The Role of Women in Taking Care of Sick Family Members in This Era of HIV/AIDS

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Introduction

When I started preparing this paper a colleague asked, "of all African women household chores, why have you chosen to discuss particularly taking care of the sick?" It must be emphasized here that in general, the majority of the household chores done by women in our African households can also be done by men, but in this particular paper, I will focus on taking care of the sick and especially HIV-/AIDS-related illnesses for the following reasons.

Early this year (2000), our president, Benjamin Mkapa, announced this year to be a national year for fighting against HIV/AIDS and its devastating effects. Globally the AIDS pandemic is said to be worst in sub-Saharan countries (Tanzania inclusive). It is believed that 70 percent of all HIV cases in the world are located within the area. The disease has yet to have its worst-margins social and economic impact, as only an estimated 10 percent of all deaths related to the disease have occurred.[1] The morbidity of the disease is incapacitating, especially in our setup, with shortages of resources, namely medicines, enough health care facilities, personnel, etc.[2] As of 1997 an estimated 1.5 million Tanzanians were already infected with the AIDS virus, with over 80 percent of the cases affecting people between the ages of 20 and 40 years. The situation is bad already, resulting in millions of orphans and an increase in cases of tuberculosis.

When someone is faced with the responsibility of taking care of a sick HIV relative, all other normal activities suffer as well. An infected person requires ongoing care until he or she dies. A working woman who takes on the care of an HIV-infected relative will definitely need to ask permission on and off from her employer to stay with the patient or to go and prepare food and feed the patient; she might even end up with a poor attendance record at work as she turns up late because of the extra duties related to caring for this type of patient. Definitely, the requirements of such care affect both her normal household chores and her career work as well at the end.

The AIDS epidemic is a women's epidemic because the available data from National AIDS Control Program show that women of reproductive age (15–35) are the most affected. These are the caretakers; they are vulnerable because they take care of the sick without protection, ignorant of the problems such a lack of protection can create. The women of Tanzania are overworked. They suffer mental stress by sharing the suffering of their sick relatives and yet caring for them until death. Because of so much effort

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invested in taking care of others who are ill, they are economically underutilized.

As a doctor, I strongly feel that, although it is late, this is the most appropriate time to talk about this topic as professionals and transfer gained experiences to our clients. Further work should be done in other fields as well.

In this paper I will attempt to come up with answers to these key questions:

- If not women, who are taking care of HIV-/AIDS-infected and other sick people in our society?
- Whose responsibility is their care?
- What is happening with the resources needed?

Situational Analysis

Traditionally and historically the responsibility of taking care of family members was and is still a task for women in most of our African households. In the old days, a sick child or relative was left with a grandmother or an elderly female neighbor while the other family members attended to the farm and other duties. Even in the townships, where most women were still housewives (unemployed outside the home), they were naturally expected to take care of the sick, even if there were unemployed men around. Has the situation changed now? one will ask. Despite the socioeconomic changes in our society, whereby more and more women are entering the labor market and struggling to maintain flexibility in their roles as family caretakers and career women, the society at large still expects women to stop working and take care of the sick when the need arises.

During this HIV/AIDS pandemic, the number of hospital admissions and readmissions in most hospitals has increased remarkably. In TOHS (Tanzania Occupational Health Hospital), we have experienced the following (source: TOHS medical department records):

- In 1999, we had seventy-one admissions due to diseases/illnesses associated with HIV/AIDS.
- Twelve (17 percent) of these admissions necessitated readmission two to four times during the period, an average of one per month.
- Nineteen (27 percent) stayed for more than seven days in the ward.
- Sixteen out of those nineteen (84 percent) stayed for more than fourteen days in the ward.
- All female cases who stayed longer than two weeks stayed with female relatives.
- Only seven of the males cases stayed with a male relative, especially at night since the hospital regulations allow only males in the male wards.

- In the same medical wards, more than 90 percent of all patients who received food from home reported that it was a woman who brought the food to them.
- Similarly, visiting-time observations show that more than 60 percent of visiting relatives were women, whether in the morning, midday or evening visiting hours, with a slight rise in the number of male visitors during evenings compared to other visiting hours.
- The male visitors are not regularly seen to assist the patient at all unless there is no female visitor around (e.g., feeding, cleaning, ambulating the patient).

It should be noted that since the cutbacks in government support in most government hospitals, the situation is the same, since food has to come from home if one is hospitalized. It goes without saying that almost all pediatric admissions in almost all hospitals are typically a mother and child. Very rarely will you find a father staying with his child, unless there is a circumstance that makes it unavoidable.

Background of the Present Situation

I. Rationalizations

Women can give better care than men. The notion that women can give the best care, so they should take care of HIV/AIDS patients also, is used to rationalize the burden of caring for AIDS patients being borne by women. But is this rationalization fair? Maybe through the childbearing and child care that women go through during their reproductive career, they do turn out to be the best in the area of caregiving. If so, different theories can be used to explain this ability. A few researchers have shown that although through learning and cultural development only small differences can be demonstrated in the native caregiving abilities of a male and female, the moral development of females is thought to be guided by ethics of care, that is, associated with doing what aids others, whereas the moral development of males is guided by ethics of justice.[3]

It is women's duty to take care of family members. Since women have this duty, the logic goes, why should they not care for HIV/AIDS patients as well? Where does such a rationalization come from? One source is religious texts. Holy books such as the Bible and the Koran somehow relate the position of women to giving care to others, to attending to their needs, and so on. Also, during wars, when the male force was used productively in fighting, it was only natural that women would assume responsibility for taking care of the wounded, sick soldiers, and others. Finally, during their upbringing, it is communicated clearly to female African children that they are expected to take their mothers' places in society (as caretakers) rather than to learn to become breadwinners. But does any of this imply that women are duty bound to be caregivers?

II. Reasons behind These Rationalizations

Lack of resources/no alternatives. In our African setup, the majority of households still depend on a male breadwinner. It is hence logical to let the women take care of the sick while the man brings money home. Besides, what other options will a low-income family have? Can they afford a family doctor to come and attend the sick relatives at home? Do they have enough room and convenient space at home for the sick, or is it better for the caregiver to stay with the patient in the hospital? Can they deal with an emergency if one arises, that is, transport the patient to the hospital when condition becomes worse?

More than half of the world's population today is excluded from any sort of state-legislated social security protection.[4] The majority are workers in the informal sector who depend on their daily wages for their living. In areas where some sort of arrangement similar to social security exists, it is a privilege restricted to those employed in bigger companies and holding permanent employment, not temporary or part-time jobs, in which category most women fall. This makes health care costs very high, as no provisions for medical services are available when sickness occurs in the family.

Women are cheap labor. The family work that is done by women is always regarded as unproductive, since no monetary value is attached to it, and so women are considered the cheapest option when a need arises. An article in the *International Labour Review* notes that "one of the most critical form of unpaid labour is care giving, It has a fundamental impact on people's well being. If its value were to be fully attributed it would surely be very expensive."[5] So are women really such cheap labor?

Even when equally trained women will end up with short service, repetitive tasks, and lower-paying jobs compared to their male counterparts, so many women in industry are doing secretarial jobs, packing, inspection, telecommunications, etc. Gender-marked jobs for women are common in all fields, even in the medical field, where majority of the nurses are females.

When building families, men are usually learning their trade or occupation and establishing their position in the labor market. Woman, on the other hand, still have a responsibility for care both at home and in the public sector. A women therefore must plan a large part of her life around the combination of gainful employment and this caregiving at home and for the family at large.[6] Her best employment options are therefore part-time jobs or temporary jobs in the service sector, but these pay less than other jobs available to men. Even within the same rank and profession, women are given different tasks than men and further training is gender-biased. In earlier years, prestigious courses were commonly offered to males, and short-term general courses were offered to females with similar qualifications. Thanks to the globalization, women are now given a higher priority. The available data from the Ministry of Education and Culture shows that there was an increase between 1995 and 1999 in women's enrollment in secondary "O" level by 2 percent, the secondary "A" level by 5 percent, the university by 5 percent, and technical training by 2 percent.

Keeping health care costs low. Health care costs are shooting up day by day in this era of HIV/AIDS when a patient may remain hospitalized for more than a week. When our lifestyles do not accommodate terminally ill patients at home, such costs are even higher. Keeping a sick relative in a hospital requires more money for medicine, special diet, and support for the remaining family members at home. The cost of keeping a breadwinning man at home with the patient is even higher. So why not choose a woman?

Sociocultural norms. It is an African norm to regard women as caretakers; in cases where the situation is opposite, the society looks at it in a negative way. If one starts talking about men taking part in domestic chores, looking after sick children, and so on, to a local community in the villages, the idea will not be accepted easily, since for them, as they were taught by their forefathers, the woman should do those jobs, and to interfere with that situation may require traditional cleansing.

It is worth mentioning that more women are now holding very influential and sensitive jobs that might not allow them to be out of office long enough to care for relatives afflicted with the HIV virus. The number of households in which the breadwinner is a woman has also increased. As Table 1 shows, we have seen a remarkable increase in the number of women in decision-making positions and women professionals in all fields: media, health, law and judiciary, politics, and so on. Although I could not get concrete data on women's representation in the public-service and private sectors, available data show a similar increase in the number of women employed in both sectors.

Table 1. Women's empowerment in different political levels in Tanzania

Job Positions	1995	1999
Women parliamentarians	28	48
Ministers	4	6 (3 deputies)
Permanent secretaries	1	4
Ambassadors	2	1
Directors and commissioners	NA	27
Judges	NA	3
Diplomatic services	NA	33
Regional commissioners	NA	1
Regional administrative secretaries	3	4
District commissioners	15	20
District administrative secretaries	NA	10
District/municipal executive directors	NA	21

Note: NA Data not available.
Source: Civil Service Commission.

Conclusion and Recommendations

Women are to be commended for what they have been doing as caretakers of the entire family, but this situation has to change, as women are now involved in income-generating activities and not only household chores. As the economic capacity of most women increases, there is a need to empower them toward better positions and support them in their struggles, in order to improve resources and the living conditions in our households, rather than depriving them of their rights to explore and utilize their capabilities in the labor market.

Women's initiative in taking care of the sick when their time allows does not mean that they are duty bound to do so. Caring for the sick should be considered in a fair division of labor, and men should take part in all household chores, including care for the sick. We have to encourage equal sharing of responsibilities in households.

As more women enter the job market today, flexibility on the part of men, a multisectoral approach toward issues such as improved health care facilities and accessibility and affordability of health services, including community sensitization, are mandatory.

Notes

[1] Hargreaves, N. J. ProTEST project, Malawi. AIDS Review (Out of Control?), *Africa Health*, 22, no. 2(2000): 25.

[2] National AIDS Control Program Strategy (NACP), 1999–2002, p. 1.

[3] Lindelow, M., and C. B. Thorjornsson. "Psychological Differences between Men and Women." In chapter 3, "Facts and Prejudices," in *Women Health at Work*, 1998, p. 77.

[4] Ginnenken, W. "Social Security for the Excluded Majority." Book review in *World of Work: The ILO Magazine*, no. 31, September/October 1999.

[5] "Women, Gender and Work," *International Labour Review*, Vol. 138, no. 3(1999).

[6] Westberg, H. "Where are Women in Today's Workplaces?" In chapter 2, "Different Worlds," in *Women Health at Work*, 1998, pp. 27–32.