

# **“It’s like giving birth to the sick person for the second time”: Family caregivers’ perspectives on providing care**

**Nina Hunter**

**Working Paper No 44**

**July 2007**

ISBN 978-1-86840-604-3

## **Acknowledgements**

The research in this paper is based on findings from the KwaZulu-Natal Income Dynamics Study (KIDS) 2004 qualitative study. The important contribution of the team involved in the qualitative study is gratefully acknowledged – centrally Makhosi Dlalisa, Themba Mbhele and Themba Mpanza who undertook the fieldwork, and Cathy van de Ruit, Myriam Velia, Michelle Adato and Julian May who managed the fieldwork process. Many thanks are also due to Francie Lund who read and commented extensively on earlier versions of this paper. I would like to acknowledge the Department for International Development – Southern Africa (DFID-SA) for their funding for the qualitative study, and the South African national Department for Social Development (DSD) for their support, as well as the Mellon Foundation Poverty Node for funding towards the qualitative study. The KIDS 2004 study was funded by DFID-SA and supported by DSD, the Mellon Foundation, and grants from the International Food Policy Research Institute (IFPRI) and the London School of Hygiene and Tropical Medicine (LSHTM). The project is a collaborative venture between UKZN, the University of Wisconsin-Madison, LSHTM and IFPRI. The opinions expressed herein are those of the author and do not necessarily reflect the views of DSD, DFID-SA or the Mellon Foundation Poverty Node.

---

## INTRODUCTION

---

Home-based care constitutes the South African government's chief response to the care needs presented by the HIV/AIDS epidemic, as well as to other care needs such as for the elderly and people with disabilities. In the National Guidelines on Home-Based Care/Community-Based Care (Department of Health, 2001:1), home-based care is defined as 'the provision of health services by formal and informal caregivers in the home, in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death'. According to the guidelines, formal caregivers include doctors, nurses, psychologists, rehabilitation therapists and social workers. Informal caregivers refer to families, community health workers and volunteers.<sup>1</sup> Home-based care may be the correct approach in the South African context for a variety of reasons, but is it being properly and adequately implemented by government, and are those who are carrying the bulk of this care workload being sufficiently supported in their endeavours?

Estimates of HIV prevalence in South Africa range from 9.8 to 16.0 percent for 2005 (Day & Gray, 2005: 289) Statistics South Africa calculates for 2004 that about half of all deaths are due to AIDS (ibid: 290) This means that in South Africa there are and will be a substantial number of people in need of care. With such high HIV prevalence levels and deaths due to AIDS, it is no surprise that the focus of much social research in South Africa has been on those infected and their care provision. This research has looked at the experience of morbidity and mortality within households (Johnson et al, 2002), the community-based care programmes in place (Russell & Schneider, 2000), and the means by which these programmes can be extended (Goudge et al, 2003; Johnson et al, 2001) It has also focussed on the gendered nature of care provision, and home-based care programmes have been described as inadequately developed and of questionable effectiveness (Akintola, 2004)

Much of this research has tended to focus on informal caregivers – usually volunteers – who are part of home-based care programmes, but who do not live within the home and who do not provide care on an everyday basis. In many cases the distinction is not clearly made between these non-resident caregivers, and those family caregivers who do live within the home and provide care on a day to day basis. Little South African research has

documented the experiences and perspectives of family caregivers who provide the vast bulk – and in many cases are sole providers – of care within the home (see Hunter, 2005) These family caregivers are in most cases not linked to home-based care organisations, usually because such programmes are present in few communities, relative to the extent of need.

The general aim of this paper is to add to the limited research on family caregivers, and specifically to enable a better understanding of the actual experience of providing care for ill adults within the home in the context of HIV/AIDS, using qualitative research findings from a KwaZulu-Natal study. HIV prevalence rates in this province are higher than the national average – one estimate is 19.2 percent for 2005 (Day & Gray, 2005: 289), and this makes it an apt site for analysing care provision. The paper focuses on understanding what care provision means to family caregivers and in turn why they provide care. More centrally it highlights various aspects of the experience of providing care and the effects of care on caregivers' lives. Through insight into the experiences of family caregivers it should be possible to gain an improved understanding of the appropriate and necessary support required by them in South Africa.

Fundamental to the study of caring is the finding that it is women who principally undertake care activities, in both developed (Pascall & Lewis, 2004) and developing countries (Chen et al, 2005; Ogden et al, 2004) Twigg (1992) defines informal care as usually occurring in the context of family relationships, and as being provided on an unpaid basis that draws on feelings of love, obligation and duty. Generally, the closer the kin relationship the greater the sense of responsibility for looking after the person, and the greater the public expectation that this will take place (Heron, 1998)

Research on caregiving in developed countries has tended to focus on the care of people with chronic conditions, particularly the elderly and people with disabilities. Cheung and Hocking (2004), in a study of spousal caregivers for multiple sclerosis sufferers find caring to be a complex emotional relationship of responsibility for caregivers, and specifically identify worrying as a care responsibility. These caregivers worried about their partners, their relationships with their partners and their future, as well as their own health, institutional care and lack of government support. These authors point out that while there are studies on the strain and stress of caregiving, the meaning of caring from the caregiver's perspective remains to be explored.

In an Australian study Pakenham et al. (1995) investigated the effects on carers of caring for a person with HIV. The most common elements of what they described as carers' burden were distressing emotions, relationship difficulties, somatic symptoms and grief. Not surprisingly, living arrangements were found to be significantly associated with carers' burden – those co-residing experienced more burden than those living apart from the patient. Moreover, patients' number of HIV-related problems and subjective health status were positively related to carer adjustment and burden.

Interestingly, the researchers found that the aspect of caring more burdensome than the practical tasks of physical care was the psychological aspect of caring. The most problematic aspect of a carer's caregiving role appeared to be his/her own process of adjustment to the reality that the loved one had a stigmatised life-threatening illness and the patient's HIV-related psychological and existential distress. Previous research on caregiving (as cited in Pakenham et al, 1995: 190) has shown that women report a higher caregiving burden than men. In addition, there is a negative correlation between the 'distance' in the blood/role relationship and the mental health of the carer (that is, the greater the familial distance, the better the carer's mental health) Further, the more poorly a patient functioned (their perceptions of their physical health and the number of illness-related problems they were experiencing) the more burden and lower levels of adjustment their carer was likely to experience.

In developing countries research on care provision within the home has included a focus on the many challenges posed to family caregivers in the context of HIV/AIDS. Providing care has been described as a physical and emotional challenge (Family Health International, 2001) A number of factors have been identified that undermine caregivers in sub-Saharan Africa in performing their caring tasks: a lack of knowledge, skills and support (at both the individual and organisational levels); physical and psychological burnout; community stigma and rejection; and the destruction of household economies (Campbell & Foulis, 2004). McCreary et al. (2004) in a Swaziland study described a lack of resources and infrastructure as adding to the burdens caregivers face. In the Democratic Republic of Congo, Nkosi et al. (2006) reported on problems in providing care as arising from psychological, social and economic factors, and these authors identified the secrecy around HIV/AIDS as a significant theme. Another study in the same country on the experiences of female caregivers of HIV/AIDS affected spouses (see Kipp et al, 2006) found caregiving to be a highly stressful role. High levels of social isolation, low self-reported health status and the deep unhappiness of caregivers were also identified. In Botswana, Jacques and Stegling (2004)

found home-based care to be problematic as an approach because of the symptomatic nature of HIV/AIDS, and the lack of human and material resources to address the needs of caregivers and those they care for. Hunter (2005) confirmed this latter finding in the South African context.

Akintola (2004) undertook research on the gendered nature of care provision in South Africa and Uganda, and found that the care burden was borne disproportionately by women as opposed to men. Moreover, caregiving was described as demanding and as leading to physical, emotional and psychological stress. Social alienation from friends and social activities was also noted, as well as the economic burden of caregiving. Many families were not in a position to offer home-based care without undermining the wellbeing of family members. Akintola argues that care models need to be rethought so as not to exacerbate poverty and existing gender inequalities among families and communities affected by HIV/AIDS.

In one of the few South African studies that focuses on the impact of caregiving on caregivers, Orner (2006) investigated the possible psychosocial impacts on caregivers of caring for people living with AIDS. Caregiving was found to place considerable demands on caregivers, negatively impacting on their mental health, and this was made worse by insufficient support, dire poverty and the added responsibilities of caring for other household members. A lack of basic resources was found to be common, and this prolonged the duration of and exacerbated the intensity of the caregiving process. Moreover, caregiving was found to impact negatively on normal working and social patterns. Stigma and prejudice towards caregivers was common and this exacerbated levels of stress. While the support received ranged widely, a lack of support was often debilitating and most caregivers were found to be overwhelmed by their care work on a practical and emotional level. Those who felt supported linked this support to improved psychosocial status. Not knowing how to access support structures was another source of stress for some caregivers.

The bulk of the paper will focus on the experience of caregiving itself, from the perspectives of family caregivers. Initially the research methodology will be outlined, followed by an account of various care situations in study households, in order for the reader to be aware of the context within which care takes place. The main focus of the paper will then shift to the experience of caregiving as described by caregivers in the study households. What is it like to provide care? Why are caregivers undertaking care? What are some of

the negative aspects of care provision? What are the social, physical and other effects of care on caregivers? What makes it difficult to provide care and when is it difficult to do so, and what would help caregivers the most in their caring duties? To end, conclusions will be drawn and recommendations made for the support of caregivers.

---

## **METHODOLOGY**

---

Results from qualitative research obtained between June 2004 and March 2005 will be analysed in this paper. Thirty-six households across six research sites in KwaZulu-Natal province in South Africa were extensively visited by three fieldworkers as part of the qualitative component of the 2004 KwaZulu-Natal Income Dynamics Study (KIDS). Two urban and four rural KIDS research sites (within Ndaleni, KwaBrush, Umlazi L Section, KwaDunuse, Mpakama, Osisweni) were selected using a careful, purposive process. Information collected in preparation for KIDS 2004 was used to select the study sites. The research sites selected were stratified on the following variables: (1) rural/urban; (2) geographical spread within the province; (3) degree and types of activities (mainly presence but also absence) pertaining to the four research themes (described below); (4) whether they had been part of another qualitative study linked to KIDS in 2001 (the Socio-Economic Study of the Persistence of Poverty and Inequality or SEPPI); (5) whether they were a part of the Political Economy of Social Capital study (another KIDS qualitative study); (6) whether the fieldworkers would be safe from a security standpoint. Telephone interview information obtained from local leaders in the KIDS research sites was used to provide information on (3) and (6)

Within each research site six households were selected – a small number but one which allowed data of sufficient depth to be collected on the research themes. The following themes were adopted for study in these households: ‘care’, ‘orphans’, ‘livelihoods’, ‘the Child Support Grant’ (CSG), and ‘changing household structure’. The first household selection criterion was that households be part of KIDS 2004, as an aim was to compare qualitative and quantitative data. The second criterion was that households contain a pair of conditions to enable data collection on two of the above four themes, in addition to the ‘changing household structure’ theme, which was covered in all households.

To begin, a mini-survey that contained information on all themes was conducted in all KIDS households in each research site.<sup>2</sup> It was not always

possible to select households with the ‘care’ theme through a mini-survey of KIDS households, since the criteria were not always met.<sup>3</sup> That is, it was relatively easy to find theme combinations that did not include the ‘care’ theme. In these cases household selection was purposive. One or more of the community caregivers in the study area, or other key informants if these were not present, were approached for assistance in identifying possible ‘care’ households.<sup>4</sup>

Permission to conduct the research was obtained from various local leaders, for the six research sites chosen for the study. After explaining the background and purpose of the study and assuring confidentiality, consent was obtained from the six case study households in each research site.

A ‘modified’ extended case study method was chosen.<sup>5</sup> Each fieldworker lived in two research sites for two one-month periods, and travelled between the two research sites at intervals.<sup>6</sup> Repeated visits were carried out to households, and formal and informal interviews and discussions were conducted with different household members. Ethnographic techniques were used, including interviewing and household events-mapping and events-mapping of illness periods, and observing and participating in activities related to the topics of the research, both at the household and community level.<sup>7</sup> The purpose of these methods was to build trust and rapport with households, and to observe and learn in a way that is not possible with more rapid research methods (Adato et al, 2004; 2005). Note-taking and elaboration on fieldnotes after household visits occurred in the field. This material was then typed up when the fieldworkers returned to Durban between field visits. Since there was no tape recording, quotations are not verbatim but the closest approximation of quotes based on interview notes.

As an outcome of purposive sampling, three of the households in each research site contained an adult who was ill and being cared for by at least one household member. Across the six study sites, in 18 households 22 family caregivers were undertaking care for 19 people – in one household there were two ill people receiving care.<sup>8</sup> In seven of the 19 cases the HIV-positive status of the ill person was volunteered.<sup>9</sup> Given the age range of the ill people (23 to 51 years), as well as the high HIV prevalence levels in KwaZulu-Natal, and since 10 of the ill people were known to have died non-accidentally by the time fieldwork was completed, it is likely that a number of the ill people had HIV/AIDS.<sup>10</sup> Interviews were undertaken with 21 of the 22 family caregivers and findings from these interviews will be reported on here.

It should be emphasised that the information collected is not representative of the situation in KwaZulu-Natal. However, the study areas were spread across the province, and there is no reason to think that care situations would be substantially different elsewhere. The interviewing process was often emotionally difficult for interviewers. It is important to note that the fieldworkers asked questions that elicited not only sad stories and stories of difficulties, but also the positive side of care provision. The study information was coded by the researcher. An attempt has been made to reflect the variety of perspectives given by study respondents, in line with one of the central aims of this paper. Both common and infrequent responses have been included.

---

## CARE SITUATIONS

---

The 22 caregivers ranged in age from 16 to 74, and all but one were female. The 19 cared-for ranged from age 23 to 51 – eight were female, 11 were male. About a third of the caregivers were aged 60 and over, and therefore no longer in their prime of life physically. In three cases the caring task was shared. In most cases the caregiver was not working for an income. A number of those caregivers who were working gave up their work, or substantially reduced their work activities, in order to care for the ill person. Two of the caregivers were traditional healers and both gave up their work for some of the time during the care period. Another caregiver had to get other women to cultivate her land as she was unable to do so because of her care obligations. Two caregivers sold goods informally – in the case of both this work was curtailed or stopped over the time that the ill people required a lot of care. Another caregiver was able to continue with her recently acquired half-day work in a school kitchen, but stated that she was fortunate that she did not have this work when her daughter required substantial amounts of care. Apart from this, seven caregivers were unemployed, one was studying and seven were receiving an Old Age Pension.<sup>11</sup> One of the latter still worked informally.

These findings on who provides care in the home are in line with the literature on caregiving in sub-Saharan Africa (Chimwaza & Watkins, 2004). In most of the study households there was only one caregiver, and she was the mother of the ill person. The one male caregiver was a nephew, who along with the ill person's mother, cared for his uncle. In 10 of the 19 households the mother of the ill person was the only caregiver. In all but one case the caregiver was



related to the ill person – in this instance an ill male’s brother’s girlfriend was providing care.

In the Ngidi household in a rural area, a child, Thenjiwe, aged 16, was caring for her mother and her aunt simultaneously.<sup>12</sup> Thenjiwe also had a one-year old daughter of her own, and her aunt, Siyanda, also had a daughter of three years. Thenjiwe’s mother died a month into the fieldwork period, and she continued to take care of her aunt who later recovered, and was still alive when the household was visited by the study team over a year after the fieldwork ended. The narratives below give an idea of Thenjiwe’s experience of providing care. It is not difficult to imagine the magnitude of the extreme burden placed upon her in having to care for two ill adults and an infant, as well as having to be on hand for the three-year old. Thenjiwe was the only female who was at home all day and old enough to take on these tasks. Her grandmother was working on a cotton farm during the day, and although there were other male household members, they did not provide care, likely because it is not seen as socially appropriate for a male to provide care to females. The total monthly income to the household of seven adults and two children was around R500: Thenjiwe’s grandmother earned R200 a month, while her uncle earned approximately R300 a month, sometimes less. This precarious financial situation added to an already burdened care situation. The following narratives, as recounted to the fieldworker, point to different ways in which this situation was burdensome.

*When at home, the situation of poverty pulled her apart as she did not know where to find the solution. There were times when she felt that God was keeping the soul of her mother intact for too long because caring had become unmanageable: poverty and illness were serious challenges to her household. She said that in trying to attend to both her child and Siyanda as well as her mother, she had to run in all directions to find solutions: trying to find food when there was none and bathing both her mother and aunt...*

*...There was no order in her life and she could not draw up a schedule of things to do and stick to it because when her mother coughed she had to rush to her. Also when her aunt called out for help, she had to decide immediately which one was more of an emergency and had to be prioritised...*

*...She even lost the presence of her child’s father because each time he wanted to see her she would be at home, attending to the ill people. Other domestic*

*tasks were also dropped: going to the river to wash clothes or fetch water had become a serious problem because there was no time...*

*...Coping with her situation was very difficult. She had to hope that her child would fall asleep so that she could catch a nap or be able to attend to her mother and aunt without the child in the background. At night, she found the going hard as the child would be demanding attention and so would her mother and aunt...*

*...Although she had not lost a lot of weight, she had tended to become too stressed and her memory was getting disorganised. (Rural 1 Ngidi)<sup>13</sup>*

Quite evidently the care burden upon Thenjiwe is inordinate. The demands upon her from a number of sides mean that she is taxed physically, socially, mentally and emotionally, and is not coping with all of the tasks that are placed upon her.

In many instances caregivers also suffer health complaints related to growing older, and they acknowledge the physical strain that caring adds to their health complaints. In the Ntini household, the caregiver of the ill person – his mother – was very unwell, and died over the fieldwork period. In the Dladla household the burdens of the care situation are compounded for the ill person's mother, Thandazile, who is the main caregiver. Not only is her son HIV-positive, but she confides that she too is HIV-positive, and that she too becomes ill and is often not able to look after her son, Bulelani, properly.

*It is very hard for Thandazile because she is also sick. She said if she is not feeling well on a particular day that means there is no one to care for Bulelani. If Thandazile is sick it means she cannot bath him. She cannot clean the house, she cannot cook food that she would like him to eat. The only thing she can do is to give him morvite porridge because one just adds water. For Bulelani it means he could starve if his mother is also sick... For Thandazile to have a son who is sick and she is sick, [she] said she does not know if it is a curse or what to her. With all the responsibility and she has to provide food for her other three children - two of them are not working, one is still a school-going child. She said she is very worried about her (eight year old daughter) because if she dies what will happen to her, and also what will happen to Bulelani, because right now there is no one (else) looking after Bulelani, she is the only one. In most cases there is no one [to care for him]*

*because her mother Gertrude, [the] granny, had a stroke [and] she cannot do any housework. (Urban 2 Dladla)*

The home- and community-based care guidelines do not make mention of, nor provide guidance on an appropriate care response in situations such as these, where poverty and illness are already placing considerable burdens upon households, before care requirements have been taken into consideration. In fact, in such circumstances it is hard to imagine how home-based care by informal caregivers in the home can be the chosen means of care. From a human rights perspective it is highly questionable.

---

## **CAREGIVER'S PERSPECTIVES ON THE CARE THEY PROVIDE**

---

Twenty-one of the 22 caregivers were asked open-ended questions on their caregiving (one caregiver who had shared the caring task with her mother was not present at the time this information was collected). This section largely presents the responses to these questions.

### **What it is like to provide care**

Caregivers were asked to describe what it is like to provide care for the ill person. In response, one caregiver gives a practical look at what it means to provide care:

*She has to make sure that Sibusiso is taking the medication, boil water for him to bath and always be available to help him when he needs assistance. She says that caring for a sick person means hard work. She has to do the washing for him. There are times when he is sweating at night and she has to wash those blankets very soon. (Rural 4 Khubona)*

This mother is 64 years old and clearly this is a noteworthy amount of physical labour for a person of her age to complete on a daily basis. As identified in Hunter (2005), caregivers undertake nursing work and domestic work. From this it can be seen that care provision for this ill person means regular provision of different forms of care. This too is reflected in another caregiver's response to this question:

*It is a difficult task because the ill person needs constant attention and care. She needs to be taken to the toilet, bathed, undressed and dressed. Clothes have to be washed most of the time and this affects other equally important duties. (Rural 1 Ngidi)*

For the most part what it is like to provide care is defined in negative terms. A number of caregivers point to care provision as being difficult work. The following seems an apt encapsulation of this perspective from the mother of an ill person:

*Helen says that caring for a sick person is a difficult responsibility to do ... She says that caring for a sick person is like giving birth to the sick person for the second time. (Rural 4 Yengwa)*

Other caregivers point to care provision as being demanding and some describe this aspect as being frustrating, as in the Luthuli household:

*Phumzile says caring is a very difficult thing to do. She says she can't even relax because Mbeje has a lot of requests. She gets a lot of complaints from Mbeje, asking a lot of things of Phumzile. She says she has to keep on checking if Mbeje is doing okay. (Rural 2 Luthuli)*

For one 72-year old caregiver, the best description of what caring is like is to point to the fact that it is a wearying job:

*She said it was very tiring since she is very old. She said she expected to be the one to receive care, not the other way around – meaning that the children must take care of their parents. (Urban 1 Sibiyo)*

Here the inversion of parent-child roles is pointed to, and this was a frequently highlighted aspect of care provision in the study. The only male caregiver in the Luthuli household defines caring as unenjoyable, irritating and horrible – it seems that he is referring to the actual tasks that have to be undertaken when caring for someone. In this case the ill person, Mbeje, had already died:

*Zamokuhle says that caring for a sick person is a compromise that you do for a person. He says that it's not the kind of work that he enjoyed to do. It caused the short temper for him. He was irritated so easily. He remembers the things like helping Mbeje to go to toilet and when Mbeje was coughing up mucous. He says that it was so frustrating because Mbeje would be so angry if Zamokuhle did not check on him in the morning. It made him feel guilty. He was depressed. (Rural 2 Luthuli)*

It is evident that the emotional aspects of providing care lie close to the surface, and again tie in with the difficult nature of this work. It is not easy work for this caregiver, but because of his relationship to and with the ill person it is work that he feels he must do. Similarly, two caregivers express an explicit dislike for the caring role they find themselves in, and link their perception to the actions of the ill person. Thembeni, the aunt of an ill person who is HIV-positive, shows some resentment towards having to pick up some of the costs of the ill person's behaviour:

*It is a horrible job. She was so angry because she felt that Bongiwe would not listen to her parental advice. And Bongiwe got into these problems. She was dumped by a man after infecting her, and the baby died. And she (Thembeni) had to carry the costs. The man was nowhere to be found. (Rural 3 Xaba)*

This resonates with the response of another caregiver, the girlfriend of an ill male's brother, who resents having to look after someone who was not responsible nor generous in the past:

*She said she does not have words to describe it but she does not like one minute of caring. Thabsile said it was not nice to care for Bheki because when he was working he never shared any of his money with them, but now she is the one who is looking after him. (Urban 2 Tembe)*

Care is defined as emotionally challenging and emotionally stressful by some caregivers. The following narratives give some indication of these perspectives. Here a mother is caring for her ill son:

*She says that caring for the ill person affects her health because it creates emotional stress. She feels that she can't relax as a person. She can't stop thinking about Mondli as a sick person. She can't sleep at night thinking about Mondli. She is always concerned whether Mondli is still okay. She says that it has become so difficult for her because there are times when she [has] had to sleep in one bedroom with Mondli, so that she can observe him [to see] if he is still okay. (Rural 4 Thwala)*

Clearly being a mother, and being emotionally attached to her ill son make having to provide care a difficult task emotionally. Some caregivers speak of the fear they experience for the well-being of the ill person, and concern that the person they love may die. As noted earlier, Thenjiwe Ngidi cares for her ill aunt and mother, and describes the caring task as follows:

*She said it was a bad experience in the sense that you face someone you love and you can see that her life may be snuffed out soon. You panic and try to do everything you can and think that whatever you are doing will heal the loved one. (Rural 1 Ngidi)*

Some caregivers draw on the positive aspects of providing care when describing what caring is like, such as this mother:

*It is a combination of issues: gratitude to God that his spirit and soul are still intact, and being grateful that this (care) is contributing to the maintenance of his soul, although it is a lot of hardship. (Rural 3 Ndaba)*

In other words, care provision presents an opportunity to remind oneself of certain mercies, apart from and in addition to any difficulty that it presents. Another caregiver, the ill person's wife, echoes this perspective. She says that she sometimes feels better when she reminds herself that her husband is still able to stand on his own.

Two caregivers, both mothers, also point to care provision as an opportunity to show love. This is how one describes what it is like to provide care:

*It is fulfilling if it is your child. You get satisfied because you have a chance to try everything. (Urban 1 Mfeka)*

Clearly here the relationship of the caregiver to the cared-for is integral to how care provision is defined. Another caregiver, also a mother, points to the fact that care for a child is different from other care provision:

*Care is best described in this way: who do you care for and what [is the] reason for caring. In this respect it is her daughter she is caring for and [she] needs to retain her spirit. (Rural 3 Mbongeni)*

It seems that any difficulty that caring presents is justified because she is caring for her daughter, and there is a need to do the very best that she can for her.

Finally, care provision is also defined in neutral terms by one caregiver. With insight, this mother picks up on the fact that she is performing the role that is usually undertaken by professionals.

*Patricia says that to care for a sick person is like doing the tasks of the health providers. She is like a nurse when she is caring for Sibusiso. (Rural 4 Khubona)*

Caregivers in the home are indeed doing the work of nurses, but in nearly all cases these caregivers are providing care to those they are emotionally close to, which makes the caring task that much more challenging and/or fulfilling.

To sum up this section, many caregivers describe caregiving as consisting of regular forms of different types of care – which is more often than not hard work. Caregiving is often defined in negative terms. It is also emotionally stressful, since most of those providing care are closely related to the ill person. Caregiving, it seems, is not that different to nursing work and domestic work, but in most cases it is both more challenging and fulfilling than the work undertaken by these workers, because the caregiver and cared-for are usually emotionally close.

### **Why caregivers provide care**

One of the aims of this study was to understand the motivations of caregivers, given the obvious burden and stress of caregiving. As noted earlier, there are a range of care situations and relationships of caregivers to cared-for among the study households. Most caregivers are mothers, one is a wife, some are daughters, and one is a nephew. Only one caregiver is not related to the cared-for. We can expect that the reason for caring will be determined in some way by the relationship of caregiver and cared-for. It seems that there are clear (often socially defined) expectations around who should and should not provide care. Some caregivers define the reason for providing care in terms of their relationship to the ill person, while others define it – either in addition to this or solely – in terms of no-one else being able to care for the ill person. This latter reason is explained by the fact that they are the only adult in the household, or the only older person, or the only female or because they are the only person at home all day (as in the case of a pensioner caregiver)

In the following case an aunt, Thembeni, is caring for her niece, and outlines the following reason for doing so:

*There is no one else to do this. Bongwiwe has no one else to look after her, as her parents passed away a long time ago. Relatives stay away from Rural 3*

*and they hardly visit her. It is [Thembeni's] responsibility to take care of her. (Rural 3 Xaba)*

Bongiwe had a brother, and a son of eleven, but it seems that it was not an option for a male or a child to provide care in this situation. However, another child is the caregiver of her dying mother and ill aunt in another study area – the only child caregiver found among the study households. As noted earlier, Thenjiwe Ngidi, 16, is providing care for her mother and aunt. Her uncle is unwell, her grandmother is working on a farm, and another uncle works in a nearby shop. She is no longer in school, having left to have a baby. There is no-one else to provide care – the other household members are two small children. Another cousin also lives in the household and does not work, but is male, and it would seem that for this reason he does not assist with care provision. Thenjiwe wants her mother and her aunt to recover so that they can work again, and so that she in turn can go back to school:

*She is motivated by the fact that her mother and aunt have to recover. She wants to return to school and if they both recover, they will be able to pay for her school fees and buy the required books. Also, if they die, poverty will be ongoing in the household. (Rural 1 Ngidi)*

Soon after this information was recorded, Thenjiwe's mother died. Her aunt recovered, and when the household was visited again, over a year after fieldwork ended in this study area, her aunt was still well, but Thenjiwe was still not in school. Her aunt did not have a job, and her grandmother who had had a job at the time fieldwork was undertaken had lost it in the interim.

In one urban household the only residents are an ill male, his brother, and the brother's girlfriend. She states that she became the caregiver because she was the only female in the household. However, she indicates that she was not motivated to care – here the caring role is seen in negative terms. This caregiver leaves the household during the fieldwork period, and even after this occurs the ill person's brother does not provide care, despite being the only other person living in the house. It would seem from this case that being female provides a stronger reason to care than being related. This points to strongly held views on who should and should not be providing care.

The duty to provide care that arises from being a female is a different kind of duty to that arising from being a mother, which was the role of most of the



caregivers. The following is a good example of a mother's perspective on why care is provided to her son of 27:

*She feels that it is her responsibility as a mother to care for Siphso. She feels that she has to take more responsibility than other people do in the household. She thinks that other people cannot have patience to clean the dirty caused by a sick person. She feels that it is the job of a mother to care for a sick child. She thinks that it is a job of a mother to bath [her son]. (Rural 4 Yengwa)*

Clearly this mother feels that mothers must meet caring needs that others simply cannot because they do not have the same inherent relationship that a mother and her child have. This thought is also reflected by a number of other caregivers who are mothers. One mother uses even stronger terms:

*Nkosazana says that she is the mother of Mondli. She has no alternative. She says it's impossible for her to give the responsibility of the caring work to another person. (Rural 4 Thwala)*

Here the duty to care for a child is portrayed as non-negotiable.

Another mother describes how one of her sons died a few years earlier, and she feels that she did not do enough to care for him; therefore she wants to try her best in providing care for the son who is currently ill. In a case mentioned previously, a mother, Thandazile Dladla – herself HIV-positive – is the only person who knows that her son is HIV-positive, and she says that this is part of the reason for her providing care for him:

*Thandazile said she is the only one in her family who knows what is wrong with Bulelani. When Bulelani came back with the result, he gave it to her and he did not say anything to her. She never had the courage to talk about it [with him] ... The other members of the family do not know that Bulelani is HIV-positive. She said she is afraid to tell them because she does not know what their attitude towards Bulelani will be. She also said no one knows at home that she is HIV-positive, not even her sick son. (Urban 2 Dladla)*

Here it seems that care is given because, in addition to being a mother, the carer's knowledge of what is wrong with the ill person is linked to a duty to assist. Thandazile also indicates a lack of motivation for this task:

*She said there is nothing that is motivating her at the moment because Bulelani is getting worse and she is not getting any help with the medication ... nothing seems to work for her when it comes to Bulelani's care. (Urban 2 Dladla)*

This points to the challenges of care provision for someone who has a terminal illness and whose condition will not improve. Bulelani died a few months after this fieldwork was undertaken.

For those mothers caring for their grown children, the fact that the caregiver is the ill person's mother and, linked to this, the love for a child are given as motivating factors for providing care. Specifically, some mothers mention that they want to make their child feel happy and loved, as in the following narrative:

*She is motivated by the fact that she is giving him the love of a mother. She says that the love of a mother for a child never ends. It never stops. She wants to see her child happy like all the other people, not suffering from pain. (Rural 4 Khubona)*

Similarly and as seen in the narrative that follows, for some caregivers providing care is a chance to give or show love and a chance to help someone you love:

*She said with her son it was going to be difficult for an outsider to care for him because he was very arrogant: he did not want to eat and to take medication. So she manages to open her heart and love him under these hardships. In short, she said [what is good about caring] is to give him love. (Urban 1 Sibiyo)*

For one caregiver care is an attempt to save a person's life and this is what is good about caring. For another it is an opportunity to try her best to help her daughter:

*It makes me feel good because I have a chance to try everything I can afford. (Urban 1 Mfeka)*

For yet another caregiver, providing care is an opportunity to try different medication in order to make the ill person better. According to a caregiver

who is a mother, if the ill person recovers and if care helps them to get better, this is the good aspect of care provision:

*Helen says that it has been good to see Siphon recovering from the pains and getting better from his sicknesses. She says that Siphon has been very sick and there was a time when she thought that he would die. She had to be strong and care for him. She feels good that she can see Siphon recovering from his illness. It's good to see that Siphon is getting life again and that has been her wish all the time when she is caring for Siphon. (Rural 4 Yengwa)*

Another caregiver has similar sentiments, but states this in a more spiritual sense. With regard to what is good about caring for her son, she says:

*To realize that the care she gives him helps him to regain energy and stop wasting away. In caring for him, she tries to put together what was once a healthy mind and body, somebody that once cared for the household. Caring for him is like compensating [him] for the good he did for them. (Rural 3 Ndaba)*

So this caregiver finds meaning in giving something back to the ill person for what he gave previously.

A number of caregivers describe caring for their own child and the related satisfaction received from caring as being positive aspects of providing care. In this narrative, a mother describes both of these to the fieldworker:

*Firstly, Thabile says that it's painful to see her child suffering from the sickness. Thabile says that what makes her feel good about caring for Gloria is the fact that she is caring for her own child. She feels good when she assists Gloria because that gives her satisfaction. The fact that she wants to satisfy Gloria's feelings makes her feel good. She feels good if she can be able to assist Gloria in her daily needs because she finds it difficult to see her daughter suffering from the pains and to see that she can't help herself or do anything for herself. She likes to see Gloria happy and being helped. This makes Thabile feel good about caring. (Rural 2 Cibane)*

For some caregivers what is good about care provision is the appreciation received from the ill person:

*She feels happy when Sibusiso appreciates her for the caring work she does for him. She feels good when Sibusiso says that it is good to have a mother like her. There are times when Sibusiso says that he would have died long time ago if he did not have a mother like her. This makes her feel good as a mother. (Rural 4 Khubona)*

Finally, for one mother caring for her adult daughter providing care means she will receive a reward from the ancestors, and this is a good aspect of caring:

*She feels good in the sense that if her daughter recovers, she will be rewarded by God and the ancestors and her [grand]children will be happy to know that she cared for their mother to the last moment. (Rural 3 Mbongeni)*

What the ill person means to the caregiver is given as a motivation for providing care by this caregiver. She points to the strong bonds that exist between her daughter and her as the motivating factor in providing care:

*She has got sons, but their contribution to the household has been very little. Philisiwe (the ill person, and her daughter) has been a pillar of strength. (Rural 3 Mbongeni)*

The recovery of the ill person and a desire to see them get better or survive is what motivates most of the caregivers in the study. Indeed, if the ill person responds to the care and treatment provided by the caregiver, this is also mentioned as a spur to care provision. Some caregivers give specific reasons for wanting the person to recover. In the following case a mother is motivated to see her daughter, Gloria, recover so that Gloria, in turn, can spend time with her own two year old daughter, Ayanda:

*Thabile says that motivation is the feeling from the bottom of her heart. She says that she has the desire to see Gloria getting stronger and becoming energetic like other children of her own age. She says that the fact that Gloria is her daughter and [that] she wants to see her happy like other people motivates her. She says that there is Ayanda, and she is still a baby, and she wants Gloria to see her child growing up because Gloria has a good relationship with her child. Thabile says that she wants happiness for Gloria. (Rural 2 Cibane)*

Here the motivation that comes with being a mother is also evident. Tragically Gloria died four months after fieldwork ended in this study area, and her daughter, Ayanda, had already tested HIV-positive.

The only caregiver who is a wife/partner describes her duty as arising from being a wife, while the nephew of an ill person says that he is providing care because of his blood relationship to his uncle, because of his desire to help his uncle and because nobody else was caring for him. It would seem that blood and marriage bonds are strong determinants of who provides care.

Finally, for one caregiver the fact that the family is pulling together and working together around the care of the ill person, is a motivating factor.

In sum, there are clear and usually socially defined expectations around who should provide care. Some caregivers define the reason for providing care in terms of their relationship to the ill person, while others define it in terms of being the only person available to provide care. A duty to care arises from being female and more frequently, from being a mother – and this tends to be accepted without complaint. Overall, caregivers are motivated by different things. Many mothers find their motivation in the fact that they are mothers; some caregivers find their motivation in the fact that they are related to the ill person. Linked to this, most caregivers point to some positive aspects of providing care: to care for one's own child; to receive fulfilment and satisfaction; to receive appreciation from the ill person; to be able to give something back to the person they are caring for; to be able to show the ill person love. A few caregivers state that they are not motivated to provide care – this is in the case of very difficult circumstances (where the caregiver is HIV-positive and unwell) or where the caregiver is unrelated to the ill person. However, the desire to see the ill person recover from their illness is frequently cited as a motivating factor in care provision.

### **Negative aspects of providing care**

A number of caregivers said that there was nothing good about providing care. The following narratives are examples of this position:

*There is no joy. No joy when you have to deal with poverty and then caring for the sick person with AIDS. (Rural 3 Xaba)*

*Phumzile says that caring is not a good thing, especially for her because she is old and doesn't have energy. (Rural 2 Luthuli)*

Here poverty and HIV/AIDS, as well as the caregiver's old age are all reasons for caregiving being seen in a negative light. For Thandazile, the caregiver who herself is HIV-positive, the fact that there is no good aspect to care provision has double resonance:

*Thandazile said, in her condition there is nothing good about caring for the ill person because she cannot give all the care that Bulelani needs. She said she cannot cook proper food that might be required by Bulelani at that particular time when she is sick. And she cannot change his linen and wash it if a need arises. If Bulelani is in a bad condition and in need of going to the hospital when Thandazile is sick, it will not be possible. Thandazile is the only one who knows what to do if Bulelani is sick. (Urban 2 Dladla)*

Since Thandazile's health is compromised it means that it is not always possible for her to properly care for her ill son. In fact, she herself needs a caregiver, but there is no-one in her home to look after her.

All but four of those that responded indicated that there had been a time when they did not know what to do to care for the ill person. For one caregiver it is when her ill son refuses to take his medication that she feels like she does not know what to do. For another, in her sixties, it is when she cannot physically lift her ill son in order to care for him. Another does not know what to do when it comes to bathing or changing the ill person. Therefore, caring tasks that involve physical activity present the greatest challenge for some.

Not knowing what to do is linked to not feeling confident. Some caregivers state that they do not feel confident because they do not know how to care for the person. Moreover, nearly all caregivers point to experiencing difficulties in care provision, with only one caregiver indicating that it had not been difficult to provide care in the home environment.

Some caregivers do not know what to do about the condition of the ill person. Here an ill male's brother's girlfriend provides care:

*She said [that she did not know what to do] when Bheki was in a very bad condition and the clinic was not helping. Till Bheki's mother suggested taking Bheki to the hospital. (Urban 2 Tembe)*

In this case the situation of not knowing what to do ends when the ill person is admitted at an institution that can provide professional care.

For the majority of caregivers who indicate that they do not always know how to do something to provide care, this is linked to the condition of the ill person: a worse condition of ill health is related to when the caregiver expresses doubt about what to do to care. Moreover, some caregivers indicate that their confidence in providing care is closely tied to the condition of those they care for: when the ill person recovers slightly they feel more confident; when the ill person's condition worsens they feel less confident. It is when the condition of the ill person is very bad, or when the ill person relapses, that many caregivers express a complete lack of confidence.

One caregiver in particular refers to recovery-relapse episodes and a fluctuation in the well-being of the ill person as being the most unpleasant aspect of providing care:

*When he seems to be showing signs of recovery, and then suddenly he relapses and he becomes very serious. As a caregiver, she says, you simply lose confidence and see yourself as a failure. In the meantime, she says, the sick [person] is relying on you completely. He knows that if you fail, it is the end of his life ... When he gets sick her mind starts roaming, searching for a solution. She thinks about the children who are also pinning their hopes on [her]. (Rural 1 Shibe)*

For this caregiver the fact that her husband recovers but then relapses on a regular basis is also what is most frustrating:

*Yes (she gets frustrated), when she realizes that she cannot cope. In one instance, she felt so hopeful after she had given him his tablets and he just snoozed off. He woke at the dead of the night and started asking for food. He sat up for two hours talking to her – he had not done this for ages. Her heart started pounding with satisfaction: he was recovering. But towards the early morning he was crying and sweating profusely. It seemed as though he was on his last lap. She went out to hire a neighbour's son's car, but he was not there. [He] was breathing heavily. There was no outside help. She just waited by him and gave him a hot bath with some pain-killers. After three hours he fell asleep. In the morning he was fine again. When she asked him what the problem was he said the same recovery-relapse episode once occurred when*

*he was on the mines ... Such episodes really take away a caregiver's patience. It is a frustrating moment. (Rural 1 Shibe)*

Here the caregiver is the only able-bodied adult in the household. She has five children and is pregnant with a sixth. Clearly the burden on her must be great, in her difficult physical state and with so many family members dependent on her.

Indeed a number of caregivers describe the lack of response to treatment, and the fact that the ill person does not recover as the most unpleasant and the most difficult aspect of providing care. The following is an example of a caregiver not knowing what to do to change the ill person's condition and make them better:

*She says that there was a time when Mondli was very sick and he was not recovering. Mondli was complaining about pains all the time. He had been sick for a long time. This was a difficult moment for her. She had nothing to offer him to take away those pains suffered by Mondli. (Rural 4 Thwala)*

For some, when the ill person does not respond to the care provided, through an improvement in their well-being, this is when they do not know what to do. Many caregivers point to feeling helpless and a sense that they are not making a difference to the well-being of the ill person.

*She said it is frustrating for her to know that she cannot help her child when he is suffering from pains. She feels the pain in her heart. (Rural 4 Thwala)*

Also, frustration experienced by caregivers is often linked to the condition of the ill person and frequently caregivers mention as frustrating the fact that the ill person is not recovering or getting better, despite the care they receive.

*She used to feel frustrated when her daughter was not responding positively to treatment. One day she would be fine and the next day she would be hopeless. That frustrated her very much. (Rural 3 Mbongeni)*

Many of the ill people being cared for in this study have a terminal illness from which they will never recover. Ayanda Mbongeni, who identified her daughter as being HIV-positive puts across the feeling of hopelessness:



*It is a nasty thing having to care for somebody seriously and for whom there is no hope of recovery. Each day you look at this sick person and apply your commitment and yet within you, you have the gut feeling that she is not going to recover. (Rural 3 Mbongeni)*

For two other caregivers the fact that the cared-for do not disclose what is wrong with them or what their illness is, is the aspect of providing care that is unpleasant. It also means that it is not always possible to organise the correct treatment:

*When he was really sick and no one knew what was wrong with him it was not easy when they wanted to buy medication because if they were to buy it, there was a question of what medicine. (Urban 1 Sibiyo)*

Not knowing what is wrong with the ill person impacts on the care that is provided: the correct treatment would be more likely to help him to recover, but it is not clear what the correct treatment should be. For one caregiver this also results in her ‘holding back’ in terms of care provision:

*When Bheki was sick he did not tell Thabsile what was wrong with him so Thabsile was also scared of caring for him. (Urban 2 Tembe)*

Here it seems that Thabsile fears becoming infected, possibly with HIV/AIDS. Not knowing what is wrong with her ill cousin also has an impact on how Gladys approaches the care task in the Mngadi household:

*She said with the others she had cared for she was confident. [But] with Thembi (the ill person) she said she is not confident because Thembi has not said what the cause of her illness is. (Urban 2 Mngadi)*

Here Gladys suspects that Thembi is HIV-positive, but Thembi will not speak about her illness. In fact, not knowing what is wrong with the ill person is frequently mentioned as something that makes it difficult to care for the person at home.

For another caregiver not knowing what to do and not knowing what is wrong with the ill person together cause her not to be confident – elsewhere she expresses a suspicion that her son has HIV/AIDS. In addition, not having materials to provide care adds to her dilemma:

*Phumzile is not confident at all. She is worried that she does not have the gloves to use when assisting Mbeje. She is not even confident to wash his sores because she does not know how to do that. She has a big problem [in] that she does not know what is wrong with Mbeje, and she is not confident to help him. And she is worried that Mbeje is coughing all the time and she does not know what to feed him. (Rural 2 Luthuli)*

Here a lack of confidence in providing care is tied to a fear of contracting HIV.

Linked to not wanting to disclose what is wrong is also denialism. For one caregiver, what is not good about caring is the fact that the ill person does not want to seek help at health facilities in order to find out what is wrong with him and to access proper treatment. This is linked to the denial that is often associated with HIV/AIDS.

*Malanga said it is hard for her because her son does not want to go for help. He does not want to go to hospital so that he can get the right treatment. She said she is giving him what she thinks will help him. (Urban 1 Madondo)*

Again, an uncertainty in terms of what treatment to give the ill person comes across as making the caring task a particular challenge.

Some caregivers mention that not having been trained in how to provide care makes it difficult to care for the person at home. This is illustrated in the narrative that follows:

*It was difficult for Zodwa – she said she is not trained for this kind of care. As Thembi is getting worse it is hard for Zodwa to cope. (Urban 2 Mngadi)*

Not being trained to provide care is also identified as something that is unpleasant with regard to the care process by the ill person's mother in the Dladla household:

*She said she is not trained to do this caring, and Bulelani needs attention because he has some complications that are developing. (Urban 2 Dladla)*

Bulelani was identified as being HIV-positive by his caregiver mother. Big lumps had developed under Bulelani's ribs, his feet were swollen and his stomach was growing larger by the day. Not being trained to provide care can

only be extremely challenging for this mother, who knows that her child's illness is terminal.

In the following case there are two caregivers for the ill person, a male aged 45: his 67-year old mother, Phumzile, and his 23-year old nephew, Zamokuhle. Clearly here, as in other cases described, not knowing what to do is linked to a lack of training in care provision:

*Phumzile says that she is uneducated, she does not know what she must do for Mbeje, and she does not know the type of food that she needs to buy for him. She says she buys food for the household and finds that Mbeje can't eat that food. She says she is scared to bath Mbeje because he has sores and she does not know how to care for the person with sores. She assumes that Mbeje has AIDS and that's the reason she is scared to help him.*

*Zamokuhle says that he did not receive health training to care for the sick person. He felt that he didn't know what to do for Mbeje, especially when he was coughing all the time and coughing out the mucous ... on the floor. He says that he was afraid and he didn't know what to do. He would call Phumzile to clean the floor. (Rural 2 Luthuli)*

Here a lack of training accounts to some degree for the inadequate care that Mbeje receives. Not being sure of what is wrong with the ill person or what is causing the ill person's unwellness, and a fear of contracting HIV is also evident in this case. It is likely that some education on caregiving would play some part in addressing this. As indicated in Hunter (2005), in about half of the study households no training or guidance whatsoever had been received by caregivers. In just over half of the households no guidance had been received from a clinic or a community caregiver.<sup>14</sup> Three caregivers had received formal training on various aspects relating to caring, and this helped them in their caring role, but this had been received prior to their being in, and not related to, the care situation. A number of caregivers had cared for a household member who had already died, and some described this as their 'training'. Training enables caregivers to feel confident about what they are doing. A lack of training in how to provide care means that caregivers do not know what to do in all care situations, and it is the caregiver and the person being cared for that suffer as a result.

Moreover, not having medical/care facilities/equipment to treat and look after the ill person was also pointed to by some caregivers as making home care

difficult. Some of the caregivers who mention this point to the trade-offs involved in having the person at home versus in an institution. There is recognition that they would be better cared for in an institution, but that they would not experience some of the benefits of home care, such as receiving love from those in the household. The following is an example of this:

*She said caring for the person was good, but the problem was that the facilities were poor and there were no professional people who could handle the sick person. She said it was good in the sense that the person was closer to the people who loved him or her and sometimes such presence made the ill person forget the pains because there was love around him. However, the family cannot handle a person who needs a drip or who needs to have his temperature taken. She also said being in hospital had its own problems because most of the time [people] go there and come out seriously ill and eventually die. (Rural 1 Ngidi)*

This caregiver seems very aware of some of the pros and cons of both institutional and home-based care provision.

Related to this, a lack of resources to provide care, linked to a problem of affordability, was also indicated as a negative aspect of care provision by some caregivers. A number of caregivers point to having little money and it therefore not being possible to buy the food the person needs or to meet other needs they may have (such as for medication), and that this is the most difficult aspect of providing care in the home. In the narrative below the caregiver, Thabile, outlines how difficult it was not to be able to provide her daughter with the special food she had requested, before money became available to do so:

*She says that it has been difficult because there are things and types of food that Gloria would ask from her and she can't afford them. There were times when Gloria would ask for maltabela, chicken, fruits, and she couldn't afford it. She says that she finds it difficult that she can't offer other things that are necessary for her daughter's sickness. She says when Gloria was at the hospital she liked eating maltabela. When she was discharged from the hospital she kept on asking for maltabela but she (Thabile) couldn't afford it. Thabile says it's good that Gloria [now] receives the Disability Grant and she can buy the food she likes. (Rural 2 Cibane)<sup>15</sup>*

Here the Disability Grant alleviates some of the difficulties of care provision for the caregiver and is seen to be having positive consequences and meeting some of its intended aims. Only two of the 18 caregivers in the study received the grant, however. Having little money means that it is often not possible to seek treatment for the ill person outside of the home, at a public hospital or by visiting a private doctor for example. Another caregiver mentions that she had sought assistance from the local clinic but that proper help had not been provided.

In the following case the ill person had been identified as being HIV-positive and a number of remedies are sought for him. What is noteworthy is the unaffordability of the medicines which seem to improve his condition:

*It is also not nice when a parent realizes that she cannot afford the best medicine on the market. She pointed out that, at one stage, she managed to buy medicine called 'cell-food' and it made him walk. But is too expensive at R200 for a very small bottle. It is an effective medicine or tonic, but it is beyond her reach financially. If she buys it often there will be no food on the table. She also used to buy him lucozade, and this pepped him up, but it is also expensive at R17 for a bottle. (Rural 3 Ndaba)*

One caregiver expresses doubt about what to do when there is no food in the house, and therefore no food for the ill person, and this is echoed in the narrative of another caregiver in an urban area:

*Another frustration she has is when she has to give Bulelani his medication [and she does not have] food to offer him first. When Bulelani feels sick sometimes it is hard for her because she must hire a taxi to the clinic, but maybe at that time she has no money and Bulelani cannot walk a long distance. (Urban 2 Dladla)*

This caregiver would like the ill person to receive better treatment, but a lack of money means that she is not able to access this treatment, which in turn leads to frustration as she is faced with a very difficult situation.

Other caregivers draw a link between not knowing what to do to provide care and a lack of medication or not having 'proper' medication for the ill person:

*Yes, when a person needs something and it is not there – like medicine or tablets. It then becomes her problem to try and find a solution for that. (Rural 1 Ngidi)*

Specifically, which medication to give the ill people is mentioned with regard to a lack of confidence, as in the following two cases:

*She said she has never felt confident, from day one when she had to [start] car[ing] for him. Bulelani had a problem with his stomach. He could not go to the toilet and she wanted to give him some laxative tablets. When she was about to give them to him, she remembered something: Bulelani was ill and he could not take laxatives because he had a loose stomach. Those are things that she cannot master. (Urban 2 Dladla)*

*Zodwa said she is not confident at all because she is not sure if the care she is giving her [mother] is the right one. The example that she made was if her mother is complaining of pains, she just goes to the shop and buys painkillers, [but] she does not know if she is supposed to be taking them or not. (Urban 2 Mngadi)*

Other caregivers point to the fact that they are providing care, not for a child, but for an adult who is not often easy to manage, and that this in itself is frustrating:

*Firstly, Babongile says that she would like to be open to me. There are a lot of frustrations when it comes to caring for Sanaz. It is very difficult to care for, to help an old person (adult) because sometimes they are stubborn and do not want to listen. (Rural 2 Mncube)*

For some caregivers providing care for an adult who is not elderly – particularly personal caring tasks such as bathing, dressing and undressing – was also specifically identified as an unpleasant aspect of providing care. The only caregiver who is not related to the person being cared for expressly points this out:

*She said she did not like the idea of bathing a man who is an adult, as Bheki [is], and [to whom she is] not related. (Urban 2 Tembe)*

Therefore, not only having to care for an adult, but also having to care for a man, and someone to whom she is not related, is unpleasant for this female

caregiver. Being related, it seems, covers over some of these difficulties. For one mother, Miriam, having to undertake personal care tasks for her adult son is also difficult – not only for herself but also for her son, Mzwandile. Here the caring task is shared with her daughter. This is what she has to say:

*When he had messed himself and Siphokazi (her daughter) was not around it was a problem because during that time he was really sick, and Mzwandile did not want his mother to see him naked. So it was worse to try and clean him because she had to touch him. (Urban 1 Sibiyi)*

Having to provide personal care tasks, which are intimate in nature, for one's grown child seems to be a particularly uncomfortable task for both parent and child. It is different to providing intimate care tasks for one's own parent in their old age, as this seems to be an expected part of what comes with growing old. In this instance the natural order of things is reversed, with Miriam having to undertake unanticipated very personal care tasks for her son.

Having to check up on the person and having to force the person to do things which they may not want to do is also noted as being difficult for some caregivers, and this is also linked to the fact that the ill person is an adult, and that this is not how things should be happening in the natural course of events. The mother of an ill person, Gloria, recounts the following:

*It has been a difficult thing for her because she has to manage Gloria and control her like a baby and care for her like a child. It is not nice that she has to force Gloria to eat food and do everything for Gloria like she was an old lady ... She is still young and people of her age are doing things for themselves. (Rural 2 Cibane)*

In sum, almost all caregivers indicate that they do not always know what to do to provide care. Not knowing what to do in terms of care provision is linked to the condition of the ill person and, more specifically, to phases or stages of illness in which they are very unwell. Some caregivers express the need for professional care when the person is very unwell and they do not know what to do to provide care. For a handful of caregivers the greatest challenge is presented by caring tasks that are physical. For others not having medication to treat the ill person means that they do not know what to do to provide care, while for some it is not having food or appropriate food to give the cared-for. Not surprisingly, a number of caregivers indicate that they do not know what to do when the person they are caring for does not respond to the care they are

providing. Some caregivers mention that not knowing what is wrong with the ill person means that they do not know what to do to provide care. In many cases not knowing what to do is linked to a lack of training in care provision, which nearly all caregivers have not received.

In all, it seems that not knowing what to do and not feeling confident are closely linked. Some caregivers do not feel confident about the medication they are giving the ill person. Others are not confident because they are not sure what is wrong with the ill person – here a fear that HIV/AIDS could be the underlying condition seems to be of concern to caregivers. Confidence seems to be strongly linked to the condition of the ill person: when their condition is better, the caregiver feels more confident; when they are less well, the caregiver feels less confident.

With regard to what is not nice about providing care, caregivers point to the following: a lack of resources to provide proper care; a lack of training in care provision; not knowing what is wrong with the ill person (linked to the cared-for not disclosing their HIV-status); the fact that the ill person does not get better despite the care that is provided (this could point to the terminal nature of the illness); having to provide personal care to an adult; and a lack of sleep – care provision occurs over a 24-hour period. One 67-year old caregiver hardly slept at all since she provided care to her son throughout the night. This example is clearly depicted in the 24-hour diary of activities told to the fieldworker, and outlined in Hunter (2005)

A variety of issues were pointed to as difficult in terms of care provision: to see the ill person unwell and not getting better; to not know what to do to make the person better; not having training and therefore often not knowing what to do to provide care; not knowing what is wrong with the ill person and therefore not knowing what treatment to provide them with. These are all mentioned as difficult in terms of care provision. Not having medical/care facilities/equipment to treat and look after the ill person, and not having money to meet the needs of the ill person (for instance, for special food, medication, treatment at a health facility) are also pointed to. For one caregiver, combining caring and household tasks is the most difficult aspect of care provision; for another it is not having any support in providing care. Finally, for one mother caring for her HIV-positive daughter the stigma associated with HIV/AIDS is what she finds most difficult.

### **Effects of care on caregivers**



Having to provide care has a number of effects on caregivers, whether it be their social lives, their physical health, their emotional wellbeing, or other needs and responsibilities that they have.

A few caregivers point to the fact that care excludes other activities and takes up nearly all of their time, and that this is frustrating. The following narrative is an example of this. Here Mbeje is the ill person and Zamokuhle his nephew and one of his caregivers:

*Zamokuhle says that it was so frustrating for him because Mbeje wanted to spend time with him all the time. Mbeje felt that Zamokuhle hates him if he does not spend all the time with him. Zamokuhle was frustrated that he couldn't live his life. He felt guilty if he had to go away to visit friends. (Rural 2 Luthuli)*

As this narrative indicates, providing care restricts where you can go and what you can do, and this is a frustration for many of those providing care. For others, the restrictive nature of caring means that they are isolated:

*Sometimes, yes (she feels isolated), because neighbours, friends and relatives can't always visit her, and she can't leave her (the ill person) for long and be with other people. (Urban 1 Mfeka)*

Caregivers who described a changed social life as a result of having to provide care, commonly mentioned that they are no longer able to visit family, friends or neighbours because of their caring duties.

*Thabile says that she used to visit her friends in the area. She had enough time to socialise with neighbours. She says that this has changed. She has to spend her time at home because she is caring for Gloria and she is also the caregiver of Ayanda (Gloria's daughter) since Gloria is not well. She says Ayanda is her responsibility. Thabile says that she has two children and she can't leave them alone. She has no other option even if she wants to go somewhere else ... Thabile says that if she is not at home, she knows that she has to hurry back home to see if Gloria and Ayanda are fine. (Rural 2 Cibane)*

Being the only caregiver means that Thabile has to spend almost all of her time with her ill daughter, and because of this she is no longer able to socialise with her friends. Some caregivers in rural areas indicate that they can no longer attend community meetings. Church and prayer meetings are also

frequently pointed to as being missed because of having to provide care. Interestingly, one elderly caregiver mentions as a notable change to her social life not being able to mourn with her neighbours if there is a death in their families. Elsewhere she indicates that this is problematic because if a member of her family dies, she will not be able to rely on the support of her neighbours at this time.

For the teenage caregiver – Thenjiwe Ngidi – the impact on her social life of having to provide care is perhaps the most noteworthy:

*According to Thenjiwe, the challenges she faced at home were impacting negatively on her relations with other young people in the area: they were progressing educationally and socially, but she had gone backwards. Her friends were socialising in a normal way ... she had to learn to respond like an adult in a situation that had little hope for solutions. (Rural 1 Ngidi)*

Thenjiwe's social progression has been disrupted. She is being 'held back' not only in terms of her education but also in her social development by having to provide care on a particularly burdensome level. This is a negative and possibly unforeseen consequence of the home- and community-based care guidelines which do not stipulate what is to be done if the only available family caregiver is a child. This raises questions about the appropriateness of such a policy response in circumstances such as these.

Another caregiver who is not related to the ill person, eventually leaves her caring role and returns to her own family. The fieldworker tracked her down at her family home in another part of Urban 2, in order to collect outstanding study information from her. This is what she had to say:

*She said that is why she has decided to go back to her own home so that she could have her social life back because it was not easy for her at Tembe family. She said she could not socialise because she would feel guilty if she left him alone. (Urban 2 Tembe)*

It seems that not being related to the ill person has a strong bearing on what can and cannot be done by caregivers in order to cope. Not being related seems to open up the option of leaving the caring situation if the burden becomes too great, something that was not evidenced for those who are related to the person in their care.

In the following case it seems that a combination of time taken up by caring as well as stigma impacts on the caregiver's social life:

*She said she hardly gets some time [to go] to the shops because [there is] no one to look after him. She cannot visit her friends as she used to do before. She cannot go to church. She cannot take a walk because neighbours are avoiding her, or they will talk about the diseases that are affecting the youth and ask if Bulelani is still ok. That is hurting her. (Urban 2 Dladla)*

Elsewhere this caregiver, who herself is HIV-positive, notes that walking down the street is also problematic because people pass comments about her loss of weight, and that of her son who is also HIV-positive. Here HIV/AIDS, or the stigma attached to it, means that this caregiver's social life is changed.

Relatedly, another caregiver points to the stigma associated with HIV/AIDS as curbing any possible social life:

*...Especially now that her husband is sick, some people have started spreading rumours that her husband is HIV-positive. She said she did not know where they got these ideas from as no tests had been carried out on her husband. Already, people are speculating. Even if she wanted to socialise, it is impossible when people are already saying such things. They are creating a stigma. (Rural 1 Shibe)*

For Thenjiwe Ngidi it is also stigma associated with HIV/AIDS that isolates her from others:

*It is a stigmatised household and this makes her feel scared of visiting friends. People create reasons why the household has the infection. (Rural 1 Ngidi)*

Later, after her mother has died, and she is caring for her aunt, Thenjiwe also ascribes feeling isolated to not being able to socialise as she did before.

Relatedly, the stigma associated with a person being ill and at home is mentioned by one caregiver as what she finds most difficult. In this instance the caregiver tells the fieldworker that her daughter is HIV-positive:

*It is sometimes a stigma because people associate the infection with immorality. They adopt a cynical attitude towards the household that has a*

*sick person. It is better for the ill person not to be in the public eye, but as a mother one needs not worry about what people say. (Rural 3 Mbongeni)*

Most caregivers indicate that providing care has not had an impact on their physical health. Where physical difficulties are experienced this is attributed to other factors, such as growing old. Some mothers who are in their fifties and sixties allude to the burden of providing care at an older age.

For a 64-year old mother caring for her son, her old age, and not care provision, is given as a reason for physical difficulties:

*No. She thinks that she is getting old with age. She is suffering from the sicknesses of old age people, like painful bones, tiredness, suffering from the back pain, but this is not caused by caring for Sibusiso. She says her age and her sickness make things difficult to do the caring work. (Rural 4 Khubona)*

This caregiver died non-accidentally a few months after her ill son's death. What is often not recognised by some caregivers, such as this one in the Khubona household, is that care provision is difficult precisely because they are old. Other caregivers point to the fact that physical ailments make care provision difficult, as for this 51-year old mother:

*She says that caring for a sick person is a lot of work for a person of her age, to care for an adult who is supposed to be fit and strong. (Rural 4 Yengwa)*

Two caregivers describe losing weight over caring periods. Thandazile Dladla is HIV-positive and is caring for her HIV-positive son:

*Thandazile said it has affected her physically. She said she is always tired because she is concentrating on Bulelani's health and [she] forgets about hers. Sometimes she spends night[ly] hours not sleeping, thinking about Bulelani, and in the morning her body will be painful. (Urban 2 Dladla)*

Here it is clear that not only actual caring tasks, but anxiety over the condition of the ill person lead to physical difficulties. The caregiver in the Dladla household appears to be suffering from the emotional effects of providing care. Indeed, some caregivers – such as Thenjiwe Ngidi – imply that care provision is affecting them not only physically, but also mentally:

*Yes, at certain stages, she felt that she was not thinking ... There were times when she would just keep forgetting and suddenly find herself talking to herself. (Rural 1 Ngidi)*

The effects of care on caregivers are not only social, physical and emotional. For about half of caregivers in the study there are other household needs and responsibilities that cannot be properly met because of having to provide care. For a caregiver in the Shibe household, the only other adult in the household apart from the ill person with four children in her care, combining caring and household tasks is her biggest challenge:

*Keeping a sick person at home has a lot of implications. As a caregiver one has to look after the sick person in the midst of all the different domestic chores ... She made an example that she has a young child who still requires her undivided, full-time attention, while on the other hand she has to battle with the sick person. Although her husband can still look after himself, she had to be around most of the time. He can need immediate help, and if she is not there, it becomes a problem. (Rural 1 Shibe)*

A number of caregivers point to some household chores as remaining unmet as a result of having to provide care, as in the following case:

*There are times when she does not do the cleaning in the house, when she is worried and caring for Sibusiso. (Rural 4 Khubona)*

Here the caregiver is 64 and the only female in the household which contains three males. From this narrative it is clear that it is not only actual caring tasks that displace other household chores, but also anxiety over the condition of the ill person. Interestingly, for a 67-year old caregiver her role as an encourager in the household has been displaced:

*She said she could not even joke sufficiently with her grandchildren to give them courage since the death of their fathers. (Rural 3 Ndaba)*

Others who cannot meet household responsibilities point to various tasks that remain unmet. For one caregiver additions to the homestead are underway at the time her daughter is ill and in need of much care. However, she is not able to supervise the builders because of her caring tasks, and notes that building material goes missing at this time, which she is not able to prevent or monitor because of looking after her daughter. For another caregiver, the aunt of the ill

person, during the time when her niece was very ill with advanced shingles she found it difficult to till in the fields, to fetch water and to make home-made beer for sale in her informal tavern. Thenjiwe Ngidi, looking after two ill people, points to not being able to clean the house as often as she would like to, and also to not being able to go to the river to wash clothes, because the ill people call for attention constantly. Finally, for Thandazile Dladla, the HIV-positive caregiver who is caring for a son who is dying of AIDS, not being able to properly meet the needs of her young daughter is described as being particularly difficult:

*She said that she feels that she has lost responsibility for looking after her eight year old daughter. Thandazile said she hardly gets time to spend with her. She cannot even do her homework with her because by the time she (her daughter) comes from school she (Thandazile) is too tired to do anything. (Urban 2 Dladla)*

In all, most caregivers point to a reduced social life because of care provision, but it is the mention of stigma that arises because of care situations that is of most concern. Also the long term impacts of having to provide care on one child caregiver's future is particularly noteworthy. Physical difficulties associated with providing care seem to be frequently experienced by these caregivers, especially those at older ages. These findings bring to the fore a question over whether those caregivers who themselves are not well should be taking the bulk of the responsibility in terms of care provision. In most cases there is no-one else to provide full-time care in these households. There is no clear guidance on this in the home- and community-based care guidelines. Caregivers also experience emotional and mental effects of having to provide care. In all it seems that the responsibilities that caregivers face in addition to their caring duties, and the extent of care required for the ill people determine whether additional household needs and responsibilities can be met by caregivers. While some are able to meet these, others are not.

### **What would make the biggest difference to caregivers**

Caregivers were asked what would make the biggest difference to them in terms of care provision, and put in another way, what would help them the most. Over a third of the caregivers in the study indicate that money would make the biggest difference to them. Others specifically mention items such as special food or medication without referring to the money that is needed to purchase these. A number of caregivers refer to the Disability Grant as what they need, and that this will then enable them to purchase these required items.

For some caregivers, having money would enable them to pay for medical expenses, including medication, and for visits to private doctors. Also immune boosters and traditional medication are mentioned, as well as special food for the ill person. One caregiver whose daughter is HIV-positive mentions the drugs for HIV as something which would make the biggest difference to her:

*Thabile says that the first thing that comes into her mind is money. She believes that money can do everything for a person. She says that she is poor. She believes that if she was rich Gloria would not have been bedridden. She says that if she can get the money she can afford to buy the treatment or the drugs for HIV. She says there are many HIV positive people but they are not bedridden or even sick because they've got the money and they can afford the drugs for the disease ... She thinks that the government should distribute drugs or give people money to buy drugs for themselves and the healthy food. (Rural 2 Cibane)*

Antiretrovirals are seen by Thabile as something that would turn this care situation around. For Thabile, not having money means that her daughter is not afforded better health despite being HIV-positive – something which those who are not poor are more likely to achieve.

For a number of caregivers what would make the biggest difference is if the person in their care were to recover. Good medicine and proper medical expertise is referred to frequently by caregivers as what would make the greatest difference to them, as it would lead to the recovery of the person. The following narrative illustrates this well:

*The only thing would be to get the relevant medication. Siyanda's recovery was also [Thenjiwe's] own salvation because she would be relieved of this duty. (Rural 1 Ngidi)*

Clearly this caregiver would like a break from the caring activity. This is reiterated by another caregiver in the Tembe household who is not related to the ill person: his recovery would enable him to take care of himself, and her assistance would then no longer be required. For this caregiver who is unrelated to the ill person, and who single-handedly cares for him despite the fact that his mother lives in the same area, support and appreciation from the ill person's family is described as what would make the biggest difference to her.

*It would be better if there was someone who could help her with support or if someone were to ask her how she was coping – that would make a difference in her life. To know that there is someone appreciating what she was doing. (Urban 2 Tembe)*

As already noted, eventually this caregiver leaves the household and moves back to her family home in the same area, likely, in part, because she receives no support in terms of care provision. What can be seen here is that there are no family ties to keep her in the caring situation, and also, not surprisingly, that recognition and support are necessary if care provision is to be sustained, in a situation where the caregiver is not related to the ill person.

Many caregivers point to times over caring periods during which they feel that a public hospital would be the only option or a better option in terms of the ill person's needs:

*She often felt maybe the hospital was better equipped to deal with the illness. She would fumble with the medicines, not knowing which one to administer. She was lost in confusion. Her mind was not functioning sometimes, looking at the crumpled body of her daughter. (Rural 3 Mbongeni)*

It is clear from this narrative that caring for a person for whom one feels emotional concern, means that care provision itself is more challenging.

Some caregivers mention the need for health care by professionals who are knowledgeable and equipped to provide care for the person when he or she is very ill:

*She said sometimes when she looks at the condition in which Bulelani is she realizes that the only care that is needed is professional care. (Urban 2 Dladla)*

Bulelani has a distended stomach and swollen feet. His illness is beyond that of a simple cold or flu, which the caregiver could be equipped to treat. He is in fact in the late stages of HIV/AIDS, and dies a few months afterwards. This caregiver has not been trained to provide the care her son needs, and yet is being called on to provide it in the home environment. Bulelani spent some time in hospital after this interview was conducted, but while attempts were made in study households to access hospital care, these were not always successful.



One caregiver in an urban area indicates that she has tried to get the ill person admitted to a public hospital, without success:

*[What would make the biggest difference] is for her to go to hospital but the hospital does not want to admit her. (Urban 2 Mngadi)*

Although this ill person was admitted at another public hospital once before, she was discharged in much the same state of health. The caregivers do not know how to care for her as repeated attempts at obtaining health care of some sort have resulted in no improvement in her condition. This ill person died non-accidentally during the fieldwork period and this indicates that the nature of her condition was likely to have been terminal, and hence it was ultimately not possible to treat her so that she would recover from her condition. This points to the stark challenges presented to both family members and the public health care system by the care needs of those with terminal illnesses.

Another caregiver speaks of sufficient emotional strength and commitment as being the thing which would help her the most. For an elderly caregiver in the Ndaba household, the importance of her staying alive so that she can continue to provide care is what she emphasises:

*[What would make the biggest difference would be] to keep her own soul. If she dies now, her son would also not be living long. (Rural 3 Ndaba)*

The death of a caregiver is not an unlikely scenario – in Rural 1 an elderly caregiver died over the fieldwork period. Four of the caregivers mention that knowing what is wrong with the ill person – that is, what is causing their ill health – would make the biggest difference to them. Some specifically mention a blood test, and it is clear from statements that they make that these caregivers suspect that the ill person may be HIV-positive. The following is an example of this:

*Miriam said if only Mzwandile can be honest with what is eating him up, because he is sick and does not want to talk about it ... If he could go for an AIDS test so that they can be aware as to what treatment to give to him. She also said [that] even if Mzwandile had been to collect his medication he never said anything about what the doctors had said about his condition. (Urban 1 Sibiyó)*

One caregiver refers to the stigma associated with HIV/AIDS, and indicates that people have made her daughter an outcast because of her illness. What would make the biggest difference to her would be if this was not the case. Moreover, for another caregiver who shares the caring task with the ill person's daughter, what would help her the most is if the daughter could be more loving in her treatment of her ill mother, and if she could communicate well with her (the other caregiver) Clearly there are challenges associated with sharing the caring task for some.

A mother, caring for her HIV-positive son notes that if she had the money she would employ someone to assist her in caring for him, and she would pay for medication to improve his condition. Employing someone else is mentioned by two other caregivers – for one caregiver this employee would provide care for the ill person:

*Babongile says that she [would like to] employ a domestic worker to take care of Sanaz because she is old and she does not have enough energy. (Rural 2 Mncube)*

For the other caregiver, an employee could work in the house and thereby free her up to solely provide care to her ill son without any responsibility for household tasks.

*She says that if she can get the money she can employ somebody to work for her in the household ... do the cooking, cleaning for the household, while she is still busy caring for Mondli. (Rural 4 Thwala)*

These narratives point to a need for the task of caring and domestic work within the home to be shared, from the perspective of some of those who are not well or older.

In all, for most caregivers having money or the Disability Grant to buy medical treatment and/or care, or the treatment or care itself, would make the biggest difference to them. Being freed up from the caring task through the ill person's recovery or by employing someone else would make the biggest difference to others. For some caregivers it is the following that is of most importance: support in providing care; knowing what is causing the ill person's ill health; being free of stigma associated with the illness of the person; having sufficient emotional strength to carry out caring tasks.

---

## CONCLUSIONS AND RECOMMENDATIONS

---

The bulk of the paper focused on the task of caregiving from the perspective of caregivers. Many of the findings on care provision in the home in sub-Saharan Africa hold true for this study too. In most cases the caregiver is related to the ill person and is the mother of the ill person. In line with other findings on caregiving in South Africa (Akintola, 2004; Orner, 2006), women constitute the bulk of caregivers in the home. Caring is stressful and physically, emotionally and socially taxing. Moreover, in households in which care takes place there is in most cases a lack of resources to provide appropriate care.

Caregiving in the home is not that different to nursing work, but in most cases it is likely to be more challenging and fulfilling than the work undertaken by nurses, because the caregiver and cared-for are usually emotionally close. It seems that there are clear and usually socially defined expectations around who should provide care. A duty to care arises from being female, or more frequently, from being a mother – and this tends to be accepted without complaint. Many mothers find their motivation in the fact that they are mothers; some caregivers find their motivation in the fact that they are related to the ill person. Related to this, most caregivers point to some positive aspects of providing care: to care for one's own child; to receive fulfilment and satisfaction; to receive appreciation from the ill person; to be able to give something back to the person they are caring for; to be able to show the ill person love. The desire to see the cared-for recover from their illness is frequently cited as a motivating factor in care provision. A few caregivers state that they are not motivated to provide care – this is in the case of very difficult circumstances (where the caregiver is HIV-positive and unwell) or where the caregiver is unrelated to the ill person.

Almost all caregivers indicate that they do not always know what to do to provide care, and this is linked to the condition of the ill person. Similarly, a lack of confidence is also linked to the ill person's condition: when their condition is better, the caregiver feels more confident; when they are less well, the caregiver feels less confident. Some caregivers express the need for professional care when the person is very unwell and they do not know what to do for them. In many cases not knowing what to do is linked to a lack of training in care provision, training which nearly all caregivers have not received.

Not surprisingly most caregivers are frustrated by some aspect of care provision and a variety of issues were identified as difficult in terms of care provision. Relatedly, caregivers point to some of the negative aspects of providing care: a lack of resources to offer proper care; a lack of training in care provision; a lack of sleep – care provision occurs over a 24-hour period; not knowing what is wrong with the ill person (linked to the cared-for not disclosing their HIV-status); the fact that the ill person does not get better despite the care that is provided (this could point to the terminal nature of the illness); and, having to provide personal care to an adult whose age should mean that they are independent and not dependent on others for care.

In all, most caregivers point to a reduced social life because of care provision, but it is the mention of stigma that arises because of care situations that is of most concern. The long term impacts of having to provide care on the one child caregiver's future is particularly noteworthy. Physical difficulties associated with providing care are experienced by caregivers in the study, especially those at older ages. These findings bring to the fore a question over whether caregivers who themselves are not well should be taking the responsibility in terms of care provision. In most cases there is no-one else to provide full-time care in these households. There is no clear direction on this in the home- and community-based care guidelines. Caregivers also experience emotional and mental effects associated with providing care. It seems that the responsibilities that caregivers face in addition to their caring duties, and the extent of care required for the ill people determine whether additional household needs and responsibilities can be met by caregivers.

For most caregivers having money or the Disability Grant to buy medical treatment and/or care, or the treatment or care itself, would make the biggest difference to them in terms of care provision. Issues of affordability came to the fore in many sections of the report. Yet even for those who have more money, it is difficult to access care in a public hospital. Being freed up from the caring task through the ill person's recovery or by employing someone else would make the biggest difference to some caregivers. For others it is the following that would make the biggest difference in terms of care provision: support in providing care; knowing what is causing the ill person's ill health; being free of stigma associated with the illness of the person; having sufficient emotional strength to carry out caring tasks.

Some issues of particular pertinence to caregivers arise repeatedly across sections in the report. One such issue is the difficulty of caring for an adult

who, if not ill, would be independent and in a stronger position than the caregiver. Most of the care situations go against the natural order – parents in middle or older age caring for adult children; a child caring for her dying mother and an ill aunt. This is the sad hallmark of HIV/AIDS.

The fact that the ill person does not get better despite the care they receive is also frequently mentioned. By the time the study sites had been revisited in February 2006, 10 of the 19 ill people had died non-accidentally. This indicates that in many cases the illness was likely to have been terminal, and that it was palliative care that was required. HIV/AIDS in its end stage requires a particular type of care which is more difficult and challenging to provide than other forms of care provision.

There is also the deep policy-level issue of how to care for someone when there is no real information as to what the problem is with the person being cared for, something that is repeatedly of concern to caregivers. Probably all carers all over the world feel at times they do not know what to do, but this is extreme. These carers do not know what to do, they receive little if any support or training, no money, and there is no chance for the recovery of the younger people in their care. Moreover, caregivers are in many cases having to provide personal care which potentially places them at risk of infection were the person to be HIV-positive. Yet since HIV/AIDS is not a notifiable disease, there is little that can be done to change this fact if the cared-for do not declare their status.

Also noteworthy from the responses given are the emotional aspects of care provision, specifically the worry and anxiety that caregivers experience over the wellbeing of the ill person, which have psychological effects and often make the caring task a draining one. This is also highlighted in other studies on care provision (Orner, 2006; Pakenham et al, 1995) The emotional effects of providing care are linked to the terminal nature of the illness, and are likely to be exacerbated by the caregiver's social isolation, which is usually the result of the care situation itself. While the person caring is expected to do the work of a professional carer they are usually emotionally bound to the ill person which makes this form of care provision more difficult. Linked to this is the traumatic nature of having the ill person in the home, to see them unwell and often wasting, making home care provision in and of itself not an easy task.

The most frequent form of home-based care is carried out by informal caregivers who live in the home and are usually family members. Government is relying on these individuals to be the ones to pick up most of the care burdens that are presented across the country. But what if the only person within the home who can undertake these care tasks is a child? Or what if she is a pregnant woman who is already caring for five children, or an HIV-positive mother who herself is unwell? The case of a child caring for her ill mother and aunt is of specific concern, as she is being ‘held back’ in her social development by having to provide care on a particularly burdensome level. This is a negative and possibly unforeseen consequence of the home- and community-based care guidelines which do not stipulate what is to be done if the only family caregiver is a child. This raises questions about the appropriateness of such a policy response in circumstances such as these. The guidelines seem to assume that care needs can simply be absorbed by those in the ill person’s home, but this is evidently not always possible or appropriate. As the case-studies have shown, there are often other care needs within households (usually child-care needs) and it may not always be suitable for the person who is available to provide care, to be doing so. Clearly home-based care is not a fair solution to all care needs. What role is to be taken by government in such situations? This question requires serious consideration.

Family caregivers pick up the care responsibilities in households in South Africa, yet they are largely ignored in the home-based care guidelines and in government action with regard to home-based care. An expressed need for help in the home with caring and/or household duties – outlined as part of the study findings – points to a need for support. What support can be given to caregivers? Kipp et al. (2006) recommend that the caregiver burden be acknowledged and that ‘care for the caregiver’ be included as a funded component of all HIV/AIDS programming.

Important support for family caregivers in South Africa would be training in how to provide care so that they have some knowledge about and practical experience in providing care at home, to enable them to help those in their care to the best of their understanding and with some confidence. Many caregivers stated that they did not always know what to do to care for those that were ill, especially when the person was very unwell. Caregivers highlighted a need for training in various aspects of care provision – elsewhere it has been shown that very few of these caregivers had received any form of training (see Hunter, 2005) This suggests that government has fallen short in terms of equipping family caregivers to provide care. It also points to the fact

that the government's care policy is not working in practice. While the state expects families to pick up on care needs, it in turn is not fulfilling its duty to skill these family caregivers in how to care for their ill relatives.

The need for training, particularly palliative care training is underscored by caregivers' expressed desire for professional care. Increased professional care for ill people in the home will be difficult for the government to address since health care workers of whatever type are already in extremely short supply in South Africa. Yet this highlights the fact that caregivers are not always able to cope with the care needs that present in the home environment, and that there are certain points over the caregiving period over which it is very difficult to see adequately to the needs of an ill person in the home because of the very nature of the ill person's condition. Training in care provision, specifically palliative care, should equip caregivers to better deal with care situations which are preferably met by health care professionals.

Ideally, support from home-based care organisations (where these are present), and health workers such as community health workers and nurses through home visits, should also be introduced into all households in which care is being provided by family caregivers. The human resource problem in the health care sector presents a challenge here. Benatar (2004) documents both a loss of critical mass and experience in several sub-specialities in the medical profession in South Africa. Yet this is even more reason to urgently address the dearth of health professionals in this country.

Pakenham et al. (1995) recommend that health care professionals assess and monitor the factors found to place carers at risk for mental health problems. It is unlikely that this will be achievable in the South African context, with a public health sector which is already overburdened and suffering from a paucity of health professionals of whatever type. Yet this is a course of action which should be followed if the wellbeing of caregivers is to be prioritised, and it is therefore unacceptable that while home-based care is the chosen means of care provision in South Africa, and while family caregivers pick up the bulk of this work, they are not being recognised and their wellbeing given appropriate attention in ways such as this.

Basic resources – such as medication, gloves, special food, and finance to pay for visits to health facilities – would also go a long way to make possible improved care provision by caregivers. Such resources would make their task enormously easier. The importance of caregivers having gloves and other

protective material to prevent possible infection is of particular import if one considers the fact that a number of caregivers mentioned that they do not know what is causing the ill health of the person in their care. The study findings show that nearly all caregivers do not have such items at their disposal. The multi-billion rand medical-industrial complex could be tapped by government to route free or nearly-free gloves through clinics and religious groups to family caregivers. In such an unequal society as South Africa where resources are extremely skewed, this is an example of something that could be easily fixed.

Provision of clean water would make a big difference to many caregivers in rural areas who have to spend much time and effort in obtaining water from rivers or waterholes that are to be found some way from their residences. In some cases the caregiver is the only able-bodied person in the household who can obtain water, yet the task of collecting water is often made difficult because of caring duties. Another reason to address water needs is that clean water is an essential component in many of the caregiving tasks. If these basic resources are to be met it is necessary for there to be an increase in funding and resources for home-based care and to needy areas more generally.

Further areas for action include support groups, as well as special radio and television programmes for family caregivers which could go a long way in assisting them in their care duties. This could provide a boost to caregivers through practical advice and moral support, and by reducing their sense of isolation. School education-intervention programmes about how to care should also be introduced in order to provide those at younger ages with this knowledge, hopefully for a caregiving role that may only await them in years to come, but also in order to be a support to the main person responsible for caregiving in the home. Associations of retired nursing professionals can and should be garnered for education and support purposes. The latter is an uninvestigated pool of knowledge and experience which could contribute enormously to the success of the interventions suggested above.

Present home-based care support through a limited number of organisations and community health workers is not even vaguely meeting the needs of caregivers within the home, something that the study findings make clear. Ultimately, regarding the family caregiver as a central part of the government's chosen response to care needs in South Africa, and allowing support – especially training in care provision – to flow in line with this, is crucial, if home-based care is to become acceptable and humane for both ill



people and their caregivers. Unless home-based care is properly resourced in the ways suggested above, and in ways in which this research has shown are necessary, it should be exposed as at best, wishful thinking, and at worst, multiple lies.

It should be remembered that caregiving within the home is an economic issue, as well as a social and health issue. As UNRISD (2006) makes clear, care is part of the fabric of society and is integral to social development, and both economic development and human welfare require inputs from the care economy, whether these are paid or unpaid. Home-based care is unquestionably a development issue, and should be viewed as such, with associated interventions and action flowing from this reality.

---

## **ENDNOTES**

---

- 1 In this paper reference to a caregiver is to a family caregiver. In the study a caregiver was defined as the person responsible for the care of an ill person on a day-to-day basis.
- 2 In the mini-survey the following questions were asked in order to identify care for ill people: During the last 30 days has anyone been frequently or continuously ill? Has anyone in this household been bedridden over the last month? Is anyone in this household being treated for TB at present? Has anyone in this household been admitted to hospital for pneumonia in the last month? If the response to any of these questions was yes, the age and sex of the person and information on any caregivers was obtained. Only households in which the ill person was over 10 and under 60, and in which informal care was taking place were eligible for selection, since the aim was to increase the likelihood of people with HIV/AIDS being selected.
- 3 In some cases the fieldworker was told why care was required. Households in which care was being received for those with chronic, non-HIV related conditions – such as diabetes, arthritis, high blood pressure – were not included, as the aim was to increase the likelihood of people with HIV/AIDS being selected.
- 4 These individuals were told that the study team was interested in studying care within households in the area, and were asked to identify households in which there was someone who had been frequently or

continuously ill over the last month, who was aged over 10 and under 60, who was not ill because of an injury, and who was receiving care by at least one other household member. The mini-survey was then administered in identified households, followed by theme selection.

- 5 The term ‘modified’ was used because the period in the field and the period with each case study household was shorter than is most often the case using an ‘extended case method’ (Burawoy, 1998) Moreover, fairly structured interview guides were used, primarily because of the low level of experience of the fieldworkers with the ethnographic method. Structured guides were developed for each of the research themes, and fieldworkers were trained in their use.
- 6 The fieldworkers were first language Zulu speakers. They undertook training in ethnographic methodology.
- 7 Household events-mapping is a research method developed by Adato, Lund and Mhlongo (2007) through the qualitative SEPPI study of the KIDS sample conducted in 2001. Interviewing is combined with participatory, visual methods to trace events over time, stimulate recall, and engage the participation of different household members. Events-mapping of illness periods involved identifying key events in the illness periods, with a specific focus on access to institutional support.
- 8 A family caregiver was defined as the person responsible for the care of an ill person on a day to day basis.
- 9 Ethical clearance for the KIDS was obtained from the Research Ethics Committee of the University of KwaZulu-Natal, Durban. Fieldworkers were given instructions to ask no questions about HIV status because of ethical reasons and because of the stigma associated with HIV/AIDS. Grocery packs, including staple foods such as maize meal and morvite porridge, were given to each study household as an acknowledgement
- 10 None of the ill people admitted to be on Anti-Retroviral Therapy.
- 11 Worth R740 per month at the time the study was undertaken.

- 12 The interview material has been edited for clarity of reading. In addition, all names have been changed for the sake of confidentiality, and all material relating to identity has been placed in secure storage.
- 13 Rural study sites have been cited as Rural 1, Rural 2, Rural 3 and Rural 4, while urban study sites have been given the names Urban 1 and Urban 2. For each narrative the study site and the household name have been given.
- 14 Community caregivers are community-based health worker cadres who are selected, trained and work in the communities in which they live. Their role is to act as agents for health promotion, care and health development (Friedman, 2002; 2005)
- 15 At the time this study was conducted, according to the KwaZulu-Natal Department of Social Welfare and Population Development, the DG could be obtained in KwaZulu-Natal by adults in late stage HIV/AIDS – either if they were in World Health Organisation (WHO) stage three or four<sup>18</sup> or if they had a CD4 count of less than 200 –subject to the decision of a District Surgeon. Being HIV-positive does not mean that one qualifies for the grant. (Personal communication, Chief Director: Social Security, KwaZulu-Natal Department of Welfare, 7 September 2004)

---

## REFERENCES

---

- Adato M, Hunter N and van de Ruit C (2004) *Draft Concept Note: KwaZulu-Natal Income Dynamics Study 2004: Qualitative Research*. Unpublished paper, International Food Policy Research Institute, Washington DC, University of KwaZulu-Natal, Durban and University of Pennsylvania, Philadelphia.
- Adato M, Kadiyala, S, Roopnaraine T, Biermayr-Jenzano P and Norman A, (2005) *Children in the Shadow of AIDS: Studies of Vulnerable Children and Orphans in Three Provinces in South Africa*. Paper presented at the IFPRI/WFP project on Orphans and Vulnerable Children in sub-Saharan Africa, 'Trends, Vulnerability and Responses', July, International Food Policy Research Institute, Washington, D.C.

- Adato M, Lund F and Mhlongo P (2007) Methodological innovations in research on the dynamics of poverty: A longitudinal study in KwaZulu-Natal, South Africa, *World Development*, 35(2), 247-263.
- Akintola O, (2004) *A Gendered Analysis of the Burden of Care on Family and Volunteer Caregivers in Uganda and South Africa*. Health Economics and HIV/AIDS Research Division, Durban.
- Benatar S R, (2004) Health care reform and the crisis of HIV and AIDS in South Africa. *The New England Journal of Medicine*, 351(1), 81-92.
- Campbell C and Foulis C (2004) Creating contexts for effective care of people living with HIV/AIDS. *Curationis*, 27(3), 5-14.
- Chen M, Vanek J, Lund F, Heintz J with Jhabvala R and Bonner C (2005) *Progress of the World's Women 2005. Women, Work and Poverty*. New York: United Nations Development Fund for Women.
- Cheung J and Hocking P (2004) Caring as worrying: the experience of spousal carers. *Journal of Advanced Nursing*, 47(5), 475-482.
- Chimwaza A and Watkins S (2004) Giving care to people with symptoms of AIDS in rural sub-Saharan Africa. *AIDS Care*, 16(7), 795-807.
- Day C and Gray A (2005) Health and related indicators. In P. Ijumba & P. Barron (Eds.), *South African Health Review 2005* (pp. 248-366) Durban: Health Systems Trust.
- Department of Health (2001) *National Guidelines on Home-Based Care and Community-Based Care*.  
<http://www.doh.gov.za/docs/factsheets/guidelines/homecare/index.html>
- Family Health International (2001) Strategies for an Expanded and Comprehensive Response to a National HIV/AIDS Epidemic.  
<http://www.fhi.org>
- Friedman I (2002) Community based health workers. In P. Ijumba, A. Ntuli and P. Barron (eds.), *South African Health Review 2002* (pp. 161-180) Durban: Health Systems Trust.
- Friedman I (2005) CHWs and community caregivers: towards a unified model of practice. In P Ijumba and P Barron (eds), *South African Health Review 2005* (pp. 176-189) Durban: Health Systems Trust.
- Goudge J Gilson L and Msimango L (2003) *How to 'roll-out' CBO provided home-based care for AIDS: Government's role?* Centre for Health Policy, University of Witwatersrand, Johannesburg.
- Heron C (1998) *Working with Caregivers*. London: JKP.
- Hunter N (2005) *An Assessment of How Government's Care Policy is Working in Practice: Findings from KwaZulu-Natal*. Working Paper No. 42. School of Development Studies, University of KwaZulu-Natal, Durban.

- Jacques G and Stegling C (2004) HIV/AIDS and home-based care in Botswana: panacea or perfidy? *Social Work in Mental Health*, 2(2/3), 175-193.
- Johnson S, Modiba P, Monnakgotla D, Muirhead D and Schneider H (2001) *Home-Based Care for People with HIV/AIDS in South Africa: What Will It Cost?* Centre for Health Policy, University of Witwatersrand, Johannesburg.
- Johnson S, Schierhout G, Steinberg M, Russell B, Hall K and Morgan J (2002) Chapter 11: AIDS in the Household. In P. Ijumba, A. Ntuli and P. Barron (eds.), *South African Health Review 2002* (pp. 203-216) Durban: Health Systems Trust.
- Kipp W, Nkosi T M, Laing L and Jhangri G S (2006) Care burden and self-reported health status of informal women caregivers of HIV/AIDS patients in Kinshasa, Democratic Republic of Congo. *AIDS Care*, 18(7), 694-697.
- McCreary L L, Mkhonta N R, Popvich J M, Dresden E M and Mndebele E T (2004) Family caregiving: home-based care in rural Swaziland. *African Journal of Nursing & Midwifery*, 6(1)
- Nkosi T M, Kipp W, Laing L and Mill J (2006) Family caregiving for AIDS patients in the Democratic Republic of Congo. *Health Care Quarterly*, 9(3), 94-101.
- Ogden J, Esim S and Grown C (2004) *Expanding the Care Continuum for HIV/AIDS: Bringing Caregivers into Focus*. International Center for Research on Women, Horizons Program, Washington DC.
- Orner P (2006) Psychosocial impacts on caregivers of people living with AIDS. *AIDS Care*, 18(3), 236-240.
- Pakenham K I, Dadds M R and Terry D J (1995) Carers' burden and adjustment to HIV. *AIDS Care*, 7(2), 189-203.
- Pascall G and Lewis J (2004) Emerging gender regimes and policies for gender equality in a wider Europe. *Journal of Social Policy*, 33(3), 373-394.
- Russell M and Schneider H (2000) *A Rapid Appraisal of Community-Based HIV/AIDS Care and Support Programmes in South Africa*. Centre for Health Policy, Johannesburg.
- Twigg J (Ed) (1992) *Caregivers: Research and Practice*. London: HMSO.
- United Nations Research Institute for Social Development (UNRISD) (2006) *Project Proposal: The Political and Social Economy of Care*. 25 August. UNRISD, Geneva.