

# What Do Rural Dementia Caregivers Find Stressful?

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## Abstract

**This study aimed to determine what carers of people with dementia in rural Australia found stressful in their caring role. It was part of a broader mixed methods study exploring carer depression, anxiety and stress and utilisation of formal community support services. The findings suggest that carer stress varies among individuals, but that a predominant source of stress is the unremitting burden experienced when caring for someone with dementia. Improved utilisation of support services in rural areas and tailoring services to individual carers dependent on the source of stress is recommended.**

## Keywords

Caregiver Burden, Rural, Dementia

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## 1. Introduction

The number of people with dementia in Australia is predicted to exceed 1 million by the year 2050 [1]. Changes to cognitive function in dementia include alterations in memory and personality and the emergence of behavioural and psychological symptoms, such as aggression, agitation, wandering and sleep disturbance [2] [3]. The behavioural and psychological symptoms of dementia (BPSD) present challenges for those caring for someone with dementia, regardless of the setting. Community care provided by informal caregivers who are usually family members, is increasingly utilised with 70% to 80% of people with dementia now being cared for at home [4]. Recent figures show that use of long term care has decreased in the last decade in Australia [5].

Carers of people with dementia are reported to have poorer health than carers of people without a cognitive

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deficit [6] [7], due to sleep deprivation, physical demands and social isolation associated with the caring role [8]. Dementia carers experience higher rates of depression, anxiety and stress than other carers [9] [10]. A recent study found that the stress associated with caring for someone with dementia results in some carers contemplating suicide [11].

Some studies have found a positive correlation between the severity of BPSD and the well being of carers [3] [10]. Despite this, many dementia carers do not receive any assistance in their caring role [12] and paradoxically, dementia specific community services report poor utilisation and short or non-existent waiting lists [13]. A recent randomised clinical trial reported that a psychological support program for dementia carers dramatically reduced carer depression and anxiety, which in turn allowed the dementia patient to remain at home for longer [4]. The study tailored the support program to identify each dementia carer's source of stress in their caring role [4].

Factors other than the severity of BPSD, such as financial burden, lack of access to formal care and support and lack of social engagement has been poorly researched in rural Australia. There are very few, if any, studies which report dementia carers personal stresses associated with the caring role in a rural specific area. As part of a broader study, which explored dementia carer stress, depression, anxiety and service utilisation, this paper reports what dementia carers found particularly stressful about their caring role.

## Background

The study was conducted in North Eastern Victoria where there was anecdotal evidence of dementia carer stress and poor referral mechanisms. The findings reported here were part of a broader, exploratory mixed methods study, which explored the emotional wellbeing of rural dementia carers and carer distress in relation to the BPSD exhibited by the person with dementia. The study also determined the utilisation of services by dementia carers and appropriateness of use.

The broader study incorporated the Depression, Anxiety and Stress Scale (DASS) and the Neuro-Psychiatric Inventory Questionnaire (NPI-Q). Briefly the DASS is a validated self reported 21 item scale that measures respondents levels of depression, anxiety and stress [14] [15]. The NPI-Q is also a validated tool with 12 items that measure care recipients symptoms and carer distress in relation to the symptoms [16]. Both measures have been widely used in Australian research. In addition to these tools, 17 common community services were listed and respondents were provided with responses that ranged from 1) I do or have used the service; 2) this service has been offered but I have not used it; 3) I have not used this service; and 4) to my knowledge this service is not available.

The full results of the broader study have been previously reported [10] [13], which showed that many of the respondents had moderate to severe levels of stress (48.7%), anxiety (25.6%) and depression (38.5%). In addition, particular BPSD of care recipients, such as aggression, was highly prevalent and caused high levels of distress for carers. Of the sample of carers who reported moderate to severe depression, anxiety and stress, less than half utilised commonly available services.

The results reported here are from the same sample of dementia carers as the broader study. Reported here are the carers written responses to an open ended question, "Is there anything at all you find particularly stressful in your role as a carer?", which has not previously been reported.

## 2. Methods

### 2.1. Participants

Participants in the study were informal community carers of people with dementia in rural Victoria. Carers were opportunistically recruited through a variety of agencies, including Family Care Carer Support Services, Home and Community Care Services, Community Nursing and through medical clinics. There were 16 services who agreed to recruit participants for the study. Carers who used these services between the months of December 2012 and January 2013 were invited to participate through provision of a plain language statement outlining the study aims and a survey. They were asked to complete the survey and to return it in a paid envelope (included). Staff employed at each service, recruited participants for the study by identifying carers. The staff were requested by the researchers, to be sensitive and to exclude carers who they felt would be further burdened by participating.

## 2.2. Data Analysis

As part of a larger survey participants were asked to elaborate on anything they found particularly stressful in their caring role. The short written responses were analysed collaboratively by both researchers plus an independent researcher experienced in qualitative data analysis. No software was used in the analysis due to the small number and length of the responses. All researchers examined the written responses and identified recurrent themes, which are illustrated by quotes.

Two researchers were nurses, one from Australia and one from Canada, and the third researcher an Australian Social Worker. The Canadian researcher had no prior knowledge of the study before analysing the responses and was therefore not biased by the findings from the broader study. Throughout the process of analysis, data and emerging themes were clarified in discussions between the researchers. Rigor was enhanced through the researchers' perspectives of professional experience with caregivers of people with dementia.

## 2.3. Ethical Approval

Ethical approval to conduct the project was granted by the University of Melbourne Human Research Ethics Advisory Group (No. 1328507.2). The project was conducted in accordance with the Declaration of Helsinki Ethical Principles for Medical Research Involving Human Subjects.

## 3. Methods

Thirty nine dementia carers completed the survey and responded to the question by elaborating on aspects that they found stressful in their caring role. Carers were predominately of female gender ( $n = 30, 77\%$ ) and identified as daughters or wives of the care recipients, with only 9 male carers. Twenty respondents were 65 years and under and 19 were over 65 years of age (ranged from 43 to 87 years). The median time spent as a carer was 4 years (ranged from 1 - 5 years).

Four main themes were identified from the text analysis which included carrying the load, the impact of the behavioural and psychological symptoms of dementia on the carer, carers feelings of powerlessness and inadequacy in their caring role and grief and loss of the care recipients character and their relationship. Many of the respondents identified more than one theme as a cause for their stress.

### 3.1. Carrying the Load

Carrying the load was the area most frequently cited by respondents as particularly stressful in their caring role. Fifteen carers of varying ages, both genders and from all locations mentioned this aspect of caring, while many spoke about their struggle to maintain balance in their lives. Two carers identified feeling resentful of being put in a position to have to assume the caregiving role. The unremitting nature of the caring role was experienced as a heaviness, a load to carry that was difficult and lonely, punctuated by lack of sleep and feelings of being unappreciated and unrecognized for all of their efforts. Concomitant with this was the feeling that "life has changed" for the carers. They experienced a sense of loss of their own personal independence and no time for their previous activities as well as feelings of being confined by the carer role that they had assumed, of previous activities or time alone for the carers. Carers frequently expressed that "the job is never done" and that it was hard to do it alone. Common responses included statements such as:

*There are no breaks or holidays...being a carer is the loneliest job in the world.  
I am not able to go anywhere or do very much, I don't feel part of the real world.  
I am unable to get time to myself—mum is demanding more and more attention.*

### 3.2. The Impact of the Behavioural and Psychological Symptoms of Dementia on the Carer

Behavioural and psychological symptoms of dementia (BPSD) were cited as a cause of stress to carers by a third of the respondents. Symptoms such as aggression or anger and repetitive questioning by the care recipient were mentioned most frequently by carers as sources of stress. Written responses included;

*When he can't get his own way—like he wants to go out and I don't he gets very angry.  
Having to deal with the aggression shown by my mother at times towards me, for no reason.  
Constant repetitiveness of day, time and questions.*

### 3.3. Carers Feelings of Powerlessness and Inadequacy in Their Caring Role

Many of the carers expressed feeling inadequate in their role as a carer and guilt or powerlessness in being unable to relieve symptoms or perceived suffering of the care recipient. Others expressed discouragement regarding the lack of progress in treating this illness. Carers of both genders and with varying relationships to the care recipients identified feelings of futility.

*I don't know how to ease her symptoms.*

*I don't get to spend as much time as I would like with my father.*

*I don't like watching my husband suffer.*

### 3.4. Grief and Loss of the Care Recipient's Character and His or Her Previous Relationship

Many of the respondents cited grief related to the loss of the person, or loss of the person's previous characteristics and their previous relationship. When writing about the care recipient, many respondents wrote in the past tense.

*The gradual change in the person's character, especially losing them already to have clear conversations.*

*I ... have found it hard sometimes because of the closeness to the person you are caring for. I am so sorry for her as she was a very outgoing person.*

*Changes in personality.*

## 4. Discussion

The findings from this small project support previous findings from carer studies, that the stress of the caring role is multi-factorial and varied among carers. This demands that support for dementia carers should also be varied and tailored to individual carers, dependent on their individual source of stress.

The unremitting burden of the carer role in dementia care was strongly identified in this study, and has been identified by other studies [8]. The social isolation that results is well recognised [17] and frequently a cause for resenting the carer role. One study, in a similar setting, found that carers do perceive positive aspects to the caring role as well [8], and not all carers in this study cited lack of their own personal time as problematic. However, the constant nature of the role which results in carers feelings of loss of control and isolation is universally recognised by other studies [18]-[21].

The stress caused by the behavioural and psychological symptoms of dementia (BPSD) of the care recipients, supports the findings from the broader study [10] [13]. Opinion is divided as to whether certain types of behavioural and psychological disturbance in care recipients is associated with caregiver stress. Some studies found a correlation between the severity of the BPSD and dementia carer stress, while others did not find this association [22]. Aggression, agitation and nocturnal disturbance occurs in as many as 80% of people diagnosed with dementia [2]. Each of these behaviours was mentioned by respondents in this study. BPSD has been identified in other studies as a strong predictor of carer stress which results in placement of the care recipient in long term residential care [23]. A literature review also found a strong link between the type of BPSD and carer stress [18], so it may be that many carers in this study were not subjected to the type of BPSD that is particularly stressful, that the carers had resilient characteristics or coping styles, or that the BPSD had not reached a severity to cause distress.

Feeling of inadequacy in the carer role was cited by respondents in this study as a cause for stress. There is not a great deal of literature on carers' feelings of inadequacy, though many publicly available websites for carers, cite feeling inadequate as a common concept. A previous Australian study found that carers of people with dementia were vulnerable to criticism and feelings of inadequacy in their role [24]. Interestingly, this study [24] did not find a correlation between the severity or type of BPSD of the care recipient and carers feelings of inadequacy. Once again, although caring for others can be associated with positive feelings [8] if it is felt to be obligatory or the role exceeds the resources of the carer, feelings of inadequacy may result [24]. Other studies have found that powerless and inadequacy may be related to the carers' personal characteristics and coping style, and therefore not common to all carers [25].

Grief and loss of the characteristics of the person with dementia and the previous relationship with the carer was also identified by the participants in this study as a source of stress. Alzheimers Australia (2014) recognises

this as a common feeling among dementia carers. One recent study referred to this loss as “pre-death” grief and noted that as a scholarly point of view, it is an emerging concept [26]. The grief cited by respondents and supported by the literature review [26] refers to carers witnessing the changes and losses in the person with dementia. Presumably, the closer the previous relationship, the greater the amount of stress felt by the dementia carer.

## 5. Limitations

The small sample size and the constraints presented by the brevity of the responses should be acknowledged as a limitation to the findings. As with all research studies, the application of the findings can only be decided by the end user.

## 6. Implications for Practice

Community care for people with dementia is increasing, with less people being admitted to long term care in Australia [5]. This means the number of carers in the community is increasing. Given that more than half of carers in this study cite the unremitting burden of providing care and loss of their lifestyle as stressful, access to respite care must be improved. Increasing the provision of respite services makes good economic sense, if it delays or prevents the admission of people with dementia into long term care. In addition, the poor utilisation of dementia specific services, suggests that referral pathways require improvement, or further research to determine if the existing services are appropriate, accessible and acceptable to carers.

The variation in causes of stress for dementia carers’ demands that support must be tailored to identify each dementia carer’s source of stress in their caring role. Support programs should not be “one size fits all” but will require adaptations for each individual carer to adapt to the trajectory of the illness of the care recipient. In addition, training and education provided to dementia carers must consider the coping style of the carer, the nature of BPSD of the care recipient and the need to foster positive aspects of the caring role.

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