) scan results *always* (37%), or *most of the time* (47%). Personal visits to the client's home (71%), or magnetic resonance imaging (MRI) results (74%) were not used by the majority of participants. These were incorporated *some of the time* to *rarely* when informing a diagnosis.

Participants were most likely to liaise with the client's GP (42%) or neuropsychologist (38%) when gathering information on the *client's history*. For *cognitive testing*, a neuropsychologist (60%) was most likely to be consulted, and for *client support and follow-up assistance*, a social worker (59%), the client's GP, (43%) or a psychiatrist (38%) was most likely consulted. Others that practitioners were likely to liaise with during diagnosis included occupational therapists (12%), Alzheimer's New Zealand (9%), and registered nurses (5%).

Participants were asked: What terms are used with the client and their family when relaying a diagnosis of MCI? When a diagnosis of MCI is conveyed to clients, 83% of participants indicated that the label MCI is used *often* during the delivery. The term "early dementia" is used to label MCI sometimes (40%). The phrases "normal ageing" (38%), or "age-related cognitive decline" (34%) are also used *sometimes* to label MCI. The terms "subjective memory complaints" (58.3%) and "benign forgetfulness" (81.1%) are *never* used by a large proportion of participants to label MCI. Three participants noted the terms used were highly dependent on the client and etiology and four noted they were usually more specific with their terminology (e.g., amnestic or non-amnestic MCI) according to the client's situation. Others labeled MCI as age-related cognitive decline and cognitive disorder not otherwise specified (CD-NOS).

With respect to information provided to a client during diagnosis, a summary of participant responses is listed in Table 8. Information on types of support recommended to clients following diagnosis included Alzheimer's New Zealand (33%), various DHB services (11%), GP (5%), Age Concern New Zealand (4%), the Parkinsonism Society of New Zealand (4%), support groups (unspecified; 4%), Ministry of Social Work (2%), Multiple Sclerosis Society of New Zealand (2%), the Stroke Foundation of New Zealand (2%), and social worker (2%). Some participants commented that information provided was dependent on the

client's individual circumstances (11%), and often cognitive impairment is diagnosed in the context of other health problems (5%).

Table 8
Types of Information Presented to Client and Family at Time of Diagnosis

Information presented	Always n (%)	Often n (%)	Sometimes n (%)	Never n (%)	Total N
Explanation of cognitive impairment	**38 (80.8)**	6 (12.8)	2 (4.3)	1 (2.1)	47
Explanation of the test results	**36 (76.6)**	11 (23.4)	0	0	47
Information on practical aspects of the condition (e.g., medication, driving, etc.)	**29 (63)**	14 (30.4)	3 (6.5)	0	46
Information on support services	**24 (55.8)**	17 (39.5)	2 (4.7)	0	43
Information on disease progression	**20 (43.4)**	17 (37)	8 (17.4)	1 (2.2)	46
Follow-up appointment offered	17 (37)	14 (30.4)	15 (32.6)	0	46
Written summary of test results and findings	15 (32.6)	8 (17.4)	18 (39.1)	5 (10.9)	46
Written information about cognitive impairment for the client to take home	5 (10.9)	19 (41.3)	16 (34.8)	6 (13)	46

Note. Entries indicated by 20 or more participants are in boldface.

Practitioner Attitudes to Diagnosis

Section C of the questionnaire was designed to ascertain what practitioners believe is helpful for their clients when diagnosed with cognitive impairment, and what practitioners' attitudes are towards diagnosis. Considered *essential* were: meeting face-to-face with the client when delivering their diagnosis (65.2%), speaking with a family member, friend or caregiver at the time of diagnosis (60.9%), and providing comfort and relief to the client and their family (56.5%). Considered very important were: giving the client and/or their family an answer (63%), being updated by other health professionals about the client (54.3%), having a

follow-up appointment with the client to discuss their concerns (45.7%), and being a source of support (43.5%).

Reaching a conclusive diagnosis was identified as *somewhat important* for 48.9% of participants. Four participants stressed several differing points of importance that were *essential*: (1) "shifting the focus to managing cognitive impairment", (2) "client safety issues (e.g., driving risk)", (3) "giving sufficient time and opportunity to ensure that client/family understand the diagnosis and feel sufficiently comfortable to ask questions", and (4) "at least a written summary of findings".

Consequences of a Cognitive Impairment Diagnosis

Results indicate participants felt more positive consequences as a result of a diagnosis (56%), than variable (29%), or negative consequences (10%). Several comments (5%) were made regarding additional related issues (e.g., "People have a right to know information about their health, so having their human rights upheld is one consequence!"). This was coded as Issues relating to Ethics. The above codes and associated explanations of consequences perceived by practitioners after disclosing a diagnosis are shown in Table 9.

Table 9

Perceived Consequences of Diagnosis

Primary code *n* (%)	Code definition *n* (%)
Positive consequences *57* (56)	Future planning *21* (21)
	Ability to access resources *12* (12)
	"Sense making" *10* (10)
	Providing a label *5* (5)
	Growing knowledge *3* (3)
	Practical benefits (e.g., able to monitor symptoms) *3* (3)
	Benefits for the family *3* (3)
Variable consequences *29* (29)	Can experience both positive and negative emotional reaction *9* (9)
	Consequences are context dependent *7* (7)
	Consequences are influenced by systemic issues *3* (3)
	Initial reaction (negative), followed by adjustment (positive) *3* (3)
	MCI diagnosis is associated with uncertainty but also hope *3* (3)
	Practical implications (e.g., potential loss of driving ability) *2* (2)
	Can be lack of resources for providing support *1* (1)
	Some consequences for family *1* (1)
Negative consequences *10* (9)	Negative emotional responses (e.g., distress, fear, anxiety, depression) *8* (8)
	Experiences of stigma *2* (2)
Issues relaying diagnosis *2* (2)	Practitioners can be hesitant to diagnose if diagnosis is uncertain *2* (2)
Issues relating to ethics *3* (3)	It is not ethical to withhold a diagnosis *3* (3)

Helpful and Unhelpful Elements of Diagnosis Delivery

Finally, participants were asked their opinion on what their clients find helpful and unhelpful during the process of diagnosis. Of the 147 individually identified codes in the open field comments, there were more helpful (*n* = 88) elements of diagnosis than unhelpful (*n* = 59). In particular, information and support featured the most in participants' comments (39%) when labelling helpful elements of a diagnosis. Practitioner approach was noted in 54% of participant comments when asked about unhelpful elements of diagnosis. Codes and associated definitions can be seen in Table 10.

Table 10

Perceived Helpful and Unhelpful Elements of a Diagnosis

Primary code *n*	Secondary code *n* (%)	Code definition *n* (%)
Helpful *88*	Practitioner approach *35* (39.77)	Clear language *11* (12.50)
		Honesty *8* (9.09)
		Empathy *6* (6.82)
		"Reassurance" (e.g., normalisation, validation, optimism) *6* (6.82)
		Tailored diagnosis approach *4* (4.55)
	Information and support *34* (38.64)	Support from practitioners and services *10* (11.36)
		Explanation (e.g., test results, support options, prognosis) *9* (10.23)
		Information sharing *5* (5.68)
		Planning for the future *4* (4.55)
		Guidance *2* (2.27)
		Understanding *2* (2.27)
		Written information *2* (2.27)
	Process of diagnosis *19* (21.59)	Chance to have a discussion with professionals *7* (7.95)
		Being heard *5* (5.68)
		Follow-up *4* (4.55)
		Time to process information *3* (3.41)
Unhelpful *59*	Practitioner approach *32* (54.24)	Unclear language *16* (27.12)
		Focusing on the negative 4 (6.78)
		Being inattentive *3* (5.08)
		Concerns dismissed *3* (5.08)
		Harsh delivery *3* (5.08)
		Incorrect information *3* (5.08)
	Diagnosis delivery *14* (23.73)	Lack of explanation *6* (10.17)
		Diagnosis not in person *2* (3.39)
		Lack of time (e.g., hurried consultations) *2* (3.39)
		Not giving diagnosis a name *2* (3.39)
		Unconfirmed diagnosis *2* (3.39)
	Process of diagnosis *11* (18.64)	Length of time to receive diagnosis *6* (10.17)
		Lack of support/follow-up *5* (8.47)
	Implications of diagnosis *2* (3.39)	Threat to autonomy *2* (3.39)

Discussion

The results from this study involving 57 NZ-based practitioners illustrate how complex and multifaceted the process of diagnosing cognitive impairment is in practice. The aim of this research was to present current practices of practitioners involved with diagnosing cognitive decline, and build on previous research (e.g., Mitchell et al., 2008).

Use of cognitive test score alone is not sufficient in determining a diagnosis of cognitive impairment (Iliffe et al., 2009). The finding that practitioners incorporate client interview, client healthcare records, and informant information for the majority of the time when reaching a diagnosis, is therefore not surprising. Inclusion of informant information is consistent with current guidelines on diagnostic processes (McKhann et al., 2013). Also consistent with previous research is the tendency for practitioners to involve family or caregivers during diagnosis delivery (Cornett & Hall, 2008; Dautzenberg et al., 2003; van Hout, Vernooij-Dassen, Jansen, & Stalman, 2006). The present results show diagnosis is almost always given in the company of family or relatives. This is important as one in three clients may not recall their diagnosis (Bradford et al., 2011), even in the case of MCI (Frank et al., 2006).

Results suggest that visiting a client's home to deliver a diagnosis was not common practice across practitioners in the sample. Recent research on client and caregivers' experiences highlight how practitioner-client relationships are enhanced through home visits (Samsi et al., 2013). Participants in the Samsi et al. (2013) study reported feeling more comfortable when assessed and diagnosed in their own home, and frightened when they were visiting unfamiliar clinics. Our results suggest a large number of practitioners (71%) often do not or are not able to visit clients in their own homes; however, it was not clear from the findings why home visits appeared to be uncommon practice. Though this may be due to

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practical or systemic restrictions (e.g., limited time), this could be an avenue for consideration when deciding where to conduct future assessments.

The finding that 83% of practitioners used the term MCI to label a diagnosis of MCI is consistent with the 82% of NZ practitioners found in the Mitchell et al. (2008) study. Although, terms such as early dementia and normal ageing were reasonably frequent in our results (38 to 40% respectively). The label CD-NOS was also used to label MCI. The present results sought to extend the findings of Mitchell et al. by asking practitioners to comment on the rationale for this practice. Practitioner comments from this study indicate that terms were used depending on the etiology of the client's symptoms, which vary from situation to situation. None of the practitioners in the current study indicated MCI was an unhelpful label or not considered a proper diagnosis. This is in contrast with a recent study by Rodda, Gandhi, Mukadam, & Walker (2013), who found several practitioners believed MCI was not helpful ($n = 20$ or 4% of sample) or a proper diagnosis ($n = 6$ or 1% of sample). On the other hand, practitioners were offered to provide comment, rather than explicitly asked whether they felt MCI was a helpful clinical label. This could be an avenue for future research.

In line with the literature on this subject (Aminzadeh et al., 2007; Iliffe et al., 2009; Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006), several practitioners noted the existence of stigma as a consequence of receiving a diagnosis. They also considered this a factor when choosing how to relay a diagnosis. Practitioners in our study identified distress, anxiety and depression as a negative consequence associated with revealing a diagnosis to a client. Wilkinson and Milne (2003) explained reasons for distress as associated with a diagnosis being withheld, a lack of explanation for symptoms, or by access to resources being restricted when an official diagnosis is not given. Anxiety has also been related to uncertainty regarding prognosis once an MCI diagnosis has been received (Frank et al., 2006). Findings

suggest negative consequences associated with a diagnosis are not only complex, but often multilayered.

The literature emphasises the importance of follow-up after the disclosure of a diagnosis of cognitive impairment (Lecouturier et al., 2008; Maguire, 2002; Wilkinson & Milne, 2003). In cases of clients with MCI, regular monitoring is essential (Leung et al., 2011). Moreover, clients generally appreciate the opportunity to have a post-diagnostic discussion session (Abley et al., 2013). Our results suggest that follow-up is not common in practice amongst NZ based practitioners. Systemic barriers, such as those discussed by Bradford et al. (2009), may account for why there is a lack of emphasis on follow-up in this sample. One recent study found that follow-up care and support was provided to those with certain types of diagnoses (Samsi et al., 2013). For instance, Samsi et al. (2013) found those with vascular dementia and MCI were discharged without follow-up, which lead to feelings of helplessness, shock, and confusion.

Limitations. Several limitations must be considered in the interpretation of these results. First, it is possible that practitioners in this study may have responded in ways that portray their attitudes and practices differently than in reality. A similar study regarding cognitive impairment diagnosis and healthcare providers have suggested social desirability bias to be a factor in the interpretation of results (Foy et al., 2007). Practitioners might also perceive their practices, as well as associated benefits or consequences, in a different light than those who are receiving the diagnosis. Previous research has reported an experiential disparity between how practitioners perceive and how family caregivers experience dementia diagnosis (Connell et al., 2004).

A second limitation relates to the representativeness of the sample. Other types of healthcare professionals involved with the process of diagnosis were not invited to participate, such as GPs, practice nurses, and social workers. Research suggests the

perspectives of primary care physicians involved with initial diagnoses of dementia should be investigated further (Aminzadeh et al., 2012). It is currently unclear how large the population of practitioners who diagnose cognitive impairment in NZ is. However, previous studies on cognitive impairment diagnosis in NZ have had slightly better response rates (Strauss et al., 2012). The reason for this may be that the topic of disclosure is perceived as a taboo subject (Kaduszkiewicz et al., 2008); therefore, some practitioners could have been hesitant to discuss these issues.

Another limitation was the wording of the questionnaire. Given the finding that 97% of participants used client interview to ascertain diagnosis, when this is an integral element of the overall process, suggests potential misunderstanding of the question. Comments left in the open comments boxes by several practitioners revealed they were unsure if they were being asked specifically about dementia or specifically about MCI. This study is not the first to experience terminology challenges in studying elements of cognitive impairment diagnosis. Rodda et al. (2013) also had difficulty in separating differences in questionnaire responses according to type of cognitive impairment. It is clear practitioners treat cognitive impairment diagnoses differently.

Concluding comments. Findings from the current study provide insight into practices and beliefs that practitioners have regarding cognitive impairment diagnosis. Future research might assess the extent to which practitioner and client attitudes are aligned with each other regarding the actual experience of receiving a diagnosis. A recent systematic literature review on dementia and disclosure reports a considerable increase in research surrounding disclosure issues in the past four years (Werner et al., 2013). Such findings emphasise the relevance of this subject as the numbers of those diagnosed with cognitive impairment in the future will increase.

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STATEMENT OF CONTRIBUTION
TO DOCTORAL THESIS CONTAINING PUBLICATIONS

(To appear at the end of each thesis chapter/section/appendix submitted as an article/paper or collected as an appendix at the end of the thesis)

We, the candidate and the candidate's Principal Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

Name of Candidate: Alison McKinlay

Name/Title of Principal Supervisor: Prof Janet Leathem

Name of Published Research Output and full reference:

McKinlay, AR., Leathem, J., & Merrick, P. (2014). Diagnostic processes and disclosure: A survey of practitioners diagnosing cognitive impairment. New Zealand Journal of Psychology, 43(2), pp. 20 - 31.

In which Chapter is the Published Work: Chapter Eight

Please indicate either:

- The percentage of the Published Work that was contributed by the candidate:

  and / or

- Describe the contribution that the candidate has made to the Published Work:

  AM conducted the study under supervision of primary and secondary supervisors.

A McKinlay   Digitally signed by A McKinlay   Date: 2015.10.25 14:28:55 Z

Candidate's Signature

25/10/15

Date

Janet Leathem   Digitally signed by Janet Leathem   Date: 2015.10.27 08:31:45 +13'00'

Principal Supervisor's signature

27/10/15

Date

Coping after Specialist Diagnosis of Mild Cognitive Impairment and

Cognitive Disorder Not Otherwise Specified

Preface

This chapter contains the findings of the second study of the thesis. Participants were recruited from older adult mental health services in three regions in the North Island of NZ. Initially, five DHBs showed interest in assisting with recruitment; however, one centre began another project at the same time on other aspects of MCI, and another was unable to assist due to low numbers of clients meeting study diagnostic criteria at their service.

As the article stands alone, some material already presented in the introductory chapters may be repeated. Parts of this paper have been submitted to an international gerontology journal; and as such, some additional information has been added for the international reader. Reference entry for material *in preparation* is as follows:

McKinlay, AR., Leathem, J., & Merrick, P. (submitted). Coping and Illness Representations in a Clinical Sample Diagnosed with Mild Cognitive Impairment and Cognitive Disorder Not Otherwise Specified.

Please note: Additional documents pertaining to this study can be found in the Appendix section. These documents include ethics approval (Appendix 3), progress reports (Appendix 4 to 5), interview confirmation slip (Appendix 6), and conclusion of study notification (Appendix 7).

Chapter Nine: Coping after Specialist Diagnosis of Mild Cognitive Impairment and Cognitive Disorder Not Otherwise Specified

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Abstract

The literature highlights numerous psychosocial responses following a diagnosis of dementia that can influence coping behaviour. Understanding these processes within the context of mild cognitive impairment (MCI) is comparatively sparse. Clinical diagnosis of MCI in New Zealand is an under-researched topic, though one recent study found that the syndrome can be subsumed under clinical labels such as 'early dementia' and 'cognitive disorder not otherwise specified' (CD-NOS). The aims of this study were to use the illness perception (IP) model as a framework to examine coping in a sample diagnosed with MCI and CD-NOS. The sample was recruited from multiple health services across the North Island. Five participants were diagnosed with CD-NOS and four were diagnosed with MCI. A mixed methods study was conducted, whereby, a phenomenological approach was used to examine participants' experiences through semi-structured interviews. Objective changes in psychosocial variables were described via coping (via Brief COPE questionnaire) and illness perception (IPQ-MCI) scores at both time points. Participants were interviewed within three months of receiving their initial diagnosis from psychogeriatric services and again three months later. Findings highlight how many individuals feel hopeful that they will not progress to dementia, though others who experienced further symptoms had begun to prepare for eventual decline. Many believed their diagnosis was caused by variable factors, which suggests a need to discuss the suitability of an illness-based theoretical model. There were many similarities across interview transcripts: many wanted more information on their diagnosis, and most felt relieved their memory loss was not Alzheimer's disease. Despite some similarities, the meaning of the diagnosis was different and seemed to depend on the clinical label used. This

is a valuable avenue for future research to examine. Future research in this area should include the experiences of family members, who are also emotionally impacted by MCI diagnosis.

Keywords: mild cognitive impairment, cognitive disorder, diagnosis, coping, interpretative phenomenological analysis, common sense model of illness representation

Mild cognitive impairment (MCI) is a condition representing a transitional phase between normal ageing and dementia. Cognitive deficits are typically found in areas such as attention, mood, memory, language, and visuospatial skills (Nelson & O'Connor, 2008). To warrant a diagnosis of MCI, everyday functioning must be preserved, which is in contrast to a diagnosis of dementia, where a person is unable to carry out activities of daily living. Though initially MCI existed only within research settings (Garand, Lingler, Conner, & Dew, 2009), the clinical utility of this concept is increasingly being explored (Kaduszkiewicz et al., 2014). "The concept has moved rapidly outside the research field providing clinicians with a helpful intermediate diagnosis, often for watchful waiting" (Petersen et al., 2014, p.215).

Varying Clinical Labels

MCI is a syndrome that goes by many different names. In a systematic review, 18 definitions of early cognitive impairment were used in peer-reviewed publications (Matthews, Stephan, Bond, & McKeith, 2007). Criteria used to diagnose MCI also varies between studies and healthcare services. Establishing consistent use of terminology and diagnosis method is important if concepts such as MCI are to be beneficial in practice (Stephan, et al., 2013). Difficulties in advancing the literature on cognitive impairment stem from variable terminology and diagnostic practices in clinical and research settings (see Bondi & Smith, 2014, for discussion).

Cognitive Impairment Diagnosis in New Zealand

NZ has a population of 4.47 million with many diverse cultures and communities. The healthcare system is comprised of individual district healthboards (DHBs) which govern healthcare services for each region. Diagnostic practices (e.g., measures, criteria) vary across regions. A framework was recently published (*New Zealand Framework for Dementia Care*;

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Ministry of Health, 2013) to facilitate early identification, consistent practice, and monitoring of cognitive impairment symptoms. This framework is based on *Living Well with Dementia*: *A National Dementia Strategy* (Department of Health, 2009) published in the United Kingdom.

Scarce published research has focused specifically on MCI in NZ, though several studies (e.g., McKinlay, Leathem, & Merrick, 2014; Mitchell, Woodward, & Hirose, 2008) highlighted variability in the label used to diagnose MCI in clinical practice. One such label included cognitive disorder not otherwise specified (CD-NOS) published in the *DSM-IV* (American Psychiatric Association [APA], 2000). With the release of the *DSM-V* (APA, 2013), it is likely that labels such as mild neurocognitive disorder (mNCD) will be used in practice to label symptoms of MCI. At present, no standard procedure exists for diagnosing MCI in specialist settings. Moreover, no research has documented the impact of varying clinical labels or psychosocial impact of diagnosis in NZ. Given that early identification of cognitive impairment is an objective of recent public policy, it is essential to examine the experience of diagnosis from a client's perspective.

Illness Perception Model on Coping with MCI

The common sense model of illness representations (CSM; Cameron, Leventhal, & Leventhal, 1995; Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984) *may* offer a theoretical explanation on coping strategies exhibited following MCI diagnosis. The model holds that individuals respond to their illness based on perceptions or 'schemata' generated about their diagnosis (Leventhal, Leventhal, & Contrada, 1998). Illness representations are made up of several dimensions: (1) "Identity" pertains to the label given to the diagnosis, (2) "Cause" is an individual's belief of what caused the condition, (3) "Timeline" is the expected duration of the illness (acute/chronic or cyclical), (4) "Consequences" refers to beliefs about the ramifications of the illness, and (5) "Control"

pertains to the degree to which the individual believes they can control or cure their condition personally or via treatment (Reynolds et al., 2012). Additional dimensions have been added to the theory on illness representations as the model has gained popularity in health psychology literature. "Emotional representations" are factored into more contemporary descriptions of the CSM, whereby emotions such as fear, anxiety, or depression are tied to diagnosis experience (Moss-Morris et al., 2002). "Illness coherence" relates to the understanding a person has about their diagnosis (Moss-Morris et al., 2002).

Research has examined the utility of the CSM to explain how people cope with early dementia (Harman & Clare, 2006), MCI (Lin & Heidrich, 2012; Lingler et al., 2006; Morgan, Garand, & Lingler, 2013) and subjective memory complaints (Hurt et al., 2013). Lingler et al. (2006) were the first to suggest the CSM had utility in explaining clients' responses to MCI diagnosis in a qualitative study. They suggested future research should examine illness perceptions over time, in order to gain a sense of influential factors in their development. McIlvane et al. (2008) also discussed the significance of threat interpretation in MCI illness perceptions, as a potential source of stress.

Lin and associates published two key papers while this research was being undertaken (i.e., Lin, Gleason, & Heidrich, 2012; Lin & Heidrich, 2012). They sought to describe clients' illness perceptions using their version of the Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002) called the IPQ-MCI. Authors interviewed 63 older adults with MCI within 3 months of receiving their diagnosis. They found illness perceptions about MCI *were* associated with how participants coped with their diagnosis. They suggested future research investigate the utility of the CSM model in a longitudinal investigation, in order to highlight other factors which may influence perceptions of illness (and coping) over time.

Finally, Morgan et al. (2013) conducted a qualitative study with 53 individuals diagnosed with MCI. Authors proposed that individuals perceive MCI as a health threat

which can impact coping behaviour. They discussed the utility of the CSM in explaining engagement with health promotion activities following MCI diagnosis, and contrasted their findings to the stress-appraisal model by Lazarus and Folkman (1984).

Illness perceptions may have clinical implications for practitioner consideration, as perceptions can influence future help-seeking behaviour (Lin et al., 2012). For example, an ambiguous illness identity may explain why some do not seek help or care for health-related symptoms (Reynolds et al., 2012). Given the potential clinical value of assessing cognitive impairment appraisal, it is beneficial to clarify the utility of the model in explaining diagnosis reaction.

Coping with MCI and Cognitive Decline

A number of theoretical considerations are relevant in discussion on coping with cognitive decline. Lazarus and Folkman (1984) proposed that coping behaviour arises from cognitive appraisal of life events (i.e., individual interpretation), and interactions with the environment. "Problem-focused coping" includes pragmatic behaviour, which relates to altering some aspect of the environment causing distress (Lyon, 2012). While "emotion-focused coping" is defined as behaviour directed at minimising emotional distress (Lyon, 2012). In past research on coping with MCI and dementia, "dysfunctional coping" has also been assessed, which includes strategies such as denial (Cooper et al., 2008; Lin & Heidrich, 2012; McIlvane et al., 2008).

Psychosocial responses can be varied following the experience of MCI diagnosis. McIlvane et al. (2008) examined coping in 46 individuals within six months of being diagnosed. Participants believed they could control their condition by implementing health promotion strategies. Many reported moderate wellbeing and some were optimistic about their future. Joosten-Weyn Banningh et al. (2008) conducted interviews with individuals diagnosed with amnestic MCI. Some managed fear of dementia by using health promotion

strategies, and others used dysfunctional coping behaviours such as denial. Lingler et al. (2006) interviewed 12 people with amnestic and non-amnestic MCI within 3-6 months of their initial diagnosis. Participant response to diagnosis was typically influenced by personal experience of dementia or an expectation of memory decline being part of normal ageing. Frank et al. (2006) reported lack of clarity in understanding the meaning of MCI, as well as anger and distress in response to diagnosis. Beard and Neary (2013) investigated the experience of ten individuals and eight subgroups diagnosed within three years. They found participants were relieved that MCI was not AD. Participants expressed uncertainty and considered their memory loss to be associated with normal ageing.

These studies highlight factors informing experiences of symptoms, and how people reconcile the meaning of these symptoms in their everyday lives. Limited research has investigated how their responses to diagnosis change over time. Little is known about the process by which a person comes to adapt and accept their diagnosis after being received.

Research Questions

This study sought to provide a detailed examination of experiences following a cognitive impairment diagnosis in NZ. The following research questions were developed to guide the implementation of the study:

1. What are clients' experiences of cognitive impairment diagnosis in NZ?
2. How do clients cope in the first six months following initial diagnosis?
3. What influences the way that clients feel about their diagnosis?

Method

Participants

Participant recruitment took place between March 2014 and June 2015. The sample was recruited from three older adult memory services across the North Island in NZ. Potential

participants were screened by their psychogeriatrician and given information on the study

following formal diagnosis. Inclusion criteria were: (a) clinical cognitive impairment

diagnosis by a geriatric specialist within three months, (b) available for several interviews

over three months following diagnosis, (c) not diagnosed with dementia, and (d) able to

communicate verbally.

Clinical criteria used to diagnose cognitive impairment varied between DHB regions.

One region diagnosed MCI based on a combination of Albert et al. (2011) and *DSM-V* (APA,

2013) mNCD criteria. The second region based diagnosis on Winblad et al. (2004) criteria.

The third region diagnosed CD-NOS based on DSM criteria. Thirteen clients were identified

as eligible to participate in the study; however, four declined to participate for personal

reasons (e.g., sickness, disinterest). In total, four participants with MCI and five participants

with CD-NOS agreed to participate (refer Table 11).

Table 11
Participant Characteristics

MCI		CD-NOS	
Name	Age	Name	Age
Harry	71	Tom	67
Martin	69	Steve	57
Simon	73	George	85
Rhonda	73	Bruce	77
		Samantha	67

Note. Names changed to protect anonymity

Demographic characteristics of participants are shown in Table 12. All participants

identified as NZ European, married, and lived with their spouse. Participants originated from

three separate regions of the North Island, ranging from urban to rural. Two participants had

been prescribed Donepezil at the time of their first interview and one additional participant

began Donepezil between their first and second interview. A fourth participant had been prescribed an antidepressant between interviews "to help with the memory".

Whanau[5] were encouraged to attend interviews if the participant wished, in order to provide support if needed. Interview questions focused on the experiences of the participant, rather than the family member. Five spouses accepted this invitation and sat in on parts of these meetings with participants. This is likely to have influenced the content of some interviews; however, as no research exists on the topic of MCI within NZ healthcare services, the participant's comfort and safety was held at the forefront of conducting this study.

Ethical considerations. The Northern A Health and Disability Ethics Committee (HDEC) reviewed and approved the study to take place (ref: 12/NTA/67). Additional ethical approval was sought and approved by each individual DHB region. All participants (including any spouses who wished to be present during interviews) signed written informed consent forms in the initial interview following a verbal explanation of the study and ethical procedures. Progress reports were sent to HDEC throughout the study, as well as notification of study conclusion (refer to Appendices 3 to 7).

Research interviews. The interview protocol was developed with guidance from the literature (e.g., Smith & Osborn, 2008) and cultural consultation. Piloting of the interview procedure was undertaken with two volunteers with personal experience of a family member being diagnosed with dementia.

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[5] Whanau is a concept in New Zealand within Maori culture, which underpins health; it is primarily associated with immediate family but can also extend beyond this traditional notion (Durie, 1985).

Table 12

Demographic Characteristics

Variable	Category	% (*N*)
Age (*n* = 9)	Mean 71 (7.68 SD)	
	Range 57 – 85	
Gender	Female	22 (2)
	Male	78 (7)
Education level	High school	56 (5)
	Tertiary training	22 (2)
	University	22 (2)
Income (NZD per annum)	Under $20,000	44 (4)
	$20,000 - 60,000	22 (2)
	≥$60,000	11 (1)
	Prefer not to say	22 (2)
Working situation	Retired	56 (5)
	Part time	33 (3)
	Full time	11 (1)
Coexisting illness	Yes	66 (6)

The interview procedure followed a semi-structured format, though care was taken to allow participants to share their experiences with minimal intervention or prompting. Participants were asked open-ended questions about the circumstances of diagnosis and how they reacted afterwards. For example, "In the first days following diagnosis, what was it like for you processing the news?" Care was taken to ensure the researcher matched the labels that participants used to describe their diagnosis. Although a topic and question guide was prepared as a prompt, questions varied between participants depending on the nature of their individual response. Topics in time one (T1) and time two (T2) interview schedules included: (1) Diagnosis Experience, (2) Perceptions of "Illness", and (3) Coping Behavior. At T2 however, questions varied in order to ask about *changes* in individual beliefs and experiences since their first interview.

All interviews took place in participants' homes. Interviews were audio recorded and later transcribed. No notes were taken by the researcher during interviews, although a field diary was kept as a way of recording observations and research progress.

Qualitative analysis. Following interview transcription, qualitative responses were analysed using interpretative phenomenological analysis (IPA). IPA is useful in the analysis of client's perceptions about experiences of declining health (Brocki & Wearden, 2005) and is commonly used to analyse illness experience (Smith, 2011).

A case-by-case analysis was undertaken on all 18 transcripts. Identifying information was removed to protect anonymity. Each interview was analysed separately and primary-order themes (from the participants) were established using the participant's own words as closely as possible. These preliminary themes were read again to ensure assigned labels fitted the dialogue. All initial themes were reviewed to form an overall impression of each individual case. Next, higher-order concepts (from the researcher) were established. A group level analysis was then conducted, where higher-order themes were reviewed. Participants' responses were grouped according to these.

Quantitative Measures

At T1 and T2, participants completed a questionnaire containing all measures, in order to provide an objective assessment of change over time. Study variables were assessed via measures of coping and illness perceptions.

Coping Orientations to Problems Experienced: Brief COPE. The Brief COPE is a freely available, flexible, 28-item measure which assesses ability to deal with life stressors (Carver, 1997). It has been used with MCI populations in the past (McIlvane et al., 2008; Lin & Heidrich, 2012). The questionnaire has 14 subscales (two questionnaire items each). Each subscale has previously been categorised as: emotion focused coping (acceptance, emotional support, positive reframing, religion, humour), problem focused coping (active coping, planning, instrumental support), and dysfunctional coping (self-distraction, venting, self-blame, behavioural disengagement, denial, substance use). Response options in the survey are

scored from one to four: *I haven't been doing this at all* (1), *I've been doing this a little bit* (2), *I've been doing this a medium amount* (3), and *I've been doing this a lot* (4).

Subscales can be created by summing individual items or calculating a mean score. A literature review on the Brief COPE describes a tendency for authors to sum two items in each scale to create a continuous total score (Krägeloh, 2011); thus, subscales were calculated by summing two items in each subdomain. Continuous scores ranged from two indicating infrequent use of this coping strategy, up to eight indicating frequent use (Snell et al., 2011). Reliability and validity indicators for the Brief COPE are satisfactory, with internal consistency for each subscale ranging from 0.72 to 0.84 (Cooper, Katona, & Livingston, 2008). In this study, Cronbach's alpha ranged from .89 to .94 across both time points on all subscales, indicating satisfactory reliability for the purposes of the present study.

Perceptions of Illness: Illness Perception Questionnaire for Mild Cognitive Impairment (IPQ-MCI). The IPQ-MCI is a newly developed, 40-item questionnaire constructed specifically for use with MCI populations (Lin, Gleason, & Heidrich, 2012; Lin & Heidrich, 2012). It is based on the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002). General IPQ response options include a five-item Likert-style scale ranging from *strongly disagree* to *strongly agree* (Moss-Morris et al., 2002; Weinman, Petrie, Sharpe, & Walker, 2000). Scores range from one to five, with scores closer to five indicating a strongly held belief (Hurt et al., 2011). Subscales in the IPQ include: Timeline Cyclical, Emotional Representation, Personal Control, Treatment Control, Illness Coherence, Timeline Acute/Chronic and Consequences. Subscales (containing four to eight items each) were calculated as a mean score, ranging from one to five.

Given that MCI is a diagnosis labelled variably across clinical settings, one key amendment was made to the questionnaire in order to be used with a NZ sample. In the original IPQ-R, participants are asked about their "illness". In the IPQ-MCI, participants are

asked about their "MCI". In regions where the label CD-NOS is used rather than MCI, neither of these terms seemed appropriate, particularly if CD-NOS is not conceptualised by clients as an illness. The term "condition" was deemed more suitable. For example, "My diagnosis of MCI" was replaced with "my condition". These changes were checked by a psychogeriatrician for appropriateness of use with the sample. Changes were submitted to and approved by HDEC.

Prior to carrying out the main analysis, reliability checks were performed. An alpha of >.80 is regarded as good and >.70 is considered adequate (Acock, 2006). Timeline Cyclical and Emotional Representation had acceptable levels of reliability (α = .75 - .98). Personal Control, Treatment Control, and Illness Coherence had variable reliability figures (α = .51 - .95). The literature is divided on an alpha of <.70, so these subscales are included with caution. For instance, Nunnally (1967) initially reported α = >.50 as acceptable, but later amended this figure to α = >.70 (Nunnally, 1978). Internal consistency values for *Timeline Acute/Chronic* and *Consequences* subscales were poor (α = < .50). As a low reliability scores can indicate measurement error (Tavakol & Dennick, 2011), these subscales were not included with the analysis.

Quantitative Analysis

As not all participants were able to provide two completed questionnaires at two timepoints, a subset of participant quantitative data was analysed (n=6). Quantitative data were entered and analysed through SPSS version 22 (IBM Corporation, 2013). Demographic data were entered as categorical variables and raw data from survey measures were computed into subscale scores. Assumptions of normality were not met in this dataset, in part, due to sample size. Positive skewness scores also indicated a cluster of typically high scores, and negative kurtosis scores indicated a number of extreme cases (Pallant, 2011). When a distribution fails to meet assumptions of normality, traditional inferential testing can lead to

erroneous interpretations (Fidell & Tabachnick, 2003). As such, descriptive statistics are presented here with this dataset.

In quantitative research, important information (i.e., effect size, practical significance) can be overlooked in favour of achieving a small p value (Kirk, 2001). "A small sample and a non-significant p value can mask a clinically meaningful effect. A non-significant p value does not mean there is no difference but, rather, no evidence was found that there was a difference" (Millis, 2003, p. 222). Effect sizes communicate the degree to which two variables are associated with each other (Carlucci & Wright, 2012), and may be of use to other researchers interested in psychosocial outcomes following MCI diagnosis. Therefore, Cohen's d effect sizes were calculated, and are reported in the following section. An effect size was considered medium when reaching >0.5 and large when >0.8 (Carlucci & Wright, 2012).

Results

Interview one higher-order and primary-order themes are listed in Table 13. The analysis was checked by an independent research consultant, to ensure the primary researcher's interpretation of participants' accounts were appropriate. The second and third authors also checked the analysis and provided feedback on the discussion.

Interview One

Theme One: Diagnosis process presents no major concern. The experience of being diagnosed was not associated with major concern amongst participants with either MCI or CD-NOS. Many wanted more information on their diagnosis, but others expressed surprise over test performance and discussed helpful aspects of their diagnosis experience.

Table 13

Interview One Themes

Higher-Order Themes	Primary-Order Themes
Diagnosis presents no major concern	1.1 Surprise about ability during testing. 1.2 Helpful having a positive practitioner
My beliefs inform my perceptions about cause of diagnosis	2.1 Disagreement with diagnosing practitioner 2.2 Always had a bad memory 2.3 Personal experience of AD
Struggling to adjust	3.1 Other serious healthcare concerns 3.2 Getting down
Optimism	4.1 Feeling in control 4.2 Feeling prepared

1.1 Surprise about ability during testing. The only identified emotion associated with cognitive testing was surprise in those who had worked in trade professions during their career (*n* = 2). Tom, an accomplished tradesman, was surprised and exasperated at not being able to complete what he thought *should* have been a basic task: "*He said I should be able to put these blocks in order (pause), but I couldn't" (Tom, CD-NOS).*

1.2 Helpful having a positive practitioner. Simon, who was interviewed within four weeks of first receiving his MCI diagnosis, spoke of how he was given ideas and strategies for assisting with his memory, and how his diagnosing practitioner was optimistic about the future. He found this helpful as he processed the news of his diagnosis: "*He gave us some instructions as in cutting back on caffeine, [increasing] exercise, omega 3, maybe help the head, and it was just, he was quite happy, quite positive" (Simon, MCI).*

Theme Two: My beliefs inform my perceptions about cause of diagnosis. Beliefs about the causes of memory impairment were predominantly fixed over interview one and interview two. Many felt their loss of memory was normal ageing, and others associated their diagnosis with lifestyle or a precipitating diagnosis they had received in the past (e.g., stress, stroke).

2.1 Disagreement with diagnosing practitioner. Five participants in the study

(George, Samantha, Bruce, Harry, Steve) disagreed with advice on the cause of their

condition, despite receiving clinical information attributing their memory impairment to the

diagnosed syndrome. Instead, they offered their own explanation based on their individual

circumstances, such as personality type, always having a bad memory, or being bad at maths.

Many felt their memory decline was due to normal ageing: "*He did all sorts of tests. But as*

far I'm concerned, I think its old age" (Harry, MCI).

Furthermore, some felt their lifestyle had contributed to the development of their

memory condition:

> *So, I thought that it's come about because I was in a job for 21 years doing the same*
>
> *old, same old, and didn't have to use a great deal of brain power. So the brain shut*
>
> *down, as such…So I thought that because I wasn't using my full ability, that things*
>
> *took a dive. This is why it's come about. (Steve, CD-NOS)*

2.2 Always had a bad memory. At T1, half of the sample described having always

had a bad memory. Diagnosis came less as a shock because it had been a suspicion that had

gradually built up over time. Rhonda, for instance, explained that memory loss (i.e.,

forgetting day-to-day tasks) had been a part of her life for ten years prior to receiving her

MCI diagnosis. To receive a formal diagnosis was no surprise. In her first interview, she

spoke of being ok with the clinical label, but still found it challenging to deal with her

memory loss on a daily basis. Feeling she could not cope with MCI was influenced by other

healthcare concerns during her first interview.

2.3 Personal experience of AD. This was a consistent topic of discussion across

interviews. Several participants (Martin, Harry, Rhonda) presumed they could eventually end

up like their relative, friend, or colleague who had 'Alzheimer's.' Notably, participants who

had a personal experience of AD were not consumed by their concern about the future. For

example, Martin hoped he would "never get as bad as my mother got", but explained it was not a good use of energy to worry about it.

Theme Three: Variable experiences of adjustment. At T1, three participants reported struggling with elements of their diagnosis. It was clear that adjustment was a process, and feelings of being overwhelmed varied. For some, the appearance of struggle was tied to other illnesses (Rhonda, Samantha) or implications of the label (Simon).

3.1 Other serious healthcare concerns. At T1, two participants were also experiencing other health complications (Rhonda, Samantha). Samantha was diagnosed with CD-NOS in the context of a number of major life changes, which felt to be all "too much". For Rhonda, who was interviewed in the first three months of receiving her diagnosis, MCI was another stressor to add to the existing list of other illnesses. Consequently, she felt she could not cope with another diagnosis. However, as the symptoms of her other health conditions abated in the months between the first and second interview, perceptions of her future were more optimistic. When asked in her final interview about whether her coexisting healthcare conditions had influenced how she felt about her MCI diagnosis, she responded: "I do, a huge effect, yes, yeah".

3.2 Getting down. At T1, Simon reported struggling in the weeks following his initial diagnosis. When it came to the experience of memory loss, this appeared to be something he was self-critical about. Simon had begun to doubt himself; not in response to the diagnosis, but as a result of the memory loss. He spoke about needing to double check things that he normally would not have, such as measuring materials for his hobbies. He appeared to take responsibility for instances where he lost his memory, as if he were to blame: "Yeah but I've just got to try and use my head a bit more".

Theme Four: Optimism. The higher-order theme of optimism represents the hope that participants expressed about the future, often despite experiencing feelings of uncertainty.

4.1 Feeling in control. Though Simon reported experiencing self-doubt following his diagnosis, there was also a discussion about what he and his wife could try together with the hope of changing the outcome of his future. He repeatedly spoke in his interviews about being able to take steps to influence future events. This appeared to provide him with a sense of control over an area of his life which, by his own account, was completely new: "*I feel happy that we're on to it, and we might be able to slow it down, and do something positive about it, understand it a bit more, a bit better*" (Simon, MCI).

4.2 Feeling prepared. Martin was first interviewed within three months of his initial diagnosis. Across both interviews, he spoke of how he and his wife were preparing for any future deterioration of health, or change in life circumstances. He hoped for the best, yet had been preparing for the worst. This process appeared to give comfort by feeling that things were taken care of, should they face any future challenges: "*We've got everything fairly well set up… Hopefully we've got all our T's crossed and I's dotted. It's all you can do*" (Martin, MCI).

Interview Two

Interview two higher-order and primary-order themes for are listed in Table 14.

Theme One: My beliefs inform my perceptions about cause of diagnosis. By the time of the second interview, some participants deferred to their clinicians advice on the significance of their diagnosis.

Table 14
Interview Two Themes

Higher-Order Themes	Primary-Order Themes
My beliefs inform my perceptions about cause of diagnosis	1.1 The doctor said ___ and I believe them 1.2 Disagreement with diagnosing practitioner 1.3 Function of memory changes with age
Variable experiences of adjustment	2.1 Noticing a decline in memory 2.2 Other serious healthcare concerns 2.3 Battling my MCI 2.4 Hiding my MCI
Optimism	3.1 Feeling in control 3.2 Thinking more about cognitive health since diagnosis
Social comparison	4.1 Compared to others, my memory is not that bad 4.2 Normalising changes in memory

1.1 The doctor said ___ and I believe them. Prior to conducting the study, it was thought practitioners would influence how participants perceive their diagnosis. In one case, this was evident in the way interview questions were answered. Simon held on to what his practitioner had told him about the diagnosis as a source of reassurance. At T2, other participants also referred back to what their diagnosing practitioner had explained about the diagnosis, (i.e., that they do not have AD; Samantha), or that their symptoms might not progress to AD (Martin and Simon). This advice was a source of hope amidst feelings of uncertainty.

1.2 Disagreement with diagnosing practitioner. As with interview one, several participants provided their own interpretations of the origins of their memory condition, such as age, lifestyle factors, or personality characteristics.

1.3 The function of memory changes with age. At T2, two participants (George, Harry) expressed competing beliefs in their transcripts, wherein they trusted their doctor to prescribe them a course of treatment for their memory decline (both were prescribed Donepezil), yet they strongly disagreed with causes of their condition, saying it was the stage

of life they were in. Harry explained that memory no longer served the same purpose for him, now that he was a retiree. He did not expect to feel the same way he once did, and expected that changes would occur with increasing age. George held a similar view: Now that he was retired and living in a retirement village, his lifestyle had changed, which meant an inevitable change in his memory function. He explained how he had intentionally kept his mind active throughout his working career, with several jobs 'on the go' at once; although now, he had adopted a slower pace of life.

Theme Two: Variable experiences of adjustment. At T2, four participants reported struggling with elements of their diagnosis. The experience of struggle was tied to symptom experience (Harry, Martin), other health conditions (Tom) or implications of the label (Simon).

2.1 Noticing a decline in memory. In comparing first interview transcripts with second interviews, those who were aware of instances where their memory had failed since diagnosis (Harry, Martin), expressed some concern about the future. Harry, interviewed within one month of receiving his MCI diagnosis, did not get 'cross' or 'sad' about the initial diagnosis, and until anything progressed, it was 'business as usual.' However, his demeanor changed by his final interview, three months later. He had experienced more symptoms of MCI, and had been prescribed Donepezil during this time. Though he attempted to positively reframe his memory decline (e.g., refer to Section 1.3: the function of memory changes in old age), he described feeling this was 'the beginning of the end': "*So when they say mild cognitive impairment, I assume that this is the polite way of saying that this is the onset of what you're going to die of*" (Harry, MCI).

2.2 Other serious healthcare concerns. Tom had experienced an accident prior to his CD-NOS diagnosis, which affected him physically and psychologically. At T2, he reported

being affected by the aftermath of this previous injury. The discussion of this previous injury was more frequent than discussion on the impact of his memory loss diagnosis.

2.3 Battling my MCI. Simon reported struggling to process the MCI diagnosis during his initial interview; however, by the second interview three months later he spoke of not wanting to admit defeat. If he had to he would "go down fighting". At T2, he likened coping with diagnosis to a fight he was determined to win. This participant appeared to conceptualise MCI as a precursor to AD, so for him, the label implications show parallels to coping with early dementia.

2.4 Hiding my MCI. At T2, Harry spoke of hiding his MCI symptoms. He felt his memory had declined since receiving his initial diagnosis, and he was taking steps to hide these events, so as to protect his wife from becoming concerned. In this case, the struggle appeared heavily linked with symptom experience, more so than the clinical label. Simon chose not to tell anyone other than two trusted family friends as a way of protecting his privacy. On the other hand, others who did not conceptualise their diagnosis as being associated with AD spoke freely with their wider support network. Throughout all interview transcripts, Martin, Bruce, Steve, and Tom reported speaking with their workplaces, friends, and neighbours about their memory condition.

Theme Three: Optimism. Optimism appeared during the second interview transcripts of almost all participants.

3.1 Feeling in control. Several participants reported that their actions would determine how they coped with their diagnosis in the future. Samantha felt her memory decline was associated with her individual lifestyle; therefore, changing her lifestyle would change the nature of her memory loss: "*Yes, things have been difficult, but that's up to me to change that" (Samantha, CD-NOS).*

3.2 Thinking more about cognitive health since diagnosis. Many participants described their cognition as being an area of health they had not considered in the past (i.e., Martin, Simon, Steve). Since diagnosis, they had begun to implement strategies to keep their mind active. Behavioural and cognitive strategies suggested by several practitioners had been taken up enthusiastically by participants. In this sense, the formal diagnosis process served to draw attention to an aspect of health that was unfamiliar to participants in the study.

Theme Four: Social comparison. Social comparison was a major component of most participants' interview scripts, as a way of coping with the realities of declining memory. This represents a higher-order theme, because all participants described this process of social comparison in a number of different ways.

4.1 Compared to others, my memory is not that bad. Several participants found comfort by comparing their level of function to other people. George was not worried about his memory loss, because compared to his brother, his was 'not too bad.' For Simon, social comparison also provided some sense of solace:

> *And it is frustrating and it does make you feel useless, because you make such a*
> *glaring mistake (laughs), you know, a juvenile mistake… You do that 2 or 3 times a*
> *day, well then you do get down a bit. Then I think 'oh well I'm not like my brother in*
> *law' and so, I try and stay positive. (Simon, MCI)*

4.2 Normalising changes in memory. Bruce spoke about having his memory loss validated as other men in his social group also had the same kinds of experiences. He felt his condition was caused by age, and he appeared to find validation for his symptoms by comparing his experiences with others. This process seemed to alleviate the fear around his diagnosis, as in: 'You seem ok, so I must be ok':

> *I've got a few mates that are roughly the same age as me. And anytime I go and visit*
> *them, the conversations are all the same, you know. It's about remembering or*

forgetting things. And I say, 'Oh I'm glad I'm not the only one at least!' Which is

good! All the blokes the same age as me appear to go through the same problems.

(Bruce, CD-NOS)

Quantitative Results

All descriptive statistics are presented in Table 15 and 16. At group level, use of emotion-focused coping strategies diminished over time from T1 to T2 (emotional support, acceptance, positive reframing). Behavioural disengagement also diminished over time from T1 to T2. As a group, two illness perceptions (illness coherence and emotional representation) became stronger from T1 to T2.

Table. 15
Descriptive Statistics by Group Time 1 – Time 2

Subscale	Time One			Time Two			
	Mdn	*IQR 25*	*IQR 75*	*Mdn*	*IQR 25*	*IQR 75*	*r*
Emotion-Focused Coping							
Acceptance	8.00	5.50	8.00	6.00	4.75	7.25	**.58**
Emotional Support	6.00	5.75	8.00	4.50	4.00	6.50	**.85**
Positive Reframing	5.50	3.50	8.00	3.50	2.75	5.25	**.65**
Religion	2.00	2.00	3.50	2.00	2.00	4.75	0
Humour	7.00	3.50	8.00	5.50	3.50	6.00	.30
Problem-Focused Coping							
Active Coping	6.00	4.25	8.00	6.00	4.25	7.25	.24
Planning	6.00	4.50	7.00	6.00	4.50	6.00	.22
Instrumental Support	5.50	3.50	6.50	5.50	3.50	7.25	.11
Dysfunctional Coping							
Self-Distraction	5.50	2.75	6.50	5.50	3.50	7.25	.15
Venting	4.50	2.75	5.75	4.00	2.75	5.00	.28
Self-Blame	4.00	2.75	7.25	3.50	2.75	5.25	.44
Behavioural Disengagement	2.00	2.00	5.25	2.00	2.00	2.00	**.55**
Denial	3.00	2.00	5.75	2.50	2.00	4.25	.45
Substance Use	2.00	2.00	3.50	2.00	2.00	2.00	.41
Illness Perceptions							
Personal Control	3.10	2.35	3.65	3.50	2.75	3.65	.13
Treatment Control	3.25	3.00	3.54	3.42	3.13	4.00	.30
Illness Coherence	2.88	2.30	3.75	3.80	3.35	4.45	**.66**
Timeline Cyclical	3.08	2.38	3.63	2.13	1.75	3.88	.28
Emotional Representation	2.86	2.54	3.54	2.43	2.18	3.32	**.56**

Note. Boldface numbers indicate moderate (>.50) to large (>.80) effect size as per Cohen (1988). *IQR* = Interquartile range; *Mdn* = Median.

At T1, those with CD-NOS were more likely than those with MCI to use positive reframing in coping with diagnosis: $r = .81$. At T2, one notable finding was a tendency for people with MCI to self-blame more strongly than those with CD-NOS: $r = .81$. Results indicate that there were no large effect sizes with emotional representation for participants with CD-NOS compared to those with MCI at T1 ($r = .36$) or T2 ($r = .09$). There were, however, some differences in personal control at T1.

Table. 16
Descriptive Statistics by Diagnosis Time 1 – Time 2

Subscale	*Time One*				*Time Two*		
	MCI	CD	*r*		MCI	CD	*r*
	Mdn	*Mdn*			*Mdn*	*Mdn*	
Emotion-Focused Coping							
Acceptance	6.00	8.00	**.63**		5.00	7.00	.18
Emotional Support	6.00	8.00	**.67**		4.00	6.00	.47
Positive Reframing	4.00	8.00	**.81**		4.00	3.00	.09
Religion	2.00	2.00	.11		2.00	2.00	.11
Humour	4.00	7.00	.37		6.00	4.00	.47
Problem-Focused Coping							
Active Coping	5.00	8.00	**.73**		6.00	7.00	.45
Planning	6.00	6.00	.09		6.00	6.00	.11
Instrumental Support	4.00	6.00	**.54**		5.00	7.00	.44
Dysfunctional Coping							
Self-Distraction	3.00	6.00	**.54**		5.00	7.00	.44
Venting	3.00	5.00	**.81**		4.00	4.00	.09
Self-Blame	7.00	3.00	**.54**		5.00	3.00	**.81**
Behavioural Disengagement	2.00	2.00	.11		2.00	2.00	0
Denial	2.00	4.00	.29		2.00	3.00	.09
Substance Use	2.00	2.00	.41		2.00	2.00	0
Illness Perceptions							
Personal Control	2.40	3.40	**.80**		3.40	3.60	.36
Treatment Control	3.00	3.33	.27		3.83	3.33	.27
Illness Coherence	2.75	3.40	.27		4.20	3.40	.09
Timeline Cyclical	2.67	3.50	.09		2.00	2.25	.09
Emotional Representation	2.57	3.14	.36		2.29	2.57	.09

Note. Boldface numbers indicate moderate to large effect size as per Cohen (1988). CD = cognitive disorder not otherwise specified; *IQR* = Interquartile range; MCI = mild cognitive impairment; *Mdn* = Median.

Discussion

Recent research highlighted clients' experiences of being worried, concerned, and anxious during assessment for cognitive impairment and dementia (Samsi et al., 2013). In the current study, participants gave a slightly different impression of being assessed. Some

participants reported surprise and disagreement with their diagnosing practitioner on the cause of their memory decline. Others wanted more general information about the type of syndrome they had been diagnosed with.

In the six months following initial diagnosis, many managed feelings of uncertainty with expressions of hope, optimism, social comparison, and implementing cognitive strategies that their practitioner had recommended. Across both time-points, participants tended to make sense of their diagnosis more strongly in terms of long held beliefs, rather than information they received clinically about the nature of cognition. Participants diagnosed with CD-NOS (more than those with MCI) attributed the onset of their memory loss to other health-related events, as opposed to potential neuropathology. This may explain the relative absence of fear and shock subsequent to diagnosis itself. Though CD-NOS is used to label symptoms of MCI in some settings in NZ, the way participants made sense of this label in our sample was subtly different to how participants reconciled the meaning of the label of MCI (perhaps health threat vs non-health threat).

One of the aims of this study was to examine how people cope in the first six months following their cognitive impairment diagnosis. An early study on the impact of MCI held that a "person's self-concept is fundamentally assaulted when given the powerful label of a diagnosis of MCI" (Corner & Bond, 2004, p. 9). In our study, although coping responses following MCI and CD-NOS diagnosis were complex and varied, participants did not report a dramatic identity shift. Four people in the study were diagnosed explicitly with the label of MCI, and all four described a process of coming to terms with this diagnosis. This was mainly tied to symptom experience, other illnesses, and conceptualising MCI as a premorbid syndrome of AD.

As with early research on MCI and AD diagnosis (Carpenter et al., 2008), none of the nine participants reported experiencing a catastrophic response to their diagnosis. Perhaps

one of the reasons for this was an underlying sense of control many described during their process of coping and implementing of health promotion strategies. In cases of non-specific health concerns, individuals may use proactive coping strategies to minimise their risk of developing disease in the future (Aspinwall, 2011). This could explain the propensity for some of the study participants to engage in strategies such as: reducing alcohol intake, taking part in more physical exercise, and engaging in cognitively stimulating activities, in order to maintain or improve their cognitive health.

Participants' responses to diagnosis did reveal some themes that were similar regardless of whether they were diagnosed with MCI or CD-NOS. Many were relieved their diagnosis was not AD, but fear they could progress. Many were hopeful they would stay the same or improve. On the other hand, there were some qualitative differences in processing a diagnosis of MCI versus CD-NOS. Considering MCI has gone by many labels in the past and that these labels may be interpreted differently, reaction to these diagnostic terms warrants further investigation.

Throughout this study, further understanding was sought on what influences the way a person feels about their diagnosis. Lingler et al. (2006) highlight the effect that having a personal experience of dementia can have on how a person feels about MCI. We found participants with personal experience *and* symptom awareness seemed to associate more with a fear of progressing to AD, than those who had a personal experience alone. It may be beneficial for practitioners to ask about their clients' familiarity of dementia, in order to gain an impression of how they may interpret their MCI diagnosis. This also reinforces the importance of clinical follow-up in the event of further cognitive decline.

One of the arguments in support of clinically delivering MCI diagnosis is that it gives clients a chance to prepare for the future should further cognitive decline occur (Knopman & Petersen, 2014). One of the participants *clearly* used the diagnosis of MCI to prepare for the

future, in case of further decline. He had a family member with AD and had experienced

further memory loss since his MCI diagnosis. He *hoped* not to develop AD, but reported

feeling prepared should it ever happen. For many other participants, receiving a cognitive

impairment diagnosis was beneficial, as it drew attention and gave access to further

information about strategies for maintaining cognitive health.

It is worth noting that in conducting the quantitative analysis for this study, certain

aspects of "dysfunctional coping" were positively associated with emotion-focused and

problem-focused coping, suggesting that certain "unhelpful" coping strategies were actually

helpful (i.e., venting about the diagnosis to others, using self-distraction as a means of

coping). Some international literature on coping with MCI defines venting and self-

distraction as a dysfunctional coping behaviour, yet in our sample, this was associated with

adaptive coping behaviour (active coping) and mental health. This finding could be a cultural

artefact, characterising the way that older adults cope with healthcare threats in NZ. No such

research currently exists to the author's knowledge. Characteristics of NZ national identity

have been described elsewhere as "laid back", with a "she'll be right" approach to health-

related matters (Braun, 2008, p. 1819). The possibility of a unique coping style in the baby

boomer generation in NZ warrants further consideration.

Potential clinical utility of findings. Further research with a more representative

sample may enhance the potential clinical utility of study findings. In considering that several

participants blamed themselves for their diagnosis, information sharing between practitioners

and clients will likely have a beneficial impact on how clients appraise their diagnosis. As

one participant demonstrated in this study, in the absence of further information on his

diagnosis, he felt being diagnosed with MCI was like being told "this is the beginning of the

end". Addressing MCI causes and prognosis with clients following diagnosis may enhance

optimism, and eliminate the tendency to internalise feelings of self-blame in the development of their cognitive symptoms.

       Limitations and future recommendations. This study has a number of strengths; although, several limitations must be noted. One clear limitation pertains to demographic diversity, which was minimal in this study. NZ is a melting pot of different cultures, beliefs and ethnicities; thus, it is essential to understand the meaning of memory loss from the perspective of individuals with various cultural backgrounds. Lin and Heidrich (2012) also suggest that future researchers consider a purposive sampling strategy to gain detailed insight into experiences of MCI for individuals with varying backgrounds. Participants were recruited from specialist older adult mental health services; therefore, their experiences may differ from those diagnosed with MCI in primary care. Finally, Smith and Osborn (2008) point out that a sample in IPA research is often defined by those who are prepared to participate. As such, four potential participants declined to take part due to ill health, perceived conflict of interest, and not being interested. These individuals could have added further to the overall findings than those in the current sample, who seemed to be coping with their diagnosis.

       This study was designed to examine experiences of people with MCI and CD-NOS; however, over the course of conducting the interviews with participants, it was evident spouses were *also* deeply affected by diagnosis. Past research has examined experiences of spouses and caregivers following MCI diagnosis (for review, see Seeher, Low, Reppermund, & Brodaty, 2013). Unfortunately, this was not possible in the current research design but would have been valuable to explore further. Others have suggested including informant account as a way of triangulating perspectives of diagnosis (Roberts & Clare, 2013) and verification (Joosten-Weyn Banningh et al., 2008). A recent pilot study in NZ found that carers for people with MCI were more likely to experience distress than carers for people

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with dementia (Boyd et al., 2015); therefore, future research should include spousal perspective on the emotional impact of their family member's MCI diagnosis.

This study is the first to our knowledge, to investigate clients' experiences of initial diagnosis and subsequent coping responses across two different time-points. Examining participants' experiences over time provided further insight into influential factors on diagnosis experience and coping behaviours. It is also the first study to examine clients' experiences of MCI diagnosis in NZ.

MASSEY UNIVERSITY
GRADUATE RESEARCH SCHOOL

**STATEMENT OF CONTRIBUTION
TO DOCTORAL THESIS CONTAINING PUBLICATIONS**

(To appear at the end of each thesis chapter/section/appendix submitted as an article/paper or collected as an appendix at the end of the thesis)

We, the candidate and the candidate's Principal Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

Name of Candidate: Alison McKinlay

Name/Title of Principal Supervisor: Prof Janet Leathem

Name of Published Research Output and full reference:

McKinlay, AR., Leathem, J., & Merrick, P. (submitted). Coping and Illness Representations in a Clinical Sample Diagnosed with Mild Cognitive Impairment and Cognitive Disorder Not Otherwise Specified.

In which Chapter is the Published Work: Chapter Nine

Please indicate either:

- The percentage of the Published Work that was contributed by the candidate:
  and / or
- Describe the contribution that the candidate has made to the Published Work:

  AM conducted the study under supervision of primary and secondary supervisors.

A McKinlay _Digitally signed by A McKinlay Date: 2015.10.25 14:35:20 Z_

Candidate's Signature

25/10/15

Date

Janet Leathem _Digitally signed by Janet Leathem Date: 2015.10.27 09:33:24 +13'00'_

Principal Supervisor's signature

27/10/15

Date

GRS Version 3– 16 September 2011

One of the advantages of collecting data from different sources is the ability to give insight into different aspects of the same phenomenon (Teddlie & Tashakkori, 2011). During the course of this thesis, specialist practitioners were asked about their practices when diagnosing cognitive impairment, including what they felt was helpful or unhelpful for their clients during diagnosis. In a subsequent study, clients of three DHBs were asked what they felt was helpful and unhelpful during their diagnosis experience. Clients were asked to share their experiences of how they coped in the six months following cognitive impairment diagnosis. Quantitative data was also examined on objective measures of coping and illness perceptions. The final chapter of this thesis will present key findings of all results, highlight contributions of the research, comment on study limitations, and provide suggestions for future research.

10.1 Overall Findings

Frequency of MCI diagnosis. In considering the broader picture from Study One, MCI was diagnosed by many practitioners in our practitioner sample (84% in the past year). However, over the course of recruitment for Study Two, MCI did not appear to be diagnosed *frequently* in the memory services involved with the research. Consequently, a much smaller number of people were diagnosed specifically with MCI during recruitment than expected. One of the reasons for this was that MCI is often given a number of different labels in clinical practice. The label used during diagnosis varies across DHB regions, as indicated by Study One and Study Two. Diagnostic labels include: age-associated cognitive decline, early dementia or early AD, and CD-NOS.

Need for follow-up and information. In Study One, practitioners were asked what they believed was helpful to their clients during diagnosis delivery. Responses included that diagnosis gives clients an opportunity to prepare for the future, access to support services and information, reassurance, and explanation on test results and prognosis. Written information and follow-up did not appear in many participants responses. In Study Two, several participants wanted *more* information on their diagnosis (despite several receiving an information sheet) and *less* time between follow-up appointments. One spouse commented on feeling in "limbo" until they were able to see the practitioner again after initial diagnosis. Taken together, these findings suggest an area that can be amended to better serve clients experiencing diagnosis.

10.2 Key Findings from Study One

Possible tensions with MCI diagnostic label. Ten years ago, Dubois and Albert (2004) discussed the potential clinical utility of MCI as a syndrome in practice. They highlight how the clinical value of the diagnosis is only evident when prognostic information can be offered. "To isolate and label a syndrome with multiple potential causes is clinically irrelevant" (Dubois & Albert, 2004, p. 247). Results from Study One suggest that cognitive impairment diagnosis is helpful because it allows clients to prepare for the future and speak with a professional about their memory-related concerns. Although Study One findings did not indicate major contention with the MCI diagnostic label, this was not an issue that was directly examined in this study and could be more thoroughly assessed in future research. Some of the general comments provided in response to the study highlight how the label is used cautiously. This comment below seems to reinforce the importance of diagnosis, but suggests the label is of less consequence than information and support.

While making a diagnosis is important for us as it informs management/prognosis, for

the patient, the label is of less value than practical strategies to address the problem

and minimise the impact it has on their life - participant, Study One.

This comment also points to caution with use of the label:

MCI and dementia are very different, and with the possibility that people with MCI

return to normal cognition I think that most clinicians appreciate that a

neurodegenerative diagnosis can't (and shouldn't) be given unless there are strong

predictive factors present... - participant, Study One.

Given that dementia-related public policy is aimed at supporting diagnosis and early

intervention, more needs to be done to clarify the usefulness of the MCI label in identifying

those who do go on to develop dementia. It would be beneficial to speak further with

clinicians (both within specialist and primary care settings) on issues relating to intervening

when cognitive symptoms first manifest.

10.3 Key Findings from Study Two

  Negotiating diagnostic uncertainty through interaction. For several participants in

Study Two, interactions with healthcare services were salient in how they processed their

diagnosis. Several participants made sense of their experience based on what their diagnosing

practitioner had told them. Thus, information shared during diagnosis delivery can be a

source of comfort to those grappling with the uncertainty of cognitive impairment diagnosis.

The finding that participants trusted their practitioner (despite at times disagreeing!) fits with

an existing discourse in the health literature that "one should trust the doctor" or "doctor

knows best" (see Haug, 1979, for discussion). In considering that culture and time may

influence how older adults experience health and illness (see Chapter Two), it was thought

that topics such as the internet as a source of information would appear more frequently in the

scripts of those making sense of their memory impairment. This was not observed in the Study Two sample.

Access to information following diagnosis. In Study Two, many participants described their diagnosis as being unrelated or different from a diagnosis of AD. Due to this difference, some felt that they did not have access to the same information as they would have with a chronic illness. Cognitive health, CD-NOS, and MCI may represent a gap in widely available public health literature compared with more established conditions such as AD or Parkinson's disease. In Study One, 55.8% of practitioners provided clients with information on support services such as Alzheimer's NZ and the Parkinsonism Society of NZ. However, in Study Two, one participant described knowing about organisations such as Alzheimer's NZ but feeling because MCI was *different,* they may not be able to recommend appropriate support services:

> *I'd like to talk to someone else, who has a husband, and see how they're coping and what they do. And I suppose if I rang the Alzheimer's they can put me through, and it's not as though he's got Alzheimer's, but there must be others who's going through what I'm going through…* – Spouse of client with MCI, Study Two.

This quote points to a desire for specific information regarding MCI in healthcare services and organisations involved with older adult healthcare and advocacy. Participants with CD-NOS also reported wanting more information on how to maintain cognitive health. Many participants in Study Two commented that cognitive health was an area of wellbeing they were unaware of prior to diagnosis.

Proactive coping and feeling in control. Results from Study Two reinforce the international literature, which argues that a carefully delivered cognitive impairment diagnosis is valuable in clinical practice. Moreover, the experience of MCI and CD-NOS

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diagnosis was helpful amongst the study sample, because it drew attention to an area of health that participants reported not knowing about prior to diagnosis. In this sense, the event of diagnosis prompted an increase in proactive coping behaviour (i.e., health promotion activities; see Aspinwall, 2011) in attempt to maintain cognitive health. The wider literature in health psychology also acknowledges how feelings on optimism and feeling in control can have a significant impact on both physical and mental health (Conversano et al., 2010). In Study Two, although many wanted more information, those that were recommended strategies for maintaining cognitive health (e.g., exercise, balanced diet) felt positive about their prognosis. This highlights how feeling in control can be a powerful resource in psychosocial coping with potential healthcare threats.

10.4 Contribution of the Research

Struggling with MCI diagnosis. In Study Two, where participants were interviewed twice in the first six months of initial diagnosis, results indicate that some participants *did* report struggling with their diagnosis; however, this experience of struggle was transient and changed between interviews. Perceptions of MCI were influenced by factors beyond the uncertainty associated with the label itself. This finding contributes to the international literature, which focuses on the uncertainty of the diagnostic label, rather than the individual and their own unique circumstances beyond the MCI diagnosis.

MCI diagnosis as an illness entity. In the scientific literature, the label of MCI may carry an assumption of underlying pathology (Ritchie et al., 2001). Although, results from Study Two indicate the same cannot be said for all clients receiving this diagnosis in everyday practice. On the one hand, one participant did conceptualise his diagnosis as the early signs of dementia, so feelings of grief, anger, and self-blame were discussed in his initial interview held one month after diagnosis. Under the illness perception model, MCI diagnosis is perceived as a healthcare threat or illness, which is associated with distress,

which might explain this response. By his second interview, this participant spoke of "fighting back" and taking an active approach in maintaining his cognitive health. This finding also fits with research on coping with early stage dementia (e.g., Clare, 2002), which indicates perception of MCI as an illness entity or health threat. In this instance, a diagnosis of MCI *was* paralleled with a diagnosis of AD.

On the other hand, the scripts of most participants involved with Study Two suggest their diagnosis was *not* appraised as an illness or health threat. This finding contributes to the international research on the theory of coping with MCI. The CSM has previously been utilized to explain chronic illness experience, which for many people, MCI is not. In speaking with participants about what MCI and CD-NOS diagnosis means to them, one person asked: "Is cognitive impairment an illness?" Another participant stated that until any further symptoms presented, it was "business as usual". This suggests that these diagnoses are not conceptualized as early AD by all.

Looking beyond the diagnostic label. Study Two highlighted how numerous factors influence how an individual feels about their diagnosis. One participant with MCI reported feeling as though she could not cope in her first interview. She was trying to manage several other chronic healthcare conditions. As the symptoms of these other illnesses abated, and she had not observed any instances of memory loss, any initial psychosocial distress tied to her MCI diagnosis had gone by her second interview, three months later. Other participants discussed their situation in terms of comparing themselves to other people, both as a source of fear (i.e., in cases where it was hoped they would not develop AD as a family member had) and reassurance (i.e., comparing ability level to others in their social group). Under the traditional stress and coping, or illness appraisal models, the propensity to draw social comparisons in this way is not accounted for (Cruikshank, 1992). This suggests additional theoretical considerations with reference to early stage cognitive impairment diagnosis.

Contribution to the theory. Study Two was carried out with the intention of adding to the international literature on the theory attributed to making sense of an MCI diagnosis. As a result of the analysis and research process, it was evident that factors influence coping behaviour that go beyond appraisal of the MCI/CD-NOS diagnostic label and subsequent "illness" representation. In the transcripts of those who reported struggling with diagnosis, many noted a complex interaction of external factors such as: changes in lifestyle (e.g., following retirement), presence of other illnesses, personality style, comparison with others, and insight into memory loss. For some, the process of retiring is associated with considerable changes in identity, coping behaviour, and psychosocial wellbeing (Osborne, 2012). In future research on the theory of coping with MCI, it would be prudent to consider wider lifestyle elements likely to impact and interact with diagnosis reaction.

In considering some of the findings from Study Two, it may be that any potential health threat associated with the diagnosis itself was perceived as ambiguous. In circumstances where the threat is ambiguous, the role of individual factors becomes more salient in appraisal of an event (Lazarus & Folkman, 1984). Together, the findings from Study Two highlight need for further consideration regarding the theory used to conceptualise MCI diagnosis reaction. Perhaps theory which focuses on the *individual* can offer more insight into psychosocial responses following cognitive impairment diagnosis, as opposed to the CSM, which focuses on one singular health threat. One such theory described in Chapter Six may provide an explanation for those diagnosed with CD-NOS and MCI in Study Two and is discussed below.

Model of individual meaning making. Another model in the health psychology field may explain instances of those who cope reasonably well with their cognitive impairment diagnosis. Menne and colleagues (2002) discuss Atchley's continuity theory (1989, refer Chapter Two) in explaining how people cope with memory loss in early dementia. They were

the first (and only) researchers to reference Park and Folkman's (1997) model of individual meaning making, which focuses less on the illness, and more on the individual. Under this model, coping strategies from earlier in life and engagement with the environment are proposed to inform how a person responds in the earliest stages of dementia (Menne et al., 2002). This framework may explain the tendency for some participants in Study Two to compare their ability to that of friends and family, as a way of coping and processing information. Several participants noted how other events in their life (i.e., other chronic illnesses and changes in life circumstances) influenced how they felt about and responded to their cognitive impairment diagnosis. It may be that those who were experiencing other life stressors were using the same coping behaviour in responding to their MCI/CD-NOS diagnosis. If so, this indicates that self-appraisal of diagnosis is impacted by other sources in addition to the initial potential health threat.

10.5 Limitations of the Research

Over the past five years, there has been increasing emphasis on early identification of MCI in primary care. Prior to this, specialist assessment would typically take place at memory clinic or specialist service. Study One invited practitioners in specialist assessment services, while practitioners in primary care were not directly approached. This population would have, no doubt, added a further dimension to study findings reported in Chapter Eight. We explored the possibility of including a GP-focused study in this thesis; however, time restrictions would not allow for an additional research project. Given the need for primary care physicians to identify, monitor, and care for those with mild memory impairment, it is essential for this sector to be supported and resourced. The findings from Study Two may be of use to primary care physicians providing information, referral, and perhaps cognitive impairment assessment. Future research involving primary care is needed, particularly as

these services are where individuals with MCI are most likely to be identified in the first instance.

The primary focus of this thesis was a phenomenological account of MCI and CD-NOS diagnosis. This approach enabled an enriched description of individual experience (Creswell, 2015; Bowling, 2014). Broadly speaking, the client-focused study of the thesis suffered from many of the limitations experienced by past researchers (refer Table 6, Chapter Six), with regard to small sample size and demographically homogenous samples. As a qualitative study, a sample size of nine people is acceptable (Teddlie & Tashakkori, 2009); however, for a quantitative study, such small numbers will struggle to meet parametric assumptions of normality and statistical significance. The generalisability of Study Two is limited in this regard. Several attempts were made to increase sample size by contacting additional memory services in Auckland. As it was, four DHBs agreed to assist with recruitment which required four individual ethics applications to the research office of each region.

A strength of Study Two was a discussion on practices during cognitive impairment diagnosis at three DHBs across the North Island. In this sense, we were able to highlight various approaches in practice with clinical follow-up, information provision, and intervention (i.e., pharmacologic and cognitive). On the other hand, given the considerable variation in diagnostic criteria and label, it is difficult to make conclusive statements beyond the immediate sample. It is likely that the experiences of those in our sample would be very different from a sample with a singular diagnostic category (e.g., aMCI). Study Two criteria did not require a specific subtype of cognitive impairment in order to participate – the sample size may have been further restricted had eligibility criteria been stricter (e.g., aMCI only).

Small sample sizes are a common difficulty in clinical research that relies on specialist referral. Despite challenges with recruitment, the presence of a high effect size

throughout Chapter Nine indicates 'practical significance' (Rosenthal, Rosnow, & Rubin, 2000), where findings may be of clinical importance. Thus, further research with a larger sample is advisable. In evaluating differences in participants' responses in Chapter Nine, it appeared factors such as symptom experience, existing illnesses, and past experience of dementia seemed influential in experiences of distress.

The construct of MCI is undergoing continual change, and as such, several key changes occurred throughout the conducting of this thesis. For instance, the *DSM-V* was released with mNCD as a diagnostic category (APA, 2013) in place of MCI, and the *New Zealand Framework for Dementia Care* (MOH, 2013) was published, which recommends MCI identification in primary care. Moreover, published studies support the utility of the CSM model (i.e., Lin & Heidrich, 2012; Morgan et al., 2013) as this thesis was being designed to evaluate this very topic. As such, elements of Study Two were modified (e.g., version of IPQ used in Study Two), in order to incorporate the most up to date knowledge and build on existing literature.

10.6 Suggestions for Future Research

It is important for researchers to continue to examine practices regarding dementia and cognitive impairment diagnosis. In 2004, Winblad and colleagues discussed the importance of management and monitoring in clients presenting with cognitive complaints at both primary and specialist care services. It is important for GPs and other primary care professionals to have access to knowledge and support to identify those at risk of developing dementia, MCI, and other forms of cognitive impairment (Langa & Levine, 2014). With the dementia pathways being implemented at various DHBs, it is likely that the landscape of cognitive impairment diagnosis will continue to evolve as feedback is incorporated into practice. In addition to these developments in dementia and cognitive impairment care, there is value in continuing to investigate ways of supporting those living with mild memory loss.

Identifying barriers in reaching diagnosis. Study One offers a platform for future research with practitioners diagnosing cognitive impairment. If early detection and intervention are goals of current national and international policy, practitioners will need to be supported to accurately identify mild cognitive decline in everyday practice. One recommendation from Study One is to conduct more detailed research into practitioners' beliefs on MCI diagnosis. Focus groups and semi-structured interviews may be a suitable method of accessing such information. This may help identify barriers or tensions with use of any pre-dementia label used in DHB settings (e.g., mNCD or MCI).

Including spouses and families. Although the focus of this research was on clients and their experiences of cognitive impairment diagnosis, spouses and other whanau were invited to attend interviews in support of their family member. In meeting with participants' spouses, it was clear the experience of MCI and CD-NOS is related to their emotional wellbeing also. A plethora of research has been dedicated to the mental health of spouses and caregivers of individuals with dementia; however, far less published literature in comparison has examined spousal perspectives on MCI. As highlighted by a recent systematic review, literature on experiences of caregiving for people with MCI is in early stages (Seeher et al., 2013). "We highlight the importance of recognizing 'early' caregivers as a group at high risk for negative psychosocial outcomes, particularly in clinical settings such as memory clinics or hospital outpatient departments. Apart from depressive symptoms, negative caregiver outcomes have been vastly neglected in the context of MCI." (Seeher et al., 2013, p. 353). Future research in NZ should include spouses, family, and caregivers from numerous regions, in order to gain a representative impression on the kind resources, information, and support services that they would find helpful.

Theoretical research. Future qualitative research on coping with cognitive impairment could examine the utility of this model further. Given the interest in the

individual under the Park and Folkman (1997) model, an idiographic case-study could be an effective method for gaining insight into the utility of this model in cases of MCI diagnosis. The qualitative methodology employed in Study Two provided a suitable framework for examining the experiences of individuals diagnosed with MCI and CD-NOS. IPA also suited the purpose of examining experiences of health-related diagnosis.

It is worth noting here that future researchers may wish to examine cases of MCI and other diagnostic labels such as CD-NOS separately. With considerable variation in diagnostic labels and criteria, this made it difficult to analyse clients' experiences as a group in Study Two. Due to difficulties with recruitment and a reliance of specialist referral, it was a challenge to obtain a sample suitable for group level analysis with the same label. With the degree of variability in dimensions of this condition between regions of NZ, transcripts might have been able to be analysed in a more in-depth, idiographic IPA case-study style paper.

10.7 Concluding Comments

There is urgent need for evidence-based dementia research in NZ. This thesis has contributed to the literature by providing an impression of diagnostic processes and experiences with two NZ samples involving numerous DHBs. Recent initiatives such as the *New Zealand Framework for Dementia Care* (Ministry of Health, 2013) have sought to provide consistent practice guidelines for dementia care in NZ. One of the focus points of this document was a recognition that cognitive impairment be identified early in primary care. Within this setting, MCI can be monitored in case of further decline. Initiatives such as the care pathway will not be without challenges, as highlighted by some of the feedback from Study One:

> *"I know there is a need to have more dementia diagnosed and managed in primary*
>
> *care. I am not clear on how primary care will be resourced to do this, as the*

diagnostic process is time consuming and does not fit well into 15 min consults that

the patient has to seek out and pay for!" participant, Study One.

Thus, it is valuable to continue to investigate means of supporting practitioners involved with early identification and diagnosis.

With trends in population ageing, healthcare systems are likely to face new challenges as the number of older adults is set to peak in the coming years. AD is a highly feared disease associated with older adulthood, and for some, MCI is a label that prompts a similar response. Given that being diagnosed with MCI does not guarantee an eventual dementia diagnosis, the results from this thesis stress the importance of information sharing between the practitioner and client. This may reduce some of the self-blame and distress observed in the scripts of those involved with Study Two. In the general population, the prognosis for many diagnosed with MCI can be a return to normal cognitive function, or a stability of symptoms. This is a noteworthy discussion point for clinicians to share with their clients with during diagnosis delivery.

At the outset of this thesis, the studies were designed with an assumption that early detection and accurate MCI diagnosis provides an opportunity for the person being diagnosed to gain access to disease-modifying intervention, as well as a chance to prepare for the future. However, the literature highlights mixed efficacy of intervention with MCI and not all of those with MCI will experience further decline. While a diagnosis is beneficial in cases of underlying pathology, what about those who revert back to normal function? Clearly, more needs to be clarified with regard to the pathological trajectory of cognitive impairment, in order for those with pre-AD to be correctly identified, so that those without are not falsely labeled.

As outlined throughout this thesis, academic literature on dementia and cognitive ageing is developing rapidly. As a result, it is difficult to know which lifestyle factors are

protective against or predisposing to cognitive decline. For instance, following a review published in *Nature Clinical Practice Neurology,* authors proposed that a diet with omega-3 fatty acids may offer neuroprotective benefits against cognitive decline (Fotuhi, Mohassel, & Yaffe, 2009). However, in the final weeks before submitting this thesis, a major longitudinal study was published in the *Journal of the American Medical Association (JAMA),* which reported no statistically significant effects of omega-3 supplements on brain health (Chew et al., 2015). This finding has implications for health-related behaviour of older adults hoping to stave off cognitive decline, and practitioners who currently recommend omega-3 supplements to their older clients for maintaining cognitive health. On the other hand, future research could find new evidence to support the use of omega-3 supplements, and healthcare recommendations may change again. For the individual navigating their way through health promotion literature, such variation in research findings may result in confusion and a lack of action to protect cognitive health.

Published literature on diagnosis of cognitive impairment in NZ is scarce, yet the number of adults entering the 65 years and over age category is increasing as the baby boom generation matures. In order to better meet the healthcare needs of this growing population, research must be conducted to reduce the gap between published literature and clinical practice. The benefits of evidence-based practice rely on the most effective techniques used in everyday practice being represented in the literature. Until knowledge has advanced with respect to prodromal dementia and early stages of cognitive impairment, MCI is likely to remain a diagnosis that is approached with caution (and perhaps apprehension) in clinical practice.

Appendix 1: MUHEC Ethics Approval

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

29 May 2012

Alison McKinlay
School of Psychology
ALBANY

Dear Alison

Re: HEC: Southern B Application – 12/07
Practitioners' processes and attitudes regarding the diagnosis of cognitive impairment

Thank you for your letter dated 28 May 2012.

On behalf of the Massey University Human Ethics Committee: Southern B I am pleased to advise you that the ethics of your application are now approved. Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Dr Nathan Matthews, Chair
Massey University Human Ethics Committee: Southern B

cc   Prof Janet Leathem   A/Prof Paul Merrick
     School of Psychology   School of Psychology
     WELLINGTON   **ALBANY**

     A/Prof Mandy Morgan, HoS
     School of Psychology
     PN320

Massey University Human Ethics Committee
Accredited by the Health Research Council

Research Ethics Office, Massey University, Private Bag 11222, Palmerston North 4442, New Zealand
T +64 6 350 5573 +64 6 350 5575 **F** +64 6 350 5622
E humanethics@massey.ac.nz animalethics@massey.ac.nz gtc@massey.ac.nz
www.massey.ac.nz

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Appendix 2: Study One Online Questionnaire

Section A – General Demographic Information

A.1 Your professional field (select most relevant)?

1. Psychology
2. Clinical Psychology
3. Psychiatry
4. Neuropsychology
5. Neurology
6. Geriatrics
7. Other _____ (please state)

A. 2 Number of years of clinical experience you have in assessing or diagnosing people with cognitive impairment?

1. Less than 1 year
2. 1-5 years
3. 5-10 years
4. 10-15 years
5. More than 15 years

A. 3 Gender?

1. Female
2. Male
3. Prefer not to say

A. 4 Region of New Zealand in which you practice (select those that apply)?

1. Northland
2. Auckland
3. Waikato
4. Bay of Plenty
5. Gisborne
6. Hawkes Bay
7. Taranaki
8. Manawatu
9. Wellington
10. Nelson
11. Malborough
12. West Coast
13. Canterbury
14. Otago
15. Southland
16. Multiple regions

17. Overseas
18. Prefer not to say

Section B – Clinical Tools Involved with Diagnosis

B. 1 What types of cognitive impairment have you assessed or diagnosed in the past 12 months? (Select all that apply)

1. Age-related Cognitive Impairment
2. Vascular Dementia
3. Lewy Body Dementia
4. Frontotemporal Dementia
5. Alzheimer's Disease
6. Mild Cognitive Impairment
7. Subjective Memory Complaints
8. Psychopathology related Cognitive Impairment (i.e., depression, delirium, psychosis)
9. Drug and Alcohol related Cognitive Impairment
10. Cognitive Impairment due to acquired brain injury
11. Other Neurological Disorder (i.e., stroke)

B. 2 Which of the following screening instruments do you use to assess and diagnose cognitive functioning? (Select as many as applicable).

	None of the time	Some of the time	Most of the time	Always
MMSE (Mini-Mental State Examination)				
3MS (Modified Mini-Mental State Examination)				
CASI (Cognitive Abilities Screening Instrument)				
FAS (Verbal Fluency Test)				
CDT (Clock Drawing Test)				
MEAMS (Middlesex Examination of Mental State)				
MoCA (Montreal Cognitive Assessment)				
ACE-R (Addenbrook's Cognitive Examination – Revised)				
RMBT (Rivermead Behavioural Memory Test)				
RBANS (Repeatable Battery for the Assessment of Neuropsychological Status)				
3WR (Three Word Recall)				
TMT (Trail Making Test)				
7MS (7-Minute Screen)				
ABCS (AB Cognitive Screen)				
CAST (Cognitive Assessment Screening				

Test)				
AMT (Abbreviated Mental Test)				
DECO (Deterioration Cognitive Observee)				
DQ (Dementia Questionnaire)				
HVLT (Hopkins Verbal Learning Test)				
IQCODE (Information Questionnaire on Cognitive Decline in Elderly)				
IQCODE-SF (IQCODE – Short form)				
Mini-Cog				
MIS (Memory Impairment Screen)				
NCSE (Neurobehavioural Cognitive Status Examination, also known as Cogistat)				
SPMSQ (Short Portable Mental Status Questionnaire)				
T&C (Time and Change)				
Other (Please specify)				

B. 3 What information <u>other than cognitive test scores</u> is used in the process of reaching a diagnosis?

	Never	Some of the time/ Rarely	Most of the time	Always
Client's health records				
Brain scan (CT) results				
Brain Scan (MRI) results				
Brain scan (PET or other) results				
Client interview (with or without family/friend/caregiver present)				
Personal visit at the Client's home				
Informant information (family, friends, caregivers)				
Other information used in your observation (Please specify)_____				

B. 4 What other professionals do you liaise with during the process of reaching a diagnosis? And what type of support do they provide?

Professional	Client History	Cognitive Testing	Neuro Imaging or Brain Scanning	Client support/ Follow-up assistance	Other (please state)
Psychologist					
Clinical Psychologist					

Psychiatrist					
Neuropsychologist					
Neurologist					
Radiologist					
Geriatrician					
Social Worker					
Counsellor					
General Practitioner					
Others _____ _____					

B. 5 If you could list the processes you follow when reaching a diagnosis (including the contact you make with other healthcare professionals) in <u>up to ten key steps</u>, what would these be?

1. ____
2. ____
3. ____
4. ____
5. ____
6. ____
7. ____
8. ____
9. ____
10. ____

Comments:

B. 6 Who is present when this information is delivered to the client? (please select those that apply)

	Never	Sometimes	Usually	Always
You				
Client				
Immediate Family				
Other Health Professionals				
Extended Family				
Friends of the Client				
Caregiver(s)				
Other _____				

B. 7 What terms are used with the client and their family when relaying a diagnosis of MCI?

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	Never	Some times	Often
Mild Cognitive Impairment			
Early Dementia			
Subjective Memory Complaints			
Benign Forgetfulness			
Normal Ageing			
Age-Related Cognitive Decline			
Other, please specify _____			

B. 8 What information is presented to the client/family at the time of diagnosis?

	Never	Sometimes	Often	Always
Explanation of the test results, scans, etc				
Explanation of what cognitive impairment is				
Written summary of test results and findings				
Information on Disease Progression				
Information on Practical Aspects of the condition (i.e., medication, driving, etc)				
Information on Support Services (if so, what support services are recommended)? _____				
Follow-up appointment offered				
Written Information about Cognitive Impairment for the Client to take home				

Overall Comments:

Section C – Attitudes towards Diagnosis of Cognitive Impairment

C.1 Please rate importance of the following:

	Not Important	Somewhat Important	Very Important	Essential
Reaching a conclusive diagnosis				
Providing comfort and relief to the client and their loved ones				
Giving the client and/or their loved ones an 'answer'				
Meeting face to face with the client when delivering their				

diagnosis				
Using a cognitive screening instrument to reach a diagnosis				
Speaking with a family member, friend or caregiver at the time of diagnosis				
Having a follow-up appointment with the client to discuss their circumstances				
Being a source of support and guidance to the client and their family				
Keeping updated by other health professionals about the client				
Other important aspects:_____				

Comments:

C. 2 In what circumstances (if at all) would a diagnosis not be fully disclosed to a client or their family?

Comments:

C.3 What do you think the consequences of full diagnosis are for a client?

Comments:

C.4 In your opinion, what do clients and their family find helpful and unhelpful during the process of diagnosis?

Comments:	
Helpful	Unhelpful

Thank you for your time and assistance with this questionnaire. Your input and feedback is extremely valuable.

Overall Comments:

Are there any further comments you would like to add in response to this survey? Please note that general themes in the content may be written up in the research findings at the conclusion of data collection. If you wish to email me privately and confidentially, my email address is _____

Appendix 3: HDEC Ethics Approval 2013

Health and Disability Ethics Committees

Health and Disability Ethics Committees
Ministry of Health
1 the Terrace
PO Box 5013
Wellington
6011
0800 4 ETHICS
hdecs@moh.govt.nz

14 March 2013

Ms Alison Mckinlay

Dear Ms Mckinlay

Re:	Ethics ref:	12/NTA/67
	Study title:	How do older adults cope with a diagnosis of mild cognitive impairment

I am pleased to advise that this application has been _approved_ by the Northern A Health and Disability Ethics Committee. This decision was made through the HDEC-Full Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Northern A Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at any locality in New Zealand, all relevant regulatory approvals must be obtained.

2. Before the study commences at a given locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Participant access to ACC

The Northern A Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of

treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Brian Fergus
Chairperson
Northern A Health and Disability Ethics Committee

Appendix 4: HDEC Approved Progress Report 2014

Health
and
Disability
Ethics
Committees

02 April 2014

Ms Alison Mckinlay

Dear Ms Mckinlay

Re:	**Ethics ref:**	**12/NTA/67/AM01**
	Study title:	How do older adults cope with a diagnosis of mild cognitive impairment

This letter is to confirm approval of the annual progress report for this study, reviewed by the Chairperson of the Northern A Health and Disability Ethics Committee on 24 March 2014. Existing approval remains valid.

Your next progress report is due by 13 March 2015.

Please don't hesitate to contact us for further information.

Yours sincerely,

Dr Brian Fergus
Chairperson
Northern A Health and Disability Ethics Committee

Encl: appendix A: documents submitted

Appendix A
Documents submitted

Document	Version	Date
Report of the progress of the research project and minor change to questionnaires (removed one, updated another).	Progress Report	13 March 2014
Survey/questionnaire: Full schedule of questionnaires	Interview 1	13 March 2014
Survey/questionnaire: Full schedule of questionnaires	Interview 2	13 March 2014
Survey/questionnaire: Full schedule of questionnaires	Interview 3	13 March 2014
Supporting literature to warrant the update of IPQ questionnaire from general IPQ to specific IPQ-MCI	Journal Article	13 March 2014
Post Approval Form		18 March 2014

Appendix 5: HDEC Approved Progress Report 2015

Health and Disability Ethics Committees
20 Aitken Street
PO Box 5013
Wellington
0800 4 ETHICS
hdecs@moh.govt.nz

30 April 2015

Ms Alison Mckinlay

Dear Ms Mckinlay

Re:	**Ethics ref:**	**12/NTA/67/AM03**
	Study title:	How do older adults cope with a diagnosis of mild cognitive impairment

This letter is to confirm approval of the annual progress report for this study, reviewed by the Chairperson of the Northern A Health and Disability Ethics Committee on 21 April 2015. Existing approval remains valid.

Your **next progress report** is due by **13 March 2016.**

Please don't hesitate to contact us for further information.

Yours sincerely,

Dr Brian Fergus
Chairperson
Northern A Health and Disability Ethics Committee

Encl: appendix A: documents submitted

Appendix 6: Study Two Interview Confirmation Slip

How do Older Adults Cope with Mild Cognitive Impairment

Research Interview Confirmation Slip

Dear _____,

Thank you for agreeing to speak with me about my memory study. Your participation is greatly appreciated.

We have confirmed an interview for the following date, time and place:

Time:
Date:
Place:

You don't need to do anything to prepare, however, you are welcome to read over the attached questions that I've included with this letter to give you an idea of some of the topics that I would like to discuss. Depending on your circumstances, some may not be applicable. If there is anything that you do not wish to discuss, we may skip any topic or question at any time.

You are also welcome to have a support person with you, who might be interested in participating in the discussion if you wish them to. This is not compulsory and only a suggestion if this would make you feel more comfortable.

Also to let you know, our interview will be voice recorded so that I may transcribe the meeting later and won't be distracted by taking notes. The recording will be stored in a locked filling cabinet, in a locked room, for the course of the study. All recordings will remain confidential and at the end of the study all recordings will be destroyed.

If you have any queries or concerns, please do not hesitate to contact Alison or one of the other researchers on the contact details included in this letter.

Warm regards,

Alison McKinlay
PhD Student
School of Psychology | Massey University, Albany
PO BOX 102-904, NSMC | Auckland, New Zealand
Website: http://psychology.massey.ac.nz/

Interview One Agenda:

- Introduction of the study (written copy will be provided)

- Informed Consent/Confidentiality/Ethics (written copy also provided)

- Questionnaire

- Open ended questions - see below

Interview 1 Preparatory Questions:

What were some of the key events that lead you to seek professional help (e.g., GP visit, neurologist or psychologist consult) for the symptoms that you had observed?

Where there any barriers which prevented or delayed you from seeking a diagnosis (e.g., lack of healthcare services, fear)?

What was the situation when the diagnosis was relayed to you and your family? How was the diagnosis given to you?

When your diagnosis was given, what words were used to describe your memory problems if you can recall?

What were the emotions going through your head at the time that you learnt of the diagnosis?

What were your thoughts about what would happen in the future?

What did you know about cognitive impairment prior to your diagnosis?

What are your thoughts about the diagnosis now? What do you think will happen in the future?

Was there anything your healthcare services could have done or were doing that was helpful or of comfort?

In the first days following diagnosis, what was it like for you processing the news?

Were there any practical steps that you took as an individual and family to help overcome some of the difficulties of this condition? (e.g., using memory aids, seeking support, having in-home help, etc).

Contact Information:

Primary Researchers: Alison McKinlay (Ph.D student), Professor Janet Leathem, Associate Professor Paul Merrick.

Appendix 7: HDEC Conclusion of Study 2015

Health and Disability Ethics Committees

Health and Disability Ethics Committees
20 Aitken Street
PO Box 5013
Wellington
0800 4 ETHICS
hdecs@moh.govt.nz

29 June 2015

Ms Alison Mckinlay

Dear Ms Mckinlay

Re:	Ethics ref:	12/NTA/67/AM04
	Study title:	How do older adults cope with a diagnosis of mild cognitive impairment

I am pleased to advise that this notification of conclusion of study has been _approved_ by the Northern A Health and Disability Ethics Committee. This decision was made through the HDEC Expedited Review pathway.

A **final report** is due on **15 June 2016.**

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Dr Brian Fergus
Chairperson
Northern A Health and Disability Ethics Committee

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