

**AN EXPLORATORY STUDY OF INFECTION
CONTROL PRACTICES IN HOME-BASED CARE IN
DURBAN, SOUTH AFRICA**

BY

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DECLARATION

I hereby declare that this dissertation, unless otherwise indicated in the text, is my own original work. All citations, references and borrowed ideas have been duly acknowledged. This research work has not previously been submitted to any other University for any degree or examination purposes.

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DEDICATION

I would like to dedicate this study to all my family, my friends and thank them for their invaluable support throughout my journey. I could never have done this without all their love and support. To my husband, thank you for encouraging me to be the best that you always knew I could be. My dad, thank you for your prayers and encouragement.

ABSTRACT

Infection control practices are a critical element in home-based care for people living with HIV/AIDS. It involves principles and procedures used to minimize the risk of spreading infections in home-based care. Infection control practices help to prevent morbidity, mortality rates and improve health for the volunteer caregivers and the patients. However, most previous studies on home-based care have focused on burdens of care, perceptions of rewards, quality of care and challenges faced by caregivers. Therefore, it is not clear how and to what extent infection control practices are carried out in home-based care. The purpose of this study is to explore the experiences of home-based care coordinators and volunteer caregivers regarding infection control practices in home-based care. Qualitative interviews were conducted with ten home-based care coordinators/project managers and ten focus group discussions were conducted with volunteer caregivers. An interview guide and a focus group schedule with open ended questions were used. Volunteer caregivers in home-based care organizations were faced with practical challenges regarding infection control practices that posed a threat to their work and health. The received insufficient infection control material resources such as gloves, masks and sanitizers. They also mentioned to have received poor quality gloves that easily broke, poor quality aprons that were not tight; easily blown by the wind and also thin masks that could not filter the bad odour. Other challenges that they faced included, insufficient water supply; insufficient knowledge on infection control and lack of cooperation from some patients and some family members regarding the use of protective clothing especially gloves and masks. Most volunteer caregivers were ridiculed by some family, community members and friends. Sometimes they could not access some patient due to HIV related stigma and discrimination. However, volunteers developed various strategies of dealing with these challenges such as replacing the torn gloves with plastics, carrying 2.5 litres of water, educating patients and family members about the importance of wearing gloves and practicing infection control. These findings require the government, NGOs, funders and donors to form a forum with volunteer caregivers to discuss the supply of materials. They need to establish a central administration that will be responsible for allocating adequate and quality materials for infection control practices. This central administration should also be responsible for supervising HBCOs including monitoring and evaluating infection control practices.

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ACRONYMS

| | |
|--------|---|
| AIDS | Acquired Immuno Deficiency Syndrome |
| ARVs | Antiretro virals |
| CBOs | Community Based Organisations |
| DOH | Department of Health |
| DOT | Direct Observation Treatment |
| EST | Ecological Systems Theory |
| HBC | Home-based Care |
| HBCCs | Home-based Care Coordinators |
| HBCOs | Home-based Care Organisations |
| HDN | Health and Development Networks (HDN) |
| HIV | Human Immune virus |
| KZN | KwaZulu-Natal |
| MAAP | Multi-Annual Action Plan |
| NASCO | National Sanitation Co-ordinating Office |
| NGOs | Non-Governmental Organisations |
| PLWHA | People Living with HIV/AIDS |
| SADOH | South African Department of Health |
| SAFAID | Southern African HIV and AIDS Information Dissemination |
| TB | Tuberculosis |
| TDOH | Tanzanian Department of Health [TDOH] |
| UNAIDS | Joint United Nation Programme for HIV/AIDS |
| WHO | World Health Organisation |

CHAPTER ONE INTRODUCTION OF THE STUDY

1.1 Introduction and background to the study

There is evidence of a worldwide increase in the HIV epidemic from 8 million in 1990 to 33.3 million at the end of 2009. Approximately 2.6 million were infected with new infections and 1.8 million AIDS related deaths were recorded in the year 1999 alone (UNAIDS, 2010). In total, approximately 30 million AIDS related deaths have been recorded since the beginning of the epidemic (UNAIDS, 2010). However, there has been a steady reduction in the number of new infections and AIDS related deaths due to the increased number of people taking antiretroviral drugs (ARVs) (UNAIDS, 2010).

Although, 10% of the world population reside in sub-Saharan Africa, this region has the highest number of people infected with HIV/AIDS. For example, 68% (22.5 million) of people infected with the disease on the globe live in this region and its estimated number of AIDS related deaths is 1.3 million. In sub-Saharan Africa, Southern Africa is the most severely affected region as one in every five people between the ages of 15-49 years are living with the HIV virus in three of the countries in this region (UNAIDS, 2010). For example in Botswana, 24.8% adults were living with HIV at the end of 2009 (Fidzani & Attah, 1996).

South Africa's AIDS epidemic remains the largest in the world with an estimated 5.6 million people living with HIV/AIDS in the year 2009 (UNAIDS 2010). The total number of persons living with HIV/AIDS in South Africa increased from an estimated 4.10 million in 2001 to 5.24 million by 2010. A study conducted in South Africa on HIV infection in pregnant women, shows that an estimated 29.4% of pregnant women between the age of 15 and 49 were HIV infected in 2009 while another study estimated that 10.9% of people aged 20 and above were HIV infected in 2009 (South African Department of Health [DoH]a, 2010). Furthermore, an estimated 10.5% of the total population was HIV positive in the year 2010 (Rehle, Hallet, Shisana, Pillay-van Wyk, Zuma, Carrara, & Jooste, 2010). Additionally, among all provinces, Kwa-Zulu Natal (KZN) is the most affected. Recent estimates show that

26.4% of KZN's working age population is HIV positive, compared to 15.9% in the other provinces (Thurlow, Gow and George, 2009).

According to Chipfakacha (2007), the HIV/AIDS pandemic has had a severe impact on people. Gachui (1999) and UNAIDS (2008) indicate that HIV/AIDS has had adverse impacts on the demography, education economic growth, workplace, household, children, life expectancy and health sector in many regions of the world including Southern Africa. The impact of HIV/AIDS on an already burdened health care system has caused more demand for better health care services. This has resulted in an increase in hospital admissions and an increase in government expenditure on public health facilities (Akintola, 2008).

For example, in the sub-Saharan and Southern African countries, studies have shown that approximately 50% or more of the hospital beds are occupied by patients with HIV related diseases who also stay four times longer than other patients (UNAIDS, 2006). In an attempt to save space in hospitals, for example in South Africa, HIV/AIDS patients are only admitted for a short period of time. Patients are also admitted during the later stages of their disease consequently, this lowers the patient's probability of recuperation (Steinberg, Johnson, Schierhout & Ndegwa, 2002). As a result of the impact of the HIV/AIDS epidemic on the public health care system, most governments, NGOs, communities and HIV affected people have (Akintola, 2004) developed home-based care programs as a key management strategy in many countries including South Africa (Akintola, 2008: Young and Busgeeth, 2010).

Home-based care (HBC) is the care given to patients with chronic illnesses such as HIV/AIDS, cancer, tuberculosis and mental illness in their own homes and within their local communities (Wegelin-Schuringa et al., 2003). Services provided in the homes include physical activities and spiritual activities such as prayers. Psychosocial activities like counselling and educating family carers on how to take care of the patients are also provided. Additionally, palliative care which involves management of pain and symptoms to the terminally ill is provided. Palliative care aims at providing hope to the patient and family members. It also helps in promoting, restoring and maintaining a person's maximum level of comfort, functioning and health (World Health Organization [WHO], 2002).

HBC can be said to be important to PLWHA because it reduces medical expenditure, enables patients to receive care in a familiar and supportive environment and creates community awareness of the disease. Furthermore, HBC relieves the duty of creating extra services by the health care system in resource limited areas and thus reduces hospital visits and increases access of HIV affected members and community to regular skilled medical care, counselling, support and home care supplies. HBC also provides education to family members and friends on the prevention of further transmission of the virus and on how to practice good health and hygiene (Young & Busgeeth, 2010; Fidzani & Attah, 1996; WHO, 1999). As the number of PLWHA increases, more health care services are needed. Thus HBC becomes more relevant as it can be given by both formal caregivers such as trained nurses and other medical personnel or by informal care givers such as family members; friends or by volunteer caregivers (Akintola, 2006; Akintola 2008).

Volunteer caregivers are people who come from HIV/AIDS affected communities and are recruited and trained by HIV/AIDS care organizations to help family caregivers in caring for PLWHA in their homes without receiving any remuneration (Akintola, 2006; Akintola, 2008). They are trained either by the organizations that recruit them for example, non-governmental organizations or by the government through the department of health in order to equip them with knowledge and skills on HIV/AIDS and T.B prevention methods. Furthermore training is provided in basic nursing care, direct observation treatment (DOT), infection control practices, basic counselling and nutrition, training for household caregivers and mentoring orphans (Uys, 2000; Schwartz and Gidron, 2002).

In home-based care the most common opportunistic infections evident with most HIV/AIDS clients include diarrhoea; pneumonia (causes fever and difficulty in breathing associated with coughing), Tuberculosis (T.B), Skin conditions; thrush of the mouth or virgina, cold sores; and genital herps (Zachariaha, Teck, Buhendwa, Fitzerland, Labanac, Chinji, Humbleta, Harriesd, 2008). Most of these infections are responsible for high mortality rates for example, 80% of all HIV positive tuberculosis cases occur in sub-Saharan Africa (UNAIDS, 2010). In PLWHA these infections can be transmitted to susceptible people around them such as family members and caregivers. These infections can be transmitted through food, unhygienic conditions, direct skin contact with infected individuals; direct contact with faeces of the

infected individual (in the cases of diarrhea). They can also be transmitted through inhalation of nuclei containing *Mycobacterium tuberculosis* organisms which is generated when a person with pulmonary or laryngeal T.B disease coughs, sneezes or shouts (WHO, 2010).

In order to relieve pain and prevent infections, volunteer caregivers physically care for their patients by methods that involve personal hygiene practices such as giving them bed baths; mouth and nail care; washing their hair; turning and lifting them in their beds; taking care of pressure sores, general care of wounds such as, cleaning sores and also cleaning of any vomitus. Physical therapy also includes pain management, administering drugs to the client in order to ensure compliance and maintaining the nutritional status of the patient/clients (Van Acker, 2007). Considering the nature of work that volunteer caregivers have, they are undoubtedly exposed to all the infections stated above. Therefore, infection control practices could help volunteer caregivers to protect themselves and their clients from acquiring infections.

1.2 Problem statement

Infection control is a critical element in home-based care for people living with HIV/AIDS (WHO, 2008). Little is to be found on infection control in home-based care literature. Most previous studies on home-based care have focused on burdens of care, perceptions of rewards, quality of care and challenges faced by caregivers. Although studies allude to the fact that caregivers are at risk of infection and have low knowledge of prevention of infection (McInerney & Brysiewicz, 2009), and that there are challenges in accessing water and home-based care kits in most home-based care organisations [HBCOs] (Hillbrunner, 2007), it is not clear how and to what extent infection control practices are carried out in home-based care. Furthermore, little is known about the experiences of volunteer caregivers regarding infection control practices in home-based care. The purpose of this study is to provide insights on infection control practices in HBCOs. The findings could be useful for policy-makers as well as programme planners working in home-based care for developing and designing policies aimed at improving infection control in home-based care across the country. It will also be a useful addition to the body of literature on home-based care.

1.3 Purpose of the Study and Research Questions

The main objective of this study is to explore the experiences of home-based care coordinators/project managers as well as volunteer caregivers regarding infection control practices in home-based care for PLWHA. The findings of this study could assist policy makers in designing interventions aimed at addressing infection control in home based care organizations for HIV/AIDS patients. The key questions that this research intends to answer are:

- What are the perceptions of infection control practices among home-based care coordinators/project managers and volunteer caregivers?
- What resources are available for infection control practices?
- How do volunteer caregivers practice infection control?
- What challenges do volunteer caregivers confront regarding infection control practices and what strategies have been developed to deal with the challenges?

1.4 Structure of the dissertation

This dissertation is divided into six chapters. *Chapter one:* introduces the study. It provides relevant background information, outlines the research problem, states the purpose and objectives of the research, and summarises the significance of the study.

Chapter two: reviews relevant literature to this study, presented according to the following themes: prevalence of HIV/AIDS, the impact of HIV/AIDS and the role of home based care in dealing with the HIV/AIDS pandemic. The roles and challenges faced by volunteer caregivers in home based care for people living with HIV/AIDS. The concept of ‘infection control practices’ with reference to its application in home based care setting is also discussed. The theoretical framework used to inform this study, namely Ecological Systems Theory (EST) is then introduced. The initial author of the EST and how the theory has been applied in different fields is discussed. Following this, a working definition of the theory is discussed. It then presents the levels of the theory as applied in the context of infection control practices in home based care organizations providing care to PLWHA in Durban Metropolis.

Chapter three: outlines the study methodology. The study area, sample considerations and criteria, and ethical considerations are presented.

Chapter four: presents the findings from the semi-structured interviews and focus group discussions as analysed using five steps of thematic analysis by Braun & Clark (2006): familiarising oneself with data; generating initial codes; searching for themes; reviewing themes; defining and naming themes.

Chapter five: presents discussions of the results using the ecological systems theory. Limitations of the study are also presented.

Chapter six: concludes this study discussing considerations and recommendations for future endeavours in this area of research.

CHAPTER TWO LITERATURE REVIEW

2.1 Introduction

This chapter reviews literature on home-based care beginning by giving the prevalence rates and the impact of HIV/AIDS, the role and benefits of home-based care in dealing with the pandemic. The role of volunteer caregivers and how they practice infection control is discussed. Next, literature is reviewed on material resources that volunteer caregivers use for practicing infection control, the challenges that they are confronted with and what motivates them to continue to volunteer despite being confronted with challenges in HBC.

2.2 HIV/AIDS Prevalence

There is evidence of a worldwide increase in the HIV epidemic from 8 million in 1990 to 33.3 million at the end of 2009. Approximately 2.6 million were infected with new infections and 1.8 million AIDS related deaths were recorded in the year 1999 alone (UNAIDS, 2010). In total, approximately 30 million AIDS related deaths have been recorded since the beginning of the epidemic (UNAIDS, 2010). However, there has been a steady reduction in the number of new infections and AIDS related deaths that are recorded annually preceding the increase in number of people on antiretroviral therapy (ART). Although, 10% of the world population reside in sub-Saharan Africa, this area has the most HIV/AIDS infection numbers. For example, 68% (22.5 million) of people infected with the disease on the globe live in this region and an estimated 1.3 million deaths are AIDS related. In sub-Saharan Africa, Southern Africa is the most severely affected region as one in every five people between the ages of 15-49 years are living with the HIV virus in three of the countries in this region (UNAIDS, 2010).

For example in Botswana, 24.8% adults were living with HIV at the end of 2009 (Fidzani & Attah, 1996). South Africa's AIDS epidemic remains the largest in the world with an estimated 5.6 million number of people living with HIV/AIDS in the year 2009 (UNAIDS 2010). The total number of persons living with HIV/AIDS in South Africa increased from an estimated 4.10 million in 2001 to 5.24 million by 2010. A study conducted in South Africa on HIV infection in pregnant women, shows that an estimated 29.4% of pregnant women

between the age of 15 and 49 were infected with HIV in 2009 while another study estimated that 10.9% of people aged 20 and above were HIV infected in 2009 (South African Department of Health [DoH], 2010). Furthermore, an estimated 10.5% of the total population was HIV positive in the year 2010 (Rehle, Hallet, Shisana, Pillay-van Wyk, Zuma, Carrara, & Jooste, 2010). Additionally, among all provinces, Kwa-Zulu Natal (KZN) is the most affected. Recent estimates show that 26.4% of KZNs' working age population is HIV positive, compared to 15.9% in other provinces (Thurlow, Gow and George, 2009).

2.3 The impact of HIV/AIDS: the need for home based care

According to Chipfakacha (2007), the HIV/AIDS pandemic has had a severe impact on people. According to Gachui (1999) and UNAIDS (2008) HIV/AIDS has had adverse impacts on the demography, education economic growth, workplace, household, children, life expectancy and health sector in many regions of the world including Southern Africa. The impact of HIV/AIDS on an already burdened health care system has caused more demand for better health care services. This has resulted in an increase in hospital admissions and an increase in government expenditure on public health facilities.

In the sub-Saharan and Southern African countries, studies have shown that approximately 50% or more of the hospital beds are occupied by patients with HIV related diseases who also stay four times longer than other patients (UNAIDS, 2006). At present, 50–60% of public hospital beds are occupied by PLWHA in Kenya, where more than 2.5 million people are living with HIV/AIDS (Opiyo et al., 2008). In an attempt to save space, in South Africa, for example, HIV/AIDS patients are only admitted either for a short period of time in the hospital or during the later stages of their disease. Consequently, this lowers the probability of the patient's recuperation (Steinberg, Johnson, Schierhout & Ndegwa, 2002).

In addition to the increased demands of health services, many of the health care professionals themselves are directly affected by this epidemic. For instance, studies revealed that 17% of the healthcare professionals died as a result of HIV/AIDS in Botswana between 1999 and 2005 while approximately 40% of midwives in Zambia were infected with HIV (UNAIDS, 2006). These deaths have an added burden to the already scarce health care professionals

(Young and Busgeeth, 2010). For example, in South Africa, some care workers have migrated to richer countries to look for better services as a result of increased workload and insufficient (Akintola, 2010; Young and Busgeeth, 2010). Furthermore, some of these health facilities are poorly equipped and are far away from the people, especially those in the rural areas (WHO, 2004; Juma, 2004).

Most studies on HBC reveal that as a result of the impact of the HIV/AIDS epidemic on the health care system, the governments, NGOs, communities and HIV affected people have intervened by seeing what assistance can be offered with regards to the care of chronically ill patients (Akintola, 2004). For instance, the Kenyan government approved the introduction of home-based care for HIV/AIDS patients to relieve both financial constraints and overcrowding in the public health facilities following suggestions from the World Bank and other donor organizations (Opiyo et al, 2008). Similarly, In Botswana, the burden of caring for the people with HIV related illness has moved from the hospitals to the community and the family due to the shortages of beds and person power. This has then led to the communities seeing the necessity of developing community home-based care programs to support their friends and relatives in need of care (Kerkhoven and Jackson, 1995). Similarly in South Africa, due to the increased strain caused by the impacts of HIV/AIDS on the health care system, the government is supporting home-based care as a way of reducing the impact on the health care facilities (Akintola, 2010).

2.4 Home based care: definition and its relevance

The term home-based care (HBC) was initially used to refer to a programme that offers health care services to support ill persons (WHO, 1999). HBC can be defined as the care given to the terminally ill in the privacy of their own home, usually by their relatives who are supported by skilled health care providers (WHO, 2002). Additionally, the definition of HBC has expanded to include a full range of services and settings available to terminally or critically ill people in their own homes. HBC is the care given to patients with chronic illnesses such as HIV/AIDS, cancer, tuberculosis and mental illness in their own homes and within their local communities (Wegelin-Schuringa et al., 2003). Some of the services provided in HBC include physical activities; spiritual activities such as, prayers psychosocial activities like counselling and educating family carers on how to take care of the patients.

Palliative care which involves management of pain and symptoms of the terminally ill is provided. These services aim at providing hope to the patient and family members and promoting, restoring and maintaining a person's maximum level of comfort, functioning and health (WHO, 2002).

HBC can be said to be relevant because it reduces medical expenditure, enables patients to receive care in a familiar and supportive environment and creates community awareness of the disease. HBC increases access of HIV affected members and community to regular skilled medical care, counselling, support and home care supplies. HBC also provides education to family members and friends on the prevention of further transmission of the virus and on how to practice good health and hygiene skills. It has thus played a crucial role in the reduction of stigma associated with the disease and the discrimination experienced by those affected and infected (Young & Busgeeth, 2010; Fidzani & Attah, 1996; WHO, 1999). Furthermore, HBC has the added advantage of enabling caregivers to care for patients without neglecting their other income generating strategies as they are not compelled to be in the hospital. In some cases patients are able to continue earning a living allowing them to continue looking after their dependents. HBC also has the advantage of saving money for caregivers as they do not have to go to and from the hospitals (Stegling, 2001).

For example, a study conducted in Tanzania on AIDS care by Nnko, Chiduo, Wilson, Msuya, Mwaluko & Msuya (2000) shows that most caregivers confirmed that compared to hospitals where nurses have many patients to look after, home based care was beneficial to their patients because most patients were able to see their children, other relatives and receive more compassion and proper care from their family members. In addition to this, care providers at home, were able to maintain cleanliness, prepare and give food needed to make the patient more comfortable. Despite the above stated advantages, HBC has its own challenges which will be discussed below in 2.7. As more and more individuals are living with HIV/AIDS, there is an increased need for more people to be provided with health care services. Thus HBC becomes more relevant as it can be given by both formal caregivers such as trained nurses and other medical personnel or by informal care givers such as family members; friends or by volunteer caregivers (Akintola, 2006; Akintola 2008).

2.5 The role of volunteer caregivers in HBC for PLWHA

Volunteer caregivers are people who come from HIV/AIDS affected communities and are recruited and trained by HIV/AIDS care organizations to help family caregivers in caring for PLWHA in their homes without receiving any remuneration (Akintola, 2006; Akintola 2008). They are trained either by the organizations that recruit them, for example, non-governmental organizations or by the government through the department of health in order to equip them with knowledge and skills on HIV/AIDS and T.B prevention methods. Furthermore, training is provided on basic nursing care, direct observation treatment (DOT), infection control practices, basic counselling and nutrition, training for household caregivers and mentoring orphans (Uys, 2002; Schwartz and Gidron 2002).

2.5.1 Physical care activities performed by volunteer caregivers

Opportunistic infections are common in people with a compromised immune system (UNAIDS, 2010). In HBC, the most common opportunistic infections evident with most HIV/AIDS clients include diarrhoea; pneumonia (causes fever and difficulty in breathing associated with coughing). Tuberculosis (T.B), skin conditions and thrush of the mouth, cold sores and genital herpes are also common (Zachariaha, Teck, Buhendwa, Fitzerland, Labanac, Chinji, Humbleta, Harriesd, 2008). Most of these infections are responsible for high mortality rates. For example, 80% of all HIV positive tuberculosis cases occur in sub-Saharan Africa (UNAIDS, 2010) with high rates of 20% to 67% being reported from East, West, Central and Southern Africa causing an estimated 13% deaths in HIV clients (Cock, Soro, Coulibaly & Lucas, 1992). In PLWHA these infections can be transmitted to susceptible persons whom they are in contact with like family members and caregivers through food, unhygienic conditions, and direct skin contact with infected individuals. Additionally, the infections can be transmitted through direct contact with faeces of the infected individual and through inhalation of nuclei containing *Mycobacterium tuberculosis* organisms which is generated when a person with pulmonary or laryngeal TB disease coughs, sneezes, shouts (WHO, 2010).

In order to relieve pain and prevent infections, volunteer caregivers physically care for their patients by methods that involve personal hygiene practices such as giving them bed baths;

mouth and nail care; washing their hair; turning and lifting them in their beds; taking care of pressure sores; general care of wounds such as; cleaning sores and also cleaning of any vomits. Physical therapy also includes pain management, administering drugs to the client in order to ensure compliance and maintaining the nutritional status of the patient/client. Volunteer caregivers also monitoring and record their client's progress such as taking notes of their toilet visits, fluid intake and any occurrence of symptoms of dehydration, dyspnea, dysphagia, oedema or fever; taking PLWHA/client to the hospital or health facilities when need arises and comforting the client at all times during these processes (Van Acker, 2007).

In a study that was conducted in Zimbabwe on young carers in home-based, results revealed that most young carers performed physical activities such as bathing and changing their patients, washing soiled linen, cleaning the vomitus of the patients, feeding, help in taking medication, fetching water, cooking and feeding the patients (Robson, 2000). Similarly in South Africa, findings show that volunteer caregivers perform the above stated physical activities (Akintola, 2004). Considering the nature of work that volunteer caregivers do, they are undoubtedly exposed to all the infections stated above. Therefore, they require infection control practices to protect themselves and their clients from acquiring infections. This will be discussed in detail in the next section.

2.5.2 Infection control practices

Infection control refers to preventive principles and procedures used to minimize the risk of spreading infections in hospitals and in any other health care settings (WHO, 2003). Infection control practices involve measures that are taken into consideration with the aim of preventing infection transmission by limiting the exposure of susceptible people (hosts) to microorganisms (agents) that may cause infection. Infection control addresses factors related to the spread of infections within the health-care setting which can either be from patient-to-patient, from patients to staff and from staff to patients, or among-staff. The purpose of infection control is to reduce the occurrence of infectious diseases that can be spread by human-to-human contact, airborne transmission through tiny droplets of infectious agents suspended in the air, and also by a common vehicle such as food or water (WHO, 2003).

In HBC, infections are a major cause of illness among patients and family members because most of the times these people share eating utensils and living accommodation. Therefore this can cause numerous admissions to hospitals. The use of guidance on infection prevention can minimize the spread of infections (South African Department of Health [SADOH] 2006). Infection control practices in home-based care settings involve taking standard precautions such as practicing hand hygiene: washing of hands after handling any blood, body fluids, secretions, excretions, known and unknown contaminated equipments or surfaces to minimize micro-organisms and using personal protective equipment (PPE). PPE are methods that use a physical barrier between micro-organisms and the caregiver to prevent micro-organisms from contaminating other patients, or any caregivers, these include gloves, masks, apron, gown, boots and head covers where necessary and also the maintenance of a clean and safe environment (WHO, 2003).

Proper infection control practices improve health outcomes and prevent negative outcomes such as morbidity, mortality rates and increased health care costs. For example in South Africa, the national policy on infection prevention and control aims at setting minimum national standards for the effective prevention and management of health care associated infections. These standards were developed so that hazards associated with biological agents are minimized for patients, visitors and caregivers (SADoH, 2006). To achieve this, national, provincial and district infection prevention and control committees were established under the *national health Act 2003* to oversee infection control practices at each level. This involves a comprehensive program that encompasses all aspects of infection prevention and control. The comprehensive program include education & training, surveillance, environmental management, waste management and outbreak investigation. It also involve the development and updating of infection prevention and control policies, guidelines and protocols, cleaning, disinfection and sterilization. The employee health, quality management in infection control and provision of HBC kits with materials are included (Health Department, 2007:6). HBC kits will be discussed in the next section.

2.6 Material resources in home-based care

Home-based care kits contain materials used for infection control practices and medication for the patients. In South Africa, HBC kits are in the form of bags or carton boxes that contain some medication such as gentian violet, multivitamin syrup, pain killers, skin and

ointment. HBC kits also contain materials that volunteer caregivers need to be able practice infection control such as disposable aprons, gauze swabs, cotton wool, gauze, bandages, surgical gloves, aqueous cream, linen severs and draw sheets, bottle of bleach, tissue, diapers, powder, vaseline, soap, garbage bag, calamine lotion, condoms and savlon (hand sanitizer) (SADoH, 2006).

Most African countries have developed some form of guidelines regarding infection control practices in home-based care. For instance, in Tanzania, the department of health developed a trainer's guide under the national policy on infection control practices for HBC providers which include the provision of what they called 'first aid kits'. These contained plastic aprons, bandages, gauze, washing soap and other medications supplies by the district departments in conjunction with the local government (Tanzania department of health [TDoH] 1999). Similarly in South Africa, the South African national department of health [SADoH] (2006) developed a framework for home-based care kits production, distribution and a list of recommended items that the kits should contain. Initially, the NDoH distributed kits in all provinces where home-based care training had been conducted but thereafter, provincial HIV/AIDS directorates in collaboration with other stakeholders were responsible for providing financial resources for the production of kits and distribution.

Currently, the provincial health departments are responsible for the distribution of the kits through local clinics, church organizations, non-governmental organizations and community-based organizations while district health offices and care organizations are responsible for replenishing the kit supplies. Most provinces and organizations have adapted the national recommended list of kit contents to meet their needs and resources, resulting in variations from one province to another (Mabude, Beksinska, Ramkissoo, Wood & Folson, 2008). In order for volunteer caregivers to practice infection control effectively, they need adequate materials such as home based care kits that contain all necessary materials. Volunteer caregivers in HBC often lack the support that is needed to practice infection control in order to give hope and relieve the pain of PLWHA in order to meet the aims of HBC programs (Nnko et al., 2000). Most of the challenges that volunteer caregivers face will be discussed below.

2.7 Challenges confronted by volunteer caregivers in HBC for PLWHA

HBC like any other programs have their own challenges. The following discussion is about the major challenges that volunteer caregivers confront when performing their duties in the communities.

2.7.1 Lack of remuneration causing demoralization to volunteer caregivers

To volunteer means to provide services without expecting to get paid hence the term volunteer caregivers (Akintola, 2005). Most Home-based care programs in South Africa rely on volunteer caregivers as the main source of labour (Akintola, 2010). These volunteer caregivers in HBC programs are not paid but they can be given gifts in form of stipends as tokens of appreciation for the services that they provide and also to cover their transport costs (Akintola, 2005). Lack of remuneration for volunteer caregivers may cause them to feel demoralized, frustrated and reluctant in performing their work which may cause the quality of care given to the clients to be compromised. This can also deteriorate the health of the patients (Shaibu, 2006). For example, in a study conducted in one of the villages in Botswana on the process of establishing community home-based care and challenges faced by University staff, students and volunteers caregivers, the findings showed that some volunteer caregivers were provided with transport money by their district offices while others were not due to lack of adequate funding. Those that were not paid became discouraged and reluctant to continue with their work (Shaibu, 2006).

On the other hand, when volunteer caregivers are given a few incentives they are able to do their work more effectively. In Zambia, for example, a study was conducted on HBC by SAFAID & HDN (2007) and findings revealed that volunteer caregivers were not paid but they were given free access to medical facilities and to community ploughs, they received seeds, uniforms, bicycles, t-shirts and they were allowed to conduct income generating projects such as gardening to meet their needs. These incentives increased their willingness to perform their care giving duties and were more productive.

2.7.2 Inadequate supply and replenishing materials in HBC Kits

Materials for practicing infection control are important for the prevention and transmission of infections in HBC. According to Kang'ethe (2010) lack of materials can cause fear of contagion among the volunteer caregivers. This is evident in his study conducted in Botswana regarding validating the fact that care giving is stressful. Results showed that due to lack of materials such as gloves, some volunteer caregivers were reluctant to do their work. The volunteer caregivers also feared contagion and sometimes were forced to buy gloves or napkins using their own money. In cases where they could not manage to buy them due to lack of finances they were forced to recycle gloves or do without them. Similarly in Zimbabwe, a 2007 report on home based care by Southern African HIV and AIDS Information Dissemination service (SAFAIDS) & Health and Development Networks (HDN) shows that, volunteer caregivers felt discouraged to perform their duties due to insufficient supply of HBC kits and poor replenishment of materials such as gloves, bleach, soap and linen savers.

In South Africa, the supply of HBC kits is still a problem. According to a national survey that was conducted on home-based care kits for PLWHA by Mabude et al., (2008), kits are supplied by the South African provincial health departments to district departments. From the district health departments they are distributed through local clinics, church organizations, NGOs and community based organisations (CBOs) and community groups and in most provinces, district health offices are also responsible for replenishing the supplies of the kits. Although HBC kits are supplied to HBC care organizations, their demand is higher than their supply and it is hard for most organizations to replenish the contents due to insufficient funding as these organizations depend on government health departments and other donors for sponsorship (Hillbrunner, 2007; Mabude et al., 2008).

Lack of materials for infection control practices can cause frustration and demoralise volunteer caregivers and prevent them from performing their duties. For example in a study conducted in South Africa in the Limpopo province on home caring for PLWHA with informal caregivers, the caregivers did not have HBC kits or materials such as gloves and napkins as a result these caregivers feared contagion. Additionally, they were frustrated to

perform their duties due to that fact that they could not even afford to buy gloves, napkins for their patients as such, they ended up using their bare hands (Azwidihwi, Tshililo, Davhana-Maselesele, & Dphil, 2009). By using bare hands most caregivers are at risk of contracting infections and this can also result in death.

2.7.3 Lack of support from family, patients and the community due to stigma

Goffman (1959) describes stigma as labelling of a person as bad or unusual and shaming them due to their undesired differentness. According to Akintola (2008) stigma in the context of HIV/AIDS is still an issue that needs urgent attention especially in the HBC for PLWHA. Stigma results in blaming, shaming and loss of status in the stigmatized people (Deacon, 2006). Stigma results in social exclusion and rejection (Holzemer, Uys, Makoae, Stewart, Phetilhu, Dlamini, Greeff, Kohi, Chirwa, Cuca and Naidoo, 2006) for example, some patients are locked up in their rooms by their families and they are denied food (Akintola, 2004). Volunteer caregivers are not immune to stigma; they are also stigmatized by family, community members and friends. In South Africa for example, most volunteer caregivers face ridicule from family, community members and friends for risking their lives by providing care to PLWHA without receiving any pay, however they ignore such ridicules by “developing a thick skin” (Akintola, 2008:360-362).

According to Akintola (2004), volunteer caregivers in his study came across family members who did not allow them to use gloves on their patients because they feared that the patients would feel unloved. To deal with this challenge, volunteer caregivers were forced to lie to the patients and their family members stating that they were using gloves in an attempt to protect the patient from infections. In other instances where families would not comply, volunteer caregivers used their bare hands or would not visit such homes. Most importantly, stigma interferes with voluntary counselling and testing; access to care and treatment (Holzemer & Uys, 2004). Stigma has a negative impact on infection control practices of the volunteer caregivers for PLWHA in HBCOs in that they have insufficient access to patients. This increases suffering, shortens life and may cause death to the PLWHA (Holzemer & Uys, 2004) consequently it hinders the aims of HBC of reducing suffering providing hope and prolonging life.

2.7.4 Inadequate water supply

According to WHO/UNICEF (2009), access to adequate potable water means to have 20 litres of water available per capita per day at a distance of no more than 1000 meters. PLWHA have compromised immune systems which makes them more vulnerable to opportunistic infections such as diarrhoea, skin and eye diseases, intestinal infections, polio, typhoid, bilharzia, malaria and worms that are caused by unhygienic practices (Phaswana-Mafuya and Shukla, 2005). As HIV/AIDS patients need ongoing assistance in HBC from volunteer caregivers to increase their optimum health, adequate potable water supply is needed for preventing opportunistic infections through practicing hygiene such as washing soiled clothing, beddings and the patients which in turn reduces water related diseases like cholera and AIDS-related deaths and improves the quality of life for patients/clients (Lule, Malamba, Downing, Ransom, Nakanjako, Wafula, Hughes, Bunnel, Kuharuza, Coutinho, Kigozi & Quick, 2005: WHO, 2008).

The UNICEF (2006) report shows that the use of potable water sources by households reduced 35% of risks of diarrhoea in PLWHA and the simple practice of washing hands with soap can reduce up to 40% of diarrheal incidences. In addition, access to potable water is important in HBC for PLWHA because they have to take antiretrovirals (ARVs). At least 1.5 litre of water is needed for taking ARVs to mitigate any possible side effects that may occur (Wegelin-Schuringa and Kamminga, 2003: Hillbrunner, 2007). In five rural communities of Botswana, a study on HIV/AIDS and access to water with volunteer caregivers and family caregivers by Ngwenya & Kgathi (2006) revealed that despite having several sources of water such as off-plot, outdoor (communal) and on-plot outdoor and/or indoor (private) water connections as well as other sources such as bowsed water, well-points, boreholes and open perennial/ephemeral water from river channels and pans, the water supply was still a problem due to technical faults as a result caregivers were forced to economize, buy and collect from river/dug wells or other alternative sources such as rain harvesting tanks in government institutions. Unreliable water supply forced caregivers to use poor quality water and practice poor hygiene such as cutting down bathing their patients from twice daily to once or none at all (Ngwenya & Kgathi, 2006:669). A study was conducted in Zambia to assess the effective access to potable water for home based care clients by Kangamba,

Roberts, Campbell, service & Adalla (2006). The study revealed that volunteers in rural areas did not have access to tap water so they drew their water from shallow unprotected wells while those in urban areas received their water from shallow wells or boreholes which were contaminated during the rainy season and therefore most of them had to travel long distances to fetch water.

As much as there are many different studies that explain how potable water is inadequate in most African countries especially in Southern African as stated above, most studies that have been conducted in South Africa show that potable water is a challenge in home-based care programs for PLWHAs. For example, a study that was conducted among six countries China, Malawi, Nigeria, South Africa, Vietnam and Zambia. The aim was to investigate the extent of adequacy of water, sanitation and hygiene in relation to home based care strategies for PLWHA. The results showed that when it came to potable water supply, there were no national policies linking water into home-based care organizations in all six countries; instead there were barriers to water supply such as high water tariffs, long distances between water sources and homes in rural areas and consequently, poor people including PLWHA had no access to potable water (Hillbrunner, 2007).

2.7.5 Poor living conditions in communities

Living conditions in communities that volunteer caregivers serve can either have a positive or negative effect on the work of volunteer caregivers. For example, unhygienic conditions can cause an increase in environmental pathogens. On the other hand, living conditions with little ventilation can cause easy transmission of opportunistic infections like T.B from patients to caregivers and from caregivers to patients adversely affecting the quality of life of the PLWHA. Furthermore, the transmission of opportunistic infections can either hasten the progression of HIV to AIDS or cause mortality amongst AIDS patients. Additionally, poor living conditions hinders proper infection control practices because most volunteer caregivers become frustrated and demoralised to do their work in deprived conditions. Due to a fear of contamination in working in such conditions, volunteer caregivers may choose to abandon the patients in such conditions (Hillbrunner, 2009).

A study that was conducted in Botswana on the challenges impacting on the quality of care on PLWHA by volunteer caregivers showed that due to poverty, most family members had poor living conditions such as inadequate living space which caused no privacy for patients that needed care. Furthermore, unhygienic environments such as inadequate sanitary facilities like toilets and water made it difficult for volunteers to wash client's clothing causing detrimental effects and as a result volunteer caregivers avoided those homes with these conditions (Kang'ethe, 2009: 26-27).

Another study by Azwidihwi, Tshililo, Davhana-Maselesele & Dphil (2009) about the experiences of home based care in South Africa in Limpopo, participants complained that poor living conditions such as a lack of toilet facilities in the homes resulted in humiliation and lack of privacy for patients with diarrhoea. There were reports that some caregivers had to carry their patients on their backs to the toilet and in most cases the patients would soil themselves and the caregiver's clothes before they could even reach the toilets. Sometimes caregivers would use plastic bags by placing them in a bucket and then carry the bucket to the toilet consequently volunteer caregivers did not frequent such homes. These findings suggest negative impacts for HBCOs with regard to infection control practices. For example, because volunteer caregivers fear contagion from work in such conditions, they could decide to quit their jobs and consequently HBCOs could lose person power. For the patients this implies that they could not be attended to; they could be at risk of developing new infections that could deteriorate their health and those that stay alone could suffer more. There also could be high death rates among PLWA in HBCOs which could have been prevented.

2.7.6 Lack of adequate knowledge by caregivers due to inadequate training

Despite the critical role played by volunteer caregivers in HBC most of them do not have adequate knowledge due to inadequate training. For example, most literature on training indicates that, volunteer caregivers are equipped with basic physical care; palliative care; basic counselling and basic nursing skills including infection control practices. They are also trained on how to mediate legal issues like drafting of the will, legal procedures of guardianship and accessing of grants for the orphans (South Africa, 2002 : Uys, 2002).

The training that is offered to volunteer caregivers has some gaps, for example, most literature on training only mentions the type of training and it does not explain its content. The training that is offered is usually of short duration and it only deals with single topic areas such as HIV or T.B DOTS (Hancock et al., 200). For example, a study that was performed in six countries (Malawi, Kenya, Uganda, South Africa, Nigeria and Cameroon) on the significance of care giving work by the volunteer caregivers for PLWHA, shows that when it comes to training, most of the participants received their training from either home-based care organizations or from the governments. The percentage that received such training ranges from 30% in Cameroon to 86% or more in Kenya, South Africa and Uganda. Of those who received training, more than half (52%) received only a once-off initial training before they started doing volunteer work. In contrast, 15% received ongoing weekly training. In between are those who have been trained more than once, but receive training less regularly than once a week. In Malawi, 94% of those who received special training received only a once-off initial training. Cameroon has the highest percentage of care-givers who have received training (46%) (Budlender, 2009).

Furthermore, the training that is offered to volunteer caregivers is not comprehensive enough to cover all emerging diverse situations in caring for PLWHA (Ledwaba, 2005) such as basic care nursing with regard to psychiatric symptoms and conditions (Uys, 2002). Additionally this training does not equip volunteer caregivers to be professionals in their field like nurses or doctors. There is lack of mentoring of volunteer caregivers which causes them not deliver their services effectively (Campbell & Foulis, 2004). These gaps in training imply insufficient knowledge for volunteer caregivers which can compromise the quality of care given to patients and may result in fatality for most patients (Budlender, 2009).

Despite having insufficient materials, insufficient water supply, knowledge, support from families and communities, lack of remuneration and facing stigma, volunteer caregivers continue to work in HBC for PLWHA due to the positive contribution that they make in their communities (Marincowitz, Jackson & Fehesen, 2004). Issues that motivate volunteer caregivers to continue offering their services in HBC for PLWHA will be discussed in the following section.

2.8 What motivates volunteer caregivers to volunteer in HBC?

According to Ross, Greenfield & Bennet, (2009), most volunteer caregivers in home-based care experience burnout due to the stress caused by their clients who expect too much from them as well as physical and emotional stress resulting from the poor working conditions that they have to endure in their organizations. These stressors have the potential of causing volunteer caregivers to quit their care giving work. A study that was conducted in Texas to investigate the reasons for burnout and dropout by volunteer caregivers revealed that most volunteer caregivers quit volunteering jobs in HBC due to “problems with their clients, role ambiguity, emotional exhaustion and depersonalization (a detached, callous and even dehumanized response to the other person)” (Ross, Greenfield & Bennet, 2009: 724-725). “It is as though the individual is viewing other people through rust-colored glasses-developing a poor opinion of them, and even actively disliking them resulting into reduced personal accomplishment by carers” (Maslach, 1982; Ross et al., 2009: 724-728).

On the other hand, some studies have been conducted in South Africa to show why most volunteer caregivers continue to work despite the challenges they experience. For example, a study that was conducted in Limpopo showed that most volunteer caregivers were motivated to work in HBCOs for PLWHA because they felt that they needed to provide support, love and hope to patients (Marincowitz, Jackson & Fehrsen, 2004). Further studies in Kwa-Zulu Natal revealed that some volunteer caregivers were motivated by a passion to make a difference in their communities after seeing the impact of the HIV/AIDS pandemic on either their family members or on community members. Some volunteer caregivers want to fulfil their religious obligations. As much as others want to equip themselves with knowledge about HIV/AIDS, some volunteer caregivers saw some career opportunities in other AIDS organizations (Akintola, 2010). Additionally, some volunteer caregivers are motivated to provide their services because they see rewards such as changing negative health behaviours, being recognized and appreciated by their patients who eventually get better and also by community members because of the work that they do (Akintola, 2010: 7-8). Despite their willingness to work for HBCOs, volunteer caregivers are at risk of physical, emotional and psychological stress. They risk being infected with the HIV virus and other infections while trying to help other people.

2.9 Theoretical Framework

This study draws on various levels of the ecological systems theory developed by Urie Bronfenbrenner as the main conceptual frame work. The ecological system theory has been in existence for over 20 years and has been used as a model to develop theories by different scholars, professionals and therapists (Engler, 2007:4). The ecological system theory is a combination of ecological principals and systems theory first developed by Urie Bronfenbrenner as a theory of human development in the 1970s (Bronfenbrenner, 1994) as shown in figure 2.1 below.

Ecological comes from the word ecology which in a scientific perspective, is the study of interactions of organisms in their environment (Begon et al., 1996). Taking from the sociological perspective, ecology shows and explains how humans or groups relate to their existing environment. The term “Systems” involve beliefs that a person is in constant interaction with in the environment within networks that can either impact the individual positively or negatively (Wilder, 2009). The Ecological systems theory also relates to the Meta paradigm in social work commonly referred to as “person in the environment” which describes how an individual and various complex environment interact with each other and also affect each other (Weiss-Gal, 2008:65). This perspective emphasizes the need to view the interdependency and mutual influence of people and their social and physical environments by recognizing individual and public issues (Coady and Lehmann, 2008:3).

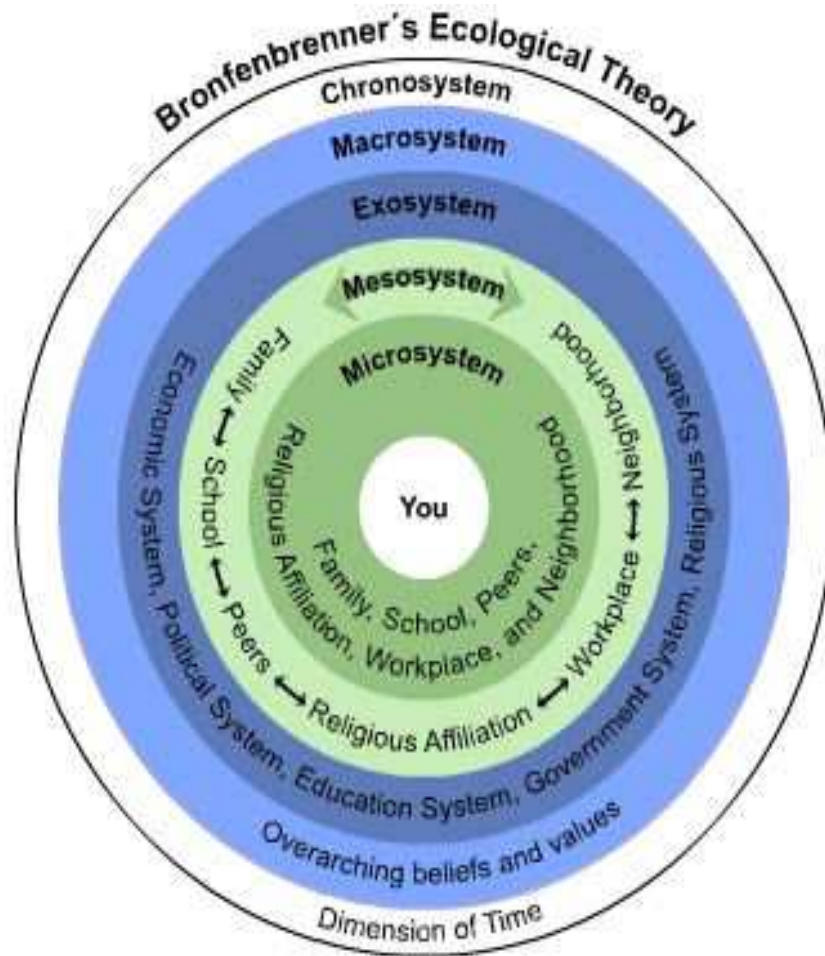


Figure 2.1 Bronfenbrenner's Ecological theory for human development (Bronfenbrenner, 1974)

Despite it being used as a theory to explain human development, the ecological systems theory has been applied and interpreted in different contexts for example, in health promotion, it has been applied in a research to understand the experiences of family caregivers taking care of aging adults (Wilder, 2009) and it has also been applied to understand the caregiver's perceptions on financing community-based long-term care (Davis, 2009). The core concept of Bronfenbrenner's ecological system theory is that, development is explained in terms of relationships between people and their environments (Engler, 2007). For the purpose of this study, EST is defined by combining the sociological perspective and the meta paradigm in social work while maintaining all the levels of the theory as developed by Urie Bronfenbrenner as seen in figure 2.2 below.

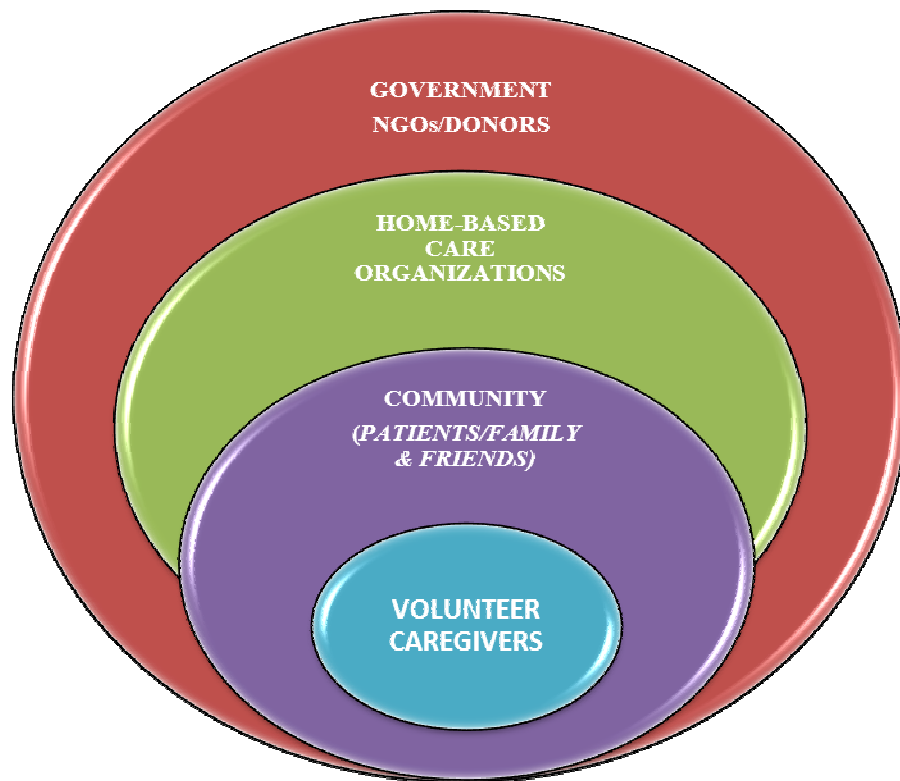


Figure 2.2 Ecological systems theory as applied to this study sourced from (Bromfenbrenner, 1974)

Taking this into consideration, the working definition for ecological systems theory for this study is, the study of how human beings interact with their complex environment either affecting each other negatively or positively. This theory is based on the assumption that, when a person or group is connected and engaged in a supportive environment, the functioning also improves (Davis, 2009). It important to note that, the ecological systems theory in this study is appropriate to describe the relationship between the HBCOs’ regulation and the outcome of the services provided by their workers. This means that, in home-based care organizations and volunteer caregivers providing care to patients will perform their duties effectively if necessary materials are provided hence improving their functioning.

2.9.1 Levels of the ecological systems theory as applied to this study

The ecological systems theory has four levels of influence and these are micro-system, meso-system, exo-system and the macro-system (Wilder, 2009).

The micro-system

This refers to the individual level and it comprises the influences relating to the individual. These influences come from the individual's family, peer groups and the neighbourhood and these are also called the social agents who belong to the meso-system level. Social agents interact directly with an individual and influence the individual's behaviour either positively or negatively. Volunteer care givers fall in this level being the ones that provide care to the people living with HIV/AIDS in the communities. It is suffice to say that volunteer caregivers are valued and relied upon by their families, peer groups, neighbourhoods and the home based-care organizations that they work for, indicating that they are appreciated for the work that they do (Akintola, 2010).

The meso-system

Meso-system is a level where the social agents belong and it is related to the micro-system where the individual's experiences, family experiences are related to the peer's experiences and the peers' experiences to the neighbourhood experiences indicating that they interact with each other. (Wilder, 2009). Individuals from the micro-level interact with the family members, peers and the neighbourhood (social agents) in this meso-system level. This level best explains how the volunteer is shaped and influenced by the social agent's attitudes towards infection control practices. This explains how the families of the patients view the volunteer's infection control practices. For instance, some families would not allow the volunteer caregivers to use gloves on their patient who is a relative because they believe that the patient would feel unloved (Akintola, 2004) therefore, the volunteer's commitment to infection control practices work will be affected negatively to an extent where he/she might not help such families by not visiting them. In turn, those families will be affected because they may not get help that they need from volunteers.

Above all, the quality of care given to the patient by the caregiver is compromised, the patient's life span can reduce and families also risk being infected with HIV and some may die after care giving (McInerney & Brysiewicz, 2009). Most of the literature tends to suggest that, in unhygienic conditions where the families in the communities do not have access to water, toilets and proper shelter with adequate space and ventilation, the volunteer's care

giving and infection control practices is compromised in that, in order to practice good hygiene there is need to have access to water and toilets therefore, volunteers would opt not to visit such homes or allow the family members to do all the work (Mafuya & Shukla, 2005; Kang'ethe, 2009).

In situations where the volunteer's peers and the entire community do not stigmatize people with HIV/AIDS, but work together by helping to draw water for the patients, feeding, cleaning and helping them to get to the toilet, the volunteer caregivers would be more committed to performing his/her work. On the contrary, in communities that stigmatize and discriminate HIV/AIDS patients, a volunteer caregiver will be reluctant to perform her/his work effectively because access to community facilities such as water sources and funds is restricted because of fear that community members will not approve. This causes patients to die of depression (Hosegood et al., 2007; Hillbrunner, 2007; Ogden et al., 2006). Within home-based care organizations in Durban metropolis, poor access to water, inadequate access to materials such as gloves and disposable dippers are the major problem affecting infection control practices as mentioned by most volunteer caregivers of this discussion for this thesis. Sometimes most volunteer caregivers would opt not to visit such homes or rather allow the family members to do all the work (Mafuya and Shukla, 2005; Kang'ethe, 2009).

The exo-system

This is an organizational level. This is a level for the organizations that an individual works for and this affects an individual's life either positively or negatively. In context of this study, this is where home based care organizations that employ volunteer caregivers fall. This level also explains the policies that exist in them. For example, one would say that a volunteer caregiver's infection control practices will be negatively affected if the organization does not create a favourable environment through internal effective policies regarding infection control practices such as adequate funding, adequate knowledge and skills and adequate materials and access to water.

In light of the above, when considering home based care organizations in Durban, it is evident that available policies that address infection control practices are taught to volunteer caregivers by the department of health in the form of "steps to follow when conducting

community work” these include wearing gloves, washing their hands with soap and being clean.

The macro-system

This describes the nation and its culture in which individuals live. This includes developing and industrialized countries, socioeconomic status, poverty and ethnicity (Woodside et al., 2006). The macro-system level in this study can be used to explain the ideology of the nation where the volunteer caregiver and home-based care organizations fall. This involves availability or absence of departmental infection control policies or guidelines provided in organizations, for example, sanitation control methods defined by the Department of Health; National policies on infection control practices in home-based care organizations and also global policies. WHO (2002) in its Framework Action for community home-based care in resource limited setting for people with HIV/AIDS document provides guidelines to policy makers, administrators, managers and all those who run and develop community home-based care programs for establishing and maintaining community home-based care in governments, national and international donor agencies, non-governmental organizations, faith based organizations for people with HIV/AIDS, disabilities and other chronic illnesses. These existing policies may affect infection control practices negatively or positively at national, organizational and departmental levels especially for those countries that fail to adopt these guidelines.

The South African government in response to international guidelines on the provision of water to people established a National Sanitation Co-ordinating Office (NASCO) undersigned by the Constitution which guarantees all South Africans the right to have access to health and the right to adequate sanitation. This further lead to the establishment of Provincial Sanitation Task Teams, Multi-Annual Action plan (MAAP) and Sanitation Communication committees in each province which oversees sanitation issues in the country (Phaswana-Mafuya and Shukla, 2005). The government also has a national policy on infection prevention and control that aims at setting minimum national standards for the effective prevention and management of health care associated infections, so that hazards associated with biological agents are minimized for patients, visitors and health care personnel in health care establishments. To achieve this, national, provincial and district

infection prevention and control committees have been established under the *National Health Act, 2003* to oversee infection control practices at each level (DOH, 2007:6).

From the above, it becomes apparent that development can be explained in terms of relationships between people and their different environments. Ecological systems theory may be used to show and explain how home-based care working environments can either affect infection control practices positively or negatively. It can also be used to understand where and what prevents the proper functioning of organizations and also what needs to be improved and how to improve it.

CHAPTER THREE METHODOLOGY OF THE STUDY

3.1 Introduction

This chapter discusses the study design; study area; participants and sampling method used. Data collection procedure by means of qualitative focus groups with volunteer caregivers and semi-structured interviews with home-based care co-ordinators/project managers are discussed. Next, how the data was analysed using thematic analysis is discussed including the role of the researcher, translator and the ethical considerations covered.

3.2 The study design

This study used a qualitative approach because it allowed for the exploration and the explanation of the experiences of volunteer caregivers regarding infection control practices in home-based care organizations providing care to people living with HIV/AIDS. A qualitative research method was appropriate for this study because according to Ospina and Wagner (2004), it emphasizes the social context, how social processes and the creation of social meanings occur within specific contexts such as what occurred before and also what is happening during the time of data collection. Ulin, Robinson, Tolley & McNeil, (2002) states that qualitative interpretivist research focuses on the subjective perceptions and understandings that result from experiences; objective actions or behaviours and the contexts in which they occur. It is important to note that the qualitative approach also allows the researcher to capture the full richness of human experiences such as how the real world is lived, felt, made sense of and accomplished unlike the quantitative approach which only focuses on gathering surface information (Polkinghorne, 2005: 137).

A qualitative approach also focuses on exploring what is real for the participants and how they make sense of their world using their own language. It is about collecting and analyzing information rather than identifying, isolating and controlling variables as it is the case with the quantitative approach (Terre Blanche, Durrheim & Painter, 2006). Furthermore, unlike a quantitative approach, the qualitative approach allows flexibility in its content, focus and question (Neuman, 2006) therefore; a qualitative approach was applicable in this study, because it allowed openness to ideas, experiences, opinions, feelings and perceptions

expressed by the research participants to the researcher. Terre Blanche et al., (2006) states that, interpretive research places emphasis on understanding phenomena in their contexts. A qualitative research focuses on the personal and social meanings of individuals, their cultural practices and also allows the researcher to explore deeper into the participants' life (Bryman,2004) as such a it provided more insight into the experiences of volunteer caregivers and HBCCs/project managers regarding infection control practices in HBCOs for PLWHA.

3.3 Study area

This research formed part of a larger study focusing on access to resources in home based care in South Africa. Research and data collection was done from July 2010 to September 2011. Data collection process occurred in nine townships and a single rural area providing home-based care to PLWHA in Durban metropolis as shown in table 3.1 below.

Table 3.1: Number of volunteer caregivers recruited from ten organisations

| CARE ORGANISATIONS | LOCATION OF THE ORGANISATION | NUMBER OF PARTICIPANTS IN FOCUS GROUP DISCUSSIONS |
|--------------------|------------------------------|---|
| A | Township (semi-rural area) | 10 |
| B | Township (semi-rural area) | 6 |
| C | Township (semi-rural area) | 11 |
| D | Township (semi-rural area) | 7 |
| E | Township (semi-rural area) | 4 |
| F | Township (semi-rural area) | 7 |
| G | Township (semi-rural area) | 8 |
| H | Township (semi-rural area) | 11 |
| I | Township (semi-rural area) | 11 |
| J | Rural Area | 5 |
| Total | 10 | 80 |

These organisations were chosen using snow ball sampling technique. Snowball sampling is “a technique used for locating informants by asking others to identify individuals or groups with special understanding of a phenomenon” (Ulin, Robinson, Tolley and McNeill, 2002:61). Because HBCOs in Durban metropolis were hard to find, snow ball sampling technique was used to locate these HBCOs and as a result, ten organisations were identified and recruited. Snow ball sampling was useful in this study in that the first few home-based care organizations that were identified through key informants from the Aids care foundation and the department of social development referred us to other home-based care organisation

that provided care to PLWHAs to access more information. These organisations were chosen based on the criteria that (1) they must have been providing home-based care to PLWHA for one year or more; (2) must have had volunteer caregivers with six months work experience or more; (3) must be based in Durban metropolis; (4) be willing to participate and be able to provide a rich pool of information on their practice and experiences of infection control practices.

3.4 The study participants

There were two kinds of participants in this study (1) home-based care coordinators (HBCCs) who were also project managers in some instances and (2) volunteer caregivers (see table 3.1). Ten HBCCs (one per organisation) were identified and chosen to participate in the study because they were responsible of overseeing home-based care programs in their organisations. Volunteer caregivers were selected because they provide care to PLWHA and hence they were in a better position to give more insight into infection control practices. Ninety participants (ten HBCC/project managers and eighty volunteer caregivers) participated in the study. These participants were homogenous in terms of language in that, they were Zulu-speaking. These participants were recruited if (1) they had worked for their organisation for atleast six months or more. This length of work experience was chosen because it felt that participants who had worked for such a period of time were in a better position to provide relevant information to the study. HBCOs/projected managers were recruited if they had the responsibility of overseeing HBC programs. Volunteer caregivers were recruited if they provided home based-care as this study aimed at exploring experiences regarding infection control practices of those providing care to PLWHA and those managing home based care programs.

3.5 Data collection instruments and procedure

Data collection used two methods (1) semi-structured interviews with HBCCs/project managers which were guided by an interview guide with open-ended questions and (2) focus group discussions with volunteer caregivers guided by a focus group schedule with open ended questions. An interview guide and a focus group schedule were developed from the literature. Open-ended questions were used because they allowed the researcher to source

data in greater detail by remaining conversational and situational (Ulin et al., 2002). Open-ended questions allowed two-way communication between the researcher and the participants which also allowed better exploration of themes of the study in a focused manner (Sociological research skills, 2010). These questions were designed in English and translated into IsiZulu. A short questionnaire consisting of closed-ended question was used to get the participant's and the organisation's demographic information (see appendix 1b). Tape recorders were used to record the data from interviews and focus group discussions.

3.5.1 Semi-structured interviews with HBCCs/Project managers

Ten HBCCs/project managers (one per organization) participated in semi-structured interviews. These interview sessions were held in the HBCCs' offices. Prior to each interview, the nature and aims of the study were explained to each participant who were then asked to fill in a short questionnaire and an informed consent form (see appendix 1a). The ethical issues that were covered in the informed consent form were also discussed verbally with the participants for purposes of clarity. Assurance of confidentiality was covered and participants were also informed that they could stop the interview at any time if they wished. Permission to use tape recorders was requested from the participants and they were assured that they would be privacy in handling and storing of the data in that, only the researcher and the supervisor would have access to the data.

Semi-structured interviews with HBC coordinators were appropriate in this research because they allowed and encouraged respondents to give in-depth information as well as their personal opinions on infection control practices in HBCOs rather than presenting participants with rigid pre-set questions that could have limited the data that was collected. These semi-structured interviews were also useful because HBCCs were in a better position to provide relevant information because they had the responsibility of overseeing HBC programs in their organisations. The research interviews were conducted in English using an interview schedule with open-ended questions (see appendix 2). In instances where participants could not express themselves in English, interviews were conducted in IsiZulu language by the facilitator and they were guided by an interview schedule in the Zulu version (see appendix 2). The themes that were covered in the interview schedule were: perceptions of infection

control practices in HBCOs by the volunteer caregivers and HBCCs/project managers; resources available for infection control practices in HBCOs; how infection control practices were conducted and what challenges were faced by HBCOs regarding infection control practices and what strategies were put in place to deal with the challenges. These interviews lasted for approximately 40 to 50 minutes and were audio recorded. Recorded interviews were later transcribed in English.

3.5.2 Focus group discussions with volunteer caregivers

Volunteer caregivers were invited to participate in focus groups. One focus group was conducted in each of the ten care organizations. These focus group discussions consisted of 5 to 11 participants and were conducted in convenient private rooms provided by each organization. Prior to each focus group discussion the nature and aims of the study were explained to the participants who were also requested to fill in a short questionnaire and an informed consent form (see appendix 2). Participants were informed that the focus group discussions would be confidential and anonymous. The ethical issues that were covered in the informed consent form were also discussed verbally with the participants for clarity purposes. Assurance of confidentiality was covered and participants were also informed that they could stop the interview at any time if they wished. Permission to use tape recorders was requested and its use for recording and storing of data was explained. Participants were assured that there would be privacy in handling and storing of the data in that, only the researcher and the supervisor would have access to the data.

Focus groups were used because they provide formal examples of everyday speech within a community (Denzin & Lincoln, 2005). Furthermore, focus groups provide direct access to intersubjective experience, how social realities of cultural groups are reflected, and how attitudes and opinions on various social issues are understood (McLafferty, 2004). Additionally, Kitzinger (1994) argues that although focus groups may not easily provide access into individual biographies for the researcher, they are useful because they allow observation of how knowledge and ideas develop and operate within a cultural context. This allows the researcher to understand shared experiences and explore differences between people who are perceived as homogenous (Terre Blanche *et al.*, 2006). Focus groups are advantageous as they allow a wide range of responses among participants and also assist

other group members to remember details that may have been forgotten (Catterall & Maclaran, 1997; Kitzinger, 1994).

In this study, collecting data from focus groups with volunteer caregivers proved useful in providing insight into how the concept of infection control practices among volunteer caregivers is carried out and understood. Focus group discussions were conducted in IsiZulu and facilitated by an isiZulu speaking facilitator who was also a member of the research team. The focus group discussions were conducted in IsiZulu in order to allow the participants to express themselves which also helped in gaining more insight to the study. The researcher was an observer and took notes. These focus group discussions were guided by a focus group guide with open-ended questions (see appendix 3). The major themes covered were: perceptions of infection control practice by volunteer caregivers; resources available for infection control practices in HBCOs; how volunteer caregivers carried out infection control practices in HBCOs; challenges that they faced regarding infection control practices and the strategies developed to deal with any challenges. These focus group discussions lasted for approximately 40 to 80 minutes and they were recorded using an audio recorder and later transcribed into English.

3.5.3 The role of a researcher and facilitator

This research is an interpretive study that relies on the ideas and interpretations of the researcher, this means that the researcher needs to be aware and critically reflexive of his/her own role and influence in the process and constructed understandings (Terre Blanche et al, 2006). For the purposes of this study, the term facilitator will be used. The researcher in this study was not a Zulu speaker and was therefore unable to facilitate focus group discussions and thus performed a role of observation, note taking and recording of the findings by means of a tape recorder. A facilitator who was a Zulu speaker and also a member of the research team facilitated the focus group discussions because he understood the literature on HBC, research objectives and questions of the research study. The role of the facilitators was to “create a non-threatening supportive climate that encourages all participants to share views; facilitating interaction among members; interjecting probing comments, transitional questions and summaries without interfering too abruptly with the dialogue; covering important topics

and questions while relying on judgments to abandon aspects of the outline, noting non-verbal responses” (Basch, 1987:415).

The facilitator in this study was in a better position to facilitate focus group discussions because this was a group research and him being part of the research team; being an isiZulu speaker, he understood the aims and the goals of the research about infection control practices in HBC for PLWHA. Millward (1995) argues that although the primary researcher may not be very experienced or not have highly polished facilitation skills, he/she should still be directly involved in facilitation, as he/she will be sensitive to relevant issues, and to understand the need for methodological rigour. In this study, the researcher was directly involved in observing the focus group discussions, operating the recording process and taking notes.

In qualitative research, translators and facilitators may be used meaning that the researcher and the facilitator/translators are therefore pivotal in the conclusions drawn. This also means that the researcher must ensure that all concepts used during the data collection and analysis phase are appropriately understood (Overing, 1987). To ensure that the quality of data was not compromised, data was transcribed in verbatim into English by the facilitator who was also part of the research team. The transcriber was in a better position to transcribe the data because he understood the aims of the study regarding infection control practices.

3.6 Data analysis

Thematic analysis by Braun & Clark (2006) was used to analyze all the transcribed data. Thematic analysis focuses on searching within transcripts for the emergence of patterns of shared understanding and themes. Thematic analysis involved the following steps (Braun & Clark, 2006). The first step of the data analysis process was reading, understanding and knowing the research data. This step began with the planning of interviews and focus groups as well as during the identification of the research participants. This means that by the time the data analysis began, the researcher already had a preliminary understanding of the phenomena being explored (Terre Blanche *et al.*, 2006). The first step in analyzing the data for this study involved familiarizing and immersing oneself with the data to be analyzed. The immersion process allowed the researcher to engage in more reading and rereading of the

transcribed transcripts of the interviews, whilst looking for emerging themes and developing explanations. Patterns of all common themes were identified (Ulin *et al.*, 2002).

The second step involved identifying themes that shared the same words, styles and terms that were used by participants. These themes were used to set up connections. Themes that emerged from the text were used; displayed in detail then reduced to essential points under major themes stated in the objectives. The identification of themes was more than simply summarizing content; it occurred with consideration given to processes, functions, tensions, and contradictions (Terre Blanche *et al.*, 2006). Each theme was examined in an attempt to discover the core meanings and feelings of the participants. This then allowed an overall evaluation, interpretation and assessing of the emergent themes and how these related to each other (Ulin *et al.*, 2002). Terre Blanche *et al.*, (2006), states that the third step in data analysis is coding. The data was marked according to themes using the research questions as a guide. Step four involved the breaking down and coding of the data into themes. Different concepts that were expressed by the participants in several ways were grouped together under a single theme. Each theme was then elaborated in more detail. The final step involved putting together the interpretation of the data, and checking it (Terre Blanche *et al.*, 2006).

3.7 Triangulation

Triangulation is “the combination of two or more theoretical perspectives, methodological approaches, data sources or data analysis methods” (Thurmond, 2004). According to Babbie & Mouton (2001), the role of triangulation in social research is to eliminate biases that result from single-method studies. Triangulation in this study was done by means of comparing the findings from the focus group discussions and the findings from the semi-structured interviews conducted with home-based care coordinators and project managers. This was done to eliminate the possibility of the researcher’s bias and to improve the quality of the data.

3.8 Ethical Considerations

The permission and ethical clearance for conducting this study was granted by the Ethics Committee of University of Kwa-Zulu Natal (see appendix 1). Permission was obtained from key informants from the home-based care organizations that were visited and volunteer

caregivers before conducting interviews and focus group discussions. Ethical principles such as confidentiality, beneficence and trustworthiness of the study through credibility; dependability; confirmability and transferability were covered in this research as part of the informed consent furthermore, how these principles were achieved will be discussed below.

3.8.1 Informed consent and confidentiality

The aims of this study were explained to participants when they were approached, and they were asked to participate on a voluntary basis. Participants who chose to participate were asked to sign an informed consent form, and were told that they were able to withdraw at any time if they felt the need. All participants were assured of confidentiality. This was achieved through the use of pseudonyms and storage of audio recordings in the supervisor's office so that only the researcher, supervisor and other members of the larger research team could access them if required. Participants were also requested during the focus group discussions to respect the confidentiality of the other participants and not reveal any information shared to others outside of the focus group discussions.

3.8.2 Beneficence

Beneficence in a qualitative research is an ethical principle that encourages doing good to others and preventing harm from happening to them (Orb, Eisenhauer & Wynaden, 2000). In this study, participants were invited to participate voluntarily and were also advised to contact the researcher and the supervisor at any time after the interviews and the focus group discussions should they need to ask or say something concerning the study. There is little doubt that caring for people living with HIV/AIDS is not easy and is a stressful job that is associated with high levels of burdens of care and requires remuneration. Participants were informed from the beginning that they would not be given any remuneration but that this study required their help through their provision of information about their experiences regarding infection control practices in their organizations. Furthermore, they were informed that, the findings of this research could assist policy makers in designing intervention programs aimed at addressing infection control in home-based care organizations with HIV/AIDS patients.

3.8.3 Trustworthiness of the study

Trustworthiness of a study means credibility and validity of qualitative research (Burns and Grove, 2005). In this study trustworthiness was ensured through credibility, dependability, confirmability and transferability and these will be explained in detail below.

3.8.4 Credibility

According to Ulin *et al.*, (2002), credibility is the extent to which the findings in the interviews or focus groups are said to be accurate, sufficiently rich, grounded in, supported by narrative data, and show a logical relationship to each other. Terre Blanche *et al.*, (2006) states that the participants' views must be reflected as much as possible in the inferences and conclusions drawn from qualitative research. Therefore, in this study, this was achieved through comparisons between focus groups and through using a translator and a transcriber who were familiar with both the English and IsiZulu language to establish similarities and differences between groups. Above all, this was also achieved through triangulation with data from home-based care coordinators, project managers and volunteer caregivers.

3.8.5 Dependability

According to Ulin *et al.*, (2002) dependability is determined by the consistency of the research process. The overall research questions in this study were considered to be clear and logically connected to the research design and objectives. In terms of the data collection process, the research questions were translated from English into IsiZulu. The questions were asked in English/isiZulu during the interviews and in IsiZulu during focus group discussions and later translated back into English; however this did not negatively affect the consistency and dependability of the findings in this study.

3.8.6 Confirmability

Confirmability refers to whether or not the findings and conclusions of a study are true to the research objectives instead of the values and biases of the researcher (Terre Blanche *et al.*, 2006). Although the researcher recognizes and documents his/her own role in the research process, the distinction is maintained between personal values and those of the research participants (Ulin *et al.*, 2002). In this study, this was achieved through documentation and

reviewing of field notes, process notes, and reviewing of proposal notes and personal expectations of the study.

3.8.7 Transferability

According to Terre Blanche *et al.*, (2006) transferability refers to whether the findings of this research are transferrable to other contexts. Qualitative research aims at producing conceptual findings that are representative of specific groups or populations within a given context. Participants for this particular research study were purposively sampled from different areas within Durban meaning that, the findings of this research accurately represent the current situation regarding infection control practices in home-based care organizations for PLWHA. The transferability of this study may also be determined through comparisons with available literature on the findings of similar studies (see literature review). Contextual factors should however still be considered if wishing to transfer findings from this study to other studies.

CHAPTER FOUR PRESENTATION OF RESULTS

4.1 Introduction

This chapter presents the findings by first describing the demographic characteristics of the participants. The findings are then presented according to the research questions as the major themes: perceptions of infection control practices by HBCCs/project managers and volunteer caregivers; resources available for infection control practices in HBCOs; how infection control practices were conducted; what challenges were confronted and what strategies were put in place to deal with the challenges regarding infection control practices in HBCOs.

4.2 Demographics characteristics research participants

The majority of the participants were female (95%, n=90). The age of the participants ranged between 20-67 years while the working experience ranged between 0.5-16 years these demographic characteristics are depicted in Table 4.2 below.

Table 4.2: Demographic characteristics of HBCCs/Project Managers and Volunteer Caregivers

| BACKGROUND CHARACTERISTICS | FREQUENCY |
|-----------------------------------|------------------|
| HBCCs/PROJECT MANAGERS | |
| <i>GENDER</i> | |
| Male | 0 |
| Female | 10 |
| <i>AGE</i> | |
| 44-49 | 5 |
| 50-55 | 2 |
| 56-61 | 2 |
| 62-67 | 1 |
| <i>WORK EXPERIENCE</i> | |
| 5-8 years | 5 |
| 9-12 years | 4 |
| 13-16 years | 1 |
| VOLUNTEER CAREGIVERS | |
| <i>GENDER</i> | |
| Male | 4 |
| Female | 76 |
| <i>AGE</i> | |
| 20-24 | 3 |
| 25-29 | 12 |
| 30-34 | 19 |
| 35-39 | 11 |
| 40-44 | 10 |
| 45-49 | 12 |
| 50-54 | 4 |
| 55-59 | 5 |
| 60-64 | 4 |
| <i>WORK EXPERIENCE</i> | |
| 0.5-1 year | 18 |
| 1-4 years | 41 |
| 5-8 years | 10 |
| 9-12 years | 9 |
| 13-16 years | 2 |

4.3 Perceptions of infection control practices by HBCCs/project managers and volunteer caregivers

Participants were asked about their understanding of infection control practices. Infection control practices were seen as important for prevention of cross infections either from the patients to the volunteer caregivers or from the volunteer caregivers to the patients. Infection control practices were also seen to be important because of the need for proper hygiene in the communities.

4.3.1 Important for prevention of cross infections from the patient-to-volunteer caregivers

Majority of the volunteer caregivers and home-based care coordinators mentioned that infection control practices were important because they felt that they were able to protect themselves from infections such as Tuberculosis (T.B); HIV and diarrhoea. For example, one home based care coordinator said:

“Our opinion is to tell the volunteer caregivers to prevent or protect themselves because they are working with people whom they do not know. Even if they find an injured person they must not take chances of touching the blood because they may happen to get diseases. They must wear the gloves and protect themselves because it is very painful to find that a volunteer got infected on duty while he/she was helping a person in the community...”

(HBCC, organisation D)

Most participants in focus group discussions emphasised that they felt protected from T.B, HIV and diarrhoea:

“It is highly important... that we are protected from T.B and HIV/AIDS because most of the patients have sores. It protects us from diarrhoea you know that one is also contagious sometimes if you are careless and if you live in unhygienic conditions. For instance if I have to touch that person I have to wash my hands first. Chances of being infected are high and with these gloves of ours ... and on T.B. especially it is important to protect yourself because you will get infected and come back to infect your children and other people so it is important it helps to protect ourselves.” (Focus group 7, organisation G)

4.3.2 Important for prevention of cross infection from the volunteer caregivers-to-patients

Some participants in focus group discussions stated that it was important to practice infection control to protect the patients from being infected by the caregiver's infections:

“We would say that it is very important, because I have my own diseases and they have their own. I should not infect my client with my disease. In the end we shouldn't then end up infecting each other with these diseases”. (Focus group 10, organisation J)

4.3.3 Need for proper hygiene in the community

Most of the participants in focus group discussions talked more about the importance of infection control practices for prevention of cross infections. However, one participant in one of the focus groups stated that, most people in the community in which she served did not practice domestic hygiene such as opening of windows and cleaning their surroundings. She felt that infection control practices were important in such communities:

“I also feel that it is important because many people in our area are not taught about these things so they don’t even open windows; their places are dirty they just don’t care about their health so...it is very important... for them to change their unhygienic habits or behaviours.

(Focus group 4, organisation F)

4.4 Resources available for infection control practices in HBCOs

Participants were asked about resources that they had for practicing infection control. Based on what was discussed in focus groups and interviews, materials, knowledge and skills were the available resources for infection control practices.

4.4.1 Knowledge and skills

Most volunteer caregivers were trained when they were enrolled to work in HBCOs by the department of health. Their training was usually a once off training which lasted for two to three weeks. The training covered basic topics on HIV/AIDS, T.B prevention methods, basic nursing care, direct observation treatment (DOT) and infection control practices. The training equipped volunteer caregivers with various skills ranging from basic counselling, nutrition, training for household caregivers and mentoring orphans. Furthermore, majority of the volunteer caregivers mentioned that they gained skills of showing love and compassion to their clients when practicing infection control:

“Being a volunteer is not something that you do because you see other people doing it. It is something that emanates from within you, from love and your passion up until you reach a stage where you can help others. They taught us that when you help a sick person you do not act disgusted, you must be relaxed, smile and show love. Even when you touch their wound you do not act disgusted, you smile.” (Focus group 4, organisation D)

Majority of volunteer caregivers were confident about the knowledge that they acquired from the training. They indicated that they acquired knowledge and skills on infection control practices such as how and when to wear gloves; masks; aprons; how to bath and change a

bedridden patient, how to maintain a clean environment for clients and how to dispose of the used gloves and other waste properly. They also learnt how to improvise when they did not have materials:

“Infection control practices are the ways in which we protect ourselves from diseases when we are doing our work on our patients. So you see! We have gained quite a lot of skills. Honestly, we didn’t know anything when we came here. Now we know that you don’t necessarily have to pick up a sick person who does not walk to the bathroom, but you can bed-bath them and change their diaper, linen and clothes without using too much effort of lifting them. We now have a lot we have learnt on how to comfort the patient, giving them hope not discriminate them, teaching family members how to do the work, love and care for their patient. With sexually transmitted diseases, we now have knowledge about them the types, signs and everything, and about T.B we are able to use masks and gloves to protect ourselves and also to explain to people how they must protect themselves from STDs or T.B.

(Focus group 1, organisation A)

“Home based care training has really helped us because we did not know a lot of things. We now even know how to take care of ourselves from infections and how to take care of our families. And for the patients, we know how to care for them. We now have the knowledge of what to do in certain situations when a patient has a certain condition or even when you don’t have material you can use what is there like plastic for bread if you don’t have gloves and salt to clean the wounds”. (Focus group 7, organisation G)

4.4.2 Materials for infection control practices

Materials are important for effective infection control practices by volunteer caregivers. Findings revealed that most participants from all organisations received home based care kits which they called “green bags” that contained various materials for medication and infection control supplied by the Department of Health (DoH). During focus group discussions, participants were asked to discuss and list the materials that were supplied in the HBC kits in order of their importance. Across all organisations, findings reviewed that, in terms of infection control practices, protective clothing were the most important. Materials that were used for practicing hygiene and for waste disposal were seen to be important compared to medication materials. Table 4.3 below shows the materials contained in the kits in order of importance as mentioned by caregivers.

Table 4.3: Contents of Home-based care kits

| Most supplied materials in the Kits by DOH | | Rate of importance |
|---|--|---------------------------|
| Protective Clothing | Gloves , Masks, Aprons ,Condoms | Most important |
| Materials for Practicing hygiene | Dippers, bar of Soap, hand sanitizer, bleach Gauze, Mouth wash, Aqueous cream or calamine lotion, Vaseline, Linen savers, Draw sheets, Bandages, gauze, swabs Cotton Wool, Powder, Roll of tissue, | Important |
| Medication | Gentian Violet, multivitamin syrup, painkillers, rush ointment | Least important |
| Waste disposal | Garbage bag | Important |

These kits were supplied to HBCOs by the DOH once every month. As one focus group and HBCC organisation highlighted:

“They give us bags with things that we need inside from the department of health”

(Focus group 9, organisation I)

“We get materials from the department of health every month. These are called kits which are the green bags. They contain everything that the volunteer caregiver needs to perform their duties.” (HBCC, organisation 8)

4.5 How volunteer caregivers practised infection control in HBCOs for PLWHA

Volunteer caregivers performed different infection prevention measures when attending to their clients in the community. These measures included: hand hygiene, domestic hygiene and personal hygiene on the patient; wearing of protective clothing and safe disposal of waste. These measures are explained in detail below.

4.5.1 Practicing hand hygiene

All volunteer caregivers emphasised the importance of being clean themselves; washing their hands before performing any task; washing their hands after removing the gloves:

“Before you do anything you wash your hands and make sure you are clean”

(Focus group 9, organisation I)

4.5.2 Practicing domestic hygiene

Volunteer caregivers also practiced domestic hygiene in order to break the chain of infection:

“In the morning when we get in homes, we open the windows because there is always bad odour so you do it for fresh air. So we also clean the whole place with a disinfectant...you check the bed, remove the soiled linen and change it and put a linen saver...”

(Focus group, organisation I)

“You must also keep their food covered. Also the patient with T.B should have their own plate to minimise infection.”

(Focus group 1 organisation A)

4.5.3 Personal hygiene on the patient

Volunteer caregivers performed personal hygiene on the patient such as washing and bathing the patient; cleaning and bandaging their sores:

“... you bath them and also change the patient after bathing them, use vaseline and powder on their body, use mouth wash or salt for their mouth and a gauze to clean them, you put a bandage on their sores and then you soak and wash their linen with a disinfectant. If you don't have dippers you can use draw sheets or napkins but dippers are the best! So Before anything you need the kit with everything that you need to be close to you.”

(Focus group 9, organisation I)

“...Make sure that after bathing the patient, they wear something clean. You cannot bath a patient and still give them dirty clothes they have been wearing... It is also important to brush and clean the teeth of the patient. You must cut their nails so that there won't be germs.”

(Focus group1, organisation A)

“Others have sores in their mouths, and they can’t eat or swallow. You find some with flies around their bodies. Then we clean the person, clean their tongue with a spatula; mouth wash or salt. We then try to feed them porridge; we now know how to use draw sheets; linen savers; bandages; gauze mouth wash; disinfectants and other things to protect ourselves”.

(Focus group 6, organisation F)

4.5.4 Wearing protective clothing

Most participants knew the importance of wearing protective clothing such as gloves, aprons and masks before performing their work on patients for protection from infections. They wore masks when handling T.B patients; aprons and gloves or other locally available plastic papers when dressing wounds, handling linen soiled with body secretions such as blood, faeces, vomits and pus, and handling soiled and dressing materials like bandages or cotton swabs:

“Before you touch anything in the patient’s house or the patient we always wear gloves correctly because you can still be infected when using gloves especially if you use them incorrectly. We also wear masks because you may not know who has T.B. and the smell in some houses is too much so the mask also helps to filter the bad odour. Then you also wear your apron so that you do not mess your own clothing. Then when you have finished performing all your duties, you must also know how to remove the glove. When you remove the glove, you must not touch your body. You must hold the glove carefully to avoid infection by touching yourself. There is also no need to use the apron twice. If you have one apron, and you need to use it the next day, you must use the other side of it, and then throw it away.”

(Focus group1, organisation A)

4.5.3 Proper disposal of waste

Majority of participants in interviews and focus groups emphasised the importance of proper disposal of the used materials such as gloves, cotton wool, bandages, diapers, swabs and some used gauze by burning; burying; storing them in waste store facilities and pouring them into pit latrines to prevent and kill disease causing microorganisms. Most of the participants stored their waste in waste storage facilities that were collected twice a week by the garbage truck:

“We have black plastics in our kits where we put in diapers and gloves, bandages, cotton wool and all the things that have been used. We tie the plastic with tape and throw it in the rubbish bin the one which is outside to be collected by the garbage truck.”

(Focus group 4, organisation D)

In order to prevent dogs and children from playing with the waste, most participants said that they dug some pits behind the patients' homes and buried the waste. They also flushed the used water into the toilets and sometimes burnt the waste because the garbage trucks were unreliable:

“When you are cleaning a person, you need to take a plastic put all the used materials in there and wrap it properly and tight so because the garbage collectors take too long to come and collect the waste and you cannot leave them because dogs will eat them up or some children will play with them. So you make sure that you throw those things dig up a pit for it so that another person may not get a disease. You can either bury them or just burn and that dirty water you just pour it into the toilet and flush.” Focus group 6, organisation F)

4.6 Challenges confronted by volunteers regarding infection control practices and strategies used to deal with the challenges in HBCOs for PLWHA

Volunteers were confronted with various challenges when practicing infection control. However, they developed some strategies that helped them to deal with these challenges in order to continue providing care to the patients. The challenges will be presented first followed by the strategies used to deal with each challenge.

4.6.1 Insufficient materials in HBC Kits

Most participants mentioned that they were receiving home-based care kits every month from the DoH. Among other materials contained in the kits, gloves, masks and aprons were named as the most important materials needed for practicing infection control. One HBCC stated,

“Because we do not have anything now and the DoH is not supplying us with Kits. Gloves, aprons and masks are more important. But of them all we need gloves because with gloves we can touch patients and perform our duties even without other materials, not that they are not important but it is because we are pushed into a tight corner we just need to continue providing our services to patients because they need us we cannot just neglect them so if we can get enough gloves.” (HBCC, organisation A)

The quantities of the materials contained in HBC kits raised some concerns by all participants. Findings show that all the materials that were provided in the kits were not sufficient when compared to the number of patients that most volunteers had to attend to on a daily basis. This made participants frustrated as shown in the following response:

“... The DoH gives us a batch of everything in kits and we should divide the kits amongst ourselves and then sign for them but the thing is these things are little such that they do not last up to the time you get new ones. So for example, you find that most of us have bedridden patients that need a lot of nappies/diapers and we have 5 to 10 patients on the minimum so this would mean that the other patients won't have materials because the ones in the kits only last for one day by the time you go to other patients you have nothing. They should add all these things and give us items for the whole month and I should sign for them. For example they give us toilet paper in the kits it is only one roll and suppose you use all of it on one person what happens if you go to the next patient? You have one tablet of soap for bathing the patient and the same soap you use it for washing! What happens when you reach the 2nd or 3rd patient? Everything in the kits is limited, and it's not enough!”

(Focus group 8, organisation H)

4.6.2 Insufficient supply of HBC kits

Since April, 2011 the DOH in trying to create jobs in health care facilities employed most of the volunteer caregivers from most home-based care organisations to work as community health workers in local clinics. For this reason it cut down the supply of HBC kits in HBCOs by supplying most of the materials to clinics. There is no evidence that shows that there were strategies put in place to deal with this challenge. This has resulted in shortages of kits in HBCOs. As HIV/AIDS continues to affect communities, PLWHA need on going assistance from volunteer caregivers. However, insufficient supply of HBC kits means that volunteer caregivers cannot provide the quality care that is needed by their patients. Findings show that therefore as one home-based care coordinator said:

“... It has been and still is the responsibility of the department of health to provide HBCOs with materials. Ever since the DOH got our volunteer caregivers this year, it stopped supplying us with materials as though we do not function anymore. They delay giving us! they only give us when they feel like! It can be 2 weeks or even months without receiving anything. So I went to the department of health and asked them that since now that you do not supply us with the material regularly, who is going to supply the materials for HBC? They said ‘go to the clinics because we also don't have enough money to buy these materials and supply them to you’! And so at the clinics they say that No! No..!! No!! We don't have funds for HBC materials they are only for the clinic!’ I just don't know how we are going to perform our duties because right now we really don't have any material to use!” (HBCC, organisation B)

To deal with all these challenges, most HBCCs tried to purchase some gloves, but they failed due to lack of funds. Some tried to ask for donations from well-wishers through friendship and connections that they created with other organisations. One HBCC said:

“Sometimes I ask for gloves from my friends who work for some organisations and also ask from the clinics from a person who is looking after the clinic. Sometimes they give us one pack but it is not enough. We also try to buy but we do not have funds to continue buying because one packet of gloves is expensive we can’t afford.” HBCC organisation B

Due to lack of funds for purchasing materials for infection control practices, volunteer caregivers had to reuse the aprons and gloves or use plastics in place of gloves. This caused them to fear contagion, feel frustrated and demoralised. This is presented in the following statements:

“When we do not have gloves they must use empty plastics for bread in place of gloves so that it can play the role that gloves play because there is no other way it is really frustrating to these carers.” (HBCC, organisation A)

“... We take those used gloves, wash and re-use them. These aprons we just use the other side, but we are supposed to use them once and get new ones. Now that we re-use them...it’s a big problem it is risky and it’s not right!” (Focus Group 7, organisation G)

Furthermore, some volunteer caregivers mentioned that they did not perform their physical duties without materials due to fear of contagion by the patients as such, they only focused on providing counselling and in some instances they would not visit any patients. This is evident in the following response:

“We tell them that we are not going to help them because we have run out of stock of materials and we are not abandoning you but there is nothing we can do. Sometimes we don’t even go there.” Focus Group 4, organisation D)

4.6.3 Poor quality materials

Most participants in focus group discussions were unhappy and complained about poor quality materials (such as gloves, masks and aprons) that they received. They feared contagion and they could not perform their work effectively and efficiently. They made the following statements:

“When we bath people...the gloves they give us here...our hands are not the same, like mine they are small, others have bigger hands. When you wear gloves and you've only washed the face of the patient, you only discover that they are torn and there is water inside the glove. Sometimes they are tight here on the wrist, some they have small holes, some they are loose and they easily break! They are just too short for this kind of work that we do!”

(Focus group 5, organisation E)

“We need tight masks these ones are too thin and loose because there are houses with very strong bad odour that you can smell while you are still outside. Some patients have T.B so masks must be thick and tight so that they protect us.” Focus group 7, organisation H)

“...You come across patients who have maggots all over the body and this gets blown away! How can one be sure that you are protected like this?” Focus group 4, organisation D)

To deal with this challenge, volunteer caregivers expressed their frustrations and mentioned that they helplessly neglected the aprons and poor quality gloves. They ended up not using the aprons and used their bare hands to perform their duties:

“You have to tie these gloves on the wrist but by the time you finish bathing the patient your hands are wet so you just wash your hands with water sometimes we just remove the glove and risk with your bare hands and just pray that God will see and hear our prayer.”

(Focus group 10, organisation J)

“...And this plastic apron is too light like a paper. It’s just like a paper! I stopped using it the day it was blown by the wind into my face!? It is even better to remove it and just mess up your clothes without it! It is frustrating.” (Focus group 4, organisation D)

4.6.4 Lack of co-operation from some patients and family members

The majority of volunteer caregivers felt disappointed and unappreciated when some patients did not want some gloves or masks to be used on them. Some family members also did not allow volunteer caregivers to use gloves or wear masks when attending to their patient who were relatives because they felt that the patients would feel unloved:

“...if you are trying to use gloves and masks some of the families stop you and say why do you want to use those things? They tell you not to use them because they feel as if you are disgusted by the patient, and also the patient gives you a bad look whereas you are just trying to protect both you and the patient.” (Focus group 6, organisation F)

“... Some people do that like it when you use gloves they think you do not love them. Some don’t like the mask you don’t just use it anyhow, you use when it is really necessary. Someone, a sick person has asked me before, and said why are you using this mask is it because you think I smell or anything?” (Focus group 8, organisation H)

Volunteer caregivers dealt with this challenge by exercising patience with families or patients who did not want gloves or masks to be used on them by explaining to them the reasons why

they wore gloves or masks. In some instances, volunteer caregivers lied to their clients that they were wearing masks and gloves because they were sick and that they did not want to infect their clients. They also offered education to family members and the patient on the importance of wearing protective clothing:

“To those that do not like it, we explain to them that it is not because we are disgusted, but it is because you also need to be protected my diseases. Others understand after you explain. We tell them that even doctors and nurses always use gloves. But others do not like it, and they feel as if you are disgusted they will just look at you disapprovingly so you just touch them with your bare hands and not protect yourself and say that God will help me through this challenge and he knows that I am trying to help.” (Focus group 1, organisation A)

One particular participant said that, she felt angry and unappreciated by the patients and family members who did not want her to use gloves or masks. Therefore on one incident she could not care or hold her anger or tell lies but she told her patient the truth as to why she wore the mask:

“... I told her of that it’s because you have messed yourself, so the smell of this shit will affect me and the patient understood” (Focus group 8, organisation H)

4.6.5 HIV/AIDS related stigma causing more burdens on volunteer caregivers

HIV/AIDS related stigma is still evident and is encountered by most of the volunteer caregivers in their communities while performing their duties. HIV/AIDS still carries a stigma. It is still seen as a taboo by some religious groups. Some patients are neglected by their family members. Some people do not go for voluntary testing and counselling (VCT). Some do not know or disclose their status. Some who know their HIV status do not access treatment and shun help from volunteer caregivers. In such circumstances volunteer caregivers may have less access to their clients. They cannot practice infection control. As result the health of the clients deteriorates. This can cause more infections and also cause death:

“People in this area take T.B and HIV/AIDS as a shame. Some families don’t want to help the patients. They locked them up inside their houses. Families do not want them to come out and talk or be seen by people. They don’t care whether the person has eaten or not. They just want the person to die quickly. And if the patients wet or soil themselves, they are beaten and some are denied food so you will find him or her in that same condition the next day. You will find that now they have developed sores because they have been doing everything on

themselves without anyone changing them. Some families see you and they just say to you 'here is your person' they leave you to do all the work and they do not help out."

(Focus group 2, organisation B)

To deal with this challenge, volunteer caregivers sometimes used force to get in to the houses of those that hid their patients inside. One participant gave an account of a time when they used force to enter a house of some family members that hid their sick relative in the house:

"Some family members ask us that who sent you? Who told you that there is someone sick in this house? If we find such people who hide their patients in the house, we do not just leave them we persist by doing whatever we can to make sure that the person gets help. There is a house where we went to, we were four of us. The husband had a stroke and HIV positive. They then locked him inside the room. If you asked the women how they were doing she would say that they were well. So we decided that this cannot go on. So we went to see this lady. When she saw us coming she locked up the door. We knocked and there was no answer, until we sent her child who was playing outside. When she opened for the child, we got in, she tried to push the door against us, but it was too late we over powered her. We got inside the house and we asked the patient how he was, he just burst into tears and cried because the wife had been hiding him for a long time not saying that he was sick. This really helped because the husband is now better. He went to the clinic to be stretched he even came to thank us for the good work." (Focus group 10, organisation J)

Volunteer caregivers also educated the family members how to love, care and support the patients. They explained their role even to their clients and those who shunned help in order to try and help family members to stop stigmatising HIV/AIDS patients. They also encouraged them to go for testing and to seek medication:

"Another thing is we try to work hand in hand with the family. When we get to the household, we don't take the whole burden of caring for the person. We explain to the family that the patient is still a human being, their relative and part of the family; it is not the end of the world to have HIV/AIDS so they must not stress or feel ashamed to anyone. They should not leave the patient for us only but he/she is for the whole family also. They must not rest because we are now here. We have to work together. We teach them how to love and care for them in the end when they see all this they stop hiding their patients to us and you see them that they become grateful and happy. They begin to care for their patient and most of the patients have hope and even recover quickly. So some families change but some they are very difficult they still leave their patients to die fast." (Focus group 7, organisation G)

Volunteer caregivers from one community were concerned about some male patients who shunned help due to fear of being stigmatised. As a result some patients died from infections that could have been prevented:

“... It is difficult to care for male patients; they don't want to get tested or to go for treatment. Some don't want people to know that they are sick so when you visit them they say that I am fine just make food for me, they feel ashamed because they think that you will tell everybody that they are sick. Others don't want you to come near them, they just refuse, and they call you 'umfazi' (woman). My patient absolutely refused until he died. He never went for a test or to get treatment fearing to be seen by people. He had a terrible STD all over his private part there were sores and his private part was destroyed. He was always sleeping with a towel around him. He could not even walk... But one could tell from the smell that this person has never been through a drop of water. He refused my help until he died.”

(Focus group 4, organisation D)

Volunteer caregivers dealt with this challenge by explaining their role, exercising patience and negotiating with such patients to accept their help:

“When you get to a male patient who is afraid and ashamed of you caring and touching him as a female, you sit down and explain to him. You explain the organisation you are coming from and the work that you do. You tell him that you will now be like a family member to him because you will be coming often to see and take care of him and you will not tell anyone about their status you tell them that if it is medication you will fetch it for them and you will do everything for them to improve their health...” (Focus group 7, organisation G)

4.6.6 Insufficient knowledge on infection control practices by community members and volunteer caregivers

Volunteer caregivers complained about insufficient knowledge on infection control practices due to once off training that they received. Once off training could not equip them with sufficient knowledge and skills to cover all emerging diverse situations in caring for PLWHA and to be professionals in their field like nurses and doctors:

“We have had different trainings but we haven't got much training about infection control but we would appreciate it if we can get it. We only had a workshop about it but it was not enough we need more knowledge about how to protect ourselves this job is too risky”.

(Focus group 3, organisation C)

Although most of these volunteer caregivers received training from the DoH, some volunteer caregivers from one newly formed HBCO were taught skills and knowledge on infection control practices by their project manager who was also their HBCC. Insufficient knowledge on infection control practices put volunteer caregivers at risk of catching infections. For example, one project manager/HBCC confirmed that she provided training to the volunteer caregivers based on the knowledge that she received during her career as a nurse because she

was still waiting for the department of health to conduct training with the volunteer caregivers in the organisation:

“... I am a nurse by profession, so I use the knowledge that I have to train the volunteer caregivers and we also still waiting for the Westville hospital to come in and do the proper training with them, because they offered us that they would come in and do the infection control with our care workers.” (HBCC, organisation E)

Some volunteer caregivers were concerned about some family members and elderly community members who had little knowledge regarding HIV/AIDS with its related opportunistic infections and infection control practices. Most family members were overwhelmed and stressed about not knowing how to handle their relatives with HIV/AIDS causing them not to take precautions:

“Some family members and older people especially grandmothers do not have the knowledge of what to do if a person is sick, some of them do not even know the symptoms of this HIV/AIDS disease. Also, when a person is ill, families don't know that they have to use gloves. They just use their bare hands to bath them. As they use their bare hands they may get infected, and then start getting sick...” (Focus group 4, organisation D)

4.6.7 Poor living conditions in the community

Poor living conditions in most communities were repulsive to some volunteer caregivers. For example, these volunteer caregivers found large families living in small rooms causing the patient not to have privacy when being cleaned. Such overcrowding allowed easy transmission of T.B from the patient to family members and volunteer caregivers impacting infection control practices of the volunteer caregiver negatively because volunteer caregivers were tempted not to visit such places and as a result patients would not have access the help that they would need:

“Other challenges that we face are that about six people stay in one house. One may have T.B and you find that the whole family becomes affected or infected because there is one room, with no proper ventilation. They do everything here, children sleep and a sick person is also there. Even if you want to help the patient, there is no space for privacy and when you want to make the room clean it is not easy. These are the problems we normally face, the poor families who do not have enough rooms but stay with someone who has T.B., and T.B is infectious they keep infecting each other without knowing. Sometimes we are tempted not to go to such homes again”. (Focus group 1, organisation A)

Volunteer caregivers were also sickened about unhygienic conditions in the communities such as pipes leaking with water causing floods, blocked sewer pipes leakages around houses

that also caused breeding of flies that could cause infections to both the affected the infected families:

“...You find that in these communities people stay in dirty places. You see what happens, there is running dirty water, people dump rotten food, bath water after bathing themselves or cleaning, washing or bathing a patients so it becomes very filthy with a lot of flies and the pipes get blocked and that’s where they even get their drinking water from. They leave squashed up in small places called shacks with everyone in there including T.B, HIV/AIDS patients they don’t open windows so they keep on infecting each other”

(Focus group 8, organisation H)

To deal with such challenges, Volunteer caregivers shared their knowledge through educating family members and other community members about hygiene; the use of protective clothing and proper waste disposal to prevent infections:

“In that household you teach the family that hygiene is very important because it prevents a lot of diseases and infections. You teach them that they should open the windows for fresh air, particularly when there is someone who is sick. We teach them how to take care of the HIV/AIDS patient and also how to protect themselves from getting T.B especially if it is MDR. We tell them that they should always throw rubbish in a bin. They should wash their hands all the time and be clean. If they do not have a pit where they could throw rubbish, they should dig one. And cleaning the surfaces is important they need to be tidy.”

(Focus group 10, organisation J)

4.6.8 Insufficient supply of water

Volunteer caregivers need water to practice hygiene such as washing soiled linen and bathing the patient. Poor hygiene causes the spread of infections and could deteriorate the health of patients. Volunteer caregivers mentioned that there was no supply of water for days in some homes:

“Water here has mood swings, it comes and goes so they announce with the truck for you to know when and draw and store in advance sometime we go and fetch it in some areas where water is available.”(Focus group 1, organisation A)

In order to continue providing care to their patients, volunteer caregivers dealt with this challenge by taking their own 2 litre containers of water and sometimes they went to fetch from nearby areas that had water:

“You bring your own 2 litres of water ... so that you don’t use up the water that the patients or family members have saved for themselves. When you go to a house you have to work in such a way that you improve the situation, not worsen it. So you don’t get there and start criticizing them if they don’t have enough water, but you show them that you have brought your own and they should try to save more next time.”

(Focus group 8, organisation H)

“When we get to our patients and find that they have no water... you have to go and fetch the water from somewhere so that you can bath the patient. In some areas the truck comes to supply water so we go there”. (Focus group 3 organisation C)

4.6.9 Ridicule from the community members, insecurity and demoralisation faced by the Volunteer Caregivers.

In spite of the fact that volunteer caregivers are not paid, there has been a lot of mockery and contempt from the members of the community. They are generally perceived as people of low status in their communities because of doing risky jobs without any pay. This causes frustration and demoralisation amongst volunteer caregivers which could cause them to quit their job:

“... We are looked down upon as people who have no intelligence, as people who do not think. They “say you are doing this job and you don’t get paid. Who can go to work for such a risky job and not get paid? We only get stress and death?”

(Focus group 3, organisation C)

Most volunteer caregivers lost most of their fellow workers who got infected as a result of the risky volunteer care giving work. They feared contagion and death due to insufficient protection from infections caused by short supply of materials. More importantly, volunteer caregivers felt demoralised to perform what they called ‘risky job’ without being paid:

“But the problem is that there is no love of doing this work because there is no money it would be better if we at least get something. These days it is difficult to volunteer because we were not this number, many of our fellow caregivers have died after doing this work; they got infected, so we are not happy to keep on volunteering without getting something. The only thing we get is death”. (Focus group 2, organisation B)

Some volunteer caregivers were also concerned about their safety while performing their duties in the communities because they had to walk long distances to reach their patients’ homes. A participant in one focus group discussion narrated a story where they came across patients who belonged to dangerous gangs that smoked dagga in the communities that they served. These experiences could cause volunteer caregivers to neglect such homes as such the

patients could be affected because they could not receive the care that they need to prolong their lives:

“Even going around houses helping people... it is not safe. I remember at one time we got to this house to check for this sick boy. Inside the house there were naked men smoking dagga. We just ran away because we were not safe... We like to see people getting well... when you go in and out of houses looking for this person who is supposed to be taking T.B medication...you would find people sitting and smoking, and the one you are looking for would be among them smoking. Then you will come in and call out his name... Maybe the person just responds by shouting at you, or he may respect you and come because of the t-shirt you are wearing. He then asks you ‘how can I help you?’ I say yes, I’m looking for so and so, he says yes, that’s me. Then you would ask him why he no longer comes to fetch the medication. And they will swear at you. What can you say to that? You are taught to be patient and beg the person. Maybe you live far away and you came all the way to see that patient on foot, because they don’t pay us anything! So you have to walk long distances to get to the patient just one patient.” (Focus group 2, organisation B)

Volunteer caregivers dealt with these challenges by ignoring such people. They continued to perform their work because they felt satisfied to offer their help to sick people:

“... we ignore such people because we know that there are people who need our help and they appreciate it and that is enough for us, but it is not that we are satisfied, we also need motivation in terms of money even just to buy things to work with like umbrellas or rain coats to use when it is raining, some warm clothing to protect us from the cold weather, uniforms for easy identification and even transport money.” (Focus group 3, organisation C)

For those caregivers who came across dangerous gangs in the communities, they exercised patience with the person they were caring for and in some cases when they smelled danger they would opt to run for their lives:

“Sometimes you can call the person aside, and see that they had been smoking dagga, they may listen to you when you motivate them and they end up accepting to go to the clinic. The next time you will find that the person has actually gone to the clinic to fetch their medication. They continue taking medication. They may even come to you and say ‘thank you my sister for helping me.’” (Focus group 2, organisation B)

CHAPTER FIVE DISCUSSION OF RESULTS

5.1 Introduction

The discussions of the findings are presented using the four levels of the ecological systems theory (EST): micro (level for volunteer caregivers), meso (level for community), exo (level for HBCOs) and the macro (the level for the government, NGOs and donors/funders. These discussions are presented under the following themes that were derived from the research questions: perceptions of infection control practices by HBCCs/project managers and volunteer caregivers, how infection control practices were carried out by volunteer caregivers; resources available for infection control practices; challenges confronted with and strategies developed to deal with the challenges regarding infection control practices by volunteer caregivers.

5.2 Perceptions of infection control practices by HBCCs/project managers and volunteer caregivers

Perceptions in this context refer to the understanding of infection control practices in terms of care that is provided to PLWHA by volunteer caregivers in HBCOs. Perceptions of infection control practices by HBCCs/project managers and volunteer caregivers help to understand the level of care that is provided to PLWHA in HBC programs.

The macro level

The government, NGOs and the donors/funders belong to this level. It is evident from the findings that, at this level there is a national infection prevention and control policy and strategy (South African Department of Health [SADoH], 2007). This policy is known by HBCCs in HBCOs. It guides the volunteer caregivers on infection control practices such as when and how to wear protective clothing like gloves, masks and aprons. It also guides the volunteer caregivers on the importance of practicing hygiene and maintaining a clean and safe environment (SADoH, 2007:6). The findings of this study also show that the government through the DoH provided training to volunteer caregivers on infection control

practices and it was responsible for providing HBC kits to assist in the effective infection control practices. These findings are consistent with that of a study that was performed in six countries Malawi, Kenya, Uganda, South Africa, Nigeria and Cameroon. The study was on the significance of care giving work by the volunteer caregivers for PLWHA. Its results revealed that HBC carers obtained training from either organizations or from the governments (Budlender, 2009). These findings imply that there could be adherence to infection control measures by the volunteer caregivers and this could also reduce the risk of opportunistic infection by the patients.

Exo level

The HBCOs operate at this level. Results of this study show that home-based care coordinators/project managers viewed infection control practices as important measures that protected volunteer caregivers from infections. They ensured that all volunteer caregivers got trained when they were enrolled into HBC programs. HBCCs explained the importance of following infection control practice guidelines to volunteer caregivers. For example, as part of a guideline that was provided by the health professional council of South Africa [HPCSA] (2008), HBCCs encouraged volunteer caregivers to wear plastics on their hands in cases when they did not have gloves when handling patients with HIV/AIDS. This implies that the transmission of infections could be reduced between the patient and the volunteer caregivers in HBCOs.

Micro level

Volunteer caregivers are part of the community who are employed to work in AIDS care organisations as volunteers (Akintola, 2006; Akintola 2008). This study gives new insight that infection control practices were seen to be important by volunteer caregivers for prevention of patient-to-caregiver infection; caregiver-to-patient infection and because of the need for proper hygiene in the communities. Such views suggest that infection control practices could have a positive impact in that volunteer caregivers could adhere to infection control protocols due to fear of being infected by the HIV virus and thus their health and those of the patients could be improved.

5.3 Resources available and how infection control practices were carried out by volunteer caregivers

The macro level

At the macro level, the government through the department of health played an important role of providing volunteer caregivers with materials. Knowledge and skills on infection control practices were also provided through workshops. These workshops were not conducted on a regular basis they were only conducted once when they recruited volunteer caregivers, there were no refresher training workshops. Considering the fact that, volunteer caregivers are at risk of being infected by HIV or T.B when performing their tasks, once off training without refresher courses are not adequate to equip volunteer caregivers with sufficient knowledge and skills about infection control practices.

Findings of this study might be an addition to literature in this area of infection control practices by documenting that insufficient knowledge on infection control practices due to inadequate training can caused frustration, demoralisation and fear of contagion to most volunteer caregivers. This implies that the quality of care that is given to the patient could be reduced and it is possible that the patients could develop new infections which could cause their health to deteriorate. This can lead to the spread of infections and can also cause death to most patients. This could also impact the HBCOs negatively in that most volunteer caregivers could quit their jobs. Additionally, this could discourage some people to volunteer in Aids care organisations.

When it comes to materials available for infection control practice in HBCOs, most available literature show that there is insufficient supply of kits or that there is a problem in replenishing them. For example, a study that was conducted in Zimbabwe on home based care by Southern African HIV and AIDS Information Dissemination service (SAFAIDS) & Health and Development Networks (HDN) (2007) showed that there was insufficient supply of HBC kits and poor replenishment materials such as gloves, bleach, soap and linen savers for caregivers in home based care organizations. In South Africa, a national survey on home based care kits was conducted by Mabude et al., (2008) and it revealed that HBC kits were supplied by the DOH; their supply was inadequate compared to their demand; their

replenishment was a challenge. On the contrary, the results of this study show that the government through the department of health cut down the supply of HBC kits. This shows more nuanced understanding of the problems on resources for infection control practices. These findings imply that infection control protocols could not be followed by volunteer caregivers. These findings could have a negative impact on the patients in that, most patients could be neglected consequently the quality of care provided to them could be compromised and patients could be susceptible to death. However, in order for HBCOs to function properly, there is need for the government to allocate adequate resources for infection control practices and establish a central office that could oversee infection control practices in HBCOs.

Exo level

Home-based care organisations in this study acknowledged the importance of training for their volunteer caregivers as such, most HBCCs/project managers ensured that volunteer caregivers received training when enrolled into HBC programs. However, this study extends knowledge in this area of training regarding infection control practices. Findings suggest that most HBCOs did not have internal trainers hence, they depended profoundly on the DoH to offer training to volunteer caregivers. This implies that most HBCOs have little influence regarding training, however, this could be the reason why most HBCOs wait for long periods of time to receive training for their volunteer caregivers. It could also contribute to lack of sufficient knowledge regarding infection control practices. For example, only one project manager/HBCC who was a retired nurse provided training to volunteer caregivers on infection control practices while waiting for an external trainer. This implies that infection control practices could be affected negatively because volunteer caregivers begin to care for patients without appropriate and adequate training as such they are at risk of being infected while caring for the patients. These findings highlight the need for the DoH to offer regular training with refresher courses and also train internal trainers in HBCOs who could also be in charge of overseeing infection control practices in the organisations.

Micro level

Although volunteer caregivers were equipped with knowledge and skills on infection control practices such as practicing good hygiene; wearing protective clothing; disposing of the waste safely, they could not follow all infection control protocols due to poor quality and insufficient materials. Knowledge and skills on infection control without adequate materials is not worthwhile. Most participants in this study feared contagion and felt discouraged to perform their duties without materials. This could cause volunteer caregivers to abandon some patients. This also could add psychological stress to volunteer caregivers and cause them to drop out. These findings show an expansion of knowledge in this area. However, there is need for the volunteer caregivers in HBCOs to form a forum to address materials issues.

5.4 Challenges confronted by volunteer caregivers and strategies developed to deal with the challenges regarding infection control practices

Macro and exo level

The mission for HBCOs programs is to provide on-going care to HIV/AIDS clients in order to alleviate pain and also to provide hope (Walker, Aceng, Tindyebwa, Nabyonga, Ogwang & Kiiza, nd). The South African community care worker management policy framework (2009) states that, international organisations and non-profit organizations are the main funders of HBCOs. However, the findings of this study show that most HBCOs depended heavily on the government, NGOs and donors for resources. The government, through the department of health, is responsible for providing home based care organizations with HBC kits for volunteer caregivers. But at the time of this research materials contained in the kits were of poor quality and inadequate to carter for the patients that volunteer caregivers cared for because they were only supplied once a month. For example 97% of the volunteer givers did not have HBC kits at the time of research.

Insufficient materials inhibited volunteer caregivers to follow the infection control practice protocols such as wearing protective clothing like gloves, masks, aprons and practicing

hygiene. However, to deal with this challenge, HBCCs tried to lobby for gloves from the clinics through connections that they established. They also asked for donations for gloves from well wishers. When all this failed, they encouraged volunteer caregivers to wear plastics on their hands in place of gloves in order to continue providing care to PLWHA.

The government has a role of providing basic needs such as access to potable water for its citizens (DWAF, 2000). Some participants in this study revealed that some communities in which they served did not have water throughout they referred water to have had '*mood swings*'. This forced them to travel long distances to draw water. Water is a valuable resource in HBCOs for PLWHA (Wegelin-Schuringa & Kamminga, 2003) for example, at least 1.5 litres of clean water is needed to take some ARVs (Wegelin-Schuringa & Kamminga, 2003 and MWA, 2004). Water is needed in home based care for bathing of the patients, taking medication, cooking, washing of clothing and beddings. Insufficient potable water supply implies that infection control practices are compromised in that there would be poor personal, domestic and food hygiene practices depending on the severity of HIV/AIDS opportunistic infections. This may result in delaying of the healing process of the patient and exposure of volunteer caregivers to infections (UNICEF, 2009). Insufficient portable water can force volunteer caregivers to resort to giving the patient a 'dry bath' as (Ngwenya and Kgathi, 2006) and dry baths could make the patients vulnerable to infections.

Caring for HIV/AIDS clients requires also hygienic living conditions. It emerged from the findings that most clients for volunteer caregivers depended on the government to provide them with a place to live. Due to poverty, most clients could not provide accommodation with adequate space as a result they lived in overcrowded households and in unhygienic conditions. There is frequent interpersonal contact in overcrowded households which make it easy for cross infections. Unhygienic conditions for HIV/AIDS clients in HBC could cause more infections on the patients consequently affecting infection control practices for volunteer caregivers negatively in that, volunteer caregivers could fear to be infected and may opt not to visit their patients who live in such conditions. The findings of this study are consistent with a study that was conducted in Botswana on the challenges impacting on the quality of care on PLWHA by volunteer caregivers (Kang'ethe, 2009: 26-27). The study

showed that due to poverty, most family members had poor living conditions such as inadequate living space which caused no privacy for patients that needed care.

Furthermore, unhygienic environments such as inadequate sanitary facilities like toilets and water made it difficult for volunteers to wash clients' clothing causing them to fear contagion as such volunteer caregivers avoided going to those homes (Kang'ethe, 2009: 26-27). In a study conducted by Tshililo, Davhana-Maselesele & Dphil (2009) about the experiences of home based care in South Africa in Limpopo province participants complained that poor living conditions such as a lack of toilet facilities in the homes, resulted in humiliation and lack of privacy for patients with diarrhoea.

This study also revealed that the government did not remunerate volunteer caregivers like it did to the community health workers. Considering the amount of work that volunteer caregivers contribute to HBCOs, regular remuneration is an incentive of appreciating and motivating volunteer caregivers to perform their work effectively. Regular remuneration has a positive impact on infection control practices in that volunteer caregivers would be motivated to perform their tasks. For example in Zambia, volunteer caregivers were not paid but they were given free access to medical facilities and to community ploughs, they received seeds, uniforms, bicycles, t-shirts and they were allowed to conduct income generating projects such as gardening to meet their needs. Furthermore, these incentives increased their willingness to perform their care giving duties and were more productive (SAFAID & HDN, 2007).

Shaibu (2006) states that if volunteer caregivers are not remunerated, they could feel demoralized to perform their duties hence they opt not to visit their patients who need their help and as a result infection control practices are impacted negatively. All these findings suggest the need for the government to allocate adequate resources to relevant departments in order to improve the functioning of HBC program. At these levels, strategies developed by the government to deal with challenges faced by HBCOs and volunteer caregivers regarding infection control practices are not clear. This study only relied on the information provided by the HBCCs and volunteer caregivers. However, there is just an assumption made from the findings that there is no strategy that was developed to deal with insufficient materials resources for infection control practices. This leaves HBCOs powerless because they depend

on the government, NGOs, donors/funder for resources and this hinders their proper function. This suggests the need for the government to consider infection control practices in HBC as important as those in the hospitals.

There is need for the government to involve HBCOs in developing strategies of dealing with challenges regarding infection control practices.

Meso level

On the community level, a study conducted in South Africa by Akintola (2006:12) on sources and the nature of support that volunteers received, findings revealed that some volunteer carers received support from community leaders and councillors in raising awareness. Family members of the patient and other community members had positive attitudes towards them and PLWHA; they helped in assisting carers to do their work such as bathing the patients. On the contrary, volunteer caregivers in this study did not receive support from some family members and some community members. For example, due to stigma some patients were hidden in their rooms, beaten for soiling themselves, denied food and denied access to volunteer caregivers. Some were abandoned and this caused more burdens of care work for the volunteer caregivers.

Additionally, volunteer caregivers were ridiculed by their family and some community members because of the nature of the work. Issues of stigma on the patients and ridiculing of volunteer caregivers pose threats to volunteer care giving work and has a negative impact on infection control practices in that volunteer caregivers will have limited access to patients; there will be high HIV/AIDS morbidity and mortality rates among PLWHA in HBCOs; there could be more burdens of care on volunteer caregivers resulting in more stress and HBCOs and the government could fail to meet its objectives of managing the HIV/AIDS pandemic.

The findings of this study suggest that there might be a link with the findings of two different studies, one performed in South Africa (Akintola, 2008) and another in Botswana (Kang'ethe, 2010). These studies revealed that most caregivers did not receive support from community members due to stigma and this caused them to be stressed. The findings of this study also adds new knowledge on what could hinder proper infection control practices in

HBC programs for PLWHA by volunteer caregivers. These findings highlight the need to educate community members on the impacts of stigma and discrimination towards PLWHA and also the importance of supporting the work of the volunteer caregivers including the role of HBCOs.

Micro level

Volunteer caregivers in this study felt they had insufficient knowledge on infection control practices due to insufficient training. Because of this, most participants feared contagion and felt demotivated to perform their work. Volunteer caregivers play an important role in home based care for PLWHA and when they are demotivated due to insufficient training it can cause them to quit their job as found by Ross, Greenfield & Bennett (1999) in their longitudinal study on predictors of dropouts and burnout amongst AIDS volunteers. This also implies that HBC program could lose manpower and infection control practiced could be affected negatively in that most patients could not be attended to causing an increase in morbidity and mortality rates. Therefore, these findings add more literature about the gaps that exist when it comes to training on infection control practices.

Even though volunteer caregivers were encouraged to wear plastics on their hands in place of the gloves, most of them resorted to use their bare hands because they could not perform their duties properly like washing clothes or beddings with plastics. This implies that volunteer caregivers are susceptible to cross infections. These finding are consistent with two different studies in Botswana by Kang'ethe (2010) and Shaibu (2006) on challenges faced by volunteers. Results showed that volunteer caregivers did not have materials to protect themselves when doing their work hence they were forced to use their bare hands. This study also reveals that when volunteer caregivers did not have materials, they resorted to teaching the family members how to care for their patients. However, the downside of educating family members is that family members could not handle the psychological, physical and emotional stress that comes with care giving. This could also imply that some patients could never be attended to especially those that live alone and those that are stigmatised by their own family members. This also could cause volunteer caregivers to be less committed to their work as a result there could be high mortality rates among PLWHA in HBC programs.

Due to insufficient water supply, volunteer caregivers took at least their own 2 litres container of water and also had to go and fetch water from distant places rather than leaving their patients unattended to. These findings indicate inadequate and unequal supply of government social services in the community and especially in home based care programs for PLWHA. Volunteer caregivers are already overburdened people thus carrying water increases their physical and psychological stress causing burnout and drop out implying that HBCOs could no longer provide quality services to its clients.

Stigma results in blaming, shaming and loss of status in the stigmatised people (Deacon, 2006:423). This study shows that some patients and family members did not want help from volunteer caregivers for fear of being stigmatised. To deal with stigma volunteer caregivers used their negotiation skills to persuade families and some patients to access their help. For the patients and family members who did not allow volunteer caregivers to use gloves, they were provided with education on the importance of using gloves. Volunteer caregivers also lied to their patients that they wore gloves to protect them from diseases this is consistent with Akintola (2005).

To handle ridicules, volunteer caregivers ignored community members, family members or friends that ridiculed them and they continued to perform their work. They developed what Akintola (2008) called 'a thick skin'. Volunteer caregivers also continued to educate family member on how to care for their patients. This shows a positive impact on (1) the patients in that they could continue to receive the help that they need from HBCOs through volunteer caregivers and their lives could be prolonged (2) HBCOs because it means that HBCOs could have volunteer caregivers that are dedicated to do their work meaning that these organizations will continue to function to meet their goals.

CHAPTER SIX CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

This study explored experiences of volunteer caregivers and HBCCs/project managers on infection control practices in HBCOs for PLWHA in Durban metropolis, South Africa. It is evident from the literature that home based care programs are developed to help deal with the high prevalence of HIV/AIDS in most developing countries. They aim at providing hope to the patient and family members and promoting, restoring and maintaining a person's maximum level of comfort, functioning and health (WHO, 2002). HBC programs are advantageous in that, most patients are able to be cared for in their homes by their family members who are assisted by volunteer caregivers. HBC relieves the duty of creating extra services by the health care system in resource limited areas and thus reduces hospital visits and increases the access of HIV affected members and community to regular skilled medical care, counselling, support and home care supplies. HBC also provides education to family members and friends on the prevention of further transmission of the virus and on how to practice good health and hygiene skills (Young & Busgeeth, 2010; Fidzani & Attah, 1996; WHO, 1999).

Just like any other programs, home-base care has its own challenges experienced by caregivers such as burdens of care leading to emotional, physical and psychological stress (Akintola, 2004). There are inadequate resources for providing food and materials to practice infection control for patients (Kang'ethe, 2009; Hosegood et al., 2007) and inadequate access to water (Ngwenya and Kgathi, 2006). There is also lack of remuneration for volunteer caregivers (Akintola, 2005). Despite all these challenges, most literature on HBC in South Africa has revealed that volunteer caregivers are the most valuable and reliable source of labour in HBCOs for PLWHA hence their role is very important. Practicing infection control helps to prevent both volunteer caregivers and patients from acquiring infections.

The ecological systems theory was used as a theoretical framework to help understand the current situation on infection control practices using the macro (for the government, NGOs,

fundere and donore); exo (for HBCOs); meso (for community) and the micro level (for volunteer caregivers). The EST model helped to achieve the aims of the study by identifying the levels of influence and how infection control practices were impacted either positively or negatively by the volunteer caregivers based on the assumption that, when these levels are well connected and support each other, their functioning improves. The EST model was adequate for this study in that, the data that was obtained specify how different levels impacted infection control practices of volunteer caregivers in HBC. It also helped to identify possible interventions at different levels that could help design policies aimed at improving infection control practices in HBCOs in the country.

The results of this study show that, when it comes to practicing infection control, volunteer caregivers are confronted with a lot of constraints. At the macro and exo levels, the government, NGOs, donors or fundere and HBCOs provided little resources for infection control practices. There were inadequate materials, insufficient water supply and insufficient knowledge regarding infection control practices. At the meso level, volunteer caregivers were confronted with lack of cooperation from some patients and some family members who did not want them to use gloves. Volunteer caregivers were also ridiculed by some community, family members and friends. Some patients were stigmatised and discriminated causing volunteer caregivers to have less access to these patients thus impacting infection control negatively.

At the micro level, volunteer caregivers perceived infection control practice as important for prevention of infections. However, they could not follow all the infection control protocols due to lack of materials. Due to insufficient materials, they replaced plastics for gloves; went with their own two litres of water due to inadequate water supply. They negotiated with family members to have access to patients who were stigmatised by explaining their role in home based care. They also educated them on how to care for patients and the importance of practicing infection control practices. They developed a hard skin to cope with the ridicules. The ecological systems theory was beneficial in providing insight into all the factors that played a role both in the proper and improper practice of infection control in HBCOs.

6.2 Recommendations

The following are the recommendations to the barriers to proper infection control practices by volunteer caregivers in HBCO for PLWHA.

Macro level

The government, NGOs, funders and donors need to work together to have effective and implemented policies to guide the planning, legislation and regulation of HBC programs. There should be a central administration responsible for allocating adequate and quality materials for infection control practices. This central administration should also be responsible for supervising HBCOs and their management including monitoring and evaluation. It should also be responsible for monitoring and evaluating infection control practices in HBCOs. There is need for the health sector to establish effective and sufficient communication among the national, provincial, district and the local level. There is need for the government to provide basic needs to destitute families such as access to potable water and housing with suitable living conditions.

There is need for the department of health to provide adequate training with refresher courses to equip volunteer caregivers with sufficient knowledge and skills on infection control practices. There is need for the health sector to corroborate with the education and other related sectors to develop infection control education programmes in HBC and develop some easy to read and easy to understand materials that can be distributed to family caregivers and other members of the community. In order to combat the HIV/AIDS related stigma and discrimination, there is need for the ministry of health and its partners to continue sensitising the general public using less threatening language regarding HIV/AIDS. There is need also for the government, NGOs, funders, donors and HBCCs to form a forum and sort remuneration issues for volunteer caregivers.

Exo and meso level

HBCOs are based in the community to reach out to community members with the aim of restoring hope in PLWHA improving their quality of life. Findings show that HBCOs depend mainly on the government, donors and funders for resources. For these HBC programs to run effectively there is need for all HBC programs to collaborate with local clinics/health care facilities. They also need to partner with other government agencies. There is need for NGOs,

faith based organisations and community based organisations to cooperate and collaborate and form a forum to address HBC resources. The forum should address strategies needed for ordering monitoring and evaluating the supply of HBC kits.

In order to promote positive attitude towards PLWHA and volunteer caregivers that help out these people, HBC programs need to put more effort to work hand in hand with influential community leaders to promote community training and education to address HIV/AIDS and its related stigma and discrimination that exist in the community this can be achieved through involving the churches in addressing HIV/AIDS issues and its related stigma during their meetings and workshops. Influential leaders could be used to sensitise community members on HIV/AIDS disease during every gatherings like funerals, weddings, church functions, community gathering or political rallies to achieve better understanding of the HIV/AIDS disease and the negative impacts of HIV/AIDS stigma and discrimination as barriers to effective prevention of the disease.

Micro level

Volunteer caregivers are worst affected because they are the ones that perform the work as such, they need to come together and form an association and forum to discuss their needs and present them to higher authorities to make sure that they are heard. Volunteer caregivers need to work hand in hand with health workers and other community care providers to continue educating patients, families and community members on HIV/AIDS issues and infection control practices.

6.3 Areas for further research

Based on the findings of this study, it is recommended that further research should be done to assess the distribution and quality of materials for infection control practices in HBCOs. There is need to assess the effectiveness of infection control policies in HBCOs. There is need to extend this study to include patients, family caregivers and also to get the community health worker's perspectives regarding infection control practices in all HBC programs.

6.4 Limitations of the study

The use of snow ball sampling method was a major limitation to this study. This technique allows the researcher to collect data based on referrals this means that, this study only gives insight on infection control practices from organisations that were referred to the researcher by the Aids care foundation. However, these findings only show the views of organisations from townships and a single rural area therefore, these views cannot be generalized to HBCOs in urban areas. Language was another limitation. Because the researcher was not Zulu speaking and could not understand what was being discussed during focus group discussions, she relied on the facilitator to find out how the discussions proceeded at the end. Furthermore, because of a language barrier, the researcher also relied on the translated data (from IsiZulu to English) to identify some gaps in the data collected thus this caused the researcher to panic after finding gaps in the data this also lead to going back to the field to recollect data however, this was overwhelming and costly. To make sure that language did not compromise the quality of the data, all research questions were clearly stated indicating all the follow up questions and the probes. The researcher also was present during the focus group discussions to note the non-verbal cues and also to ask questions that needed to be clarified.

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APPENDIX 1A: INFORMED CONSENT FORM

Good Morning, /afternoon/evening, my name is Ms Lydia Hangu. I am a masters student in the School of Psychology, University of Kwa-Zulu Natal, 4041, Durban, South Africa. I am conducting research on infection control practices in home-based care organisations for people living with HIV/AIDS in Durban, South Africa, I would speak to you only if you are willing to participate in this research.

This discussion will take about 40 minutes-1 hour. I will ask you to talk about your experiences regarding infection control practices in home-based care. I will need your permission to use an audio-tape recorder to capture our discussion.

All information that you give will be kept confidential. The information collected will be stored in my supervisor's office and only research assistants working with me on this project will have access to it. Information will be used for research purposes alone and raw data will be destroyed as soon as the study is completely over. Also, we will not use your actual name or designation in reporting the findings of the study but will use disguised name to make sure that no one links the information you have given us to you.

You will not be given any monetary payments for participating in the study but your department/ organizations/ community/ the government will benefit from this study immensely. The results will help us to understand the challenges encountered by your organisation regarding infection control practices.

Your participation in this study is voluntary. If you agree to take part in the study, we will ask you to sign a form as an indication that we did not force you to participate in the study. Please note that you will not be at any disadvantage if you choose not to participate in the study. You may also refuse to answer particular questions if you don't feel comfortable answering them. You may also end the discussion at anytime if you feel uncomfortable with the interview. In case you want to withdraw information given after the interview, you can call me on 0733356091 or my research supervisor (Dr. O. Akintola) on (031) 260 7426, email: Akintolao@ukzn.ac.za.

INFORMED CONSENT FORM

I _____ have read the information about this study and understand the explanations of it given to me verbally. I have had my questions concerning the study answered and understand what will be required of me if I take part in this study.

Signature _____ Date _____

(or mark)

Zulu Version

Incwadi Yemvume

Mina, _____ Sengfundile mayelana nokuqukethwe inhlolovo noma ngiyaqonda izincazelo zenhlolovo njengoba ngazisiwe futhi ngachazelwa ngazo ngomlomo. Isiphenduliwe imibuzo yami ngalenhlolovo, ngakho ngiyagonda ukuthi yini ebhekeke kimina uma ngiba yngxemye yalenhlolovo

Signature _____ Usuku: _____

APPENDIX 1B: DEMOGRAPHIC QUESTIONNAIRE

We appreciate your consent to participate in this study. For the purpose of this research may you please provide answers to the following questions.

- 1 What is the name of your organisation?
- 2 What is your organisation's physical address?
- 3 What is your position in the organisation?
- 4 What is your gender?
- 5 What is your age?
- 6 How long have you worked in this organisation?

APPENDIX 2: INTERVIEW GUIDE FOR HBCCS/PROJECT MANAGERS

| MAIN QUESTION | FOLLOW UP QUESTION | PROBE QUESTIONS |
|---|---|--|
| 1. May you please explain the resources available for infection control practices in this organization? | <ul style="list-style-type: none"> • What materials have been set aside for infection control practices? • Any finances set aside? | <ul style="list-style-type: none"> • Where do these materials /finances come from? How adequate are they? How often are they supplied? |
| 2. What guidelines do you have regarding infection control practices | <ul style="list-style-type: none"> • What are the dos and don'ts that you have regarding infection control practices? • What are the volunteers taught about infection control practices? • How are these guidelines influenced by external regulations? | <ul style="list-style-type: none"> • How were these guidelines formulated? • How are they documented? E.g. written down or not? May we please have a copy? • E.g. are there government sectors that emphasis the implementation of these guidelines? And what are these sectors? What are their requirements? |
| 3. How do you view infection control practices | <ul style="list-style-type: none"> • How important is infection control in this organization. • How important is infection control practices with regard to the work that volunteers do? | <ul style="list-style-type: none"> • How does it help the volunteers? |
| 4. How do you sustain infection control practices in this | <ul style="list-style-type: none"> • | <ul style="list-style-type: none"> • |
| 5. What challenges does the organization face regarding infection control practices? | <ul style="list-style-type: none"> • How adequate are the materials, finances • How do they respond to the challenges? | <ul style="list-style-type: none"> • What do you do when you don't have materials, finances? |

ISIZULU INTERVIEW GUIDE FOR HBCCS/PROJECT MANAGERS

| Questions | Follow-ups | Probes |
|--|--|--|
| Sicela nisichazele ngezinsiza-kusebenza kanye nezezimali kulesi sikhungo ezibekelwe ukusiza ukuvimbela ukwesuleleka kwezifo? | Ngabe izimali namaHBC kits ziqhamuka kuphi? | Kungabe zanele yini (izimali, HBC Kits)? Kwenziwa njani uma zingenele? |
| Yiziphi izinqubo mgomo (guidelines) ezikhona zokuvimbela ukwesuleleka kwezifo? | Nilutholephi lolu lwazi lwenqubo mgomo (guidelines)? Ngabe lubhalwe phansi noma yinto ekhulunyayo? Yiziphi izinto enizifundisa amavolontiya mayelana nokuvimbela ukwesuleleka kwezifo? | Yimiphi imigomo yangaphandle enomthelela ekwakheni izinqumo zenu zokuvimbela ukwesuleleka kwezifo? |
| Ithini imibono yenu ngawo wonke umsebenzi wokuvimbela ukwesuleleka kwezifo? | Ikakhulukazi ngalokhu okwenziwa ngamavolontiya | |
| Yiziphi izinyathelo enizithathayo ekuqhubezeni umsebenzi wokuvikela ukwesuleleka kwezifo kulesi sikhungo? | | |
| Yiziphi izingqinamba enihlangabezana nazo njengesikhungo uma nizama ukugwema? | Nenzenjani ngalezi zingqinamba? | |
| Yiziphi izinyathelo ezingathathwa ekwenzeni ukuvimbela ukwesuleleka kwezifo kube ngcono? | | |

APPENDIX 3: FOCUS GROUP GUIDE FOR VOLUNTEER CAREGIVERS

| MAIN QUESTION | FOLLOW UP QUESTION | PROBE QUESTIONS |
|---|---|--|
| 1. How many patients do you have? | <ul style="list-style-type: none"> • How often do you visit them? • Who takes care of the patient during the days that you do not go? | <ul style="list-style-type: none"> • These family members how do they have the knowledge on caring for the patients? |
| 2. Could you please name all the things that you use when caring for the patients in order of their importance? | <ul style="list-style-type: none"> • Do you have HBC kits? • What do they contain? | <ul style="list-style-type: none"> • Who supplies them? • How often are they supplied? |
| 3. May you please explain how you care for the patients in the community? | <ul style="list-style-type: none"> • How do you practice hygiene? • What you are supposed to do step by step when you reach your patients premises? | <ul style="list-style-type: none"> • E.g., washing of hands, opening windows, changing linen, washing of bedings, dippers, cleaning sores & rash, cleaning the surrounding at you patient's house? |
| | <ul style="list-style-type: none"> • How do you use personal protective equipment | <ul style="list-style-type: none"> • E.g. using barriers such as gloves, aprons, masks |
| | <ul style="list-style-type: none"> • What were you taught about waste disposal • How do you dispose of the things that you use like the gloves, cotton wool, bandages, dippers, | <ul style="list-style-type: none"> • If you burn, how do you do it? Where? How often do you do so? What happens on the days that you don't go who does it? • If you put in black plastics for garbage collectors to collect. How often are they collected? What happens if they are not collected? |
| | | <ul style="list-style-type: none"> • If you bury, where, and how often do you do this? What happens the days when you don't visit the patients? |
| 4. What challenges do you face regarding infection control practices in the community? | <ul style="list-style-type: none"> • How enough are the materials that you use? • Name those that are not enough? Name those that you feel must be enough? • How do families and patients react when you want to use PPE like gloves and masks? • Are there situations when there is no water in the community for doing your work effectively? | <ul style="list-style-type: none"> • How adequate are the kits to everyone? • What do you use when you don't have? • If you buy where does the money come from? And how adequate is this money? • How do you deal with those that react like that to you? • If so how do you deal with such situations? |

THE ZULU VERSION OF THE FOCUS GROUP GUIDE

| Questions | Follow-up | Probes |
|---|--|---|
| Zingaki iziguli umuntu ngamunye azinakekelayo? Ngabe uwabona kangaki? | Ubani obanakekelayo ngalezi zinsuku eningasebenzi ngazo? | Balithathaphi ulwazi labo abasuke bebanakekela? |
| Engabe nizivikela kanjani ukuba ningasuleleki ngezifo uma nisiza iziguli? | | |
| Ngicela nibale izinto enizisebenzisayo uma ninakekela abagulayo? | Nizithola kangaki lezizinto? | Eg, gloves, masks, linen servers, aprons, salvon, jik, diaper, cotton wool, tong, black plastic bags, bandages) |
| Ngabe nizivikela kanjani ukugwema ukwesuleleka ngezifo? | | Inhlanzeko, |
| | | Izinsiza-kusebenza |
| Ngobe nizisiza kanjani iziguli uma nizinakeke | | Ukulahlwa kwezinto ezingcolile ebenizisebenzisa (gloves, diapers etc.) Nizilahlahphi? |
| | | Udoti uthuthwa kangaki? |
| Nilutole kanjani ulwazi lokuzivikela ezifweni? | Engabe uqeqesho lwathatha isikhathi esingakanani? | Ngabe nifundisweni maqondana nezinsiza kusebenza, |
| | | Inhlanzeko, |
| | | Ukulahlwa kwezinto ezingcolile ebenizisebenzisa (gloves, diapers etc.) |
| Ithini imibono yenu ngawo wonke umsebenzi wokuvimbela ukwesuleleka kwezifo? | | |
| Yiziphi izingqinamba enihlangabezana nazo uma nizama ukugwema ukwesuleleka kwezifo? | Eg, ngabe zanele izinsiza-kusebenza? Yini eningenakho? | Nenzenjani ngalezi zingqinamba? |
| Bathini abagulayo kanye nemindeni uma nisebenzisa izinto zokuvikela ukwesuleleka kwezifo ekunakekeleni? | Nenzenjani ngalokho? | |
| Yiziphi izinyathelo ezingathathwa ekwenzeni ukwesuleleka kwezifo kangcono? | | |