

Experiences of co-resident carers of elderly persons in Mangaung (Bloemfontein)

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Abstract

In South Africa, the majority of elderly people reside in multi-generational households and it is therefore conceivable that over a million co-residents are faced with caring responsibilities. Yet little is known about informal caregiving in the country generally, and neither about carers of elderly persons and their experiences. This paper reports on an exploratory study of the experiences of a group of informal caregivers who reside in a black African urban township. Negative aspects of caring identified by carers include social isolation, family conflict, work-related problems and stress. As great demands are placed on informal carers, the researchers conclude that the carers should be supported, to enhance this important yet often overlooked care resource.

Introduction

An aspect often overlooked when family care of older persons is encouraged is the burden that caregiving places on carers. A situation is developing world-wide whereby the number of older individuals who need care is increasing, while the pressures on individuals who provide the care are intensifying. Although untrained and relatively unsophisticated carers in the community may often provide better services than trained professionals in institutions, the burden carried by many informal caregivers may cause them severe stress, exhaustion, depression, marital conflict and family breakdown (Osei-Hwedie, 1994: 153).

Several studies have been conducted on caregivers to elderly persons which have focussed on the stress which the carers experience, the formal and informal support which they receive, and their sense of strain (Wilson, 1990; Fisher, 1994; Schultz, Smyrnios, Grbich & Schultz, 1993; Parsons & Cox, 1989). It has been shown, for example, that caregivers make considerable personal sacrifices and must curtail their social activities. They are often required to make numerous changes to their daily routines and frequently experience interpersonal conflict with other family members (cf. Hooyman, 1983: 143).

In studies of caregivers, a distinction must be made between co-resident and non-resident carers, as the nature of caregiving appears to differ in each case. Evandrou (1991: 4) found that co-resident carers (persons caring for individuals in the home) are more likely to experience intensive long-term caregiving, i.e. longer hours of caregiving with fewer breaks than non-resident carers, and that this type of care is more likely to be directed to relatives. According to Dooghe

(1992: 372) the workload of caregiving is greater for co-resident carers.

Studies have also shown that care is usually provided by a single person, referred to as a "central attendant," or the principle carer. Even when there are several adult children, only one sibling will usually assume the principal caring responsibility. Once an individual has been ascribed the role of "carer," support from other relatives and friends tends to be not forthcoming (cf. Dooghe, 1992: 371; Evandrou, 1991: 2).

Informal caring tends to be predominantly a female activity. Studies have shown that daughters and daughters-in-law constitute the largest group of informal carers of elderly people (cf. Ungerson, 1993; Etten, 1995; Laczko & Noden, 1991). Ungerson (1993: 4) states that "in practice care by the family equals care by women." This fact has prompted authors such as Finch (in Fisher, 1994: 661) to reject community care because it exploits women. The extent of the caring role of women has been highlighted in a study which reported that women may expect to spend 17 years of their lives bringing up children and another 18 years caring for an ageing parent (Etten, 1995: 131-132). Echoing the above, Laczko and Noden (1991: 32) state that:

The years of middle age, a period in their lives when women are likely to be returning to full-time employment, are precisely those years when they are most likely to face the responsibilities of caring for other, older dependents. This may entail perhaps irreconcilable demands of work and family or domestic responsibility.

However, an over-emphasis on women as caregivers has been challenged, with studies in Britain showing that men are far more involved in providing informal care than previously thought, and that often men will be caring for a spouse even when they themselves are elderly (Bond, 1992: 7; Evandrou, 1991: 3). It thus appears that when caregiving involves caring for someone other than a spouse, daughters and daughters-in-law are the most likely to be involved and that adult women below retirement age are more likely to be carers than men of the same age.

The ages of informal carers vary but some studies show that the majority of carers are middle aged (cf. Dooghe, 1992: 371). On the other hand recent research has highlighted the fact that many carers are elderly themselves, thus making elderly persons not only the recipients but also the providers of care (Fisher, 1994: 660).

In some countries, for example the USA, European countries (Britain in particular) and Australia, the plight of infor-

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mal carers has recently come to the fore, with a surge of articles published in the past decade. However, scant research has been conducted in this area in developing countries, including South Africa. A study of the *Bibliography of research on ageing in Southern Africa, 1970-1994* (Ferreira et al., 1995) showed that fewer than ten studies in 24 years had pertinently focussed on informal caregivers to elderly persons.

Multigenerational households are the most common living arrangement in South Africa (Ferreira, Møller, Prinsloo & Gillis, 1992; Møller, 1993). It is thus conceivable that over a million people in the country who co-reside with an older person are faced with the responsibility of caring for that person. Given that very little is known about informal caregivers and their experiences, this is an area that should receive considerable research interest at this time.

To address a gap in knowledge an exploratory study was conducted in 1996 on the experiences of a group of informal carers to elderly persons. The study was conducted separately among groups of white and black caregivers, and only the findings pertaining to the group of black caregivers are reported in this paper. (In some cases reference is made to the experiences of the white caregivers.)

Method

The literature shows that studies on informal caregiving tend to be qualitative and small scale. The researchers therefore employed the focus-group interview method to study the caregivers' experiences. The focus-group method had an added advantage in this study, in that the carers were not interviewed in their own homes and were thus not inhibited by the possible presence of other family members, including the care recipient, during the interviews. A snowball sampling technique was used to select informal carers in a historically black township, Mangaung, outside Bloemfontein, to participate in interview sessions.

Three focus-group discussions were conducted with six people in each group (a total of 18 participants). The discussions were conducted in the language of the participants, i.e. Sesotho. The funnel approach – a broad question followed gradually by more narrow questions – was employed by the facilitator of the discussions, who is the second author of this paper. The sessions were tape-recorded with the permission of the participants and the recordings were later transcribed. The transcriptions were then translated by the second author into English and the translated transcriptions were content analysed.

Of the 18 participants in the three groups, 14 were females. The ages of the participants ranged from 19 to 50 years. Thirteen of the caregivers were unemployed, three were employed and two still attended school.

Findings

Becoming a carer

Considering the profound influence which caregiving has on an individual's life in terms of effort and time – with some caregivers caring for 20 years or more, a feature of caregiving that became evident in this study is that carers acquire the position by accident; in other words they acquire the status involuntarily. External factors, beyond the control of carers, bring about the situation. The two main factors reported by the participants were the deteriorating health of a parent(s) and the death of one of the parents. Once either or both of these situations had occurred, the proximity of the elderly person to the closest child, the number of siblings or adult

children of the elderly person, the marital status of the siblings, their financial position, and whether or not the siblings are employed appeared to play a role in who became the carer.

On my side, she is my mother and she had a stroke in 1982. We are two at home and I am the elder. The second one is working; as a result, I am compelled to look after my mother as there is nobody else who can look after her.

None of the participants in the group discussions stated that they wanted the position of carer but pointed out that they had little choice. What is significant is that few people set out to be carers and thus are often unprepared for the role. A lack of preparation and a forced situation could contribute to feelings of frustration in a carer and an inability to cope with the situation.

Caring tasks

The study showed that once the status of caregiver had been assumed, the tasks relating to this status consumed much of a caregiver's time and energy. It is evident from this study as well as the literature that carers do not have much help with their care responsibilities. Again, once a person has assumed the role of carer, other relatives distance themselves from the role.

When asked to describe what caregiving entails, the participants identified the following tasks:

- Personal care and hygiene (feeding, dressing, toileting and bathing the elderly person)
- Mobility (helping the person in and out of bed, and to move around inside the house and to other places)
- Administering medication
- Household tasks (laundry, house cleaning, meal preparation)
- Shopping
- Transportation and accompaniment
- Financial help (seeing to payments of accounts, documents, etc.).

The tasks reported are consistent with the forms of caregiving identified in other studies. However, it appears that transport is particularly problematic for the carers. None of the participants owned a car and other forms of transport, such as taxis and buses, must be arranged when needed and are expensive, and travel by these means is time consuming. Another interesting finding was the extent to which the caregivers must accompany their charges to various places, such as a clinic, a hospital, a pension pay point and church. This task was not reported by white caregivers and neither does it feature strongly in the literature on the experiences of caregivers abroad. The participants reported that they do not have the means to hire additional help and thus they perform most of these tasks themselves.

Negative aspects of caring

The following negative aspects of caregiving were identified by the participants: social isolation, time constraints, role conflict, work-related problems, family conflict, a decline in their own health, financial strain and emotional stress. Four of these aspects are discussed.

- **Social isolation.** Studies show that carers feel isolated as a result of their care responsibilities (Dooghe, 1992: 375; Wilson, 1990: 419). The daily tasks associated with caregiving take up a great deal of a caregiver's time. In addition, the nature of the tasks means that they require immediate attention, e.g. feeding and toileting. The carers reported that they are reluctant to leave the house because

often there is no-one to look after the elderly person and that when they do go out, they feel guilty or worry. This leads to carers having to give up time spent on hobbies, visiting, going to church and other activities, and consequently to the isolation of the caregiver. The following quotations capture feelings of isolation reported by the participants:

I can say that I can no longer do the things that I have been used to. What I am doing now is just killing time by talking to my mother. I don't have friends anymore.

I cannot visit people anymore. If I go I can't stay long there, because when she becomes hungry, there is nobody who can help her and she will have to wait for me...

Even if you want to go out, you cannot... It is even more difficult when it is cold like now. You have to try and find a warm place for her, it is only then that she can wash, or you have to light the heater or make a coal fire...

- **Family conflict.** Parsons and Cox (1989: 122) state that "although elder caring by families is common, decision making about such arrangements is not usually harmonious." In this study it became evident that conflict is particularly manifested in two relational types: carer – care recipient and carer – other family members.

In the case of conflict between a carer and a care recipient, the conflict seems to revolve around two issues: the refusal of an elderly person to "follow orders" and money. The participants related how their elderly charges refuse to "follow orders that are for their own good." In particular, refusals to bathe, or to wash themselves and to adhere to a prescribed medication/diet regimen were mentioned. While carers may view an elderly charge as stubborn, care recipients apparently view carers as domineering. Thus in many instances caregiving does not simply involve performing routine tasks but is a ongoing battle of wills.

I'm struggling with my mother-in-law... she doesn't want to wash... she doesn't want to get into the bath... and I was so upset... Why? I can't understand it! Why is it such a problem to clean your body!

These people [the elders] are at times stubborn... when you say 'here is the water, come and wash your teeth'... then there will be a fight. There are times when she just feels that she is not going to wash...

It is stubbornness. Sometimes when she had to go for treatment she does not want to go. Even when she has to pay at Pelonomi [hospital] she is reluctant to take out the money, yet at other times she buys sweet things like a child...

The second (and most strongly emphasized) source of conflict tended to be the monthly social pension which the elderly person receives. The majority of the participants were unemployed and their only source of income was the elderly person's pension – which made them dependent on the person. The care recipients appear to know that they are at a financial advantage and the carers feel that the elderly person uses this source of power against them. One might argue that the pension is an elderly person's last source of power.

Sometimes she buys things from hawkers without my knowledge... hawker after hawker will knock, wanting their money for things I know nothing about. If you ask her why she bought such useless things, she will lash out at you saying 'I am getting a pay... this money is mine... do you want to control me or my own money...?'

If I buy something that is needed for the house... she will start complaining... 'you have bought food, you have bought this and that with my money, while I, the owner of this money, have bought nothing!'

... she will say 'you talk too much... there is not even a cent that is coming from your side, but you are the one who dictates to me what we should do with the money'... then you become fed up... Do you understand... these words are not good, because if you look, you are not working because of the fact that you are caring for her! They [the words] are hurting, they hurt.

When the social work people or other people visit while she is sitting outside, she will relate how hungry she is, although she is getting an income. Then questions will pop up as to what is done with the money. But when you buy sugar and other things ... you have messed up. You have to come home having bought clothes, suitcases, shoes, berets, pantihose... then she will be satisfied. But the money is only about R400 and if you think what she is going to eat for the month, there is no way that you can buy her those things...

A third source of conflict, i.e. conflict between the carer and other family members, also concerns money. Interestingly, money was also the greatest source of conflict reported by the white caregivers – but in their case inheritance was the issue, whereas in black families conflict arose from the expenditure of the pension. The black participants reported that other non-resident family members feel that caregivers squander the elderly person's money and that they too have a right to the money. Carers state that non-resident family members have no idea what caring entails and costs, and thus feel that it is unfair to be subjected to suspicion and criticism.

The family likes to get something out of you. Like when my father is from [returns from collecting] the pension, you will find that the house is full of them... they have come to eat their father's money... but they do not understand that this person is sick and the problems you are experiencing...

They [the other family members] are really useless! It is the people outside there who will help you and not one of your family members, their [role] is but to bring problems to you... yes, a lot of problems...

...when the family members visit, they will insist that they have also come to eat their parents' money. I don't know where these people think the money comes from. They say it is a lot – we [carers] are eating it...

- **Emotional stress.** Research has shown that the emotional stress of caregiving is often greater than the demands of providing finances or daily physical care, and that the majority of carers regard the emotional aspects of caring as the most taxing (Hooyman, 1983: 143; Schultz *et al.*, 1993: 4). The participants experienced feelings of anxiety relating to financial matters as well as a concern for their future. The overwhelming sentiment expressed by the participants in this study is that life is passing them by. They feel that their role as a carer has put their lives on hold and that opportunities are eluding them.

I have to provide my child with a future so the time is running out. Yes, it is running out! Tomorrow she [the care recipient] will have gone, so if I am still staying at home, I will remain there for the rest of my life...

When you are caring like this, your life changes a great deal, it goes backwards. You are unable to meet your needs

because of this job. Everyday you are in a state of worry, especially if you are someone who is needy. At this moment the child needs this, she can't get it... the next moment I need that, I can't get it. Sometimes you feel pressurized... [at] especially our age, we are still young.

- **Problems at work.** Studies of carers indicate that caregiving creates conflicts between caring and work responsibilities and that this affects work performance and in extreme cases withdrawal from the labour market (Wilson, 1990: 419). Carers are often unable to juggle the demands of work and caring. Although many of the participants were unemployed (which probably contributed to their becoming a carer), those who had jobs reported that caring also negatively impacted on their work performance. Some also reported that their caregiving responsibility actually prevented them from getting a job.

I am working for three months now and each month I have to take three days off to help my mother attend her appointments at Pelonomi [hospital]. It now becomes a problem because during pension payouts I also have to ask a day off, and it seems as if my employer is not going to tolerate this very much longer... I have to work as there is no one who can help me... so if I don't work who is going to help me?

What is significant is that when carers are unemployed, they are dependent on financial contributions from other people (including the elderly person's pension) and cannot afford any form of additional help. This makes it extremely stressful for carers who, while fulfilling an important function in society, receive no or little acknowledgment for it and have no prospects of hiring help, even for a brief period of respite.

Positive aspects of caring

Not all caregiving is negative; caregiving also has a positive side. Fisher (1994: 668) argues that "...the portrayal of all caring as an unwelcome burden fails to recognize some of the views of carers themselves." The main positive aspects of caring that emerged in this study were the feelings of pride and fulfilment which many carers felt, despite all the problems.

The norm of reciprocity featured very strongly in this regard, with caregivers stating that their parent(s) had done so much for them in the past and that it was now their turn to return the favour. Although black elderly persons are unlikely to bequeath large inheritances, it strongly appears that these caregivers truly feel that they are returning a favour irrespective of not being financially rewarded in the future.

However, in the focus-group discussions, the negative aspects of caring far outweighed the positive aspects. This finding may have been a function of the research methodology whereby the caregivers felt that they could express themselves frankly in the discussions. Caregivers would otherwise not want to appear too critical of their situation, as it might be interpreted as a desire for the elderly person to die. The participants expressed surprise and appreciation that anyone could actually be interested in their experience.

What is needed in order to make caregiving easier?

Many caregivers are thrust into their caregiving role and know little about how to provide care for a dependent relative, where to locate resources, and how to handle mixed feelings towards the relative. In extreme cases feelings of anger, resentment, hopelessness and guilt may culminate in instances of abuse and neglect (Hooymann, 1983: 144). It

appears that the more one needs support, the less likely one has the personal resources to reach out and to obtain it.

It is thus important, not only for a carer but for a care recipient as well, that support (both formal and informal) be forthcoming. It is little wonder that many authors argue that informal carers must receive fiscal, medical and social support, and that particular attention must be paid to providing services that reduce the stress of carers (such as day care or respite care) and that offer emotional support. The following two suggestions of what would make their lives easier were emphasized by the participants:

- **Information.** The participants expressed a need for more information, particularly advice on how to deal with family conflict. Scarce published material is available to carers and few guidelines thus exist on how to render care to an ageing parent. It is therefore important that programmes and materials be developed to educate caregivers. These programmes should focus on the coping skills of carers and should also attempt to increase carers' technical caring skills and competency as well as their knowledge of the ageing process. The end result would hopefully be a reduction in stress and an increased ability to cope (cf. Biegel, 1984: 66-67; Lund & Madlala, 1993).
- **Home help.** Carers also expressed the need for formal home-help services, specifically nursing services. In this regard they stated that it would be helpful if a nurse could visit the elderly person at home. Yet from the discussion it appears that the participants want the nurse to also help with a variety of tasks, not all health related. It appears that the carers may be unsure of themselves, not knowing if they are caring in the right way, and actually want approval of what they are doing.

In addition to the suggestions made by the participants, the authors wish to stress the importance of support networks, self-help groups and policy recognition.

- **Support networks.** The burden of caregiving is intensified by a lack of effective support for carers who are isolated and do not know how to develop support networks. An appropriate intervention thus appears to be the strengthening of family support systems, or where none exist, the development of alternative supportive networks (Wilson, 1990: 421). Studies are needed to establish what resource networks are available to carers and how these networks may be strengthened.
- **Self-help groups.** Another way to make life easier for carers is through support from self-help groups. An opportunity to communicate in support groups could provide a vital support link. It may be argued that caregivers possess the expertise to solve their own problems and are able to offer suggestions to one another based on personal experience. Support groups can have various emphases, some stressing information, others stressing emotional support, and so on. They may be self directed with leadership coming from within the group, or they may involve professional staff as group leaders or facilitators. If a professional facilitates a group, he/she could serve as a consultant to the family caregivers by providing information about the processes of ageing and services – thus offering support, encouragement and help with problem solving.
- **Policy recognition.** Often scant recognition is given in policy to the important role that informal carers play; yet their invisible contribution often saves the government large sums of money. Unfortunately, rather than providing assistance, policy often makes the lives of informal carers

more difficult. This can happen when the state diminishes its role in welfare provision which results in a reduction in formal service provision. A greater burden is therefore likely to fall on informal care providers and on the financial resources of elderly people themselves (Ginn & Arber, 1989: 114). In similar vein, Wilson (1990: 421) points out that governments often ignore the financial burden of caring for an elderly person and that families should advocate more strongly for a national policy that provides direct assistance to family caregivers. In this regard national carers' associations are important.

Conclusion

Evandrou (1991: 25) puts it in a nutshell when she argues that: "Such heavy duty long term caring should not be assumed to be a 'natural part of family life' to be done with little or no support" and that "...it should not be taken for granted that informal care is a substitute for statutory services, but rather it should be seen as a complement." It is important that informal carers are included in overall planning of care for the elderly. The researchers are of the opinion that through increased knowledge on the subject, the role of informal carers could enjoy greater recognition and should be advocated, and that the strengths and weaknesses of informal care should be exposed so that this important care resource may be strengthened and mobilized.

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