Summary of “Respite Care in Dementia: Carer Perspectives”
Report on Full Study
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Dementia Collaborative Research Centre:
Carers and Consumers

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The cost of care of people with dementia is a significant portion of the government health budget, and this cost will continue to grow as the population ages over the next 50 years. Continuing to care for people with dementia in the community, rather than in aged care facilities, entails considerably lower costs and is generally preferred by people with dementia and their family carers. One of the crucial government-funded programs that support unpaid family carers to continue caring in the community is respite care in its various forms. This report describes the results of a recent survey of carers of people with dementia concerning their experiences with respite services.

The study consisted of a cross-sectional survey administered both online and by telephone during the period April to September 2011. Carers of family members with dementia living in the community were recruited through websites, flyers, mailed (or handed out) postcards via numerous carer and dementia support organisations (such as Carer’s Australia and Alzheimer’s Australia), as well as respite providers, Commonwealth Respite and Carelink Centres, and online newsletters such as Dementia News.

The survey contained both closed- and open-ended questions about carers’ knowledge of, use of, and satisfaction with government-funded respite services. Also asked were questions about other types of formal and informal support carers received in caring for the person with dementia. Finally, the survey included two short questionnaires to assess caregiver burden and depression and two assessments concerning the behavioural and psychological symptoms of dementia of the person with dementia.

Results

In total, 336 carers of a family member with dementia responded to the survey, with 64 being interviewed by phone and 272 responding online. Most responding carers were either the spouse (58%) or the child (34%) of the person with dementia. Respondents were well distributed across Australia, with each state being represented by at least 30 carers.

Most of the people with dementia being cared for had at least moderately severe dementia. Carers displayed substantial levels of burden and had rates of depression much higher than those in the general population.

While many carers reported receiving help from family and friends in caring for their relative with dementia, nearly three-fifths (59%) had no informal (non-government) support. Furthermore, only a relatively small portion (just less than one-third) of the carers felt that they had a relative or friend they could call on to care for the person with dementia for a few days if something unexpected came up.

Over three-quarters (77%) of the carers had used some kind of respite service in the last year, with many of those having used multiple types of respite. Approximately half had used each of In-Home, Care Centre and Residential types, with 6% using Emergency and 19% an ‘other’ type of respite in the last year. Reasons for using respite care varied and included: needing a break from the caring role; enabling socialisation or travel; allowing carer to work; attending to personal health needs; or performing household duties, such as regular shopping. Carers were grateful for the respite services they received, and satisfaction from the carer’s perspective was high; at least 85% were either satisfied or very satisfied with each type of
respite used. In addition, the majority (over 90% for all respite types) of carers wanted to continue using the respite services recently received. When carers provided proxy reports for the person with dementia’s satisfaction, levels were somewhat lower, especially for residential respite (62% satisfied or very satisfied).

Whereas respite normally was helpful from the carer’s point of view, some carers did report negative experiences. For example, some carers utilising in-home respite were frustrated by needing to repeatedly orient frequently changing respite care workers to their home and to the needs of the person with dementia. Most carers also thought that the respite experience had been helpful to the person with dementia, especially in terms of increased socialisation and participation in activities. The notable exception was for residential respite, which many carers characterised as having been unhelpful in terms of the care, activity and socialisation levels of their family member with dementia.

Fifty-eight (17%) of the carers responding had been refused some (or multiple) type(s) of respite service. Reasons for this refusal included: being over their annual limit for that particular service (a small number of carers); lack of place availability (a relatively large number, especially for residential respite); lack of dementia-specific places; issues related to physical or behavioural conditions of the person with dementia (e.g. incontinence, aggression); and did not meet eligibility criteria (e.g. age of person with dementia).

Among those carers who had never used respite (n = 77; 23%), the most frequently given reason (multiple reasons possible) was “never needed to use respite,” followed by “person with dementia refuses to attend respite.”

Discussion

The crucial role of respite in the lives of carers of people with dementia living in the community was confirmed in this study. Many carers expressed that they would not be able to continue caring at home without respite services. While the current system of government-funded respite care is working for many carers, it is definitely not working for others. Barriers to the effective use of respite care identified in this survey included: lack of appropriate information; financial hardship (particularly with regard to residential respite); cultural impediments (such as lack of language-specific respite care workers for people with dementia who have reverted to their first language); geographic variability of services; family conflicts and refusals to accept respite on the part of the person with dementia; and factors related specifically to the person with dementia particularly, age (too young to qualify for specific service) or behavioural or physical care needs.

Many carers reported doing well with the respite services that had been receiving; and some were able to access multiple types of respite in order to meet their needs. Other carers were severely limited by either the types and/or the quality of the respite available to them. For example, some carers noted that respite became unavailable to them just as their need for it rose due to the increasing complexity of the physical or behavioural care required by their family member with dementia. Of note, some carers were so concerned by the quality of the respite care received that they feared for the health or safety of their family member and discontinued using the service. Other carers emphasised that they might have preferred a different, better, or more flexible respite service, yet intended to continue using the one they were using because that was what was available to them.

Due to the recruitment methods used, the responding carers may not be representative of all carers of people with dementia in Australia. In particular, carers with no or limited
information about respite care, or those who are not connected to carer’s or dementia support organisations may not have been well represented among the survey participants.

Policy Implications

Carers were asked in the survey whether they had any suggestions for changes to respite services to better meet their needs. Many of their suggestions have direct implications for policy, especially in light of the recently announced aged care reform package entitled “Living Longer. Living Better.” [DOHA, 2012]. Other policy implications stem from the overall results of the survey. The authors recommend the following:

1) That the Australian Government Department of Health and Ageing endorses, in-principle, the recommendations of this report.

2) That the Australian Government Department of Health and Ageing implement the following recommendations from the “Living Longer. Living Better.” package as confirmed by the survey results:

   a. Provide for greater flexibility in current respite care service models to adequately meet assessed carer respite needs. Frequently, carers in this survey expressed that nothing was wrong with the respite they received except that they could use more of it or it could be more flexible. Seemingly arbitrary conditions such as requiring a two-week minimum stay for residential respite or prescribing specific starting hours for in-home respite were described by carers as very frustrating. For example, one carer needed to leave for work at a particular time in the morning, but was unable to get an in-home respite care worker that early, so had to leave the person with dementia alone and unsupervised. Another concern among carers was the lack of availability of respite care during the evening and weekends. Not being free to socialise with friends or family members who work or are in school during normal day increased carers’ social isolation.

   b. Support innovation in new models of effective respite care for carers of people living with dementia, particularly including: carers of people living with advanced dementia; those with high physical and/or high behavioural care needs; for special needs groups as defined in the Aged Care Act (1992), and younger people living with dementia. Traditional residential respite care (long-term stays in a residential aged care facility) generated the most complaints among the carers surveyed. Those who had experienced alternatives, such as a more home-like “cottage” style respite, were much more positive about their and their relative with dementia’s experience. One model highly praised by carers involved the carer (normally a spouse) going to stay at a respite facility with their family member, being engaged in separate activities (with other carers) during the day, and re-joining their family member in the evening. Other popular models included in-home overnight respite and regular weekend (2-3 nights) respite periods in a familiar location.

For carers in this survey whose relatives were in the advanced stages of dementia or who had high physical and/or high behavioural care needs, being refused respite services because of their relative’s care needs provoked anxiety and increased burden, making some consider placing their relatives in
residential care. With access to appropriate respite services, these carers might be able to continue caring in the community for considerably longer.

Carers in rural areas, carers of those with younger onset dementia, younger carers, carers from culturally or linguistically diverse (CALD) backgrounds, and indigenous carers all noted that their needs were not being met by the current system of respite care. For example, one carer from a CALD background had great difficulty with respite services until they were able to access a service with a care worker who spoke the same (non-English) language as the person with dementia.

c. **Standardise access to respite across regions and the urban-remote continuum within Australia.** This survey documented substantial variability in levels of access to respite services across states, regions and between urban and remote areas of Australia. For example, waiting lists for residential respite places varied across areas from as short as a few weeks to as long as eighteen months.

d. **Streamline the referral process by which carers are informed about what respite services are available to them.** Carers in this survey expressed that the process through which they became aware of services was sometimes confusing and overwhelming. In addition, very few mentioned GPs as the source of their initial information about respite services. Several noted frustration that their GP had not mentioned the availability of such services.

e. **Promote best practice respite care models, including staff training and performance through the provisions of the Community Care Common Standards.** Carers in this survey expressed concern about the lack of dementia-specific training among respite care workers. In one example in the in-home respite environment, the care worker did not seem to understand why the person with dementia needed help with personal hygiene tasks. Carers noted additional concerns with regard to the quality of care in the residential respite environment, reporting such errors as inappropriate medication and/or misunderstandings about care needs (e.g. toileting schedules).