

ORIGINAL RESEARCH

Life after placement: experiences of older rural caregivers after placing a family member into residential care

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Submitted: 24 June 2008; Resubmitted: 17 August 2008; Published: 15 September 2008

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Rural and Remote Health 8: 1030. (Online), 2008

Available from: <http://www.rrh.org.au>

ABSTRACT

Introduction: The community care philosophy in Australia has led to a number of older people remaining in their own homes, dependant on others for the majority of their care needs. A small number of older people being cared for by a family member or friend will move into residential aged care facilities for full-time care. This article describes a qualitative study that explored the meanings that older rural Australian caregivers gave to their day-to-day lives after their care-receiver had entered full-time residential aged care.

Methods: Semi-structured interviews with seven older caregivers were conducted to gain understandings about their 'life after placement'. Thematic analysis was employed to identify common themes. Quality of life concepts provided the boundaries to the research questions.

Results: The sample included four men and three women. In the study, the men reported spending more time continuing their carer role, while the women reported being more focussed on reconnecting with the community. Both men and women reported that their own health was a major constraint in being able to maintain these two tasks. The findings mirrored those of similar studies with one notable exception: this study highlighted the meanings that caregivers gave to their lives after placement in a more holistic way, as opposed to focussing on caregivers in relation to the residential aged care facility context alone.



Conclusion: This study demonstrated that there are differences found in relation to gender and tasks after in-home caring roles have ended. Worry about loss of driving ability was a major concern in the caregivers' lives. The experiences of the caregivers in this study give a better understanding of what life is like for caregivers after in-home caring has ceased. Understanding of 'life after placement' expands our knowledge about carers and the role of carer. The findings suggest a need for funding and programs for caregivers after their in-home carer role has ended to assist caregivers (particularly men) in reconnecting with people and activities outside their immediate family. The findings may direct rural community development workers to appreciate the challenges that older rural caregivers face when their in-home caring role ends and visiting and socializing is dependant on their ability to drive. This study also offers a perspective for residential aged care staff to consider as they work with families placing an older family member into full-time care. If aged care staff recognise the value of the continuing caring role of the caregiver and integrate them into the care plan, enhanced positive outcomes could transpire for both caregiver and care-recipient.

Key words: caregiver, older people, residential aged care, rural, placement.

Introduction

The community care philosophy in Australia has led to older people remaining in their own homes, dependant on others for the majority of their care needs. In-home caregivers are the foundation of community care¹. In 2003, 2.5 million in-home caregivers provided assistance to 2.1 million people that were older and/or had a disability². Of older people aged 65 years and over, 113 200 reported themselves as primary caregivers³ with the majority of them (83%) caring for their partner. At some point, a small number of older people being cared for by a family member or friend in their own home will move into residential aged care facilities for full-time care. Australia figures show that 11.5% of people aged 65 years and older with a disability are living in cared accommodation, including residential aged care facilities and hostels⁴.

Being an in-home caregiver can impact on health and wellbeing. The Australian Bureau of Statistics² found that more than one-third of Australian caregivers reported that they felt weary, worried and/or depressed, and 15% felt resentful or angry often. Caregivers also reported sleep disruptions and stress related illnesses. Caring has the potential to negatively impact on family relationships and relationships with friends². The challenges of the caring role

are increased by living in a small rural community⁵. Rural communities in Australia often have a higher proportion of older people than major cities⁵. Therefore, rural communities have higher numbers of older people with chronic illness who are being cared for by family members, who are often older themselves³. Older caregivers and rural caregivers can face particular difficulties, for example, lack of services, particularly respite care, lack of support and awareness of their role, lack of psychosocial education, extra expenses and difficulty accessing metropolitan centres for required medical services^{1,5,6}. While independence and self-reliance may be traits of older rural people⁷, vulnerability to the loss of friends, isolation and loneliness are also significant concerns for older rural caregivers¹.

Caregivers' own poor health, high levels of burden, exhaustion and/or increasingly difficult behaviour by the care-receiver lead to the placement of care-receivers^{2,8}. For caregivers, this difficult decision is frequently followed by a continuation of the caring role⁹⁻¹¹. Once a care-receiver has moved into full time residential care, it is reported that while caregivers can feel less burdened by day-to-day care tasks, they can also experience considerable feelings of guilt^{10,12} and often remain involved with their care-receiver^{9,10,13,14}.

Most studies on caregivers after placement of their care-receiver focus on caregivers' experiences in relation to their



changing caring role within the residential aged care context, while the experiences of adjusting to life outside of the residential aged care facility context have received far less attention. The social and emotional needs of caregivers, after in-home caring has officially ceased, has been relatively ignored in the literature. In particular, few studies have gathered qualitative data on caregivers' experiences of life after the placement of their care-receiver into full time residential care, and how this phenomenon affects their day-to-day lives.

This article summarises a qualitative exploratory research¹⁵ project into the experiences of older rural caregivers in a small Victorian town after placement of their care-receiver into full time residential care (placement). Seeking caregivers' views about this phenomenon is relevant in the current climate of interest regarding the ageing population. Through asking caregivers about their experiences of life after placement, an understanding of their lives was obtained. The findings have the potential to assist workers who plan services for, or work with, older rural caregivers after placement.

Methods

Study design

A qualitative exploratory¹⁵ study was conducted using semi-structured interviews to collect data. Objectives included documenting the perceptions of the participants about what was important, what made life better and what made life more difficult, what they liked to do, what were they able to do and what were their hopes, dreams and concerns. To provide some boundaries to the interview process, the guiding questions were loosely based on a subjective quality of life framework^{16,17}.

Sampling

Non-probability sampling¹⁵ was used to target participants who met the criteria of the phenomena being studied and to

allow the researcher to gather information from older rural caregivers who had experience of the issue being studied¹⁵.

Sites

Participants were recruited from the target community, a small rural town in Central Victoria, through residential aged care facilities participating in the study. Initially, all of the residential aged care facilities in the rural shire were contacted and two out of three agreed to assist in recruitment. After obtaining organisational consent, these facilities were provided with a number of packages that contained: a letter of introduction; information about the researcher and the study; and a consent form with contact details.

Criteria

The criteria for selecting participants stipulated that they had experienced being an in-home caregiver and had the ability to share their experiences with the researcher. They were aged between 65 and 85 years and had been caregiver for a minimum of 12 months. The participants had placed their care-receiver into a residential aged care facility at least 6 months previously and lived in the target area.

The criterion of having been a caregiver for 12 months or longer was chosen to target caregivers who had experienced a long-term, in-home caring role. The minimum of 6 months since their care-receiver had been placed into residential aged care was chosen to minimise the potential impact of feelings of guilt and sorrow and allow time for people to experience their new situation and establish new routines. The age limits were chosen to meet the research goal of talking to older people and to reduce the probability of talking to people with early stage dementia. Care staff and residents were not included in this study because the focus of the study was older people who had been full-time in-home caregivers.



Participants

The directors of nursing of the participating facilities approached potential participants meeting the criteria. These caregivers were given an information package. Those who chose to participate signed a consent form and mailed it to the researcher (in the envelope provided) with their contact details. The researcher made a suitable time to meet with and interview each participant. This ensured that the participants' privacy was maintained; caregivers not wishing to participate did not have their details released to the researcher and details of those that chose to participate were not discussed with staff from the facilities involved in the study.

Qualitative research seeks to understand the participants' interpretations and does not claim to be representative. The sample of seven participants in this study represented caregivers from a variety of situations and yielded an abundance of rich, in-depth, comprehensive data. The sample of three women and four men were all Anglo-Australian. The age range of the caregivers was 65 years to 85 years. Five were spouse caregivers and two were adult children caregivers. All the caregivers reported visiting the care-receiver at the residential aged care facility regularly, ranging from three times a day to twice a week.

Data collection

Face-to-face semi-structured or guided interviews^{15,18} were conducted to obtain rich data that represented the perceptions of the participants. Each participant was interviewed at a time and place of their choice; all nominated their own homes. Participants were invited to choose pseudonyms to protect their identity and that of family members. They were also assured that the names of health professionals, facilities and towns would be altered to negate the possibility of participant identification.

The semi-structured interviews were guided by an outline of topics to be investigated, but were very flexible to allow the participant to cover topics, perspectives and meanings that

were important to them and to allow the researcher to explore all the issues raised through the interview process. Open-ended questions¹⁵ were asked which encouraged the participants to describe their subjective experiences, without leading, and to obtain rich data. The interviews ranged in length from 45 to 90 min. The audio-taped interviews resulted in the collection of data, which was transcribed as soon as possible, and before subsequent interviews.

Analysis

The data were analysed using qualitative thematic methods¹⁹ and strategies designed to clarify the meanings and motives of the participants. The aim of qualitative analysis was 'to describe the objects or events to which our data refers ... through describing phenomena, classifying it and seeing how our concepts interconnect'²⁰.

After two interviews, the search for common themes, patterns of behaviour and major issues that encompassed the experiences of the participants and initial coding and memoing¹⁹ began. From that point on, data collection and analysis was conducted concurrently, so that the initial themes and emerging themes could be investigated in the interviews, and continued until no new themes were found. After all the interviews were completed, the recurring themes were reviewed to find connections and grouped together into categories. Each category was reconceptualised by checking back with the literature.

Credibility was maintained through verifying the soundness of the themes through the supervision process, use of a good interview technique, coherence and referential adequacy²¹. The inclusion of a clear description of the sample allows the reader to assess whether or not transferability is applicable to another sample. Dependability was assured through a dense description of the research methods, debriefing with colleagues, the supervision process and the code-recode procedure²¹.



Ethical considerations

Prior to the research being carried out, Ethics approval (number FHEC05/87) was obtained by application to La Trobe University Ethics Committee. Appropriate internal organisational approvals were discussed with the manager of each facility and organisation involved in the study. A facility staff member was asked to nominate only caregivers who, in their professional judgement, were not cognitively impaired. During the research process, all participants were fully informed, via the information sheet, about the type of study, the aims of this study, and the potential benefits of this study.

Results

This article reports on the findings ‘reconstruction of social roles’ and ‘reconstruction of caring roles’ and the sub-theme of how the caregivers’ health impacted on these two tasks.

Reconstructing social roles

Analysis of the data revealed that reconstructing social roles was an important task for the caregivers after their care-receiver had moved to full-time residential care. There was a marked difference between the ways in which women and men perceived this task. Female caregivers described wanting to resume their pre-caring lives and some talked about the importance of ‘being busy’. Male caregivers, however, indicated that they only needed their family for support and, on average, spent more time visiting their care-receiver wives.

The women caregivers in the study described moving on with their lives while maintaining their obligations to their care-receiver. The women caregivers expressed wanting to reconnect with others outside of their immediate family. For example, one caregiver said:

It’s up to you to make contact with people... and you have to have conversation which is the lifeblood you know. (Jean)

The women caregivers described taking up new activities and picking up on previously enjoyed activities and projects that had been put on hold. They talked about making new friends through mixing with people at community events such as church and community organisations. They often went back to activities and organisations to which they had previously been connected. They said that they felt that they could reconnect easily with their old groups, for example:

I’ve found [that] because I’ve lived here for such a long time people come, you know, [and] say ‘Can I come and see you?’ (Marion)

Underlying the value placed on reconstructing social roles was the prevention of loneliness through provision of company, emotional support, having someone to talk to and maintaining self-esteem. The women in this study talked about needing to feel less lonely, needing to keep busy and not wanting to be a burden on their adult children. For example:

I mean it’s very lonely on your own, particularly of a night when you’ve got nobody to discuss anything with.... (Jean)

Reconnecting or seeking new social connections and finding activities to fill their time helped caregivers compensate for what had been lost by creating a sense of gain. The ability to deal with loss in a positive way was an important component of readjustment.

The men in the study did not actively choose to take part in their community or social interactions to the same extent as the women. One male caregiver said:



I'm not very social [I] don't go out and don't go to the pubs... [I] stay at home and between my kids and my work and my wife it's 'bout all I want. (Thomas)

The men caregivers talked about taking up activities such as home renovation and maintenance, and spent more time visiting their care-receiver than the women in the study. They also described spending more time with their adult children while, as the women described, not wanting to be a burden on their children. For the men caregivers, it appeared that they either did not have the skills to create social networks, or were happy to rely on their children to undertake the social role previously undertaken by their care-receiver, or did not place as much importance on reconnecting socially outside of their family relationships.

Reconstructing the carer role

All the caregivers in this study reported continuing the care-giving role. The caring role continued in a variety of different ways and sometimes under difficult circumstances. Caregivers maintained contact with their care-receiver, undertook some caring tasks and took on new caring tasks. The caring role was not relinquished, it was changed. One caregiver said:

I'm still caring for her even though she's not living with me. (Rosemary)

Caregivers in the study reported visiting their care-receiver regularly, ranging from twice a week to three times per day. Men reported, on average, visiting more often than the women. Although the majority of physical care tasks had been delegated to the residential care staff, the caregivers in this study reported helping their care-receiver move around in the grounds outside, helping with feeding, sitting and talking, taking them for trips out and washing clothes. They also reported undertaking new tasks such as negotiating with staff and monitoring quality of care. One caregiver said:

I can go there, I can see her, I can check that everything is all right and if there's things that aren't I can speak up about it. I can help rectify it ... (Harold)

The caregivers in this study also reported feelings of renewed closeness, and continuation of closeness, for example:

I am back to being a daughter... I'm not the mother anymore ... I'm the daughter again and it's beaut', I love it ... (Rosemary)

Caregiver health

The caregivers in this study expressed their concern about their own health. It emerged that their health was impacting on their ability to socialise and their ability to visit their care-receiver. Most of the caregivers reported past, current and future concerns with their own health and, in particular, their ability to continue driving. In the rural area where all the caregivers lived, it was reported that there was very limited public transport and the residential aged care facilities were not within walking distance of the train station. The caregivers talked about what would happen when they were too sick to visit the facility and when they had to stop driving. It was a major concern, especially for the women in the study, for example:

... as long as you are capable of driving, I think that helps to keep you going ... and I think it helps your whole being you know. Because you've got [the ability to drive] it makes you feel good in yourself ... (Jean)

Most of the caregivers talked about their worry about not being able to drive in the future and the impact this would have on their social and daily lives. Some caregivers said they did not want to ask for help from their family but, equally, they did not want to stop visiting their care-receiver.



One participant reported spending \$AU40.00 each week on taxi fares to visit their care-receiver.

Discussion

The challenging role of caring does not end for older caregivers after their care recipient moves into full time residential aged care. Some caregivers find it easier than others to reconnect with social networks in their community. For most of the older caregivers in this study, worry about future driving ability was significant .

This study highlighted a difference in the ways in which women and men reconstructed their social roles after their in-home caring role ended. Female caregivers described wanting to pick up on previously enjoyed activities, keeping busy and not being a burden on their adult children. Male caregivers, however, indicated that they only needed their family for support and, on average, spent more time visiting their care-receiver wives. This suggests that, for the women in the study, the underlying value placed on reconstructing social roles was the prevention of loneliness through provision of company, emotional support, having someone to talk to and maintaining self-esteem¹⁶. This finding is similar to those from studies on spousal bereavement^{16,22,23} that found caregivers began to focus on their own needs, re-establish former connections, join groups and take up new interests after the death of their care-receiver. This study also suggests that men rely on their adult children to maintain social connections after their partner can no longer perform this role²⁴.

Larger studies into social isolation and caregivers after placement, both rural and urban, are now needed to verify whether older men caregivers are particularly at risk of social isolation after placement of their care receiver, what role gender may play in the reconstruction of social roles after placement, and the impact of social support on health.

To assist this group of caregivers in their transition from full-time, in-home caregiver to living alone and having a

minor role in caring for their family members some interventions could be considered.

Services attending the homes of caregivers and care-receivers could withdraw less abruptly after the care-receiver enters a residential facility, in order to give the caregiver a chance to disconnect from relationships that have developed. Services could provide one or two follow-up visits to the caregiver. The service workers are also in an ideal position to provide a form of referral and information about social support agencies and counselling options in the community²³.

Government funding for support groups for caregivers after their formal caring role has ceased should be made available. Support groups could provide another useful connection for caregivers during this life phase. Evaluation of such groups would be needed to ascertain whether support groups for caregivers after placement are useful in increasing wellbeing.

Education for community nurses, social workers and doctors that increases their knowledge of local resources and their ability to recognise the particular needs of caregivers after placement of their care-receiver may increase referral to appropriate allied health workers and supports.

The caregivers in this study continued to fulfil a caring role after placement of their care-receiver. This finding is congruent with previous studies^{11,25} that found caregivers do not generally abandon their care-receiver when they enter a residential aged care facility. Brody¹¹ found that providing some help in the residential aged care setting has positive effects for adult children caregivers, and suggests that continuing to fulfil their responsibilities may mitigate feelings of guilt. So continuing to care could be in order to minimise feelings of guilt for some caregivers. Kelley et al.²⁵ in their qualitative Australian study found that core values such as being faithful and dutiful influenced caregiver involvement after placement.



Larger studies are now needed in the Australian context that include not only the voices of caregivers who are connected with their care-receiver after placement, but also consider perspectives from other stakeholders - residents, facility staff and other family members. Studies that include the perspectives of relatives who do not visit their relatives in residential care may also contribute to our knowledge of this group. These studies may reveal more insights into the lives of caregivers after their full-time caring role has ended.

This study does offer a perspective for residential aged care staff to consider as they work with families placing an older family member into full-time care. If aged care staff recognise the value of the continuing caring role of the caregiver and integrate caregivers into the care plan, enhanced positive outcomes are possible for both caregiver and care-recipient. This could be in the form of a caring role, such as assistance with activities in the facility. Encouraging caregivers to join in activities provided for the residents, ensuring caregivers feel welcome and ensuring good communication and joint decision making is maintained may also contribute to the wellbeing of caregivers.

Most of the caregivers in this study reported worrying about driving ability in the future and the impact this could have on visiting their care recipient. Dissatisfaction with public transport in the rural towns within the research site was expressed. Given that poor health of the caregiver has been linked to a greater likelihood of placement^{10,26}, it was anticipated that the caregivers in this study would have their own health problems. This finding highlights the importance of affordable and accessible public transport for older rural people once they are no longer able to drive themselves safely. Poor public transport has been found to have a negative impact on the quality of life of older people¹⁶ and it is generally recognised in the healthy ageing literature that access to affordable transport is important for the wellbeing of older people²⁷.

Given the fears of loss of driving capacity, public transport issues in relation to older people need to be addressed in rural communities. Funding should be made available for

local governments to run local transport schemes for older members of the community, such as a free taxi scheme for caregivers to travel from their home to the residential facility and back. Such arrangements could reduce caregivers' anxiety about their own deteriorating health and help them visit their care-receiver on a regular basis.

This study supports other studies in the finding that caregivers maintain a caring role after placement. The unique contribution of this study is the findings that after placement female caregivers undertake a process similar to that of bereaved caregivers in relation to reconstructing their social roles, while male caregivers do not place as much importance on reconnecting socially. This study also found that the women and men in the study were forward-thinking about their own health and its impact on their ability to maintain their social connections and/or to visit their care-receiver.

Overall, more research into this group of people is needed because this is an under researched area. Further research would provide more insights into the well-being of this group of people, provide evidence for individual and group interventions, education for health workers, and contribute to policy change.

Conclusion

The experiences of the caregivers in this study give a better understanding of what life is like for older rural caregivers after in-home caring has ceased. Understanding 'life after placement' expands our knowledge of caregivers and the role of caring.

Acknowledgements

The author would like to acknowledge the support of the following people during the research project and writing this article: the caregivers who shared their stories with the researcher; Dianne Cox for her guidance throughout the project; Martin Ryan, Janice Pascal and Virginia Dickson-



Swift for their advice and support during the editing phase of this article.

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