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Man enough to care

Involving Men in Home-based Services for People Living With HIV/AIDS in Rural Zimbabwe

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Man enough to care: involving men in home-based services for people living with HIV/AIDS in rural Zimbabwe

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ABSTRACT

This study explores the challenges of involving men in HIV/AIDS-related home-based care and the impact of male involvement on the quality of home-based care services in a rural Zimbabwe. With a prevalence of greater than 25% among adults ages 15 -49, HIV/AIDS is significantly straining an already stressed healthcare system. In Mutasa District home and community-based care are essential coping strategies. Despite the magnitude of the problem, men have played less of a direct role in the care of the chronically ill. As a result, women are now doing "triple duty"—responsible for the home, providing the lion's share of agricultural labor, and caring for family members living with HIV/AIDS. Africare's Male Empowerment Project supported by the Development Cooperation of Ireland and John Snow International, UK, was designed to address this imbalance by expanding men's role in care for people with HIV/AIDS. The project equips men with the training and support necessary to become effective voluntary caregivers. The purpose of the project was to increase male participation in the provision of home-based care and support for people living with AIDS, as well as the provision of HIV/AIDS education, while supporting female involvement in home-based care. Objectives: Mobilize, train and support Home Based Care (HBC) supervisors, 120 male HBC workers and 120 Ministry of Health trained female HBC workers in 6 selected wards in HIV/AIDS prevention, care and support; and increase the access of 720 men and women living with AIDS (clients) and their families to HBC and support. A qualitative evaluation of the project was conducted after 18 months of operation. Data gathering included focus groups, key informant interviews, and a review of project reposts and documents. In addition, a pre-coded questionnaire was administered to 76 voluntary caregivers (VCG) who had been operating under Phase 1.

Major findings: Men are willing to play a practical role in promoting the health of their families, neighbors and communities; Men can be effective home-based care volunteers, capable of providing nursing care, psychosocial support, and assistance with household chores to affected individuals and households; and Men accept that providing care to people living with AIDS and other chronic illnesses is an appropriate and acceptable behavior.

HIV/AIDS IN ZIMBABWE

With a prevalence of 25% among adults aged 15-49¹, HIV/AIDS is significantly straining an already stressed healthcare system in Zimbabwe. It is estimated that 70% of hospital admissions are related to HIV/AIDS. As the demand for health services increases, shortfalls in Government funding have led to a shortage of drugs and equipment and caused trained personnel to flee not only the rural areas but also the country². With limited resources available, the burden of caring for people living with HIV/AIDS (PLWA) falls to family members, especially women since traditionally they are responsible for the health and wellbeing of the household. Furthermore, as men become too sick to work, women become the sole contributors to household income³. As a result, women are now doing "triple duty", responsible for the home and family, providing agricultural labor and other forms of income, and caring for family members living with HIV/AIDS. Often, these women are also HIV +.

Increasing women's roles and responsibilities represents a major social change that has consequences for the family and community. As the need for additional income grows, women resort to selling sex. Girls are often withdrawn from school and forced to work. Additionally women have less time for community activities, reversing decades of effort to increase their involvement in local development activities. While the burden on women grows with the scale of the epidemic, men's behavior is not changing fast enough to respond in ways that positively impact the health of the family.

Given the challenges facing Zimbabwe's health care system and the magnitude of the epidemic, home-based care (HBC) has emerged as the most viable option to meet the long term health needs of PLWA. With proper training, equipment and monitoring, volunteers can treat many of the common symptoms and illness associated with AIDS. This will not only reduce the mental and physical suffering of PLWA, but it will also reduce the burden on primary caregivers. Currently, there are not enough HBC programs in rural Zimbabwe. Africare's Male Empowerment Project supported by the Development Cooperation of Ireland and John Snow International, UK, was designed to address the gap in HBC programs and the gender imbalance by expanding men's role in providing HBC care and support for people with HIV/AIDS.

HIV/AIDS IN MUTASA DISTRICT

Mutasa District, a rural mountainous region in eastern Zimbabwe, has a population of 214,000 and an HIV prevalence rate of 25%. The HIV/AIDS epidemic has devastated the region by decreasing the economic productivity of the area and increasing the number of orphans. District health services are unable to meet the needs of the population, frequently

¹ UNAIDS

² Woelk, G. et al. Do we Care? The Cost and Quality of Community Home-Based Care for HIV/AIDS Patients and Their Communities in Zimbabwe. SAFAIDS, Harare, Zimbabwe.

³ Willan, W. (2002). "Women's Empowerment": Africa's AIDS vaccine? *Gender Studies Seminar Series*. Health Economics and HIV/AIDS Research Division (HEARD), Durban: University of Natal.

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running out of essential drugs, and there are only a few prevention, care and support programs in the district. Only recently did Hauna Hospital begin providing community outreach services. Therefore, the burden of care has fallen to women. Men are seen as the rightful heads of household, and their only responsibility is to provide economic stability to the family.

The men's empowerment program in the Mutasa District worked to change the gender perceptions and equip men with the training and support necessary to become effective voluntary caregivers. Men could then reduce the burden on women involved in home based care, by becoming more involved in HIV/AIDS prevention, education and care within the community.

MALE EMPOWERMENT PROJECT

During initial community assessment, men expressed an interest in becoming more actively involved in addressing the HIV/AIDS pandemic. Home based care was identified as a critical unmet need, in which male involvement would have a strong beneficial impact on the community. Not only would more families and individuals affected by HIV/AIDS receive care and support, but current primary care givers, the majority of which are women, would receive much needed assistance, reducing their burden.

In order to break the traditional barriers that prevented men from caring for PLWA, the project sought to build upon men's traditional roles and characteristics as the heads of households and community leaders. The name "male empowerment" was chosen to instill a sense of pride and responsibility in the male volunteers. Through these male volunteers the project aimed to expand the culturally accepted definition of masculinity to include caring and supportive behavior as desirable male traits.

Eighty male volunteers between the age of 20 and 65 were recruited from four wards in the Mutasa District of Zimbabwe. It was assumed that male volunteers would feel more comfortable caring for other males, so the voluntary care givers (VCG) were only expected to assist male clients. At this time there was a separate project operating in the district that assisted female clients. Clients were selected based on a positive HIV diagnosis, as well as the presence of chronic illnesses, due to the lack of voluntary counseling and testing services in the district.

Once trained, VCG were expected to perform a variety of tasks including: providing nursing care; HIV/AIDS education and prevention counseling; psychosocial support; assistance with household chores; and bereavement counseling for family members.

The male VCG organized themselves into four "male empowerment groups", one per ward. These groups were support groups that met weekly and allowed the men to share information, plan activities and work through challenges and problems. The male empowerment groups also met with project staff regularly to receive HBC supplies obtain in service technical assistance and continue discussions concerning important topics, such as

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conflict resolution, stigma and discrimination and cultural practices that promote HIV transmission.

EVALUATION METHODOLOGY

A qualitative evaluation was conducted in September 2003, after the project had been underway for 18 months. VCG, clients and caregivers from each of the projects four wards participated in the evaluation. The evaluation consisted of a questionnaire completed by 76 of the 80 VCG, focus group discussions, interviews and a review of project documents. Two focus group discussions were conducted with a total of 26 VCG (25%). Five interviews were conducted with VCG, ten interviews were conducted with project beneficiaries and their primary caregivers and four interviews were conducted with primary caregivers of deceased beneficiaries. The evaluation was designed to identify project successes and challenges in order to improve current efforts and guide the second phase of the project, in which activities were to be extended to additional districts.

FINDINGS

At the time of the evaluation, 2,000 home visits had been performed and only 2 male VCG had dropped out of the program. Replacements were found, but they did not receive a full orientation and training. Instead they received on the job training from other volunteers.

1. VCG visits attributed to improvements in clients physical and mental health

Clients were pleased with the VCG visits and contributed improvements in their mental health and physical well-being to support provided by VCG. Knowing that "someone cared enough to visit" gave some clients the will to keep fighting and also helped them continue to feel like a member of the community. Families were more accepting of the client, leading to an improvement in the client's mental health. Furthermore, supplies, such as soap, bleach and antiseptics, provided by the VCG helped improve the basic health of the client.

2. Quality Care requires frequent in-service training and consistent monitoring of VCG. Providing HBC requires a high level of training and support due to the fear, stigma and discrimination associated with HIV. VCG felt that the initial training provided them with the necessary skills, but in-service training would have given them the opportunity to reinforce and practice these skills. Although initial in-service training was planned for every month, in reality as many as three months passed between training activities. This resulted in variations in the quality of care and type of care clients received. Towards the end of the project, field-based monitoring was improved by strengthening the staffs' skills and clarifying expectations. This should lead to a decrease in inconsistencies in the quality of care clients receive.

3. VCG found it difficult to move outside their comfort zone

The male VCG perceived their role as facilitating improvements in the care provided by the primary caregivers (PCG) through the provision of materials and the dissemination of information. VCGs were more comfortable performing tasks that were traditionally performed by men, such as patient counseling, spiritual support and exercising the patient, so these tasks were more effectively and consistently preformed. VCG were less comfortable bathing, providing wound care and feeding the client. They preferred to provide information and support to the primary caregiver, so that they could take sole responsibility for these tasks. Female primary caregivers were disappointed that male VCG were not more willing to take on nursing activities. Although, no data was collected on the level of assistance VCG provided with respect to household chores, they expressed a willingness to perform these duties and primary caregivers were able to take advantage of the VCG visit to complete some of these chores themselves, while the VCG cared for the patient.

4. Prevention efforts hindered by lack of voluntary testing and local taboos

Although clients expressed a desire to be tested for HIV, there are limited testing services in the district. The project does not offer testing services. The VCG must rely on their knowledge of symptoms and related infections to diagnose their clients and discuss their conditions. Without tests, many people refuse to accept they may be HIV + and attribute their conditions to other illnesses. This allows clients and VCG to avoid sensitive but important discussions regarding HIV prevention measures and referrals for services such as Mother to Child Transmission.

VCG felt most comfortable discussing positive living, home remedies and providing spiritual support for clients. They were not comfortable discussing "safe sex" and HIV prevention activities, and reported feeling that their work did not increase spousal communication about HIV/AIDS. They also did not feel comfortable discussing bereavement issue with family members. This is not surprising as discussions regarding sex, illness and death are considered taboo. However, as time progressed and trust developed among VCG and their clients HIV counseling was more likely to occur. There was an increase in requests for condoms, which VCG attributed to counseling during home visits. It is difficult to know if the increase in condom requests is due solely to this project.

5. VCG expressed concern over lack of monetary incentives

The VCG are all volunteers and did not receive a stipend or financial support for participating in the project, although they did receive non-monetary support and supplies such as bicycles to travel to client homes and HBC kits filled with supplies to help treat the clients. They consistently expressed concern over costs associated with HBC and requested funds for income generating activities or stipends to help off-set these costs. None of their requests were for especially large stipends, demonstrating that they were only looking for ways to off-set the cost of HBC and time away from agricultural or other income generating activities. Although VCG did not condition their continued volunteerism on financial support, it is feared that they may do so in the future.

DISCUSSION

The Male Empowerment Program has shown that men are willing to become involved in their family's and community's response to HIV/AIDS. This alone was a significant accomplishment. With proper training, monitoring and support males provided effective HBC including psychosocial support, assistance with household chores, education and some nursing care to PLWA and their families. Additionally, male VCG voluntarily recruited women clients because the Ministry of Health program that was supposed to be serving women had little impact due to inconsistent funding. The original fear that men would not feel comfortable providing HBC services to women was unfounded and by the end of the project women comprised 25% of VCG's clients. However, male VCG never offered all the services the project had envisioned because of stereotypes regarding appropriate male behavior. Continuing to link nursing activities with the theme of empowerment and strength may eventually lead to men accepting these activities as part of their responsibility.

The evaluation showed there was a discrepancy in services expected by the primary caregivers and those provided by the VCG and emphasized the need for more clearly defined expectations and guidelines for VCG and continued training in order to increase the quality of care and make VCG more comfortable in providing bathing and other nursing care. A protocol has been developed and all VCG have been trained using the protocol. The protocol has also been shared with clients, primary caregivers and community leaders, so they know what services to expect from VCG. The protocol will provide a standard against which all services can be measured and should eliminate discrepancies in services provided. VCG are also receiving monthly in-service training sessions to enhance their skills and train more VCG. These training sessions utilize the Male Involvement Tool Kit created by SAfAIDS and John Snow International⁴ and focus on increasing nursing and counseling skills, as well as addressing VCG concerns to reduce stress and burnout. Furthermore, a qualified nurse now oversees all HBC and VCG services to further ensure quality care.

The project also highlights the need for more voluntary counseling and testing services within the district. VCG found a significant demand for testing among their clients, but with a limited number of testing services in the district, the VCG were unable to follow through with testing services. It is important for a person to know their serostatus, so that they can accept their situation and benefit from the counseling and prevention work VCG are offering. As more community members become aware of their HIV status, there may be a reduction in stigma, which often hinders prevention efforts.

In poor communities such as Mutasa, men are expected to earn cash and provide for the family. For this reason, involving men in unpaid volunteer activities is often difficult and the study has shown that incentives of some kind are needed in order to ensure sustainability of the program. Furthermore, incentives could be based on VCG's performance, ensuring the quality of care and services provided.

⁴ "Involving men in community hone based care for HIV and AIDS toolkit: Information Manual." (2003). SAfAIDS and John Snow International.

http://www.synergyaids.com/documents/Safaids_InvolvingMen_HBC_manual.pdf

CONCLUSION

The Male Empowerment project has shown that men are willing and able to become involved in PLWA care, and their involvement not only reduces the burden on female caregivers, it improves the mental health of their clients. With adequate training and support the VCG can continue to broaden their skills and provide quality care to PLWA and their families. Hopefully, male VCG will use their new skills within their own homes to care for infected family members. Thus, as the AIDS epidemic grows, both men and women will assume responsibility for providing care and support to PLWA.

Ultimately, it is hoped that the Male Empowerment approach can be used to address other gender issues and inequalities such as gender-based violence, sexual abuse and education for girls.

RECOMMENDATIONS

As the project moves into phase two and expands into additional districts, the following changes will ensure that high-quality, sustainable care is provided to clients. Male VCG should continue to actively recruit and provide care to female clients, so that all individuals in the projects wards who are in need of HBC care are receiving it. Project coordinators need to increase the frequency of training and in service activities to ensure that male VCG have the necessary skills to provide high-quality care to all their clients. Furthermore, nursing activities should continue to be linked with themes of strength and empowerment so that men continue to accept and perform these activities as part of their responsibility.

In conjunction with project services, communities need to increase their voluntary testing and counseling services, so that clients cannot deny diagnosis and attribute their symptoms to other illnesses. With increased testing facilities available, the demand for HBC services will likely increase, making it even more important to ensure that VCG are committed to the program, even if it requires providing them small incentives.

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