Dementia, Stigma and Intentions to Help-Seek

A pilot study of Australian adults 40 to 65 years

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What is Dementia?

- A progressive degenerative neurological syndrome associated with profound disability\(^1\)
- No accepted treatments or cures\(^2\)
- Alzheimer’s Disease (AD) (50% of cases)
  Vascular Dementia (VaD) (20% of cases)\(^3\)
- Type & severity of symptoms vary according to type & stage of dementia.
- Impairment of brain function in different areas (Memory, Personality, Language, Perception, Cognitive skills) \(^4\)
The dementia epidemic?

• By 2050 the number of people living with dementia will increase fourfold to 1.13 million
  dementia will be the leading single cause of disability in older Australians (65 yrs +)

• By 2060 spending on dementia will outstrip any other health condition

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Impact of Dementia

Major health service stresses

Health care system

Quality of life

Impact of Dementia

Residential aged care beds

Dementia care staff

Family carers

University of Wollongong
Dementia – a loss of self?

- Dementia (taken from Latin, originally meaning "madness", from de- "without" + ment, the root of mens "mind")

- Described in popular and medical literature as:
  - ‘a state between life and death’
  - ‘the living dead’
  - ‘replaced cancer as the most feared disease’
Public perceptions of Dementia?

• Increase in government funding for dementia research and care over the past 5-10 years
• Increased discussion in popular media and scholarly discourse

Increased understanding of the seriousness of dementia?
OR
Increased fear and prejudice?
Dementia and Stigma

What is stigma?

• Prejudicial views or negative stereotyping against people with particular characteristics
• In health, has been associated with mental illness, infectious disease and disability

What is the impact of stigma?

– social exclusion
– discriminative practices within health services
– delays in ‘help-seeking’, delays in diagnosis and access to treatment
Domains of stigma

Model of Stigma according to Link and Phelan (2001; 2006)

- Labelling
- Stereotypes
- Separation
- Discrimination (individual and institutional)
Research on Stigma

• **Limited research**:
  • Impact on psychosocial wellbeing in early stages\(^{12}\)
  • May experience ‘double-stigma’ (mental illness and ageism)\(^{13}\)
  • Particularly dehumanising – ‘the living dead’\(^{6}\)
  • Seek to avoid diagnosis because don’t want the label\(^{14}\)

**URC Partnership Grant (2010)**

• Jones, Magee & Phillipson
• Alzheimer’s Australia
• National consumer network
Objectives of Current Research

- **Online survey** (n = 616 adults, 40 – 65 years)

- **Recruited** via Facebook (40.3%) & community networks (43.3%) & other

- **Examine different domains of stigma:**
  - Do people express a desire for avoidance/separation from people with dementia?
  - Do people hold ‘positive’ views about people with dementia?

- **Response to Diagnosis of Stigma:**
  - How would they respond if they were diagnosed with dementia?

- **Examine help-seeking intentions**
1. **Fabrioni Ageism Scale** (1990)
   - 9 items of Interest
   - Modified ‘older people’ to ‘people with dementia’

2. **Positive beliefs** (Consumer network; Kitwood, 1997)

3. **Perceptions Regarding Investigations Screening for Memory in Primary Care** (PRISM-PC) (Boustiani et al, 2008)

4. **Help-Seeking Intentions** (Wilson et al, 2007)
   ‘If felt you were becoming more forgetful and were concerned it might be the signs of early dementia…’
<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>134</td>
<td>21.8</td>
</tr>
<tr>
<td>Female</td>
<td>482</td>
<td>78.2</td>
</tr>
<tr>
<td><strong>Country of Birth</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>468</td>
<td>76.0</td>
</tr>
<tr>
<td>Other</td>
<td>148</td>
<td>24.0</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ High School</td>
<td>132</td>
<td>21.4</td>
</tr>
<tr>
<td>TAFE</td>
<td>180</td>
<td>29.2</td>
</tr>
<tr>
<td>University</td>
<td>304</td>
<td>49.4</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single/Divorced</td>
<td>231</td>
<td>37.5</td>
</tr>
<tr>
<td>Married</td>
<td>385</td>
<td>62.5</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not working</td>
<td>218</td>
<td>35.4</td>
</tr>
<tr>
<td>Casual/part-time</td>
<td>197</td>
<td>32.0</td>
</tr>
<tr>
<td>Full-time</td>
<td>201</td>
<td>32.6</td>
</tr>
<tr>
<td><strong>Know Someone with Dementia</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>554</td>
<td>89.9</td>
</tr>
<tr>
<td>No</td>
<td>62</td>
<td>10.1</td>
</tr>
<tr>
<td><strong>Dementia Carer</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>134</td>
<td>21.8</td>
</tr>
<tr>
<td>No</td>
<td>482</td>
<td>78.2</td>
</tr>
</tbody>
</table>
RESULTS –
Negative Beliefs

People with Dementia:

- Cannot be expected to have meaningful conversation (50.8%)
- Can be irritating (34%)
- Have poor personal hygiene (14.3%)
- I would prefer to avoid spending time with PLD (11.7%)
- Lower agreement with desire for broader social exclusion
  (e.g. < 2% agreed should live where they won’t bother people; did not need to use community facilities)
RESULTS – Positive Beliefs

People with dementia:

• Can participate in a variety of activities (46.1%)

• Company is enjoyable (38.6%)

• Good source of wisdom (37.7%)

• Can pass on valued traditions (34.4%)
RESULTS
How you might feel if you found out you had dementia?

• **Negative affective response**
  - Shame (60.3%)
  - Anxiety (76.4%)
  - Depression (70.1%)
  - Humiliation (46.7%)

• **Fear of discrimination**
  - Would not want my employer to find out (38.3%)

• **Health sector concerns**
  - Doctor would not listen to me (16.3%)
  - Doctor would not provide best care (11.7%)
RESULTS – Attitudes towards Dementia

Avoidance/Separation
- e.g. Avoid eye contact
- Don’t like conversation with
- Wouldn’t bother visiting
- No point talking to
- Prefer not to go to social group with

Person-centred
- e.g. Good source of knowledge
- Can pass on valued traditions
- Enjoyable company
- Can participate in variety of activities

Fear of labelling
- e.g. Don’t want family to know
- Humiliation, Shame
- Depressed, Anxious
- Give up on life

Fear of discrimination
- Doctor would not provide best care
- Doctor/health professional won’t listen to me
- Do not want health insurance company to know
- Do not want employer to know
If YOU felt you were becoming more forgetful and were concerned it might be the signs of early dementia, how likely is it that you would seek help from the following people?

<table>
<thead>
<tr>
<th>Seek help from:</th>
<th>% Likely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent</td>
<td>14.8%</td>
</tr>
<tr>
<td>Friend</td>
<td>35.7%</td>
</tr>
<tr>
<td>Relative</td>
<td>40.8%</td>
</tr>
<tr>
<td>Psychologist</td>
<td>47.5%</td>
</tr>
<tr>
<td>Phone</td>
<td>37.5%</td>
</tr>
<tr>
<td><strong>GP</strong></td>
<td><strong>83.7%</strong></td>
</tr>
<tr>
<td>No-one</td>
<td>8.2%</td>
</tr>
<tr>
<td>Delay seeking help for as long as possible</td>
<td>22.6%</td>
</tr>
</tbody>
</table>
## Likelihood of seeking help from

<table>
<thead>
<tr>
<th></th>
<th>A partner</th>
<th>Another Relative</th>
<th>Psychologist</th>
<th>GP</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Avoidance</strong></td>
<td>0.96</td>
<td>0.97</td>
<td>1.02</td>
<td>0.96</td>
</tr>
<tr>
<td><strong>Fear of Labelling</strong></td>
<td>0.96*</td>
<td>0.99</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td><strong>Person Centred</strong></td>
<td>1.02</td>
<td>0.96</td>
<td>0.99</td>
<td>1.00</td>
</tr>
<tr>
<td><strong>Fear of Discrimination</strong></td>
<td>0.99</td>
<td>0.93*</td>
<td>0.91*</td>
<td>0.80*</td>
</tr>
<tr>
<td>Stigma &amp; Help-seeking</td>
<td>Not seek help from anyone</td>
<td>Delay seeking help</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------------------</td>
<td>-------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoidance</td>
<td>1.05</td>
<td>1.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear of Labelling</td>
<td>1.08*</td>
<td>1.08*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Person Centred</td>
<td>1.06</td>
<td>1.04</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear of Discrimination</td>
<td>1.15*</td>
<td>1.08*</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# Attitudinal Clusters

<table>
<thead>
<tr>
<th></th>
<th>Dual views, yet fearful</th>
<th>Disease centred &amp; fearful</th>
<th>Dual views, low fear</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Avoidance</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>0.0</td>
<td>100.0</td>
<td>47.7</td>
</tr>
<tr>
<td>Low</td>
<td>100.0</td>
<td>0.0</td>
<td>52.3</td>
</tr>
<tr>
<td><strong>Person Centred</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>57.4</td>
<td>22.5</td>
<td>59.9</td>
</tr>
<tr>
<td>Low</td>
<td>42.6</td>
<td>77.5</td>
<td>40.1</td>
</tr>
<tr>
<td><strong>Fear of Labelling</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>67.9</td>
<td>74.3</td>
<td>5.9</td>
</tr>
<tr>
<td>Low</td>
<td>30.3</td>
<td>25.7</td>
<td>94.1</td>
</tr>
<tr>
<td><strong>Fear of Discrimination</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>73.9</td>
<td>88.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Low</td>
<td>26.1</td>
<td>12.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

**Latent Cluster Analysis**
## Attitudinal Clusters & Help-seeking Intentions

<table>
<thead>
<tr>
<th>Would seek help from:</th>
<th>Dual views Fearful</th>
<th>Avoidance Fearful</th>
<th>Dual view Low fear</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychologist</td>
<td>0.59* (0.39 – 0.89)</td>
<td>1.16 (0.78 – 1.73)</td>
<td>Ref</td>
</tr>
<tr>
<td>GP</td>
<td>0.50* (0.27 – 0.93)</td>
<td>0.31* (0.17 – 0.55)</td>
<td>Ref</td>
</tr>
<tr>
<td>No-one</td>
<td>2.69* (1.08 – 6.68)</td>
<td>3.23* (1.32 – 7.89)</td>
<td>Ref</td>
</tr>
<tr>
<td>Delay seeking help for as long as possible</td>
<td>2.20* (1.28 – 3.80)</td>
<td>3.03* (1.80 – 5.08)</td>
<td>Ref</td>
</tr>
</tbody>
</table>
Discussion – Beliefs about Dementia

• Issues surrounding stigma in dementia are complex

• We identified four types of dementia attitudes, three of which were associated with stigma:
  1. Avoidance beliefs
  2. Fear of Labelling
  3. Fear of Discrimination
  and
  4. Person Centred beliefs
• Evidence for stigma in relation to dementia
  • Some adults may desire to avoid people with dementia
  • Positive person-centred views
  • Both

• Evidence of fear associated with dementia diagnosis
  • Fear and shame associated with label
  • Fear associated with (anticipated) direct discrimination
**Discussion**

- **Disease centred and Fearful**
  - Most likely to seek help from no-one
  - More likely to delay help-seeking as long as possible
  - Less likely to see a GP or a psychologist

- **Dual view, yet fearful**
  - More likely to delay help-seeking as long as possible
  - More likely to seek help from no-one
  - Least likely to seek help from a GP or a psychologist

- **Dual views, not fearful**
  - (reference)
Further research

- More representative sample
- Other domains of stigma?
- Experience of actual stigma and discrimination (PLD and their caregivers)?
- Relationship between beliefs and help-seeking behaviours (vs. intentions)?
- Stigma: dementia vs. ageism?
- How to mediate/intervene to reduce stigma and discrimination?
• Any comments or questions?

