

Caregiving for people with dementia in a rural context in South Africa

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Background: This research is an exploratory pilot study into the phenomenon of caregiving for people with dementia in a rural context in South Africa.

Method: This study used a qualitative method of inquiry for conducting individual interviews with five caregivers to collect the data. The interviews were conducted in the local language of isiZulu. All interviews were audiotaped, and then transcribed into English. Transcriptions were analysed using thematic analysis.

Findings: There were three main emergent themes, namely views and responsibilities of the caregiver, impact of caregiving, and skills and services to assist the caregiver. There were numerous subsidiary themes such as acceptance of the ageing process, a sense of duty and kinship in African culture, and dealing with problem behaviours. Caregiving was also viewed as a character-building experience, and has major implications such as promoting social isolation, restricting activities of daily living, reducing employment and increasing financial burden. Services that would alleviate caregiver burden are education, caregiver training, a financial grant and respite care.

Conclusions: Although these findings are not generalisable, it would appear that caregivers of people with dementia suffer significant psychosocial distress, and would benefit from emotional and financial support. It remains to be seen who will provide this support, but policy-makers as well as governmental and non-governmental organisations will have to factor this into their forward planning to render an effective service for people with dementia and their families. Advocacy groups should also disseminate information on dementia and caregiving responsibility, whilst healthcare professionals should screen for caregiver stress or caregiver burden in individuals caring for people with dementia.

Keywords: caregiving, dementia, rural context in South Africa

Introduction

Caregiving carries with it serious psychosocial sequelae, such as stress, depression and social isolation.^{1–3} In terms of caregiving in a rural context, it is anticipated that the challenges may magnify. This article is an attempt to uncover the difficulties of caring for a loved one with dementia in a rural context in South Africa. It is important to tease out the differences between caregiving and caregiver burden, when looking at the lived experiences of caregivers. Caregiving refers to the activities involved in providing help and assistance to family members who are unable to do so independently for themselves, and precludes any psychological distress that may ensue as a result.⁴ Caregiver burden, in contrast, has been conceptualised as 'a multidimensional response to physical, psychological, emotional, social and financial stressors associated with the caregiving experience', and is thought to impact negatively on caregivers' social, personal and occupational roles.^{5,6}

The incidence of dementia is expected to increase exponentially due to an ageing population worldwide. In the US it was found that 80% of home-based care was being provided by family members for people with dementia.⁷ Although caring for an individual with dementia is a complex task exacting its own emotional toll, 80% of caregivers in a study by Archbold and Stewart reported that they were willing to sacrifice almost anything to be able to care for their loved one at home, for as long as possible.⁸ Caregiving duties often fall to family members, usually a spouse, but increasingly this now falls to adult children or siblings.⁷ A survey conducted by Statistics South Africa of time use for 2010 reported that the participation of women in caregiving activities was thrice the incidence for men.^{5,6} This

finding was not unexpected, as in most cultures women are perceived as nurturing, and so caregiving is often a socially imposed occupation.⁹

Numerous sources of stress and caregiver burdens have been identified by research. These stressors range from having to perform daily self-care tasks, such as bathing and feeding, to coping with adverse problem behaviours, such as wandering off and becoming disorientated in the environment.^{10,11} In two studies it emerged that dementia patients' behavioural problems were one of the most important factors contributing to caregiver burden, with aggression being singled out as the critical symptom that is most often associated with burden.^{12–14} It has been postulated that burden occurs as a result of the continuous vigilance that must ensue as a result of these other related behaviours.¹⁵

In a study undertaken by the Alzheimer's Association, 80% of caregivers to people with Alzheimer's Disorder reported high levels of stress, with almost half of that number having a comorbid depression as well.⁷ These findings were echoed in the study by Schulz *et al.* who found caregiver burden to be correlated with negative health outcomes such as depression, illness and reduced quality of life.¹⁶

It has emerged that caregivers of people with dementia engage in more caregiving tasks than other long-term illnesses, and, as already been reported, have decreased quality of life, and higher anxiety and depression than caregivers of people with physical illnesses.¹⁷ The amount of time spent in performing caregiving tasks is expected to increase as the dementia progresses.¹⁸ This

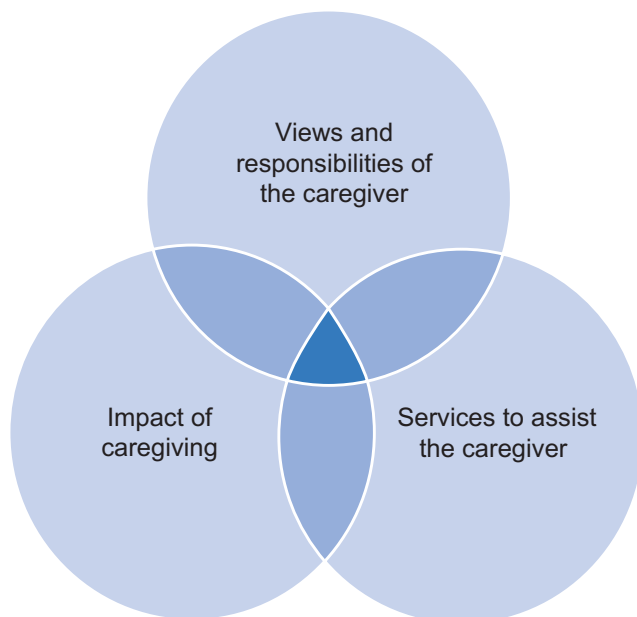


Figure 1: Main themes of research

too is not unexpected, as dementia is a serious neurodegenerative condition, with a progression over approximately 10 years from diagnosis to death.

Caregiver burden is also linked to characteristics of the caregiver such as age and presence of illness.¹⁹ There is a positive correlation between closer kinship ties and increased burden.²⁰ Higher educational qualifications and better remuneration of caregivers were found to be protective factors in terms of caregiver burden.²¹

There are gendered perspectives to caring. Male caregivers resisted formal help, and preferred to handle their allocated tasks by themselves.²² Women seemed to be more prone to relational deprivation, which is a restriction in one's social life and feelings of social isolation.^{3,23} It has been noted that women tend to use more emotion-focused coping strategies whilst men utilise more problem-focused methods. A combination of mixed coping methods yielded more efficacious results.²⁴ Culture also colours the caregiving experience, and shapes the attitudes of family responsibility.²⁵ In addition distress as a result of caregiving may find varying forms of expression in people from diverse ethnic backgrounds.²⁶

Research design

Phenomenology, which is located in a qualitative paradigm, was used as a theory and method in this case, as it brought the lived experiences of caregivers for people with dementia into focus.

Sampling

Non-probability purposive sampling was carried out. The research participants were referred from Alzheimer's South Africa (previously known as ARDA Alzheimer's and Related Dementias Association), a support group operating in the area. The community care workers (CCWs) and the researchers worked together to identify potential participants for the research study, based on the inclusion criteria formulated.

Initially seven people had volunteered to participate in the research. Based on the inclusion criteria, five primary caregivers were identified by the CCWs. There were four females and

one male, all of African descent, who participated in the research. The four women were the three daughters and one wife of the dementia clients, while the male was the son of an individual with dementia. All were adults in the 46–68-year age category.

Inclusion criteria

The inclusion criteria were formulated as follows:

- Caregivers of people with dementia who lived in a rural area were eligible to participate.
- Caregivers of all cultural, language and race groups were eligible to participate.
- Caregivers who lived in the same homestead as the individual with dementia were eligible to participate.
- Caregivers were required to spend a significant amount of time (face to face) with the individual with dementia on a daily basis.
- Primary caregivers had to be involved with the care of the client with dementia (for example, bathing, dressing, feeding, and toileting) on a regular basis.

Data-collection method

Semi-structured individual interviews were conducted with the participants at their homes. The date and timing of the interviews was determined by the researchers in order to best accommodate the respondents' schedule and allow them to express their opinions in familiar and uninterrupted conditions as far as possible. The interviews were done in the first language of the participants to ensure trustworthiness, and were conducted in isiZulu by a trained Zulu translator.

One critical question was formulated for the individual interviews. Probes were also created in the event of the participants not giving the required information. The question that was asked is as follows: "Please tell us what it is like to be the caregiver of someone with dementia?"

The translator had been trained by Alzheimer's South Africa and was familiar with the research process. All interviews were audiotaped. Each participant was interviewed once for a duration of about 45 minutes. Accuracy was ensured by the translator reading the transcripts and cross-checking this against the audiotaped interviews to ensure they were correct.

Analysis

The individual interviews were transcribed verbatim and then translated into English by the translator. The translated English transcripts were read and analysed thematically.

Ethical clearance was granted by the University of KwaZulu-Natal Ethics committee on July 18, 2012, and the ethical clearance number is SHSEC 039/12.

Findings

The thematic analysis yielded three primary themes (Figure 1) and a host of sub-themes.

Views and responsibilities of the caregiver

Three secondary themes emerged under this category, namely the sense of responsibility to a family member, acceptance of the ageing process and handling problem behaviours.

Impact of caregiving

Five sub-themes were uncovered under this theme. These were the tasks involved in caring for the individual with dementia, positive and negative emotions in caring, community interactions, work, and financial implications of caregiving.

Services to assist the caregiver

These were discussed under the following sub-themes of education and caregiver training, as well as promoting awareness of available support.

Discussion

Views and responsibilities of the caregiver

It has already been stated that caregivers to people with dementia engage in more caregiving tasks than for other chronic disorders, and that the magnitude of these tasks increases with disease progression.^{17,18} This resonated with the participants having a huge caregiving burden, which they felt was present for 24 hours in the day.

There is an implicit understanding in African culture that you have to care for your parents and family, as embodied in the concept of Ubuntu. This notion of collectivity means that the individual is a part of the community, and needs to fulfil his/her obligations to the collective.²⁷ It has been found that increased burden is correlated with closer kinship ties, as is found in African culture.²⁰ This provides an explanation for the strong sense of kinship and duty that the participants expressed in caring for their relatives.

Caregiving was seen to have character-building spin-offs for the carer, such as increased empathy and perseverance. Some participants felt that dementia was a normal part of ageing, and did not realise that it was a mental illness. As a result of this perception, they took the problem behaviours in their stride, as they felt that the person with dementia could not control this voluntarily. So they cleaned up after the person when they wet or soiled their underwear, or listened patiently when they began to talk nonsense, or to wander away from the home.

The above themes are personified in the quotes of the participants, below:

"It is difficult but I have got used to it, because she is my mum and she needs me". (P2, female, 65 years old, unmarried, domestic worker)

"She is just an old person who is confused and that is part of the ageing process ... sometimes my mum wets herself, and by the time she reaches the toilet, it is finished, and I have to again clean the urine and do the washing". (P5, male, 63 years old, unmarried, retrenched and unemployed).

"I have personally changed myself. I used to be short tempered but now there is a lot of perseverance towards the sick". (P2, female, 65 years old, unmarried, domestic worker).

Impact of caregiving

There was also a significant restriction in activities of daily living, especially with regard to community (such as weddings, funerals and church) events and leisure pursuits (gardening, as well as visiting friends and family). This restriction in social life has been established previously in the caregiving research.²⁸

Financial stress was increased as a result of caring for a person with dementia. Increased funds were needed for food, medication and transport costs to the clinic or hospital.

There was a need for constant supervision when caring for an individual with dementia. Performing caregiver tasks increased the daily workload of the caregiver, and the quality and amount

of tasks performed was dependent on the stage of the illness. These tasks included bathing, feeding and dressing the individual with dementia, dealing with problematic behaviours, and managing the finances at home. It is obvious that a large amount of material and emotional support is needed when one is caring for a person with dementia, and these needs increase as the disease progresses.

"When there is a wedding, I can't go. When there is a funeral, I also can't go. That has changed my life. And church is my other cry ... A good thing is I am able to care for a sick person and I have a caring heart". (P2, female, 65 years old, unmarried, domestic worker, cares for her mother who is 84 years old).

"Because when taking her to the clinic, one needs to hire transport and pay for all those things". (P4, female, 46 years old, unmarried, unemployed).

"Since he is sick, everything is done by me, he cannot do anything. That is why there are changes in my life, and I feel like a person who is also sick". (P1, female, 68 years old, unemployed, cares for her husband who is 99 years old).

It has been corroborated by research that undue pressure and conflict may result in declining physical health of the caregiver, as many of the participants alluded to in this research.²⁹

Services to assist the caregiver

Caregivers should also be given support by their families. They need both material and emotional support. The material support that is being referred to here is cash, food and transport. The emotional support must come from the family, who should allow the caregiver some respite from their tasks for a few hours or days, so that they may pursue their own life goals.

Caregiver training is also important because once the caregivers understand the illness they are able to care better for their loved one. In addition, they need to be informed by community workers or the local hospital what support is available to them locally, and not a few hours away in the next district, as this would serve to reduce travelling time and increased transportation costs.

"I wish they could give us soup. She can no longer swallow even nutritional porridge ... she can't swallow at all ... and wound care medicines, because when taking her to the clinic one needs to hire transport and pay for all those things". (P4, female, 46 years old, unmarried, unemployed, grade 8 level of education, has one daughter, cares for her mother who is 67 years old).

"It means that we'll sleep without food ... I go around asking assistance from neighbours. You see, if nobody gives me, my mother will sleep on an empty stomach". (P5, male, 63 years old, unmarried, unemployed, cares for his mother who is 84 years old).

Conclusion and recommendations

It would appear that caring for a relative with dementia is an arduous task, with many repercussions for the client, caregiver and family. It is essential that some education be given to families caring for people with dementia. Traditional belief systems, especially in Africa, may interpret dementia as a curse of punishment or bewitchment.

It is suggested that advocacy groups such as Alzheimer's South Africa engage with this community to promote education regarding dementia, and the caregiving responsibilities and

dangers that accompany this. Lastly health professionals need to screen for caregiver burden in people caring for individuals with dementia and refer them for help in a timely way.

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