Respite Care in Dementia: Consumer Perspectives

Professor Elizabeth Beattie
Dr Elaine Fielding
Queensland University of Technology and DCRC: Carers and Consumers

Additional Project Team Members

• **Investigators:**
  – Assoc Prof Christine Neville, University of Queensland
  – Ms Meredith Gresham, HammondCare

• **Research Assistants:**
  – Margaret Readford
  – Mitchell McMaster
**Project History, Background and Significance**

- It is estimated that 60% of Australians with dementia are living within the community (Access Economics, 2009)

- A high proportion of the care for this growing population falls on spouses and families.

- The burden and stress placed on informal carers by their roles has been shown to place them at greater risk of physical and psychological health problems (Musil, Morris, Warner, & Saeid, 2003; Shanks-McElroy & Strobino, 2001).

**Cont.**

- Respite is a **key service** to assist people living with dementia to remain living at home.

- **Varying levels of satisfaction** with, and utilization of, respite are reported by consumers.

- While Government funding in Australia for respite care has increased in recent years, utilization of residential respite remains low.
Significance

- No systematic Australian study in the last 15 years has sought carer feedback about the respite experience or evaluated what carers consider responsive and helpful respite for themselves and the person with dementia.

- Survey prompted by carer request. Survey design and pilot testing were informed by early carer participation facilitated by the CDRN.

Study Background and Development

- Broad focus → broad survey of carers

- To capture less common experiences or types of respite → large number of participants

- To cover people from different areas → national survey
Survey Background and Development

- Participants: Carers of people with dementia in the community

- Survey: Mixture of short- and long-answer questions, choice of online or phone interview

- Recruitment: Multi-method, including working with Commonwealth Respite & Carelink Centres and peak bodies (Alzheimer’s Australia, Carers Australia), e-newsletters, and attendance at conferences

Survey Results

- **N = 337** (64 phone and 273 online) between late April and September.

- For this preliminary analysis, working with first 307 cases, representing all Australian states and territories.

- Most respondents were the spouse (60%) or child (33%) of the person with dementia.

- The majority (84%) lived with the person they cared for and cared for them on a full-time basis (90% at least 40 hours a week).
Survey Results

• More than three-quarters (77%) of respondents had used some type of respite care.

![Graph showing the distribution of respite care types]

Survey Results

Satisfaction with In-Home Respite Service

Carers

- Very Satisfied: 68%
- Satisfied: 24%
- Neutral: 3%
- Dissatisfied: 3%
- Very Dissatisfied: 2%

Persons with Dementia

- Very Satisfied: 42%
- Satisfied: 34%
- Neutral: 18%
- Dissatisfied: 5%
- Very Dissatisfied: 1%
Survey Results

Satisfaction with Care Centre Respite Service

Carers
- Very Satisfied: 72%
- Satisfied: 23%
- Neutral: 5%
- Dissatisfied: 2%
- Very Dissatisfied: 1%

Persons with Dementia
- Very Satisfied: 52%
- Satisfied: 29%
- Neutral: 14%
- Dissatisfied: 3%
- Very Dissatisfied: 2%

Survey Results

Satisfaction with Residential Respite Service

Carers
- Very Satisfied: 1%
- Satisfied: 8%
- Neutral: 39%
- Dissatisfied: 3%
- Very Dissatisfied: 49%

Persons with Dementia
- Very Satisfied: 4%
- Satisfied: 26%
- Neutral: 6%
- Dissatisfied: 35%
- Very Dissatisfied: 29%

Translating dementia research into practice
Survey Results: Open-Ended Questions

• **Reasons for using respite:**
  – “It was essential rather than helpful. I would have gone completely around the bend if I hadn’t have got it.”
  – “To get peace and quiet and getting out to get things done...”

• **Positive outcomes for carer:**
  – {with residential respite} “You can just totally switch off and it’s just that peace of mind.”
  – {care centre respite} “It enables me to have time to do other things rather than taking care of my husband 24 hours of the day. I find it very stressful to be always on call.”

• **Positive outcomes for person with dementia:**
  – {care centre} “Gives him social interaction and a break from me.”
  – {care centre} “I believe (xxx) needs more exercise and stimulation that I can give him at home by myself. I just run out of time and energy!! At the centre (xxx) plays table tennis, has outings and attends the "... Centre" to make "stuff" twice a month with the group.”

• **Negative outcomes for carer:**
  – Most answers centred around scheduling and availability.

• **Negative outcomes for person with dementia:**
  – {In-home} “Very disruptive for xxx, respite workers made him very angry.”
  – {care centre} “xxx stated he would keep going to the (name of organisation) centre to give me a break but that he didn’t find it enjoyable. At (name of organisation) centre he said all the people were too old and were deaf and he couldn’t talk loud enough to make them hear.”
  – {residential} “It has been extremely unhelpful in that, with it being his first experience and it being a bad experience it is going to be very hard to get him to agree to go into residential care again.”
Survey Results: Open-Ended Questions

- Carer suggestions for improvements:
  - Increased flexibility, availability of respite available e.g., weekend/evening in-home or care centre hours, residential periods of less than two weeks, shorter waiting times
  - Better training for care staff (dementia-specific)
  - More focus on activities for persons with dementia while in respite
  - Increased availability of “cottage” or “home-style” respite services

Survey Results

- Seventy-one respondents had never used any type of respite service.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never needed to use</td>
<td>29</td>
</tr>
<tr>
<td>Person with dementia refuses to use</td>
<td>13</td>
</tr>
<tr>
<td>Don’t think it would be helpful to PWD</td>
<td>11</td>
</tr>
<tr>
<td>Don’t know enough about respite services</td>
<td>4</td>
</tr>
<tr>
<td>Don’t think it would be helpful to carer</td>
<td>3</td>
</tr>
<tr>
<td>Times or days available are not convenient</td>
<td>3</td>
</tr>
<tr>
<td>Preferred type not available in my area</td>
<td>14</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
</tr>
</tbody>
</table>
Survey Results

• Other reasons for not using respite include:
  – Financial reasons
  – Unwillingness to have stranger in home
  – Waiting lists, frustration of arranging it

• Also noted by carers:
  – Some people with dementia can be left alone
  – Some carers have strong family support/respite
  – Some people with dementia are reluctant to admit they need help

Carers were also asked if they had ever been refused respite care; 54 (18%) reported that they had been.

• Majority (34) had been refused residential respite, but some had also been refused in-home and care centre respite (12 each).

• Most frequent reason for refusal was lack of availability of spaces, e.g. bookings for some residential care spaces need to be made 12-24 months in advance.
Survey Results

- Other refusals stemmed from the respite service being unable/unwilling to deal with a physical or behavioural issue with the person with dementia.
  - Examples include incontinence, wandering, and entering other residents’ rooms.

- Some carers reported considerable stress at being unable to secure respite when needed.

Policy Implications

- Current system is working well for some carers and the person they care for (particularly for in-home and care centre respite services).

- However, for those without access (e.g. because of geographical, financial, or physical/behavioural constraints), the caring burden can be very high.

- Inflexibilities in the system, particularly for residential respite, make it not ideal for many carers and the person they care for. E.g. while bookings for residential respite must often be made a year in advance, approval of funding for a given stay may not come until two months in advance of the stay, making the carer anxious about finances.