

Family Caregiving for AIDS Patients in the Democratic Republic of Congo

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Abstract

We conducted a qualitative study of women who were caregivers for HIV/AIDS-affected spouses in Bumbu Zone, Kinshasa, Democratic Republic of Congo in 2003. Twelve caregiving women, six home-based care workers and five key informants were interviewed via focus group discussions. Most women reported huge problems in providing care to their spouses due to psychological, social and economic factors. The secrecy around HIV/AIDS issues and care was a significant theme in the findings. The self-reported health status of the caregivers indicated poor health.

Introduction

Sub-Saharan Africa is considered the region most affected by HIV/AIDS. AIDS is now the leading cause of death worldwide, killing 2.4 million people in 2002. Approximately 3.5 million new infections occurred worldwide in 2002, while 29.4 million Africans now live with the virus. UNAIDS estimates that some three million Africans with clinical AIDS require medical care (UNAIDS 2002). However, adequate treatment and care of HIV/AIDS patients is almost non-existent, and only a tiny fraction of those who are in need of treatment is receiving it.

Supporting and caring for people living with HIV/AIDS depends on many factors: family income, family cohesion and the country of residence, to name a few. UNAIDS reported that, in developed countries, people living with HIV/AIDS are well taken care of, and that HIV/AIDS-related mortality has been significantly reduced. In contrast, UNAIDS concludes that treatment services for AIDS are not accessible for most of the sub-Saharan rural population, and that the gap in HIV/AIDS care between the rich and poor countries is widening quickly (UNAIDS 2002).

Literature Review

No published research from the Democratic Republic of Congo (DRC) regarding caregiving for AIDS patients was found. Several authors reported from Uganda that traditional home care is not always feasible, and that neighbours often refused to help families requesting it (Ntozi 1997; Seeley et al. 1993). Others stressed that home care services in Africa, if they exist at all, are often

overwhelmed in the attempt to provide adequate services (Jackson and Kerkhoven 1995; McDonnell et al. 1994). These authors stressed that new approaches are needed. Most often the burden of care for AIDS patients in Africa falls on family members, especially on women, who are traditionally considered the principal caregivers (MacNeil 1996; Olenja 1999). This poses enormous stress on women in a society where they are already overburdened with their responsibilities for the general health of their families, household food security, their children's welfare/education and for managing scarce resources. Furthermore, persons with HIV/AIDS (PWAs) and their caregivers in sub-Saharan Africa live in communities where stigma surrounding HIV infection and clinical AIDS exists (Kalondo 1996; Anderson 1994; Mill 2000; Mwinituo and Mill 2006). Stigma often leads to social isolation and loneliness, not only for PWAs, but also for their informal caregivers at home (Casaux and Reboredo 1998).

The importance of family caregiving, especially in poor rural settings where formal healthcare services are virtually absent, has been stressed (Robson 2000; Ntozi 1997; Chela et al. 1989; Reijer 1999). However, few studies have addressed issues facing family caregivers for AIDS patients. Brouwer and colleagues (2000) and MacNeil (1996) described the struggle and difficulties of Buganda women in Uganda of providing love and care for their relatives with HIV/AIDS. Ndabam-bata and Seloilwe (2000) reported that family caregiving in Botswana was poor because family caregivers were not trained to provide basic care. Olenja (1999) found that training in AIDS care was grossly lacking at the community and household level in Kenya, and that AIDS caregivers were worried about their lack of skills. In South Africa, caregivers for children with AIDS had a huge knowledge gap related to the provision of appropriate primary care for affected children (Zimba and McInerney 2001). Ugandan mothers caring for their children with HIV/AIDS had a heavy emotional burden, which prevented them from following the advice given to them by healthcare workers and from delivering proper care for their children (Brouwer et al. 2000). Robson (2000) found that young Zimbabwean girls were disproportionately burdened with caregiving responsibilities for family members with AIDS, which negatively affected their education and career options.

From the literature review, it is evident that the care of the caregiver is a neglected aspect of HIV/AIDS research. Most of the HIV/AIDS control programs in sub-Saharan Africa do not provide caregiver support, with the Democratic Republic of Congo (DRC) being no exception. Home-based care programs, which exist in a number of countries, primarily focus on the needs of HIV/AIDS patients with limited attention to caregiver issues. Our experience with caregiver support programs in sub-Saharan Africa has demonstrated that care for the caregiver is a topic of little importance to the public, governments and the international donor organizations. However, as caregiving is predominantly the responsibility of women, it impacts women in a most dramatic way and poses a major obstacle for the advancement of women's issues and rights.

To highlight problems associated with caregiving of HIV/AIDS patients, Thomas Matukala Nkosi conducted a study in Kinshasa, the capital of the DRC, from September to November 2003, as part of the requirements for a Master's thesis. The remaining authors of this paper participated as members of Nkosi's supervisory committee in the research during the study design, data collection, analysis and dissemination phases. In particular, this study had the following objectives: (1) to describe the problems faced by women as informal caregivers for their husbands living with HIV/AIDS; (2) to identify the problems, which influence the health status of women caregivers; and (3) to describe the process caregivers use to seek support for the care of their AIDS patient(s) from family, friends and local organizations.

This information was considered crucial for policy formulation, as well as for planning and resource allocation for new and existing support programs to help female caregivers of family members suffering from HIV/AIDS. This study was part of a larger study that included both quantitative and qualitative methods to assess the care burden of informal caregivers. The quantitative part of the study showed, in addition to the high care burden, a low self-reported health status of the women caregivers in Kinshasa (Kipp et al. 2006).

Background Information

In the DRC, 25% of the sexually active population are HIV positive (Congolese Ministry of Social Affairs and Public Health 2002). The average age of men with HIV/AIDS is 35, and the average age of women with HIV/AIDS is 25. The highest HIV prevalence is found among young women 20–24 years of age.

Kinshasa, the capital of the DRC, is administratively divided into zones. The responsibility for HIV/AIDS control lies within the municipal health departments in the zones. Bumbu zone (190,000 population) is poor and has particularly low development indicators. HIV/AIDS-affected patients are cared for in municipal health centres. Bumbu has a home-based care program (Sacome+) that provides care for primarily HIV/AIDS patients.

Sacome+'s home-based care program for people living with HIV/AIDS and their families mostly relies on unpaid volunteers with limited autonomy. The Sacome+ activities include home visits and surveys, home-based counselling, psychological support group meetings, nursing care or medical assistance, the provision of supplies such as laboratory tests, basic treatments, help with hospitalization fees, referrals, psychosocial counselling, pastoral support, welfare assistance (funeral organization and costs) and legal aid (related to inheritance). In terms of preventive activities, Sacome+ has organized training and awareness-raising sessions throughout Kinshasa. Currently, Sacome+ has approximately 300 clients infected with HIV/AIDS in its outreach program in Bumbu. The capacity of the home-based care services is limited, so that on average only one home visit per client is possible within one month.

Methodology

A mixed method research design, using surveys and focus groups to collect the data, was used for the study. The survey results are published elsewhere (Kipp et al. 2004). Participants of the study were identified from the population of Bumbu through the Sacome+'s existing client list. Women, who were caregivers for husbands who had been living with HIV/AIDS for at least six months, and who voluntarily agreed to participate in the study, were recruited for focus group discussions (FGDs). Eligibility criteria were as follows: between 18 and 49 years, caring for a spouse with AIDS in the home and having one or more children. We focused on caregivers whose family responsibilities also included caring for children. All care recipients had clinical AIDS, which would have required antiretroviral (ARV) treatment, but none of them received ARV treatment. Most of their HIV positive caregivers, however, seemed to be in an asymptomatic stage of HIV infection, as assessed by their working capacity (no clinical examination was done), and few may have been eligible for or required ARV treatment.

In addition, key informants from Bumbu and Sacome+ staff were also asked to participate in FGDs. Persons who were seen as being a meaningful source for information on caregiving issues for AIDS patients were contacted by Nkosi, and the study objectives were explained. Those who agreed to be interviewed were recruited into the study on a volunteer basis. The membership of the FGDs is shown in Table 1.

Table 1. Characteristics of the focus groups

Population	Total number	Number of females	Number of males	Language of discussion	Number of focus group discussions
Caregivers	12	12	0	Lingala	3
Sacome+ staff	6	3	3	French	1
Key informants	5	3	2	French	1

The topics of the FGDs were designed to address the issues identified through information from the literature, from Sacome+ staff, as well from our own experience. For example, caregivers were asked questions around their daily work with the patient, their care burden and how they were coping with it. Sacome+ staff questions focused on the service delivery of the home-based care program, their perspective of the caregiver problem and shortcomings in their support to the caregivers and their patients. Key informants were asked more general questions about home-based care for AIDS patients (e.g., whether these services are important and how they could be strengthened, and if the home-based care services were appropriate and culturally accepted.)

A focus group discussion guide was developed to explore the experiences of the caregivers. Twelve caregivers were selected from the home-based care list of Sacome+. Participants in the key informant FGD were health planners, policy-makers and civic leaders from the zone of Bumbu. All FGDs were tape recorded after consent for recording was given by participants.

Qualitative analytical techniques included content analysis (theming, coding, categorizing, abstracting). Abstracting was done by transforming data from individual instances to create general categories that were derived from the data. Transcriptions from the tape were done word-by-word in the language as shown in Table 1. Transcripts in Lingala were translated by Nkosi and a research assistant into French and then into English. Transcripts in French were translated by N. Nkosi into English. All translations of transcripts were reviewed by a faculty member from the University in Kinshasa, who was fluent in all three languages. A trained research assistant in qualitative methods was the moderator of the FGDs. The first author took notes and recorded facial expressions and body language.

The study was approved by the Ethics Review Board of the University of Alberta. Local approval for this study was given by the Director of Sacome+ who accepted the ethical approval of the University of Alberta and decided that it was not necessary to seek approval by the ethics review committee at the School of Public Health in Kinshasa. All participants were provided with an information and consent letter. Participants signed the consent form. The focus groups were conducted in locations suggested by the participants, and names were not recorded on the data collection sheet, thus protecting the anonymity of all participants.

Results

All individuals who were approached by Sacome+ staff agreed to participate in the study. During the interviews, it became evident that all caregivers were also HIV positive. Interestingly, the caregivers disclosed their HIV status voluntarily to the interviewers without being directly asked.

Becoming a Caregiver

Most caregivers said that they became a caregiver because of love and a sense of family responsibility for caregiving. Their devotion to their spouse is reflected in the following statements.

“At the beginning, I did not know that my husband had HIV/AIDS. He had a fever almost every day, but all the fever medications could not stop his fever. Later he told me ‘I am condemned to die because I was diagnosed as being infected with HIV/AIDS.’ I was disappointed and shocked; I cried a lot [cries and pause]. I asked myself what to do. Should I leave him alone or not? I thought of my children, and I decided to stay with him because I still loved him. I also thought that leaving my husband alone would never solve any problems. Since nobody was there to take on my responsibility, I took over my family responsibility in a positive way. I said, ‘I am not giving up on my loved (my children and husband) ones.’ (Caregiver, participant #3)

“My husband became sick with fever, cough, diarrhea and headaches and was taken to the hospital where he was diagnosed as being infected with HIV/AIDS. My husband’s supervisor asked me if my husband hadn’t told me anything about his medical situation. I said no, and his supervisor told me, ‘Madam your husband has HIV infection. Our company doesn’t need

his services anymore, so you must leave it.' Because I loved my husband, I decided to take care of him. I also decided to ensure that my children would always be taken care of." (Caregiver, participant #7)

Lack of alternative treatment options was the second factor that influenced participants' decisions to become informal caregivers. In the excerpts below, two of the 12 participants recount their experiences.

"We tried to get the medications for my husband. We were told that tritherapy is very expensive and hard to handle. We could not afford it. I asked how expensive tritherapy was, and when I heard how much it would cost, I immediately understood that we didn't have that money to get my husband access to tritherapy, so I took him home." (Caregiver, participant #4)

"My husband was hospitalized. After two weeks, it became difficult to pay the hospital fees. We did have outstanding fees to pay. A nurse came to tell me that the hospital needs money. If we cannot pay, we better go [long pause] home. I did not have any choice, so I decided to go home with my husband." (Caregiver, participant #9)

Stigma was also a factor that led the caregivers to take on their husband's care at home. Patients and their caregivers did not want to risk being shunned by their relatives and friends and did not want to appear in public. In the following statements, two participants share their experiences following diagnosis.

"Since everybody not only left us alone, but also did not want to see us or even to hear from us, I could not leave my husband dying, quietly but surely, alone. That's why I am taking care of him." (Caregiver, participant #2)

"Having HIV/AIDS infection in Congo is like being a dangerous criminal. As soon as my neighbours and relatives heard about my husband's sickness, they concluded that [stammering] no one in my family could be visited. I had then to do something for my nuclear family." (Caregiver, participant #10)

Experiences of Caregivers

Most participants reported that their caregiving experiences were traumatic and very stressful. They said that they had been very disappointed by family, friends and the community's reaction to their husband's sickness and found caregiving a difficult task to handle. These difficulties included an overwhelming lack of resources, low health status of the caregiver and economic constraints as highlighted in the following four statements.

"How can it be easy if you have to do everything by yourself? Besides, you have nothing [sad smile], and you have been diagnosed as being infected with HIV/AIDS yourself?" (Caregiver, participant #3)

"Like now I haven't eaten yet since yesterday, but I have to care for my husband. I have to find some food for him because if he doesn't eat, it will affect him a lot. On the other hand, my children must eat too, but I have nothing to give them. Can somebody live with all of this stress [cries]?" (Caregiver, participant #6)

"I cannot help my husband 100% since I have to first think about my own medical condition [Long pause]. I think my husband is somewhat lucky to have me. I wonder if anyone will help me like that. My children are still too young to care for a sick person, so they will not be able to

help me out. You see, when this comes to mind (and it does all the times), I feel like I have to give up and kill myself. In that context, how can it be easy to take care of my husband?" (Caregiver, participant #9)

One participant reflected on social aspects of family life in a polygamous household setting and the consequences when the male breadwinner of the household becomes HIV infected. She said

"My husband had three wives. I am his first one. He married the other two only a year ago. At that time, he was not aware of his sero-positive HIV/AIDS status. When all of us knew it, my husband's two last wives left us leaving behind them two little kids they had with my husband. I now have to look after my own children, my husband and those two little abandoned ones. Can you imagine how hard it can be?" (Caregiver, participant #11)

Support for Caregivers

The only formal support participants mentioned came from Sacome+, but the sources of informal support varied. Six caregivers had not received any informal support. One caregiver reported that extended family were the only members of her informal support system, whereas three caregivers mentioned religious leaders/people, husbands' professional colleagues and friends as part of their support network. Two caregivers said that friends and neighbours were the only ones providing informal support for them. In the following comments from participants, it is apparent that the support from friends was not always positive.

"One day I was crying with my three kids. My husband was laying flat and could not even move his legs. I did not know what to do or where to go, so I started crying loudly. My neighbours heard me and called for my mother. Instead of coming alone, she came with one of my best friends. When they got to my place, they just looked at me and said 'why are you killing yourself without asking for any help?' I did not say anything, I just kept crying. Spontaneously, they went on by doing what was required to help me." (Caregiver, participant #5)

"At the beginning, we were hesitant to approach anyone. We were worried that they would turn against us, and some of them (despite their social rank) actually did. Because of that, we still feel hurt and angry. We received some help from people (neighbours) but they were negative and judgmental. We could not even lie because the help we were seeking would lead to questions, which required us to tell the truth. Since we were in need, we did not have a choice. We had to take the risk of being truthful even when we were not sure how the person would react." (Caregiver, participant #8)

Caregivers Health

Many participants pointed out that their lives were very negatively impacted by the caregiving burden. Caregivers believed that, as a direct consequence of their caregiving responsibilities, they were not able to participate in social activities, to work and to enjoy life. Almost all participants mentioned experiencing many health problems since they became caregivers. These may have arisen due to the physical and psychological burden associated with their caregiving tasks. Two of the caregivers comment on their health in the following passages.

"Before, I never came down with all these diseases I have now. I almost never got sick before. Since I am doing all of this for him [the husband], it looks like I am even more sick than him." (Caregiver, participant #4)

"You know what? I have been out of my mind since I started caring for my husband. Knowing that this will end when he dies, I always have headaches, stomach-aches and anorexia. I don't

think I will ever get well again in my lifetime. Don't forget that I am sero-positive myself.” (Caregiver, participant #6)

Opinions of Health Workers and Community Leaders about Caregiving

Healthcare workers and opinion leaders confirmed what was mentioned by the caregivers, that the caregiving responsibilities were huge, and that the problems associated with it were often insurmountable. They also reported that support services were inadequate and that the stigma associated with HIV/AIDS was very strong.

“Helping a loved one with a serious illness such as HIV/AIDS is a big responsibility, especially as the illness progresses. In the majority of our cases, the husband whom the wife is caring for has become very dependent on her. It is an especially big responsibility when we know that those women (caregivers) don't have the help they need to do their job.” (community leader)

“The thing is they [caregivers] never been prepared for their role and don't even have enough skills to handle their tasks, which is a risk because it happens that they have to act like us [health professional providers], especially at night.” (health worker)

“I don't think caregivers realize how big their responsibility is because they don't always take care of themselves. I know that they don't have the means to do so, but it seems like they have lost the sense of purpose in their lives. Some of them sometimes express the feeling that they have given up on everything.” (health worker)

“There are a lot of gaps between what we know are needed and the services provided.” (medical doctor)

“There is a lot that could be done to develop the services given to HIV/AIDS people and their families in terms of infrastructure, service provider training, medical supplies, etc. But nobody cares.” (community leader)

“Most communities still make moral judgements on people living with HIV/AIDS and on their families. Consequently, individuals' fears regarding confidentiality are particularly strong. Because patients and their families have the perception that staff can spread the content of their files behind their backs, confidentiality must be the principle that leads home-based care programs.” (community leader)

Discussion

We assessed the experiences of 12 women in the Bumbu Zone, Kinshasa, Democratic Republic of Congo, who were caring for their husbands with AIDS. This was supplemented with information about caregiving issues from health workers in the home-based care program for AIDS patients and key informants. Results from this research demonstrate that in the study population, women's caregiving responsibilities for AIDS patients are enormous and overwhelming. It is likely that there is an even greater burden on caregivers in rural areas of the DRC, where conditions are much worse than in the capital and very few support services exist. All women who participated in the study were also HIV positive, highlighting the need for prevention efforts to limit HIV/AIDS transmission in discordant married couples. The women experienced considerable suffering when they saw the clinical consequences of the disease in their spouses. They worried about how they would handle their own illness and who would care for them when they became sick.

There was a high level of stigma and secrecy around HIV/AIDS issues in the current study. For example, one woman was told by her husband's employer that he was HIV positive. In addition, there was little communication between couples themselves, because some of the caregivers learned about their husband's HIV infection very late in the disease process.

The overall results from our study indicate that women who are caregivers for their HIV/AIDS-affected husbands are overwhelmed with their responsibilities and bear a high burden due to the poor conditions in Kinshasa. Participants reported high levels of social isolation and stress, low levels of health and a deep unhappiness in life. This is congruent with most of the findings from the other studies from Botswana, Kenya, Uganda and Zimbabwe about caregiver burden, which we reviewed.

Lack of support was a common theme among all of the participants in the study. Support was often not available or refused to be given. It also seemed sometimes that the caregivers do not ask for the needed support given the stigma or the “shame” of being HIV infected or having a husband who is HIV positive. In Kinshasa, care for an AIDS patient in the final stage of the illness means “intensive care” at home on an earthen floor, possibly without water and electricity. Lack of support, including support services for caregivers, was also highlighted as a major caregiver issue in studies from Botswana, Uganda and Zimbabwe (Ndaba-Mbata and Seloilwe 2000; Seeley et al. 1993; Jackson and Kerkhoven 1995). The lack of formal support services for caregivers is highlighted by the fact that care for the caregiver does not appear as a component in most documents about HIV/AIDS programming in sub-Saharan Africa.

Conclusion

Our study highlights the significant problems in sub-Saharan Africa, which are associated with family caregiving for patients with AIDS. Based on the findings, we wish to highlight three issues.

- 1) The caregivers in our study were so overburdened and so desperate that they could not look after their own physical, social and mental well-being. The limited research on informal caregiver burden emphasizes the absence of, or the limited capacity of, specific support programs to provide family caregiver support. Although a goal of HIV/AIDS control programs in several African countries is “to reduce the social impact of HIV/AIDS on families and communities,” little action exists to address caregiver issues and socio-economic problems related to them.
- 2) Stigma toward HIV/AIDS patients and their caregivers was a significant problem for the participants in our study. This is somewhat surprising, considering that the HIV/AIDS epidemic is very mature in the DRC. This is in contrast to our experience in western Uganda, where stigma toward persons with HIV/AIDS appears to be diminishing. The broad social impacts of stigma, trends in AIDS stigma and factors that promote or reduce stigma require further investigation. This knowledge is necessary to design specific interventions to actively mitigate the stigma against HIV/AIDS.
- 3) The huge caregiving responsibilities in sub-Saharan Africa are a gender-related issue of utmost importance and are a significant obstacle to the advancement of women’s issues and rights. It is surprising that the burden that women experience in providing AIDS care has not been identified more often in the international development literature or by the international donor community as a major gender issue. Caregiver burden and stigmatization against persons and households with HIV/AIDS is strongly associated with, and contributes to, the care burden of caregivers, who are mostly women (Powell-Cope and Brown 1992). It prevents women from participating in social and developmental activities and programs. This is counterproductive to international efforts to strengthen the role of women in societies of developing countries and to enhance their rights. Community development in Africa suffers because women cannot contribute. Over time and on a large scale, the impact of HIV/AIDS will have serious negative consequences for women specifically, and for society as a whole.

These three issues are so interwoven in the sub-Saharan African culture that it will take amazing skills and substantial resources to break the negative impact of this vicious cycle, which causes desperation at both the individual and societal level. The rollout of ARVs in the Congo would be a tremendous boost to address each of the above issues. Many care recipients could again become

productive within their families and caregiver burden would be reduced substantially. In addition, it has been shown in Haiti and South Africa that when AIDS patients are treated, stigma decreases (Castro and Farmer 2005; World Health Organization 2004). Although the discussions about the benefits of ARVs have not been linked to caregiver burden, it is logical that immediate and successful treatment of AIDS patients would be the best relief for family caregivers.

Our study results, which reveal limited or absent support services for family caregivers with extremely high care burden and who are therefore at great risk for ill health, indicate the need to address the agenda of caregiver burden in the DRC Congo and elsewhere in sub-Saharan Africa. We suggest three immediate steps in a change process that could make a difference for female family caregivers in Africa: (1) The decision of HIV/AIDS programs to include family caregivers as legitimate clients in their plans and budgets, which would make it possible to initiate programs of support for them. These could be delivered in an integrated fashion in combination with other programs such as family planning outreach. (2) The conscious decision of local health and social services to target this caregiver population as one of their priorities with the existing resources. This could result in specific indicators for program development of caregiver support and resource deployment. (3) The direction of funds for female caregivers. There are many national and international agencies that generously fund gender programs of all types. Some of these funds could be diverted and targeted towards the female family caregivers of AIDS patients.

It must be recognized that the most challenging aspect of this magnitude of change is not the policy development per se, or even the allocation of the resources required, but rather the shift in thinking required that would result in recognizing and serving families rather than individual patients.

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