Community and home-based care: willingess to care for family with HIV/AIDS

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ABSTRACT

Sub-Saharan Africa, with 28.1 million people living with HIV/AIDS at the end of 2002 is experiencing a severe development crisis. The epidemic has diminished the ability of households to meet their basic nutrition and health needs while increasing the demand on non-infected family members to provide palliative care for those with AIDS. There have been numerous reports of families and communities ostracizing their members when they test HIV positive or develop AIDS. These incidents have challenged the idea of traditional systems of family care for the sick. This study was conducted to determine the willingness of family members to provide nutrition and health care for people living with AIDS. A cross-sectional survey of 299 Ghanaians and 4 focus group discussions was used to describe knowledge about HIV/AIDS and care of individuals with AIDS, attitude of families and communities towards people with AIDS, willingness to provide home care, and factors associated with willingness to care. Of the 299 adults surveyed, at least 65% indicated that they and their families were willing to care for family members living with AIDS. However, the study population showed poor knowledge of appropriate care, including health-seeking and dietary-management of AIDS patients. There was reported fear, and behaviors of shunning and avoidance among community members. This may translate into reduced social capital of the affected individual and their families, further limiting their access to food and health-related resources. In Ghana, programs are needed to assist families to acquire the knowledge and skills to provide adequate nutrition and health palliative care of family members living with HIV/AIDS.

INTRODUCTION

At the end of 2001, there were 28.1 million people living with HIV/AIDS in Sub-Saharan Africa (1). This figure represents more than two-thirds of all estimated cases to date. In Ghana, AIDS was first reported in 1986. By the end of 1998, AIDS had become one of the top ten causes of death. Currently, the estimated prevalence rate of HIV in the population is a little over 4% (2).

The HIV/AIDS problem in Ghana, as in other developing countries, is complicated by social and economic factors. These include poverty, gender inequity, high levels of illiteracy, unavailable health information, intense stigmatization, and denial (3). These determinants result in a spectrum of impact indicators including but not limited to broken families, loss of income-earning family members, collapse of family enterprises including farming capability, and orphans who must be cared for by extended family, increasing that family's financial burden (4).

The cost of these impacts might be mitigated by the traditional African communal way of dealing with disease and disasters. This is exemplified by a statement by Jonathan Mann, the first coordinator of WHO's worldwide AIDS program: "*African societies had some advantages over western industrial countries in that AIDS patients would not be isolated, and their families would look after them*".

However, AIDS presents a formidable force that challenges the traditional norms of the African society as suggested by documented reports of HIV/AIDS patients being ostracized and stigmatized, both by their families and the community (5).

References

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STUDY AIMS

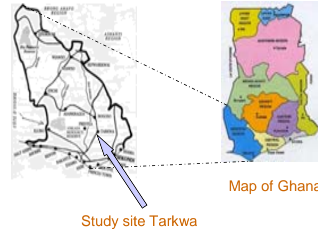
- To examine the willingness of families to provide nutrition, health, and other types of care for family members living with AIDS.
- To determine the factors that are related to the willingness of family members to provide care for persons with HIV/AIDS.
- To describe the knowledge, attitudes, and practices of families and community members involved in home and community care for HIV/AIDS patients.

METHODS

Study Site

The study was conducted in 2 areas in Tarkwa, in the western region of Ghana, West Africa (Fig. 1). The two areas represent a rural (*New Atoabo)* and urban (*Cynide*) setting.

Fig. 1 Map of Study site



Map of Ghana

Study site Tarkwa

Sample

The study used two complementary data collection approaches: a cross-sectional survey of 299 respondents and four focus group discussions with a total of 33 participants in two communities.

The eligibility criteria for both the survey and the focus group discussions were
- 25 years or older at the time of survey
- living in the selected communities
- willing to be a participant

A sampling frame of all houses in the community was used to select every second house to recruit participants for the survey. At each house, a participant was selected based on their willingness to be interviewed.

Participants for focus group discussions were purposively recruited by community health nurses living in the selected communities. Selection was aimed at bringing together participants with varied backgrounds (socioeconomic and education) and who were knowledgeable about the community. There were at least 8 participants in each focus group.

Methods

The study was carried out between July and August 2002 during which pretesting of the survey instrument, focus group discussions and the survey were completed.

Both the survey questionnaire and the focus group discussion guide were designed to capture information on the themes listed below. In the focus group guide, questions were built around a Vignette.

The key data that were collected in the study are listed below:
- SES
- Knowledge on HIV/AIDS
- Knowledge of AIDS care
- Attitude of families towards people with AIDS
- Attitude of the community towards people with AIDS
- Willingness to provide home-based care for family members with AIDS.
- Willingness of family members to provide home-based care for people with AIDS.
- Factors associated with willingness to care. (e.g., source of infections, income generating ability of patient)

Analysis

Factors associated with rural-urban setting and willingness to care were tested with chi-square and Student's t-test using EPI INFO software.

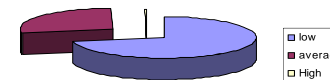
RESULTS

Table 1. Characteristics of study population

Respondent Characteristics	Urban (N=111)		Rural (N=188)		
	N	%	N	%	
Age groups (y)					
25-29	44	39.6	63	33.5	
30-39	39	35.1	73	38.8	
40-49	17	15.3	30	16.0	
≥50	11	9.9	22	11.7	
Christian	96	86.5	144	76.6	*
Akan ethnicity	83	75.8	136	72.3	
Married	66	59.5	126	67.0	
Completed Middle/J.S.S.	50	45.0	80	42.6	
Self-employed	58	52.3	129	68.6	**

Christianity was more common among urban participants * ($p<0.05$). Rural participants were more likely to be self employed compared to urban participants ** ($p<0.01$).

Fig. 2 Knowledge about caring for AIDS patients



Even though general knowledge about HIV/AIDS was high (>75% correct answers), knowledge about caring for AIDS patients was low (< 25% correct answers).

Table 2. Willingness to provide care

Variable	N	%
Individual willingness to care in your home?	219	73.0
Individual experience in providing care	223	76.9
Family willingness to care	196	65.3
Family refusal to care	143	48.0

Most respondents were willing to provide care and had experience doing so. However, almost half of them thought their families would refuse care for a family member with HIV.

Table 3. Factors associated with willingness to care

Variable	p
Sex (female)	0.002
Marital status	<0.001
General knowledge on AIDS	0.017
Education	0.022

Being female, married, and knowledgeable about AIDS, and having at least primary education were significantly associated with willingness to care.

Table 4. Community reaction towards individuals with HIV/AIDS

Community attitude	N	%
Avoidance	238	79.6
Concern/empathy	38	12.7
Indifference	11	3.7
No Opinion	12	4.0

Most respondents (~80%) reported that the community members would avoid people with AIDS.

Focus group discussion with women in Tarkwa

Table 5. Principal responses in focus group discussions

Variable	Rural Community	Urban Community
Attitude	*People will talk about you so much that you can't even go out*	*If it happens to me, that is my sister sitting there. She won't give me food to eat Government must build a big house and put all of them there*
Willingness to care	*Is my family so I will do everything to make him comfortable*	*Theoretically, I may say that I will accept to do it, but it is not easy Lets fact the fact*
Factors affecting willingness to care	*Somebody who has the disease through prostitution will be treated badly*	*What we are saying involves money.*
Challenges of home care	*Pointing of fingers at the person with AIDS and his/her family*	*Because everybody is working, you can't even get anyone to clean her up*

Respondents expressed their need to offer care for HIV patients. However the willingness to care was not without consideration of factors like financial impact and community attitude.

CONCLUSIONS

- Families in Tarkwa were willing to provide care for their members living with AIDS.
- Families, however, faced the challenge of meeting basic daily needs including food as household food security becomes much worse with an AIDS patient who cannot help contribute to the economic support of the family.
- Programs are needed to assist families to acquire the knowledge and skills needed to provide adequate nutrition and health palliative care of family members living with HIV/AIDS.

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