



EDUCATION FOR HEALTH

BRIEF COMMUNICATION

Home-based Health Care(HBHC): Are Women Caregivers at Risk? A Study of Busia and Teso Districts in Western Kenya

RO Onyango

*School of Public Health & Community Development, Maseno University, Maseno,
Kenya*

Published: 18 May 2009

Onyango RO

Home-based Health Care(HBHC): Are Women Caregivers at Risk? A Study of Busia and Teso Districts in Western Kenya
Education for Health, Volume 22, issue 1, 2008

Available from: <http://www.educationforhealth.net/>

A B S T R A C T

Context: Most caregivers of people living with HIV/AIDS (PLWHA) in rural Kenya are women. In resource-limited situations, this can be a challenging and risky responsibility.

Objective: Assess the risk factors to which home-based caregivers are exposed.

Setting: Study of Home-based Health Care (HBHC) activities done in the Busia and Teso Districts of Western Kenya, with 824 patients under HBHC, from April 2004-April 2005. The Ministry of Health HBHC Policy in 2000 reduced bed-occupancy in Government Health facilities. Consequently, many AIDS-Related-Infections (ARI) patients, upon discharge, were nursed by relatives.

Methods: Relevant information reviewed and data collected using: questionnaires; personal and key informant interviews (KII); and observation of caregivers' working conditions and protective measures.

Results: The majority of home caregivers were women. Most caregivers (85%) were unaware of risks involved in PLWHA caregiving. Fifty-two percent had chest pains and coughs, 55% skin infections and 24% tuberculosis. Over 8% were found to be HIV+ upon testing at the Voluntary Counselling and Testing (VCT) clinic.

Conclusions: Women, and sometimes young children, assume the caregiving burden. Ignorance of risks and non-use of protection may predispose these caregivers to infections. Results point to the need for advocacy to improve the working conditions of home-



based caregivers by primary health care policy makers. Finally, because the caregivers were sexually inactive, the caregivers that were HIV+ attributed their infections to nursing PLWHA.

Keywords: Home-based health care (HBHC), caregivers, people living with HIV/AIDS (PLWHA), AIDS-related infections (ARI), risks, community health workers (CHWs)

Introduction

Home-based long-term care is the care necessary for people of all ages who have chronic health problems and need assistance with activities of daily living (ADLs) in order to enjoy a reasonable quality of life (WHO, 2000). Home-based health care takes advantage of the security and comfort of familiar environs, keeps the patient's family and social relationships intact and is, therefore, most often the preferred alternative to (or a continuation of) institutional care. However, the type and duration of illness put specific demands on families (WHO, 1999).

The magnitude of the HIV/AIDS pandemic in Kenya has necessitated the introduction of home-based care as an alternative way of managing infected patients who oftentimes remain ill for prolonged durations. The disease burden on health facilities is high, where over 50% of bed-occupancy in most government hospitals is from patients suffering from HIV/AIDS-related infections. These patients occupy beds for long periods and on repeated occasions, due to the frequent re-occurrence of the opportunistic diseases that inflict them (Crouch, 2002). The patients require extended periods of health care, along with emotional and social support, and the busy, overworked hospital staff may not be able to provide this.

In 2002, Kenya's Ministry of Health introduced a home-based health care (HBHC) initiative to reduce bed-occupancy in government health facilities, on the assumption that the home was a supportive and caring environment. Consequently, many AIDS-Related Infections (ARI) patients were discharged to home to be nursed by their relatives, mostly women (Ministry of Health, 2003). While patients feel comfortable among their kin at home, families usually lack the basic resources essential for long-term home-based care, such as adequate and nutritious food, clean drinking water and sanitation and protective clothing like hand gloves for use when handling these patients.

Purpose

Caregiving can be stressful and may contribute to serious illness and depression on the part of the caregiver. Studies show that the health of 16% of caregivers worsens due to caregiving, and about half of caregivers caring for someone with prolonged disease develop psychological distress (Schultz *et al.*, 2004). Chronic stress can lead to reduction in the number of immune cells in caregivers or impaired function of these cells making caregivers vulnerable to infections (Glaser *et al.*, 2000).

Caregivers may not even know the extent to which their own health can be jeopardised in the course of caregiving (Schulz *et al.*, 1999). This can result in dire consequences for quality of care for families and in particular for the health of women and children who are the main caregivers. Yet, caregivers are rarely trained on safety and protective measures against ARIs; and since PLWHAs need long-term care, their caregivers need protection against any risks.



Methods

The study was carried out in four villages in the Busia and Teso Districts of Western Kenya between April 2004 and April 2005 using questionnaires, observations and personal and key informant interviews.

Systematic sampling was used to identify the households from the four selected villages that had people living with HIV/AIDS under home-based care. Every fifth patient was selected from a population of 824 patients, yielding a sample of 165 patients. The study targeted the main caregivers (those caregivers who spent most of the time with patients and whom the family considered responsible for the patient's care) of people who had been to the VCT clinic, were found to be HIV+ and were bedridden at the time of the study.

Questionnaires were administered to caregivers and their responses written down by the interviewer. Information obtained included: demographics of caregiver; relationship to the patient; duration of caregiving; number of people cared for; and any diseases/infections caregivers had suffered from during caregiving periods.

Personal interviews on the subjects' working conditions and use of protective measures were recorded. This information supplemented questionnaires and information given by the caregivers and the community health workers (CHWs).

Key Informant Interviews (KII) of 38 caregivers with multiple patients (≥ 2) and/or prolonged caregiving (≥ 10 months) were conducted to obtain qualitative information. The elements of the discussion guide included: level of education; source of income; relationship to patients; duration of caregiving; number of patients taken care of; use of protection against infection; HIV status; tested at VCT clinic; caregiving-related infections; awareness of caregiving risks; specific difficulties experienced during caregiving; and respite. This study was reviewed and approved by Maseno University Institutional Research and Ethics Committee (IREC).

Results

Caregivers were mainly women (127; 77%) and were close relatives of the patients (see Table 1). Caregiver ages ranged between 10 to 79 years ($sd=18.7$). There were 62 (38%) caregivers between the ages of 50 and 65 years. There were also 25 (15.2%) very young caregivers, whose ages ranged from 10 to 15 years, looking after their ailing parents.

Most caregivers (140; 85%) were unaware of the risks they are exposed to when handling patients with ARI. Many caregivers (107; 65%) used their bare hands even when handling body fluids of patients. Fourteen (8.5%) of the caregivers were ill and had been found HIV+ at the VCT clinic.

Caregiving may also contribute to other ailments and infections and tuberculosis as reported by caregivers: 38 (23%) had tuberculosis; 91 (55%) skin infections; and 86 (52%) coughs and chest pains. Other ailments reported were malaria (81; 49%) and diarrhea (41; 24.8%). The Busia and Teso districts where this study was carried out are both malaria endemic areas. A total of 25 (15%) caregivers indicated they were involved with multiple caregiving.



Table 1: Characteristics of home-based caregivers of persons living with HIV/AIDS (PLWHAs) in two districts of Western Kenya (n=165)

Districts	Age		Gender				Relationship to the Patient						Duration of Caregiving (months)		HIV Status	
			Male		Female		Spouse		Child		Other					
	Mean	sd	n	%	n	%	n	%	n	%	n	%	Mean	Sd	HIV+	HIV-
Busia District n=86	40.73	19.07	19	22.1	67	77.9	9	10.5	24	27.9	53	61.6	10.06	5.19	8 (9.3%)	78 (90.7%)
Teso District n=79	39.19	18.29	20	25.3	59	74.4	13	16.5	22	27.8	44	55.7	9.29	3.58	6 (7.6%)	73 (94.4%)

A Pearson correlation coefficient was computed to see if there was any relationship between the number of patients cared for and HIV+ status of the caregiver. The correlation was significant, $r=.552$ ($p < 0.01$; 2-tailed). Similar analysis was conducted to examine the correlation between duration of caregiving and HIV+ status of caregivers. The correlation was not significant, $r=.427$ ($p = 0.092$).

Key informant interviews revealed that cultural beliefs and practices influenced non-use of protective materials when handling a close relative, even when hand gloves were available. For instance, the key informants reported that it was against the culture of the community to wear gloves when handling a patient. This would be taken as a sign of disgust by the patient.

Discussion

If home-based care is to serve as an effective and adequate alternative to institutional care, caregivers need adequate resources and training, coupled with improved continuity of care between the hospitals, community facilities and the home. Community participation in caregiving for PLWHAs is poor in this community, leaving caregiving as the responsibility of immediate family members – most often very young children and old women. Overall, caregiving is considered a woman’s duty.

In view of the findings, there is need for further research into the potential risks to home-based caregivers, especially related to the ailments and infections reported by caregivers. An appropriate intervention should include health education, health promotion and training on the best practices of caregiving that will benefit both the caregivers and their home-care patients. There also should be supervision of caregivers to increase their knowledge and skills. There is need for advocacy by primary health care policy makers to improve the working conditions of home-based caregivers. Families of PLWHAs need easy access to food, water, sanitation and fuel to reduce caregivers’ workload.

Caregivers face many risks in these communities. Cultural beliefs and practices detrimental to good caregiving practices should be discouraged by CHWs. It was difficult to confirm the fourteen HIV+ caregivers’ claims that their infections were due to caregiving for PLWHAs because they were not sexually active. It is important that people’s HIV status be known before they start caregiving. Since home-based care is important for both patients and families, it is essential to make it safe to reduce risks to the caregivers.



Acknowledgements:

Thank you to Public Health officers of the Busia and Teso districts, Busia District and Alupe Sub-district Hospitals, Chakol Catholic Mission and all the Home-based Caregivers and Community Health Workers who provided valuable information for this study.

References

Crouch, M. (2002). *Home Care Handbook: A Reference Manual for Home-Based Care for People Living with HIV/AIDS in Kenya*. National AIDS/STD Control Programme, Ministry of Health. Nairobi, Kenya.

Glaser, R., Sheridan, J., William, B., Malarkey, W.B., Robert, C., MacCallum, R.C., & Kiecolt-Glaser, J.K. (2000). Chronic stress modulates the immune response to a pneumococcal pneumonia vaccine. *Psychosomatic Medicine*, 62, 804-807.

Ministry of Health. (2003). *Home-based Care: An Orientation Package for Health Workers and Programme Managers*. Nairobi, Kenya.

Schulz, R., Scott, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality. The Caregiver Health Effects Study. *Journal of the American Medical Association*, 282, 2215-2219.

Schulz, R., Belle, S., Czaja, S., McGinnis, K., Stevens, A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *Journal of the American Medical Association*, 292, 961-967.

WHO (1999). Home-based and Long-term Care. *Home Care Issues at the Approach of the 21st Century from a World Health Organisation Perspective, An Annotated Bibliograph*. Geneva, Switzerland.

WHO (2000). *Home-based Long-term Care*. Technical Report Series 898. World Health Organisation. Geneva, Switzerland
