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Gender Roles and Informal Care for Patients With AIDS

A Qualitative Study From an Urban Area in Tanzania

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As HIV/AIDS imposes an overwhelming pressure on the capacity of an already overburdened health care system in many African countries, families have increasingly been noted to supplement hospital care services for patients with AIDS. The aim of the present study is to generate knowledge on the experiences of family caregivers to the patients with AIDS at the household level in Dar es Salaam, Tanzania. Data were collected through in-depth interviews with 20 family caregivers and were analyzed using thematic content analysis. The article provides the reader increased insight on the obligations that AIDS caregiving has imposed on women within the close kin group of the patient. The study indicates that caregiving has increased the workload and in the same vein the economic marginality of women, who themselves are increasingly widowed heads of households. The study findings demonstrate strong gendered implications for community and policy makers.

Keywords: HIV/AIDS; women; informal care; caregiving; Tanzania

Tanzania is among the many sub-Saharan African countries that have experienced a very high rate of HIV and AIDS. The present HIV prevalence rate for adults 15 to 49 years old is 6.5 (Indicators Country Report Template, 2006). The impact of HIV/AIDS extends far beyond those living with the virus, however, as each infection produces complex consequences that affect the lives of the family, friends, communities, as well as health systems surrounding the infected person. Previous studies have also indicated that the burden of care for HIV/AIDS patients has been placed on the family (Gilks, 2001; UNAIDS, 2000), as kin caring for the sick is the customary pattern in Africa. The home-based care (HBC) initiative emerged as a response to the fact that the hospital bed occupancy by patients with AIDS has been estimated at 50% to 60% (Ministry of Health, 2003), with a recognition that the enormous demands for care cannot be met by the hospital system and had to fundamentally be located at family level. Informal caregivers have become of vital importance in meeting the needs of AIDS patients all over the world. Also from Western contexts, studies have

indicated that informal caregivers of people with HIV/AIDS provide practical help and nursing care at home (DeCarlo & Folkman, 1996) and that patients in the last phase of the disease need care for their complex conditions at all times. Beedham and Wilson-Barnett (1995), for instance, note that patients with HIV/AIDS in the United Kingdom require substantial practical support, which involves activities like shopping, cooking, laundry, and personal care, including bathing and help at night with the change of bed linens, toilet visits, or with medications. Such situations are often associated with heavy physical caregiving demands for bedridden patients

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(MacNeil, 1996). Raveis and Siegel (1991), who carried out an early study in relation to HIV/AIDS care in a high-income country, argued that the lack of controllability or manageability of the symptoms associated with chronic diseases is an important factor leading to stress in the caregiving situation. This becomes no less true in African contexts. On top of the physical challenges that accompany the care for AIDS patients, the emotional aspects of issues related to stigma and discrimination have been reported, showing tremendous impact on caregiving in Africa contexts (McGrath, Ankrah, Schumann, Nkumbi, & Lubega, 1993; Mwinituo & Mill, 2006). In Africa, such demanding caregiving responsibilities are commonly coupled with difficult economic demands, such as working in the fields (Kipp, Tindyebwa, Karamagi, & Rubaale, 2007). The involvement in such comprehensive informal care to loved ones suffering from AIDS may bring about substantial emotional and physical stress in the caregivers' daily lives. It is indeed increasingly recognized that the burden of caring for patients with HIV/AIDS adversely affects family caregivers who lack adequate resources or are insufficiently prepared for this new and complex role (Gilks, 2001; UNAIDS, 2000).

Several studies have shown that the caring role of patients with AIDS is mainly carried out by women (Castro, Orozco, Aggleton, Eroza, & Hernandez, 1998; Kabira, Gachukia, & Matiangi, 1997; Kipp et al., 2007; Knowlton, 2003; Lie & Lothe, 2002; Lindsey, Hirschfeld, & Tlou, 2003; Nkosi, Kipp, Laing, & Mill, 2006; Seeley, Kajura, Bachengana, Wagner, & Mulder, 1993; Uys, 2002), who often lack training about how to provide basic care for seriously ill patients (Ndaba-Mbata, 2000; Olenja, 1999). Despite the fact that the caring role for patients with AIDS is complex, women have been found primarily responsible also for all kinds of other domestic activities (Koda, 1996; Sweetman, 1996). From the Democratic Republic of Congo, female informal caregivers for people with HIV/AIDS have been reported to have poor health because of low income, rented accommodation, and little support (Kipp, 2007). The present article sets out to explore gendered aspects of informal care for patients with HIV/AIDS in urban areas of Dar es Salaam, Tanzania. No earlier study has been carried out on the topic in Tanzania.

The definition of *informal care* employed in the present study context is "care provided to patients with AIDS by a family member, a friend, a relative, or a volunteer at home." We thus set out to interview persons who at the household level are recognized as the one taking the main burden for the caring responsibility for the patient with AIDS.

Research Method

This study has a descriptive and exploratory design and employs qualitative research principles. A qualitative approach was chosen to uncover and explore what lies behind a phenomenon about which little is yet known (Morse & Richards, 2002; Straus & Cobin, 1990). Data were collected from August to September 2003 in Dar es Salaam, Tanzania.

Informants

The research informants were made up of a purposive sample of family caregivers of patients with AIDS in Dar es Salaam, Tanzania. The informants were all supported by the organization Pastoral Activities and Services for People With AIDS Dar es Salaam (PASADA), which gives support to family caregivers of patients with AIDS at the household level. The informants were recruited through a PASADA contact nurse. The informants' sample was driven by the selection criteria of bedridden patients who have been under HBC. Twenty family caregivers ages 16 and 70, 19 women and 1 man, were recruited. All the informants had been in contact with the HBC initiative for at least 1 month. Caregivers under 15 years of age were encountered, but only individuals older than 15 were recruited because of the general permit given. The number of informants was based on the principle of saturation; that is, data collection continued until no major new categories of information emerged from the interviews.

What is moreover becoming a new situation in this particular context is that many of the main caregivers—the mothers, sisters, daughters, aunts, or sisters-in-law, who are providing care for their relatives with AIDS—are either widowed or single women.

Informed Consent

Prior to data collection, both the Norwegian Regional Medical Ethics Committee University of Bergen and the Muhimbili University College of Health Sciences Research and Publications Committee in Tanzania approved the study. Permission to conduct the study was also sought and obtained from PASADA prior to data collection. Before each interview, informants were given a consent form to read in Swahili (the national language of Tanzania), where the principles of voluntary participation, anonymity, and rights of withdrawal without any consequence were described. The interviewer also orally reviewed these principles before initiating the interview. All the study informants signed a consent form that informed them about the details of the study and their

rights as informants. Fifteen (15) caregivers consented by signing, and five consented by stamping using their right thumb. All informants accepted tape recording of the interviews. Aspects of confidentiality were strictly adhered to throughout the study. Confidentiality was assured by conducting the interviews in privacy and according to caregivers' preference. Anonymity was secured by not recording the informants' names or residences on the tapes and transcripts.

Data Collection

The in-depth interview was the primary data collection method. The interview guide, a flexible tool guiding the talks, was initially prepared in English followed by translation to Swahili. All interviews were conducted in Swahili by the first author, who is herself a native Swahili speaker. The audio-taped interviews lasted 30 to 75 min. Most (17) of the interviews were conducted at the informants' home to maintain the informants' comfort zone. However, a few interviews were carried out in a nearby shop, under the shade of tree, and in one of the PASADA offices for reasons of confidentiality or privacy. The main research questions addressed in the interview guide were as follows:

- Who carries out the various chores associated with caregiving for patients with HIV/AIDS at the household level?
- What are the main caregiving tasks carried out by family-based care providers for patients with AIDS at the household level?
- What are the key challenges experienced by caregivers of AIDS patients?
- How has caring for AIDS patients affected the caregivers' life?
- What are the resources available to minimize the burden of care to the caregivers?

In this article, the authors focus on the first four questions. The other data are reported elsewhere (Tarimo, 2004).

Data Analysis

Thematic content analysis guided by Steinar Kvale's (1996) approach was used in the data analysis. Analysis takes place from the very first interview in qualitative work and continues to the point where the final research report is written. The material was transcribed word by word from the audiotapes. The first author did all the transcription herself. The interview transcripts were, upon completion, thoroughly reviewed before the process of coding started. This was done through repeatedly reading

every transcript to define core aspects of what each informant communicated. The meaning of each statement was then written in the margin of the transcript (code) manually. Through this process, the author simultaneously identified the recurrences of the key phases and patterns of statements. Codes and responses were subsequently organized by categories according to recurrences of the major themes. Direct quotations from informants were pulled out to ensure that the direct concerns of the informants were reflected. Lists of categories finally were reorganized in appropriate sequence to be employed in the presentation of the findings.

Findings

Caring for patients With AIDS at Household Level

A key finding in the present study was the enormous gender disparity related to caregiving; women simply bear the brunt. In the sample, there was in fact only one male caregiver, whereas the rest were female. The following relationship between caregivers and patients were recorded: mothers of the sick (8), siblings (5), spouses (3), daughters (2), aunt (1), and sister-in-law (1). Two caregivers were known to be HIV-positive spouses, whereas the HIV status of the remaining 18 was unknown. Eleven of the 19 caregivers were married, 5 were not married (single), and 4 were widowed. Eight caregivers were older than 50. The occupational status of the caregivers consisted of petty business (8), women who work on the family plot or take care of the family (7), peasants who moved from the village to the city (3), a primary school teacher (1), and a vocational training student (1). The informants belonged to different ethnic groups: Zaramo (3), Chagga (3), Nyamwezi (3), Pogoro (2), and one each from Ngoni, Makonde, Kwere, Yao, Nyasa, Zigua, Matumbi, Manyema, and Rangi. The Zaramo are the native inhabitants of the Dar es Salaam region, but the many ethnic groups represented in the study indicate the enormous diversity of the current city. Half of the caregivers were Moslems, and half were Christians.

Twenty patients were under care, hence corresponding to the number of caregivers. One additional family was visited, but the 50-year-old patient did not want his 87-year-old mother to be interviewed because of her age and limited understanding capacity. The patients' ages ranged from 20 to 70, with a median age of 34. The majority (17) were females. Twelve of the patients were single, four were married, three were widows, and two were separated. Nine of the patients had children who were living with them in the homes that were visited.

The Ideal Caregiver Is the Mother

Mothers of the sick deeply felt that it was their responsibility to give care to their sick children. They felt that they could not leave the responsibility to anyone else because they viewed the task as “inherently theirs.” They claimed that even if their children had “misbehaved” before falling sick with AIDS, they still loved them and strongly wished to take care of them. One mother in her 60s said:

This is my child. The one who feels pain is me. Others will say: my daughter has just harvested from her prostitution. But always a mother is a mother. Despite her stubbornness, I will never leave her alone.

When nonmaternal caregivers were asked to explain why they were caring for the patients, they mentioned that they were taking care of the patients because the mother of the sick person was incapable of performing the task. The male spouse who was the main caregiver for his sick partner similarly related that the caring role principally belonged to either a “mother” or a “spouse’s mother.” However, he was giving care when mothers were not available or not capable of carrying out the task. He shared the following:

I am caring for her because she is my wife. Her mother would have taken care of her but she is not alive. My mother could also have assisted but she is sick and she is very old.

Daughters moreover found caregiving to their mothers (not fathers) as a most fundamental task to perform. The daughters felt obliged and were willing to take care of their sick parents. A 16-year-old girl who was caring for her bedridden mother said:

I have to. Because my mother brought me up, I regard her as my main caregiver. Even in the Bible it is written that we should respect our parents in order to live longer and in peace. Firstly, when I think of my mother, the difficulties she went through while bringing me up, I will never neglect her. We have come a long way. I understand her problems.

The second category that came up as a common or “natural” category of caregivers was the sisters of the patients. A 32-year-old married woman with very young children left her family to take care of her sick sister who lived 10 kilometers away from her home. She said:

I do not live here. I live near the Airport. I have left my children with their father. I come here to take care of my sister. I do not find it as a problem in my life. It has not severely affected my family. I have got the courage to take care of my sister.

The Caregivers’ Burden

Physical hardships. Whereas personal care and hygiene were given high priority, caregivers mentioned washing clothes, particularly the bed linens, as the most time-consuming activity because of the bedridden patients’ inability to properly manage going to the toilet. When the researcher visited the family where the caregiver was an old woman of 70 years, another woman of around 30 years was observed helping with the washing. Beside her, there was a large bundle of clothes waiting to be washed. Many caregivers commented that such dirty/soiled clothes had to be washed by an adult member of the family. For instance, one female caregiver in her 50s emphasized the following:

This is not a responsibility that you can delegate to children. It is my own responsibility. If it is other issues related to food and diet then I could ask my children to help. In African customs and traditions, to ask the child to clean the floor where the patient had soiled . . . no, I have never done that! I do the cleaning myself. Sometimes the patient may get up and soil all over the place! But I do it myself. I do that work willingly because I can’t delegate it to children.

In many homes, the caregivers had to fetch water from other places because water was often not available in their places. This made their already difficult task of providing assistance to the patients even more strenuous. Fourteen of the 20 caregivers interviewed mentioned further that lifting and assisting the patients with toilet needs was extremely tiring. The aged caregivers experienced more difficulties with the lifting of the patients. A 57-year-old widow who was taking care of her 39-year-old daughter told the following story:

You can see the condition; she can’t do anything. A few days ago, I was forced to make a hole in her bed so that when she passes watery stools the beddings will not get soiled. She is passing watery diarrhea. I did not have any more energy to lift her. As you can see my body, I am already weak. I am a widow. I have no support from a husband.

Social/emotional hardships. Some of the caregivers had experienced starkly the still-existing fear and stigma surrounding HIV/AIDS. In these families, it was noted that stigmatization was directed toward the entire family as much as toward the patient. A primary school teacher who was taking care of her daughter had strongly noted the difference before and after taking care of her daughter. She said:

Yes, we have been discriminated. The patient does not have any friends who visit her now. . . . On my side, none of my colleagues do. They assisted me in the very beginning, but now there is nothing!

In some families, the caregivers were in fact left entirely alone with the patients because of the stigma and discrimination. Even relatives sometimes ceased to communicate with them, leaving the caregivers completely isolated with their patients. A 27-year-old sibling who was taking care of her sister expressed with emotions that her sister (the patient) had been separated from her husband because of the illness. In tears she related:

I am left alone to take care of my sister. She is married, yet it is a month now and her husband has not appeared here. We also have other relatives, but it has been several months since we saw them visiting us. I am left alone. . . .

This situation was confirmed through the first author's observation when she visited this family in the slums of Dar es Salaam. Because of relocation searching for care, the mentioned patient was offered a side room at her aunt's house, while it was the sister who was living in a nearby house who took care of her. The caregiver (sibling) lived with her husband in a small house with only one room and a kitchen, and because there was no room for her sister, she had to go back and forth to the aunt's house to care for her sister. The aunt never visited her dying niece living in her house.

Economic hardships. Being a caregiver to a patient with AIDS commonly means being with the patient most of the time. Caregivers had to postpone most of their other activities to be sure that they were available almost full-time for their patients. A 35-year-old woman caring for her sibling commented:

Due to the present condition of my patient, there isn't any activity going on. Every time I am here for her, because she may call me at any time. If I will not be around, she will feel bad in one way or another.

Throughout the time of illness, the lives of many of the caregivers completely changed. They emphasized that caring had to be given a top priority. A 57-year-old woman who had been in town for 3 months taking care of her daughter said:

I do not know exactly what to say because this is my patient. I live in the village, but currently I have to stay here, to see how the patient gets on. Meanwhile the farm has to be forgotten. I have to care for my daughter. . . .

Such movement or relocation of caregivers or alternatively of the patients was noted among many of the informants. Seven caregivers left their homes to care for the sick in the city, whereas six patients moved from their normal residence to be cared for by their mothers, siblings, female in-laws, or aunts during the terminal stages of the illness. Challenges of various kinds emerged in relation to these relocations. An elderly peasant woman who had just moved to the city to take care of her ailing daughter said:

I would not be here if my daughter was okay. I would see her coming to see me in the village. My life has changed. Even if I decide to go home now, I cannot do anything (at the farm plot). At home, the cassava crop has already disappeared in an uncultivated bush!

Most women were not formally employed but depended either on small-scale farming or petty business. In both cases, the caregivers realized harshly that their income had decreased dramatically. One woman said:

I was doing petty business, moving here and there so that I could manage living expenses. I was keeping chickens, but when my daughter became bedridden, I had to postpone everything.

Another revealed:

Truly, I have been affected. First of all, I am not employed. I spend most of my time with the patient, and I do not have even a chance to get out to meet other people or look for a "project"! I get very tired, staying awake, caring.

Many of the caregivers are fully dependent on support from friends, neighbors, and other relatives. They did, however, perceive the support as highly unreliable as they had to contact one person after another searching for assistance. Because of prolonged illness, the supporters

got overwhelmed by their own daily living expenses and could not maintain their offer. One caregiver explained:

Friends! You know living expenses are high. Friends would like to help, but they cannot afford it. They have their own families. You can not blame them.

In cases where husbands were alive, the situation could be somewhat better, although husbands would rarely take part in the caregiving to let the women take care of their petty business and would moreover only in very rare cases take over the female cultivating tasks. This implied increasing scenarios of missing subsistence crops as well as funds for purchasing crops.

Discussion

The present study material strongly indicates caretaking of patients with AIDS has increased women's burden of work as well as their marginality in quite dramatic ways. The vast majority of those who care for patients with AIDS in the families are women. The gendered labor situation commonly described from East Africa implies that women are rarely the main bread winners but have their main responsibility linked to the domestic sphere, where caregiving is located at the core of their domain. This means that the women are expected to and are accustomed to handle situations of caregiving. Hence, the demands of caregiving for AIDS patients is "naturally" delegated to and taken on by women, whether mothers, sisters, daughters, aunts, sisters-in-law, or other women with kin or family ties, rather than by husbands, brothers, fathers, or other men.

Such a gendered burden of care for AIDS patients is hence not new, nor is it particular to sub-Saharan African scenarios. Studies from outside the African cultural context report women as carrying the role as informal caregivers of patients with AIDS (Aujoulat, Libion, Bois, Martin, & Deccache, 2002; Castro et al., 1998; Knowlton, 2003). In Mexico, for example, women mainly provide care of the sick at home, while men provide support in terms of money and access to health services (Castro et al., 1998). A study from Canada similarly reports that the burden of informal care in general (not specifically linked to AIDS care) falls disproportionately on mothers, wives, and/or daughters, who remain unpaid for such services (Sawatzky & Fowler-Kerry, 2003). This scenario can of course not be understood without a fundamental recognition of well-established societal and cultural logic that generates the particularities of gender expectations and roles (Koda, 1996). But the divisions of

labor and related gendered roles prescribed to women and men seem to be strengthened and emphasized in times of AIDS (Kabira et al., 1997).

What is moreover becoming a new situation in this particular context is that many of the main caregivers—the mothers, sisters, daughters, aunts, or sisters-in-law—who are providing care for their relatives with AIDS are either widowed or single women. In the Kilimanjaro Region of Tanzania, Lie and Lothe (2002) report that the burden of care that the women shoulder in times of AIDS is particularly heavy because most of the women are not adequately empowered to take control of their lives. The traditional upbringing of girls and women, which emphasizes their roles in performing domestic chores with little relations to the public and economic spheres, reinforces the heavier burden of HIV/AIDS problems that women carry (Kabira et al., 1997). Women certainly do cultivate, but in East Africa this primarily implies subsistence cultivation and does not bring additional income to the household. Although not considered main "breadwinners," in the sense of "earning an income," women are often in fact the main producers of food (Buckshee, 1997; Isaksen, Songstad, & Spissoy, 2002; Panos, 1992) and are hence the true breadwinners. In sub-Saharan Africa, in general, the proportion of women working in the agricultural sector is reported to be around 80% (Kabira et al., 1997). Although we have not carried out systematic research to map reduction of hours spent on cultivation, the study informants uniformly related that the time demand of AIDS care dramatically reduced the hours available for cultivation and many abandoned their farms altogether. The reduced time spent on cultivation has a direct impact on the demands for funds to purchase food. What has become clear in the present study is that the shouldering of the responsibility of caregiving for AIDS patients with a simultaneous responsibility for the yielding of a harvest or the keeping up of petty trade is almost impossible because of the comprehensiveness of the caregiving task. The consequence is new staggering poverty scenarios, with women located at the core.

Conclusion

As HIV/AIDS continues to devastate African communities in contexts where the rollout of treatment services is still hampered for economic, political, logistic, and other reasons, the role of informal care at the family level has taken on enormous proportions. The present study has indicated that the demanding and complex caregiving tasks are carried out by female kin, often elder mothers or aunts or sisters, women who themselves may

be widowed or single with no separate income. The challenge of the caregiving is further augmented by the extremely marginal economic contexts in which the caregivers find themselves. Hence, although informal care by women is normalized to the extent that it generally implies “no surprise” to anyone, the enormous stress implied by the work burden placed on the care takers for AIDS patients, combined with extremely marginal life contexts, are scenarios that no policy maker, whether in Tanzania or elsewhere, can hide behind notions of culturally appropriate coping mechanisms. We will then be shutting our eyes for the sufferings of the ones carrying one of the toughest burdens of our time.

Implication for Practice

There is an immediate need to inform the policy makers about what informal care to patients with AIDS implies for African women and, in this context, for Tanzanian women. Listening to the voices of caregivers reveals the particularities of the caring task and the particular hardships experienced and thus opens up for the targeting of assistance by policy makers. It moreover opens the door for establishing “a sharing spirit” among community members, both men and women. In this context, it seems like nurses and family caregivers can assist each other in approaching both central individuals in the local communities as well as policy makers to inform them about the challenges at hand. Openness about the topic is the very first step in reaching an understanding, an acceptance, and eventually an empathy with the ones struck by the most devastating pandemic of our times.

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