

“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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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.

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List of Abbreviations

ACh	Acetylcholine
AChE	Acetylcholinesterase
AChEI	Acetylcholinesterase Inhibitor
ADL	Activities of daily living
aMCI	Amnesic 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-amnesic 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.

