

Men As Carers
A Case Study

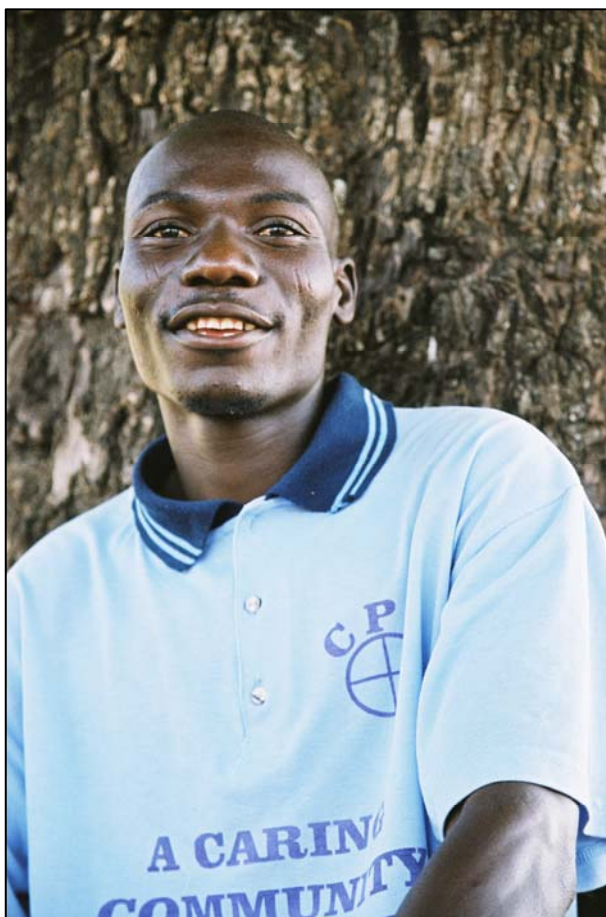


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1. INTRODUCTION

1.1. Brief Description of the Case Study Question

This case study was undertaken to:

- Research and document men's involvement in home based care activities in South Africa
- Document five men's experiences of undertaking home based care
- Contextualise men's practical experiences within the context of research on home based care.

This research and its documentation are to be used to articulate effective strategies to address masculinity and HIV issues, and to highlight lessons learnt for sharing with other organisations working in the field of HIV and AIDS.

1.2. Background and Literature Review

In South Africa, the impact of HIV and AIDS on health services is emerging at a rapid pace, overburdening the system and leaving households and communities with the responsibility of care. People living with HIV and AIDS often constitute a large proportion, if not the majority of people seeking medical treatment at hospitals. Many hospitals do not have adequate resources to care for HIV patients¹.

When AIDS enters the household, women and girls provide most of the care to the ill, as expected by society. Globally, up to 90 per cent of such care is provided in the home by women and girls².

The United Nations General Assembly Special Session (UNGASS) approved a declaration of commitment in 2001, where a call was sent out to nations to review the social and economic impacts of HIV and AIDS at all levels of society, especially on women and the elderly in their role as care-givers³.

¹ Olagoke Akintola 2004: Gendered Burden of Home Caregiving- www.ukzn.ac.za/heard

² Women and Caregiving: Confronting the Crisis- www.unfpa.org/hiv/women/report/chapter4.html

³ <http://www.un.org/ga/aids/coverage/FinalDeclarationHIVAIDS.html>

Most home based care (HBC) programmes in South Africa rely on unemployed (mainly female) volunteers from affected communities⁴. In a few cases, they are paid a small stipend. Many care-givers share food and other material goods with the patients they visit, spending long days working free of charge instead of looking for paid employment⁵.

A three-province survey in South Africa found that almost three quarters of AIDS-affected households were female-headed, a significant proportion of whom were also battling AIDS-related illnesses themselves. Poverty and faltering public services in many areas are combining with AIDS to turn the care burden for women into a crisis that has far-reaching social, health and economic consequences⁶.

In a four-province research study of Home Based Care organizations conducted by the Population Council, qualitative data from focus group discussions with beneficiaries of funding similarly revealed that care-givers within the family tend to be female. Respondents felt that fathers and brothers do not provide support.

According to a female respondent in that study, *“Fathers can’t take care of the sick; they only help out with money once in a while.”* Another woman from a different province commented: *“You know males they are not that sensitive. Mothers can take care of so many things. Most males don’t like taking care of sick people... women are patient and caring. Men can’t be like that”.*

2. INVOLVEMENT OF MALES: CURRENT CONTEXT

According to the Men as Partners⁷ programme in South Africa, men are playing an increasing role in adopting tasks and responsibilities within the household that are culturally perceived to be ‘women’s work’. As part of its strategy for addressing violence against women and its effect on HIV and AIDS, the Men as Partners programme also focuses on the need to transform gender relations within the household.

This view however, does not resonate with other documents referred to in this report.

⁴ www.sarpn.org.za/documents/d0001853/8_SA_Child_Gauge_2005.pdf

⁵ Plusnews:2005-01-21: <http://www.hst.org.za/news/20040618>

⁶ AIDS epidemic update December 2004 Women and AIDS.htm

⁷ MAP is a programme that aims to involve men by bringing them on board through specially designed education and training programmes looking at a variety of focus areas within sexual and reproductive health.

The picture of men's involvement in care-giving in South Africa shown in the report by the Health Professions Council⁸ of South Africa gives a different reflection of the involvement of men in home based care activities. The involvement of men in caring activities is in reality much lower than the involvement of women, as shown in the table below.

Table 1: Palliative care workforce in South Africa

CATEGORY	EMPLOYEES		
	Female	Male	Total
Palliative care workforce capacity (employees)	188	10	198
Palliative care workforce capacity (volunteers)	1 116	138	1 254

It is important to note that the cited report only reflects the number of care-givers who have been registered through a formal process, and may have missed out on the actual numbers of carers working in informal non-governmental, community based and faith based organizations. If inference is made, however, it is evident that the number of males involved in home based care activities still are in most cases lower than 10%, and at best just above it. Other statistics show that the low numbers of men involved in care-giving is not a phenomenon unique to South Africa, but is reflected in other literature from within the region⁹ and beyond.

In Zimbabwe, the Red Cross reported in 2002 that of the 1042 home based care-givers, there were 104 males and 938 females, a ratio of 1:10. Similarly in the Zambian copper belt, one of the areas hardest hit by HIV and AIDS, 90 percent of care-givers are female. Closer to home, the Centre for Positive Care (CPC) reflects an even more skewed picture, with 9 out of 458 care-givers being male, much lower than the noted averages.

⁸ The Health Professions Council of South Africa (HPCSA) is a statutory body, established in terms of the Health Professions Act no. 56 of 1974 with a mandate to protect the public, all consumers of health care services, and to provide guidance on educational, professional and ethical issues to medical and allied practitioners

⁹ The region is the Southern African Development Community (SADC). It has been in existence since 1980, when it was formed as a loose alliance of nine majority-ruled States in Southern Africa with the main aim of coordinating development projects in order to lessen economic dependence on the then apartheid South Africa. The founding Member States are: Angola, Botswana, Lesotho, Malawi, Mozambique, Swaziland, United Republic of Tanzania, Zambia and Zimbabwe.

3. METHODOLOGY

Interviews were used to collect information from five (5) male and five (5) female care-givers. A further interview was held with a male member of management who used to be a care-giver as well.

All eleven respondents, forming one heterogeneous group then became participants in a focus group discussion.

4. DISCUSSION OF RESULTS

The questionnaire was divided into 5 sections, seeking to answer questions related to:

- Demographic and Personal Information
- Care-giving activities
- Being a care-giver
- Relationship with stakeholders
- Challenges
- How to attract males to be care-givers

4.1. Demographic and Personal Information

The aim of this section was to address issues related to the carer and their personal attributes like age, gender, level of education (including training to become a care-giver) marital status and responsibilities related to being a breadwinner.

All of the male care-givers were married with children. Of the five, two were primary breadwinners (60%). All of the care-givers were educated to grade 12 level.

4.2. Care-giving activities

This section looked at issues related to the work of caring as undertaken and understood by the care-giver. The questions were related to the duration of care-giving (how long the respondent has been a care-giver; hours per session of contact, number of patients cared for); and nursing activities undertaken.

The male care-givers undertake all nursing activities related to home care, taking care of bed-bound, home-bound or mobile clients. The nursing activities are bathing,

wound care, and feeding, patient counselling, spiritual support, and exercising the patient.

Management indicated that no assignment of duties according to gender takes place; that after recruitment, community mapping is done for averages of burden and clients are assigned according to this mapping.

The hours committed to caring range from five to six hours a day, but sometimes the care-givers are called for emergency care by their clients, leading to added time outside the normal hours of operation.

4.3. Being a care-giver

The aim of this section was to explore the reasons why the participant became a care-giver, and to find out how the initial motivation had evolved over time, and whether it became stronger or weaker.

Four out of five participants (80%) cited the church as a motivation for becoming a care-giver. This compared consistently with the response from female care-givers, all of whom were recruited in church.

All the care-givers indicated that they were motivated to be care-givers by compassion and the desire to be of assistance to the ailing and the weak.

All respondents reported that their motivation had grown since they started their work, and that they did not regret their decision to help.

The management representative's response to how recruitment for care-givers was done reiterated responses by care-givers; that it is done mainly through churches. He further added that it was decided not to use Chiefs for recruitment of care-givers as they may not have been able to recruit the right calibre of people for training as care-givers.

4.4. Relationship with stakeholders

Issues related to how the carer relates to other carers (either male or female, depending on the respondent), the community, the family, the clients as well as friends and peers were addressed.

4.4.1. Other carers

All male care-givers indicated that they felt accepted by female colleagues, but one respondent felt that there are still instances where he feels that he is sidelined because of his gender. He indicated that in some sessions, particularly support group activities, he felt unwelcome as a male.

The management respondent felt that males are easy to train and catch up quickly, and where they work in pairs or in teams with females, there is apparent quick uptake of information. Men can display leadership qualities and guide females in decision-making. The Manager felt that this is a good indication that men can be trained to take the lead in what is traditionally viewed as a female domain.

4.4.2. The community

The relationship with the community is generally good where nursing activities are concerned. The challenges in relationships arise where the carer assists clients with procurement of grants. Two of the care-givers cited instances where there was issues with the family after the grants were received and the clients still did not enjoy proper nutrition.

The carers indicated that the communities want to know why there are fewer male carers. This may require follow-up research with beneficiaries or the community to qualify their thoughts on men as carers.

4.4.3. Family, friends and peers

While four of the respondents reported total support from their families, one of the respondents was being ridiculed by his wife and mother to '*get a proper job*'.

All respondents, including the management respondent, cited examples of being laughed at and mocked by friends when they first became care-givers, but that they persevered and were motivated by the desire to assist the community. They find that friends now easily walk up to them and enquire about HIV and AIDS from them, and are also free to request condoms as well.

4.4.4. Clients

The carers feel that their clients are happy to work with them. The male carers reported that it is quite challenging to care for female clients, especially those that are bed-ridden. Female carers did not report a challenge with regards caring for male

clients. Management concurred that most male clients have indicated a desire to be taken care of by male carers. Male clients find it easy to confide in males and can easily disclose to males.

All were in agreement that it is easier for same-sex care as compared to the other way round.

It will be interesting, through further research, to investigate the extent to which the sexuality of the client determines the choice of carer in home-based care, and contrast this to the practice in formal nursing.

Issues of culture came up during the focus group discussion: all participants concurred that it is against their culture for a man to take care of a woman who is not kin. Further comparative studies between home based care and formal nursing may need to be conducted to evaluate this assertion.

A question was posed to management once again regarding assignment of duties, and the response was that duties are not assigned according to gender, but responses from other participants paint a different picture as it is quite evident that there appears to be an element of assignment of care-givers to clients based on gender.

4.5. Challenges faced by male care-givers

This section looked to establish what challenges are faced by care-givers. The intention was to also draw comparison between the different genders of care-givers, then analyse these in the South African context and the broader region as well. Issues related to impact on physical and emotional well-being, as well as personal and social relationships were looked at. The section also looked at coping strategies inherent of the care-giving sector (debriefing), or those that the care-givers themselves apply (religion-based or any other counselling services used).

4.5.1. Female clients

The male care-givers indicated that they do not find it easy to deal with bed-bound female clients. To add to this, most patients do not have primary care-givers and it makes the job difficult for carers as they have to either request assistance from

neighbours, or improvise by using sheets or curtains as screens behind which they can wash the client.

4.5.2. Low Stipends

The South African Department of Health as well as the Department of Social Development give grants to care-givers. The amounts range from R500 to R1700¹⁰. The care-givers who participated in this study felt that what they received in terms of stipends were far too low to sustain themselves and their dependents. What was interesting, however, was that they had been care-givers for an average four (4) years at the current rate of pay, and they report that their love for their job is still getting stronger.

4.5.3. Links with Clinics

There is a feeling that the relationship with local clinics is not as formalised as should be. It becomes a challenge when the care-givers have to refer a patient to a clinic or request supplies as they still have to explain who they are and what their involvement with the particular client is.

4.6. Management responses on challenges

The respondent representing management indicated that the following are challenges faced by male care-givers:

4.6.1. Being undermined by peers

There is a feeling that males are being undermined by females in care-giving. The respondent indicated that because care-giving of the sick and the infirm has traditionally been a responsibility associated with women, female care-givers sometimes treated males as if they are encroaching on their territory.

4.6.2. Being a smaller number within a large group

The male carers sometimes feel sidelined (especially in support groups comprising mostly of women). Instances were cited where male care-givers had been sent out of support groups comprising of women clients, confidentiality cited as a reason for the request. The request had come from peer care-givers and not the clients, and the respondent felt that this was not acceptable as it made them as male carers feel 'second grade'.

¹⁰ Plusnews 2005-01-21: <http://www.hst.org.za/news/20040618>

4.6.3. Clients' request for assistance from female carers.

The respondent cited examples where male clients have requested that their assigned care-giver be a female. While some thought that males would prefer to be cared for by males, this was not always the case. He felt that this could be attributed to the earlier presumption that it is traditionally thought that care-giving is the work of women.

4.6.4. Self doubt and doubt of the discipline

Men sometimes doubted their ability to undertake care-giving activities, which may lead to overall questioning of the discipline of care-giving.

4.6.5. Pride (looking down on the work of care-giving)

This is also aligned with the point above. The issue of stigma was also raised; the stigma associated with what friends and family are saying about you being a male carer.

4.6.6. Men, being breadwinners, cannot understand volunteerism

The respondent indicated that it is not easy for men to understand volunteerism. Even society expects men to be breadwinners; that every time they leave home to work, there should be a demonstration of economic output. It is not easy for men to be attracted to activities that are not likely to assist them in addressing their perceived obligatory role of being breadwinners. Further study may be needed to explore the concept of males as care-givers on a part-time basis or on the basis of them being employed somewhere else and volunteering little amounts of time to care-giving.

4.6.7. Bed-bound patients

There are situations where the care-giver is a primary care-giver and this, it was felt, poses a challenge due to the number of follow-up visits. The respondent commented that men are impatient and therefore do not have the perseverance to continuously return to the same place and repeat the same things.

5. ATTRACTING MALES TO BE CARE-GIVERS

It was quite interesting to note the differences in response between the male and female respondents. The responses by the management representative also did not mirror these responses, as expected by the researcher.

5.1. Response by male participants

5.1.1. Provision of stipends/payment

The males find it difficult to work as volunteers as they are breadwinners. Even though in this case, they would otherwise be unemployed if they were not care-givers, they feel that the stipends that they receive are too low and not able to satisfy their societal role of being a breadwinner. An increase in the stipends may help enhance recruitment of males to care-giving.

5.1.2. Attitude towards care-giving

The males feel that men need to be sensitised towards home based care, and that more information about the field should be made available to them.

Men still look down on care-giving, and this may be due to lack of information on what the field entails. Within the community, care-giving is still portrayed as woman's work, and for this to change, more information and education should be given to men and the community.

5.2. Response by women participants

Female participants reported that men lack affection and compassion, and since this is something one is born with, it cannot be taught. The women felt that men are also not able to keep their temper in check, losing it easily; and care-givers are not supposed to behave this way.

There was a feeling that men do not want to work with women and if they do, they want to assume leadership and command the women.

5.3. Response by Management

The management representative felt that the confinement of the recruitment of care-givers to within the church stifles the opportunity of attracting males to care-giving. The recruitment should be spread out to include other areas than churches, to

include places where men may generally be found. These places include meetings in bars, at borders, on the streets and street corners and can take forms of drums and plays. Men, it was said, usually just pass by, but can be attracted by promotional items which would make it easy to talk to them.

He acknowledged, however, that this current strategy seems to work more on prevention education than on recruitment, but that this can be explored further.

6. KEY FINDINGS AND RECOMMENDATIONS

6.1. Recruitment of care-givers

The recruitment practices indicate a focused drive that capitalises on the universal belief that the church represents what is compassionate and caring. It is evident that the drive did work in principle, with 80 percent of all those interviewed having heeded the church structures' call to assist in the community. Studies from Namibia, Uganda and Zimbabwe have also shown that in the recruitment of home based carers; the church is the preferred recruitment base.

There are other success stories throughout Africa. Where participation by males in care-giving activities has been higher, the recruitment has been extended to more than one focus group. Tovwirane AIDS Organisation in 52 villages in northern Malawi has 520 volunteers, of which 208 (40%), are men¹¹. Chiefs and church leaders were used to help identify possible volunteers who were provided with training, bicycles and team support.

Similarly, a project in Zimbabwe funded by the Development Cooperation of Ireland and John Snow International, UK, designed to address this imbalance by expanding men's role in care for people with HIV and AIDS. Recruitment employed the involvement of Headmen, Kraal Heads, local health clinic staff, and the Councillor in each of the four wards selected for the program. The programme succeeded in recruiting 120 participants¹².

¹¹ [http://www.alertnet.org/Mercedes Sayages](http://www.alertnet.org/Mercedes_Sayages)

¹² Man enough to care: Involving Men in Home-based Care Services for People Living with HIV/AIDS in Rural Zimbabwe.

Based on this evidence, it is recommended that recruitment of male care-givers should not be restricted to churches but should be expanded to other societal structures and institutions like traditional leadership, political leadership and clinics. In rural areas especially, traditional leaders have a multiplier effect and still enjoy support from the grassroots areas.

6.2. Men are looked at with suspicion

This response came up during interviews of both males and females, as well as during the focus group discussions. It is still a big challenge for men to provide care especially to women clients without having to 'prove' that they are legitimate, and without requesting the assistance of a female observer who is not necessarily a care-giver.

The Hospice Association of Zimbabwe found a similar view in a study of challenges of one of the home based care initiatives. The support group comprises mainly men who work closely with the women in the local communities. Males commented that when they had to visit a female patient, they could not bathe her, change her clothes or take her to the toilet. This makes it imperative to work in teams with female care-givers, which is not always feasible¹³.

The study also noted that in some cases women regarded their male counterparts with suspicion and blocked their efforts to provide care, since traditional culture had taught them to view tending to the sick as their domain¹⁴. Similar feelings were expressed in this case study in South Africa.

It is recommended that recruitment and involvement of men as care-givers should occur within a holistic programme which does not portray the drive to involve men in care-giving as a lack of faith in female care-givers and their ability to effectively carry out their duties. Female care-givers should be made to understand that the involvement of males will be in partnership with, and not against female care-givers.

¹³ (<http://www.hst.org.za/index.php>).

¹⁴ : <http://www.hst.org.za/index.php>

6.3. Relationship with stakeholders

The case study found out that there are no major challenges with relations between the male care-givers and stakeholders. Challenges identified were related to relations between one respondent and his family, and this was related to economic viability. The issue of stipends is discussed in detail further later in the report.

The current amicable relationships should be maintained through continued quality provision of services, and enhanced awareness to both the beneficiaries and the care-givers as to the importance of sustaining this endeavour.

6.4. Caring for care-givers

It is often assumed that care-givers are capable and healthy individuals with enough skills, attitudes and knowledge to provide care. The truth, however, is not always so rosy. Most care-givers themselves are either infected or directly affected by HIV and AIDS.

This case study revealed that there are no formal counselling sessions for care-givers, and none of the respondents felt that they needed debriefing or counselling despite acknowledging that their work at times becomes stressful.

In contrast, a research study of 41 care-givers by Dr. Olagoke Akintola from the University of KwaZulu-Natal demonstrated that women working as care-givers suffered severe psychological, emotional, physical and economic stress as a result of providing care. They often became so involved in supporting their clients that it undermined the wellness of their own families¹⁵.

Care-givers bury their feelings of anger, frustration, despair and helplessness which often lead to burnout in caring for people with HIV and AIDS¹⁶.

It is recommended that a formal programme for counselling or debriefing be implemented for care-givers so that they can vent their feelings and express their emotions in relation to caring for people with HIV and AIDS.

¹⁵ <http://www.mrc.ac.za/aids/oct2004/home.htm>

¹⁶ Larri Hayhurst-Australian nurse working in the Phillipines- <http://www.ipsnews.net/index.asp>

6.5. Stipends

The South African Department of Health reports to have recruited 40,000 health workers across the country by 2005, being paid stipends ranging from R1000-00 to R1700¹⁷ per month. This was in response to a report by Dr. Oleguke Akintola that the government should refine volunteer-based programmes, provide stipends and assist care-givers to ultimately obtain formal employment.

This case study affirms the study by Dr. Akintola, and reveals the need to refine volunteer-based programmes and standardise stipends as it is totally unacceptable that respondents in this study were being paid 20% of what is termed the national minimum average.

People living with HIV and AIDS easily constitute the majority of people who seek medical treatment at hospitals in South Africa. This picture is not likely to change unless a cure for HIV is found, or more hospitals and health care centres are built; but both are unlikely to happen in the short-term. Therefore, home based care is the best option in care for people with HIV and AIDS. The beacon of hope for those living with or affected by AIDS are volunteer care-givers like the respondents in this case study.

It is of utmost importance for the issue of stipends to be addressed. An imperative is placed on both the management and the funders of the care-giving activities to address the provision of stipends as they have a major impact on recruitment and retention of (male) care-givers. With the government reporting provision of stipends, it is recommended that management of the organisation forge a stronger linkage with the Department of Health to enhance their chance of benefiting from the government's non-government and community based organisation support.

All of the respondents commented on the need for a review of the stipends, and it did not make a difference whether they were breadwinners or not. The care-givers would prefer to have a minimum monthly stipend of five hundred rand (R500).

¹⁷ <http://www.hst.org.za/index.php>

7. CONCLUSION

There is a great need for the involvement of men in home based care, judging by the views of participants in this case study. The challenges raised by this and other studies have highlighted that there still is a need to overcome the conventional view that caring for the terminally ill is the responsibility of women. To ensure sustainable participation by males in home-based care programmes, social gender stereotypes need to be broken down.

Working with men is essential as they can play an equal role in providing home-based care within their communities, and can participate more fully in domestic work in their own homes¹⁸.

The recruitment of men to participate in home based care initiatives can have a major impact in the overall fight against HIV and AIDS. Men currently shape much of the world in which women live; as such, they must be partners in social change.

Men's participation in home-based care and other support programmes would be one way of heeding their responsibilities for the health and welfare of their communities and societies. Men and boys are best placed to challenge and recast harmful stereotypes of masculinity, to confront the scourge of violence against women, and to assume their share of responsibility for HIV prevention and protection, especially within intimate relationships¹⁹.

This study further highlights the need to review the concept of volunteerism in the time of AIDS. It can also act as a vehicle to perhaps get donors thinking more around these issues, and perhaps some common approaches with regard to sustainability of community based caring of HIV and AIDS patients. The study also highlights the need to investigate whether home based care becomes a formal occupation and whether there is a need to broaden home based care skills so that carers can become Community Health Workers.

¹⁸ UNICEF, UNAIDS, *Africa's Orphaned Generations*, New York, 2003. 2 Steinberg, M., Johnson, S., Schierhout, G. and Ndegwa, D., *Hitting Home: How Households Cope with the Impact of the HIV/AIDS Epidemic: A Survey of Households Affected by HIV/AIDS in South Africa*, Kaiser Family Foundation and Health Systems Trust, 2002.).

¹⁹ AIDS epidemic update December 2004 Women and AIDS.htm

This study was able to provide an insight into challenges faced in relation to recruitment of males as care-givers. The findings of the study were not easy to come to, as many responses were similar and did not provide enough range of views for comparison. Review of relevant literature has, however, confirmed the results of this case study as there is evidence of similarity between these results and those obtained through extensive qualitative studies.