

**EFFECTS OF HOME BASED CARE SERVICES ON THE PREVENTION AND  
SPREAD OF HIV/AIDS IN KAMPALA CENTRAL**

**BY**

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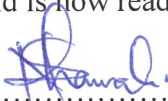
### DECLARATION

I **Kamwine Everlyne** declare that to the best of my knowledge, the work presented here is original and has never been presented to any institution of learning for any academic award.

Signature.......... Date.....21.09.2017.....

### APPROVAL

This is to acknowledge that this research is done under my supervision as a University Supervisor and is now ready for submission.

Signature..........Date.....21.09.2017.....

**Ms. Shamillah Nassiwa**

## **DEDICATION**

I wish to dedicate this research to the Almighty God who protected me during my three years course.

In as special way I wish to dedicate this research to my parents Mr. James Kapoteri, mum Mrs. Joy Kapoteri, my sisters Annet Twine. K., Vanessa K. Eva Samuel Lupai and my brother Kiribata for the endless support, love and care since my childhood thank you so so much, it is an endless appreciation but God should keep you alive.

To all my dear friends who gave me good advices and support and every one who has been their, for me ever since I started campus.

Lastly to my supervisor Ms. Shamillah Nassiwa who guides me in compiling work inside this research. Thank you very much.

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## **LIST OF ACRONYMS**

AIDS.....	Acquired Immunodeficiency Syndrome
FBO.....	Faith-Based Organizations
HBCS.....	Home-Based Care Services
HBC.....	Home Based Care
HIV.....	Human Immunodeficiency Virus
LMICs.....	Low-and middle-income countries
MOLISA.....	Ministry of Labor, Invalids and Social Action
NGOs.....	Non-Governmental Organisations
NSPs.....	Needle and Syringe Programmes
OST.....	Opioid substitution therapy
TRIPS.....	Trade-Related Aspects of Intellectual Property Rights
WHO.....	World Health Organization



## **CHAPTER ONE**

### **INTRODUCTION**

#### **1.0 Introduction**

This chapter presented the background to the study, statement of the problem, purpose of the study, research questions, hypotheses, conceptual framework, significance of the study, justification of the study, scope of the study, operational definitions and anticipated constraints of the study.

#### **1.1 Background to the study**

##### **Historical perspective**

Globally, the epidemic of AIDS has become one of the most pressing public health emergencies of this century. Initial reports of AIDS date back to 1981. However, current data suggest that AIDS has existed for at least several decades. While both forms of the human immunodeficiency virus (HIV), type 1 and type 2 are retroviruses capable of causing fatal AIDS, infection with the latter generally results in a longer incubation period and a more indolent course of disease. However, the vast majority of people living with HIV are in low and middle-income countries. Sub-Saharan Africa is the most affected region with an estimated 25.6 million people living with HIV in 2015. About 66% of new HIV infections in 2015 occurred in sub-Saharan Africa, an estimated 35 million people have died from AIDS-related illnesses since the start of the epidemic including 1.1 million in 2015. However, effective treatment with antiretroviral drugs can control the virus so that people with HIV can enjoy healthy lives and reduce the risk of transmitting the virus to others, Epping-Jordan et al. (2014).

The HIV epidemic not only affects the health of individuals, it impacts households, communities and the development and economic growth of nations. Many of the countries hardest hit by HIV also suffer from other infectious diseases, food insecurity and other serious problems, despite these challenges, there have been successes and promising signs. New global efforts have been mounted to address the epidemic particularly in the last decade. Prevention has helped to reduce

HIV prevalence rates in a small but growing number of countries and new HIV infections are believed to be on the decline. In addition, the number of people with HIV receiving treatment in resource-poor countries has dramatically increased in the past decade. Progress also has been made in preventing mother-to-child transmission of HIV and keeping mothers alive. In 2015, 77% of pregnant women living with HIV globally had access to antiretroviral medicines to prevent transmission of HIV to their babies; new HIV infections among children have declined by 50% since 2010, Duffy (2017).

East and Southern Africa is the region that is hardest hit by HIV. It is home to 6.2% of the world's population but has 19 million people living with HIV, over 50% of the total number of people living with HIV in the world. In 2015, there were 960,000 new HIV infections, 46% of the global total (UNAIDS, 2016). South Africa accounted for 40% of the region's new infections in 2015, with another 50% occurring in eight countries: Ethiopia, Kenya, Malawi, Mozambique, Uganda, the United Republic of Tanzania (Tanzania), Zambia and Zimbabwe.

In East Africa, Kenya and Tanzania are all home to significant populations of people who inject drugs. Although regional data is limited, country surveys among people who inject drugs suggest high HIV prevalence. In Kenya, HIV prevalence among people who inject drugs was 18% in 2011, compared to 5.6% among the general population. In 2012, the country introduced needle and syringe programmes (NSPs) and Opioid substitution therapy (OST) to help reduce HIV transmission among this population. In 2015, nearly 90% of people who inject drugs reported using a clean syringe last time they injected compared to 51.6% in 2012.

In Uganda, back in the 1980s more than 30% of Ugandans had contracted the HIV virus. Now the national prevalence rate is around 6.4%, an achievement attributed largely to the country's rapid acknowledgment of the crisis it faced, the roll out of national prevention and treatment messages and its embrace of open discourse around causes and solutions to the virus. Around 130,000 Ugandans are infected with the HIV virus every year, according to the Uganda Aids Commission. However, according to United Nations Report of 2016, if youth are not sensitized, the government's new national HIV/Aids strategic plan bleakly predicts that the number of HIV

positive Ugandans will rise from 1.1 million in 2006 to 1.3 million in 2022, (Harding et al. 2014).

### **Theoretical perspective**

Social influence theory was used in the research since it explains why some people listen to others and how one person persuades others to change their beliefs, opinions and attitudes. Thus research has found that people are willing to go against their own beliefs to harm another when instructed to do so by an authority while some use opinions of others as a guide to reality in situations that are ambiguous and uncertain (Miltenberger, 2015). The theory focuses on the social realities of participants with implications for understanding social influence, messages, and meanings from their viewpoint. From this perception, social influence consists of the processes whereby people aggregate appropriate behaviour and form, maintain or change social norms and the effects thereof, as well as the social conditions that give rise to such norms.

In HIV and AIDS prevention, social influence and social norms directly impact high-risk sexual behaviours for example, in their study among adolescents' perceptions on condom use (Chartonet al. 2011). *AIDS and Behavior*, 10(6), 723–729 found that those who perceive that their peers support condom use are more likely to use them. Social influence approaches emphasize behavioural expectations and standards (social norms) present in the environment and prepare the learner to resist pressure to engage in risk-taking behaviours, Kloos et al. (2015).

### **Conceptual perspective**

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 health facilities. As such the practice has provided for a palatable solution to the overwhelming congestion witnessed in general public health facilities, Osborne et al. (2015).

**Concept of HIV/AIDS;** HIV stands for human immunodeficiency virus and if left untreated which can lead to the disease called AIDS (acquired immunodeficiency syndrome). Unlike some other viruses, the human body can't get rid of HIV completely. So once you have HIV, you have it for life. Over time, HIV can destroy so many of these cells that the body can't fight off infections and disease, Blackstock (2015). These opportunistic infections or cancers take advantage of a very weak immune system and signal that the person has AIDS, the last state of HIV infection. However there is no effective cure for HIV currently exists but with proper treatment and medical care, HIV can be controlled. The medicine used to treat HIV is called antiretroviral therapy and if taken the right way, every day this medicine can dramatically prolong the lives of many people with HIV, keep them healthy and greatly lower their chance of transmitting the virus to others. Today, a person who is diagnosed with HIV, treated before the disease is far advanced and stays on treatment can live a nearly as long as someone who does not have HIV, Bock, et al (2014).

Acquired Immunodeficiency Syndrome (AIDS) is the final stage of HIV infection, and not everyone who has HIV advances to this stage. AIDS is the stage of infection that occurs when your immune system is badly damaged and you become vulnerable to opportunistic infections. HIV infection can cause AIDS to develop. However, it is possible to be infected with HIV without developing AIDS. Without treatment, the HIV infection can progress and, eventually, it will develop into AIDS in the vast majority of cases. Once someone has received an AIDS diagnosis, it will always carry over with them in their medical history, Bateman (2011). When the number of your CD4 cells falls below 200 cells per cubic millimeter of blood (200 cells/mm<sup>3</sup>), you are considered to have progressed to AIDS. (The CD4 count of an uninfected adult/adolescent who is generally in good health ranges from 500 cells/mm<sup>3</sup> to 1,600 cells/mm<sup>3</sup>).

### **The Contextual perspective**

According to a study by UNAIDS (2014), the practice of Home Based Care 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, Home Based Care

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; Tarwireyi (2015). 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. Up to 80% of AIDS-related deaths occur in the home and 90% of care is provided in the home and is linked to health services. Home-based care programmes were developed with a view to assisting family caregivers in providing AIDS-related care, because public health services could not cope with the increasing demand for treatment and care. These initiatives have evolved and they vary in the types of care and support they provide. Some home-based care services focus on providing social and psychological support, with some nutritional support and basic nursing care.

## **1.2 Statement of the problem**

HIV is the virus which attacks the T-cells (CD-4 cells) in the immune system and appears in the advanced stage of HIV infection, it attacks the body's immune system specifically the CD4 cells (T cells) which help the immune system fight off infections. If left untreated, HIV reduces the number of CD4 cells (T-cells) in the body, making the person more likely to get infections or infection-related cancers. On the African continent, upon the discovery of the first AIDS case in the early 1980s, AIDS was being treated as a medical problem resulting in medically designed 'AIDS control' programmes, ignoring the social dimension, Bock et al (2014). As a result difficult policy issues such as condom advertising in the mass media came to light and no specific regulations or laws were in place, Cintron, (2014). In the early 1990s as the number of AIDS deaths began to increase and external, international organisations started to highlight the social and economic impact of AIDS, multi-sectoral responses were encouraged, Kloos et al. (2015) .

With the disease having an impact on a wide range of issues and groups and with social and gender inequalities exacerbating the scale of the epidemic a comprehensive and wide national policy framework was considered necessary (Seidel, 2007). However, irrespective of all the improvements put in, many people still test positive and in Kampala district; youth are more

vulnerable to the disease than any other group although there is an increasing involvement of the private sector, non-governmental organisations (NGOs) and communities emerged. Others also dispense ARVs and treat opportunistic infections, these services, whether provided through NGOs, government health clinics, or community groups are essential in supporting people living with HIV and AIDS, as well as people who provide care and support within families. Therefore this research analyzer the effects of home based care services on the prevention and spread of HIV/AIDS in Kampala district (WHO, 2013).

### **1.3 Purpose of the study**

To establish the effects of home based care services on the prevention and spread of HIV/AIDS in Kampala central Kampala district.

### **1.4 Specific Objectives of the study**

- i) To examine the different types of home based care services used in the prevention of HIV/AIDS in Kampala central division.
- ii) To establish the relationship between home-based care services and the spread and prevention of HIV/AIDS in Kampala central division.
- iii) To establish the challenges faced by home based care services on the prevention and spread of HIV/AIDS in Kampala Central division.

### **1.5 Research Questions**

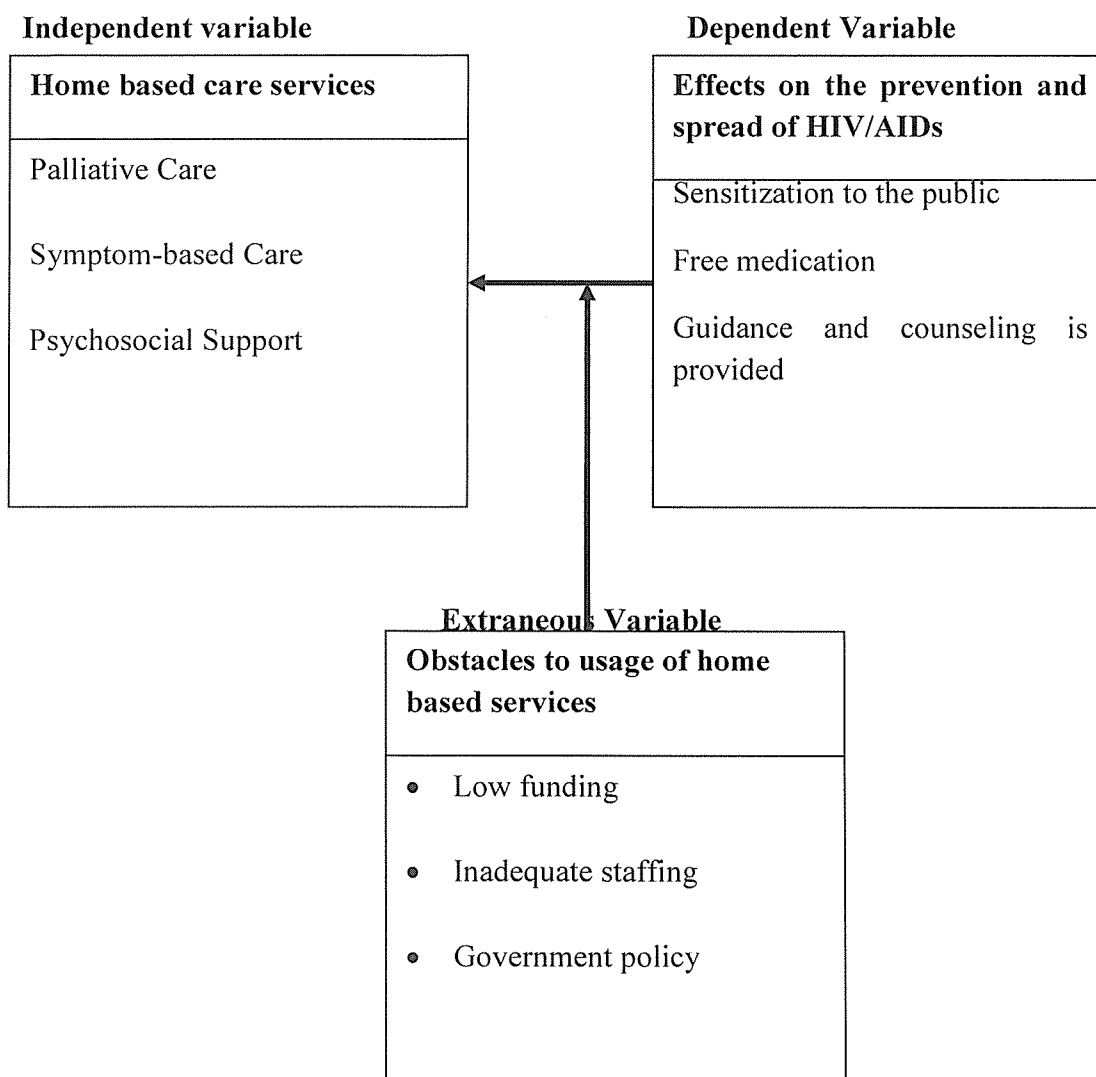
- i) What are the different types of home based care services used in the prevention of HIV/AIDS in Kampala central division?
- ii) What is the relationship between home-based care services and the spread and prevention of HIV/AIDS in Kampala central division?
- iii) What are the challenges faced by home based care services on the prevention and spread of HIV/AIDS in Kampala Central division?

## 1.6 Hypotheses of the study

**H<sub>i</sub>:** Home based care services have a significant effect on the prevention and spread of HIV/AIDS

**H<sub>ii</sub>:** There is a positive relationship between home based care services and the prevention of HIV/AIDS

## 1.7 Conceptual framework showing the relationship between the different variable in the study



The conceptual framework shows diagrammatically the relationship between home based care services and the prevention and spread of HIV/AIDS. In this, the researcher has perceived the

effects of home based care services as the independent while prevention and spread of HIV/AIDs as dependable and the researcher also identifies the extraneous that also affect the outcome of the study as low funding, inadequate staffing and government policy.

## **1.8 Significance of the study**

### **To the researcher**

It will help the researcher accomplish her three years course in social work and social administration as per the Kampala International University Guidelines.

### **To the community/farmers of Maddu**

This research is of much interest to local people in Kampala central division as it informs them on the ways through which they can gain from usage of home based care services and how it can guide them to prevent the high spread of HIV/AIDs. The study also, sheds light on how to reduce on the impacts of HIV especially to positive patients.

### **To the government**

It will help the Ugandan government identify the challenges to usage of home based care services and as well find out the causes for high spread of HIV/AIDs and ways how it can be used to overcome such challenges.

### **To future researchers**

The research will also act as a reference for future research study by researchers who will have topics related to home based care services or HIV/AIDs spread.

## **1.9 Scope of the study**

### **Geographical scope**

The study was carried out from Kampala central division in Kampala district. Kampala central division which is in the central part of the city, bordering Wakiso District to the south and west. The eastern boundary of the division is Murchison Bay, a part of Lake Victoria. Nakawa



Division lies to the northeast of Kampala central Division. Kampala Central Division lies to the north and Lubaga Division lies to the northwest.

### **Time scope**

The study was carried out for a period of three months and it focused on a period between 2010 up to date and was carried out for a period of four months that is to say from May to September 2017.

### **Content scope**

The study focused on establishment of the relationship between home based care services and prevention and spread of HIV/AIDs in Kampala central division in Kampala district. The objectives of the study were to examine the different types of home based care services used in the prevention of HIV/AIDS in Kampala Central Division, to establish the relationship between home-based care services and the spread and prevention of HIV/AIDS and establish the challenges faced by home based care services on the prevention and spread of HIV/AIDS in Kampala Central Kampala district.

### **1.10 Limitations**

**The researcher encountered the following obstacles during her study;**

Poor infrastructure; geographically Kampala central division has poor roads especially when it comes to rainfall hence the researcher experienced difficulties in traveling especially in rainy season.

Time factor, due to time limit, the researcher did not cover all the areas intended in Kampala central division.

Further insecurity caused interruption where people thought that they were collecting information about their personal lives.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.0 Introduction**

This chapter concentrated on what scholars, academicians and philosophers wrote about the subject under investigation. This information was solicited from primary sources mainly textbooks, newspapers and journals.

#### **2.1 Conceptual Review**

##### **Concept of Home Based Care Services**

A study, which was done on the accessibility of home-based care by PLWHA in France Baard district revealed that factors that hindered accessibility of home-based care included lack of acceptance by people in the community which makes it very difficult for volunteers to execute their duties. Ignorance and illiteracy on the side of the community with regard to HIV/AIDS constitute barriers which lead denial about HIV/AIDS. On the other hand, disclosing their HIV-positive status leads to ostracism and rejection by the community, which makes it more difficult to reach PLWA, Bohman et al. (2013).

study conducted by Smith in North of Namibia on HIV risk assessment and HIV testing intention revealed that personal experience and belief impacted the perception of the personal risk of contracting HIV. It also revealed that people who have discussion or experiences with people living with HIV are more likely to seek an HIV test. The study shows that it is not the perceived risk to contract HIV which motivates people to seek for HIV test but the education and information received, which in turn influence the intention to undergo HIV-testing. It was also reported that age did not influence the behavior of testing and that the negative belief, peers, witchcraft, looking sick, perceive seriousness did not contribute to the perception of other's risk, Charton et al. (2014).

## **Concept of HIV/AIDS**

The Human Immunodeficiency Virus (HIV) and the subsequent Acquired Immunodeficiency Syndrome (AIDS), hereafter to be referred to collectively as HIV/AIDS, remains one of the most significant public health challenges in our lifetime, and certainly one of the biggest obstacles to socioeconomic development especially in developing countries. All nations across the world, particularly, low-and middle-income countries are significantly affected by HIV/AIDS and Vietnam is no exception. The World Health Organisation (WHO) reports that HIV/AIDS is one of the world leading infectious killers, claiming more than 25 million lives over the past three decades. Of the estimated 34.2 million people living with HIV/AIDS world-wide, 2.1 million are children (defined as boys and girls up to the age of 18 years), with 280.000 deaths reported per year. It is well recognised that HIV/AIDS epidemic affects children in many ways including, making them orphans (defined as parental loss like lost mother, father or both parents dead), increasing their vulnerability (defined hereafter as children affected by HIV/AIDS) and threatening their survival. It is predicted that even if a leveling off of new infections occurred, due to the long incubation period of the virus, mortality rates will not plateau until at least 2020, and the proportion of orphans will remain strikingly high at least through to 2030, Epping-Jordan et al.(2014).

Another study conducted to explore the attitudes of Japanese-American families toward community-based long-term care services and also to determine factors that influence community-based service utilization among Japanese-American families showed that families played an active role in sustaining and augmenting the care giving, regardless of living environment, the more involve the family, the better the care. The study shows that sustainability of care for chronically ill patients depend on the level of family commitment to care for their own patient, Harding et al. (2014).

An enhanced patient evaluation study in Southern Africa by family health international (FHI) on stigma revealed that community support services have no influence in reducing stigma and that the influence of home-based care on adherence declined between 12 months and 18 months, an indication that after the first year of the programme, home-based care may not be the most effective outlet for support Karus et al. (2015).

## **2.2 Types of home based care services used in the prevention of HIV/AIDS**

The advent of primary prophylaxis and treatment for opportunistic infections, including tuberculosis, prolonged survival to a limited extent but did nothing to restore immune function. Such restoration was not possible until the advent of antiretroviral therapy. Because clinical intervention in HIV is so recent in resource-limited settings, few cost-effectiveness studies are available. Those that are available on the treatment of and prophylaxis for opportunistic infections were largely conducted before the availability of antiretroviral therapy and therefore need to be re-estimated to be relevant for decision making today. Fortunately, because the determinants of biological responses are better conserved across countries and cultural settings than the determinants of behavior, effectiveness data from high-income countries can help inform decisions about treatment in resource-limited settings, Kloos et al. (2015).

Unlike drugs for many other high-burden health conditions in developing countries, antiretroviral therapy for HIV and drugs for some of its associated opportunistic infections depend on medications that are still under patent protection. Nevertheless, generic drug makers in India and Thailand have produced a range of effective antiretroviral therapies that combine multiple drugs into single tablets and reduce the pill burden to one tablet twice daily. These companies have made it possible for prices to drop dramatically for some antiretroviral therapy combinations to less than US\$250 per year, compared with more than US\$4,000 for the same combinations (from the original manufacturers) in high-income countries. In response to this threat, some multinational pharmaceutical companies have introduced a system of price differentiation among countries depending on their per capita income and HIV/AIDS burden, Spence (2014).

In addition, the World Trade Organization's Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) includes a provision that permits compulsory licensing of pharmaceutical products in cases of national emergency and other circumstances of extreme emergency, which is clearly the case for HIV/AIDS in much of the developing world. A 2003 World Trade Organization decision also made it easier for low- and middle-income countries (LMICs) to import cheaper generics made under compulsory licensing if the countries are unable to manufacture the medicines themselves WHO (2013). As a result, some countries including

Brazil, India, and Thailand, have begun to produce generic versions of antiretroviral drugs to be sold at greatly reduced prices. The TRIPS provision has also improved developing countries' bargaining power with large pharmaceutical companies, to the point that some countries have been able to secure drugs from the original manufacturers at substantially reduced prices. As a result, the relative cost-effectiveness of different drug combinations has been in rapid flux, increasing the importance of updating recommendations frequently, UNAIDS (2013).

### **Palliative Care**

Palliative care has traditionally focused on patients in the terminal stages of disease. More recent definitions of palliative care including WHO's definition have been broadened to encompass quality-of-life issues of patients and their families throughout the course of a life-threatening illness (WHO 2012b). The control of pain and other symptoms is the crux of any palliative care model, but the WHO model also addresses patients' and their families' psychological, social, and spiritual problems. Under this definition, in many developing countries, most people living with HIV/AIDS are not receiving the minimum standard of palliative care. Of the 5 million people living with HIV/AIDS in South Africa, one of the wealthiest countries in Sub-Saharan Africa, Charton (2014) estimates that only 250,000 have access to palliative care services. In the face of a growing epidemic of historic dimensions, the provision of comprehensive palliative care represents a critical, but neglected, global priority.

Health care professionals have promoted community home-based care as an affordable way to expand the coverage of palliative care (Cintron-Bou, 2014) but the great heterogeneity among home-based care programs complicates comparisons. Most programs for which data are available are community-based outreach programs administered by local clinics or hospitals. These programs can consist of simple home visits to provide basic care for AIDS patients or may be comprehensive schemes that provide care, palliative medications, meals, psychosocial support and counseling, and links to primary and secondary health care.

## **Symptom-based Care**

Pain management is extremely important in HIV, Diarrhea and nausea; vomiting and skin problems are all symptoms that are targeted for treatment in palliative care. Oral rehydration for diarrheal treatment costs pennies per episode. Nausea and vomiting are prevalent in people with AIDS and can lead to anorexia and weight loss, Butt, et al. (2014). Treating nausea costs an estimated US\$1.75 per episode and continuous treatment of nausea and vomiting in end-stage patients costs about US\$2 per day; Bock et al (2014).

Approximately 90 percent of people with HIV suffer from some form of skin condition. These conditions include infections, drug reactions, scabies, pressure sores, and cancers. Skin often becomes dry in the middle and late stages of AIDS because of dehydration caused by persistent diarrhea, vomiting, and mal-absorption. The cost of treating an episode of skin rash is estimated to be US\$2. No estimates are available on the benefits of providing such care in terms of DALYs, especially to terminally ill patients; Karus et al (2015).

## **Psychosocial Support**

Psychosocial support is an integral component of the multidisciplinary management strategies that care providers regard as essential for people with HIV. Support for patients and families can have a positive effect on adherence to therapies and can contribute to the critical aim of integrating prevention with treatment and care, Harding et al. (2014).

Psychosocial support and counseling has a positive effect on the quality of life of people living with HIV/AIDS. Charton (2014) study of U.S. women demonstrated that the use of mental health services was associated with reduced mortality and that AIDS-related deaths were more likely among women who had symptoms of chronic depression. While results have not been replicated in resource-constrained countries, an assessment of clinic-based psychosocial support and counseling services in northern Thailand showed that 50% of PLWHA became more positive about their lives and 40% stated that they learned how to live with the disease; Epping-Jordan et al. (2014). Although few data are available on the costs of various strategies, interventions for psychosocial support appear to be cost-effective especially where innovative solutions, such as

group counseling sessions, are implemented. Although studies indicate an improved quality of life for these patients, little information is available on the cost of the interventions. Additional evaluation research is needed to guide decisions about how much to invest in psychosocial support.

### **2.3 Role played by home-based care services in the spread and the prevention of HIV/AIDS**

The role of home-based caregivers is that of visiting and caring for chronically ill patients, disabled, the weak and the elderly people in order to prevent the stigma. The volunteers do provide help with household chores, such as fetching water, collecting firewood, cooking their food and feeding them. They facilitate the referral of patients to the social worker, health facility, raise and donate funds to take patients to the hospital, encourage community to go for testing, give them information on PMTCT, VCT and HAART; Harding et al. (2011).

In addition, they offer psychosocial support, advice and encourage patients to live positively. In the provision of service, it is important to identify needs of people who require to be enrolled in the home-based care that are specific to the PLWHA, to the family, and to the community within which the PLWHA lives. There are different needs like physical, spiritual/pastoral, social or psychological, which vary from person to person and from one community to the other. These needs should be identified when a PLWHA is being enrolled into a home-based care program for effective service to be provided Kloos et al. (2015).

The survey conducted in New York to assess the client satisfaction about comprehensive home healthcare demonstrates that there is need of such a comprehensive service as more people felt comfortable to receive most prophylaxis for HIV-related treatment in home settings. The survey shows that patients were satisfied with the provision of care in the home setting because the majority of care can be delegated to the paraprofessionals; Laschinger (2015).

In a study assessing the patients satisfaction with home healthcare services for clients with HIV in 1995, HBC was found to be appropriate and feasible in the era of HIV because having health home-based care to alleviate hospital the burden as long as the quality of care is maintained. It is

important that caretakers receive the appropriate in-service education and supervision to enhance their skills profile; Murray et al. (2016).

The study conducted in Caprivi region in Namibia by Thomas in 2004 shows that localized and participatory approach is necessary to promote the involvement of other household members and community members in contributing to caring duties. The same study reports that the psychological well-being of the patients was influenced by the way others view the patient. As some patients start recovering and contributing to the household activities, the better the patient feels accepted and improves the well-being, and the less the stigma. The compassion and sympathy towards ill patients was evident at the early stage of the disease but long term HIV and AIDS makes caring a burden upon household livelihood security and intra-household relation as the patient condition deteriorate over time. It is important that people should get tested early and access antiretroviral treatment when they are not ill to reduce the cost of long term care. The author recommended that local initiative can be developed in order to decrease the burden of care and subsequently the stigma and neglect of ill people; Tibebu et al. (2016).

It is known that the provision of health service closer to people's home helps to promote the sustainability of care. In the study conducted by Sadler in 2005 revealed that the continuum of care combines the medical and nutritional treatment with home and clinic-based support. By decentralizing the treatment sites, it decreases the barriers to access of treatment at the same time reduce the default to treatment and encourage community participation. The use of treatment of acute malnutrition and provision of high nutritious food in the community instead of the hospital can be used as an entry point that provides an opportunity to healthcare workers to establish trust with community and the mechanism which allows people infected and affected with HIV to access the support whilst minimizing stigma. If community-based care is well understood by the community, the participation of this community will lead to cost effectiveness and sustainable home long-term care. It was demonstrated that utilizing food nutrition programme as entry point by involving close family members of the patient with HIV and increase their productivity will enhance trust and reduce stigma; UNAIDS (2014).



A Study on the role of volunteers in home-based care in South Africa indicated that HIV/AIDS accounts for between 25-40 % of deaths in South Africa and there are more women caring for AIDS patients with low male involvement and a substantial part of home-based care costs are borne by volunteer caregivers who are largely poor, infected and affected women thus exacerbating their burden. WHO (2015) reported that the role of volunteers is to provide patients and their families with information on resources that are available in the community and to relieve HIV/AIDS affected families of the burden of care by teaching family members skills and knowledge on the various issues that relates to care ;WHO (2015).

Home-based care, the program that offers health care services to support the care process in the home of the HIV infected person (WHO, 2015), has been a major care and support strategy since the inception of the epidemic in Uganda. This was against a background of scarce health care facilities, difficulty in accessing the available care facilities by the very ill and the preference for terminal care and death in the home-setting; Tibebu (2016). Consistent with the comprehensive care strategy recommended for HIV/AIDS infected and affected individuals (UNAIDS, 2014), Home-Based Care Programs aim to alleviate human suffering and pain, and mitigate the impact of HIV/AIDS through comprehensive care package of nursing care, treatment of opportunistic infections including symptoms and pain; counseling and emotional support; assistance with essentials like food and soap; poverty alleviation measures like income generating activities; orphan care; legal aid including will making; advocacy; prevention strategies of education and awareness programs for behaviour change and condom distribution.

According to AfriCASO Directory of 2000, there were 39 registered home-based care programs in Uganda, a likely underestimate as many community-based organizations operate unregistered. Some home-based care programs are initiated and operate within the community (community-based organizations CBOs); some are faith-based organizations (FBO), operating as facility outreaches; some Non-governmental (NGOs), operating from facilities or within the communities; and a few are governmental (attached to government facilities). The FBOs and

NGOs operate with varying degrees of community mobilization and participation. The facility based programs utilized medical personnel, mainly nurses while the CBOs utilize mainly volunteers, Tarwireyi (2015).

An umbrella organization, the Joint Home Care, aims at promotion of experience sharing through networking among the Home-based care programs in Kampala. Each program is allocated a specific area to avoid overlapping of activities, duplication of efforts and a waste of resources; Coughlan (2014). There is no government policy and direct participation in Home-based Care. Therefore there are no guidelines or standards to regulate their activities. The cost of home-based care is borne by the private sector, often religious or charity, with funds largely from external donors. However some CBO programs receive insufficient funds from the District Sexually Transmitted Infections (STI) Program; Breux, et al. (2006).

As other countries seek to learn from the Uganda experience and success in reducing the HIV prevalence from about 30% to 5% (Mbutaiteye et al, 2002), Home-Based care will be one of the strategies focused on. Furthermore with the current recognized inadequacy of prevention alone in HIV/AIDS epidemic control and the new thrust on care and support, including treatment for opportunistic infections and anti-retroviral therapy, there is a need for strengthening and expanding the existing Home-Based Care Programs. This would position them for participation in this new thrust. A need therefore arises for an overview of the existing programs regarding the care offered and strengths and weaknesses, with the overall aim of improving the quality of care, and drawing out lessons for other AIDS programs and policy both nationally and internationally.

In Uganda, Home-Based Care Programs in Uganda was conducted to improve the quality of home-based care provided for the people living with HIV/AIDS and terminal cancers through assessing the components and practices of home-based care by programs of different strategies, including the cost of care; identifying the factors necessary for providing quality home-based care; and identifying the strengths and weaknesses in the delivery of home-based care by the programs using the UNAIDS Best Practice criteria for AIDS Home-Care; Butt, et al (2014) .

Best Practice, defined by UNAIDS as the continuous process of learning, feedback, reflection and analysis of what works or does not work (UNAIDS 2014), identifies effective programs

based on research and evaluation. Such programs present lessons in strengths and weakness and information useful for programs and policies. The UNAIDS recommended the following criteria for identifying Best Practice programs regarding home-based care programs like relevance, ethical Soundness, sustainability, effectiveness and efficiency. A relevant program is in alignment with identified local and national needs, taking into consideration, in its planning and implementation, factors such as leadership structure, community educational and economic status, and local cultural practices and norms especially with regards to women and children's situation, Charton, et al (2014).

Ethical soundness is the degree to which the program planning and implementation are guided by appropriate professional and social conducts. These include equity, access to care, distributive justice with no discrimination, confidentiality, informed consent, autonomy in care, respect for human rights and dignity of the beneficiaries. The workers need to demonstrate compassion, solidarity, tolerance and responsibility. Sustainability refers to the capacity of a Home-based care program to continue to function with some degree of autonomy in the mid- or long-term. A sustainable program partners with local authority and power structure, networks with community organizations, links with preexisting institutions and builds local capacity. Sources and reliability of funding are critical to program stability and longevity. Flexibility and adaptability of programs allow for response to resource availability fluctuations, Cintron (2014).

Efficiency is the ability of a Home-Based Care Program to produce its desired outcome with minimum resource expenditure, in terms of time, money and labor. This is critical in AIDS work in communities with limited resources despite many and complex needs. It includes issues of resource (financial, human and material) management; records and information management; monitoring and evaluation with defined indicators; and cost-benefit analysis using measures like cost/treatment and staff person hours/visit. The effectiveness of a program/practice is the extent to which it produces the defined outcomes and meets its objectives. Effectiveness of a program is demonstrated by: a clear link between its activities and the effects; a quantifiable change in the situation that is being addressed, demonstrated through quantitative data or interview of the beneficiaries; outcomes (medium-term results) and overall impacts (long-term results); Breux, et al. (2006).

A literature review of articles on the pattern of access to community palliative care services in 2009 shows that the utilization of home-care service depend on the presenting symptoms. The hypothesis is that older people have different needs and sickness which need a referral from a general health professional to the home-care, and older people's attitudes towards palliative care may affect their use of service. It was revealed in another study that the use of home-care depends on the age of the caregivers; as the younger the caregivers, the greater the support needs, or greater effectiveness in obtaining help but from all these studies, there was age related influence on utilization of the palliative; Bateman (2011).

On a gender related effect, some studies demonstrated that gender does not affect the utilization of palliative care but for those studies that did identify a difference, the majority reported that women were more likely to utilize the palliative home service compared to men but no clear explanation was given for this tendency. On ethnicity, it was found that general practitioners were more likely to refer members of ethnic groups to home-care than inpatients hospice because of the emotional and feeling that home care is more compatible with the family wish to care for the loved one at home. It was also found that the socioeconomic situation impact in the utilization; the income level, the higher the income, the easier it is to access cares. On education level, some studies found that the lower the education level, the greater the need of palliative care and that those who own homes and live in urban areas are less in need of palliative care but can access care than those in rural areas (Walshe, 2009).

A retrospective study conducted in Sweden in 2007 on end-of-life care and the pattern of utilization of health care services revealed the use of different combinations of health services at the end-of-life: hospital care, primary care and care at home. It was found that majority of people used hospital-based care at the end of life and this care was not the same for everybody as it was dependent on demographic, type of illness characteristics and social environment. It was found that the acute care provided at the hospital to older people was not ultimate or necessarily required during the end-of-life period as the problem at this period is the age and chronic condition of the patient (Epping-Jordan, 2014).

A cohort study conducted to investigate medical health care utilization following the decision about long-term care at home versus special accommodation of older people in Sweden revealed

that from the 1079 participants followed in the study for 3 years, the majority of people who received care at home were more younger and showed increased utilization of medical healthcare in comparison with older people who were in special accommodation. It was also found that under the long-term care, the earlier the detection and treatment of medical condition by health professionals, the lesser the need for medical healthcare. The utilization of outpatient service was more for the patients receiving care at home than those in special accommodation. This does not mean that the special accommodation is the best solution for everyone. The age did not influence the utilization of medical service but the environment where a patient was given care did. If older people are cared at home it will imply an increase in utilization of medical healthcare (Condelius, 2009).

A quantitative study was conducted in Potchefstroom in South Africa on community-based care for children with HIV. The majorities of the participants (non-professional caregivers) in the district were females (88 %) and aged between 19 to 30 years (47 %). Disease stigma occurs when individuals or population groups are blamed for their illness because they are viewed as immoral, unclean, and/or lazy. Furthermore, it has been acknowledged that throughout history, stigma has imposed suffering on groups vulnerable to diseases and impaired efforts to thwart the progression of those diseases. It is well acknowledged that stigma and discrimination contribute to increased HIV/AIDS epidemic. Compared to adults, children and adolescents affected by HIV/AIDS are disproportionately impacted by the HIV/AIDS epidemic and associated stigma and discrimination. In HIV/AIDS, the detrimental role of stigma has become so clear that national and international health agendas explicitly identify stigma and discrimination as one for the major reasons limiting the access, care and treatment services and is considered an overall major barrier to effective responses to the HIV/AIDS pandemic. Children are particularly more vulnerable to stigma than adults and are at a heightened vulnerability to discrimination because they are often not in control of their circumstances and often do not know and/or are less likely to assert their rights.

Moreover, stigma can affect children in multiple ways when it leads to active discrimination. For example, a study of the Institute for Social Development Studies showed that children living with, and/or affected by HIV/AIDS in Vietnam can be refused entry to schools and are often

isolated as school friends dissociate with them. The affected children are also ridiculed, attacked and beaten by their peers. It has also been reported that HIV/AIDS affected children find it difficult to access care and support due to negative attitudes by health care providers and other service and support workers. Additionally, it has been noted that stigma can affect children indirectly when caregivers (e.g. parents) suffer from the effects of stigma and discrimination; or when children and/or parents take certain course of action like withdrawal to avoid expected stigma and discrimination. UNICEF identifies tackling stigma and discrimination as one of five key imperatives for success of HIV/AIDS programs. Addressing the needs of children affected by HIV/AIDS is particularly important in developing countries, not only because of the high proportion of young people infected by HIV/AIDS in these societies, but because young people are at a heightened risk of contracting HIV/AIDS as well; Breux, Jet al (2006) .

Vietnam and HIV/AIDS Scourge; located in Southeastern Asia, the Socialist Republic of Vietnam, commonly known as Vietnam, has a population of about 90.5 million people with more than two-thirds aged between 15-64 years. Hanoi, the Capital city is located in the north of the country. Other major cities include Ho Chi Minh City and Can Tho in the South, Hai Phong in the North, and Da Nang in the Center. Vietnamese is the official language and English is increasingly referred to as the second language. When the HIV/AIDS epidemic started in Vietnam in the mid- 1990s, it was concentrated among “adult males” and injecting drug users in Ho Chi Minh City. Today however, the epidemic has entered the sex industry, and has spread into what is often misleadingly known as ‘the general population’. The proportion of teenagers (10 to 14 years olds) living with HIV/AIDS is also increasing, Butt, et al. (2014).

The Vietnam Administration of HIV/AIDS Control Program estimates inform that 9,800 children live with HIV/AIDS, and up to 457,700 children are affected by HIV/AIDS, including being orphans and others made vulnerable because of HIV/AIDS in the family. A major assessment conducted by the Ministry of Labor, Invalids and Social Action (MOLISA) and UNICEF in 2005, reported that children who are affected by HIV/AIDS faced several problems including shortage of food and nutrition support, lacked shelter, had insufficient protection, had poor healthcare, suffered psychosocial problems, and had less access to education and vocational training compared to children who were not affected, Bateman (2011).

The same assessment affirmed that stigma and discrimination was one of the main causes that led to increase of HIV/AIDS epidemic in Vietnam. From May 2009, The Vietnam Government started the national plan of actions to a strategic HIV/AIDS response for the orphans and vulnerable children affected by HIV/AIDS. Additionally, non-governmental and community-based organizations increasingly supported and offered a range of services to children affected by HIV/AIDS with the purpose of integrating orphans and other children affected by HIV/AIDS into mainstream society and to help them lead healthy lifestyle, Butt, et al. (2014) .

#### **2.4 Relationship between home-based care services and the spread and prevention of HIV/AIDS**

There is a strong relationship that exists between HIV and AIDS prevention, treatment and care programmes and the health system in Zimbabwe from the literature that we reviewed. There are multidimensional positive and negative implications of HIV and AIDS programmes on the health system. However, this analysis needs to be interpreted with caution because accounts of positive and negative effects of HIV and AIDS prevention, treatment and care programmes are available in general and specific evidence on the implications of the programmes on the health systems in Zimbabwe is slim. In addition, the scaling up of programmes such as ART, provider-initiated counseling, and testing and comprehensive home-based care is fairly recent in the country; Murray et al. (2016).

At various levels of the health system in Zimbabwe, HIV and AIDS prevention, treatment, and care programmes produce various effects to the health systems components. For example, HIV and AIDS programmes by locating PMTCT sites in district and mission hospitals, the programme was able to rapidly scale up to 155 centres, supported by guidelines, Nurse training, manuals and protocols to standardize implementation and some facilities are using trained lay counsellors to decrease the work burden on nurses; Osborne et al (2015) .

Several studies have demonstrated such indirect effects of ART on child survival, in which treatment of HIV-infected mothers has reduced mortality of uninfected children, orphan hood, and the incidence of infant diarrheal disease. In this regard, HIV and AIDS programmes have been positive on some aspects of the health system. However, in relation to ART, El-Sadar et al. highlighted that the expansion of access to antiretroviral therapy for millions of persons living

with HIV in low-income countries has been lauded by many yet the investment in such programs has at the same time been criticized by others who claim diversion of resources from HIV prevention efforts and from other important health threats. It is argued that the provision of ART exacerbates existing inequities and weaknesses in health systems; Tarwireyi (2015).

Additionally, some critics maintain that HIV and AIDS have received a disproportionate share of global health funding and that HIV programs were overwhelming health systems and were not sustainable. PMTCT programmes have become imperative as a good entry point for women to learn about access to other health programmes, services and health resources, such as support groups, sexual health, nutrition, and home-based care, and for bringing in their partners and children who may also be HIV positive. Whilst women identified as clinically eligible through PMTCT are referred to treatment programmes, those who are still relatively healthy are followed up through community outreach and advice given for child health including vaccinations and providing ongoing support for them to stay healthy.

It can be argued that the antiretroviral therapy programme is improving general health indicators such as life expectancy through increasing survival of infected individuals. The percentage of adults and children with HIV known to be on treatment 12 months after initiation of ART was 75% in the 2009 cohort analysis carried out in 22 districts that were supported by Global Fund round in Zimbabwe. The percentage of infants born to HIV-infected mothers that were infected was estimated using spectrum at 32.3% in 2007, 31.1% in 2008 and 30% in 2009. The marginal decline in infection rates could be due to increase in PMTCT services uptake between 2007 and 2009; Spence (2014).

One anticipated evidence suggests that HIV and AIDS programmes expansion has to some extent increased utilization of non-HIV-related services to advance broader health goals. The impact of scale up has not been consistent in Zimbabwe yet some programmes are contributing to the expansion of control efforts for related conditions, enhancing utilization of sexual and reproductive health services for example with male circumcision), promoting access to better nutrition (in PMTCT), improving infection control in healthcare facilities (in linking Tuberculosis to HIV), promoting task shifting and health worker training, enhancing infrastructure and laboratory services and facilitating a shift from an episodic to a continuous



model of care. At a more general level although there are some reservations, HIV and AIDS programs have helped strengthen the national health system by attracting vital new financial resources, building systemic capacity, and introducing chronic disease management approaches time in many resource-limited settings like Zimbabwe; Tarwireyi (2015).

The rapid expansion in the number of persons receiving ART means that the health system must continue to provide acute life-saving care for those with advanced HIV/AIDS although also providing chronic care services to expanding cohorts of more stable patients who are doing well on ART. This expansion has meant a transition from an emergency response to the epidemic, characterized by a public health approach to a more integrated and durable approach to HIV and AIDS prevention, care and treatment services. In a positive light, these have motivated a change in the health system from a fractured demoralized system barely able to cope with acute illnesses to that able to provide the continuity care necessary in the management of a chronic condition such as HIV and AIDS. The authors also highlight that innovations in governance, models of care, procurement of medications and commodities, human resource utilization, and other domain catalyzed by HIV programming can serve as a platform on which to build a response to other health threats. However, the rapid scale-up of HIV and AIDS interventions has also exposed the frailty of the health system to effectively mount an HIV response and cope with management of AIDS as a long-term illness.

Besides the fears that existing inequalities in health care may be intensified in scaling up HIV and AIDS services and programmes, there is evidence that HIV and AIDS programmes have had both negative and positive effects on human resources in the health sector in Zimbabwe in terms of recruitment, distribution, and retention of health care workers. Early studies reported negative effects of HIV and AIDS and the delivery of HIV and AIDS services on health care workers' morale with stigma, burn-out, resignation, and deaths due to HIV and AIDS, while more recent ones speak of hope, high prestige, high motivation, and better retention of HCWs in HIV and AIDS programmes, largely due to effective ART which has improved the prognosis of AIDS.

However, new cadre ship has been brought into support HIV and AIDS services, including expert patients. Innovations such as task shifting and the integrated management of adult and adolescent illness have been applied to more efficiently use available health care workers. Many

vertical programmes also recruit their own health care workers, especially counsellors and home-based caregivers. This has increased the pool of health care workers and such programmes have also attracted a lot of funding, especially through Global Health Initiatives such as the Global Fund and PEPFAR. Although some positive aspects can be seen on the human resources component of the health system, by relying on the health system for the more skilled health professionals, the programmes have also undermined other health programmes such as those for PHC.

There is also evidence which suggest well-run HIV and AIDS services can serve to attract and retain health care workers as they offer incentives, such as higher salaries or salary supplements, better furnished facilities, and appointment at higher levels. However, this has had very negative effects on the health system human resources as these incentives targeted at workers for HIV and AIDS programmes exclude other health care workers. These selectively applied incentives also tend to demoralize and discourage those who are excluded. The expansion of HIV and AIDS programmes in Zimbabwe also raise the issues of sustainability. It has been observed that the remarkable success of HIV scale-up has inevitably spawned new debates about sustainability, the need for health systems strengthening, and whether funding for HIV has been disproportionate to funding for other health needs.

The notion of sustainability is usually defined as the ability of country health programs to continue independent of international aid has come under increasing scrutiny in Zimbabwe. It is important to note here that Zimbabwe currently has been denied funding from the Global Fund for TB Malaria and AIDS to fund HIV and AIDS health needs yet the country has achieved a commendable reduction in HIV prevalence rate. It is also imperative to acknowledge that some widely lauded programs, such as the ESP on immunization and the polio-eradication programme, have yet to achieve sustainability.

One can also highlight that such instruments will have other knock on effects that will lead to reduction of stigma or discrimination because of illness. However, despite the current lack of legal frameworks to support targeting of high risk groups such as sex workers, prisoners, men who have sex with men and IDUs with prevention activities, lobby groups representing gays and lesbians living in Zimbabwe and organisations working with sex workers are in existence and

need to be formalized to strengthen the health system. Targeted programs such as condom promotion and other prevention strategies in order curb the spread of the HIV among these groups will further strengthen the health system and it is through effective governance that will ensure that these are recognized. With regards to strengthening the health system, more needs to be done to strengthen and make the health system more water tight by protecting subpopulations such as men having sex with men, intravenous drug users, and commercial sex workers.

## **2.5 Challenges faced by home based care services on the prevention and spread of HIV/AIDS**

The Kaiser Foundation examined the challenges facing Swaziland's home-based caregivers and reported that the country has few care givers who are poorly paid but they have a major role to play in nursing the people living with HIV/AIDS. The reason is the negative attitude of the community towards the caring job and the traditional view of gender which often prevent men from becoming caregivers. Some of the caregivers' duties include feeding, washing, dressing and reading to people living with HIV/AIDS, as well as imparting health advice and offering companionship. Many of them also face the challenges of working in rural areas where it is necessary to travel long distances on dusty or muddy roads, according to one of the care givers report. The recommendation of the report is that there should be attitudinal change towards job type and gender, Kloos et al. (2015).

A study was conducted on AIDS and palliative care in South Africa with the purpose of examining the major challenges involved in providing quality end-of-life care to people with AIDS in South Africa, as many people die of AIDS in South Africa as a result of limited access to antiretroviral treatments. The finding was that AIDS patients need palliative care but there are still some challenges like, ineffective control of pain, integration of community-based home care model that relies heavily on community caregivers to meet the needs of people dying of AIDS, and the living conditions of AIDS patients and their families, and AIDS-related stigma remain a challenge, Laschinger et al. (2015).

Mapping of community home-based care services in five regions of Tanzania mainland by Pathfinder international in 2006 identified some of the gaps, and challenges for provision of good home-based care services (HBC) as lack of confidentiality, lack of work material like

gloves, inadequate and irregular supply of medicines. Other client and family related challenges are fear to disclose their HIV positive status and some knowingly, spreading HIV; Murray et al. (2016).

The study conducted in Entabeni, South Africa on supporting people with AIDS pointed to multiple needs of AIDS patients and their caregivers. At material level, people spoke of shortages of money, food and affordable transport to clinics or hospitals. At practical level, people have difficulty working without many of the basic resources for home nursing, such as gloves, bedding or clean accessible water. The burden of care was often the final straw for already over-extended women. At emotional level patients and caregivers felt isolated in a community where stigma made people reluctant to disclose their HIV status. However, the community still has some volunteer health workers, who played a central role in facilitating the informal home-based care of people with AIDS. Their work involved walking long distances on foot, often up steep hills, and often in conditions of searing heat, to households which might be several kilometers from their villages, WHO(2015). A South African study that evaluated the home-based care services showed that the success of the HBC services is connected to the combination of funds allocated for the implementation, advocacy, home visits, technical support, support groups and comprehensive care practices. A good monitoring and evaluation system should also be in place to track the progress; Karus et al. (2015).

A qualitative/quantitative assessment of a home-based care services in Maputo, Mozambique revealed that the main reasons for refusing home visits or not taking part in it by both patients and caretakers, are connected to stigma and discrimination. Accepting visits may be seen as a way of publicly revealing the patient's HIV/AIDS status to his community and family. However, home-based care services are seen to be having positive effects in combating stigmatization by enlarging the visibility of the epidemic before the community and society (Benedetti et. al., 2004).

Many low and middle-income countries face numerous challenges in health care delivery including weak national health systems, poor infrastructure, civil war, corruption, and meager financial resources. In addition to overall supply deficiencies, health workers are distributed unevenly. Countries with the lowest relative need actually have the greatest number of health

workers. Conversely, the African region has the greatest burden of disease (24%) with only 3% of the world's health workers and 1% of the financial resources. Uneven distribution also exists within countries through urban/rural and public/private imbalances, Harding et al.(2011).

Scaling-up ART is estimated to require between 20% and 50% of the available health workforce in many African nations. Specifically, it is projected that (at best) the supply of health workers would reach only 60% of the need in Tanzania and would be 300% greater than the available supply in Chad by 2015.<sup>14</sup> Therefore, efforts to address HRH are essential to the successful scaling-up of HIV/AIDS interventions. Yet such efforts require much planning and coordination, Charton, et al (2014). Despite the impact of combination prevention interventions that target high risk marginalized populations, the major challenges in the region are the discriminatory environments and in-country legislation that not only sustain, but fuel the epidemics resulting in extraordinarily high prevalence. Major challenges exist in maintaining the declining rates of HIV infections. It is imperative that structural, behavioral and biomedical interventions are evidence and rights based, are non-discriminatory and gender transformative.

Therefore, some experts like those of Joint United Nations Programme on HIV/AIDS advocate for moving away from specific global estimates to the use of simple costing methods using country-level or regional data based on local factors such as training costs, transportation expenses, use of various technologies, and availability and capacity of human resources. However, some studies have estimated annual costs per person per year for HIV/AIDS services. Bertozzi (2004) found the cost of testing, prophylaxis, treatment, drug costs and laboratory monitoring to be US\$ 913 for low-income countries and US\$ 4743 for middle-income countries (constant 2000 US\$).<sup>27</sup> A study in Mexico by Bautista-Arredondo, Mane and Bertozzi (2006) found average annual drug costs per patient to be between US\$ 2430 and US\$ 4270 (prior to the availability of generic drugs).

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.0 Introduction**

This chapter involved the research design, study population, sample size and selection, sampling techniques and procedure, data collection methods, data collection instruments, pre-testing (validity and reliability), procedure of data collection, data analysis and management.

#### **3.1 Research Design**

The research design was both qualitative and quantitative in a sense that, under quantitative, the researcher applied questionnaires. Under this both primary and secondary data sources were used to provide raw data required by the study objectives. Qualitative data analysis using documentary review for the purposes of triangulations as stated by (AMIN 2005) was used.

#### **3.2 Study Population**

The study population refers to the larger population to which the researcher ultimately would like to generalize the results of the study (Mugenda & Mugenda, 2003). Hence a total population of 100 respondents was considered for the study, these mainly comprised of residents in the division, health personnel, local leaders and local people and more focus was put on patients from selected health centers in the division. The study subjects included local people, local leaders and district health officers. Two sets of questionnaires were used, one set for the literates and the other for the people who could hardly read and write.

#### **3.3 Sample size and selection**

This was achieved through use of Krejcie, R.V. & Morgan and D.W. (1970) table which illustrated that if the target population is 100 the sample size was 80. Therefore from the estimated population of 100 respondents, 80 were taken as the sample size.

#### **3.4 Sampling techniques and procedure**

The study employed random sampling for patients as they were the major target of home based care services and so detailed data was got from them and purposive sampling technique for

healthcare personnel in the division since they were more concerned with issues related to the spread and prevention of HIV/AIDs.

Purposive sampling was used to ensure that precise information from respondent who were not easy to allocate yet crucial for the study is got. Patients in the division were used as the respondents for random sampling as this helped get a wild range of ideas from them. On the other hand, purposive sampling was used to health care personnel; reason being that they had great knowledge about the increasing spread of HIV/AIDs.

### **3.5 Data Collection Methods**

The researcher applied both primary and secondary data collection methods. These methods included questionnaire and secondary data by documentary review.

#### **Questionnaire**

This was directly administered to the respondent at the various levels of the population sample patients, local leaders and healthcare personnel from the division were considered. Questioners were used because they were easy to manage and cost effective as Mugenda & Mugenda (1999) states that questionnaires are valuable methods of collecting a wide range of information from a large number of respondents.

### **3.6 Pre-testing (validity and reliability)**

#### **Validity**

The questionnaires were pretested to ensure clarity and Validity of the instrument. Mugenda and Mugenda (2003), defines Validity as the accuracy and meaningfulness of inferences which are based on results. For a research instrument to be considered valid, the content selected and included in the questionnaire must be relevant to the variable being investigated (Mutai, 2000). The responses of the subjects were checked against the research objectives. The questionnaire was pilot tested on ten (10) respondents who were part of the target population but not in the sample. After pre-testing the questionnaires was revised to incorporate the feed back that was provided.

### **Reliability**

The researcher measured the reliability by determining the degree to which the research instruments yielded consistence results or data after repeated trials (Mugenda & Mugenda 2003). The test re-test technique was used to estimate the reliability of the instruments which involved administering the same test twice to the same group of respondents who were identified for this purpose (patients who had ever prevented HIV/AIDS through use of home based care services) to establish whether the questionnaire elicited the same responses.

### **3.7 Procedure of Data Collection**

The researcher got an authorization letter from the department of guidance and counseling for Identification then she proceeded to the administration of Kampala central division for information about the purpose of the study and got permission so as to conduct research. The researcher then visited some patients in some health centers consulting them of how they had found home based care services and asking for permission to carry out the study.

### **3.8 Data Analysis**

Data cleaning and tabulation was carried out as part of the pre-analysis activities to ensure that data was presented in a desired and appropriate manner, help keep track of the questionnaire that was processed as well as aid in speeding up the data entry process. The final data was then analyzed both qualitatively and quantitatively using descriptive statistics. The responses in the Questionnaires were coded into common themes to facilitate the analysis. The coded data was then entered into the computer using frequency tables and percentages to represent the outcomes.

### **3.9 Ethical Consideration**

The researcher got a letter from the college of humanities and applied economics that service as an introduction to various respondents; she proceeded to the field for the research. In addition some people were voluntarily asked to participate in a short face to face interview.



## CHAPTER FOUR

### DATA PRESENTATION, ANALYSIS AND INTERPRETATION OF FINDINGS

#### 4.0 Introduction

This chapter presents data presentation, analysis and interpretation of findings.

#### 4.1 Socio-demographic characteristics of the respondents

The respondents had differences in terms of background. The respondents included different age groups, education level, marital status and sex. The following issues were obtained from the questionnaires submitted to different groups of people in **TASO Uganda Mulago hospital and Kampala central division at large;**

##### 4.1.1 Distribution of respondents by Gender

The study targeted both male and female respondents this was done to avoid bias and as well as ensuring equal representation of both male and female respondents.

**Table: 1 Represents the distribution of respondents by gender**

Gender	Frequency	Percentage (%)
Male	30	30
Female	70	70
Total	100	100

**Source: Primary Data, 2017**

From study results in Table 1 above, majority 70% respondents were female while minority 30% was for male respectively. This therefore implied that female are mostly involved in issues related to home based care services than does to men.

#### 4.1.2 Distribution of respondents according to age bracket

**Table: 2 Represents age bracket of respondents**

Age	Frequency	Percentages
Below 18 years	5	5
19 – 30 years	25	25
31 – 44 years	40	40
45 and above	20	20
Total	100	100

**Source: Primary Data, 2017**

From table 2 above, majority 40% respondents were aged 31–44 years followed by 25% aged 19–30 years, 20% for 45 and above and 5% for those Below 18 years. From the study results most of the respondents were aged 31 years and above meaning that home based care services is mostly used by elder people than youth. This therefore implied that youth fear to know their status in regard to HIV/AIDs status.

#### 4.1.3 Distribution of respondents according to education background

**Table: 3 Represents respondent's level of education**

Education level	Frequency	Percentages
Not gone to school	22	22
Primary	38	38
Secondary	25	25
Tertiary	15	15

Total	100	100
-------	-----	-----

**Source: Primary Data, 2017**

Study results in table 3 above indicated that majority of respondents from TASO Mulago stopped in primary with a percentage of 38%, 25% completed secondary, 22% did not go to school and only 15% went for tertiary institutions hence home based care services used is dominated by illiterates and minority are educated. This therefore shows that most respondents were not so much educated but could easily read and write implying that few people can resist application of home based care services due to lack of enough qualifications or education.

#### **4.1.4 Distribution of respondents according to marital status**

**Table: 4 Represents distribution of respondents by marital status**

Marital status	Frequency	Percentages
Married	65	65
Single	25	25
Divorced	5	5
Separated	5	5
Total	100	100

**Source: Primary Data, 2017**

From table 4 above, majority of respondents were married with 65%, 25% of the respondents were single, 5% were divorced and separated respectively. This therefore shows that irrespective of most of them being 30 years and above, dominants of home based care services are mostly married people and this according to them has helped them to analyze their status in regard to HIV/AIDs. It implies that to some extent two heads are better than one for instance a husband and wife can jointly advise one another.

#### 4.1.5 Distribution of respondents according to period stayed in Kampala central division by respondents

**Table: 5 Represents distribution of respondents by duration of stay in the division**

Duration	Frequency	Percentages
Less than 1 year	45	45
1-5 years	14	14
6-10 years	21	21
Over 10 years	30	30
Total	100	100

**Source: Primary Data, 2017**

From the study results in table 5, most of the respondents had stayed in Kampala central division for Less than 1 year, 21% had stayed for over 10 years, 21% had spent 6-10 years and 14% had stayed for 1-5 years. This was due to the fact that most respondents were residents from other areas but not in Kampala central division. Hence the research was mixed that is to say; it targeted both people from Kampala central division and those from other areas which helped her to balance information sharing.

#### 4.2 Types of home based care services used in the prevention of HIV/AIDS.

The first research objective sought to assess the types of home based care services used in the prevention of HIV/AIDS. In order to get information to answer the above question, the researcher asked respondents various questions and the response rate from the respondents are tabulated in the tables below;

##### 4.2.1 Palliative Care which focuses on patients in the terminal stages of disease

The respondents were asked whether Palliative Care is amongst the types of home based care services used in the prevention of HIV/AIDS and the results were depicted as seen below;

**Table: 6 Represents respondents' views on palliative care as a type of home based care service used in the prevention of HIV/AIDS**

Response	Frequency	Percentage%
Strongly agree	55	55
Agree	25	25
Strongly disagree	15	15
Disagree	5	5
Total	100	100

**Source: Primary Data, 2017**

From study results in table 6, (80%) of the respondents agreed to the statement that palliative care is one of the types of home based care service used in the prevention of HIV/AIDS while 20% disagreed. The indication therefore is that palliative care which involves quality-of-life issues of patients and their families has with no doubt been applied as one of the home based care services. This in agreement with WHO (2012) view that the control of pain and other symptoms is the crux of any palliative care model but the WHO model also addresses patients' and their families' psychological, social, and spiritual problems. Under this definition, in many developing countries, most people living with HIV/AIDS are not receiving the minimum standard of palliative care.

#### **4.2.2 Symptom-based Care which helps to manage pain**

The respondents were asked whether symptom-based Care which helps to manage pain is amongst the types of home based care services used in the prevention of HIV/AIDS and the results were depicted as seen below;

**Table: 7 Represents respondents' views on Symptom-based Care which helps to manage pain**

Response	Frequency	Percentage%
Strongly agree	45	45
Agree	15	15
Strongly disagree	17	17
Disagree	23	23
Total	100	100

**Source: Primary Data, 2017**

From Table 7; 60% of the respondents wholesomely agreed that symptom-based care which helps to manage pain is also amongst the home based care services used by TASO Mulago though minority 40% disagreed with a statement meaning that symptom-based Care through for instance pain management is extremely important in HIV, Diarrhea and nausea; vomiting and skin problems are all symptoms that are targeted for treatment in due course of home based care services. This therefore implies that usage of symptom-based Care has helped to simplify home based care services. This view goes with authentication of Butt, et al. (2014) who argued that Nausea and vomiting are prevalent in people with AIDS and can lead to anorexia and weight loss. Treating nausea costs an estimated US\$1.75 per episode and continuous treatment of nausea and vomiting in end-stage patients costs about US\$2 per day.

#### **4.2. 3 Psychosocial support which helps in multidisciplinary management strategies**

The respondents were asked whether Psychosocial support which helps in multidisciplinary management strategies is amongst the types of home based care services and below were the results;

**Table: 8 Represents views on psychosocial support which helps in multidisciplinary management strategies**

Response	Frequency	Percentage%
Strongly agree	45	45
Agree	15	15
Strongly disagree	15	15
Disagree	25	25
Total	100	100

**Source: Primary Data, 2017**

From table of the findings above majority 60% agreed that through psychosocial support, home based care services are extended to people in Kampala central division yet the least 40% disagreed to the statement due to the high mortality rates existing amongst youth. This goes in line with views expressed by Harding et al. (2014) who argued that psychosocial support is an integral component of the multidisciplinary management strategies that care providers regard as essential for people with HIV and the support for patients and families can have a positive effect on adherence to therapies and can contribute to the critical aim of integrating prevention with treatment and care

#### **4.3 Role played by home-based care services in the spread and prevention of HIV/AIDS**

The respondents were asked to examine the role played by home-based care services in the spread and prevention of HIV/AIDS and to be able to get answers to the question; the following were asked;

#### 4.3.1 Caregivers visit and care for chronically ill patients

The respondents were asked whether caregivers visit and care for chronically ill patients and below were the results;

**Table: 9 Represents respondent's views on whether caregivers visit and care for chronically ill patients**

Response	Frequency	Percentage%
Strongly agree	33	33
Agree	27	27
Strongly disagree	24	24
Disagree	16	16
Total	100	100

**Source: Primary Data, 2017**

From the table of findings above, 60% of the respondents were supportive with the agreement that caregivers visit and care for chronically ill patients hence simplifying home-based care services delivery. Minority 40% had disagreement since they revealed that home based care services are not extended to local people especially those in congested and insecure places of Kampala central division. This therefore implies that the chronically ill patients get a chance to meet health workers at their places of residence. This view goes with the argument of Harding et al. (2011) who argued that this at times involves volunteering where the volunteers do provide help with household chores such as fetching water, collecting firewood, cooking their food and feeding them. They facilitate the referral of patients to the social worker, health facility, raise and donate funds to take patients to the hospital, encourage community to go for testing, give them information on PMTCT.



#### 4.3.2 Caregivers offer psychosocial support, advice and encourage patients to live positively

The respondents were asked whether caregivers offer psychosocial support, advice and encourage patients to live positively and the below were the results;

**Table: 10 Represents respondent's views on whether caregivers offer psychosocial support, advice and encourage patients to live positively**

Response	Frequency	Percentage%
Strongly agree	66	66
Agree	24	24
Strongly disagree	10	10
Disagree	0	0
Total	100	100

**Source: Primary Data, 2017**

Table 10 indicated that majority 90% of the respondents agreed that caregivers offer psychosocial support, advice and encourages patients to live positively since most of them have worked hand in hand in reducing HIV/AIDs especially through providing counseling to patients who test positive to reduce on psychological torture. However, 10% disagreed that they don't get such services. This implies that people are cared for in form of psychosocial support, advice and encourage patients to live positively. The interpretation of the above findings in comparison to the literature is that though such support is given much effort needs to be put in sensitization of people to know their status.

#### 4.3.3 Home-based care services reduce on burdens of hospitals

The respondents were asked whether home-based care services reduce on burdens of hospitals and the below were the results;

**Table: 11 Represents respondent's views on whether home-based care services reduce on burden of hospitals**

Response	Frequency	Percentage%
Strongly agree	55	55
Agree	15	15
Strongly disagree	27	27
Disagree	3	3
Total	100	100

**Source: Primary Data, 2017**

From Table 11, majority 70% respondents agreed that Home-based care services reduce on burdens of hospitals since they deliver services in time and to the right people without failure and delay. Only 30% of the respondents disagreed that home-based care services reduce on burdens of hospitals. This therefore implies that Home-based care services reduce on burdens of hospitals which helps in quick services delivery especially in HIV/AIDs.

#### 4.3.4 Helps to promote the sustainability of care

The respondents were asked whether home based care services help to promote the sustainability of care and below were the results;

**Table: 12 Represents respondent's views on whether home-based care services help to promote the sustainability of care**

Response	Frequency	Percentage%
Strongly agree	33	33
<b>Agree</b>	<b>27</b>	<b>27</b>
Strongly disagree	22	22
Disagree	18	18
Total	100	100

**Source: Primary Data, 2017**

Table 12 results indicated that majority 60% respondents agreed that home based care services help to promote the sustainability of care. Minority 40% disagreed with the view where by they argued it is does not promote the sustainability of care since some people are excluded. This therefore implies that home based care services help to promote the sustainability of care. This view is supported by Tibebu et al. (2016) who argued that the compassion and sympathy towards ill patients was evident at the early stage of the disease but long term HIV and AIDS makes caring a burden upon household livelihood security and intra-household relation as the patient condition deteriorate over time. It is important that people should get tested early and access antiretroviral treatment when they are not ill to reduce the cost of long term care.

#### 4.3.5 They promote experience sharing through networking

**Table: 13 Represents respondent's views on promotion of experience sharing through networking with home-based care services**

Response	Frequency	Percentage%
Strongly agree	47	47
Agree	13	13
Strongly disagree	22	22
Disagree	18	18
Total	100	100

**Source: Primary Data, 2017**

Table 13 results depicted that majority 60% of the response argued that home based care services help in the promotion of experience sharing through networking. This implies that the creation of networks can help to simplify the delivery of HIV/AIDs services amongst patients. However; minority 40 % disagreed with the statement where by they argued that networking cannot help extend services to all people but to a selected few that is to say those in such networks.

#### 4.4 Challenges faced by home based care services on the prevention and spread of HIV/AIDS

The third research objective of the study sought to identify the challenges faced by home based care services on the prevention and spread of HIV/AIDS. In coding the data from respondents the results were presented;

##### 4.4.1 Poor payment of care givers

**Table: 14 shows poor payment of care givers as a challenge to home based care services**

Response	Frequency	Percentage%
Strongly agree	46	46

Agree	14	14
Strongly disagree	28	28
Disagree	12	12
Total	100	100

**Source: Primary Data, 2017**

Table 15 results depicted that majority 60% of the response argued that home based care services is challenged by poor payment of care givers which not only affects management but also creates gaps for corruption and embezzlement. This implies that poor payment slows down service delivery and employee performance. However minority 40% disagreed arguing that it is not about payment but the love and ethical standards health personnel has towards his or her job.

#### **4.4.2 Shortage of funds to cater for the multiple needs of AIDS patients**

Table: 15 shows shortage of funds to cater for the multiple needs of AIDS patients as a challenges to home based care services

<b>Response</b>	<b>Frequency</b>	<b>Percentage%</b>
Strongly agree	23	23
Agree	57	57
Strongly disagree	15	15
Disagree	5	5
Total	100	100

**Source: Primary Data, 2017**

From the table of findings above, 80% of the respondents were supportive with the agreement that shortage of funds to cater for the multiple needs of AIDS patients. Minority 20% had disagreement since they revealed that funds are not few but health personnel are reluctant in

service delivery. This therefore implies that shortage of funds to cater for the multiple needs of AIDS patients affects the proper extension of services especially to congested areas.

#### 4.4.3 Weak national health systems poor infrastructure, civil war and corruption

Table: 16 Represents respondent's views on weak national health systems poor infrastructure, civil war and corruption as **challenges to home based care services**

Response	Frequency	Percentage%
Strongly agree	80	80
Agree	10	10
Strongly disagree	5	5
Disagree	5	5
Total	100	100

**Source: Primary Data, 2017**

From Table 16, majority 90% respondents agreed that home based care services are challenged by weak national health systems poor infrastructure, civil war and corruption. Only 10% of the respondents disagreed that home based care in Kampala is not affected by the above mentioned incidents but few health personnel and lack of professionalism in service delivery. This therefore implies that home based care services irrespective of being in Kampala, faces serious challenges which come due to corruption and greedy for money amongst health personnel.

## **CHAPTER FIVE**

### **SUMMARY OF FINDINGS, CONCLUSION AND RECOMMENDATIONS**

#### **5.0 Introduction**

This chapter presents a summary of findings, conclusions and recommendations of the research study. The researcher thus presents a detailed discussion of the results, draws conclusions and makes recommendations from the study.

#### **5.1 Summary of findings**

The summary of findings is based on the results presented in chapter four of this report as given by the respondents. The main aim of this was indicated in chapter one as to establish the effects of home based care services on the prevention and spread of HIV/AIDS in Kampala central Kampala district.

##### **5.1.1 Social demographic characteristics of respondents**

From the demographic characteristics of respondents; Gender, age bracket, education background, marital status, majority of them 70% were females aged between 31-44 years and most of them stopped at primary level by a 38% and married with a 65% response respectively. These biographies deemed relevant to the study since they simplified a critical basis of the phenomenon and as well suggest possible solutions.

##### **5.1.2 Types of home based care services used in the prevention of HIV/AIDS**

In regard to the research question what are the different types of home based care services used in the prevention of HIV/AIDS; Palliative Care which focuses on patients in the terminal stages of disease is amongst the types and it is mostly applied to improve the quality-of-life issues of patients and their families.

From study findings, it was established that symptom-based care which helps to manage pain is also used in delivering home based care services and this is done to manage pain for those patients with for example skin rashes and appetite loss. Further it was also established agreed that through psychosocial support, home based care services are extended to people

### **5.1.3 Role played by home-based care services in the spread and prevention of HIV/AIDS**

Home based care services in the spread and prevention of HIV/AIDS play roles like visiting and caring for chronically ill patients, offering psychosocial support, promote experience sharing through networking, advice and encourage patients to live positively, reduce on burdens of hospitals and promoting the sustainability of care. It is therefore important to extend the link to local people because they know the most pressing needs.

### **5.1.3 Challenges faced by home based care services on the prevention and spread of HIV/AIDS**

Despite the above identified achievements brought up by home based care services, some challenges still exist for example poor payment of care givers, shortage of funds to cater for the multiple needs of AIDS patients, weak national health systems poor infrastructure, civil war and corruption which is mostly practiced by employees who do not have good work ethics and ever complaining that their money delays.

## **5.2 Conclusions**

**From the study results in chapter four, conclusions were made as follows;**

### **5.2.1 Types of home based care services used in the prevention of HIV/AIDS**

From the findings of the study, it can be concluded home based care services involves Palliative Care which focuses on patients in the terminal stages of disease, Symptom-based Care which helps to manage pain, psychosocial support which helps in multidisciplinary management strategies. Hence there are a variety of services used in reducing the burden of HIV/AIDs amongst patients. Such arguments are supported by authors like Cintron-Bou, (2014) who argued that most programs for which data are available are community-based outreach programs administered by local clinics or hospitals and these programs can consist of simple home visits to provide basic care for AIDS patients or may be comprehensive schemes that provide care, palliative medications, meals, psychosocial support and counseling and links to primary and secondary health care



### **5.2.2 Role played by home-based care services in the spread and prevention of HIV/AIDS**

In regard to the research question what is the role played by home-based care services in the spread and the prevention of HIV/AIDS;

From study findings, it was established that it is extended through visiting and caring for chronically ill patients which is done by the volunteers who provide help with household chores such as fetching water, collecting firewood, cooking their food and feeding them.

It was also established that home based care services offer psychosocial support, advice and encourage patients to live positively. In the provision of service, it is important to identify needs of people who require to be enrolled in the home-based care that are specific to the target groups of people. These views are supported by WHO,UNAIDS and Tibebu (2016) who argued that home-based care offers health care services to support the care process in the home of the HIV infected person has been a major care and support strategy since the inception of the epidemic in Uganda. Consistent with the comprehensive care strategy recommended for HIV/AIDS infected and affected individuals, Home-Based Care Programs aim to alleviate human suffering and pain, and mitigate the impact of HIV/AIDS through comprehensive care package of nursing care, treatment of opportunistic infections including symptoms and pain; counseling and emotional support; assistance with essentials like food and soap; poverty alleviation measures like income generating activities; orphan care; legal aid including will making; advocacy; prevention strategies of education and awareness programs for behaviour change and condom distribution.

### **5.2.3 Challenges faced by home based care services on the prevention and spread of HIV/AIDS**

Research question three on the challenges faced by home based care services on the prevention and spread of HIV/AIDS. Despite the achievements, gaps still exist in delivery of home based care services for example poor payment of care givers, Shortage of funds to cater for the multiple needs of AIDS patients and weak national health systems poor infrastructure, civil war and corruption .

However, irrespective of the challenges truth prevails that home based care services lead to extension of quick services to especially vulnerable, people with disability and those in remote areas.

### **5.3 Recommendations**

#### **Government**

Government should be supportive and protective of health workers to reduce on issues related to corruption. This should be achieved through government releasing salaries in time and still setting the minimum wage to all public servants in addition to privileges like daily allowances. Lastly the government should set favorable policies, laws and regulatory frame works to fight against corruption which has been found as one of the hindrances to delivery of health services to people at the local level.

Government should accept to open up an equal basis, discuss and formulate policies jointly with health care providers to equally analyze challenges they meet while at work.

Laws should be enforced against any person involved in issues of embezzlement to reduce on the high prevalence of medical shortage especially in government hospitals.

#### **Health workers**

Health care workers should build networks and alliances with people inside hospitals to investigate challenges they meet in the due course of delivering home based care services. The researcher therefore recommends TASO Mulago creates a leadership committee especially to handle employee salaries, facilitation and quick feedback platform for their complaints.

#### **Patients**

Further if home based care services is to be made more effective towards prevention and spread of HIV/AIDS, there is need to involve more patients(especially those who test positive) to analyze the challenges they meet in affording, using medication provided by medical personnel.

#### **5.4 Areas for further research**

**The researcher recommends further research into the following areas;**

- i) Relationship between home based care services and spread of HIV/AIDS in Kampala central division
- ii) Impact of early payment of workers on health services delivery.
- iii) Challenges to home based care services and prevention and spread of HIV/AIDS in Kampala central division

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## LIST OF APPENDICES

### APPENDIX 1

#### QUESTIONNAIRE

Kampala International University,

College of humanities and social sciences

I am **Kamwine Everlyne** a student from Kampala International University pursuing a Degree in guidance and counseling, year three, semester two. In our final year we are required to carry out research on a topic of our choice therefore my topic is about “**effects of home based care services on the prevention and spread of HIV/AIDS in Kampala central division**”. Thus the questionnaire below will help me gather the data required for my topic of research and I request you to respond to the following questions appropriately. I declare that the information given shall be treated with maximum confidentiality it deserves for academic purpose. Thank you

Tick one and write the relevant information in the space provided.

#### SECTION A: SOCIO-DEMOGRAPHIC DATA OF RESPONDENTS

##### 1. Age

- a) Below 18 years ☐      b) 19 – 30 years ☐  
c) 31 – 44 years ☐      d) 45 and above ☐

##### 2. Sex

- a) Male ☐      b) Female ☐

##### 3. Marital status

- a) Married ☐      b) Single ☐  
c) Divorced ☐      d) Separated ☐

e) Others specify .....

**4 Level of education**

a) Not gone to school ☐

b) Primary ☐

c) Secondary ☐

d) Tertiary ☐

e) Others, (specify).....

**5 Period stayed in Kampala central division by respondents**

a) Less than 1 year ☐

b) 1-5 years ☐

c) 6-10 years ☐

d) Over 10 years ☐

e) Others (specify).....

**RESULTS FROM RESEARCH OBJECTIVES**

Dear respondent, Kindly TICK the correct answer if you strongly agree, agree, strongly disagree and disagree, neutral in the spaces provided;

Code	1	2	3	4	5
Status	Strongly agree	Agree	Strongly disagree	Disagree	Neutral

Types of home based care services used in the prevention of HIV/AIDS	1	2	3	4	5
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Palliative Care which focuses on patients in the terminal stages of disease					
Symptom-based Care which helps to manage pain					
Psychosocial Support which helps in multidisciplinary management strategies					
<b>Role played by home-based care services in the spread and prevention of HIV/AIDS</b>					
Caregivers visit and care for chronically ill patients					
Offer psychosocial support, advice and encourage patients to live positively					
Reduce on burdens of hospitals					
Helps to promote the sustainability of care					
They promote experience sharing through networking					
<b>Relationship between home-based care services and the spread and prevention of HIV/AIDS in Kampala central division</b>					
HIV and AIDS prevention, treatment and care programmes produce various effects to the health systems components					
Antiretroviral therapy programme is improving general health indicators such as life expectancy					

HIV and AIDS programmes expansion has to some extent increased utilization of non-HIV-related services					
HIV and AIDS services can serve to attract and retain health care workers as they offer incentives					
<b>Challenges faced by home based care services on the prevention and spread of HIV/AIDS</b>					
Poor payment of care givers					
Shortage of funds to cater for the multiple needs of AIDS patients					
Weak national health systems poor infrastructure, civil war and corruption					

**THANK YOU FOR YOUR RESPONSE.**

