Practitioners processes and attitudes in the diagnosis of cognitive impairment

Alison McKinlay - PhD Candidate
School of Psychology, Massey University

Supervised by Professor Janet Leathem and
Associate Professor Paul Merrick

Presentation for the New Zealand Psychological Society conference,
Outline

Literature on diagnosis and disclosure
Purpose of the study
Study methods
  Sample, questionnaire
Study results
Key findings
Final practitioner comments
Background of the study

Increased interest in early diagnosis and ethical issues
  – ‘Best practice’ when giving an early diagnosis?
  – Studies on dementia, not mild cognitive impairment (MCI)
  – Ongoing area of investigation in the literature
  – See Werner, Karnieli-Miller, & Eidelman, 2013

Diagnosis of cognitive impairment varies widely
  – Why? More harm than help, lack of insight, client wishes
  – What influences this variation in New Zealand (NZ)?

Dementia vs MCI
  – Present study asked Qs mostly on cognitive impairment
    – More research needed focusing on MCI
Purpose of the study

Identify general processes that practitioners follow when diagnosing dementia or mild cognitive impairment

Identify attitudes around diagnosis disclosure

Research questions

What are the current practices of NZ practitioners who diagnose cognitive impairment?

What factors influence the variation in practice?
Ethics approval granted in 2012 by MUHEC

Invitation to participate sent to:

- Australia and New Zealand Society for Geriatric Medicine (ANZSGM)
- The College of New Zealand Clinical Psychologists (NZCCP)
- New Zealand Psychologists for Older Peoples (NZPOPs)

Inclusion criteria:

- Diagnosed dementia or MCI within past 12 months
- Currently practising in NZ
Questionnaire

One-off anonymous online survey
The questionnaire consisted of three sections:
A) General demographic information
B) Clinical tools involved with diagnosis
   Likert style/open ended
   E.g., ‘What information is presented to the client/family at the time of diagnosis?’
C) Attitudes towards the diagnosis of cognitive impairment
   Open ended
   E.g., ‘Are there any instances in which a diagnosis of cognitive impairment might not be delivered?’

Analysed using content analysis
N=57

Participants mostly from:
- Auckland
- Wellington
- Canterbury region

Participants mostly worked in:
- Geriatrics (36.5%)
- Clinical psychology (25%)
- Neuropsychology (13.5%)
- Psychiatry (11.5%)

Experience levels:
- 15+ years (32%)
- 1-5 years (24%)
- 5-10 years (22%)
- 10-15 years (18%)

**Figure 1**
*Types of Cognitive Impairment Commonly Diagnosed*
Figure 2
What General Steps do Practitioners Follow when Assessing and Diagnosing Cognitive Impairment?

- Review referral
- Discuss referral with referral source
- Liaise with other professionals

- Discussion with client to obtain history
- Review clients history
- Obtain collateral info
- Discuss with client’s family

- Neuro, physical, medical assessment
- Integration of results

- Produce report

- Feedback with client, family
- Feedback results to referrer
What General Steps do Practitioners Follow when Assessing and Diagnosing Cognitive Impairment?

1. **Review Referral Information**
   - Discuss referral with referral source
   - Liaise with other professionals

2. **Review Client History**
   - Discussion with client to obtain history
   - Review clients history
   - Obtain collateral info
   - Discuss with client’s family

3. **Assessment**
   - Neuro, physical, medical assessment
   - Integration of results

4. **Report Writing**
   - Produce report

5. **Provide General Feedback**
   - Feedback with client, family
   - Feedback results to referrer

Multi-disciplinary support

Exact process is tailored to the individual

Liaising with other professionals
Liaising with other professionals

Exact process is tailored to the individual

Multi-disciplinary support

Liaising with other professionals

Study results

Table 1
Which Professionals are Involved with When Reaching a Diagnosis?

<table>
<thead>
<tr>
<th>Type of Professional</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical psychologist*</td>
<td>Caregivers</td>
</tr>
<tr>
<td>Counsellor</td>
<td>Case manager</td>
</tr>
<tr>
<td>General practitioner*</td>
<td>Driving assessor</td>
</tr>
<tr>
<td>Geriatrician*</td>
<td>Neurologist*</td>
</tr>
<tr>
<td>Neuropsychologist*</td>
<td>MDT staff members</td>
</tr>
<tr>
<td>Nurse</td>
<td>Occupational therapist</td>
</tr>
<tr>
<td>Psychiatrist*</td>
<td>Psychogeriatric services</td>
</tr>
<tr>
<td>Psychologist*</td>
<td>Radiologist</td>
</tr>
<tr>
<td>Social worker</td>
<td>Support workers</td>
</tr>
</tbody>
</table>

*All involved with providing client history, cognitive testing, support, follow up assistance

**Multidisciplinary (MDT)
Study results

Table 2
Types of Information Presented to Client/Family at the Time of Diagnosis

<table>
<thead>
<tr>
<th>Information Presented</th>
<th>Always</th>
<th>Often</th>
<th>Sometimes</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Explanation of what cognitive impairment is</td>
<td>80.8</td>
<td>12.8</td>
<td>4.3</td>
<td>2.1</td>
</tr>
<tr>
<td>Explanation of the test results</td>
<td>76.6</td>
<td>23.4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Information on practical aspects of the condition (e.g., medication, driving)</td>
<td>63</td>
<td>30.4</td>
<td>6.5</td>
<td>0</td>
</tr>
<tr>
<td>Information on support services **</td>
<td>55.8</td>
<td>39.5</td>
<td>4.7</td>
<td>0</td>
</tr>
</tbody>
</table>

** Support services included Alzheimer’s New Zealand, home support services, GP, needs assessment and service coordination agency, Age Concern, DHB, pamphlets, Parkinson’s Society, support groups
Study results

Figure 2
Factors Considered When Relaying a Diagnosis to a Client

Disclosure is of Utmost Importance
- Important to be honest
- Disclosure is important
- Family should be notified at least
- Diagnosis is always disclosed
- Client has a right to know
- Diagnosis is usually delivered

Disclosure Influenced by Client Factors
- Other illnesses to deal with
- Lack of insight
- Diagnosis conflicts with client’s wishes
- Diagnosis is tailored according to individual
- Disclosure can cause more harm than help
## Study results

Table 3
*Terms Used During Diagnosis to Label MCI*

<table>
<thead>
<tr>
<th>Label</th>
<th>Mitchell et al Study</th>
<th>McKinlay et al Study</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Responses % of</td>
<td>Responses % of</td>
</tr>
<tr>
<td></td>
<td>Responses Responses</td>
<td>Responses Responses</td>
</tr>
<tr>
<td>MCI</td>
<td>28 82</td>
<td>39 83</td>
</tr>
<tr>
<td>Early Alzheimer's Disease/ Dementia</td>
<td>1 3</td>
<td>5 12.5</td>
</tr>
<tr>
<td>I don’t usually relay the diagnosis</td>
<td>0 0</td>
<td>0 0</td>
</tr>
<tr>
<td>Normal ageing</td>
<td>0 0</td>
<td>1 2.6</td>
</tr>
<tr>
<td>Other</td>
<td>15 44</td>
<td>11 13</td>
</tr>
</tbody>
</table>

* Responses in Mitchell et al. (2008) study were rated as ‘preferred’
**Responses in McKinlay et al. (in press) study were rated as being used ‘often’
Clinical practice is never clear cut!

MCI, vascular dementia and Alzheimer's disease commonly diagnosed

Explanation of results commonly given during diagnosis. Follow up and written info less commonly given
- What do clients find most helpful?

Variation in practice is necessary to suit the needs of each individual client

Numerous factors influence diagnosis disclosure

MCI is usually labelled directly during diagnosis, however, the label can vary according to the individual

Ongoing research on MCI and diagnosis is needed
“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...”
“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!”
Practitioner comments in response to the study

“... I would be keen to hear more from patients and families about whether early diagnosis is helpful...”

Research in progress!
“Minimal cognitive impairment has not reached the collective unconscious whereas dementia has...”

Practitioner comments in response to the study
“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.”
If you have any queries, my email address is A.R.McKinlay@Massey.ac.nz

References:


Practitioners' processes and attitudes involved in the diagnosis of cognitive impairment

McKinlay, AR

2014