

The Plight of HIV and AIDS Care Givers in Thohoyandou in South Africa

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ABSTRACT This paper explored the profile of HIV and AIDS caregivers in Thohoyandou in South Africa. It used a quantitative exploratory - descriptive research design. Thirty-nine female respondents aged between 20 and 35 completed a self-administered questionnaire. The findings of the study confirmed the general perception that HIV and AIDS was associated with marginalisation. Majority of the care-givers were women with little education, based in a rural environment with inadequate amenities essential to enhance their vocation. Apart from the educational status and environment, the care-givers' training on HIV and AIDS palliative care was inadequate, thus rendering them susceptible to HIV and AIDS infection. The findings implied that although HIV and AIDS care-giving was beneficial, it could pose risks to both the patient and the care-giver. Recommendations on how to make care-giving more beneficial to patients and care-givers was also given.

INTRODUCTION

The discovery and spread of the HIV and AIDS pandemic had put tremendous strain on both the world health services and the economies of countries as evidenced in Kenya where in 2008, 50-60 beds in public hospitals were occupied by HIV patients (www.avent.org). Moreover, the virus infects the most productive individuals of society, with women younger than 24 years carrying the largest burden of the disease, thus affecting a country's economy (www.avert.org). Sub-Saharan Africa has been the hardest hit with 22.5 million people infected with the HI virus in 2009 (Keeton 2011). In 2005, it was estimated that between 4.5 and 6.2 million people in South Africa, are HIV positive (Nelson Mandela Foundation), with the youth between the ages of 20 and 30 being the most vulnerable. In the Limpopo province where this study was carried out, it was estimated that 13.7% of the adult population aged between 20 and 64 was HIV positive (Department of Health and Social Development 2006), and Statistics South Africa estimated the infection rate to be at 10.98% (Statistics South Africa 2011/2012).

The information about South Africa above intimates that HIV and AIDS had put the country's health system under tremendous strain in terms of personnel and financial resources, thus the need for the introduction of

Home Based Care (HBC). The Committee on a National Strategy for HIV and AIDS suggested that communities should be involved in caring for patients at their own homes (Uys and Cameron 2003). This was because patients with terminal illnesses often expressed a desire to die at home within the security of a known environment, with their significant others (Project Literacy 2008). The efficacy of HBC in lessening the burden on both the health and family systems cannot be under-estimated, but there is a persistent question about the efficiency and effectiveness of HBC services.

HIV and AIDS Care Giving: An Overview

HBC is care given in the home of the person living with a terminal illness. The caregiver is often a family member, friend, with the support of a trained community caregiver. In ideal circumstances, a multi-disciplinary team supports the caregivers to meet the specific needs of both the individual and the family (Van Dyk 2005). HBC is thus a voluntary activity aimed at benefiting those that are terminally ill. Proponents of HBC state that it offers the primary care giver the opportunity to work temporarily, lessens travelling costs and time to the hospital and that the patient is not exposed to hospital borne opportunistic infections (www.avery.com).

Volunteerism can be understood within the following contexts; socio-economic, cultural,

religious and political. Although HBC espouses positive values, HIV and AIDS care-giving did not only put a strain on a country's financial and human resources but on women who bear most of the HIV and AIDS care-giving burden. This is in addition to their daily domestic chores, which though necessary, society hardly recognises and acknowledges. Therefore whether women engage in volunteer work, informal support and domestic labour all of these are classified as unpaid labour (Petrzelka and Mannon 2006).

Models of Home-based Care

Two home based care models, which differ on the basis of the nature and the level of support given to both the patient and the caregiver will be discussed here. The first one, the integrated home-based care model links all the service providers with patients and their families in a continuum of care. A multi-disciplinary and multi-sectoral team, which includes the community, supports the patient and their family. This model builds trust and enhances referrals between partners and most importantly the caregivers receive training, support and supervision. This is the ideal model for quality physical care and psychosocial support for a person living with HIV and AIDS and their family, as it is inclusive (Uys and Cameron 2003). In terms of this model, the caregivers become competent in the services that they render to their patients and have the necessary support system to help them cope with the challenges inherent in caring for terminally ill patients; such as dealing and coping with grief.

The second model is the single-service home-based care model, where volunteers are recruited and trained under the auspices of a service provider usually a clinic, hospital, Non-Government Organisation (NGO) or church (Uys and Cameron 2003). The nature of this model prevents mutual learning and integration of resources. The final model is the informal home-based care setting where families care for their sick loved ones at home, with the informal assistance of their own social network. There is hardly training, access to external support from a formal organisation or supervision of the care. Without the necessary knowledge, skills and emotional support, informal care becomes a challenge as the primary caregiver often lacks the requisite competency to care for an HIV and AIDS patient (Uys and Cameron 2003). While the integrated

and the single service models are common, the level of government support offered to HBC makes the informal model a common option.

MATERIAL AND METHODS

The study design was exploratory - descriptive in nature. Exploratory research promoted insight into the social situation of caregivers, thus exploring new ideas and knowledge. The complexity of the subject under study and the need to understand the context of the subject under study necessitated the use of a descriptive research design (Goddard and Melville 2001). The researchers used convenience sampling to select thirty-nine full time care-givers and volunteers from the Community-Based Organisations (CBO's) offering HBC in Thohoyandou. The respondents completed self-administered questionnaire. Prior to conducting the study permission was sought from the Department of Health and Social Development: community development directorate, the managers of the organisations and the participants, whose rights to participate in the study were explained.

FINDINGS

Demographic Profile

The study consisted of 39 female respondents between the ages of 20 and 35 with the 28-35 years age group accounting for 64% of the study population. Of the study group, 44% were unmarried, 54% were married and 2% were widows. In terms of educational status 84% of the respondents had completed short courses, or did not complete grade 12, 3 % had a diploma whereas the remaining 13% did not reveal their qualifications.

Table 1: Working term

<i>Term</i>	<i>Number</i>	<i>Percentage</i>
Full-time caregiver	22	56%
Volunteer	17	44%
Total	39	100%

Table 1 presents the caregivers' working terms. It shows that 56% were full-time caregivers and 44% were volunteers. The experience that one has is a yard-stick that determines whether one will be a remunerated care-giver or a vol-

unteer. Full-time caregivers are more knowledgeable and thus receive a stipend for providing HBC services. This is unlike volunteers, who have limited knowledge on HBC. Despite this, their contribution to HBC cannot be underestimated.

Table 2: Receipt of monthly stipend

<i>Earnings</i>	<i>Number</i>	<i>Percentage</i>
Yes	14	36%
No	25	64%
Total	39	100%

Table 2 indicates that 64% of the caregivers provided services to patients without earnings against 36% who did. This indicates that caregivers are faced with financial challenges, as the majority was not remunerated. This however did not deter them from attempting to meet their patients' needs, keeping them well and comfortable until they became better or died.

Table 2a: Monthly income

<i>Income</i>	<i>Number</i>	<i>Percentage</i>
Less than R1000	11	28%
R1500-R2000	2	5%
R2100-R2500	1	3%
No response	25	64%
Total	39	100%

Data on Table 2a shows that 28% of the caregivers earned less than R1000 per month, 5% earned between R1500-R2000 and 3% earned R2100-R2500. This data reveals that care giving is more emotionally than financially rewarding. The income levels depicted on the table are rather consistent with South African per capita income of R 526 or \$ 5 a day (The Presidency 2011). The 64% non-response supports the data in Table 2 regarding non-remuneration of some of the respondents.

Table 3: Year of Engaging in HBC

<i>Year</i>	<i>Number</i>	<i>Percentage</i>
2001	4	10%
2003	3	8%
2004	17	44%
2006	4	10%
2008	9	23%
Non-response	2	5%
Total	39	100%

Table 3 illustrates that the majority 44% of the caregivers started providing care in 2004, 23% joined in 2008, 10% started in 2001 and 2006 respectively and only 8% joined in 2003. The table illustrates that the sector hardly attracts the necessary human resources due to its stressful nature and the lack of financial rewards. With the exception of the year 2006 fewer people participated in HBC, this may be attributed to the myths and misconceptions about HIV and AIDS infection and it is during this period that HIV and AIDS dissent was rife in the government curtailing the provision of anti-retroviral treatment to HIV positive patients (Airhihenbuwa and Webster de Witt 2004).

Table 4: HIV and AIDS training and duration

<i>Duration</i>	<i>Number</i>	<i>Percentage</i>
Week- 1 month	20	51%
2-3 months	6	15%
7-12 months	2	5%
More than a year	7	19%
No response	4	10%
Total	39	100%

Professional nurses employed at the Department of Health (DoH) offered initial training to the respondents prior to them assuming duties. Subsequently, the organisations had to train their own caregivers. The duration of the training ranged from less than 5 weeks for 51% of the caregivers; 2-3 months 15%; 7-12 months 5% and only 19% received training for more than a year (Table 4). The complexity of HIV and AIDS caregiving renders the nature of training that was offered to the caregivers inadequate, as such the quality of care is affected (Kathenge 2009).

Table 5: Knowledge of HIV and AIDS

<i>Level of knowledge</i>	<i>Number</i>	<i>Percentage</i>
Excellent	10	25%
Good	5	13%
Average	21	54%
Very poor	1	3%
No response	2	5%
Total	39	100%

Table 5 shows that 54% of the caregivers had average knowledge about HIV and AIDS; 25% had excellent knowledge; 13% had good knowledge and 3% had poor knowledge about HIV and AIDS. This information mirrors earlier data;

that revealed that the majority of the caregivers had insufficient HIV and AIDS training. Inadequate knowledge has an impact on the morale of care-givers, the provision of quality care and adherence to protective measures. Five percent of the respondents did not specify their level of knowledge, this might be attributed to the fact that self-esteem and knowledge are closely related.

DISCUSSION

The findings of the study was consistent with the cultural- gendered perspective of womanhood and the general predictors of volunteerism, which are sex, age, educational, marital status and locality (Petrzelka and Mannon 2006). All the caregivers were women, who generally bear the traditional burden of domestic and nurturing roles (ILOAIDS 2004). This is despite the involvement of men in feminine professions such as teaching, nursing and cooking (Burns 1998). This unequal division of labour is based on culture, which is a system of high order values that influence and condition perception, judgement, communication and behaviour within a specific environment (Airhihenbuwa and de Wet 2004). As a result an individual's environment will influence their attributes and dictates associated with volunteerism (Budlender 2003). Consequently, volunteering trends will be different in urban and rural areas, for urban-based high-class families, volunteerism is a hobby unlike in urban poor and rural areas where it is a socio-cultural religious obligation. As the Limpopo Province is 89% rural, it is evident that women are the main caregivers of HIV patients (Abdool Karim and Abdool Karim 2008; Statistics SA 1996). Volunteerism is closely tied to social class, context and the cultural belief system which defines what should happen in relation to sickness (Airhihenbuwa and de Witt 2004; Petrzelka and Mannon 2006).

Women, Unpaid Labour and Time Use

The HBC activities that the caregivers engaged in were not different from what they do in their homes. Time use surveys reveal that women over the age of ten spent 216 minutes a day on unpaid work, with 116 minutes spent on productive activity, 74 minutes less than what men spend on activities that contribute to the Gross

Domestic Product (GDP) calculations (Budlender 2003). In rural areas, women are responsible for food security through subsistence farming (Abdool Karim and Abdool Karim 2008). When taking HBC activities in to consideration, care-givers spent an average of 180 minutes a day, depending on the patient's illness, women spent between 5 hours 43 minutes to 7 hours per day on unpaid labour (Akintola 2004a). The time that women spend on non-paying activities prevents them from engaging in income generating activities and also reduces their leisure time.

Educational Status

The majority of the respondents in this study did not receive formal education; this finding reveals another dimension of care-giving, literacy versus illiteracy. Women who are formally educated are more likely to offer their services in organisations with tangible benefits like national recognition, networking and power (Petrzelka and Mannon 2006). The lack of formal education not only prevented respondents from accessing gainful employment in the labour market but also compromised the quality of care offered to their patients. Low literate caregivers are unable to access care giving education, assessing disease progression and following medical and hygiene protocols. As a result, illiteracy compromises both the quality of care the patient receives and the caregiver's coping strategies (Kathenge 2009).

Economic Benefits

Although volunteerism is a conduit for community development that benefits the government, the economic benefits hardly trickle down to the caregivers. The majority of the caregivers were unemployed, had no income or their earnings were insufficient to provide for their material and financial resources. In a study conducted among Batswana caregivers at Kanye village, the caregivers stated that since they were poor there was nothing else to do except HBC (Kathenge 2009). The statement above asserts the economic value that is associated with home-based care, a sector for the under-educated, lowly paid and socially marginalised. Apart for the low or absence of wages; the care-giving sector is not regulated by labour laws; a condition that increases the vulnerability of the caregivers (De-

partment of Social Development 2006). Most importantly, the high levels of youth unemployment in the country and the minimal skills required to be a care-giver might be a motivator for youth to volunteer, with the hope for future employment (Akintola 2004; Coovadia et al. 2009).

Knowledge of HIV and AIDS

HIV and AIDS care-giving is a biologically, economically, socially and politically complex phenomenon. With the majority of caregivers having average knowledge about HIV and AIDS the implications can be dire. A Limpopo based care-giver stated that “we only know how to use gloves, but not the handling of the patient, even minor complaints such as pain relief” (Mieh et al. 2012). While a study conducted in KwaZulu-Natal revealed that some caregivers fail to use gloves as they attribute their use to discrimination against the patient and when they did, they often lied about the reasons for their use (Akintola 2005). Furthermore, the symptoms and the opportunistic infections associated with HIV and AIDS are highly technical, requiring English proficiency, which is lacking or minimal among the majority of the caregivers. This lack of skill can have dire consequences for patient care, particularly when the caregiver has to give a report to the doctors (Akintola 2005). In addition, inadequate training has been attributed to high levels of burn-out and dropout as the caregivers were unable to cope with the work challenges (Kathenge 2009; Marinowitz et al. 2004). Therefore, in order to make volunteerism effective, training must be adequate (Campbell et al. 2009).

CONCLUSION

HBC plays an innumerable role in lessening the care-giving burden on the health care system. However positive its contribution is, this is sector marginalised. The HBC sector is manned by survivalists, women who are on the margin of society and have inadequate formal education and HIV and AIDS knowledge. In addition, the necessary human resources, which are students, can be engaged to offer a variety of services to these organisations. Unlike in other countries, the study revealed that the majority of the caregivers were youth, this is desirable in that the youth are not only capable of further learning but as the group bearing the greatest HIV and

AIDS burden, care-giving might deter them from engaging in risky sexual behaviours. Additionally, the findings illustrates that the youth as the largest segment in society can make a considerable contribution to the prevention and treatment of HIV and AIDS as is committed to the notion of volunteerism.

Despite the majority of the respondents not receiving any remuneration, the study revealed that more than 60% have participated in HBC for four years and more. This information challenges the notion that youth are not keen in voluntary services as they are not remunerated, but on the other hand, this might also be attributed to the dearth of employment opportunities in the region. The involvement of women in HBC is a norm the world over. In order to change the situation, it is important that the concerted efforts are made to involve men in the system.

While the study sample was small and quantitative, it revealed interesting facts, such as the need to professionalise the field, which would ultimately ensure security of tenure for the caregivers, labour law protection and livable wages.

RECOMMENDATIONS

The South African government should collaborate with higher education institutions to provide adequate training for caregivers. These institutions are tasked with community outreach as one of their mandates so they can provide accredited training to the caregivers; which can lead to qualifications, thus professionalising the field.

Campaigns targeting the attitudes of men towards care-giving and their role in the reduction of the spread of the HI virus should be introduced.

While it is desirable and commendable that the government has introduced stipends for some of the caregivers, this is a catalyst for tenuous caregiver relationships and retention. Therefore, the government needs to look at a funding model or even a reward system (vouchers) for those involved. The introduction of such measures might help retain the caregivers.

It is recommended that future research looks at the following areas: firstly; the barriers and the opportunities to men-volunteerism in care-giving. Secondly, a comparative study of the profiles of caregivers in both rural and urban areas. Lastly, an investigation into the financial spinoffs

that the government receives from HBC services needs to be investigated.

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