Prevalence of dementia in Maori and non-Maori octogenarians: from LiLACS NZ to LiDIA.

Ngaire Kerse, PhD, FRNZCGP
GP and Head, School of Population Health
NZ population projection
Our older population is becoming more culturally diverse, and organisations will need to target more culturally appropriate information and services to older people.

Our Māori and Pacific populations are much younger than our NZ European population. Therefore, most services for older people are aimed at NZ Europeans. We will see large percentage increases in our older Asian, Māori and Pacific populations by 2026.
Māori and Non-Māori

Source: Statistics New Zealand – Māori ethnic group population by age and sex at 2015
Inequities in Life Expectancy

Life expectancy at birth (years)

- Maori females
- Non-Maori females
- Pacific females
- Maori males
- Non-Maori males
- Pacific males
Te Puāwaitanga o Ngā Tapuwae Kia Ora Tonu-LiLACS NZ

- Longitudinal cohort
- Bay of Plenty and Lakes DHBs
- Recruited **421 out 766 Māori** 80-90 years (56%)
- **Non Māori 516 out of 870** aged 85 yrs (59%)
- Visit every year until death

Measures – **Core and Full**

- Functional transitions, care
- Cognition – 3MS, MMSE
- Health
  - Multimorbidity
  - Medications – STOPP, START
  - 3MS-cognition
  - Function - NEADL
- **NHI match**
  - Hospitalisation,
  - mortality

Kerse, *cohort profile* Int J Epi, 2015, 1–10
<table>
<thead>
<tr>
<th>Variable</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>254/421</td>
<td>400/516</td>
<td>654/937</td>
</tr>
<tr>
<td>Age (sd)</td>
<td>82.7 (2.8)</td>
<td>84.6 (0.5)</td>
<td>83.8 (2.1)</td>
</tr>
<tr>
<td>Gender Men</td>
<td>176 (42%)</td>
<td>237 (46%)</td>
<td>413 (44%)</td>
</tr>
<tr>
<td>Residential Care</td>
<td>30 (7%)</td>
<td>44 (9%)</td>
<td>74 (8%)</td>
</tr>
<tr>
<td>Lives alone</td>
<td>110 (41%)</td>
<td>195 (48%)</td>
<td>305 (46%)</td>
</tr>
<tr>
<td>Fell</td>
<td>138 (34%)</td>
<td>205 (40%)</td>
<td>343 (37%)</td>
</tr>
<tr>
<td>Physical activity PASE</td>
<td>111 (81)</td>
<td>99 (66)</td>
<td>104 (73)</td>
</tr>
<tr>
<td>Alcohol use in last month <strong>Never</strong></td>
<td>120 (47%)</td>
<td>105 (26%)</td>
<td>225 (35%)</td>
</tr>
<tr>
<td>Disability 0-14/22 NEADL</td>
<td>44 (17%)</td>
<td>63 (16%)</td>
<td>107 (16%)</td>
</tr>
<tr>
<td>N meds</td>
<td>5.0 (3.3)</td>
<td>5.4 (3.5)</td>
<td>5.2 (3.4)</td>
</tr>
<tr>
<td>Comorbidity n conditions</td>
<td>4.7 (2.5)</td>
<td>4.9 (2.2)</td>
<td>4.8 (2.3)</td>
</tr>
<tr>
<td>Mortality</td>
<td>253 (60%-4.5 yrs)</td>
<td>286 (55%-4.9 yrs)</td>
<td>539 (58%)</td>
</tr>
</tbody>
</table>
Education

Māori

Non Māori

Gender
- male
- female

Percent

Education

Primary  secondary  completed secondary  trade  tertiary

Māori

nonMāori
Figure 2 Living arrangement, by sex and ethnic group.

Source: LiLACS NZ first wave of data collection

Note: living with spouse included partners
Health conditions

» CVD 66-68%
» Māori have more heart failure (30 vs 20%) and Atrial Fibrillation (30 vs 20%), diabetes (30 vs 16%), lung disease (35 vs 25%)
  – Less arthritis (35 vs 44%), eye disease (49 vs 66%).
» Men have more Coronary disease (40%) and peripheral vascular disease (20%)
» 52% Māori bilingual

Teh RO, NZMJ 2014, Vol 127 No 1397;
<table>
<thead>
<tr>
<th></th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Māori</td>
<td>Non-Māori</td>
</tr>
<tr>
<td>Dementia by MMSE a</td>
<td>31 (18%)</td>
<td>22 (9%)**</td>
</tr>
</tbody>
</table>

Results
Dementia

ROC curves

Maori

<table>
<thead>
<tr>
<th></th>
<th>3MS Normal 81+</th>
<th>3MS Low &lt;81</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Dementia</td>
<td>18</td>
<td>2</td>
</tr>
<tr>
<td>Dementia</td>
<td>2</td>
<td>10</td>
</tr>
</tbody>
</table>

Non-Maori

<table>
<thead>
<tr>
<th></th>
<th>3MS Normal 85+</th>
<th>3MS Low &lt;85</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Dementia</td>
<td>24</td>
<td>5</td>
</tr>
<tr>
<td>Dementia</td>
<td>1</td>
<td>11</td>
</tr>
</tbody>
</table>

Legend:
- Blue line: Maori
- Gray line: Non-Maori
At Baseline

Figure 2-1: Dementia prevalence by sex and ethnic group, Wave 1

Source: LiLACS NZ
Note: Proportion scoring in the range meaning they are likely to have dementia on the Modified Mini Mental State Examination: 80 or less for Māori, 84 or less for non-Māori, Wave 1.
Over time

Source: LiLACS NZ

Note: ‘Dementia’ denotes a score of 80 or less for Maori or 84 or less for non-Maori on the 3MS cognition scale, associated with significant likelihood of dementia diagnosis. The number of people scoring in the range indicating dementia and no dementia are shown with the diagonal lines indicating the number (and percent of group of origin) transitioning between. Numbers do not add to totals as some participants died or dropped out.
Accrued dementia prevalence - Māori

Percent

Wave 1  Wave 2  Wave 3  Wave 4  Wave 5  Wave 6
Māori women  Māori men  Māori women  Māori men  Māori women  Māori men
Accrued dementia prevalence -non-Māori

No diff by ethnicity, adj Age, sex, SES

Percent

<table>
<thead>
<tr>
<th>Wave 1</th>
<th>Wave 2</th>
<th>Wave 3</th>
<th>Wave 4</th>
<th>Wave 5</th>
<th>Wave 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>non-Māori women</td>
<td>non-Māori women</td>
<td>non-Māori women</td>
<td>non-Māori women</td>
<td>non-Māori women</td>
<td>non-Māori women</td>
</tr>
</tbody>
</table>
Trajectories of cognition - Maori
Maori cognition trajectories

None/pri mry | Age | Occup % blue | Functn | comorbid
---|---|---|---|---
19% | 82 | 42 | 18.2 | 4.6
33 | 82 | 50 | 18.1 | 5.0
40 | 83 | 55 | 16.3 | 5.4
33 | 84 | 87 | 4.2 | 5.3

No diff in; childhood poverty, gender, lives alone, depression, grip strength, BMI
Trajectories of cognition – non-Maori

30.7%

59.2%

10.1%
Non-Maori cognition trajectories

<table>
<thead>
<tr>
<th>None/pri mry</th>
<th>Chldhd poverty</th>
<th>Functn NEADL</th>
<th>Grip str men kg</th>
</tr>
</thead>
<tbody>
<tr>
<td>9%</td>
<td>83%</td>
<td>19.0</td>
<td>33</td>
</tr>
<tr>
<td>20</td>
<td>73</td>
<td>17.8</td>
<td>30</td>
</tr>
<tr>
<td>21</td>
<td>58</td>
<td>13.9</td>
<td>28</td>
</tr>
</tbody>
</table>

No diff in; gender, occup, lives alone, depression, BMI, comorbidities,
Product-Limit Survival Estimates
With 95% Hall-Wellner Bands

Censored
Logrank p < .0001

Survival Probability

0.0
0.2
0.4
0.6
0.8
1.0

0
2
4
6

non-Maori women
Maori women
non-Maori men
Maori men
Aims and Objectives

• To develop a Māori theory and understanding of dementia
• To develop tool/s to assist in the diagnosis of dementia in Māori

Kaumātuatanga ō te roro - the ageing brain
Maori world view
Qualitative Hui

WAIRUA

Protective Factors
Language
Causes
Kaitiakai/Caregiver
Acceptance of illness
Dementia Services
Mate Wareware - Dementia

- Mate = be sick, ill, ailing, unwell, diseased
- Wareware = to forget, forgotten

MATE WAREWARE
Ngā Ratonga (Services)

- **Aged Care Services** “keeping at home and out of rest home avoids dementia.” TM

- **Clinicians** “Need to have a basic understanding of tikanga (Māori protocols)” TE “Should be more culturally competent” WKP

- **Lack of support** “Support is important to reduce burden and stress on kaimahi whānau.”

- **Lack of Information** “Not much info.” WKMx
Ngā Rongoa/Protective factors?

- Te Reo Māori (Māori language)
- Waiata as a memory facilitator
- Whakapapa
- Karakia (Prayers)
- Roopu Kaumātua
- Marae environment
“Māori very spiritual people” WaitM

“Wairua plays a big part” WaitP

“Prayers for those people are very powerful and very good” CHM

“Spiritual guidance from God helps” CHP2

“Spiritual and mauri aspect put aside in English society.” TM

“importance of holistic approach, medicine as well as wairua, mauri” TM
Tool Development

• Kimberley Indigenous Cognitive Assessment (KICA)
• Cognitive Assessment Tool
• Functional Assessment Tool
• Contextual/Whānau Assessment Tool
• Maximum uptake
• Online version for clinicians using a Māori interpreter
• Name
Tool Development

Māori and Non-Māori specialists

Māori Team Consultants

Māori Community Consultants

Pilot (End of 2019)

Validity (End of 2019)
Network
Chicago ADI Conference
LiDiA
Living with Dementia in Aoteoroa

Sarah Cullum
Old age psychiatry, University of Auckland

Margaret Dudley - Māori world view of dementia and developing a cognitive screening tool for Māori

Ngaire Kerse - LiLACS NZ.
Life and Living in Advanced Age, a Cohort Study in NZ
Māori and non-Māori octogenarian cohorts
Unexpected results for screening and prevalence
Is MMSE culturally biased?

We need a NZ dementia prevalence study that includes all major NZ ethnic groups
Maori and Pacific appeared to present at an earlier age to the South Auckland memory service

*Cullum et al, 2018*
We need a **community-based** NZ dementia prevalence study: diagnosis and door-knocking

<table>
<thead>
<tr>
<th>No blood test or scan for dementia</th>
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<tbody>
<tr>
<td>Dementia diagnosis is by clinical assessment</td>
</tr>
<tr>
<td>Need one standardised assessment of dementia to use in all</td>
</tr>
<tr>
<td>Assessment to capture family/caregiver experience too</td>
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</table>

<table>
<thead>
<tr>
<th>Diagnosis needs to be culture-fair and education-fair</th>
</tr>
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<tbody>
<tr>
<td><strong>10/66 dementia protocol</strong></td>
</tr>
<tr>
<td>(used in China, India, Latin America, Africa &amp; Singapore)</td>
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<table>
<thead>
<tr>
<th>Sampling methods</th>
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<tbody>
<tr>
<td>Random door knocking because no register available</td>
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</table>
How to do a prevalence study in NZ

Translate the 10/66 protocol:
Te Reo Māori, Samoan, Tongan, Hindi, Cantonese & Mandarin

Interviewers:
Bilingual bicultural interviewers trained in 10/66 methods

Participants:
No one likes a cold-caller
Community engagement
Bottom-up not top-down

Community engagement
Co-design projects
Culturally safe research
Education is two-way

Qualitative research
Lived experience (stories)
How do families cope?
Culturally specific issues

Raise awareness. De-stigmatise. Have fun!
Study launch of LiDiA Feb 2018: Living with Dementia in Aotearoa
LiDiA qualitative research projects

Team leaders
Māori – Margaret Dudley
Tongan – Tony Kautoke
Samoan – Fiva Fa’alau
Chinese – Gary Cheung
Indian – Rita Krishnamurthi

Pākehā – Liz Smith, Litmus
Alzheimer’s NZ Report

Kaumātuatanga ō te roro
-the ageing brain

LiDiA
LiDiA validity studies

Translation/adaptation of 10/66 dementia protocol
Māori, Tongan, Samoan & Hindi
Training for 10/66 interviewers
Test the diagnostic accuracy in Māori, Tongan, Samoan & Fijian Indian communities
LiDiA feasibility study

Community engagement
Over-sampling
Door-knocking
South Auckland

Māori
Qualitative
Validity 10/66

Samoan
Qualitative
Validity 10/66

Tongan
Qualitative
Validity 10/66

Indian
(Hindi)
Qualitative
Validity 10/66

Pākehā
Qualitative only
(Alzheimers NZ)

Chinese
(Cantonese)
Qualitative only

Chinese
(Mandarin)
Qualitative only
2018: Qualitative interviews of lived experience

2019: Adaptation and validity testing of 10/66 in Te Reo Māori, Samoan, Tongan, & Hindi

2019: Feasibility study for sampling methods
2020: Dementia prevalence study?
LiDiA research team leads:

Sarah Cullum (PI)
Margaret Dudley (Māori)
Fiva Fa’alau (Samoan)
Tony Kautoke (Tongan)
Rita Krishnamurthi (Indian)
Gary Cheung (Chinese)
Susan Yates
Ngaire Kerse
LiLACS NZ to LiDiA
n.kerse@auckland.ac.nz


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