Why Caregivers of people with Dementia don’t utilise Out-of-Home Respite Services

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• Progressive disabling neurological syndrome\(^1\)
• No widely accepted treatments or cures\(^2\)
• Many living with dementia require residential care
• Having a co-resident carer improves likelihood that people able to remain living at home longer\(^3\)
Caring for a family member can have many positive aspects\textsuperscript{4-5}

However, can also be associated with physical and psychological stresses\textsuperscript{6-7}

Particularly if the caregiver feels trapped\textsuperscript{8}
Respite and Caregiving

Respite - Temporary relief of the caregiver through provision of substitute care

Importance to Family Caregivers

- Identified by carers as a critical unmet need
- Enables them to continue role for longer

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Respite Service Use and Non-use

• Proportion of caregivers of people with Dementia using available respite programs is low\textsuperscript{12,13}
  - 9% of families in US use a day centre\textsuperscript{14} and 2% used nursing home respite\textsuperscript{15}
  - only 32% with an approval used residential respite in Australia \textsuperscript{16}

Why don’t some caregivers use out of home respite services?
Andersen Behavioural Model of Service Use\textsuperscript{17,18}

- **Predisposing**
  - Being a spousal caregiver\textsuperscript{16};
  - English second language
  - Beliefs – Health
  - Caregiving and family

- **Enabling/Impeding**
  - Not knowing where to find services

- **Need**
  - CR Behavioural Problems
  - CG disturbance at
  - CR functional problems\textsuperscript{16}

Non-Use of Out of Home Respite Services

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• Health **beliefs** have low correspondence with health service use **behaviours**\(^{19}\)

• Attitudes towards outcome of specific behaviour better predictor of health service use behaviour\(^{20}\)

• Knowledge of caregiver beliefs about respite services may:
  – inform strategies to address non-use of particular services
  – improve the success of implementing clinical practice guidelines as part of community care pathways
• **Lack of research exploring the following:**
  – What are the roles of different kinds of caregiver beliefs?
  – How do caregiver beliefs contribute to service non-use?
  – How do beliefs interact with (or inform us about) other factors contributing to service non-use?

• **Aim:** Identify factors that are associated with caregivers *not* utilising out of home services for respite
### Survey Items

<table>
<thead>
<tr>
<th>Stigma Beliefs: 4 items</th>
<th>Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Embarrassing to take CR out in public; Self conscious when in public with CR; Avoid company in home; Easy to have guests in home*</td>
<td>4 point scale 1 SD to 4 SA; Dementia Stigma (/24)</td>
</tr>
<tr>
<td>Dementia is a type of mental illness; I feel embarrassed about CR’s memory problems; I feel embarrassed about CR’s behaviour problems</td>
<td></td>
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<table>
<thead>
<tr>
<th>Treatment Beliefs: 5 items</th>
<th>Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early treatment can delay progression; Delaying treatment has negative effect; Medication slows deterioration; Effective treatments are available (Bond et al., 2005). A variety of treatments are available (Authors, unpublished)</td>
<td>4 point scale 1 SD to 4 SA; Treatment Score (/20)</td>
</tr>
<tr>
<td>Survey Items</td>
<td>Scoring</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Normative Beliefs</td>
<td>Family - Caregiving for CR is a personal duty; I feel morally bound to provide care</td>
</tr>
<tr>
<td></td>
<td>Government - The government should: provide more money for respite programs and services to assist carers; help families care for persons at home</td>
</tr>
<tr>
<td>Behavioural Beliefs</td>
<td>Service Use will lead to negative (or no positive) outcomes.</td>
</tr>
<tr>
<td></td>
<td>Use may: lead to CR deterioration; cause conflict with CR; or provide no benefit to CR</td>
</tr>
</tbody>
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### Service Beliefs – TRA and TPB

<table>
<thead>
<tr>
<th>Control Beliefs</th>
<th>Survey Items</th>
<th>Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CR reluctance or refusal: My family member/friend refuses/does not want to attend a day centre (Authors, 2010a, b).</td>
<td>5 point scale; 1= A or SA; 2= D, SD or DK to any belief</td>
</tr>
<tr>
<td></td>
<td>Access: I don’t know how to access services; or not available when I need them; or not close to where I live; or waiting times are too long</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Suitability – Can’t provide for CR physical or behavioural needs (Authors, 2010a, b).</td>
<td></td>
</tr>
</tbody>
</table>
• **Negative Behavioural, Normative and Control Beliefs** will be associated with day care and RRC non-use

• **Negative Service Beliefs** will be more strongly associated with *non-use* than negative health beliefs
Survey of Caregivers

• Convenience sample (paper based survey)

• Help-seeking caregivers of people with Dementia

• 152/294 returned completed questionnaires (51.7%)
Expanded Andersen Behavioural Model of Service Use

**Predisposing Characteristics**
- Demographics: Age; Gender; Caregiver relationship; Co-residency; Language spoken
- Beliefs: Health Beliefs
  - Behavioural, Normative, and Control Beliefs

**Enabling/Impeding Factors**
- Personal: Income, education, family member/friend to navigate
- Community: Geographic region; Service provider to navigate
- CG need: Zarit Burden Screener; CES-D
- CR need: ADLS; Behaviour; Cognitive status

**Non-use of Day and RRC Services**

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Results – Respite Service Use

- 22 (19.5%) not using any in or out of home services for respite
- 50 (44.2%) not using day care
  - 51 (45.1%) reported an unmet need
- 68 (60.2%) not utilising RRC
  - 66 (58.4%) indicated an unmet need for RRC
Results

Caregivers
- 57.5% Spousal
- Mean age (66.36 yrs)
- 64.6% female
- 89.4% speak English at home

- CES-D
- 28.3% scores indicative of mild depressive symptoms, 28.2% of more major depressive symptoms
- Zarit Burden
- 7% scores indicating they were experiencing a high degree of burden

Care recipients
- Mean age (78.2 yrs)
- 55.8% female
- 90.3% speak English at home

- 77% required at least some assistance with their ADLs
- 58% occasionally or frequently exhibited behavioural problems
- 22% had a problem with wandering.
- moderate degree of cognitive impairment (M=19.7; SD 5.39) 46
### Profile of Day Care Non-Users

<table>
<thead>
<tr>
<th>Andersen Model</th>
<th>Factors</th>
<th>Day Care Non-use</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Predisposing</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CR Refusal/Reluctance</td>
<td>12.11</td>
<td>3.52-41.64*</td>
</tr>
<tr>
<td>CG Expects Negative or no positive outcomes</td>
<td>13.11</td>
<td>3.75-45.89*</td>
</tr>
<tr>
<td>CG Access Beliefs</td>
<td>0.21</td>
<td>0.06-0.78*</td>
</tr>
<tr>
<td><strong>Enabling</strong></td>
<td>Assistance to Navigate</td>
<td>0.26</td>
</tr>
<tr>
<td><strong>Need</strong></td>
<td>CG Depression (CESD)</td>
<td>1.21</td>
</tr>
<tr>
<td>CG Zarit Burden</td>
<td>0.86</td>
<td>0.69-1.08</td>
</tr>
<tr>
<td>CR ADL</td>
<td>1.16</td>
<td>0.25-5.45</td>
</tr>
<tr>
<td>CR Cognition</td>
<td>0.99</td>
<td>0.87-1.13</td>
</tr>
</tbody>
</table>
## Profile of RRC Non-Users

<table>
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<tr>
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<th>RRC Non-use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Predisposing</td>
<td>CR Refusal/Reluctance</td>
<td>1.512</td>
</tr>
<tr>
<td></td>
<td>CG Expects negative or no positive outcomes</td>
<td>6.15</td>
</tr>
<tr>
<td></td>
<td>CG Access Beliefs</td>
<td>1.18</td>
</tr>
<tr>
<td>Enabling</td>
<td>Assistance to Navigate</td>
<td>0.67</td>
</tr>
<tr>
<td>Need</td>
<td>CG Depression (CESD)</td>
<td>1.10</td>
</tr>
<tr>
<td></td>
<td>CG Zarit Burden</td>
<td>1.21</td>
</tr>
<tr>
<td></td>
<td>CR ADL</td>
<td>1.68</td>
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<td></td>
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Discussion

• First study using theory to compare role of different kinds of caregiver beliefs, regarding *non-use* of out of home respite services
• Negative service beliefs are the strongest correlates with *non-use* of respite services
• Non-use likely to persist unless caregivers believe that service use will be beneficial for the person with dementia to whom they provide care
• Need improvements in service quality and promotion
Limitations

• Small convenience sample
• Sample may not represent need of caregivers who are yet to actively seek support
• Sample under representative of caregivers from remote geographical regions and of Aboriginal or Torres Strait Islander communities.
Future Directions

• Promotion of respite services could be improved by highlighting positive outcomes for care recipients as well as for carers
• Need to improve our understanding of preferences of people with Dementia regarding what makes day centres more appealing
• Ways to build trust & confidence and improve RRC image and outcomes

• Identify successful strategies to facilitate transitions from *non-use* to use

• Longitudinal research designs to establish causative relations
References


21. Authors. (2010a). 'I want to…keep Mum out of a nursing home for as long as I can… but I have to take a break': The beliefs that caregivers of people with dementia associate with the use residential respite care. *Under review*.

22. Authors. (2010b). 'Sure I need a break…but she would have to get something from it too': The beliefs that caregivers of people with dementia have regarding the use of day centres for respite. *Under review*.