

# Diagnostic Processes and Disclosure: A Survey of Practitioners Diagnosing Cognitive Impairment

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The literature reports widespread variation in practitioners' disclosure of a dementia diagnosis, though it is currently unclear what factors influence this difference in practice. 57 New Zealand based practitioners completed an online questionnaire relating to how they reach a diagnosis of cognitive impairment and under what circumstances (if any) a diagnosis might be withheld from a client. The findings indicate that a diagnosis of cognitive impairment is never completely withheld by practitioners. All qualitative responses were analysed using conventional content analysis. Practitioners noted more positive consequences associated with disclosing a diagnosis to their clients, suggesting that providing a diagnosis is perceived by practitioners as helpful for people experiencing cognitive impairment. This study adds to the field of ethics and diagnostic disclosure in that it highlights what specific factors are considered when a practitioner chooses how to relay a cognitive impairment diagnosis to their client. Such considerations include when disclosure conflicts with the clients wishes, lack of insight, and the presence of other illnesses. Ongoing research on the subject of disclosure is needed as the number of adults who will experience cognitive impairment is predicted to rise.

**Keywords:** cognitive impairment, diagnosis, disclosure, attitudes, ethics

The 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 ability 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 the realities of older age (Schneider & Yvon, 2013). For this reason, a diagnosis of dementia has been linked with stigma and fear (Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Phillipson, Magee, Jones, & Skladzien, 2012). As the numbers of those diagnosed with dementia increases (Portacolone, Berridge, Johnson, & Schick Tanz, 2014), the news of such a diagnosis has become significantly more feared than any other age-related health condition (Batsch & Mittelman, 2012). These reactions are fuelled 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 drivers 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, although 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 been an ongoing debate since 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, 5<sup>th</sup> Edition (DSM-5; American Psychiatric Association, 2013) has arguably added to the controversy, with terms such as dementia and mild cognitive impairment replaced with major and mild neurocognitive disorder (NCD; Breitner, 2014). Mild NCD is identified as a form of cognitive disorder which may or may not progress to dementia (Sachs-Ericsson & Blazer, 2014). 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; Peterson et

al., 2014) and the lack of peer reviewed literature in NZ relating to diagnostic issues around cognitive impairment, the present 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 that there is no “one size fits all” approach 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 that 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, if not impossible (Ilfie et al., 2009). Suicide rates are also higher in the elderly population in general (Ciripriani, 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 et al., 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 that 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. The objectives of this research were to shed light on how diagnosis of cognitive impairment is delivered in NZ, and to illustrate how practitioners delivering diagnoses feel about disclosure issues identified in the literature. The intention was to present results 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

This research examined the processes that practitioners follow when they reach a diagnosis of cognitive impairment. It also investigated their attitudes regarding delivery of diagnosis. Cross sectional information was gathered through an online, self-report questionnaire. Participants were asked about issues that have been

highlighted in international literature around disclosure of a diagnosis of dementia (Bamford et al., 2004; Cornett & Hall, 2008; Fisk, Beattie, Donnelly, Byszewski, & Molnar, 2007; Karnieli-Miller, Werner, Aharon-Peretz, & Eidelman, 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.

### Participant Recruitment

The process of recruitment was guided in part by a recently published NZ study which targeted a similar practitioner population (Strauss, Leatham, 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. At the time of study design, the aforementioned 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<sup>NZ</sup>, 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).

Inclusion criteria were that the practitioners were currently practicing in NZ and would have been involved in the diagnosis of 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.

**Participants**

Of the 57 practitioners who completed the online survey, participants were mostly from three major centres: Auckland, Wellington and Canterbury region. The majority of participants worked primarily in geriatrics (36.5%), followed by clinical psychology (25%), neuropsychology (13.5%) and psychiatry (11.5%). It is also possible that practitioners were involved in multiple professional fields. Although such professions were not specifically targeted during recruitment, two participants were nurses and one practiced internal medicine. Participants varied in levels of experience with diagnosing cognitive impairment: 32% had more than 15 years of experience, 24% had 1-5 years, 22% had 5-10 years, 18% had 10-15 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. Section A collected broad information on demographics and practitioner experience levels, whilst preserving anonymity of participants. 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?” The 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, through the inclusion of comment boxes throughout the questionnaire.

Several practitioners currently practising clinical psychology were consulted throughout the development of the questionnaire 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 version 21.

A combination of qualitative and quantitative information was collected. Data from sections A and B were described in terms of trends, and section C was analysed using conventional content analysis (Berg & Lune, 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 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 1 for an example of how this was approached.

The data was primarily coded by the lead researcher and checked by the study supervisor. 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.

**Ethical Considerations**

The research protocol for this study was reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 12/07.

**Results**

**Diagnosis Process**

Results indicate that of the 57 participants, 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%

Table 1

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	1. Follow up 2. 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	1. Support 2. Chance to have a discussion with a professional

Table 2  
*Screening Instruments Commonly used by Practitioners*

Measure	Always (%)	Most of the time (%)	Some of the time (%)	None of the time (%)
Clock Drawing Test	28.5	28.5	28.5	14
Three Word Recall	25	4	11	61
Mini-Mental State Examination	24	18	42	16
Verbal Fluency Test	20	17	23	40
Addenbrooke's Cognitive Examination – Revised	11	36	31	22
Montreal Cognitive Assessment	3	3	57	37

( $n=32$ ) frontotemporal dementia, and 54% ( $n=31$ ) had diagnosed cognitive impairment due to an acquired brain injury, in the previous year.

The number of available cognitive screening and assessment instruments is extensive; however, the most commonly reported instruments as rated by participants are reported in Table 2. Diagnosis of cognitive impairment *always* included a client interview (97%), client health care records (84%), and informant information (76%). Participants used computed tomography (CT) scan results *always* (37%) or *most of the time* (47%). A personal visit 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. Other professionals and organisations that practitioners were likely to liaise with during diagnosis typically included occupational therapists (12%), Alzheimer's New Zealand (9%), and registered nurses (5%).

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 that the terms used were highly dependent on the client and etiology; and four noted that they were usually more specific with their terminology (e.g., amnesic or nonamnesic MCI) according to the client's situation.

With respect to information provided to a client during diagnosis, a summary of participant responses is listed in Table 3. Information on types of support recommended to clients following

Table 3  
 Types of Information Presented to Client/Family at the Time of Diagnosis

Information presented	Always $n$ (%)	Often $n$ (%)	Sometimes $n$ (%)	Never $n$ (%)	Total $N$
Explanation of what cognitive Impairment is	<b>38 (80.8)</b>	6 (12.8)	2 (4.3)	1 (2.1)	47
Explanation of the test results, scans, etc	<b>36 (76.6)</b>	11 (23.4)	0	0	47
Information on practical aspects of the condition (e.g., medication, driving, etc)	<b>29 (63)</b>	14 (30.4)	3 (6.5)	0	46
Information on support services	<b>24 (55.8)</b>	17 (39.5)	2 (4.7)	0	43
Information on disease progression	<b>20 (43.4)</b>	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 that were indicated by 20 or more participants are in boldface.

Table 4

Primary Factors Considered by Practitioners when Relaying a Diagnosis

Primary code <i>n</i> (%)	Code definition <i>n</i> (%)
Disclosure is a priority 22 (41)	Diagnosis is usually delivered 7 (13) Family should be notified at least 7 (13) Client has a right to know 1 (2) Diagnosis is always delivered 5 (9) Important to be honest and truthful 2 (4)
Client factors 15 (28)	Diagnosis conflicts with client's individual wishes 7 (13) Client has other illnesses to deal with 4 (7) Lack of insight into illness 4 (7)
Issues of diagnosis are complex 12 (22)	Disclosure can cause harm than help 7 (13) Diagnosis can be inconclusive 4 (7) Sometimes the diagnosis is given but the 'label' is not 1 (2)
Client is a priority 5 (9)	Diagnosis delivery should be tailored to the individual 5 (9)

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 that often cognitive impairment is diagnosed in the context of other health problems (5%).

*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 diagnostic disclosure. 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 loved ones (56.5%). Considered *very important* were: giving the client and/or their loved ones an "answer" (63%), being kept 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 *somewhat important* for 48.9% of participants. Four participants stressed several differing points of importance that were also considered *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/outcome and feel sufficiently comfortable to ask questions, and (4) At least a written summary of findings.

Table 5

Perceived Consequences of a Diagnosis

Primary code <i>n</i> (%)	Code definition <i>n</i> (%)
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)

Table 6  
Perceived Helpful and Unhelpful Elements of a Diagnosis

Primary code <i>n</i>	Secondary code <i>n</i> (%)	Code definition <i>n</i> (%)
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)
Process of diagnosis 19 (21.59)	Understanding 2 (2.27)	
	Written information 2 (2.27)	
	Chance to have a discussion with professionals 7 (7.95)	
	Being heard 5 (5.68)	
	Follow up 4 (4.55)	
Unhelpful 59	Practitioner approach 32 (54.24)	Time to process information 3 (3.41)
		Unclear language 16 (27.12)
		Focusing on the negative 4 (6.78)
		Being inattentive 3 (5.08)
		Concerns dismissed 3 (5.08)
	Diagnosis delivery 14 (23.73)	Harsh delivery 3 (5.08)
		Incorrect information 3 (5.08)
		Lack of explanation 6 (10.17)
		Diagnosis not in person 2 (3.39)
		Lack of time (e.g., hurried consultations) 2 (3.39)
Process of diagnosis 11 (18.64)	Not giving diagnosis a name 2 (3.39)	
	Unconfirmed diagnosis 2 (3.39)	
	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)

**Factors considered when relaying a diagnosis.**

Participants were asked about circumstances (if any) in which a diagnosis of cognitive impairment might not be fully disclosed to a client or their family. No comments indicated that diagnosis was ever completely withheld from a client or their family. Results suggest that disclosure is of primary concern when making a diagnosis based on the number of times *disclosure is a priority* featured in participants’ qualitative responses (41%). *Client factors* were identified in 28% of participant responses when considering disclosure of a diagnosis; and 22% of qualitative responses indicated that *issues associated with*

*diagnosis are complex*. Table 4 displays the codes and associated explanations of factors considered by practitioners when disclosing a diagnosis.

**Consequences of a cognitive impairment diagnosis.**

Figures show that participants indicated 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 beyond the consideration of positive or *negative consequences* (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 5.

**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 6.

## 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. This research sought to present current practices of practitioners involved with diagnosing cognitive decline, and build on previous research (e.g., Mitchell et al., 2008; Strauss et al., 2012) around the processes and attitudes of NZ practitioners in diagnosing cognitive impairment. Several trends were noted following analysis of the results.

### Diagnosis Process

As with previous research in NZ on this subject (Strauss et al., 2012), the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975), Clock Drawing Test (Sunderland et al., 1989), Verbal Fluency Test (Bechtoldt, Fogel, & Benton, 1962) and Three Word Recall (Kuslansky, Buschke, Katz, Sliwinski, & Lipton, 2002) were the most commonly used instruments when reaching a diagnosis of cognitive impairment. The Addenbrook's Cognitive Examination – Revised (ACE-R; Mioshi, Dawson, Mitchell, Arnold, & Hodges, 2006) was rated by 36% of practitioners as used *most of the time*. Only 11% of the participants from this survey reported *always* using the ACE-R compared with 21% reported by Strauss et al. (2012). This result could be due to an improvement in MMSE sensitivity thresholds and ease of use in comparison with the ACE-R (Larner & Mitchell, 2014). This result might also be explained by the withdrawal of the ACE-R and the gap between the introduction of the ACE-III (see Neuroscience Research Australia, 2013), which coincided with data collection for this study.

The use of cognitive test scores alone is not sufficient in determining a diagnosis of cognitive impairment (Iliffe et al., 2009). The finding that practitioners incorporate client interview, client health care records, and informant information for the majority of the time when reaching a

diagnosis, is therefore not surprising. The 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 that diagnosis is almost always given in the company of family or relatives. This is an important step in diagnosis disclosure as it is likely that 1 in 3 clients will 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 carers' experiences of assessment suggests that the practitioner-client relationship is 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 that 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 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. Terms such as early dementia and normal ageing were reasonably frequent in our results (38-40% respectively). 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 the present study illustrated 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 that 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 that several practitioners felt that MCI was not a helpful concept ( $n=20$  or 4% of sample) or a proper diagnosis ( $n=6$  or 1% of sample).

To our knowledge, previous research has not examined what information is provided or what happens after clients have received a cognitive impairment diagnosis in NZ. Explaining the nature of cognitive impairment, explaining test results, providing practical information (e.g., driving implications) and providing information on support services are all rated highly amongst the practitioners in our sample. The present results are consistent with international literature, where providing information on support services following diagnosis is considered vital (Wilkinson & Milne, 2003). Alzheimer's New Zealand was the most frequently recommended organisation for clients following diagnosis, illustrating the importance of this resource for providing information to newly diagnosed clients and their families.

### Practitioner Attitudes to Diagnosis

Despite even the most experienced practitioners occasionally having difficulty when delivering a diagnosis of cognitive impairment (Lee & Weston, 2011), there is a growing understanding that dementia diagnoses should be revealed to clients in healthcare settings (Byszewski et al., 2007; Gauthier, Leuzy, Racine, & Rosa-Neto, 2013). Previous studies in the United States show approximately half of practitioners withhold a diagnosis of cognitive impairment (Carpenter & Dave, 2004), with many practitioners being reluctant to reveal a dementia diagnosis (Mormont, de Fays, & Jamart, 2012). A recent literature review also found that non disclosure of a dementia diagnosis is a common practice in healthcare settings around the world (Mitchell, McCollum, & Monaghan, 2013a). Results from the present study suggest that, contrary to these international findings, a diagnosis of cognitive impairment is never completely withheld from a client and that disclosure is a priority for the majority of practitioners.

### Factors considered when relaying

### *a diagnosis.*

Numerous factors were highlighted in the consideration of how a practitioner relays a diagnosis to their client. In line with previous research on cognitive impairment and diagnosis (Cornett & Hall, 2008), impaired insight, the possibility of causing further harm and the wishes of an autonomous client were given reference to by practitioners in the study. As observed elsewhere (Byszewski et al., 2007; Lecouturier et al., 2008; Samsi et al., 2013), our results highlight the importance of a pre-diagnosis discussion with the client and their family as to their preferences in approaching disclosure. Discussing diagnostic disclosure issues with the client and their family prior to proceeding with assessment is useful (Lecouturier et al., 2008), as this can be an effective way of honouring the client's wishes at the conclusion of the assessment. Some clients prefer to be eased into the results (Connell, Boise, Stuckey, Holmes, & Hudson, 2004), and some prefer diagnosis disclosure to be a progressive process (Byszewski et al., 2007). As seen in the literature (Lecouturier et al., 2008; Cornett & Hall, 2008; Robinson, 2011), there is value in tailoring diagnosis delivery to the individual needs of the client. Therefore, diagnosis delivery must be considered on a case by case basis (Maguire, 2002; Mitchell, McCollum & Monaghan, 2013b).

Practitioners are often faced with the complex interplay between upholding the client's right to their autonomy and upholding ethical principles, such as non-maleficence (e.g., 'do no harm', Gauthier et al., 2013). The subject of ethics is inextricably tied to the delivery of a diagnosis of cognitive impairment because cases where a diagnosis might cause harm or help will vary according to the individual client. Therefore, deciding how to relay such news to a client requires careful consideration and professional judgement from the practitioner. The qualitative findings from this questionnaire highlight a difference in perspective according to a diagnosis of dementia or MCI. Several practitioner comments pointed to a difference in approach between the two diagnoses. The findings from this study do not completely clarify how

practitioners feel about specific types of cognitive impairment and how their perceptions might differ according to the stage of the client's cognitive functioning. However, it is important that ongoing discussions on this topic take place, particularly as increased numbers of older adults are predicted to experience cognitive decline in future.

### *Consequences of a cognitive impairment diagnosis.*

International literature reports a mixture of benefits and harms associated with disclosing a dementia diagnosis (Karnieli-Miller et al., 2012). Practitioners in the present study noted numerous positive (56%), negative (10%), and varied (29%) consequences as a result of delivering a diagnosis of cognitive impairment. The current results illustrate how practitioners observe a brief negative reaction occurring immediately following diagnosis, which tends to dissipate with time. The distribution of the present results suggest that practitioners' attitudes regarding the benefit of a diagnosis are skewed towards the more positive and pragmatic end of the spectrum.

In line with the literature on this subject (Aminzadeh et al., 2007; Illiffe 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 also 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). These findings suggest that negative consequences associated with a diagnosis are not only complex, but often multilayered.

### *Helpful and unhelpful elements of diagnosis delivery.*

Literature suggests that one

explanation for why a diagnosis is not always delivered is due to practitioners' own views that providing a label is unhelpful (Bradford et al., 2009). The present study has similar findings with recent research on MCI (Roberts, Karlawish, Uhlmann, Petersen, & Green, 2010), that most practitioners felt a diagnosis is helpful for their clients. Helpful elements of diagnosis observed in present results were a practitioner approach when delivering a diagnosis (e.g., using clear language, being honest); providing information at the time of diagnosis (e.g., explaining test results, planning for the future); and the process of diagnosis (e.g., the chance to have a discussion with a professional).

Several practitioners suggested that being optimistic about the future was an inherent element to their approach when delivering a diagnosis to their client. Their perception was that clients found this optimism helpful when receiving a diagnosis. Lee and Weston (2011) discuss ways in which practitioners can assist their clients in maintaining hope and managing their change in identity as someone who has cognitive impairment. They suggest introducing lifestyle changes as a practical step in maintaining optimism about the future, such as regular exercise, diet, and discussions about changes the client might expect in the future (e.g., changes in driving ability). The current study did not gather specific information on this topic of achieving optimism in practice, however, this could be an avenue of further investigation.

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 a strong emphasis is not necessarily placed on follow-up amongst NZ based practitioners. On the other hand, 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 that 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 significant 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). Further, an associated recruitment bias may have impacted on study results, as suggested in past questionnaire research with a practitioner based population (Kaduszkiewicz, Bachmann, & van den Bussche, 2008; Roberts et al., 2010; Rodda et al., 2013). Of all the practitioners who were sent the email invitation to participate, it might be that more interested, available or experienced practitioners responded to the questionnaire over others in the field.

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. Current research suggests that the perspectives of primary care physicians involved with initial diagnoses of dementia should be investigated further (Aminzadeh et al., 2012). Also, the small sample size means that results may not be generalised to the entire population of practitioners involved in diagnosing cognitive impairment. It is currently unclear how large the population of practitioners who diagnose cognitive

impairment in NZ is. However, previous studies that have explored practitioner processes in NZ relating to the diagnosis of cognitive impairment, 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 may have been hesitant to discuss these issues.

Another limitation was the wording of the questionnaire. Comments left in the open comments boxes by several practitioners revealed that 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. Our questionnaire was deliberately worded to increase the potential sample size by including practitioners' attitudes on varying severities of cognitive impairment. However, the wording could have been clarified to reflect the difference in attitude toward the diagnosis of dementia versus the diagnosis of MCI.

### Concluding Comments

The findings from the current study provide insight into what factors a practitioner might take into consideration when choosing how to impart a potentially life changing 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. Rigorous empirical research is needed so that changes beneficial to the older adult population can be implemented. The present study and others highlight that making changes to older adult healthcare has a degree of complexity that cannot

be overstated (Iliffe et al., 2009). Due to the increasing longevity of older adults than recorded in previous decades, the demand for healthcare services, and the provision of appropriate follow-up and post-diagnostic care is essential (Cahill et al., 2008; Szymczynska, Innes, Mason, & Clark, 2011).

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