

The impact of hiv aids on family care givers in a home setup

[Life](#), [Home](#)



**ASSIGN
BUSTER**

Abstract

Management of a Chronic HIV patient at home involves enormous dedication, effort and is stressful. The psychological, spiritual and financial needs of the caregivers are largely ignored. Reeling under enormous financial strain, compounded by the lack of support network, African women are forced to singlehandedly manage care delivery for the HIV patient and are stretched to breaking points. Stigmatization and social isolation that arise out of HIV care giving make them even more isolated and overwhelmed. The present study clearly highlights these failures. It is very clear that financial woes are among the biggest followed by the lack of support services. The Zimbabwean government is unstable and social welfare programs are hardly functioning. Even for those support services that are maintained and run by the Government, bureaucratic difficulties have made them inaccessible and out of reach of the poor caregiver. There is clear indication that support networks do not exist or atleast they are inaccessible. A collaborative action involving government, NGOs and other health agencies is called for. Home based carers should be trained, supported and counseled and policy level initiatives must be practically implemented. Only then could the quality of life for the patients as well as for the carers improve.

Introduction

HIV/AIDS is one of the most pandemic diseases in the world with an estimated 34 million people infected with the HIV virus. (amfAR, 2012)

Zimbabwe, in particular, has been worst hit by the HIV epidemic with more than 27% of the adult population diagnosed with HIV in 1997. Currently though, the prevalence rates have reduced significantly to 14% of the adult population (National AIDS Council, 2012). However, this decline is largely attributed to the significant number of deaths of people with HIV. Persistent political turmoil and the resultant economic decline have further contributed to the literal collapse of the Zimbabwean health care system. The failure of the Public health care system has cast the major burden of health care provision to private agencies, NGOs and Home based care has become the indispensable and only feasible model under the prevailing circumstances. Statistics suggest that of the 35, 000 children in the country that needed 'Antiretroviral Therapy' (ART) only 17, 000 have had access to the drugs (UNICEF, 2009). Though the availability of ART has vastly improved from just 15% in 2007 to around 80% by 2010, (National AIDS Council, 2011) there is still a huge unmet demand. Zimbabwean government's opposing attitude towards NGOs and its accusations about the NGO funds being used for anti governmental activities has further limited the already strained financial aid flowing into the country for AIDS care. Amidst these tiring circumstances, familybased care giving has become the central strategy for the national HIV/AIDS management programs. This paper attempts to study the impact of HIV/AIDS care delivered in the family based setting and how such care provision affects the care giver. In particular, this paper strives to highlight the issues such as the psychosocial impact on caregivers and using the caregiver's views assesses their coping and support mechanisms.

Home Based Care

A brief outlook into what constitutes home based care is appropriate before we proceed further. The World Health Organization defines home based care as “ a programme that through regular visits, offers health care services to support the care process in the homeenvironmentof the person with HIV infection. Home visits may be the only service provided or be part of an integrated programme which offers the patient and his/her family services in the home, hospital and community”. Ministry of Health and Child Welfare, (2004). From the definition it is clear that home based care is considered a holistic care solution that addresses the needs of both the care receiver as well as the care giver. This understanding is crucial for the successful implementation of the home based care delivery model.

Literature Review

Family based care provision is proving to be the important model in the delivery of care to chronic illnesses such as AIDS. Particularly in Zimbabwe, where decades of political and economic turmoil have weakened the health care system, the role of family based care provision could not be more emphasized. The political friction between the West and the Mugabe government, and the accusations about the political motives of the NGO operations in the country, led to a sharp decline in the active healthcare interventions in the country. NGO funding to Zimbabwe for its healthcare programmes reached a record low in 2006. During this year, the average aidmoneyfor HIV care per person in Zimbabwe was limited to \$ 4 which when

compared to the average aid money allotted per person in Zambia (\$184) is a meager amount (Matimba, 2010). However, since 2008, the aid to Zimbabwe is again on the rise with the USAID and DFID being the two key contributors. The USAID contributed 26. 4 million in 2008 while the DFID pledged in 2010 to contribute \$40 million over a five year period. Despite this the total aid money that Zimbabwe received for its HIV healthcare operations during this period is just one tenth of the aid money received by neighboring Zambia and one fourth that of the aid amount received by Namibia in the corresponding periods (AVERT, 2012). These statistics project the grim scenario from the financial standpoint in delivering HIV care in Zimbabwe where HIV has assumed endemic proportions.

HIV being a chronic condition, patients have to undergo continuous care for a protracted period of time and the hospital setting cannot handle the enormous demand. Statistics suggest that in Zimbabwe roughly 70% of all hospital admissions are connected to HIV care. Statistics also suggest that even a 5% increase in the number of HIV patients would result in a 25% increased demand for hospital beds. The figures indicate that hospitals, as care provision centers, for a country such as Zimbabwe where there is a swelling HIV population, is a highly unviable model and therefore community and home based care provision assume great significance. The policy stance of the Zimbabwean government to promote home based care provision could be understood based on these ground realities. The Zimbabwean government has been actively promoting care giver training by employing community nurses as trainers for these family care givers. With funding

limitations, even the training and support provided by the community nurses to the family care givers has been affected making them vulnerable to the enormous pressure of managing the care provision all by themselves (Matimba, 2010).

National Community Home-Based Care Standards (2004)

The enormity of the HIV problem and the limited nature of the government health care resources forced the home care system of care delivery in Zimbabwe. However, the quality of life of the HIV infected patient depends a lot on quality of the home care givers. In most cases these home based care providers have absolutely no training at all and even lack the knowledge to protect themselves from accidental exposure to HIV infection. To improve the quality of home based care delivery, support services must also be improved. With this in view the government of Zimbabwe set up the ‘National Community Home-Based Care Standards’ in 2004 that included the following important features

Care and Support for patients and Family

Team Service Provision

Governance and Management

Training , information and Education

Monitoring and evaluation

The main objective of establishing the standards for home based care delivery is to change home care from being perceived as a third rate care provision by improving its overall quality. It should be noted that Home care

is not just about the patients but also about the care giver. The national standards for Home care therefore lay this stress on providing holistic care support through an established standard. The process involves training, education, monitoring and continuous evaluation. The National Community Home-Based Care Standards (2004) neatly defines its purpose as “ Provision of a support system through the development of strong partnerships with the community, family and patient, home-based caregivers, and the health system, thus assuring patients an acceptable quality of life until death”. (Ministry of Health and Child Welfare, 2004). The definition also considers the aspects of support provided for the carer and other family members including “ emotional, spiritual and other psychosocial support, bereavement counseling, and other appropriate assistance that meets their special needs” (Ministry of Health and Child Welfare, 2004).

Psychosocial Impact of Caregiving

Literature is abound with studies that analyze the impact of care giving for a HIV patient, on the care-giver. Almost all of these studies indicate that care giving results in enormous psycho social impact on the provider. Typically, the family care giver maybe overcome with emotions ranging from , depression, anxiety, fear, anger , helplessness along with the overwhelming financial burden that is involved with HIV care provision. Lindsey et al., (2003) explored the effects of care giving on older and younger women in Botswana who were caring for family members with chronic HIV. The authors of the study identified that older women, in particular, were overwhelmed with the physical and mental demands of care giving. These women had to

manage demanding tasks such as caring for the patient with frequent episodes of vomiting, incontinence and confusion. Care giving family women had to do all this along with their household chores and this creates enormous physical hardships not to mention the emotional drain. Furthermore, in many cases, care providing women are subjected to economic strains when the productive member of their family is affected by HIV (Lindsey et al., 2003).

Another study by Ssengonzi (2007) explored the impact of care giving on Ugandan older women. The results of this study also chimed in with the findings of the previous study with the elderly Ugandan women reporting that care giving left them financially affected due to three main reasons

The ill relatives and the consequent loss of family income
the negative effect of care giving on the employment opportunities of the care provider

Expenses incurred on procuring medicine for the patient under their care

The care giving women also expressed social isolation as a result of their inability to participate in the usual social activities (Ssengonzi, 2007).

One study by Thomas F (2006) that assessed the impact of home based care giving for HIV patients in Namibia again reported that financial constraints due to care giving is a serious problem. This study collected information from both the patient as well as the care giver in the form of solicited diaries. The study found that the inability to provide for family created severe emotional strain for the care giver. Significantly, the study also reported that the

quality of care provision is affected over time when the worsening financial situation in the household coupled with the lack of recovery of the patient lead to escalating tensions and emotional upheavals in the house (Thomas F (2006).

One urban study conducted in Kinshasa, the capital of the republic of Congo, involved self reported health and emotional status of 80 spouses and caregivers of HIV infected men in the region. What surprised the researchers was that despite this being an urban study with better hospitals and home care support networks, around 94% of the women caregivers expressed that care-giving was very difficult for them and 99% reported that it affected their social lives. Importantly, 90% of these women care givers stated that they were stigmatized by friends and their husband's employers. This study clearly highlights that the stigma of AIDS care could further contribute to the emotional strain of HIV care. As a revealing study on the psychosocial impact of care giving, this research found that 48% of these care providing women were so unhappy with their circumstances that they lost interest in their life and expressed the lack of interest and energy to continue. Furthermore, 94% of these women had some form of physical ailment including frequent headaches, fatigue, body pain, lack of appetite, anorexia, etc (Kipp et al., 2006).

Studies done elsewhere in the developed countries also reflect similar feelings from the care givers. For instance one earlier study by Flaskerud & Tabora (1998) based on low income female care givers in California who provided care for heterosexual and homosexual HIV patients attested to the

findings from the African studies. These women expressed the same concerns as the previously listed studies including depression due to poor functional outcome of the patient, loneliness due to uncooperative and unsupportive friends and relatives, etc. Around 59% of the care giving women also reported that their physical health was affected considerably due to the prolonged period of care giving. Worn out by their care-giving duties these women were moody and even expressed their anger at the patients as their irresponsible behavior put them in this place. Last but not the least, the women subjects of this study welcomed being interviewed for the study as it provided an emotional vent for them to lay out their feelings which they could not so far share with anyone due to the absence of an appropriate support network. (Flaskerud & Tabora, 1998).

One recent South African study by Hlabyago et al. (2009) focused on one of the important problems faced by care givers of terminally ill HIV/AIDS patients. This problem is the caring for the orphaned children of the parents who succumbed to HIV. As per 2010 data, more than a third of the 50 million or more orphaned children in Sub Saharan Africa lost either one or both their parents to HIV. Given the huge scale of the problem, this study by Hlabyago assumes great significance in terms of policy formulations and also with respect to assessing the impact on family caregivers. The researchers of this study employed one on one interview technique which sought answers to the following important question from the care givers – “ Would you please tell me your experiences as a family caregiver concerning your care of the orphans?” (Hlabyago et al., 2009). The Interviews were conducted for nine

subjects who were home caregivers recruited from the Hoekfontein Clinic in South Africa. The demographic details of the subjects were noted down. Six out of the 9 (63%) care givers were grand mothers, 2 of them were aunties and one of them sister to the orphaned children. Thematic analysis of the data resulted in the observations that are listed in the following table.

As could be inferred from the above results table, financial constrain is a major problem for care givers affecting 77% (7 out of 9) of the study subjects. However, one concern that is uniformly expressed by all the care givers involved in the study was that of the existence of Bureaucratic difficulties and the lack of social support services. Though the government has programs to support orphans in the form of orphan grants, accessibility problems and processing delays and the lack of proactive approach within the social works departments hinder the outreach of such programs to the people. For instance, one of the caregiver, who was the grand mother of the orphaned child, expressed her helplessness stating, “ I got the heart to help this child by applying for this orphan grant. I am still waiting for the money because it is not yet released. I sent the documents a long time ago. The social worker has since told me that they will send someone at home and I am still waiting. I wish that money can come so that I can save some for him (the orphan) because I am old – anytime I can die, you see”. (Hlabyago et al., 2009).

The study also revealed that lack of support from family members is a pressing issue. One of the care giver subjects who were interviewed for the study reported that she received little support from her husband in taking

care of the orphaned Children. “ The day Johanna died he came and found me struggling with her, he came into the room and walked out, and when he came back again the child was already dead” (Hlabyago et al., 2009). Some of the care givers expressed concern about the rebellious attitude of the orphaned kids while some of them expressed concerns about the growing family conflicts due to the care giving. “ I decided to take him in and care for him. I think that she (the orphan’s biological grandmother) is thinking that because I am receiving this child’s orphan grant, she is not sending anything for this child who is basically her responsibility” (Hlabyago et al., 2009). The literature reviewed so far clearly highlighted that caregiving for HIV patients could be a stressful event and debilitate the care giver in the absence of suitable support mechanisms.

Methodology

The following sections will revolve around a questionnaire based primary study in which 15 subjects who were care providers for HIV patients in Zimbabwe were provided with 6 questions with various choices and their answers analyzed for themes. The choice of questionnaire was due to its informal nature and usefulness in gaining valuable data. The use of open ended questions helps in ascertaining more information from the subject whenever appropriate. Though initially I had sent my questionnaires to 15 recipients only 10 of them returned the completed information. All the 10 subjects were properly apprised of the nature of the study. Though the respondents knew that the study was purely for academic purposes they were delighted in providing the valuable information for the study. All the subjects

were assured of the confidentiality of their responses and that their responses would be used purely for academic knowledge improvement purposes. Thematic analysis was employed to discern useful themes and patterns about the various aspects of caregiving.

Results

The data from the questionnaires answered by the 10 subjects who participated in the study were analyzed to identify the emergent themes. In all, six questions with varied responses to each question were provided to the subjects. These questions were particularly relevant to understanding the wide impact that care giving has on the home based care providers. The results revealed some of the important psychosocial aspects of caregiving. The repetitive themes that were identified from the data attested to the key findings reported in the literature review early in this paper. These common themes suggest the need for urgent action.

Care giving challenges

The data from the questionnaires revealed some demographic profile about the subjects. Most of the carergivers in the study were relatives of the HIV Patient and on an average care provision period lasted between 2 and 3 years. 80% of the caregivers were elderly females. Economic difficulties dominated the challenges that were reported by the caregivers with almost 90% of the subjects reporting financial constrains as a serious issue involved in prolonged caregiving for the HIV patient. As discussed earlier in the paper this may stem from loss of income if the patient was a productive member of

the family. Caregivers are also constrained by the fact that they could not be gainfully employed when they are tied down with caring for the patient.

One other important aspect pertaining to caregiving at home was the lack of adequate transport services. 80% of the caregivers opined that they find transporting the patient to the hospital during times of emergency a huge problem as the Ambulance services are not prompt. Subjects also complained that the ambulance services charge them for the fuel costs. Most of the subjects stated that they took the responsibility of caregiving out of love and compassion to the patients. When asked about the support services that could have helped them a lot with their care giving almost all the subjects mentioned transportation as an important feature. 30% of the subjects felt that providing food care for the patients and opportunities for part time employment for themselves would have been greatly helpful. 40% of the caregivers also expressed their concern that the scarcity of water in rural Zimbabwe added more problems to them as they could not walk several kilometers to fetch water leaving their sick patients at home. This is a very relevant issue as Zimbabwe is one of the African countries that is hard hit by water crisis, and more often than not, functional borewells that are the only nearby sources of water would be several kilometers away. There were also concerns about the medication supply with 40% of the caregivers complaining about shortage and availability of ' Anti retroviral Drugs' at the local dispensary. The continuous availability of ART is critical for HIV patients in order to prolong their life.

It was also interesting and informative to note down that 7 out of the 10 subjects felt that this small questionnaire project, though it was done for educational purposes, provided them with an opportunity to discuss the problems involved in care giving. The seven care providers felt that the questionnaire provided them an emotional purge as they had not had a chance to discuss their difficulties with anyone else. They all felt that there was a complete lack of support mechanisms available for carers and that this made them feel helpless and emotionally dissipated time to time.

Conclusion

Caregivers undergo enormous stress during the protracted period of care giving that is involved in managing a chronic HIV patient. Just as care givers provide so much of love, effort and care to the patients they look after, their needs should also be looked after. The psychological, spiritual and financial support that caregivers require are however largely unfulfilled. Especially when there is political and economical turmoil in a country, such as that seen in Zimbabwe, the needs of the home based care provider is more likely to be ignored.

As the numerous studies that were discussed in the paper reported care givers are mostly women and predominantly elderly women. Reeling under enormous financial strain, compounded by the lack of support network, African women are forced to singlehandedly manage care delivery for the HIV patient and are stretched to breaking points. Stigmatization and social

isolation that arise out of HIV care giving make them even more isolated and overwhelmed.

The present study based on the information gathered from caregivers in Zimbabwe clearly highlights the plight of the caregivers. It is very clear that financial woes are among the most important to the caregiver, followed by the lack of support services. Zimbabwean government is unstable and social welfare programs are hardly functioning. Even for those support services that are maintained and run by the Government, bureaucratic difficulties have made them inaccessible and out of reach of the poor caregiver. Counseling support services for caregivers are distinctly lacking. Based on the opinion gathered from the study and other relevant literature, it is clear that holistic care as advocated in the National Community Home-Based Care Standards (2004) is still far from reality. There is clear indication that support networks do not exist or are inaccessible. Based on these findings this paper concludes that family based care givers are struggling without access to support services. A collaborative action involving government, NGOs and other health agencies is required to correct the defects. Home based carers should be trained, supported and counseled, and policy level initiative must be practically implemented. Only then could the quality of life for the patients as well as for the carers improve.

Bibliography

AVERT, (2012), HIV and AIDS in Zimbabwe, viewed Jan 1st 2012,

< <http://www.avert.org/aids-zimbabwe.htm#contentTable5>>

<https://assignbuster.com/the-impact-of-hiv-aids-on-family-care-givers-in-a-home-setup/>

amfAR, (2012), Statistics Worldwide, viewed January 1st 2012

Hlabiyago KE & Ogunbanjo GA (2009), The experiences of family care givers concerning their care of HIV/AIDS Orphans, SA FAM PRACT Vol 51, no 6 pg 506-511.

Kipp W, Matakula Nkosi T, Laing L, Jhangri GS, (2006), Care burden and self-reported health status of informal women caregivers of HIV/AIDS patients in Kinshasa, Democratic Republic of Congo. AIDS Care, Oct; 18(7): 694-7

Lindsey E, Hirschfeld M, Tlou S, Ncube E. (2003), Home based care in Botswana: experiences of older women and young girls. Health Care for Women International; 24: 486-501

Ministry of Health and Child Welfare, (2004), National Community Home based Care Standards, viewed Jan 1st 2012,

< http://www.jsieurope.org/docs/national_community_hbc_standard.pdf>

Natsayi Matinba, (2010), The Psycho Social impact of Care-Giving on the Family Care-Givers of Chronically ill AIDS/HIV Patients in Home based Care. Research Report, University of Witwatersrand, SA.

National AIDS Council, (2011), UNAIDS highlights Zimbabwes progress in response to AIDS, viewed January 1st 2012,

< <http://www.nac.org.zw/news/unaidshighlightszimbabwe%E2%80%99s-progressresponding-aids-0>>

<https://assignbuster.com/the-impact-of-hiv-aids-on-family-care-givers-in-a-home-setup/>

Ssengonzi R. J. (2007), The plight of older persons as caregivers to people infected/affected by HIV/AIDS: evidence from Uganda. *J Cross Cult Gerontol*; 22: 339-353

Thomas F. (2006), Stigma, fatigue and social breakdown: Exploring the impacts of HIV/AIDS on patient and carer well-being in the Caprivi Region, Namibia. *SocialScienceand Medicine* 63: 3174-3187

UNICEF, (2009), HIV and AIDS Issues, viewed January 1st 2012,

< http://www.unicef.org/zimbabwe/hiv_aids.html >