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Why caregivers of people with dementia don't utilise out-of-home respite services

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Abstract
Carers of people with dementia consistently report an unmet need for respite. Despite this, the overall proportion of carers who utilise available day centre, in-home and residential respite programs tends to be low and, even then, use is often delayed and only at very low intensities. In order to support carers in appropriate and supportive use of respite services, program planners and service providers need a good understanding of the factors influencing use and non-use of respite services. With this in mind, a community based survey of 152 help-seeking caregivers of people with dementia (NSW, Australia) was undertaken to establish what variables make the use of day, in-home and residential respite services difficult for caregivers. Results from multivariate logistic regression of survey data reveal that factors such as refusal of the person with dementia to attend services, and low perceived utility of services for the care recipient with dementia, are significantly correlated with caregivers not utilising available services for respite. Such results highlight that whilst the focus of respite services has legitimately emphasised the needs of caregivers for a break, low utilisation of services is likely to persist unless caregivers believe that service use will also be acceptable and of benefit to the person with dementia to whom they provide care.

Keywords
respite, caregivers, people, dementia, why, don, services, t, utilise, out, home

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

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Dementia

• 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\(^3\)
Dementia and Caregiving

- 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 - 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}

Non-Use of Out of Home Respite Services

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

- Not knowing where to find services

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

Predisposing

Enabling/Impeding

Need
What about service beliefs?

- Health **beliefs** have low correspondence with health service use **behaviours**\(^1\)
- Attitudes towards outcome of specific behaviour better predictor of health service use behaviour\(^2\)
- 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
Rationale for Study

• 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
## Beliefs tested – Health Beliefs

<table>
<thead>
<tr>
<th>Survey Items</th>
<th>Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stigma Beliefs: 4 items</strong></td>
<td>4 point scale 1 SD to 4 SA; Dementia Stigma (/24)</td>
</tr>
<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></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>
</tr>
</tbody>
</table>

| **Treatment Beliefs: 5 items** | 4 point scale 1 SD to 4 SA; Treatment Score (/20) |
| 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) | |
## Service Beliefs – TRA and TPB

<table>
<thead>
<tr>
<th>Survey Items</th>
<th>Scoring</th>
<th>Survey Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normative Beliefs</td>
<td>Family - Caregiving for CR is a personal duty; I feel morally bound to provide care.</td>
<td>4 point scale (SD to SA); 1= A or SA; 2= D, SD or DK</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>
<td>Total Family Beliefs (/8)</td>
</tr>
<tr>
<td>Behavioural Beliefs</td>
<td>Service Use will lead to negative (or no positive) outcomes.</td>
<td>5 point scale; 1= A or SA; 2= D, SD or DK to any belief</td>
</tr>
<tr>
<td></td>
<td>Use may: lead to CR deterioration; cause conflict with CR; or provide no benefit to CR</td>
<td></td>
</tr>
<tr>
<td>Control Beliefs</td>
<td>Survey Items</td>
<td>Scoring</td>
</tr>
<tr>
<td>----------------</td>
<td>--------------</td>
<td>---------</td>
</tr>
<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>
Research Hypotheses

• **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

**Need Factors**
- **CG need**: Zarit Burden Screener; CES-D
- **CR need**: ADLS; Behaviour; Cognitive status

Non-use of Day and RRC Services

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• 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

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# 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>Predisposing</td>
<td>CR Refusal/Reluctance</td>
<td>12.11</td>
</tr>
<tr>
<td></td>
<td>CG Expects Negative or no positive outcomes</td>
<td>13.11</td>
</tr>
<tr>
<td></td>
<td>CG Access Beliefs</td>
<td>0.21</td>
</tr>
<tr>
<td>Enabling</td>
<td>Assistance to Navigate</td>
<td>0.26</td>
</tr>
<tr>
<td>Need</td>
<td>CG Depression (CESD)</td>
<td>1.21</td>
</tr>
<tr>
<td></td>
<td>CG Zarit Burden</td>
<td>0.86</td>
</tr>
<tr>
<td></td>
<td>CR ADL</td>
<td>1.16</td>
</tr>
<tr>
<td></td>
<td>CR Cognition</td>
<td>0.99</td>
</tr>
</tbody>
</table>
## Profile of RRC Non-Users

<table>
<thead>
<tr>
<th>Andersen Model</th>
<th>Factors</th>
<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><strong>CG Expects negative or no positive outcomes</strong></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><strong>CG Depression (CESD)</strong></td>
<td>1.10</td>
</tr>
<tr>
<td></td>
<td><strong>CG Zarit Burden</strong></td>
<td>1.21</td>
</tr>
<tr>
<td></td>
<td>CR ADL</td>
<td>1.68</td>
</tr>
<tr>
<td></td>
<td>CR Cognition</td>
<td>1.06</td>
</tr>
<tr>
<td></td>
<td>CR Cognition</td>
<td>1.512</td>
</tr>
</tbody>
</table>
• 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


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.*