

GENDER INEQUALITY IN HOME BASED CARE FOR PEOPLE LIVING WITH HIV/AIDS IN MONDULI DISTRICT, TANZANIA

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Abstract: Gender inequalities are universal and in most cases women have been the victim. This study was conducted to compare the quality of home based care received by female and male people living with HIV/AIDS in the households in Monduli district. The sample included 52 females and 24 males. Results showed no significant difference (at $P \geq 0.5$) in care quality between women and men and more than 50% were getting high quality of care. This has enabled them to resume doing their normal daily activities. More effort should be put in ensuring quality care to people living with HIV/AIDS as it has shown to improve their quality of life.

Background

The distinct roles and behaviors of men and women in a given culture, dictated by that culture's gender norms and values, give rise to gender differences. Gender norms and values, however, also give rise to gender inequalities - that is, differences between men and women which systematically empower one group to the detriment of the other. Both gender differences and gender inequalities can give rise to inequities between men and women in health status and access to health care (WHO, 2009b).

The socio-cultural beliefs that value the male and female lives differently lead to differential access to health care services (Opiyo *et al.*, 2008). The position of women is exacerbated by their low financial base especially in the rural community where their main source of livelihood, agricultural production, does not pay much. But even their active involvement in agricultural production or any other income ventures is hindered when they have to give care to the sick and bedridden friends and relatives. This, in itself, is a threat to household food security (Opiyo *et al.*, 2008).

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So long as lives are valued differently there will always be differences in investment in potential life saving activities such as medical treatment and prevention from HIV/AIDS infection. If a woman's life is considered less valuable than a man's, it is likely that when she is ill she will be given or allowed access to fewer care/treatment opportunities (Ambasa-Shisanya, 2007). In a study by Opiyo *et al.* (2008) in households which had experienced recent prime-age mortality in Western Kenya, it was found that men were more likely to be admitted to hospital multiple times, while most females were admitted only once before death. About 90% of afflicted men received hospitalised care before their death compared to only 64% of women. One frequently given reason for delay for women's hospitalisation was lack of someone to remain with children at home even where the husbands were still alive and well. Another reason was that, it is seen to be easy to replace a wife as men can be polygamous. Thus there tends to be greater efforts to save the life of a male compared to that of a female. The study further revealed that since women had relatively little cash to use at their own discretion and depend on their husbands' decisions even on issues concerning their health, many women were unable to receive hospital care.

HIV/AIDS affects both men and women but it is not gender neutral. Women, especially young women, are biologically more at risk of contracting HIV than men in a sexual encounter. According to the 2008 WHO and UNAIDS global estimates, women comprise 50% of people living with HIV. In sub-Saharan Africa, women constitute 60% of people living with HIV (WHO, 2009a).

In Africa young women are 3 times more likely to be HIV-positive than young men (UNIFEM, 2006). In Tanzania, the overall prevalence rate is 5.1 % whereby it is 6.2% and 3.8 % in females and males respectively implying that women are about 2.8 times more likely to HIV-positive than men (TACAIDS, 2012).

When HIV/AIDS was first identified in Tanzania in 1983, the country had only three cases. By 2003 about 2 million people were living with HIV /AIDS, and up to 50 percent of the beds in hospitals were occupied by patients with HIV /AIDS related illnesses. The increase in HIV/AIDS patients coupled with the congestion in public health facilities prompted the government to opt for home-based care (HBC) approach where families with sick relatives are encouraged to look after their patients. TACAIDS (2012) defined as provision of comprehensive services, including health and social services by formal and informal caregivers in the home.

HBC includes physical, psychosocial and spiritual care. The service also focuses on reducing stigma and discrimination, prevent further spread of HIV and to mobilize community resources for

people living with HIV/AIDS (PLWHA) and their families, provide hope and comfort through good quality and appropriate care that helps patients and families improve the quality of life. Since most terminally ill patients prefer to die at home, there is need to bring hope to all of them in more friendly and familiar environments (NACP, 2005).

The family has been identified as the key actor in provision of care and support to HIV/AIDS patients in the homes. The family members provide sympathy and care as well as emotional and financial support. While many family members provide support out of love and compassion, those who are already poor are frequently pushed into destitution by additional financial and emotional burdens (UNIFEM, 2009). On the other hand, more affluent families seek medical care from different hospitals and clinics as well as herbalists, willing to spend considerable amounts of money on medical care, which they believe might prolong their lives (Opiyo *et al.*, 2008).

The home based care provider and the family in general are supposed to provide high quality HBC services to PLWHA (NACP, 2005). These services include adequate and balanced diet, general hygiene, emotional and spiritual support and care and assisting the patient to get medical support at home. The family also is supposed to link the patient with faith based, legal aid and care provider from community home based care (CHBC) organizations. People suffering from AIDS also need frequent exercises so that they remain active. Most important is to reduce the stigma and discrimination attached to HIV/AIDS so that the care provider can spend enough time with, listen to and give due respect to the patient.

HIV- testing is the first step in the comprehensive care for PLWHA. Once an individual has tested and found to be HIV-positive, then he/she becomes eligible for enrollment in home based care organization if he/she wishes and eligible for ARV if CD4 count is below 200 (NACP, 2005). Treatment of people living with HIV/AIDS using ARV has shown significant reduction in replication of HIV which attacks the immune system of the body and slows the progression of the disease. Restoration of the immune system results in weight increase, reduction of HIV- related illnesses, improvement of quality of life and ability to participate again in daily functioning and work. One of the possible signs of the onset of clinical AIDS is a weight loss of about 6-7kg for an average adult (FAO, 2002b). When a person is already underweight, a further weight loss can have serious effects.

A healthy and balanced diet, early treatment of infection and proper nutritional recovery after infection can reduce this weight loss and reduce the impact of future infection. HIV/AIDS infection

also impairs absorption of nutrients and this necessitates special diets and frequent eating for. People living with HIV/AIDS therefore need to increase the nutrient intake by 10-30% of an individual with same age and weight who is not affected (MoH-Uganda, 2003). There is a strong interaction between working mechanism of ARTs and food/nutrition which can significantly alter the expected results (Castleman *et al.*, 2004). The food consumed can affect efficiency of drugs, adherence to drug regimes and therefore the nutritional status of people living with HIV/AIDS. In addition regular exercise makes a person feel more alert, helps to relieve stress and stimulates the appetite. It is the only way to strengthen and build up muscles which the body uses to store energy and protein that the immune system can draw upon when required (FAO, 2002a). Exercises significantly reduce depressive symptoms and improve cardiopulmonary fitness.

On the other hand, holding religious beliefs may reduce depression and increase optimism. Evidence demonstrates that personal faith of HIV-infected people positively influence their experience living with HIV and that prayers give hope to live with it and support their adherence to medication (Watt *et al.*, 2009). Religious engagement, therefore, holds important potential for improving the physical and psychological health and well-being of PLWHA.

Stigma and discrimination are also detrimental to PLWHA as they can prevent people from getting tested, contribute to further infections, and prevent infected persons from receiving adequate care, support and treatment (Panos, 2005). Stigma can be reduced or eliminated if HIV-infected persons speak out their health status and this can be facilitated by wider access to voluntary counseling and testing (VCT) which will in turn encourage others to come forward for testing. Access to ARV also can change the profile of HIV infection from an illness progressing to death to a chronic manageable disease (Nixon *et al.*, 2005) and this can reduce stigma. With ARV, people become energetic and can resume their normal daily activities which can further encourage openness for PLWHA. The disappearance of AIDS symptoms such as *kaposi sarcoma*, muscle wasting and other body marks after ART could also reduce stigma (Kitahata *et al.*, 2002).

In Tanzania, the customary laws have given men more power and control over resources and decision making. The pattern of skewed gender relationship has tended to prevail even in the AIDS era. It is the women who bear the burden of caring for HIV/AIDS patients regardless of whether they are HIV positive or sick with AIDS. Property grabbing from widows and orphans is increasing as husbands die of AIDS related illnesses and they are also blamed and stigmatized more for HIV/AIDS transmission. Some studies in Africa suggest that families are more likely to seek and

pay for medical treatment for a male than a female member with AIDS (UNAIDS, 2000b). In Uganda, Obbo (1995) observed that when all members of the family are ill, priority for immediate treatment is accorded to the husband and children. Health-wise, women get special consideration for treatment in case of reproductive problems but least priority in other diseases.

Gender inequality coupled with the HIV/AIDS pandemic has negative effect to the development of a nation because women form the major part of food production systems particularly in Africa. So their contribution to the welfare of the family and household economy and nation at large is vital. On the other hand, men are the heads and major income earners of the family and evidence shows that majority of female-headed households have tended to be poorer. Further the death of the husband, in most societies, often results in dissolution and relocation of the household leaving widows from HIV/AIDS with less access to the family's assets and hence more prone to food insecurity and poverty in general.

Tanzania has been active in the fight against gender inequality since 1987 when she signed and ratified the Convention on Elimination of all forms of Discrimination Against Women (CEDAW) (URT, 2002). The country also established the policy on gender and women empowerment in 2001. There are also various governmental and non-governmental organizations dealing with gender equalities in all spheres of life, such as Tanzania Gender Networking Project (TGNP), Tanzania Women Lawyers Association (TAWLA) and other gender activists all over the country. Further, the establishment of National AIDS Control Programme (NACP) in 1988 and Tanzania Commission for AIDS (TACAIDS) in 2002 by the government to provide education on HIV/AIDS to ensure HIV/AIDS is well known to all, is another strategy by the government to reduce if not eliminate inequalities as far as HIV/AIDS is concerned. Not only that but also HIV/AIDS has been introduced in the curricula in all levels of education in the country. With all the above initiatives, can there still be gender inequalities in Tanzania? The current study therefore intended to compare the quality of care and support services received by female and male PLWHA in households in Monduli district and suggest areas of intervention and improvement by policy makers, development partners and other stakeholders.

METHODOLOGY

The study was conducted in Monduli district which is one of the six districts of Arusha region. Others are Arusha municipal, Arusha rural, Longido, Meru and Ngorongoro. The sample was drawn from the population of PLWHA who were participating in the Arusha Archdiocesan

Integrated Development and Relief Office-HIV/AIDS Community Based Health Care (AAIDRO-HIV/AIDS CBHC) programme which is under the Roman Catholic church in Arusha region. A total of 76 PLWHA (52 females and 24 males) were randomly selected. Data were collected through questionnaires and focus group discussions as well as in-depth interviews from the key informants. For quality assessment of home based care services the score index below developed by Masako (2007) with some modifications was used.

Variables and scoring system for assessing quality of home based care for PLWHA

Variables	Coding
Disclosure to family member(s)	Yes = 1, No = 0
Training of home carer	Yes = 1, No = 0
Getting medical support at home	Yes = 1, No = 0
Missed medical support at home when actually needed it	Yes = 0, No = 1
Getting psychosocial at home	Yes = 1, No = 0
Getting enough food per day at home	Never = 0, Sometimes = 1, Usually = 2, Always = 3
Number of meals per day	Once = 0, Twice = 1, Thrice = 2, 4 times = 3, > 4 times = 4
Getting consideration in food quality to suit condition	Never = 0, Sometimes = 1; Usually = 2; Always = 3
General hygiene Times get bath; Times clothes get changed; Times bedding get changed; Times room get cleaned	For each sub-parameter; Daily = 3, Once in 2-3, days = 2, Once in 4-5 days = 1, Once in 6-7 days = 0
Food groups eaten yesterday since morning Cereals, roots and tubers; Animal protein, Plant protein; Fats and oils; Vegetables; Fruits	For each sub-parameter; Yes = 1, No = 0
Frequency of visits by care provider from CHBC programs	None = 0, Annually = 1, Semi-annually = 2, Monthly = 3, Fortnightly = 4, Weekly/daily = 5
Services provided by home based care provider that is seen on regular basis by an individual living with HIV/AIDS Listens to me, Cares about me, Answers my questions, Spends enough time with me, Involves me in decisions about my care, Respects my choices, Deals with my problems, Engages me in my care, Is helpful to me, Respects me,	For each sub-parameter; No experience/never = 0 Sometimes = 1 Usually = 2 Always = 3

Supports my decisions, Sees me when I ask, Provides me information	
Suffer loneliness and neglect from family, neighbours or Community members	Never = 3, Sometimes = 2, Usually = 1, Always = 0
Involvement in faith based organization	Yes = 1, No = 0
Getting spiritual care at home	Yes = 1, No = 0
Getting legal aid information	Yes = 1, No = 0
Number of days participated in exercise (at least 30 minutes) in the last seven days	1-2 = 1, 3-4 = 2, 5-7 = 3
Maximum/Minimum	86/1

Quantitative data analysis was conducted using computer program Statistical Package for Social Sciences (SPSS) version 12.0. Descriptive statistics, which included frequencies and percentages, were computed to determine the quality of care provided to PLWHA. Inferential statistics were computed to show relationship between dependent and independent variables. These included cross-tabulations with Chi-square (X^2) statistics. Qualitative data were analyzed using content analysis. In-depth interviews and FGDs were classified to see what gender issues emerged in provision of care to male and female PLWHA and what respondents talk about the most.

RESULTS

The scores were converted to percentages of the maximum possible score in order to allow for comparisons. Each parameter had 100 as the maximum score and 0 as the minimum score. Scores were grouped into 5 categories as very low quality of care (0-20), low quality of care (21-40), moderately high quality of care (41-60), high quality of care (61-80) and very high quality of care (81-100). Chi-square statistic testing indicated that there was no significant difference at $P \leq 0.05$ in quality of care received by male and female PLWHA in their homes. Results show that more than half of the respondents received high quality of care and none received very low or very high quality of care (Table 1). This may be contributed by, as was also reported by the PLWHA themselves, the use of ARVs which has enabled them to resume their daily activities to earn some income to meet their health needs. Also the nutritional support, particularly for those on ARV, and income generating projects initiated by the AAIDRO-CBHC programme to PLWHA has improved their livelihoods.

Table 1: Distribution of the surveyed PLWHA according to score of care quality

Quality level	Percent		
	Males N = 24	Females N = 52	Total N = 76
Low quality	12.5	19.3	17.1
Moderately high quality	37.5	28.8	31.6
High quality	50.0	51.9	51.3
Total	100.0	100.0	100.0

Chi-square value = 0.836 df = 2 Level of significance = 0.658

Families with people living with HIV/AIDS are required to have special considerations in food quality and quantity to suit the condition of their patients. Findings of the study revealed that about 49% of PLWHA reported to have no habit of considering food quality and quantity, that is, only sometimes did they consider it. More than half (53.8%) of the female PLWHA fell under this category. Majority (62.5%) of the male PLWHA reported to be getting enough food usually compared to only 42.3% of female PLWHA. Results further show that about 15% and 8% of female and male PLWHA respectively were not getting enough food at all. In order to meet the increased nutrient intake, PLWHA are required to have either larger quantity of food or more frequent meals than those not infected (FAO, 2002a). If three meals are usually taken per day, then snacks be taken in between meals. Failure to achieve increased food intake results in muscle wasting and worsening conditions of the body. Findings further show that, majority of the respondents (59.2%) were getting 3 meals per day and none had snacks between meal times. Very few (2.6%) had 4 meals and above.

Results in Table 2 below show various care aspects that were received by PLWHA. More than 80% of the respondents had disclosed their HIV/AIDS status to their family members and majority of those who disclosed their health status, and in particular the males, did so to only one member of the family. Only about 21% of these family members received training on care for people living with HIV/AIDS. The table further shows that more females (92.3%) than males (79.2%) had told their household members the truth about their health status. Confidentiality might be a factor contributing to such male behaviour. Failure for males to open up their HIV/AIDS status to family members may be the reason for 50% of them missing medical support at home when actually

needed it. Economic hardship was reported by focus group members to be the contributing factor to only 43.4% of the PLWHA getting medical support at home. More than 57% of respondents received psychosocial support and spiritual care at home. This can be due to the fact that the organization they were enrolled in (i.e. AAIDRO-CBHC) is a faith-based organization (FBO). It is worth noting that legal literacy is a problem among PLWHA. Only about 13% of respondents received information on legal and human right issues. This can be one of the reasons for property grabbing from widows after death of the husbands.

Table 2: Summary of care services received

Care Aspect	Males N= 24	Female N=52	Total N=76
Member of household knows HIV/status	19 (79.2)*	48 (92.2)	67(88.2)
Member of household received training	5 (20.8)	11(21.2)	16(21.1)
Get medical support at home	11 (45.8)	22(42.3)	33(43.4)
Missed medical support when needed	12 (50.0)	19(36.5)	31(40.8)
Get psychosocial support	13 (54.2)	32(61.5)	45(59.2)
Involved in faith based organization	9 (37.5)	14(26.9)	23(30.3)
Get spiritual care	14 (58.4)	30(57.7)	44(57.9)
Get information on legal and human right issues	4 (16.7)	6(11.5)	10(13.2)

* Figures in brackets are the percentages

Exercise is another aspect of care that people living with HIV/AIDS need for their health. Table 4 shows that majority (77.6%) of the interviewed respondents were participating in exercises almost every day. The types of exercises undertaken were the daily activities like working in the fields and household activities, all of which involve walking too. The respondents reported that ART and the food supplements provided after enrolling themselves in home based care programmes have enabled them to resume their normal duties.

Table 3: Participation of PLWHA in physical exercises

Frequency of exercise (per week)	Percent		
	Males N = 24	Females N = 52	Total N = 76
1-2	0.0	5.8	3.9
3-4	12.5	21.1	18.4
5-7	87.5	73.1	77.6
Total	100.0	100.0	100.0

Limitations of the study

These findings should not be generalized because the study involved only one home based care organization.

Conclusion and recommendations

High quality of care for PLWHA had improved the quality of life of PLWHA in the study area since they were now participating in their normal daily activities hence be able to take care of themselves and their families instead of depending on their caregivers and other people. The study has revealed that improvement in the livelihoods of PLWHA greatly reduces stigma and discrimination, as majority of PLWHA were receiving high quality care, which is one of the causes of gender inequalities in the care for PLWHA. However legal rights education is a problem to almost all of the surveyed PLWHA. It is therefore recommended that the government and all stakeholders put more effort in supporting PLWHA as well as their caregivers in terms of provision of ARVs, food and nutrition as well as caregiving education. The government and other legal and human right practitioners should also make sure they provide training to PLWHA on legal and human right issues.

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