



Components, Practices and Benefits of Home Based Care of HIV and AIDS Patients in Kenya: Butula Local Community's Perspective

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Abstract

With the current diminishing global funding for the HIV/AIDS containment and dramatic increase in the reliance on Home Based Care (HBC) throughout Africa (Akintola, 2006) and other parts of the world, a rich understanding of the various components and benefits of HBC is indispensable. The main aim of this study was to examine the components, practices and benefits of HBC of HIV/AIDS patients with the reference to Butula Local Community in Kenya. The study employed a cross-sectional survey research design. The sample included three hundred and seventy seven respondents from Butula Division. Questionnaire method was used to collect data owing to its appropriateness in collecting data from a large sample. A statistical application, namely SPSS aided data analysis process. The study revealed that the key components of HBC were counseling (38%), nutrition (30%), social support systems (17%) and nursing (15%). The main practices of HBC included referral systems of HBC, medication and nursing of the HAPs Benefits of HBC were patients are nursed in familiar environment (41%), affordability (31%) and good support from family members (14%). Registered patients also benefited from free food rations and free medication. In order to realize the greater benefits of HBC, the study recommended integration of informal and formal referral systems, greater involvement and support of Ministry of Health in local community networks and initiatives for social protection.

Keywords: Home Based Care of HIV and AIDS patients, home based care components, home based care benefits, Butula HIV and AIDS home based care program, HIV and AIDS patients

1. Introduction

The concept of Home Based Care (HBC) entails the provision of care to HIV/AIDS patients and their affected families at home. In the modern society, HBC programs and practice have gained dominance and popularity due to the beneficial assistance that this program grants to health care facilities as well as reducing the expenses that could have otherwise been used to expand the care facilities in government hospitals. Moreover, studies have indicated a constantly enlarging number of HIV/AIDS infected patients leading to over stretching of the available facilities. As such the practice has provided for a palatable solution to the overwhelming congestion witnessed in general public health facilities. Further, HBC offers adjustable and flexible care provision for the HIV/AIDS patients as well as for the loved ones and affected families (International Labor Organization [ILO], 2011) According to a study by UNAIDS (2007). the practice of HBC for HIV/AIDS patients can be categorized into almost seven different but related activities. These categories include: the actual provision of care; continuum of care; education; supplies and equipment's; staffing; financing and sustainability; monitoring and evaluation. Moreover, HBC has strong founding principles in involving the community at large to provide care for HIV/AIDS patients. It is noted that this program focuses on preserving the traditional patterns of care which encourages family members to take the forefront responsibility in caring for their sick loved ones (Kronenfeld, 1982). As such the program seeks to ensure that the family members and community in general get actively involved in creating a caring community for the sick individuals within it.

In Sub-Saharan Africa, the most practiced HBC provided for HIV/AIDS patients involves activities such as physical, psychosocial, palliative and spiritual accompaniments (Kronenfeld, 1982). This may be for the reason that most of the affected countries have limited resources kept aside for the provision of adequate HBC practice for HIV/AIDS patients. Notably, HBC programs supplements largely the formal health care provided in the government hospitals, clinics and other community and local posts. It is noteworthy that initially in Africa, HBC programs were administered by professional nurses and social workers, who could move from door to door to offer necessary support both for the infected individuals and the affected families (Wringe, Cataldo, Stevenson, & Fakoya, 2010). Today, in the light of constantly enlarging number of infected people who need health professionals' attention and care, the number of patients have overwhelmed the skilled personnel. This lack of skilled professional to attend to the large number of people has inevitably necessitated the birth of a new approach to help in the care provisions. As such, most Sub-Saharan countries have adopted community mobilization as a strategic intervention for the continuity of HBC programs (UNAIDS, 2008)

Further, studies have also shown that the affected persons also need a lot of counseling guidance from professional councilors as a way of enabling them cope with the reality of the HIV/AIDS epidemic. This has also increased the need for professionals and so enlarging the window for more people to be absorbed in the practice to ensure adequate facilitation of HBC program. Therefore, the adopted community mobilization approach

gave space for the conception of volunteer caregivers who were mainly lovers, spouses, friends or family of an individual with AIDS (Kronenfeld, 1982). In most cases, volunteers are not trained professional care providers, yet they provided though restricted services to the patients and family members. They also visit homes, provide essential nursing administrations, health education as well as offer guiding and counseling session. They also provided nutritional monitoring services together with some psychosocial support to the infected and affected families (Kronenfeld, 1982). With the current diminishing global funding for the HIV/AIDS containment and dramatic increase in the reliance on HBC throughout Africa (ILO, 2011) and other parts of the world, a rich understanding on how HBC is practiced is essential. Thus, this study sought to establish the components and benefits of HBC of HIV/AIDS patients in Kenya's rural context.

2. Methodology

The study employed descriptive cross-sectional survey research design. The design was appropriate since it allows data collection from a sample which is statistically representative (Owens, 2002) and makes use of questionnaire method. Further, the design allows use of quantitative approach in analysis. The target population included members of local communities in Butula Division and health care providers. Cluster and random sampling procedure were used to arrive at three hundred and seventy seven respondents from the division. The division was first clustered into its locations from which a list of households was prepared. A representative number of respondents were picked from the list using simple random sampling procedure. Data were collected using questionnaire method. The choice of this method was informed by the following reasons: administration is comparatively inexpensive and easy even when gathering data from large numbers of people spread over wide geographic area, reduces chance of the researcher's bias because the same questions are asked of all respondents and is easy to code and tabulate data. Descriptive statistics were used to report the findings. A statistical application, namely IBM SPSS aided data processing. The processed data were reported using frequencies and percentages and summarized using Tables and Figures.

3. Results

3.1 Demographic Characteristics of the Respondents

The demographic characteristics of the respondents included sex and age. Out of the three hundred and seventy seven respondents who took part in the study, 32% of them were male. The remaining 68% were female. The age distributions showed that majority of them, (62%) were between the ages of 21 to 25 years.

3.2 Components of Home Based Care

The study sought to establish the major components of Home Based Care of HIV/AIDS patients among the people of Butula Division in Kenya. In order to assess the knowledge of these components, respondents were asked to identify them.

Table 1: *Components of Home-Based Care for HAPs*

Componets	Frequency	Percentages
Counselling	132	35
Nutrition	91	24
Social support systems	75	20
Nursing	41	11
Treatment	38	10
Total	377	100

As illustrated by Table 1, about one third of the respondents, (31%) recognized counselling was one of the key components of HBC. Another 20% of the respondents indicated that nutrition was also a key component. Other components included social support systems (20%), nursing (11%) and treatment (10%).

3.3 Practices of Home-Based Care for HAPs

The study examined knowledge of various key practices of HBC of HAPs in Butula Division. The practices covered included referral systems of HBC, medication and Nursing of the HAPs

3.3.1 Referral system practice

In reference to the referral system as a practice of HBC, 41% of the respondents indicated that they had no knowledge of its existence. Another 34% were aware of the practice while 25% indicated that the practice did not exist at all.

3.3.2 Medication of HAPs

The respondents were also asked to indicate about the practice of medication and its sources. These included government health centres and hospitals, community health centres and Traditional herbal medicine practitioners.

Table 2: *Sources of medication by the HAPs*

Sources of medication for HAPs	Frequency	Percentage
Government health centres	122	32
Community health centres	232	62
Traditional herbal medicine practitioners	23	6
Total	377	100

As illustrated by Table 2, about a two third (62%) of the respondents indicated that their main source of medication was community health centres. Another source of medication as indicated by 32% of the respondents was government health centres and hospitals. Only 6% indicated that their source of medication was traditional herbal medicine.

3.3.3 Nursing of the HAPs

Under Nursing of the PLWHAs practice, the study considered the issue of HAPs nursing persons and the nursing protective gears used for HAPs

The main nursing persons for HAPs as established by the study were relatives (61%), and community health workers (32%). Other persons included church members (5%) and friends (2%).

In regards to nursing protective gears used for HAPs, the study found that over two third (75%) of the respondents indicated that nursing agents used gloves and/or protective clothing. Others indicated that the practice was done with bare hands (18%) and nylon papers (7%).

3.4 Benefits of home based care of HAPs

The study was interested in establishing the key benefits of Home Based Care of HAPs in Butula. The distribution of the respondents on the key benefits of HBC is shown by Table 2.

Table 3: *Benefits of home based care*

Benefits of HBC	Frequency	Percentage
Patients nursed in familiar environment	153	41
Affordable	113	31
Close support from family and relatives	54	14
Other benefits (flexible visitations, easy access to patients, helps in reducing stigmatization)	57	14
Total	377	100

Over one third (41%) of the respondents indicated that the key benefit of HBC was that the patients are nursed in familiar environment. Another 31% of the respondents indicated that affordability was also a key benefit. Other benefits as indicated by a few others included close support from family and relatives, flexible visitations, easy access to patients and stigmatization reduction.

4. Discussion

There are various components of HBC. According to National Guidelines for the Clinical Management of HIV/AIDS [NACP] (2005), HBC components include the following: Treatment of opportunistic infections, nursing care, monitoring for early side effects, medication, Nutritional care, Hygiene, Exercises, Emotional support, Social support, Spiritual support, Legal support, Economic support. About one third (31%) of the

respondents in this study, indicated that counselling was one of the key components of HBC of HAPs in Butula.

Counselling has been shown to be the most effective gateway for getting those who tested HIV-positive into care at an early stage of HIV disease, before they became ill (Leach-Lemens, 2012). Thus, it remains to be a major component of HBC. Another key component indicated by 20% of the respondents was nutrition. According to Education Training Unit [ETU], (2003), good nutrition is one of the most important ways of strengthening the immune system for HIV/ADS patients. Thus, it can also be considered as a key component as identified by some of the respondents. In essence, counselling without nutritional accompaniment is meaningless.

The study examined the key practices of HBC, namely referral systems of HBC, medication and Nursing of the HAPs. Referral systems form one of the key element for an effective continuum of care for HIV/AIDS patients. Therefore it remains to be a vital element in the practice of HBC for HAPs. The finding of this study, however, showed that almost half (41%) of the respondents were not aware of the practice, which could imply low penetration and lack of sound referral systems of HAPs in Butula. Family Health International (2005) observes that low resource areas lack sound referral networks for comprehensive HIV care. Butula experience thus appeared not to be an isolated case.

Medication is another common practice of HBC. The study showed that the main source of the medication as a key practice of HBC was community based health centres (62%). This could be attributed to the fact that Community Based organizations play a critical role in community health interventions. As such, the Community health centres become the main sources of medication in Home Based Care for HAPs in rural set up like Butula.

Nursing was another common practice in HBC of HAPs. According to 61% of the respondents in the study; relatives were the main nursing persons in HBC of HAPs. Other studies also showed similar trend where relatives have been found to have the largest share of contribution in HBC of PLWHAs (NASCOP, 2000; Kija 2011; Avert, 2012). According to Avert, (2012), much of the care for people living HIV and AIDS is provided at home by relatives, friends and care givers from community based organizations.

There are various benefits that come with HBC for HAPs. From the study, nearly half (41%) of the respondents indicated that through HBC, patients are nursed in familiar environment. HBC is also shown to be considerably affordable and the patients get easy support from family members and friends. The study also found that HBC helps in stigma reduction. Earlier studies showed related findings. A study by Tanzania Commission for AIDS, (2015) revealed that HBC has benefits to the patients and family as well as the community at large. Through this program, the financial expenses of caring for patients away from the family are also reduced. For the family, HBC helps hold the families together with the objective of caring for the patient as well as assisting the

family to accept the patient's conditions. It reduces costs of care as well as enabling the family to attend to other tasks as they care for the patient.

In the same vein, another study by Akintola (2006) indicated that owing to the rapidly diminishing capacity of many nations' health sectors which basically cannot contain the increasingly ballooning HIV/AIDS epidemic, HBC thus becomes palatable means to put the citizen's lives in the right course. Further, Ogden, Esim, Grown (2006) observed that HBC program keep the patients from being exposed to hospital-based infectious diseases as well as allow the terminally ill patients to spend their final moments of their lives with their family members. Through HBC program, the care givers are also in a position to work even as they care for the sick. According to Mabude (2008), HBC at times may results as a necessity rather than a voluntary choice for the patients. This can be attributed to the fear of stigma and discrimination from health care practitioners directly especially to the HIV/AIDS patients which can somehow can deter people to seek care in the hospital setting.

5. Conclusions and Recommendations

5.1 Conclusions

Based on the key findings, the study concludes the following:

- a) The success of the HBC program is hinged primarily on the successful execution of every component including community physical, emotional and social support components which are inherently interrelated.
- b) The good gains of HBC in rural settings can be thwarted if sound HBC practices such as referral system, medication and nursing are not closely supported.
- c) Without full government support of HBC, the full realization of the potentials and benefits of Home Based Care may not be achieved.

5.2 Recommendations

To ensure adequate knowledge of the various components of HBC among the local community of Butula, Health institution in collaboration with Community Based Organizations (CBO) are to come up with awareness and sensitization programs. To this end, additional resources in terms of personnel and finance may be required to ensure the sustainability of these programs.

The government initiatives geared towards attainment of national health objectives should be well structured and collaborated to ensure the various components of HBC are effectively executed. These government initiatives should primarily focus on the importance of collaborating the local community in the fore-front workforce to ensure continuity and sustainability of the program. This will call for adequate integration of both the informal and formal referral systems. Moreover, the general public and health care providers should be educated on the importance of cost effective functional referral systems. To ensure enshrined importance of HBC, private health facilities should be encouraged to refer back patients to HBC services. In addition, a dialogue should be

initiated between private medical providers on how they can adequately fit in the community health care referral framework.

Granted the overall benefits of HBC as an alternative approach of caring for patients with HIV/AIDS, the government and all the other stakeholders need to closely monitor and so evaluate the progress of the program in the particular community. This is essential to determine the achievements in light of the expected outcome and all the other input and out-put related factors and provisions.

Most importantly, the community at large should be adequately be informed and properly sensitized so that every community member identifies him/herself as the core drives of the HBC initiative. The community should satisfactorily understand the benefits of Home Based Care and the role they play in the sustainability of the program.

References

Akintola, O. (2006). Gendered home-based care in South Africa: More trouble for the troubled, *African Journal of AIDS Research* 5(3).

Avert, (2012). *HIV & AIDS Home-based Care*. Retrieved from <http://www.avert.org/hiv-aids-home-based-care.htm>

Education Training Unit [ETU]. (2003). *How to deliver care for people with HIV/AIDS and their families*. Retrieved from <http://www.etu.org.za/toolbox/docs/aids/family-care.html>.

Family Health International [FHI] (2005). *Establishing referral networks for comprehensive HIV care in low-resource settings*. Retrieved from http://pdf.usaid.gov/pdf_docs/PNADF677.pdf.

International Labor Organization [ILO] (2011). The cooperative model for the delivery of home based care services for people living with HIV. Retrieved from http://www.ilo.org/public/english/employment/ent/coop/africa/download/wp19_cooperativemodel.pdf.

Kija M, (2011). Home based care for people living with HIV/AIDS: Assessment of knowledge, attitude and practice among family care givers at Ukonga ward in Ilala district, Tanzania. *The Dar-es-salaam Medical Students' Journal - DMSJ*

Kronenfeld, J. J. (1982). *Organization of ambulatory care by consumers*. *Sociology of Health & Illness*, 4: 183–200. doi: 10.1111/1467-9566.ep11339942

Leach-Lemens, C. (2012). *Home-based counseling and testing identifies people in need of treatment earlier*. Retrieved from

- <http://www.aidsmap.com/Home-based-counselling-and-testing-identifies-people-in-need-of-treatment-earlier/page/2210157/>
- Mabude, Z. (2008). A national survey of home-based care kits for palliative HIV/AIDS care in South Africa, *AIDS Care*, 20(8).
- National Guidelines for the Clinical Management of HIV/AIDS [NACP] (2005). Components of Home Based Care. Retrieved from <http://collections.infocollections.org/whocountry/en/d/Js6885e/11.4.html>
- National AIDS and STDs Control Programme [NASCOP]. (2000). *National AIDS Strategic Plan*. Nairobi: Government Press
- Ogden, J., Esim S, Grown C. (2006). Expanding the care continuum: Bringing carers into focus. *Health Policy and Planning* 21(5):333-42. Available from <http://www.ncbi.nlm.nih.gov/pubmed/16940299>.
- Owens, L.K (2002). Introduction to survey research design. Retrieved from <http://www.srl.uic.edu/seminars/Intro/introsrm.pdf>
- Tanzania Commission for AIDS (2015). Home Based Care (HBC) Retrieved from http://www.tacaids.go.tz/index.php?option=com_content&view=article&id=121:home-based-care-hbc&catid=46&Itemid=243
- United Nations Programme on HIV/AIDS [UNAIDS]. (2007). Reducing HIV Stigma and Discrimination: a critical part of national AIDS programmes. A resource for national stakeholders in the HIV response. Retrieved http://data.unaids.org/pub/Report/2008/jc1521_stigmatisation_en.pdf.
- United Nations Programme on HIV/AIDS [UNAIDS]. (2008). Report on Global Aids Epidemic. Retrieved from http://data.unaids.org/pub/GlobalReport/2008/jc1511_gr08_executivesummary_en.pdf
- Wringe, A, Cataldo, F, Stevenson, N & Fakoya, A (2010). Delivering comprehensive home-based care programmes for HIV: a review of lessons learned and challenges ahead in the era of antiretroviral therapy', *Health Policy and Planning*, 1-11.
- Zerfu1, T. A., Yaya, Y., Dagne, S., Deribe, K., Ruiseñor-Escudero, H. & Biadgilign, S. (2012). Home and community based care program assessment for people living with HIV/AIDS in Arba Minch, Southern Ethiopia. *Annals of Surgical Innovation and Research*. Retrieved from <http://www.biomedcentral.com/1472-684X/11/8>.