

CARE GIVERS' OPINION ON HOME BASED CARE SERVICES PROVIDED TO PEOPLE LIVING WITH HIV/AIDS IN MONDULI, TANZANIA

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Abstract

The attitude of home based care givers as far as provision of care services and support to people living with HIV/AIDS is determined by their knowledge of the disease. Correct understanding of HIV/AIDS helps to remove the myths and blame about the disease. The purpose of this study was to determine the attitude of care givers on home based care services when provided to female and male people living with HIV/AIDS. It involved a sample of 59 care givers. Results revealed no significant difference at $P \geq 0.05$ of attitude between the male and female care givers. Majority (86.4%) of the care givers had positive and gender neutral attitude towards provision of home based care services to both of their male and female clients, though they still hold that family property should be managed by male members of the family. This, therefore, implies that more gender training be provided to the care givers.

Background

The Sub-Saharan Africa remains the hardest hit region by human immunodeficient virus/acquired immunodeficiency syndrome (HIV/AIDS). Almost 70% of the world's people living with HIV/AIDS (PLWHA) live in this region (Amfar, 20014). In 2011, Tanzania was estimated to have 1.6 million PLWHA (Avert, 2014). The diminishing capacity of many countries' health sectors forced them to opt for home based care for PLWHA. Much of the care for people with HIV and AIDS is provided at home by immediate family members and friends, as well as by home-based care organisations.

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Patients on ARV treatment are strongly encouraged to identify an adherence assistant e.g. a family member, friend, colleague or community member to help them with ART medications (NACP, 2005). The home based care provider and the family in general are supposed to provide high quality HBC services to PLWHA. According to Tanzania national guidelines for home based care services, care providers are required to provide comprehensive care and support to PLWHA which include physical, psychological, emotional, economic, social, legal and spiritual care and support to PLWHA in the homes. Others include hygiene care, nutritional care and support, exercises, shelter, preventive therapy, simple medications and adherence to long-term treatment (NACP, 2005). Most important is to reduce 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 (Gallant, 2004). It is also recommended that men in the households participate actively and directly in the care and nursing of the chronically ill and not to leave the task to women only (NACP, 2005). Yet, around the world, gender norms assign women the primary role in caring for people who are ill and dying from HIV and AIDS, along with the orphans left behind (Fung, 2005). By some estimates, up to 90% of care-giving work related to the epidemic occurs at home. Most is performed by women and girls. Elderly women, children and orphans bear an increasing share (UNIFEM, 2009).

In order for home based care givers to be effective in the provision of care to PLWHA in the home, adequate and correct knowledge of the disease is of vital importance, something which the National home based care guidelines in Tanzania emphasizes (NACP, 2005). In Africa, Tanzania inclusive, where the spread of HIV/AIDS is largely due to heterosexual transmission of the HIV (Onipede and Dortöcher-Sulser, 2005), women bear the burden of blame and stigmatization. This is because women are associated with prostitution. Poverty, in some cases, forces women into sex trade (UNIFEM, 2006). African culture does not consider men as prostitutes even where they are partners of female sex workers (TGNP and SARDC-WIDSAA, 1997). African culture is mostly patriarchal and children are socialized into believing that men are superior to women (Opiyo, 2008). Home based care providers who hold such belief will be likely to provide biased care for their patients. Further still, less educated people tend to be less knowledgeable, more fearful about AIDS and more likely to have negative attitude toward PLWHA (Lau and Tsui, 2005). Under such circumstances, home based care givers may exercise

stigma and discrimination to their patients and this can prevent PLWHA from receiving adequate care, support and treatment. Thus the purpose of this study was to examine the attitude of care givers towards suitability of various components of care and support services when given to women and men.

Methodology

The study was conducted in Monduli district Arusha region. The sample involved care givers of 76 PLWHA who were studied earlier (about three months ago) to assess gender inequality in the home based care services they were getting. These PLWHA and their care givers were members of 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. However, the study failed to get the required sample of 76 carers due to either; some of PLWHA had not disclosed their HIV status to their relatives or had their care givers living far away from them. Therefore a total of 59 care givers were purposely selected. Data were collected through questionnaires and in-depth interviews from the key informants who consisted of the AAIDRO-HIV/AIDS CHBC programme as well as the district officials.

Data analysis

To assess the knowledge and belief of the care givers on HIV/ADS as well as their attitude on HBC components the score indexes below were used:

Score index for assessing knowledge and belief care givers on gender and HIV/AIDS

What is your opinion on the following statements?

Variable	Coding
HIV/AIDS is God's punishment for wicked people	Strongly disagree = 5 Disagree = 4 Undecided = 3 Agree = 2 Strongly agree = 1
HIV/AIDS is a witchcraft issue	Strongly disagree = 5 Disagree = 4 Undecided = 3 Agree = 2 Strongly agree = 1
Women are responsible to a greater part for HIV/AIDS transmission	Strongly disagree = 5

	Disagree = 4 Undecided = 3 Agree = 2 Strongly agree = 1
Men are responsible to a greater part for HIV/AIDS transmission	Strongly disagree = 5 Disagree = 4 Undecided = 3 Agree = 2 Strongly agree = 1
So far there is no cure for HIV/AIDS	Strongly disagree = 1 Disagree = 2 Undecided = 3 Agree = 4 Strongly agree = 5
Witch doctors or traditional healers can treat HIV/AIDS	Strongly disagree = 5 Disagree = 4 Undecided = 3 Agree = 2 Strongly agree = 1
Prayers can heal PLWHA	Strongly disagree = 5 Disagree = 4 Undecided = 3 Agree = 2 Strongly agree = 1
Condoms can prevent HIV/AIDS infection	Strongly disagree = 1 Disagree = 2 Undecided = 3 Agree = 4 Strongly agree = 5
Maximum/Minimum	40/8

Variables and scoring system for assessing attitude of care givers on suitability of home based care components when given to males and females

What is your opinion on the following statements?
When attending a male and a female PLWHA in the household:

Variable	Coding
Much care should be given to a male than a female PLWHA because he is the head of the household	Strongly disagree = 5 Disagree = 4 Undecided = 3 Agree = 2 Strongly agree = 1
Care provider should spend much time with male than female PLWHA	Strongly disagree = 5 Disagree = 4 Undecided = 3 Agree = 2 Strongly agree = 1
The female PLWHA should be given more assistance/help than male PLWHA	Strongly disagree = 5 Disagree = 4 Undecided = 3 Agree = 2

	Strongly agree = 1
The male PLWHA should be given more food	Strongly disagree = 5 Disagree = 4 Undecided = 3 Agree = 2 Strongly agree = 1
It is important to provide spiritual support to a female than a male PLWHA	Strongly disagree = 5 Disagree = 4 Undecided = 3 Agree = 2 Strongly agree = 1
The female PLWHA should not be left alone for a long time	Strongly disagree = 5 Disagree = 4 Undecided = 3 Agree = 2 Strongly agree = 1
Maximum/Minimum	30/6

Quantitative data analysis was conducted using computer program Statistical Package for Social Sciences (SPSS) version 17.0. Descriptive statistics, which included frequencies and percentages, were computed to determine the attitude of care givers towards HBC components. 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.

Ethical consideration

Ethical clearance for conducting the study was granted by AAIDRO-CHBC programme and the Monduli District Commissioner's office. Informed consent and permission was sought from individual respondents.

Results and discussion

Findings from the study showed that women care givers formed almost three –quarters (74.6%) of all the care givers surveyed. These findings are similar to Niikondo's *et al.*, (2001) in Namibia. As far as education level is concerned, majority (59.3%) of the care givers had primary level of education (Table 1) and more women than men had no formal education.

Table 1: Education level of the surveyed care givers

Education	Percent		
	Males N= 15	Females N = 44	Total N = 59
Few years in primary school	20.0	18.2	18.6
Completed primary school	53.3	61.4	59.3
Few years in secondary school	20.0	4.5	8.5
Completed secondary school	6.7	0.0	1.7
Adult education	0.0	2.3	1.7
None (no formal education)	0.0	13.6	10.2
Total	100.0	100.0	100.0

The study also found out that, majority of the women care givers were caring for their husbands while very few male care givers were caring for their wives. This was revealed by asking the PLWHAs' relationship with their carers where 40% of male PLWHA were being cared for by their wives compared to only 11% of the female PLWHA who were being cared for by their husbands as indicated in Table 2. This implies that women were less likely to receive adequate care from their husbands. This means that majority of men are not yet ready to take up the caring roles as stipulated in the Tanzania national home based care guidelines. Similar results were also observed in studies from the Dominican Republic and Mexico where married women with AIDS had to return to their parents' home for care (UNAIDS, 2000).

Table 2: Relationship of care giver to patient

Relationship	Percent		
	Males N= 24	Females N = 52	Total N = 76
Husband/wife	40.0	11.4	18.6
Elder son/daughter	13.3	18.2	16.9
Brother/sister	6.7	15.9	18.6
Father/mother	0.0	6.8	5.1
Male/female relative	6.7	25.0	20.3
Male/female neighbour	13.3	2.7	20.3
Total	100.0	100.0	100.0

In order to assess the respondents' knowledge and beliefs on gender and HIV/AIDS, the index scale (indicated under methodology) was used. For comparison purposes, the scores were categorized into low knowledge and negative belief (0-24) and high knowledge and positive

belief (>24). Score of 24 was taken as the cutting point considering that, a person who was undecided in all the 8 questions could score 24. Results indicated about 92% of the care givers had high and positive knowledge and belief on gender and HIV/AIDS (Table 3). This may have been contributed by the efforts of AAIDRO – CHBC programme and the Department of Community Development in the district in raising community awareness on HIV/AIDS and gender. It was also learnt from the key informants and the care givers themselves that all the care givers have had two 5-day trainings on HIV/AIDS under the programme. The problem might be in the control of family resources as indicated in Table 4 below. About 68% and 54% of care givers perceived the father as the appropriate person to manage family income and to decide, respectively, on how the income should be used. Also majority were of the opinion that the male child (95%) against the female child (5 %) was the right person to inherit family property.

Table 3: Distribution of the surveyed care givers according to their knowledge and belief on gender and HIV/AIDS

Level of knowledge and belief	Percent		
	Male N = 15	Female N = 44	Total N = 59
Low and negative	6.7	9.1	8.5
High an positive	93.3	90.9	91.5
Total	100.0	100.0	100.0

Table 4: Care giver's perception of the appropriate person as manager and decision maker of family income

Perceived appropriate person	Percent	
	Manager of family income	Decision maker on use of family income
Father	67.8	54.2
Mother	5.1	3.4
Father and Mother	22.0	0.0
Elder son	1.7	37.3
Elder daughter	3.4	5.1
Total	100.0	100.0

The score index shown in the methodology to assess the attitude of care givers on suitability of home based care components when given to male and female PLWHA was used. The scores

were categorized as negative attitude (gender biased) for scores 0 – 18 and positive attitude (gender neutral) for scores above 18. Score of 18 was taken as the cutting point because an undecided respondent in all the six parameters would score 18. Chi – square statistic testing for the difference of attitude between the two sex groups indicated that there was no significant difference at $P \leq 0.05$ (Table 5). More than 86% of the care givers were gender neutral and positive with respect to suitability of home based care components when given to male or female PLWHA. This implies that the care givers were likely to be treating their male and female patients equally. This can be a result of the trainings on HIV/AIDS provided to the care givers by the AAIDRO-CHBC programme and therefore proves what a study conducted in Uganda concluded, that people with correct information on HIV help in the reduction of misconception, myths, blame and discrimination (UNAIDS, 2003).

Table 5: Attitude of care givers with respect to home based care service

Level of sufficiency	Percent		
	Male N = 15	Female N = 44	Total N = 59
Gender biased	20.0	11.4	13.6
Gender neutral	80.0	88.6	86.4
Total	100.0	100.0	100.0

Chi-square value = 0.712 df = 1 Level of significance = 0.399

Limitations of the study

Findings of this study cannot be generalized to all home base care givers because the study involved only one faith-based organization.

Conclusion and recommendations

It was encouraging to learn that people entrusted with HIV/AIDS patients have positive attitude toward provision of care and support services to both of their male and female clients. However, there were problems in their perception on who should control family property; they still have patriarchy ideas on this. This indicates training deficit in gender. Therefore, more gender trainings, workshops and seminars are needed to change their attitude. Such trainings should also include sensitization of males to participate effectively in caring for people living with HIV/AIDS in the homes.

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