

# Caregiving on the edge: the situation of family caregivers to older persons in Botswana

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## Abstract

*Little is known about the long-term care of older persons in Africa. In Botswana it is assumed that families care for their elderly relatives. Yet, the African family is undergoing change, due to more women entering the labour force and rural-to-urban migration of young adults in search of better employment opportunities. The purpose of this study was to explore the experiences of family caregivers to older persons in Botswana. A qualitative, grounded-theory methodology was used to interview 24 participants who were caring for an older person. The findings indicate that the caregivers are "living on the edge," as they struggle to meet basic survival needs. Implications of the findings for nursing practice, research and policy that address the plight of the caregivers are discussed.*

Numerous studies have shown that families take care of elderly members who are no longer able to care for themselves. For a long time, the myth has prevailed that the African extended family takes care of its elderly and that the problems of ageing are therefore rendered insignificant (Apt, 1996). However, African families are undergoing many changes, which now challenge this belief.

In Botswana, families generally take care of their elderly relatives. However, given present demographic trends and other social change in the country, the ability of the family to render this service is becoming increasingly curtailed. Other factors which impact family structure are a decreasing fertility rate, rural-to-urban migration (for job opportunities), increased entry of women into the labour force and, lately, the HIV/AIDS epidemic. At present, there are no residential care facilities for older persons in Botswana. Indeed, families are expected to take care of their elderly relatives, but their ability to do so has not been determined.

The purpose of this study was to gain insight and to provide perspectives on family caregiving to older persons in Botswana. Better understanding of some of the issues and concerns which confront family caregivers may encourage policy makers to design policies to address the needs of caregivers.

## Literature review

The role of the family in the care of elderly relatives in several African countries has been documented (Apt, 1996). The literature seems to indicate that the main type of support forthcoming from the family is economic (Adamchak, Wilson, Nyanguru, & Hampson, 1991; Guillette, 1990), whereas a

need exists for other social services for this population which are not necessarily economic (Apt, 1993; Guillette, 1990).

In Africa, women are the primary caregivers of elderly persons (Apt, 1996; Ingstadt, Bruun, Sandberg & Tlou, 1991; Tlou, 1998), as indeed are they in Western countries (Abel, 1991; Brody, 1990; Horowitz, 1985). However, the plight of elderly women as both caregivers and care recipients has also been reported (Apt, 1993; Guillette, 1990; Ingstadt *et al.*, 1991), as has the care of frail elderly persons by grandchildren been reported (Ingstadt *et al.*, 1991; Peil, Bamisaiye & Ekpenyong, 1989).

Very little is known about caregiving to older persons in Botswana. Research in this area has been limited and there is a lack of knowledge regarding caregiving roles of family members generally.

## Method and sample

A qualitative research approach was used to explore the experiences of family caregivers to elderly relatives. The grounded-theory method (Glaser & Strauss, 1967; Strauss & Corbin, 1990) was used to identify the caregivers' experiences.

Twenty-four caregivers were recruited at health clinics in a city and two villages, with the assistance of nurses, family welfare educators and social workers. The non-random, purposive sample thus included both urban-based and rural-based caregivers. The caregivers' ages ranged from 23 to 74 years (a mean of 49 years). Each had been caring for an elderly relative of 60 years or older for a minimum of three months; the mean duration of caregiving for the relative was 5.4 years. The care recipients' ages ranged from 60 to 96 years.

After obtaining informed consent, data were collected from each subject with the use of an unstructured interview schedule. The subjects were asked to tell how they had come to look after the elderly relative. All were interviewed in their homes at a time convenient to them. Each interview lasted for about an hour and was audiotaped. The recordings were transcribed verbatim, the transcripts content analysed in Setswana, and the results of the analysis written up in English. Each subject also gave demographic background information.

## Results

What emerged prominently in the analysis of the data was that caregiving is rendered "on the edge." Three interrelated but distinct categories of data common to all the caregivers

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were identified. The categories were (1) survival on the edge, (2) basic needs, and (3) consequences of caregiving on the edge.

### *Survival on the edge*

The caregivers reported that they were "surviving on the edge" because they must struggle with pragmatic matters of everyday living, such as securing food, water and shelter, and sanitation. They are faced with dilemmas such as who to choose to feed (there was seldom enough food to feed everyone in the household) and whether to forgo purchasing enough food to be able to meet the cost of other necessities such as shelter. What emerged from these data is the importance to caregivers of being able to provide for their charge; being a caregiver means being able to provide for the person for whom one is caring. Families and caregivers who are unable to provide for their elderly charge agonize over this. Since elderly people are regarded as vulnerable as children, the needs of both groups have to be met on a regular basis.

### **Poverty**

Very few of the caregivers were employed in a formal job (21%). The remainder engaged in subsistence farming (41%); operated small businesses, such as selling snuff, cigarettes, grass for thatching and traditionally-brewed alcohol (21%); or were homemakers (17%). Hence, although many were not formally employed, some were involved in small businesses that earned them a small income or subsistence farming. A number had given up farming and the care of livestock to take care of the elderly relative. This tended to worsen their economic situation. In addition, relatives who may have assisted them with the farming may long since have moved to a city. Many saw no alternative to their caregiving obligations, even if this meant giving up their livelihood and plunging themselves into a life of poverty. A caregiver acknowledged that her family fell short because of economic constraints.

*We are not able to give her [grandmother] much of the food that is needed. We fall short because we are also ordinary people who do not have much.*

Several caregivers were aware of their family's poor economic situation and did not anticipate receiving help from relatives, who were in fact in the same position as they were.

*There is no help from relatives; really, they cannot help in any way because they also have nothing to offer. They are just as poor as we are, so anticipating any financial help from them is a bit unrealistic. They have nothing to give.*

This caregiver was aware of her double jeopardy:

*There is no one who can help. When you are poor and have no one to help you it is ... like I said, I have no parent, and my husband has no parents either. Since this illness began, no one has ever come here ...*

The poor economic situation was worsened by a lack of extended kin and better paying job opportunities. Most of the caregivers were not well educated (their level of education ranged from none to seven years of schooling) and therefore had limited job opportunities available to them. As a caregiver explained:

*The kind of job of working as a maid does not bring in much income. When someone pays you 150 Pula (US\$30) a month, when you have to distribute that money over several things in the home, it cannot make much of a difference. I really wish I had gone to school. I wish I could go now. I*

*wish I could get a job in a secondary school, but I am not educated.*

As caregivers left jobs or changed occupations to render care to an older relative, their economic situation declined even further and they acknowledged the concomitant difficulties which this entailed.

*The difficulty relating to taking care of my aunt ... I can say it is difficult because I am poor. Because if people are poor it becomes difficult, because she is also an adult ... All I can say is things are difficult because I am poor, or maybe I can say because our financial situation has declined, because in previous years God used to help me.*

The economic conditions of the caregivers therefore put them in a predicament. A lack of resources impacted their ability to fulfil their caregiving responsibilities.

### **Needs**

To most of the subjects, caregiving is equated with "providing for the elderly relative." The care recipients are viewed as family members who need to be provided for on a regular basis, much like children. Inability to fulfil this role entails a great deal of emotional pain and guilt for the caregivers. Caregiving on the edge is exemplified most prominently in the caregivers' ability to provide three necessities directly associated with survival: food, soap and shelter.

While it was anticipated that most caregivers would ask for assistance with hands-on tasks, the majority actually sought assistance with food. Caregivers were concerned with meeting needs that were at a very low level, such as food and shelter. Maslow's (1954) hierarchy of needs is well illustrated in the caregivers' concerns with basic maintenance, especially making food available to the elderly relative for whom they are caring, or being helped themselves with food.

*The care that I give is to provide my parents with food; if I have ploughed, then they can have a life. We can only live if I have gone to plough, then we have a life. But unfortunately, even if I plough, I do not reap much sorghum. So my parents do not live well at all. If I do not plough then they do not have a life. They live under difficult circumstances.*

When asked what kind of assistance they thought would best help them, most replied as follows:

*If only [they] could help with a bit of food. It would be better if we could be helped with food, it would really be helpful, because we know that money is something that is difficult to give out. But, if they could help us with food and clothes, I think it would be better.*

Indeed, what may be perceived as basic survival necessities are not available to some caregivers; if they are available, they can only be procured some of the time.

### **Food**

In discussions pertaining to food, it was evident that food availability was not a given but a temporally conditional commodity. Food was described as a commodity that was sometimes available and at other times not available. A caregiver noted in reference to his father as follows:

*He is the kind of person that if he has, or better still if you provide him with a bit of food ... if you can get the food, he will stretch the food to last as long as possible.*

Another caregiver stated that she gave her mother food, "if the food is available." Yet another noted:

*There is no food right now. We are waiting for the month to end. When month end comes, then mother will receive her pension cheque.*

In instances where a caregiver relies on family remittances to purchase food, this arrangement does not always ensure the availability of food. A caregiver who relies on her children's income noted the uncertainty of this type of arrangement.

*I rely solely on my children. But they are also failing as they are struggling. The reason I say so is because on some days we go to bed hungry. Then on some days they are able to buy food.*

A caregiver who was taking care of her diabetic husband lamented the problem of money, as she noted the cost of a diabetic diet.

*Even with the food the doctors say he should eat, the problem is money. I have no money. There is no one who works between the two of us. But this illness which requires foods like these [pointing at fruits], it requires certain foods. These foods are difficult, difficult, my child, it is too heavy for me. As it is now, he does not eat beef anymore, he does not eat any meat except chicken. It is expensive food which I just do not have the money for all the time.*

Indeed, when I spoke to a care recipient who had suffered a stroke, I asked her if she was able to eat and she replied:

*The heart is wishing for the food, but the stomach is empty. There is no food in my stomach.*

The experience of hunger is one which many of the caregivers' families have to live with quite often. Even when it is possible to obtain the food, they are faced with the near impossible task of stretching the food to feed everyone in the household. Deciding who should receive food and who should not is part of the everyday experience of many caregivers.

#### **Difficult survival choices**

When there is not enough food to go around, choices must be made as to who will go hungry and who will eat the little food that is available. Frailty and age are among the principles which govern the allocation of food. Often, a sick elderly person is given preference. A caregiver noted as follows:

*Seeing that we are so many, it means that sometimes there is an insufficient amount of food and no soap to do laundry. Even the children, sometimes they have nothing to eat when they come from school. We try and feed the elderly person first, with whatever food is available, as he is sick. If there is any left, then the children are given the plate to scrape. The rest of us adults just have to go without food.*

This kind of pragmatism is also found in families who rely on food rations from the government. Here too, the food received is often insufficient to last a month or to sustain an entire family. Therefore, decisions pertaining to food allocation among family members force a replay of the drama on a daily basis.

Food takes on an even greater importance in circumstances where the diet is part of a treatment protocol. A diabetic woman ate nothing but corn-meal porridge (*phaletshe*) and cabbage. Her daughter explained that they had no food in the house. What their mother was eating was food which they had asked a neighbour for. In this instance, a decision was made that out of the 16 people in the household, the diabetic elderly mother would be the one who should eat.

#### **Basic needs**

##### **Shelter**

Shelter is another basic need which some caregivers must strive to obtain for elderly relatives. Unlike caregivers in the rural areas, who mostly own their homes, the caregivers in the city have an added burden of paying rent. A caregiver explained that she had to forgo buying food for her elderly mother so that she could pay the rent. As difficult as this was, the caregiver had to make the choice, so that the family was not evicted from the house. She explained:

*The biggest problem that I have is that even when the children have helped me with some money, I have to go and pay rent at the Self-Help Housing Office and Christian Council. Then for that month, we do not have food in the house. The Christian Council already helps me to stay in this two-roomed house. I mean, I am absolutely poor. I have nothing. I really have serious problems.*

In some instances, an older person is already living with a family relative long before the person needs care. However, if the daughter is married, she may prefer that the older relative has a place of his/her own. A caregiver explained that her greatest wish was to build a hut for her parents so that they might have their own place. At the time of the interview, they were living with her and her husband in their small home.

*If only the spirit would grant this request ... this wish of mine to provide a roof for my elderly relatives, then my heart would be healed. Even my blood pressure would heal, because being preoccupied with where these people will go when I am no longer around worsens it. I worry that when I die my in-laws will ask them to move out, since I will be gone.*

She has brothers who should be living with her parents, but they were too poor to care for their parents. Her husband had also expressed discomfort with having to live with his in-laws.

##### **Sanitation**

A need identified by 13% of the caregivers was sanitation. In one home, both pit latrines were full and needed to be emptied. The caregiver noted:

*I have problems. During the month of March, my pit latrine collapsed, so now I have problems. My mother does not walk, so I have to carry these buckets in the morning and empty them. There is another house that side and they have allowed me to use their toilet. So, every morning, and all day long, I take the bucket, just as if I am nursing her, doing everything for her. Mother is sick and unable to walk. But really, I am unable to look after her. You see, my husband also died recently.*

The death of her husband had further curtailed the caregiver's resources. Consequently, she was now the head of the family and had limited resources with which to take care of her mother. Yet another caregiver complained about the scarcity of water in their village. This prevented them from installing a flush toilet in the house, which would make it easier for the older person to use the toilet. The present pit latrine is too far away for the frail 96-year-old woman to use.

Another basic need that was frequently mentioned was soap. Soap is an important commodity, not only for cleaning incontinent elderly persons but for routine purposes such as bathing. However, the availability of soap also embraces a broader meaning: that of enabling families to maintain the ritual of bathing in the morning before handling or eating food.

This is an important aspect of Tswana life. An inability to provide soap for themselves therefore represents not only severe poverty but also the loss of an important cultural norm.

A caregiver, who acknowledged that she was constrained in helping her mother, mentioned with relief that at least she obtained help from the government in the form of soap. The caregiver's mother receives a government pension and is at least able to buy soap.

### *Consequences of caregiving on the edge*

#### **Unfulfilled caregiving**

The ability to provide food was viewed as an indication of successful caregiving and was important to most caregivers. Many caregivers explained how they struggled to fulfil this caregiving responsibility.

*She does not go hungry. She can only go hungry if I lack the resources to take care of her, or if I get sick.*

However, those who are unable to meet the demands of caring for their elderly relative are often emotionally overwhelmed. Such persons anguished over their inability to provide what the care recipient needed. This caregiver commented on her inability to provide sufficiently for her parents.

*Because they are old people, they are almost like small children in their need to eat regularly. In the morning they need to drink something warm, eat some food in the afternoon, and again in the evening. When they eat properly, their skin is good to look at even if they are sick. But, I am unable to do all that as things are not going well. That is the only thing that I am unable to do, and my heart really aches for them.*

#### **Loss of crops and animal livestock**

During the ploughing season, temporary homes are set up near the fields. In some instances this seasonal move from one home to another is disrupted due to caregiving responsibilities. Consequently, some caregivers are forced to walk great distances to and from the fields so that they may plough and also see to the needs of the elderly relative. Yet, some of the caregivers were themselves elderly, and this back and forth movement meant that the caregivers, their elderly care recipients and the crops all suffered from lack of attention. In some instances caregivers were forced to give up farming because of caregiving roles, as a caregiver stated about her demented husband.

*I no longer plough because I have to take care of him. When I have tried to plough, he harasses the children a lot. I was afraid I might come home to find that he has killed the children. I thought it would be better to stay and watch over him.*

Another caregiver expressed her views on the consequences of caregiving in a particularly direct way. She noted how in addition to her loss of livelihood, caregiving had fragmented her personhood.

*It [caregiving] has made a difference. It destroys a person's mind and body. You see, if you give care for a long time, sometimes it seems as if you are mad. Even your animal livestock, eventually it disappears; the farmlands, they disappear. Truly, caregiving for a long time destroys your entire well-being.*

For women caregivers, taking care of a spouse means that the wife now has to assume the role of head of the household and to learn how to do without the income that used to be gener-

ated by the spouse. It also means assuming a new and unfamiliar role of decision maker and overall household manager.

#### **Silent endurance**

Silent endurance constitutes the ultimate paradox: caregiving was described as "just doing tasks." Yet some tasks are highly complex, often described as routine and mundane but difficult. These caregivers did not complain; they simply acknowledged the difficulty, if at all, in a stoic matter-of-fact manner, usually devoid of emotion. Despite their silence, there was a palpable sense of despair associated with what they were doing. Some mentioned without affect, for example, how they were unable to feed their parent that day. There seemed to be no expectation that things would or could improve. This caregiver mentioned in her resignation: "I guess I have just given up, because I see how my relatives have just left everything to me."

#### **Positive aspects**

Despite the difficulties which the caregivers encountered, a number were able to step back from their caregiving experiences and describe positive aspects of caregiving. Some expressed a sense of pride and accomplishment at being able to assist older persons with activities of daily living, in spite of financial difficulties.

#### **Discussion**

Family caregiving in Botswana occurs within a dynamic and changing socio-cultural context which is steeped in poverty. This study focussed on the experiences of family caregivers to elderly persons. The findings of an analysis of the data from 24 interviews indicate the issues and concerns of the caregivers.

Caregiving on the edge comprises a simultaneous process of surviving on the edge and taking care of an elderly relative. The goal of surviving on the edge is to obtain basic necessities for survival. Life was difficult for many of the caregivers in the study. In addition to the burden of caring for an elderly relative, inherently difficult choices had to be made to meet basic survival needs. For many caregivers, there were negative consequences of caregiving, such as the loss of a job or being unable to continue to engage in subsistence farming, upon which they depended for survival. The caregivers typically reacted to these catastrophes with silence. They described their tasks as routine and mundane, yet difficult. Diminished resources posed a dilemma for them, as they had to choose between competing demands for meagre resources. These findings are consistent with the literature on caregiving in Africa and include the prevalence of women as caregivers (Tlou, 1998). Sons in this study, although small in number, also took care of elderly parents and were committed to that responsibility. One son was motivated to do so out of a sense of love that was not dependent on the availability of a sister. The other son cared for his father because the son was divorced and had no sisters in his family.

Botswana has a record of successful economic development and management (Hope, 1997). Yet there is increasing concern over perceived persistent poverty and deepening inequality. Indeed, the findings from the study show that poverty permeated many areas of the lives of the caregivers. The availability of financial resources was pivotal, since many families perceived the provision of food and shelter to an elderly relative as the key element of caregiving; yet a lack of resources inhibited the fulfilment of this important role.

Many caregivers were unemployed and depended on subsistence farming and raising cattle and goats. Many were

unable to carry out this role and this worsened their economic situation.

Although previous studies have shown that families generally take care of elderly people in Africa, there is some evidence that the family is no longer able to cope as well with this responsibility as it previously did. There are no nursing homes, day-care centres or programmes for home-bound older persons in Botswana. A lack of such facilities and services perhaps contributes to the sense of helplessness and despair of the caregivers; alternatively, these feelings may have been due to their struggle to meet basic needs. Many caregivers did not expect any change in their current circumstances.

The concept of silent endurance must be understood in the context of Setswana culture. Suffering in silence is regarded as virtuous and may explain the lack of affect with which caregivers acknowledged the difficulties they experienced in caregiving. Silent endurance did not mean that caregivers reported their situations as easy, or that they were devoid of emotions. To an unsuspecting onlooker, at face value these caregivers seemed devoid of emotion because of the stoic manner in which they expressed their needs. Yet, painful emotions were frequently evoked during interviews. There was pain and anguish on the faces of some widows as they talked about the recent deaths of their husbands.

The study findings deviate from Western literature on caregiving to the elderly, which emphasizes needs that are completely different from those reported by the caregivers in Botswana. Botswana caregivers expressed a need to be able to meet basic survival needs, such as food, sanitation, soap and shelter. In contrast, the Western literature focusses on the need for flexible work schedules, psychological counselling, respite care and the provision of supportive assistance (Biegel & Blum, 1990; Crossman, London & Barry, 1981; Hooyman, 1992; Montgomery & Borgatta, 1989; Montgomery & Prothero, 1986). Such needs were not even considered by caregivers in Botswana, who are still struggling with basic physical, material and survival needs.

## Implications

The study findings have implications for policies pertaining to the care of older persons in Botswana and other African countries. Clearly, family caregivers are struggling with the burden of caregiving while battling to meet basic needs. There is a need therefore to identify social systems which can assist the carers, as traditional systems are increasingly affected by demographic forces and social change (Apt, 1996).

Implications of the study findings for nursing practice include raising awareness of the plight of caregivers and advocating on their behalf. Where possible, nurses should assess the needs of family caregivers and assist them to mobilize community resources, such as home-based care services, within communities; this will require intersectoral collaboration.

The study was conducted in only two areas of the country, and the findings should therefore be interpreted with caution and not generalized beyond the study population. The sample is also biased towards low-income family caregivers. The data collection was cross-sectional, yet caregiving is a dynamic process and this research design factor may also be regarded as a limitation of the study.

## Conclusion

Caregiving to older persons in Botswana presents specific challenges to caregivers and compromises their economic

activities. As families continue to be the main carers of older persons, it is important that resources be made available to assist family caregivers in this role.

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