Gendered home-based care in South Africa: more trouble for the troubled

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This study investigates the experiences of informal caregivers of people living with HIV in two semi-rural communities in South Africa. Ethnographic methods were used to collect and analyse data on the gendered nature and consequences of home-based care from 21 primary caregivers and 20 volunteer caregivers as well as 10 key informants. It was generally women who were poor, unemployed and unmarried who combined the care-giving role with their traditional role as homemaker and that of being the household head and breadwinner. The caregivers experienced physical strains and emotional problems, and were at elevated risk of being infected with HIV and TB. Men were largely absent in HIV/AIDS-affected homes and usually did not assist because of rigid gendered divisions of labour. Home-based care, by creating a disproportionate burden on women, is exacerbating existing gender inequities. It is argued that a thorough understanding of how home-based care undermines the physical health and psychological wellbeing of already vulnerable women is crucial for informing policies on home-based care. Thus, there is a need to incorporate gender perspectives when planning and implementing home-based care programmes.

Keywords: burden of care, family care, HIV/AIDS, home care, PLWHAs, primary care, volunteers

Introduction

Currently, a large proportion of the patients seeking care at public hospitals in South Africa are those infected with HIV. A recent national survey of the impact of HIV and AIDS on the health sector revealed that 46.2% of patients served in the medical and paediatric wards of public hospitals in South Africa were HIV-positive (Shisana, Hall, Muleke, Stoker, Scwabe, Colvin, Chauveau, Botha, Gumede, Fomundam, Shaikh, Rehle, Udjo & Gisselquist, 2002). However, many of these hospitals are unable to cope because of lack of capacity to care for these patients (Department of Health [DOH], 2001). In response, South Africa, as well as other African countries, has begun to promote home-based care for people living with HIV or AIDS (DOH, 2001).

In December 2001, the South African government published the National Guideline on Home-Based Care/Community-Based Care (DOH, 2001) to assist implementation of home-based care in the country. Although the guidelines recommend the involvement of a wide range of stakeholders, including the formal healthcare sector, implementation to date has placed the primary responsibility for care and support squarely on communities and the immediate families of the sick (DOH, 2001). Consequently, family and community members participate more actively in the care of people living with HIV or AIDS (DOH, 2001; Akintola, 2004). Already, a large proportion of people with HIV-related illnesses in South Africa are being cared for at home by their kin and community members (Uys, 2003; Akintola, 2004). Given the demands of home-based care on family members, it seems inevitable that there will be a considerable increase in both the caring roles and the magnitude of care-giving activities traditionally performed by women.

Home-based care has been widely acclaimed as having many advantages, which include improving the experience of illness, dying and death for people with AIDS illnesses and their families alike (DOH, 2001; Nsutebu, Walley, Mataka & Simon, 2001; Uys, 2001 and 2003; WHO, 2002; Campbell & Foulis, 2004). For instance, Uys (2003) found in a study of home-based HIV/AIDS care in seven South African communities that many HIV/AIDS-affected families prefer that their sick kin die, with dignity, at home rather than in hospital. However, studies on the household impact of HIV/AIDS in the country suggest that care of the sick accounts for a substantial part of the burden that HIV/AIDS imposes on households and communities (Barnett & Whiteside, 2002; Steinberg, Johnson, Schierhout & Ndegwa, 2002; Bachmann & Booyesen, 2003). This suggests that considerable hidden costs are associated with care-giving, which have otherwise not been captured in studies that have focused on the impact of HIV/AIDS on households. Indeed, studies conducted in the US among caregivers of men who have sex with men suggest that care-giving can adversely influence caregivers’ psychological health through added strain, stress and depression (LeBlanc, London & Aneshensel, 1997). LeBlanc et al. (1997) indicated that caregivers in their study experienced deteriorating health and that their roles as caregivers exacerbated their health problems.

Given the differences in context and culture, such studies can merely provide a partial insight into the experience of caregivers in a developing-country context. Although a few
studies have been conducted on care-giving for people with HIV-related illnesses in Africa, the findings point to a need to further investigate issues that relate to the impact of care-giving on caregivers in the African context. For example, a study by Nnko, Chiduo, Wilson, Msuya & Mwaluko (2000) in Mwanza, Tanzania, showed that family caregivers spent 3–7 hours every day in care-related activities and that nursing needy and dying patients placed a considerable socio-economic burden on them. Steinberg et al. (2002) surveyed HIV/AIDS-affected households in several provinces of South Africa and found that many of the affected families did not have access to home-based care programmes or any kind of support from government but rather had to depend solely on family and community members to provide care for them (Steinberg et al., 2002).

Although the burden of care falls primarily on HIV/AIDS-affected families and communities, women are disproportionately affected. Steinberg et al. (2002) indicated that women and girls constituted 68% of the primary caregivers in their study. Additionally, the study by Nnko et al. (2000) showed that most men were unwilling to care for the sick except in circumstances where women were unavailable. In a recent study that focused on the experiences of older women and girls providing care in Botswana, a country sharing a border with South Africa, only three of the 35 caregivers interviewed were males (Lindsey, Hirschfeld, Tlou & Ncube, 2003). However, none of these studies explored the gendered processes and dynamics involved in care-giving.

In South Africa, there is a paucity of empirical data on the burden of informal care-giving for people with AIDS-related illnesses. Some studies have examined the general impact or burden of HIV/AIDS on affected households as a whole (Gow & Desmond, 2002; Oni, Obi, Okorie, Thabede & Jordan, 2002; Samson, 2002; Steinberg et al., 2002; Bachman & Booysen, 2003) or the efficiency of home-care service delivery to people living with HIV or AIDS (Russel & Schneider, 2000; Uys, 2001, 2002 and 2003), but the findings only marginally relate to the impacts on caregivers. Furthermore, much of the information on the gendered impact of care-giving is based on anecdotes and assumptions. No empirical study in South Africa has focused exclusively on the gendered nature and consequences of caring for people living with HIV or AIDS.

This paper reports the results related to the gendered nature and health consequences of care-giving from the findings of a larger study of the gendered impacts of home-based care on caregivers of people living with HIV/AIDS in KwaZulu-Natal Province, South Africa. The results relating to the socio-economic impact of home-based care on caregivers are presented elsewhere. The purpose of this article is to provide empirical evidence of the health burden that home-based HIV/AIDS care places on women, and to discuss implications for home-based care policies and programmes in South Africa.

**Methodology**

This ethnographic study used a range of research methods: participant observation, informal discussions, key informant and in-depth interviews, and a review of archival records to investigate the social and cultural patterns and meanings associated with home-based care-giving (Schensul, Schensul & LeCompte, 1999; Parker & Ehrhardt, 2001).

**Theoretical framework**

Consistent with the principles of ethnography, an interpretivist framework was used to guide the design of questions and data analysis. According to Ulin, Robinson, Tolley & McNeill (2002) the theoretical framework for most qualitative research emerges from an interpretivist perspective that sees the world as constructed, interpreted and experienced by people in their interactions with each other and the wider social system. The interpretivist paradigm sees research participants as experts whose interpretation of their experience can help researchers learn about the issue being investigated. It allows the researcher to link findings from respondents’ subjective perceptions and understanding (which arise from experience, objective actions or behaviours, and context) in order to explore the multiple relationships among them (Ulin et al., 2002). Hence, by employing ethnography, this research places the problem in an interpretivist framework, which implies that theoretical direction was allowed to unfold as the study progressed. As Schensul et al. (1999) have pointed out, ethnographic theory is constructed recursively, beginning with a set of connected ideas that undergo continuous redefinition throughout the life of the study until the ideas are finalised and interpreted. In this regard, themes derived from an extensive review of the literature on home care were used to inform the design of interview questions and the analysis of the data that followed (see Glaser & Strauss, 1967).

**Study setting and context**

This exploratory and descriptive study was conducted in two Zulu-speaking semi-rural communities (townships) that make up the greater Marianhill area located approximately 35kms west of Durban. The communities have high unemployment rates as well as low levels of literacy (Leclerc-Madlala, 2000; Community Outreach Centre, 2002). A specific community-based organisation (CBO), which operates as an arm of a district hospital, owned by missionaries and serving the communities, recruits and trains community members to become volunteer caregivers (VCGs). These volunteers then assist family members in providing home-based care to people in their own families living with HIV or AIDS. There is a high rate of non-marriage in the Marianhill area, due both to a high bride price and to a general breakdown in family structures as a result of apartheid (Cross, Bekker, Clark & Wilson, 1992; Preston-Whyte & Zondi, 1992; Preston-Whyte, 1993; Leclerc-Madlala, 2000). However, this does not preclude childbearing, and women who do not marry typically have children from relationships with their partners; some continue to live with their parents or grandparents, usually mothers or grandmothers, until the prospective husband is able to pay the bride price (Preston-Whyte, 1993; Denis & Ntsimane, 2006).

**Study sample**

Ethical permission for the study was obtained from the ethical review board of the Faculty of Human Sciences,
Informal caregivers constituted the primary sample population. They are defined as family caregivers and 20 volunteer caregivers were interviewed. These informal caregivers consisted of family members who are usually the main caregivers of people living with HIV or AIDS (PLWHAs), hereafter referred to as family caregivers (FCGs), as well as community members who volunteered to be trained, hereafter referred to as volunteer caregivers (VCGs). Because family caregivers are usually the main care providers, they are also referred to as primary caregivers. Nonetheless, in cases where there was no family member providing care, others outside the family could function as primary caregivers. Information was also obtained about those who provide support or respite to the primary (or family) caregivers, and they are referred to as secondary caregivers.

Key informants, such as home-based care managers, coordinators of volunteer caregivers, PLWHAs, community health workers, local health officials and local government officials, were also interviewed. The home-based care manager of the CBO was recruited by visiting the organisation and requesting her participation in the study. She introduced us to the local councillor and the local health officials in the study communities. Key informants who had already been interviewed then referred interviewers to other key informants.

In order to be included in the study, the family or volunteer caregivers must have been caring for at least one patient for a minimum of three months, and the patients must have moved beyond the asymptomatic stage. In other words, they must have had symptoms of AIDS illnesses. These inclusion criteria ensured that the caregivers had a great deal of care-giving experience that would yield rich and meaningful data. Special effort was also made to include as many male caregivers and female caregivers as possible in order to obtain a broad range of care-giving experiences and perspectives, yet we could only identify and interview a few male caregivers. Based on interviews and discussions with key informants, it was inferred that the small number of male caregivers reflected males’ low level of participation in care-giving in the study communities.

Procedure

Two separate but similar interview schedules — for volunteer caregivers and family caregivers — consisting of topic guides and open-ended questions, were developed from an extensive review of the literature on home and family care. The caregiver interview schedules focused on socio-demographic variables, the nature of care provided and level of involvement, the context of care, and the sources and nature of help and support needed and received. A list of themes or topics relating to care-giving for PLWHAs and information about prevailing norms in the communities was also developed and used to conduct interviews with key informants. All the instruments were drawn in English before being translated to Zulu, the local language in the study area.

Given the secrecy surrounding HIV/AIDS, which is fuelled by stigma in the study communities (Community Outreach Centre, 2002; Akintola, 2004), it was impossible to access caregivers of PLWHAs who were not linked to a care organisation or an organised source of support. Therefore, all the caregivers in this study were linked to the CBO providing home-based care. Volunteer purposive sampling was used to recruit these caregivers, which comprised volunteer and family caregivers. This technique entailed approaching and soliciting assistance from volunteer coordinators through the programme office of the CBO that offers home-based care training and service to the communities. Volunteer coordinators in each of the communities assisted us in convening meetings with the volunteer caregivers, where the purpose of the study was discussed and those who consented to participate were recruited.

Verbal informed consent was obtained from volunteer caregivers before the interviews were conducted. Given the sensitive nature of HIV/AIDS, special effort was made to ensure that participants were not obliged to participate in the study and that only those who felt comfortable with participating and who gave informed consent were included in the study. An informed-consent statement included voluntary and informed participation, freedom to withdraw at any time without giving any explanation, and confidentiality. Interviews took place in offices provided by the local councillor, at the community resource centres or in respondents’ homes, depending on their preference and logistics.

In order to recruit family caregivers, the volunteer coordinators visited families enrolled in the home-based care programme of the CBO, and which included people living with HIV or AIDS or who had recently lost someone to AIDS-related illness. The coordinators explained the purpose of the study and solicited the family caregivers’ permission to participate in the study. Next, two community members working as volunteer coordinators were recruited and given two days of training to function as interviewers.

For interviews with FCGs, the author and interviewers accompanied the volunteer caregivers on daily rounds to the homes of patients who consented to participate in the study. Once there, interviewers again read out an informed-consent statement to each participant, and all participants gave verbal informed consent. Thereafter, we observed and documented care-giving practices and also conducted in-depth interviews with family caregivers.

The entire study was conducted over a 19-month period (June 2002–December 2003). All interviews were conducted in Zulu, except for key informant interviews which were conducted in English. In-depth and key informant interviews took 40–90 minutes; all interviews were tape-recorded, transcribed verbatim, and translated on an ongoing basis as the fieldwork progressed, and the findings were used to improve on questions for subsequent interviews (see Schensul et al., 1999). Key informant interviews were also used to triangulate information obtained from in-depth interviews. In all, 10 key informants, 21 family caregivers and 20 volunteer caregivers were interviewed.
Data analysis
Two people performed separate transcriptions and translations and these were compared before proceeding to familiarise and immerse ourselves in the data and to make sense of it. Data analysis was done using constant comparison, which is consistent with the principles of grounded theory (Glaser & Strauss, 1967). Line-by-line and sentence-by-sentence comparison were used to identify and label concepts. Relationships among concepts and set of concepts were then used to develop themes and categories. Further examination of the themes and categories resulted in the identification of sub-themes.

Findings
Socio-demographic profile of the caregivers
Although the study was designed to include as many caregivers of both sexes as possible, an overwhelming majority of the total sample (n=41) of family and volunteer caregivers were women (n=39).

Of the 21 family caregivers, 20 were women, and 12 were heads of households and breadwinners. Most of the caregivers were sisters (6) of the patients, followed by mothers (5), three of whom were elderly (between ages 55 and 65). The other family caregivers were neighbours (4), daughters (2), grandmothers (2), and one friend. Notably, one of the daughters providing care was a 10-year-old child; the other daughter was a 33-year-old single mother of two children, head of household and family breadwinner. Most of the caregivers were unmarried (16) but had children. The only male family caregiver was a cousin of the patient. Moreover, nine of the 21 family caregivers had received some training in home-based care and were also volunteering as caregivers to other families, while the remaining 12 had not received any training. Most family caregivers had between eight and 12 years of education.

Of the 20 volunteer caregivers, 19 were women, 17 were unmarried, 12 were heads of households and breadwinners, and they were between age 27 and 55. Like the family caregivers, most volunteer caregivers had between eight and 12 years of education, but two were university graduates.

There was a common pattern in the employment and socio-economic status among both the family and volunteer caregivers. Only three family caregivers were employed: one as a petty trader and two as domestic workers, with incomes ranging from R15–20 (US$2.1–2.9)2 per day. One was a student. The others did not have any particular employment or source of income. However, most of them were receiving some type of government grant: these included an old age pension (R740 per month) or child support grant (R170 per child/month); very few were receiving a foster-care grant (R530 per month) or a disability grant (R740 per month).3 Using relative measures of wealth, which included kind of house, possession of piped water and latrines, and ability to afford decent meals, among other measures (Lindsey et al., 2003), we judged seven of the HIV/AIDS-affected families to be of very poor socio-economic status, seven as poor, six as moderate, and one as well-off by local standards. Four of the volunteer caregivers were employed: two as part-time domestic workers, one as a self-employed trader, and one was a tailor, but they earned only very meagre incomes ranging from R100–300 (US$14.3–43) per month. It is important to reiterate that the volunteer caregivers who participated in this study were not being remunerated in any way for providing care. In addition to the fact that most of the primary caregivers were women and girls, there were also more women and girls who served as secondary caregivers by providing assistance or respite to the primary caregivers when required.

The nature of care-giving tasks
Caregivers were asked about the nature of the home-care work they performed. Their responses showed that care-giving entails a wide range of tasks. Most frequently mentioned was the provision of spiritual and moral support to the patients. Volunteers indicated that they provided spiritual support by praying with the patients. They also indicated that they provided moral support by showing them love and compassion, and by talking and listening to them. In addition, caregivers provided basic nursing care, including mouth care, cleaning pressure sores, skin care, turning bedridden patients, support for adequate nutrition, and monitoring drug adherence, among other things. The caregivers also assisted patients with daily activities such as feeding, bathing, dressing, walking, and going to the toilet (usually outside the house). They also assisted with household chores, shopping, cooking, transportation, and making telephone calls. A few caregivers assisted with soliciting financial and material assistance from neighbours or dealing with doctors or other medical personnel.

On average, each volunteer was expected to provide care for five patients in different stages of illness but some indicated that they often helped more patients. Volunteers, who served as primary caregivers, spent an average of five hours per day with patients in the advanced stages of illness. However, they typically spent more time with patients who were living alone and had no primary caregiver. Those caring for patients with clinical AIDS who were immobile or had constant bouts of diarrhoea needed to give them more attention and thus had to stay on standby day and night. Some of the primary caregivers reported combining the caring role with the care of the sick person’s child/children, some of whom were HIV-positive. Also, volunteer caregivers sometimes had to solicit material and financial support for their patients.

Gendered division of caring roles
The gendered division of caring roles in the HIV/AIDS-affected homes and communities that participated in the study reflects the pre-existing gendered nature of, and social expectations about, household work in general, and care work in particular. The gendering of caring activities was evident through the greater proportion of women in the sample but also through the kind of care-giving activities performed by various members of the affected households. In most households where the caregivers were unmarried women and heads of households, adult men were not always present to assist the women in providing care. Interestingly, the reasons given for men’s absence did not include the death of a spouse or divorce; rather, most of the
women had non-resident partners who did not feel obliged to assist in providing care. The non-resident status of some of the male partners, which meant that they were not available as often as they were needed, also excluded them from caring roles. Others had abandoned their partners, either as a result of their HIV status or even before they were infected or revealed their status. In this study, abandonment of partners emerged as a subtle but effective and pervasive way of avoiding caring roles. It should be noted that these women combined their care-giving role with being household heads and breadwinners, as well as with their traditional role as homemakers.

In a particular instance, a male partner had abandoned an HIV-positive woman when she revealed her HIV status, leaving her to care alone for their young son:

‘After receiving my results from the hospital it was written on my card HIV-positive, I told my boyfriend. He said he was not sick and asked me where I got it [HIV] from, he has since left me. When he passes in front of my house, he will just greet me…but does not assist me with caring for our son…. He [her former partner] just went away and I can see that he is sick too. Yesterday I saw him on the road and sometimes he comes to take his son to visit his family’ (44-year-old PLWHA).

Although the male partner had left this sick woman, he was not completely absent from her life and that of their son. But it seems he was interested in only one aspect of the fathering role, that of occasional ‘bonding’ with his son, but not with his former partner. However, he was not available to provide either with regular financial and material support or day-to-day physical and emotional support. There may be various explanations for why he left his partner, which is beyond the scope of this paper. What is clear is that he was able to avoid performing certain caring roles and responsibilities and his absence invariably placed the responsibility of caring for the sick child solely on the HIV-positive mother who also needed someone to provide care for her.

Observation of people in caring roles as well as some narratives related by family and volunteer caregivers showed a general lack of male participation in home care. Men and boys were often not at home during our visits, but girls typically assisted their mothers with cooking and other household chores. Girls were often the ones designated to ask for food or financial assistance from neighbours. In a particular instance, a 10-year-old girl provided assistance to her sick mother while her two elder brothers went out to play with their friends. Many of the family caregivers echoed this common theme: ‘Boys don’t stay at home, they go…until the afternoon and come back to check what the mother has cooked, then they will go out again.’ This was a confirmation of what we commonly observed during our visits to affected households.

The HIV-positive woman described above was, in addition to her HIV-positive son, caring for two other children and two nephews. She was so ill that she could barely stand, yet her two adolescent nephews who were living in the same house did not assist with any work. She was the one who cooked and performed other household chores for them and the other children. When asked about the role played by her nephews in assisting with care she had this to say:

‘I do everything in the home…my nephews will sometimes help me only if I shout at them that I cannot do it. Abangi nakekeli ngoba bona banga bafana. [They are not taking care of me because they are boys.] Inkolelo yethu thina maZulu abafana abawenzi umsebenzi wasekhaya. [In our culture boys don’t do anything at home.] I will wash, cook even if I feel sickly and my body is aching; I do not have a choice but to do it when my children want food’ (44-year-old HIV-positive FCG).

Other participants indicated that men participate in caring only when forced to do so by circumstances, such as when no one else is around. Even in such circumstances, their roles are usually gendered:

‘They [men] care only when there is a need, like when a girl is living with a boyfriend [and she becomes ill] and there is nobody else [females] around. He might cook and do other chores but will not touch her or bathe her…but when the men are sick the women bathe them’ (28-year-old VCG).

Yet, not all men conform to these social expectations about masculine and feminine roles. The fact that only two male caregivers participated in the study meant it was not possible to establish a pattern in men’s care-giving roles. Nonetheless, neither conformed to the social expectations that ‘men provide care only when there is no woman available.’ It was interesting to find that the only male family caregiver was caring for a female cousin. He provided the whole range of care except bathing her, which was done by a female volunteer. The boy had been prepared for the caring role by his grandmother with whom he lived before coming to live with the patient. Surprisingly, he indicated that, although there was no adult female in the house to provide care, he was not coerced into providing care for that reason but offered his services because he had been taught from childhood to carry out household chores and care work. This assertion was also supported by the fact that he was, at the same time, providing care for the patient’s mother who had had a stroke. The only male volunteer caregiver also indicated that he enrolled because of his willingness to help people and that he performs the whole range of caring activities, including bathing both male and female patients.

In a few cases, other men were present and willing to help, serving mainly as secondary caregivers (providing support or respite to the primary caregivers). In such cases, their activities were also gendered. In a few of the households where women or girls were the family caregivers, men were reported to have given some form of support. With few exceptions, men typically assisted with activities such as arranging for transportation to health facilities, lifting patients, and some financial support to cover the costs related to caring. In other cases men gave moral support and assisted in taking the sick person to the hospital when the need arose. Women, on the other hand, typically carried out the whole range of care-giving tasks.

Observations revealed that men, in many instances, sent their wives or daughters to assist their HIV-positive relatives residing elsewhere. This was common in instances where care was lacking from their male relatives living with them.
Perceptions of gendered care-giving roles

The attitudes of some of the female caregivers betrayed an acceptance of culturally prescribed gendered roles and expectations. Most stated that it was normal for men not to assist with caring or other household chores and that it was difficult to change men’s attitudes towards caring for people. Some of the women believed that, by nature, men were not suited to provide care, stating that men were fearful and that some would simply not cope. Others indicated that many of the men who enrol to be volunteers quit soon after they begin visiting homes because they are unable to cope with the state of the patients. One 28-year-old volunteer caregiver said, ‘Culturally it is mostly women who take care of the sick. You can see that the nurses are mostly women so it has always been like that.’

Men also had similar perceptions about gendered care-giving roles. The two male caregivers in the study corroborated the women’s general perceptions about men’s involvement, or lack thereof. They affirmed that other men in the community see them as ‘deviants,’ doing unmanly duties, and that some even ‘insult’ and ‘tease’ them. They have nonetheless persisted because of their belief in assisting ill people.

The gendered burdens of care

The gendered division of care-giving roles, coupled with the terminal and drawn-out nature of HIV infection, creates a burden of care that weighs disproportionately on women. Surprisingly, women were reluctant to report that they experienced any health-related burdens as a result of care-giving. Instead, they readily reported the socio-economic problems confronting them. However, observations and information from key informant interviews revealed that women do experience considerable health-related burdens — costs as a result of care-giving. Further investigation revealed that women did not readily report such burdens because of socio-cultural reasons, as doing so would amount to complaining, and caregivers are supposed to be stronger than care-receivers. Three major themes relating to the gendered burdens of care-giving are presented below: the physical burdens of care, gendered risks, and emotional and psychological burdens of care.

Physical burdens of care

Most of the participants experienced some form of physical burden as a result of care-giving. A few of the respondents in this study reported sudden and recurring headaches resulting from their care-giving activities. The most frequent problems reported by the caregivers were headaches, body aches, backaches and physical exhaustion. Some reported that physical stress caused them to lose their libido. Elderly women who were providing care to their children had chronic illnesses such as arthritis, diabetes, and hypertension and reported experiencing deteriorating health. A 75-year-old woman reported that her health had deteriorated due to stress from caring for her sick daughter and granddaughter; she reported frequent headaches and body pain and weakness of the heart as part of the difficulties of caring for her child in the terminal stages of illness.

Women were the ones that carried out the most physically taxing care-giving tasks. These included bathing patients; assisting them with using the toilet; changing soiled nappies, clothing and bed sheets; and fetching water, sometimes from long distances. Some volunteer caregivers had to walk long distances, sometimes in the scorching sun, to get to the homes of patients. Furthermore, volunteer caregivers had to stretch themselves in order to reach the large number of community members who needed care, resulting in work overload and burnout. For family caregivers, however, work overload was a direct result of the lack of support from other family members.

Gendered risks

The frequency and nature of care-giving activities caused women to have a disproportionate share of the risks associated with providing care for people living with HIV or AIDS. As primary caregivers, women carried out most of the care-giving activities that involved frequent and close contact with patients’ vomit, faeces and other body fluids, resulting in gendered risks of infection with HIV or TB. Some primary caregivers, particularly elderly ones, often put themselves at risk of HIV infection by declining to use gloves or any other barrier protection while caring for their children or grandchildren. Others did not take any precautionary measures because of a lack of awareness about the HIV status of the patient or a lack of access to gloves. Yet others were at elevated risk of infection with tuberculosis since most patients receiving care suffered from TB and coughed frequently. One HIV-positive woman expressed the fear that her 10-year-old daughter who was caring for her could become infected with TB. Another HIV-positive caregiver expressed similar fears, and in addition she indicated that her open sores could be infectious to her children since she slept in the same bed with them. Some girls who served as secondary caregivers may have been at greater risk of infection with TB and HIV because they took fewer precautionary measures as compared to adults. However, it was not possible to confirm whether anyone had actually become infected through the caring process.

Another gendered risk was the risk of sexual abuse. Key informants indicated that the study communities have a high incidence of rape and other forms of violence against women. The findings of this study suggest that volunteers may also be at an elevated risk of sexual abuse as they go about their volunteering duties, especially from rapists who are ill or pretending to be ill. Although none of the participants reported an incident of rape, volunteers expressed fear of being raped. One voluntary caregiver narrated an encounter with an HIV-positive rapist: ‘This guy was a known rapist in the community but he was very sick and the volunteers knew he was HIV-positive. The home-based carers were scared of this guy, that he could rape them. I asked two of them to pair up and go but they were still afraid. I was afraid of this guy too and I asked two other home-based carers to go with me. He could not even walk to the bathroom’ (28-year-old VCG/home-based care coordinator). The risk of being raped is heightened for women who are volunteers because many of their clients live alone and could easily abuse a woman that comes to care for them without anybody noticing.
Emotional and psychological burdens of care
There was consensus among the caregivers about the emotional and psychological consequences of care-giving. Signs and symptoms of emotional and psychological problems experienced by caregivers included tearfulness, nightmares, insomnia, worry, anxiety, fear, despair and despondency. The psychological consequences were classified into various sub-themes (see below), illustrating the multiple emotional consequences of care-giving and the link to specific care-giving activities. These include empathy and feelings of guilt, distress about the state of their patients, the traumatic consequences of identifying with patients' symptoms of AIDS, worrying about the illnesses and imminent deaths of patients, the consequences of emotional trauma, dealing with severance of emotional bonds, the burden of non-disclosure, and the negative impact of the socio-economic context on caregivers' psychological wellbeing.

As with the physical burdens of care discussed earlier, the emotional and psychological burdens were also gendered. Women had a disproportionate share of these burdens because they were generally closest to the patients and performed the most emotionally wrenching tasks. Women were more likely to witness the deaths of these patients, and, because women constituted the majority of family and volunteer caregivers, they were more likely to witness frequent deaths. Women were also likely to experience more far-reaching emotional and psychological consequences from caring because the general absence of men meant that they did not have adequate support, such as from a male partner, during the grieving process.

Empathy and feelings of guilt — Many women caregivers reported that constant worry about the pain and suffering of their patients caused them to have sleepless nights and nightmares. Their inability to provide a cure for their illness caused them guilty feelings, which was exacerbated by the eventual death of the patient:

‘Providing care to her changed my life, because I felt like I was sick as well; I thought about her every time, even when I was asleep; she was also the first person I had to see every morning’ (31-year-old FCG/VCG).

‘We take responsibility for the patients. When our patients die we take responsibility that maybe we did not do enough…maybe we could have prevented the patient from dying’ (25-year-old VCG).

Fear and distress about the state of patients — Similarly, for those women caring for siblings and close family members, bathing them, cleaning their sores and changing their nappies produced intense emotional distress because it highlighted the deteriorating state and imminent demise of the patient. Women were overwhelmingly the ones that carried out these tasks. They indicated that the physical state of the patients and the fact that they may cry and express pain and agony when bathing them caused them constant emotional trauma: ‘When I started caring for the patient, I found it too difficult because her condition was very terrible. I can’t even find words to describe her condition. I was scared’ (19-year-old FCG/VCG). Another said, ‘I am still traumatised seeing how a person who is HIV-positive suffered’ (25-year-old FCG/VCG). One volunteer caregiver who was also caring for a sick sister was so emotionally overwhelmed that she could not continue to bathe her and had to call for help. ‘She told me that she could not continue bathing her because it was too emotional for her to do so…that it would be better for me to help give her a bath while she does the washing. She felt that calling someone else to do it [the bathing] at least for a while would relieve the hurt’ (23-year-old FCG/VCG).

Identifying with patients’ symptoms and pain — Some family members and volunteers were themselves living with HIV or AIDS while at the same time providing care to other people, including family members, living with the same condition. These people saw symptoms of AIDS daily while providing care to their patients and this as well as the pain that patients go through was a constant reminder that they or their relatives would probably go through similar experiences. Caring for patients and witnessing their death was thus a constant source of psychological trauma: ‘You know sometimes the caregivers may have HIV or have siblings or relatives who have similar sickness and symptoms like their patients, and when their patient dies they feel it and say — so this is how I or my sibling or relative is going to die too’ (28-year-old home-based care coordinator). One volunteer described how a colleague had noticed that she had symptoms of AIDS but had not taken an HIV test; she broke down in tears at their meeting, saying in frustration, ‘I am tired of not knowing what is wrong with me.’

Worry about patients’ illnesses and imminent death — Parents reported experiencing enormous emotional stress while caring for their children or witnessing their death. They were also worried about who would take care of their children after their own death. One HIV-positive mother struggling to put up with her own deteriorating health became psychologically devastated and depressed when she discovered that her last child was HIV-positive: ‘When they told me that I was positive I cried because I felt very sorry for my children [who] I am going to leave. I was also worried and stressed because of my last child, I did not know he had HIV and I also got depressed and was even admitted to the hospital for two weeks. If I look at other children of the same age they look very healthy and they are taken care of properly and you can see that they are not sick like he is’ (44-year-old HIV-positive FCG).

Consequences of emotional trauma — The participants caring for close relatives and the volunteers who had lost more than one patient were generally in a state of psychological distress at the time of the interviews, stating that frequent experience with the death of patients was extremely emotionally disturbing and haunted them constantly: ‘I have the fear that the emotional pain I feel might affect me sometime in the future, because the things I experience always come back to my mind: it is not easy to deal with these things’ (28-year-old, FCG/VCG). Others who experienced physical costs as a result of care-giving linked it to the emotional pain that they carried. One 35-


A 24-year-old woman who had given up her temporary domestic work to care for her mother explained, ‘I always felt pains at the back of my head, and I don’t know what it is, but I think it is due to the fact that I was thinking and worrying too much because I wondered a lot as to what my mother was suffering from’ (35-year-old FCG).

Severing emotional bonds — We observed and documented numerous special relationships between volunteer caregivers and their patients. These were also frequently mentioned in interviews with volunteer caregivers, particularly those serving as primary caregivers. Patients often shared intimate secrets with caregivers that they did not share with anyone else while they assisted them in securing financial and material assistance and also took care of the patient’s children. As a result, caregivers often developed bonds with their patients such that some had even closer relationships with them than their own family members. Hence, the death of a patient was often very traumatic for volunteer caregivers:

‘Sometimes you form a relationship or bond with a patient and if the person dies, you will just feel that you are left just alone. This has affected me greatly… A patient becomes a part of your family. There was a time I vowed not to care for terminally ill people any longer because it was always very sad to lose them’ (24-year-old VCG).

‘You form a bond with your patients. You bathe and do other things for them and the patients tell you… — when I get better next year I am going to do this and that — then you come the following week and they are dead. I had a personal experience with one patient who was HIV-positive and [who] did not want to come to the hospital or let his mother touch him. I went and spoke to him kindly and he agreed to take his bath and to come to the hospital with me, and did X-rays and all other tests. He was to come [back to the hospital] on Monday to start his TB treatment; I felt we had a special bond. And on Monday, they phoned me that he passed away on Saturday. I went to my boss’s office and I cried. Because I felt like — my God, this is someone that trusted me and now he is gone. I still remember his name because he died May of 2002’ (28-year-old VCG).

Although volunteers lose their terminally ill patients frequently, some remarked that there is usually no one to counsel them. One said, ‘We counsel people when their patients die but there is no one to counsel us when we lose our patients.’

Carrying the burden of non-disclosure — HIV stigma and discrimination were rife in the study communities and many of the patients did not disclose their HIV status to any member of the family except volunteer caregivers. However, the volunteers in the study had all signed an oath of secrecy that they would not disclose to any member of the family without the patient’s permission. Volunteers indicated that they had to keep the status secret: ‘We have to take the secret to our graves.’ What was emotionally burdensome for them, however, is that they are usually caught between patients and their families as family members will frequently ask the cause of a patient’s illness, which they then feel they must lie about. The requirement to not disclose even after a patient has died and in the midst of this pressure creates a heavy psychological burden.

Emotional impact of the socio-economic context — Most women providing care were unmarried and poor as shown in the socio-demographic profile of participants. Their poor economic condition and lack of financial support from men, as in homes where women were the household heads and breadwinners, was a key variable that in general presented an overall stressful situation for family members. A 75-year-old woman, who was the breadwinner and head of a multi-generational household and had spent a lot of money caring for her daughter and granddaughter, expressed her pain: ‘It is hurting so much because sometimes I am unable to sleep at night thinking of what to do and not to do. Because all the money I spend and everything I do just disappears. Nothing is going on well.’ In homes where volunteers were serving as the primary caregivers, they were also under pressure to provide food and money for transport to health facilities. Thus, caregivers experienced psychological stress while worrying about their own financial situation and that of their patients.

Overall, the findings show that informal care-giving entails performing a wide range of activities that are often stressful and overwhelming. This coupled with the gendered division of caring activities in HIV/AIDS-affected households exacerbates the pre-existing gendered divisions of labour, with more serious health ramifications for women than for men. The burden related to caring for people living with HIV or AIDS weighs disproportionately on women but is rarely reported because of socio-cultural reasons.

Discussion and conclusions

This study offers new perspectives into the gendered nature and consequences of care-giving within the context of informal home-based care. The findings are critical for informing policy and programmes on home-based care in South Africa given the benefits to the healthcare system.

Most of the caregivers were women and girls; this is in accordance with the results of previous studies that have looked at primary caregivers of people living with HIV or AIDS (Lindsey et al., 2003). Of note is the presence of elderly persons and children among the caregivers — a finding reported in other studies as well (Lindsey et al., 2003). Noteworthy is that none of the family caregivers was a spouse of the patient, in contrast to the findings of previous studies in East Africa (e.g. Ntozi, 1997) but consistent with other southern African studies (e.g. Lindsey et al., 2003; Chimwaza & Watkins, 2004). This might be a result of the sampling method, which entailed recruiting participants linked to a community-based organisation. Possibly, those caring for spouses perceive themselves as wholly capable of providing care and thus refrain from enrolling in the home-based care programme. But this may also reflect the high prevalence of single-parent households in the study communities (see Cross et al., 1992; Leclerc-Madlala, 2000), which is similar to the situation in some
other southern African countries (Lindsey et al., 2003; Chimwaza & Watkins, 2004).

In addition to examining the gendered nature of caregiving, the study provides a novel understanding of the gendered division of labour in HIV/AIDS-affected households and communities, hence an elucidation of the dynamics involved in the gendering of caregiver activities and burdens. Although only two male caregivers were interviewed, the use of ethnographic methods, which entailed multiple data-gathering techniques, shed light on the gendering of care in homes. In homes where men were present, there was often a lack of male participation in caregiving activities and women invariably performed the more physically and emotionally taxing caregiving activities, leading to work overload and psychological stress among women. Nonetheless, these women had certain perceptions about men’s role in caring that tended to perpetuate existing gender stereotypes, even if injurious to women. These notions can prevent women from seeking help and may indeed explain, in part, why women rarely report symptoms of physical and psychological stress and ill-health as they continue to provide care with a sense of compulsion (Avotri & Walters, 1999) and amid feelings of guilt. Thus, it is not surprising that some women caregivers reported deteriorating health, while at the same time trying to appear strong and capable when interacting with their patients.

These findings have far-reaching implications for the physical and mental wellbeing of both primary and secondary caregivers. This is even more so with HIV-positive caregivers, the elderly and children serving as secondary caregivers, all of whom experience considerable emotional and physical stress while performing arduous care-giving tasks amid their own worsening health.

This exploration of the experiences of both family and volunteer caregivers enhances our understanding of the practice of home-based care and how the duties of family and volunteer caregivers interface and overlap within the context of home-based care. Of particular note is the finding that, although volunteer caregivers are supposed to teach and assist family caregivers in affected homes, many also, at the same time, serve as primary caregivers in their own family and to other community members who need their services. These multiple-caring commitments contribute largely to the burdens experienced by women.

The use of a gender perspective in exploring the burdens of HIV/AIDS home care helps to elucidate the profound difficulties encountered by single mothers, who made up a substantial proportion of the caregivers in this study. These women found it more difficult to combine the multiple caring roles that may potentially overwhelm them. They had to care for themselves, their sick children, and their kin (which may include orphans), without support from their partner or partner’s family, mainly because of men’s absence in HIV/AIDS-affected families. Nonetheless, despite the burdens experienced by these women, all of them were receiving some support from a community-based organisation. There are many caregivers who could not be accessed and do not have access to any organisational support and who may be experiencing greater burdens.

Also of great concern is the vulnerability of women volunteer caregivers to rape while on duty and their heightened risk of infection with HIV or TB. Caregivers’ vulnerability to rape should not be taken lightly given the prevalence of rape in South Africa, and the reported intention of some youth to deliberately infect others if they find that they are HIV-positive (Leclerc-Madlala, 1997). Although many health professionals face an elevated risk of contracting HIV, the risk is also heightened among primary caregivers who have little or no training in providing hands-on care (Ndaba-Mbata & Seololwe, 2000). HIV-positive caregivers may be mostly susceptible to TB due to their compromised immune system.

The gendering of care-giving within the context of home-based care can be linked to the social construction of masculinity and femininity and is no longer new in Africa. However, it has grave implications for home-based care policies and programmes given the special demands of HIV/AIDS care as compared to other forms of care (Wardlaw, 1994) and in the context that the care is provided, as highlighted in this study. Traditional gendered prescriptions see household work and care work as the exclusive preserve of women (Taylor, Seeley & Kajura, 1996; Elson, 2005). In this study, the lack of support in the form of day-to-day assistance from male partners was compounded by lack of employment and abject poverty — a common feature in most of the participating households. However, the absence of men in affected households and the desertion of women documented in this study predate the HIV/AIDS epidemic and is corroborated by a wealth of old and recent literature (e.g. Preston-Whyte & Louw, 1986; Denis & Ntsimane, 2006; Desmond & Desmond, 2006; Richter, 2006; Hunter, 2006). A recent study among HIV/AIDS-affected households in KwaZulu-Natal found that men were not available in about 72% of households; of these, only 10% were absent because of divorce or separation, and just 34% of the fathers provided any support to their children (Denis & Ntsimane, 2006).

Nonetheless, there is a need to make use of information on the existing state and structure of HIV/AIDS-affected families in the planning and implementation of home-based care policies and programmes, which work on the assumption that family members are available, willing and capable of taking care of ill people in their homes. By deserting their partners, men not only avoid caring responsibilities, which have become enormous in the era of HIV-related home-based care, but this also precludes women from accessing potential support from their former partner’s family network. Women are therefore likely to be left with little choice but to carry the burdens of care alone: providing care for themselves, their own children, as well as orphaned children. Thus, they may depend solely on volunteers who already have similar caring responsibilities and burdens.

These findings have significant implications for the government’s home-based care policy and programmes, as the results do not support an assumption of involvement by stable, willing and available families. The findings underscore the importance of stable, healthy families in providing home care for people living with HIV or AIDS. Although there is an urgent need for interventions that will ensure more male participation in actively providing care and respite for women, this should be seen as a starting point. Interventions need to take cognisance of the fact that men are indeed absent in many HIV/AIDS-affected
households; men can only be oriented to participate in caring for family members in families where they are present; and it is highly unlikely that men who have deserted their partners will return to provide care when AIDS affects them. Given these circumstances, the absence of men poses a threat to home-based care.

In sum, home-based care undermines women’s health and wellbeing, creating an inordinate burden on women and thereby exacerbating existing gender inequities. It is argued that home-based care as currently practiced in the study communities amounts to the transfer of the responsibility of care to women who are already burdened by poverty and deprivation; thus, it serves to aggravate the existing burdens on women who are, and will continue to be, the main caregivers of the sick for a long time to come.

Recommendations and suggestions for future research

The following recommendations are made to influence policy and programmes on home-based care; suggestions for future research are also included:

• There is a need to incorporate gender perspectives when planning and implementing home-based care programmes.
• Ideally, patients should not be discharged into homes that have not been assessed as capable and willing to provide home care. Therefore, it is imperative to draw up policies and protocols guiding discharge of patients from public hospitals into home-based care.
• Government should look into the feasibility of training primary caregivers about the importance of using universal precautions, and making home-based-care kits widely available to HIV/AIDS-affected households, especially to reduce the elevated risks of infection facing women who provide care.
• There is a need to provide respite for women, who are particularly overwhelmed and burdened by care-giving duties.
• The health risks associated with care-giving underscore the need for huge resources to be allocated to the health and welfare of caregivers. Policy on home-based care should stipulate that the physical and mental health and wellbeing of caregivers is monitored to identify symptoms of illness early and to facilitate quick access to health care. In this regard, there is also a need to provide quality mental healthcare at the primary healthcare level. This may require training psychosocial personnel at community-care levels.
• Further studies are needed to investigate the willingness and readiness of families to provide care for people living with HIV or AIDS.
• There is also a need for research that seeks to better understand the socio-cultural factors that make women provide care out of a sense of compulsion and amidst feelings of guilt, as more and more women will be pressed into informal care-giving as the AIDS epidemic continues its stride.
• Further studies are needed that seek to better understand the negative implications of prevailing family structures on home-based care.

Notes

1 Further discussions on the socio-demographic profile of the caregivers are provided in the Findings section.
2 At an approximate exchange rate of R7 to US$1.
3 The amounts of these grants have twice been increased by the Department of Social Welfare since the study was completed in 2003.

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