

**EXPERIENCES OF SECONDARY STIGMA AMONG AIDS CARE VOLUNTEERS**

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## **Abstract**

HIV/AIDS is a disease that is still highly stigmatised around the world and it affects the quality of life for people living with HIV/AIDS (PLWHA). By virtue of taking care of PLWHA, volunteer caregivers also bear the burden of HIV/AIDS-related stigma as well as discrimination. Studies show that stigma is one of the heavy challenges that volunteer caregivers experience in their daily work. However, most studies talk about HIV/AIDS stigma towards volunteer caregivers in passing, and not in-depth. Thus the aim of this study is to explore the experiences of secondary stigma on HIV/AIDS volunteer caregivers, its influence and how they deal with it. Six focus group interviews of HIV/AIDS volunteer caregivers were conducted from six different organisations that provide home-based caregiving services to PLWHA in township communities in Durban, South Africa. The findings of this study reveal that the main agents of stigma towards volunteer caregivers are their family members or relatives, community members as well as nurses. Gossips, name-calling and ridicule were the most popular stigmatising behaviours that volunteer caregivers encountered, particularly from their communities. Volunteer caregiving is perceived as work done by people with low social status and low education. Due to stigma associated with HIV/AIDS, volunteer caregivers found it difficult to gain access to potential patients because family members refused their services in fear of being stigmatised by neighbours and other community members. Overall, stigma and discrimination towards volunteer home-based caregivers impedes their daily work and results in a compromised service for PLWHA. These results indicate that there is a great need to teach communities about the role of HIV/AIDS home-based care organisations and volunteer caregivers. In order to foster a good working relationship between caregivers and nurses in clinics, it is also important that nurses be clear about the work and services of home-based care volunteer caregivers. This will then reduce the secondary stigma burden experienced by volunteer caregivers, thus improving the quality of HIV/AIDS home-based caregiving.

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## Contents Page

|  |    |
|--|----|
| CHAPTER ONE.....                                     | 8  |
| 1.1 Introduction and background of the study.....    | 8  |
| 1.2 Rationale of the study.....                      | 10 |
| 1.3 Aim of the study.....                            | 11 |
| 1.4 Research questions.....                          | 11 |
| CHAPTER TWO.....                                     | 13 |
| LITERATURE REVIEW.....                               | 13 |
| 2.1 Introduction.....                                | 13 |
| 2.2 Definition of home-based care.....               | 14 |
| 2.3 Challenges of Volunteer Caregivers.....          | 15 |
| 2.4 Caregivers' Motivations.....                     | 18 |
| 2.5 Conceptualisation of stigma.....                 | 19 |
| 2.6 Stigma towards PLWHA.....                        | 21 |
| 2.7 Stigma towards caregivers of PLWHA.....          | 24 |
| 2.8. A Model of the Dynamics of HIV/AIDS Stigma..... | 31 |
| 2.8.1 Contextual Factors.....                        | 32 |
| 2.8.2 Stigma process.....                            | 32 |
| CHAPTER THREE: METHODOLOGY.....                      | 36 |
| 3.1 Type of design.....                              | 36 |
| 3.2 Study area.....                                  | 36 |
| 3.3 Research participants.....                       | 36 |

|   |    |
|---|----|
| 3.4. Data Collection procedures.....  | 37 |
| 3.4.1 Role of researcher.....   | 38 |
| 3.5 Data analyses.....  | 39 |
| 3.6 Trustworthiness of the study.....                                       | 39 |
| 3.6.1 Credibility.....  | 40 |
| 3.6.2 Dependability.....  | 40 |
| 3.6.3 Transferability.....  | 40 |
| 3.6.4 Confirmability.....   | 41 |
| 3.7 Ethical consideration.....  | 41 |
| CHAPTER FOUR: RESULTS.....  | 42 |
| 4.1 Introduction.....   | 42 |
| 4.2 Demographics characteristics of participants.....                       | 42 |
| 4.3 Table of themes.....  | 43 |
| 4.4 The nature of secondary stigma experienced by volunteer caregivers..... | 43 |
| 4.4.1 Stigma from caregivers’ families .....                                | 43 |
| 4.4.1.1 Family Concern and disapproval .....                                | 43 |
| 4.4.2 Stigma from patients’ families.....                                   | 44 |
| 4.4.2.1 Difficulty in getting access to PLWHA.....                          | 44 |
| 4.4.3 Stigma from the community and nurses.....                             | 44 |
| 4.4.3.1 Ridicule, name-calling and gossip from the community.....           | 44 |
| 4.4.3.2 Name-calling from nurses.....                                       | 45 |

|  |    |
|--|----|
| 4.4.3.3 Caregivers are perceived as being HIV positive.....                | 46 |
| 4.5 Feelings of alienation from government.....                            | 47 |
| 4.6 The effects of stigma on volunteer caregivers.....                     | 47 |
| 4.6.1 Attrition of caregivers.....   | 47 |
| 4.6.2 Decrease of morale.....  | 47 |
| 4.6.3 Discrimination from nurses impedes volunteer caregivers' work.....   | 48 |
| 4.6.4 Emotional burden.....  | 49 |
| 4.7 Volunteer caregivers' ways of dealing with stigma.....                 | 49 |
| 4.7.1 Counselling.....   | 49 |
| 4.7.2 The use of name-badges.....  | 50 |
| 4.7.3 Persistence and perseverance.....                                    | 51 |
| 4.7.4 Testimonies of patients helped reduce stigma towards caregivers..... | 51 |
| CHAPTER FIVE: DISCUSSION OF RESULTS.....                                   | 53 |
| 5.1 Introduction.....  | 53 |
| 5.2 Environment.....   | 53 |
| 5.3 Healthcare system.....   | 55 |
| 5.4 Agents.....  | 57 |
| CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS.....                           | 61 |
| 6.1 Conclusion.....  | 61 |
| 6.2 Recommendations.....   | 62 |

## **Declaration**

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

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## **Chapter One: Introduction**

### **1.1 Introduction and Background of Study**

Despite a decline in the number of new HIV infections, HIV/AIDS still remains a serious challenge within healthcare sectors around the world. Globally, about 34 million people are said to be living with HIV/AIDS (UNAIDS, 2012a). Sub-Saharan Africa remains the most hard-hit, as it accounts for 69% of people living with HIV/AIDS (PLWHA) worldwide. Though sub-Saharan Africa has achieved a 25% reduction in new infections from 2001 to 2011, it still accounts for 72% of all new infections worldwide (UNAIDS, 2012a).

Between 2001 and 2011, South Africa managed to reduce new infections by 41%. Yet, about 5.26 million people are living with HIV/AIDS. By 2013, the HIV prevalence in South Africa is said to be at 10% (Statistics South Africa, 2013). Approximately 17% of women in their reproductive age are HIV positive and 15.9% of adults between 15-49 years are living with HIV/AIDS in South Africa. The increased number of PLWHA means that the limited resources of the healthcare system are becoming overstretched. It is estimated that in Southern Africa, between 50-60% of patients occupying public hospital beds have HIV-related illnesses (UNAIDS, 2012b). In order to bear with the challenge of an increasingly overburdened healthcare system due to the HIV epidemic, South Africa, as well as other countries in sub-Saharan Africa have opted to promote home-based care (HBC) programmes for PLWHA. “Home-based care is the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person’s maximum level of comfort, function and health including care towards a dignified death” (South African Department of Health, 2001).

In Tanzanian public hospitals, 50-60% of adult patients were admitted for HIV-related causes. This has resulted in the overburden of the healthcare system and a compromised quality of care for patients. Hence the Tanzanian government is strengthening home-based care programmes to assist in improving the capacity of the healthcare system (Tanzanian Ministry of Health and Social Welfare, 2010). Similarly to South Africa, the Tanzanian HBC programme draws its strength from communities and families, where home-based care organisations are initiated by communities. Also, Uganda created a Home-Based Care National Policy Guidelines for



HIV/AIDS in order to support the overwhelmed healthcare system of the country and increase access to care for PLWHA in poor regions of the country (Ugandan Ministry of Health, 2010). Uganda has two models of HBC; the Facility Based Care Outreach and the Community Based Home Care Model. The first one is a model initiated by health facility staff that support, coordinate and supervise community level workers to offer HIV/AIDS care within homes. This first model is more advantageous for home-based caregivers because they get support from health workers like nurses and doctors. The second one is model initiated by community-based organisation, non-government organisation as well as faith based organisations who offer HIV/AIDS home-based services within their communities on a volunteer basis. These organisations then work with local health facilities on patient referrals and also receive patients referred to them by health facilities. Home-based care programmes thus seem to be the most effective response by countries whose health sectors are overstretched by HIV/AIDS (Ugandan Ministry of Health, 2010).

In South Africa, home-based care programmes are organised and initiated by non-government organisations (NGOs), community based organisations (CBOs) and faith-based organisations (FBOs). Volunteer caregivers of PLWHA are the backbone of HBC. Volunteer caregivers are recruited from the communities that they serve or work in and they receive training from home-based care organisations (HBCOs) together with the Department of Health (Akintola, 2006; Akintola, 2008b). Volunteer caregivers offer healthcare services, psychosocial support and palliative care as they do home-visits caring for PLWHA. Their work includes bathing patients, cooking and cleaning, cleaning sores, counselling, accompanying patients to the clinic, helping with treatment adherence and also giving spiritual support (Akintola, 2006; Akintola, 2008a; Hangulu, 2012; Uys, 2003). Though there are significant benefits and contributions of home-based caregiving, studies show that caregiving comes with a lot of psychosocial burden (Akintola, 2004; Lindsey, Hirshfield, Tlou & Ncube 2003; Orner 2006; Uys, 2003).

Some of the challenges that volunteer caregivers face is working in poverty stricken communities, shortage of care resources, lack of support from the community and families, work overload, as well as discrimination and HIV/AIDS-related stigma (Akintola, 2006; Lindsey, Hirshfield, Tlou & Ncube 2003; Orner 2006; Uys, 2003). HIV/AIDS is generally a highly stigmatised disease in the world (Haber, Roby & High-George, 2011). By virtue of taking care of

PLWHA, HIV/AIDS home-based volunteer caregivers also experience stigmatisation and discrimination (Haber, Roby & High-George, 2011). This is called secondary stigma or stigma by association. This is one of the distressing factors which kills HIV/AIDS volunteer caregivers' morale and impedes their daily work of caregiving (Akintola, 2008a; Kipp, Nkosi, Laing & Jhangri, 2006; Uys, 2003).

Eliminating stigma and discrimination of PLWHA and those affected by it is one of the 15 goals of the 2011 United Nations Political Declaration on HIV and AIDS (UNAIDS, 2012b). PLWHA still encounter stigma and discrimination from the communities they live in. The People Living with HIV Stigma Index indicates that 52% of the participants in Zambia reported to being verbally abused because of their HIV status, and in Nigeria and Ethiopia 1 in 5 people living with HIV reported having suicidal feelings. PLWHA also face a challenge of being discriminated within the healthcare system. About 21% of people living with HIV in Nigeria reported being denied access to healthcare services as a result of their HIV status. Seventy-five percent of participants living with HIV in Zambia reported to being gossiped about and 34% said they were excluded from family events (UNAIDS, 2012b). This results in compromised health and wellbeing and a poor quality of life for PLWHA (Dos Santos, Kruger, Mellors, Wolvaardt, der Ryst, 2014; Holzemer et al., 2007; Neuman & Obermeyer, 2013; Thomas, 2006).

## **1.2 Rationale of the Study**

Informal caregivers are normally friends or family members of those who are ill. Many studies reveal that informal caregivers do experience stigma because of their work with PLWHA. Most of these studies touch on secondary stigma in passing, or as one of the distressing impacts of the burden of care (Akintola, 2006; Orner 2006; Singh, Chaudoir, Escobar & Kalichman, 2011). A study by Ogunmefun, Gilbert and Schartz (2010) on informal caregivers in South Africa shows that they experienced isolation from relatives and others were jeered and gossiped about in their communities. However, very few studies have focused specifically on the experiences of HIV/AIDS stigma and general discrimination as a challenge among formal or volunteer caregivers. Studies show that informal and family caregivers are sometimes stigmatised and discriminated by their neighbours, relatives, nurses and the community, but fewer studies have explored the dynamics of stigma on volunteer or formal caregivers (Aga, Kylma & Nikkonen 2009). Furthermore, little is known about how secondary stigma and discrimination affects

HIV/AIDS home-based volunteer caregivers and how they respond to these experiences. This study therefore seeks to explore the experiences of volunteer caregivers with regards to the stigma they encounter due to caring for PLWHA as well as the effects this has on them. The study intends also to understand how caregivers deal with or emerge from secondary stigma and its effects. Also, the study further explores the discrimination that volunteer caregivers encounter, which may not necessarily be HIV/AIDS-related. This discrimination may be the unjust treatment, act and prejudice towards home-based caregivers just because of the volunteering work that they do. The findings of this study could help to better understand the processes of stigma towards volunteer caregivers so that there can be appropriate designs of interventions to combat HIV/AIDS-related stigma. Also, the study may reveal the appropriate and effective ways of volunteer caregivers in coping and fighting secondary stigma. All of this would then help to significantly reduce the burden of care on volunteer caregivers, thus improving home-based care service.

### **1.3 Aim of study**

The aim of the study is to explore the experiences of HIV/AIDS volunteer caregivers in relation to the secondary stigma they encounter due to caring for PLWHA, as well as the discrimination that comes with being a volunteer home-based caregiver. This study could help in better understanding how stigma affects volunteer caregivers, and what interventions can be used by HBCO and the government to combat secondary stigma as well as HIV/AIDS-related stigma. This will in turn improve the quality and efficiency of HBC services for PLWHA.

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

- To understand the experiences of secondary stigma and discrimination among volunteer caregivers.
- To explore the ways in which secondary stigma affects volunteer caregivers.
- To understand how volunteer caregivers deal with secondary stigma.

### **1.5 Research Questions**

- What are the experiences of secondary stigma and discrimination among volunteer caregivers?

- In what ways does secondary stigma affect volunteer caregivers?
- In what ways do volunteer caregivers deal with secondary stigma?

## Chapter Two: Literature Review

### 2.1 Introduction

This chapter reviews the experiences of HIV/AIDS home-based caregivers. It highlights the burden of HIV/AIDS epidemic, which has led to an important shift from hospitalised care to home-based care. It also looks at the nature of caregiving, the achievements as well as the challenges faced by caregivers in their everyday work. One of the main foci of these challenges is that of HIV/AIDS-related stigma and discrimination, the implications on caregiving work and how volunteer caregivers experience these challenges.

HIV/AIDS is one of the most serious diseases which pose a challenge to health care sectors worldwide. It is estimated that about 34 million people are living with HIV globally (UNAIDS, 2012a). Sub-Saharan Africa remains highly affected, as it accounts for 69% of PLWHA (UNAIDS, 2012a). South Africa is a country with the highest number of PLWHA in Sub-Saharan Africa. In South Africa, about 5.6 million people are now living with HIV (UNAIDS, 2012a). Although the number of new HIV infections have declined (UNAIDS, 2012a), HIV/AIDS is still a heavy burden in the health care system in South Africa and the globe.

Due to the increasing number of PLWHA, hospitals have become overburdened and they lack the capacity to bear with the demands to care for patients (Akintola, 2011; Shisana & Simbayi, 2007). In Southern Africa, it is estimated that about 50% of public hospital beds are occupied by PLWHA, who stay four times longer than other patients (Shisana et al., 2009). It is estimated that the cost of caring for an inpatient in a hospital is about R650 (Fox, Fawcett, Kelly & Ntlabati, 2002). A study done over a decade ago revealed that two hospitals in Pietermaritzburg and other rural hospitals in the area of KwaZulu-Natal (KZN) were found to have medical beds running at 120% over capacity because of AIDS (Bateman, 2001). KZN is estimated to have 25.8% of HIV prevalence between people of ages 15-49, which is the highest number out of all provinces in South Africa (Shisana et al., 2009). It is for this reason that the Department of Health seeks to minimise patients' stay in hospitals in order to reduce costs and make more space for the availability of beds.

Thus the government promotes home-based care (HBC) as a model that responds to supporting the public health care system. The aim of promoting the home-based care model in South Africa

is to relieve the overburdened public hospitals due to the increased number of patients infected with HIV/AIDS. This will result in the decreased number of patients occupying hospital beds, thus reducing the cost of care for the public health (Akintola, 2008b). Other countries in the sub-Saharan Africa (Botswana, Lesotho, Malawi, Mozambique, Swaziland, Zambia and Zimbabwe) are also developing and promoting home-based care programmes for PLWHA to ease the load on their limited healthcare resources (South African Department of Health, 2001; Tanzanian Ministry of Health and Social Welfare, 2010; Ugandan Ministry of Health, 2010). As a result there has been an increased number of families and communities taking responsibility to care for PLWHA in their homes as an effort to face the challenge of the HIV/AIDS epidemic (Akintola, 2008b; Ncama, 2005; Orner, 2006).

## **2.2 Definition of Home-Based Care**

HBC is defined as a form of care for sick people in their own homes by either their formal or informal caregivers in order to promote and maximize a person's comfort and health, even towards a dignified death (WHO, 2002; Uys, 2003). This mostly includes physical, psychosocial, palliative and spiritual support (WHO, 2002). Formal HBC is implemented through an organisation or a formal structure that renders service of caregiving to sick people in their homes. Informal caregiving refers to primary caregivers who are likely to be family members or friends of the ill person (Ncama, 2005). Non-government organisations (NGOs), community-based organisations, faith-based organization and families are the main initiators of home-based care programmes for PLWHA (South African Department of Health, 2001). These home-based care organisations (HBCO) employ volunteer caregivers who visit patients to offer them health and palliative care in their homes. HBCO are mainly supported by the department of health in the training of volunteer caregivers and in providing a certain number of them with stipends (Ncama, 2005). HBCOs work closely with clinics in the communities where they render their services. Some HBCOs also receive funding from international and private donors (Ncama, 2005).

The primary caregivers of PLWHA in homes are their family members (Akintola, 2004; Opiyo, Yamano & Jayne, 2008; Orner, 2006). These are referred to as family caregivers. People who volunteer or are recruited by home-based care organisations (HBCOs) are referred to as volunteer caregivers or formal caregivers (Akintola, 2006). Volunteer caregivers form an integral part of HBCOs. Home-based care organisations (HBCOs) partner with the Department of Health

and other stakeholders in providing training and support for volunteer caregivers. The training that volunteer caregivers receive includes supportive counselling, pain management, cleaning and dressing of wounds, supervision of medication adherence, oral hygiene and diagnosis of opportunistic infections (Fox, Fawcett, Kelly, & Ntlabati, 2002; Hangulu 2012). The training also includes DOTS (directly observed treatment, short course) for treatment (Akintola, 2010; Mabude, Beksinska, Ramkissoo, Wood, & Folsom, 2007; Ncama, 2005). Though few caregivers receive a stipend from the government, the majority of volunteer caregivers are unpaid (Akintola, 2006).

The primary service that volunteer caregivers offer is basic nursing care through home visits. This includes bathing, feeding, dressing, toileting, and cleaning wounds of bedridden patients (Akintola, 2008a; Akintola, 2011; Kipp, Nkosi, Laing & Jhangri, 2006; Orner, 2006). At times they clean the patients' rooms, cook, wash their clothes and accompany them to the clinic (Campbell, Nair, Maimane & Sibiyi, 2008). Volunteer caregivers counsel patients and ensure that they adhere to their medication (Schneider, Hlophe & Rensburg, 2008; Uys, 2003). Caregivers also encourage sick people to visit clinics so that they can seek help and test for HIV/AIDS. They also help to fetch medication in clinics for patients who are too ill to visit clinics.

### **2.3 Challenges of Volunteer Caregivers**

Studies have shown that caregiving comes with a lot of emotional, psychological, physical and financial burden (Abasiubong, Bassy, Ogunsemi, Udobang, 2011; Akintola, 2008a; Akintola, 2008b; UNAIDS, 2012b). A study by Orner (2006) revealed that poverty, lack of infrastructure, lack of family and community support, as well as stigma were one of the main challenges that made caregiving work emotionally distressing for volunteer caregivers. Volunteer caregivers normally work in low-income townships and rural areas where poverty is rife. Though this is not part of their job description, a lot of studies reveal that caregivers find themselves having to provide their own food to patients who live in poverty (Akintola, 2008a; Orner, 2006; Rodlach, 2009; Uys, 2003).

In a study exploring the challenges of volunteer caregivers working in semi-rural communities in Durban in South Africa, volunteer caregivers felt obliged to assist patients who were unable to

feed themselves or pay school fees for their children (Akintola, 2008a). Rodlach (2009) reported in his study on AIDS volunteer caregivers' concerns in Zimbabwe that caregivers found it difficult to deal with patients living in poverty who were unable to take their medication because they had no food. They felt hopeless that apart from caregiving work, they could not provide any material support for the patients.

In other instances, volunteer caregivers reported that because of poverty and unemployment, some patients expected to be given food by caregivers. They showed disinterest when volunteers came without food (Dageid, Sedumedi & Duckeit, 2006). Due to poor and crowded living conditions that patients live under, volunteer caregivers face a high risk of being infected by HIV and TB (Hangulu, 2012). A study by Akintola and Hangulu (2014) done in the semi-rural area of Durban found that a lot of households with PLWHA were overcrowded, with about 6 people living and sleeping in one room. This created difficulty in volunteer caregivers' work and also increased their chances of infection with HIV and TB, since Durban is in a province with the highest HIV/TB prevalence in South Africa.

Hangulu's (2012) study on infection control practices in home-based care found that volunteer caregivers complained about the insufficient supply of material used to care for PLWHA. They ran out of important materials like gloves, aprons, soap, bleach, napkins and linen savers. Other caregivers had to use plastics instead of gloves to protect themselves from possible infection. Volunteer caregivers would sometimes get materials like gloves from their private sources or friends who work in clinics. The study also discovered that volunteers complained that personal protective factors such as gloves, aprons and masks were of a poor quality. A study done in Botswana by Kang'ethe (2010) reported that due to a shortage of caring material, volunteer caregivers were sometimes forced to use their own money to buy gloves and napkins.

Another challenge that volunteer caregivers face is the lack of support from families of patients as well as their stigmatising attitudes towards their sick members. Families of patients did not cooperate with volunteer caregivers. Volunteer caregivers reported that the families of patients would leave their sick members unattended. They found them to be in the same condition they left them. Some families left the whole burden of care to volunteer caregivers altogether and were not willing to assist where needed (Hangulu, 2012; Rodlach, 2009).



A study on the experiences of HIV/AIDS informal caregivers in Tanzania discovered that the physical burden of caring lead to stress, loss of appetite and exhaustion for caregivers (Pallangyo & Mayers, 2009). In a study on the burden of care on HIV/AIDS volunteer caregivers and family caregivers in the semi-rural area of Durban, participants reported headaches, backaches, body aches and physical exhaustion as a result of caregiving activities (Akintola, 2006). Walking long distances in hot weather conditions to get to patients' homes and having a large number of community members to serve led to work overload and burnouts for volunteer caregivers (Akintola, 2006). The study also reported about the signs and symptoms of emotional distress that caregivers experienced. These were anxiety, nightmares, insomnia, fear, and despair. The work of caring for patients, cleaning their sores, bathing and turning them on their beds resulted in caregivers feeling emotionally distressed. The study further showed that many caregivers felt worried and guilty about their patients' conditions. Some saw the work they did as not good enough when patients continued to be ill or died.

A study by Dageid, Sedumedi & Duckeit (2006) reports that volunteer caregivers felt unprepared to deal with the deteriorating health and death of their patients. They reported that they would sometimes cry after seeing the symptoms of their patients. Other caregivers reported feelings of guilt, self-blame and helplessness when patients do not recover. Another study assessing the psychological wellbeing of HIV/AIDS family caregivers in Nigeria reported that 45% of participants had anxiety, 7.5% were depressed and 17% had both anxiety and depression (Abasiubong, Bassy, Ogunsemi, & Udobang, 2010). The study mainly attributes the increased stress for caregivers as resulting from work overload, stigmatisation and a lack of support.

A study of informal caregivers in Congo found that 90% of participants reported that they experienced stigma and ostracism by relatives, neighbours and friends (Kipp, Nkosi, Laing & Jhangri, 2006). The different forms of discrimination which are not necessarily HIV/AIDS-related are also a challenge to volunteer caregivers and the HIV/AIDS caregiving work. Due to HIV/AIDS being a highly stigmatised disease, volunteer caregivers faced difficulty accessing patients in their homes. Some family members would hide their ill members and deny that there is someone ill in their homes. At times they will not welcome caregivers or even chase them away (Akintola, 2008a). The burden of stigma towards volunteer caregivers will be discussed in detail later on.

## 2.4 Caregivers' Motivation

Most volunteer caregivers have shown great tenacity and persistence in their work, even against all the challenges they face in their daily work. There are various reasons that help volunteers to find meaning in their caring work and be motivated to continue doing it. Rodlach's (2009) study on the motivations and concerns of Zimbabwean volunteer caregivers found that most caregivers volunteered because of religious obligations or duty to take care of those who are ill and in need. Religion also served as a pillar and strength in difficulties during their caregiving work. A study by Akintola (2011) on what motivates volunteer caregivers discovered that most caregivers were heeding to their Christian beliefs to take care of the ill. These caregivers also prayed and gave spiritual support to patients and their families. Another factor that motivated volunteer caregivers was that of altruism and love for the community. Both studies by Akintola and Rodlach attest to this. A study done in Marianhill in South Africa on volunteer caregivers' motivations found that caregivers referred to this as *Ubuntu*, which is a sense of community and togetherness. They felt that those who were sick were their 'brothers' and 'sisters', and it was their duty to be of help to them (Mahilall, 2009). This is also affirmed by a study done on the resilience of home-based caregivers in Limpopo in South Africa where caregivers believed it was their responsibility to care of those who live in their community (Mieh, Airhihenbuwa & Iwelunmor, 2013).

Some caregivers volunteered because they had had an experience of how it is to care for someone who is HIV positive in their homes. This resulted in empathy towards PLWHA (Akintola, 2010; Rodlach, 2009). The study by Rodlach revealed that being HIV positive was another factor that motivated some caregivers to become AIDS care volunteers. These caregivers had the hope that they will one day receive the kindness and empathy they have extended to those who are ill when they also happen to be sick. Another common motive of volunteering was that of reciprocity, where caregivers believed that their caring work will attract good things or blessings in their lives (Akintola, 2010; Mahilall, 2009; Rodlach, 2009).

Since volunteer caregivers in Rodlach's (2009) study came from very low-income communities (which is common with other caregivers), the stipend they got did make some difference in their lives. This encouraged them to continue volunteering. Akintola (2010) discovered that career-motive was quite a strong factor for volunteers. However, caregivers felt shy to raise this issue as

they did not want to appear selfish. Volunteer carers saw their AIDS care work as an opportunity to get formal employment in the HBCOs they work for. Some believed that one day the government will recognise their work and it will eventually be a paying job. Caregivers also saw volunteering as positioning themselves for employment outside of the organisations they work in. As a result, some caregivers were disappointed that they still had not received any opportunity of employment. Mahilall (2009) reports that even though volunteer caregivers did not put it overtly; they did have hopes to be formally employed by the organisations they work for.

## **2.5 Conceptualisation of Stigma**

For most theorists who work on stigma, sociologist Goffman (1963) is seen as the pioneer in defining and conceptualising stigma. Goffman explains stigma as an attribute that deeply discredits a person's worth or social value. Goffman states that stigmatisation occurs when a culture in a particular context deems a certain character as undesirable and devalued. The label alters the way a person view themselves and how others view him/her as a person. This results in a person's social identity being tainted and reduced to less than 'others'. Stigma has a strong socially discrediting factor (Alonzo & Keynolds, 1995). Most importantly, stigma is relational and context-specific; it plays itself out in the social context (Major & O'Brien, 2005). Linking to Goffman's original definition of stigma, Holzemer et al., (2006) define stigma as having these components; low value, exclusion and disadvantage.

In conceptualising stigma, Link and Phelan (2001) argue that stigma exists when four interrelated components intersect. The first component is difference. This occurs when people label or overemphasize human difference. The second component is negative stereotypes. These are dominant cultural beliefs that link the labelled persons to undesirable attributes or characteristics. The third component is that of placing a distinct separation of "us" and "them". In the fourth, the person or group experience status loss and discrimination. Lastly, stigmatisation impedes access to social, economic, and political power. Thus when elements of labelling, stereotyping, separation, and status loss occur in a power situation, Link and Phelan apply the term stigma. This understanding of stigma is in accordance with that of Parker and Aggleton (2003), who see stigma as feeding on, strengthening and perpetuating existing power inequalities in class, gender, race, age or ethnicity. They emphasize more on stigma as a social

process that produces and reproduces power and control. Overall, the common thread that runs through many of the frameworks are those of labelling which results in those who are stigmatised to be perceived as having less social value.

The ancient Greek term for the word stigma refers to a mark or label that was tattooed on a person who was considered to be outside of what is regarded as normal and acceptable by society (Holzemer & Uys, 2004). People who are stigmatised are negatively valued, disadvantaged and discredited. Stigma is a discriminatory attitude or behaviour based on certain groups or individuals that are seen as of less social status (Hereck, 2002). The society holds a general view that the group is of less value than the rest of the people. It undermines the value of the person to be lesser than that of other groups within the community. HIV/AIDS-related stigma refers to hatred, prejudice and discrimination on PLWHA or those associated with them. This can manifest itself in violence, aggression, and lack of access to services by PLWHA (Florom-Smith & Santis, 2012). There are three kinds of stigma that a person may experience. These are received stigma, internal stigma and stigma by association.

The early definition of stigma that has a notion of both the physical deficit and poor social identity is still relevant to HIV/AIDS today (Holzemer & Uys, 2004). PLWHA are often blamed and are never seen as victims, but rather as people who contributed to their illness (Holzemer & Uys, 2004). The association of HIV/AIDS with promiscuity and immorality results in the disease being highly stigmatised. Thus PLWHA are seen as not deserving of care and sympathy. They are viewed as 'having brought this to themselves' (Campbell et al., 2011). The physical symptoms that people may acquire are also likely to bring stigma and discrimination. This is seen by derogatory words used to define and describe PLWHA. Uys et al., (2005) have documented the words and expressions used to secretly refer to those living with HIV/AIDS. Also, because HIV/AIDS is life-threatening and infectious, the fear of being contaminated by PLWHA leads to stigma and discrimination (Holzemer & Uys, 2004).

This negative view of the public distorts how PLWHA see themselves, which leads to what is called internal stigma (Parker & Aggleton, 2003). This results in a sense of despair, hopelessness and complacency with one's situation. Internal stigma, also called felt stigma, is a feeling of shame and fear of encountering discrimination by the person who has an attribute that is labelled as socially negative (Duffy, 2005). PLWHA may internalise the belief that they are less of value

by accepting and expecting to be treated discriminately. This is also referred to as self-stigmatisation. The person is likely to be socially-withdrawn and have self-exclusion from services and opportunities useful to him or her, leading to a poor health and wellbeing (Florom-Smith & Santis, 2012).

## **2.6 Stigma towards PLWHA**

In December 1998, South Africa witnessed the most tragic impact of HIV/AIDS-related stigma when Gugu Dlamini, an HIV/AIDS activist, was killed after having disclosed her status (Baleta, 1999). Dlamini, who lived in KwaMashu Township in Durban, was reportedly attacked by a mob carrying sticks and stones, accusing her of being a disgrace to their neighbourhood by revealing her HIV status. Although South Africa went through this shameful history, a comparison in the findings of the 2002 HIV and AIDS Household Survey and the 2005 indicates that HIV/AIDS-related stigma is decreasing in the country. The 2002 survey indicated that 94.5% of the participants would not talk to someone who was HIV positive, while 80.8% would not sleep in the same room as someone who is HIV positive. In comparison with the 2005 survey, it revealed that 46.5% of the participants indicated hesitance to marry someone who is HIV positive, while 46.8% said they would not have protected sex with a partner who had HIV/AIDS (Shisana et. al., 2009; Shisana & Simbayi, 2007). There has also been an increase in the number of people who go for Voluntary Counselling and Testing (VCT). The 2008 survey indicates that half of the participants had an HIV test, compared to 27.6% in 2005 (Shisana et. al., 2009). A study done by Dageid, Akintola & Saeberg (2015) on the motivations of HIV/AIDS volunteer caregivers in KwaZulu-Natal revealed that even though they encountered HIV/AIDS-related stigma, generally, they were well received by the community. However, there is still a significant number of PLWHA who experience stigma in their communities, families and healthcare facilities.

In Lesotho, there seems to be a decline in HIV/AIDS stigma and discrimination. During a 2006 survey, 55% of participants responded that they would care for a person living with HIV/AIDS. In 2009, more than 80% of participants reported that they would be willing to take care of a PLWHA (UNAIDS, 2012b). The *Oral Testimony Works* is a project by the International Planned Parenthood Federation (IPPF) that helps PLWHA to record and communicate their personal accounts of experiences with HIV/AIDS. Speaking about HIV stigma, one participant from

Ethiopia reported that “the worst time has passed.” He describes that the discriminatory attitudes that the community held previously is changing. Another 29 year old participant from Swaziland mentioned that discrimination has decreased compared to years 2005 and 2006. She attributes this to an increase in knowledge and information about HIV/AIDS in her country (IPPF, 2014). An old South African study done by Akintola (2004) revealed that people were generally hopeless about HIV/AIDS, such that when volunteer caregivers came to do home visits, some of the families of patients would say “have you come to check if she/he is still alive.”

A survey on the perceptions of stigma in South Africa indicated 81.9% responded positively to the question “If you knew that a food seller is HIV, would you buy from them.” Over 90% of participants said they were willing to care for a family member with AIDS. Only 16% responded yes to the question “Is it a waste of time or money to train or promote someone who is HIV positive?” This is an indication that there is a decline in the levels of HIV/AIDS-related stigma and some progress is being made (Shisana et al., 2014).

A survey by Dos Santos, Kruger, Mellors, Wolvaardts & Ryst (2014) measuring stigma and discrimination experienced by PLWHA in South Africa showed that they encountered gossips, verbal insults, physical assaults, discrimination against their partner or family member, and sexual rejection. The survey showed that 16.1 % of the participants reported to have been physically assaulted due to being HIV positive. Of the 16.1%, it was indicated that 57.7% were assaulted by either a husband, wife or partner. The study further revealed that participants suffered from internalised stigma. Participants experienced feelings of self-blame (49.2%), shame (47.5%), guilt (40.9%), low self-esteem (31.9%), and suicidal ideation (10.08%). These feelings compromise the health and well-being of PLWHA. Also, 14.4% of the participants reported that whenever possible, they avoided going to the clinic while 16.9% isolated themselves from friends, family and social gatherings.

A study done in five African countries (Lesotho, Malawi, Swaziland, South Africa and Tanzania) by Uys et al., (2005) documented a series of derogatory words used to refer to PLWHA. These words carried negative labels and beliefs about HIV/AIDS. Of the 290 words evoked, 49 fell under the death-related category. Some themes that emerged from these words were those of promiscuity, blaming the infected, and the physical symptoms of HIV/AIDS. This study shows that PLWHA are commonly viewed as hopeless by the community.

Stigma and discrimination are major barriers to effective care and services for PLWHA. A study which was done in Ethiopia to assess stigma towards PLWHA by health care providers found that health workers would unnecessarily refer them to other facilities or refuse to treat them. The fear of work-related HIV transmission had the highest score of 52.3% among health care providers (Feyissa, Abebe, Girma, & Woldie, 2012). The study also found that health care providers who received training on HIV/AIDS stigma and discrimination scored lower on stigma scales. This highlights the important role of training to reduce HIV/AIDS-related stigma within the healthcare system.

A Zimbabwean ethnographic study by Duffy (2005) on HIV/AIDS stigma revealed that PLWHA preferred to suffer in silence and were not able to disclose their status in fear of being stigmatised, thus reducing their chances of receiving care and support. Participants spoke about how strongly HIV/AIDS is associated with promiscuity and the blame they receive for being infected. Commonly reported stigma acts that participants received were those of isolation and avoidance of contact (people avoided the normal handshake greeting when they met them). A Nigerian qualitative study on home-based care and PLWHA indicated that HIV positive participants reported to being discriminated in areas like salons where they were refused services and some lost business since people were no longer buying from them because of their status (Agbonyito, 2009). Some participants reported discriminatory words used by community leaders who say PLWHA should not be given ARVs but should instead be injected with poison and die. However, some participants reported that they did receive acceptance and support from family members after disclosure of their status.

An ethnographic study done in an informal settlement in Cape Town in South Africa on HIV/AIDS-related stigma reveals how fear of being stigmatised can affect a person living with HIV/AIDS (Mills, 2006). A woman who had an HIV positive daughter who received services of caregiving and food parcels from *Vuyolwethu* (an NGO) refused further assistance and home visits from volunteer caregivers. She feared that the neighbours would discover her daughter's HIV status. Also, her daughter stopped visiting the nearest clinic due to the possibility of nurses knowing about her status since they lived in the same community. This shows how stigma can affect PLWHA and their family members, as well as their access to healthcare facilities. Carers from *Vuyolwethu* had to wear their casual clothes and do home visits as 'friends' in order to keep

their caregiving work a secret and conceal their patients' HIV status, thus protecting them from possible HIV-related stigma. Many of the clients receiving care had to get out of their way and use other health facilities outside their area because they did not trust that nurses from the local community will keep their status confidential. They also hid their HIV/AIDS medication and avoided taking their medication where they can inadvertently disclose their status.

Knowledge of HIV/AIDS appears to be a good weapon in reducing HIV/AIDS related stigma. A study comparing negative attitudes and perceived acts of discrimination towards PLWHA in four countries (Tanzania, Thailand, South Africa, and Zimbabwe) showed that a lack of knowledge about ARVs was associated with high negative attitudes (Genberg et. al., 2009). The study showed that participants who never talked about HIV scored high in the negative attitudes towards PLWHA. Never having tested for HIV was also associated with negative attitudes towards PLWHA. This study concurs with that of Nyabblade et al., 2003 which showed that a lack of in-depth knowledge about HIV/AIDS is a cause for stigmatising attitudes. Stigmatisation is not only limited to PLWHA. Due to being associated with those who are infected, family members, friends and caregivers of PLWHA, may also suffer from stigma and discrimination. This is known as secondary stigma or stigma by association.

## **2.7 Stigma Towards Caregivers of PLWHA**

HIV/AIDS-related stigma is a hindrance to HIV/AIDS health promotion and prevention (Duffy, 2005). It is related to delays in testing and help-seeking behaviours (Ware, Wyatt, & Tugenberg, 2006). Due to the fear of being stigmatised, patients may have a low motivation to visit clinics or adhere to treatment. Some of the people who are ill would choose to risk death rather than going to test and taking treatment (Duffy, 2005). Ongoing treatment is viewed as exposing them to more stigma and discrimination (Ogunmefan, Gilbert & Schatz, 2010). Apart from the emotional burden, physical exhaustion, and financial constraints of caregiving, secondary stigma is also a major challenge for caregivers, and it impedes the smooth provision of care for PLWHA. In a study exploring the psychosocial impacts of caregiving in Khayelitsha in the Western Cape, Orner (2006) points out that stigma towards caregivers was a common response among respondents who were family caregivers of PLWHA.



Like family caregivers, volunteer caregivers also experience stigmatisation. A study on the psychological well-being of volunteer caregivers in Nigeria indicated that one of the discouraging factors was the associate stigma they received simply by caring for PLWHA (Abasiubong, Bassey, Ogunsemu & Udobang, 2011). In a quantitative study of HIV/AIDS home-based caregivers by Singh et al., (2011) in KwaZulu-Natal, the negative effects of stigma and the harsh burden of care resulted in caregivers feeling discouraged to assist PLWHA in the future. This study reported that home-based care workers received very little or no support from family even though they had support from nurses and community health care workers (CHCW). Perceived support from nurses and CHCW was found to be a strong factor in increasing the willingness of caregivers caring for PLWHA in the future, despite the little family support. This emphasizes the importance of professional support for volunteer caregivers.

In a study by Haber, Robyn and High-George (2011) which used both focus groups and scaled quantitative questionnaires with open ended questions on the side, it was discovered that stigmatisation towards HIV/AIDS health workers (doctors, nurses, counsellors, home-based caregivers, community health care workers) lead them to contemplate leaving South Africa to work abroad. Other reasons for contemplating leaving were poor management, work overload, emotional distress and a lack of appreciation for the work they do. Doctors and nurses had the highest frequency of contemplating leaving South Africa. The study reveals also that counsellors and HIV/AIDS caregivers' perception of associate stigma was higher compared to nurses and doctors. This may be due to the different context or people they encounter in the kind of HIV/AIDS work they do.

In this study, 27% of AIDS health workers reported that they kept their AIDS work a secret because they did not want to be stigmatised (Haber, Robyn and High-George, 2011). The 73% of participants said they disclose their AIDS work because they want to end the stigma associated with the disease and give hope to PLWHA. They believed this would encourage more people to seek help. In a scale of very negative, negative, neutral, positive, and very positive, when AIDS health care workers were asked about people's response to their job, 39% choose very negative. They further explained that the kind of stigmatisation they encounter is being labelled as HIV positive, avoidance or professional disrespect. They report to being despised due to being HIV/AIDS health workers. Seventy four percent of participants responded that people do assume

that they are HIV positive because they work with PLWHA. Another study by Dageid, Akintola & Saeberg (2015) showed that some community members believed that volunteer caregivers were also HIV positive since they care for PLWHA.

Stigma is associated with burnout, poor physical health and depressive mood. In a study exploring the challenges of volunteer caregivers in South Africa, Akintola (2008a) found that stigma was one of the prominent barriers faced by volunteer caregivers. Families of the ill hid their members from the caregivers who approach households to offer help and care. They denied caregivers access into their homes in fear of being stigmatised by the community because of the presence of volunteer caregivers. Other families would insult volunteer caregivers and downplay their work and assistance. The study further reports that volunteer caregivers were distressed by witnessing the discrimination and ill-treatment of patients by their family members. To combat discrimination of patients by family members, volunteer caregivers coped by giving education on HIV/AIDS and the importance of home-based care. The task of keeping their patients' status secret to family members was also stressful for volunteer caregivers.

This study by Akintola (2008a) concurs with other various studies which reveal that volunteer caregivers work under highly stigmatising conditions, which makes caregiving work more strenuous and emotionally distressing on caregivers, thus hindering the effectiveness of HIV/AIDS HBC services (Lindsey et al., 2003; Orner 2006). A Zimbabwean study by Rodlach (2009) also confirms that volunteer caregivers were not welcomed in other households due to the families' fears of being stigmatised by the community. The study documented that between the years 1990 to 2009 there has been a decline in caregivers' commitment due to HIV/AIDS-related stigma, lack of funding and burnouts. More volunteer caregivers reported that patients preferred to be visited by caregivers who are not from the same neighbourhood as them, since a well-known caregiver will make it too obvious that there is someone who may be HIV positive. Because of this, most volunteers stopped wearing uniforms and carrying bags that may indicate they are from a HBCO. Volunteers also avoided identifying themselves as AIDS workers but as caregivers of people with chronic and terminal illnesses. Yet, participants in this study reported that unlike when they started their AIDS care work, people are now more receptive and trusting towards volunteer caregivers, and more patients are willing to disclose their HIV status.

In a study on the experiences of HIV/AIDS informal caregivers in Tanzania, family caregivers reported a lack of support from their relatives as well as being discriminated and socially rejected by their community (Pallangyo, 2009). Some participants resorted to keeping their family member's status a secret, in fear of being discriminated against. They avoided contact with relatives, which increased the level of emotional distress and reduced chances of receiving help and support. Others reported that relatives would blame their sick family members and call them 'prostitutes' or people deserving to suffer. The act of informal or family caregivers secretly providing care for PLWHA and having to conceal their HIV status is very common (Akintola, 2008a; Bogart et al., 2008; Campbell, Foulis, Maimane & Sibiyi, 2005; Demmer, 2011; Mitchel & Knowlton, 2009; Mwinituo & Mill, 2004; Ogunmefan, Gilbert & Schatz, 2010).

A qualitative study on older female caregivers and HIV/AIDS-related secondary stigma showed that family caregivers had fear and concern about the community gossips, thus caregiving was kept secretly by most informal caregivers (Ogunmefan, Gilbert & Schatz, 2010). Some family caregivers would turn away friends from visiting so that they will not see their sick family member. Participants who received support from relatives, neighbours and the community believed it was because they managed to conceal the HIV status of their family members. They perceived that keeping it a secret protected them from possible stigmatisation by the community and the shame of having a family member who had an HIV/AIDS-related death.

A study on stigma associated with Ghanaian informal caregivers showed that families ensured that they conceal the HIV diagnosis of their family member (Mwinituo & Mill, 2004). Family members perceived the disclosure of the actual cause of death as a disgrace to the family. These family caregivers made great effort in hiding the very activities of caring for their ill members from the outsiders. They lived under shame, fear and anticipated stigma. Thus they ensured that the HIV diagnosis remains unknown. This resulted in a lot of burden for caregivers since they physically and emotionally distanced themselves from friends and families, thus receiving no support at all. Stigmatisation and non-disclosure leads to caregivers feeling emotionally distressed. A quantitative study on informal caregivers, stigma and disclosure done in Baltimore in the United States found that greater reported stigma from respondents was associated with more depressive symptoms. The study also revealed that disclosure was associated with fewer depressive symptoms, which means that those informal caregivers who were more open about

their caregiving status were less depressed compared to those who hid and did not disclose their caregiving status (Mitchel & Knowlton, 2009). Also, anecdotal evidence from the study indicated that some caregivers required assistance and guidance on how to disclose their caregiver status. This shows there is a strong need to support caregivers of PLWHA.

In a study exploring the experiences of informal caregivers in Ghana, caregivers reported feeling disregarded and disrespected by health care workers when they brought their sick family members to the hospitals (Mwinituo & Mill, 2006). A study done in South Africa by Schneider, Hlophe & Rensburg (2008) revealed that there was some tension between volunteer caregivers and nurses. In this study, volunteer caregivers felt that they were not appreciated and the significance of their work was not recognised. Volunteer caregivers in this instance worked closely with nurses in duties like tracking drop-out patients, counselling, providing health talks in communities and conducting ART readiness training as part of the formal health system. Caregivers reported to being discriminated by nurses, and were excluded to be part of meetings in clinics. Nurses worked to demarcate their territorial space and distinguish themselves as professionals who were better than volunteer caregivers. Some volunteer caregivers reported that nurses would be angry if patients mistakenly referred to them as 'sister'. A study exploring the perceptions and emotional burdens of HIV/AIDS health workers in the rural area of Limpopo, South Africa, lay counsellors and home-based carers accused nurses of being arrogant and having an 'attitude' towards patients. Nurses themselves admitted that they sometimes become rude and shout at the patients. They attributed this to the work overload and rude patients (Dageid, Sedumedi & Duckeit, 2006). It is important to note here that the discrimination by nurses towards volunteer caregivers is not related to the fact that they care for PLWHA, but caregivers are neither accepted nor recognised by nurses as belonging to the health care team.

Contrary to Schneider, Hlophe & Rensburg (2008), a Zimbabwean study by Rodlach (2009) on volunteer caregivers, reports that clinic personnel coordinated making patients aware of the importance of volunteer caregivers' services. Thus volunteer caregivers received support from health care workers. However, some health care providers were reluctant to make more use of volunteers because they saw them as not adequately trained. They had little faith in their skills and the service they provided. This resulted in some caregivers feeling disregarded as valuable partners in the provision of care for PLWHA. This increased their frustration and dissatisfaction.

This study also confirmed findings by Schneider, Hlophe & Rensburg (2008) that some of the clinic-based health workers saw volunteer caregivers as intruding their space and competing with them.

Another critical issue that Schneider, Hlophe & Rensburg (2008) raise is that of the ambiguous and unclear relationship between government and volunteer home-based caregivers. HIV/AIDS home-based caregivers seem to be both volunteers and workers. A lack of recognition from the health care system is one of the major challenges facing volunteer caregivers (Akintola, 2015; Schneider & Lehmann; 2010). From this study, home-based caregivers believed that government is their employer, even though they worked under NGOs which provide HBC services to the community. Volunteer caregivers felt that the work they do was not recognised and appreciated by health authorities. They also felt that their work was looked down upon and that nurses discriminated against them by treating them as outsiders. Their status is seen to be less than that of other health workers. Schneider and colleagues argue that home-based caregivers should be formally integrated into the primary health care (PHC) system so that their roles and responsibility would be standardised and appreciated, and thus receive fair remuneration. Nurses were reported as being opposed to CHWs wearing uniform. This indicates that nurses saw CHWs, including home-based caregivers, as a competition and not a part of the health care system (Schneider, Hlophe & Rensburg, 2008). The failure of government to integrate home-based caregivers has an effect on the poor relationship they have with other health care workers like nurses and doctors (Hunter & Ross, 2013).

In a study by Dageid, Akintola & Saeberg (2015) which explored sustained motivation for caregivers, caregivers reported that a lack of government support was their main challenge. They mentioned challenges such as lack of supervision, shortage of proper material equipment, and insufficient remuneration. Those volunteer caregivers who received stipends from the government said that they were sometimes not paid regularly. This created resentment towards the government. Some caregivers who volunteered with the hope to receive remuneration ended up being disappointed and quitted. Others continued because they saw future job prospects in HIV/AIDS caregiving.

Schneider, Hlophe & Rensburg (2008) believe that the government has been avoiding incorporating volunteer caregivers as employees of the state. This has led to the discrimination,

exploitation and marginalisation of volunteer caregivers. As they still remain outside of the PHC system, they are easily excluded and discriminated against by other health professionals since there is a strong divide between them (Schneider and Lehmann, 2010). Caregivers are yearning for appreciation and believe that they will eventually be recognised by the government (Akintola, 2011). In a study on stipend-paid volunteerism in South Africa, Hunter and Ross (2013) hint that volunteerism could be seen as low-paid work in disguise. In this study, community health care workers did feel that they were undervalued and used as ‘cheap workers’. The low remuneration of volunteer caregivers leaves them to feeling exploited (Ncama, 2005; Schneider, Hlophe & Rensburg, 2008). In a study on who benefits from home-based care, Thabethe (2011) argues that volunteer caregiving is a ‘cheap way out’ for the government to keep the public expenditure of social services low. The work of Dageid, Akintola & Saeberg (2015) also alludes to this, saying that the promotion of the ‘spirit of volunteerism’ may be equated to exploitation of labour by government.

Apart from the HIV/AIDS-related stigmatisation they receive because they care for PLWHA, volunteer home-based caregivers encounter general discrimination by nurses, families and the community due to the nature of the work they do. This kind of discrimination stems from the perception of caregiving work being seen as representing a low status. A study by Naidu & Sliep (2012) on the agency of volunteer home-based caregivers in KwaZulu-Natal, participants reported that people in the community saw them as being desperate and very poor because they did HIV/AIDS volunteer care work that did not pay. Other acquaintances of participants commented that they would never do caregivers’ unpaid work, especially the ‘cleaning of other people’s dirt’. A study by Akintola (2008a) reported that volunteer caregivers were often strongly criticised by their friends who despised their work and were especially offended that it was unpaid.

Many authors have strongly recommended that the integration of volunteer caregivers into the PHC and their proper remuneration should be the goal of government (Akintola, 2008b; Akintola, 2011; Akintola, 2015; Mashawu & Davhana-Maselesele, 2009; Morton, Mayekisa & Cunningham, 2015; Schneider, Hlophe & Rensburg 2008; Thabethe, 2011; van Pleitzen, Zulliger, Moshabela & Schneider, 2013; Wringe, Cataldo, Stevenson & Fakayo, 2010). Thus there is an effort from the government to change and improve the PHC system to not appear as

marginalising CHWs. The South African government has therefore introduced a new policy of ‘re-engineering’ PHC with the aim of formalising the integration of community health care workers into the health system for the purpose of extending a comprehensive community-oriented primary health care. In this de-hospitalised model, home-based caregivers (as well as other CHWs) will form part of the multidisciplinary teams that will offer outreach services to communities. CHWs will be the core members of these ward-based outreach teams. This means that home-based caregivers (at least some of them) will be absorbed into the health workforce (South African Department of Health, 2010). This model is a population-based approach that is in line with the National Health Insurance which seeks to provide equitable primary health care to poor and marginalised communities (South African Department of Health, 2011). This formal integration and recognition of home-based caregivers is likely to give home-based caregivers a respectable place within the primary health care system, and possibly reduce the discrimination and marginalisation they receive. This is not to say that home-based caregivers are operating completely outside the formal health care system, but currently, they are employed by HBC organisations and not all of them are recipients of stipends. Even though the Community Care Worker Policy Management Framework of 2009 recognises CHWs as a formal resource for basic PHC services in communities, it stipulates that the employer of community home-based care workers is not the Department of Health, but NGOs (who may be state-funded) offering HBC services (South African Department of Health, 2009). Thus the Department of Health can be seen as indirectly employing CHWs and home-based caregivers through funding NGOs that offer community-based services.

## **2.8 A Model of the Dynamics of HIV/AIDS Stigma**

This study uses a Model of the Dynamics of HIV/AIDS Stigma as a conceptual framework (see diagram on page 34). This model is relevant to the context of where the study is done, as it was developed through data collected from Southern African countries (Lesotho, Malawi, South Africa, Swaziland and Tanzania). It was developed through experiences of HIV/AIDS-related stigma from home-based caregivers, nurses as well as PLWHA. This makes the model more applicable to the kind of study we conducted.

In an attempt to develop a conceptual model of stigma, Holzemer (2007) and colleagues conducted a qualitative study from 5 African countries (Lesotho, Malawi, South Africa,

Swaziland and Tanzania) through 43 focus groups of PLWHA, nurses and volunteer caregivers. The aim of the study was to use a data-based approach to integrate theories on the context and process of stigma mainly in Southern Africa. From the textual data, it was clear that “stigma might be best conceptualised as a process occurring within a context of the environment, healthcare system and different agents or people (Holzemer et al., 2007:545).” Hence the study asserts that the stigma process is understood to occur in three contextual factors: 1) the environment, 2) the healthcare system and 3) the agent or people. The process of stigma itself comprises of triggers of stigma, stigmatising behaviours, types of stigma and stigma outcomes. From the above, the team then combined the stigma process with the context of stigma and developed a *Model of the Dynamics of HIV/AIDS Stigma*.

### **2.8.1 Contextual Factors**

#### *(i) Environmental Factors*

Environmental factors entail cultural, economic, political, legal and policy environment. For our study, this will include the community, the culture and the beliefs they hold regarding HIV/AIDS and caregiving.

#### *(ii) Healthcare System*

The healthcare system includes health facilities (clinics, hospitals and home-based care settings) and healthcare workers like nurses and doctors. In this study by Holzemer et al., (2007), participants reported to have been stigmatised by healthcare workers. This concurs with other studies which have similar findings (Schneider, Hlophe & Rensburg 2008; Mwinituo & Mill, 2006). For our study, we will look closely on the relationship between volunteer caregivers and nurses, as well as their experiences of stigma within the clinics (since volunteer caregivers work very closely with nurses in community clinics).

#### *(iii) Agents of Stigma*

Agents of stigma refer to family members, colleagues, community members and the individual who may self-stigmatise. Data from participants confirmed findings of other studies about family members, colleagues and community members as agents of stigma to PLWHA and their caregivers (Akintola, 2008a; Duffy, 2005, Hove-Musekwa, 2011; Ogden & Nyblade, 2005).



## 2.8.2 The Stigma Process

Holzemer et al., (2007) have proposed four elements of the stigma process: stigma triggers, stigmatising behaviours, types of stigma and stigma outcomes.

### (i) *Triggers of Stigma*

A trigger refers to any action that may lead to one being labelled as HIV positive. Stigma can be triggered or activated by an HIV diagnosis or disclosing your HIV positive status. Taking care of someone living with HIV/AIDS can trigger stigma by association. Some patients may avoid going to a particular clinic if they perceive that to possibly activate stigmatisation and discrimination. The presence of volunteer caregivers in a household can also trigger stigma towards the patient and their family by the community members or relatives. Being a volunteer caregiver can in itself be a trigger of associated stigma.

### (ii) *Stigmatising Behaviour*

Stigmatising behaviours may vary from gossip, rejection, denial of access to healthcare, avoiding, and verbal to physical abuse. These are actions that ‘stigmatisers’ do towards PLWHA, their families or formal/informal caregivers.

### (iii) *Types of Stigma*

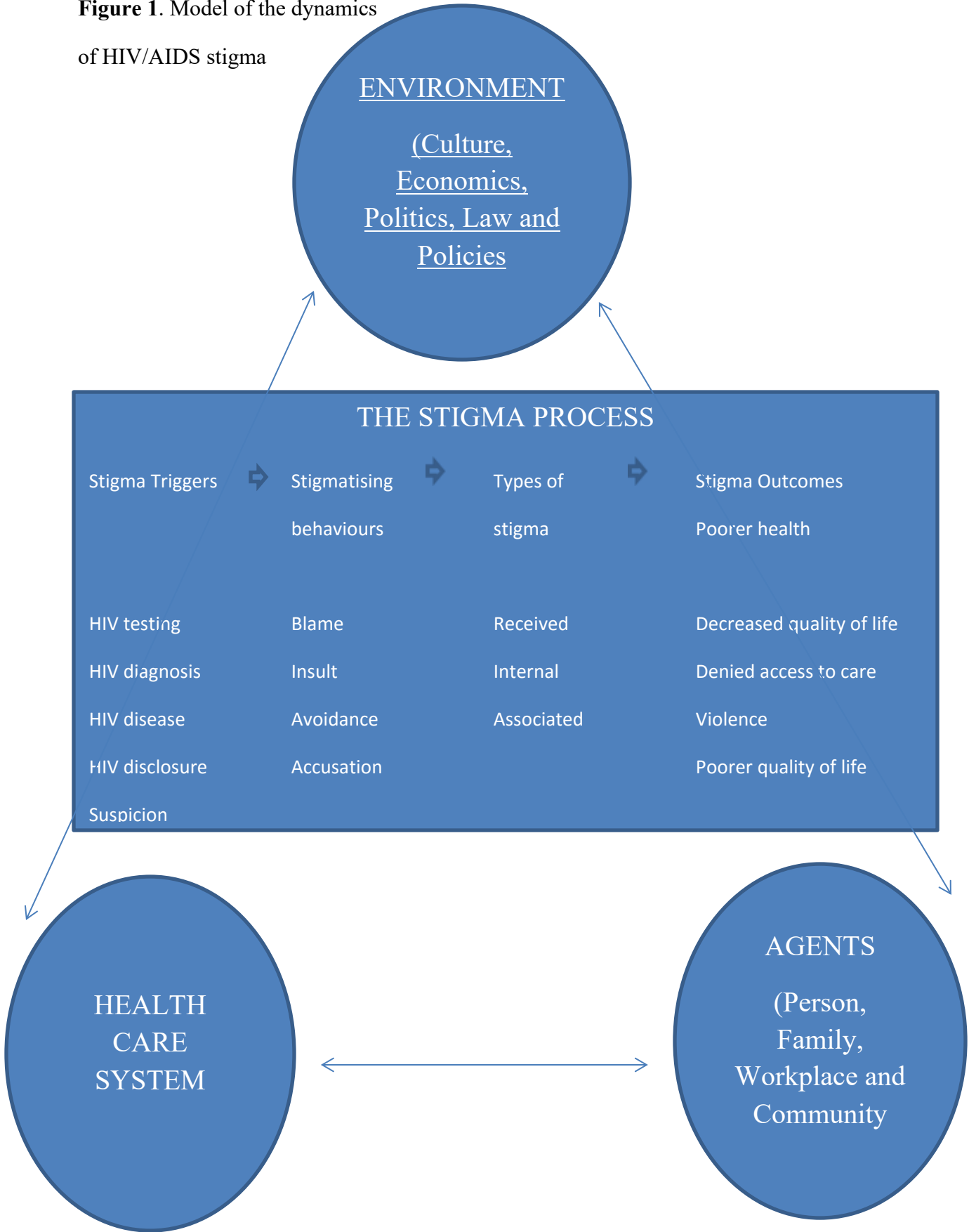
There were three types of stigma identified from the data in this study by Holzemer et al., (2006): received, internal and associated stigma. Received stigma refers to all kinds of stigmatising behaviours towards PLWHA as experienced or reported by themselves or others. Received stigma includes gossips, neglecting, rejection, labelling, and verbal and physical abuse. Internal stigma is one’s subjective thoughts, feelings and behaviours which is a result of their negative perceptions due to them being HIV positive. It is also known as self-stigmatisation. These may include low self-esteem, self-exclusion and social withdrawal. Associated stigma refers to stigma received by one who is associated with a person who is living with HIV/AIDS. These may be family members, caregivers, colleagues or healthcare workers. Our main interest in this study is the process, context and effects of associated stigma experienced by volunteer caregivers.

(iv) *Stigma Outcomes*

Stigma outcomes are the effects of stigma towards those who are stigmatised. Holzemer et al., (2007) showed that there are consequences of stigma for PLWHA. Stigma resulted in poor health, poor quality of life and reduced access to health for PLWHA. For the purpose of our study, we shall explore the outcomes of stigma on volunteer caregivers, and how it affects their daily caregiving work.

This *Model of the Dynamics of HIV/AIDS Stigma* will help in the objectives of this study. That is to better understand the overall experience of secondary stigma on volunteer caregivers, the nature of that secondary stigma, how it affects them and their caregiving work, as well as the context and process on which it occurs. This model has also shaped the design and development of instruments for data collection in terms of asking the relevant questions from the participants about the nature and the context of secondary stigma that they encounter, as well as in anticipating certain responses in line with the model. The application of this framework will focus more on the 3 contextual factors of stigma. This will reveal how volunteer caregivers experience secondary stigma in their families, community and clinics as this is their context. Also, this will extend to the stigmatising behaviors they encounter and its outcomes or effects, which is referred to as the process of stigma. In this way, the framework will assist in giving us a guide on the discussion of the findings.

**Figure 1.** Model of the dynamics of HIV/AIDS stigma



## **Chapter Three: Methodology**

### **3.1 Design**

This is a qualitative study. Qualitative research takes an interpretive approach to studying a phenomenon. This means that researchers seek to understand the behaviour of participants within their natural settings (Mertens, 1998). It is interested in the subjective meanings that they attach to their behaviour and it uses ordinary everyday language of the participants. A qualitative design was chosen because of the nature of the research questions that need detailed in-depth information in order to understand the topic more broadly and extensively. It is more suitable in eliciting the rich experiences of volunteer caregivers by allowing them to express themselves in a personal way (Mertens, 1998). It is flexible in that it allows for open ended questions where a researcher can further probe on issues emerging from interviews.

### **3.2 Study Area**

This research was part of a large study focusing on home-based care organisations and HIV/AIDS volunteer caregivers in South Africa. Data collection was done in six organisations providing home-based care services to PLWHA in Durban metropolis, as seen in table 3.1 below. All organisations were located in peri-urban (township) communities.

**Table 3.1: Number of volunteer caregivers recruited from six organisations.**

| <b>Organisation</b> | <b>Location of the organisation</b> | <b>Number of Participants in Focus Group Discussions</b> |
|---------------------|-------------------------------------|--|
| A                   | Township                            | 8  |
| B                   | Township                            | 7  |
| C                   | Township                            | 9  |
| D                   | Township                            | 8  |
| E                   | Township                            | 10   |
| F                   | Township                            | 9  |
| <b>TOTAL</b>        | <b>6</b>                            | <b>51</b>  |

### **3.3 Research Participants**

Participants of this study were HIV/AIDS volunteer caregivers working under HBCOs who provide care for PLWHA. There were six HBCOs who were part of this study and 51

participants were involved. All participants involved were *isiZulu*-speaking. Volunteer caregivers were recruited because they work with PLWHA and are the main informants on their experiences of HIV/AIDS secondary stigma. The criterion I used to recruit volunteer caregivers was that they should have had six months of doing caregiving work to PLWHA. It was assumed that this period of work is enough for volunteer caregivers to have had significant information regarding secondary stigma and discrimination they experience due to caring for PLWHA.

Snowball sampling was used to recruit participants from organisations providing home-based care services. “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 & McNeill, 2002: 61). This technique was more appropriate for this research because one organisation referred us to another home-based care organisation that provides care for PLWHA. The initial HBCOs that were contacted were able to give us a reference of other organisations that care for PLWHA. This ensured that participants used had the valuable information on HIV/AIDS home-based care giving. The criteria used for HBCOs was that they 1) must have been rendering home-based care services to PLWHA for a minimum of one year, 2) must have volunteer caregivers with a minimum of at least six months, 3) must be within the Durban metropolis, 4) and be willing to participate and able to provide rich information on the experiences of secondary HIV/AIDS-related stigma towards volunteer caregivers.

### **3.4 Data Collection Procedure**

Data collection was conducted from November 2012 to August 2013. A focus group schedule was used to collect data from participants. The focus group schedule was designed in English and translated into *isiZulu*. It contains open-ended questions which were developed from the literature reviewed, with HIV/AIDS secondary stigma as the main theme (See appendix A) and used as a guide for the discussion. Focus group discussions were used as a data collection technique because they elicit more responses from participants as they share their common experiences and stories (Ulin, Robinson, Tolley & McNeill, 2002). A focus group schedule allowed for structure in exploring various themes as well as probing further to explore deeper the responses and meanings of volunteer caregivers. Focus group discussions helped to prompt greater depth of information within participants and to compare their responses for validation

(Carey & Asbury, 2012). Focus group discussions also gave access to the inter-subjective experiences of volunteer caregivers regarding their experiences of HIV/AIDS-related stigma (Carey & Asbury, 2012; King & Horrocks, 2011).

Focus group interviews worked well with volunteer caregivers as they were able to share their experiences around secondary stigma and how they deal with it in their everyday work. Volunteer caregivers expressed themselves in their own language (*isiZulu*) during the interviews and were able to give in-depth information as the discussions elicited more commonalities as well as differences in their experiences. Focus group discussions allowed for a wide range of responses and a reminder to other participants of the significant details that they might have forgotten. The focus group schedule covered the following themes: volunteer caregivers' experiences of stigma and discrimination, perceptions of family and community on volunteer caregivers and ways of dealing with secondary stigma.

Focus group discussions took place in the offices provided by the respective home-base care organisations and each focus group was between 45-60 minutes long. Each organisation had one focus group which consisted of participants ranging from 6-10. Participants were first informed about the purpose of the study. All focus group discussions were conducted by the researcher in *isiZulu*. This allowed for participants to express themselves freely in their own language. The researcher was also an *isiZulu* speaker, which made it easier to pick up language nuances and follow up for more information. All focus group discussions were recorded by the researcher using an audio recorder. Data was transcribed verbatim from *isiZulu* to English by the same researcher in order to retain the quality of data. In addition participants were informed about their right to withdraw from the study at any time they wished to.

### ***3.4.1 The Role of the Researcher***

The researcher was directly involved in conducting focus groups interviews to volunteer caregivers in *isiZulu*. Interviews were also transcribed and translated into English by the researcher. The researcher was in a better position to facilitate the focus group interviews since he is fluent in *isiZulu* and understands the objectives of the study about stigma towards volunteer caregivers of PLWHA.

### **3.5 Data Analyses**

The tape recorded data was transcribed and translated from *isiZulu* to English. Further the collected data was analysed using thematic data analyses. Thematic data analysis is a long process that entails a researcher immersing in and constantly familiarising themselves with the data. Then data is arranged into different categories or themes that are similar (Terre Blanche Durrheim & Painter, 2006). Thematic analysis was used in this study because it takes a bottom-up approach. That is as the researcher analyses data; the themes are produced inductively from the data and are not imposed by the researcher (Punch, 2005). Focus group discussions produce vast information, thus using thematic analyses also helps to break down chunks of information into smaller and well-ordered themes.

The steps that were followed in analysing were 1) familiarisation and immersion 2) inducing themes 3) coding 4) and elaboration. The first step in the process of thematic analyses was for the researcher to familiarise and immerse himself in the data. It included reading and re-reading of the transcripts. The initial process of collecting data, transcribing and translating data from *isiZulu* to English, helped the researcher in the preliminary understanding of the data. This was part of being familiar with the data even before the familiarisation and immersion stage. The second step was to find patterns from the data that can be sorted into themes or categories that have a bearing on the research questions (Terre Blanche, Durrheim & Painter, 2006). The third step was the coding of data. Phrases, sentences and paragraphs were marked or highlighted according to the themes they belong to. The fourth step was to compare and refine the themes, redefining them to sub-issues or merging them to other main themes (Terre Blanche, Durrheim & Painter, 2006). This is the elaboration stage. The very last stage done was putting together the interpretation of data and checking it (Terre Blanche, Durrheim & Painter, 2006).

### **3.6 Trustworthiness of the Study**

In qualitative research, trustworthiness is equivalent to credibility and validity in quantitative research. In this study, trustworthiness was made certain through credibility, dependability, transferability and confirmability (Flick, 2002).

### **3.6.1 Credibility**

In qualitative research, credibility seeks to answer the question; “How congruent are the findings with reality?” (Shenton, 2004). Terre Blanche Durrheim & Painter (2006) states that the inferences and conclusions deduced from the data must accurately reflect the participants’ views. To achieve the above, the focus group schedule was developed through rigorous engagement with literature. Also, comparisons of data were made between focus groups to establish the similarities and differences. Results were also evaluated to determine the extent to which they are congruent with the previous studies.

### **3.6.2 Dependability**

Terre Blanche, Durrheim & Painter (2006) describe dependability as “the degree to which the reader can be convinced that the findings did indeed occur as the researcher says they did”. The focus group schedule that was developed in *isiZulu* was translated into English. All focus group discussions were conducted in the *isiZulu* language. From the data collection process, the researcher was the one collecting data, transcribing and translating it from *isiZulu* to English. This process ensured that there was consistency and dependability, and that the interpretations were rooted in the contextual interaction with participants. Also, there was an on-going process of supervisor review to minimise researcher bias.

### **3.6.3 Transferability**

Transferability refers to the extent to which the data from this study can be transferred to other populations, settings or contexts (Terre Blanche, Durrheim & Painter, 2006). Qualitative study should be understood within the context of the characteristics of participants and the geographical area where the fieldwork took place (Shenton, 2004). The participant of this study were HIV/AIDS volunteer caregivers recruited through snowball sampling from the Durban area through home-based care organisations for PLWHA. The findings of this study about the experiences of secondary stigma on volunteer caregivers can be transferable to other similar settings, but contextual factors need to be taken into consideration when doing so. The transferability of this study can also be evaluated through comparing the findings with that of the literature (see literature review section).



### ***3.6.4 Confirmability***

It is important that the result presented in a qualitative study must be the experiences and ideas of the participants rather than the preferences or bias of the researcher (Shenton, 2004). In this study, this was ensured through the writing and reviewing of field notes, process notes and constantly revisiting the transcripts during the writing up.

### **3.7 Ethical Consideration**

Approval of the research study was sought from the University of KwaZulu-Natal ethics committee. Permission to conduct the interviews was obtained from home-based care organisations and the participants involved. The purpose of the study was clearly explained verbally to all participants in the language they understand. All participants involved in this study did so willingly, in their full informed consent. Both verbal and written informed consent was obtained from the participants. Permission was obtained from participants for the use of a tape-recorder during the focus group discussions. They were informed of their rights to withdraw from the study anytime they wish to, and that this would in no way result in any negative consequences on them. No risk occurred on any of the participants. To adhere to confidentiality and anonymity, participants were asked not to use their names during the course of the focus group discussions. Audio-tapes were kept safely where they could only be accessed by the research team and will eventually be destroyed after 5 years.

## Chapter Four: Presentation of Results

### 4.1 Introduction

This chapter present the findings of this study by first describing the socio-demographic characteristics of volunteer caregivers. The themes that emerged from this study are presented according to the research questions that they answer.

### 4.2 Table: Demographics characteristics of volunteer caregivers

| Background Characteristics | Frequency |
|----------------------------|-----------|
| <b>Gender</b>              |           |
| Male                       | 2         |
| Female                     | 49        |
| <b>Age</b>                 |           |
| 20-24                      | 3         |
| 25-29                      | 5         |
| 30-34                      | 11        |
| 35-39                      | 14        |
| 40-44                      | 8         |
| 45-49                      | 5         |
| 50-54                      | 3         |
| 55-59                      | 1         |
| 60-64                      | 1         |
| <b>Work Experience</b>     |           |
| 0.5-1 Year                 | 6         |
| 1-4 Years                  | 24        |
| 5-8 Years                  | 14        |
| 9-12 Years                 | 5         |
| 13-16 Years                | 2         |

Most of the participants were female, only 2 of were male. The age of volunteer caregivers ranged from 20-64 years, and the years of experience were from 0.5-16 years, as indicated by table 4.2 above

### 4.3 Table of Themes

| <b>Nature of secondary stigma and discrimination experienced by volunteer caregivers</b> | <b>Influence of stigma on volunteer caregivers</b>                     | <b>Caregivers way of dealing with stigma</b>                         |
|--|--|--|
| 1. Family concern and disapproval  | 1. Attrition of volunteer caregivers                                   | 1. Counselling   |
| 2. Difficulty in getting access to PLWHA.  | 2. Decrease of morale  | 2. The use of name badges  |
| 3. Ridicule, name-calling and gossips  | 3. Discrimination from nurses impedes volunteer caregivers' daily work | 3. Persistence and Perseverance                                      |
| 4. Volunteer caregivers perceived as being HIV positive                                  | 4. Emotional burden  | 4. Patients' testimonies reduced stigma towards volunteer caregivers |
| 5. Nurses' discrimination against volunteer caregivers                                   |  |  |
| 6. Feelings of alienation from government  |  |  |

### 4.4 The nature of secondary stigma experienced by volunteer caregivers.

#### 4.4.1 Stigma from caregivers' families

##### 4.4.1.1 *Family concern and disapproval*

Most volunteer caregivers revealed that when they started HIV/AIDS caregiving work, their families and relatives saw it as irrational. This was because of the fear of infection and death associated with HIV/AIDS. They saw it as risky and bringing infection and death to themselves, thus they disapproved of the work they did. As a result, volunteer caregivers did not receive support from families in their caregiving work.

*It was tough for me. My husband did not like it. He didn't understand why I did this work. Other relatives of mine said that I am intending to infect myself by doing this, and that I am going to bring the disease home. People were not educated at the time. (Organisation A)*

*No one had a problem (with me being a caregiver) in my family but my relatives were reluctant about my job. They would ask me what makes me want to work with sick people because I will be sick. "We are going to bury you, do you know that", they would say. (Organisation B)*

#### **4.4.2 Stigma from patients' families**

##### ***4.4.2.1 Difficulty in getting access to PLWHA***

Caregivers expressed the difficulty of getting access to sick people in their homes. Family members would chase them away, hide their sick members and tell them to go away. Family members did this because they saw that the presence of volunteer caregivers will make it easy to be labelled as people who are living with someone who is HIV positive, and thus be possibly discriminated against. In other instances, families would even threaten to harm them physically. They were also concerned that caregivers themselves will gossip about their family member who is living with HIV/AIDS. They did not trust that they could keep the matter confidential. In other households they would be treated in unpleasant ways which conveyed a message that they were unwelcomed. This was very common in all focus group interviews.

*At times others don't welcome you in their homes. They make you stand outside even when the sun is hot. And you don't know whether to continue talking or what. Others don't even open for you when you knock. In other households they just say "look at these gossipers". (Organisation B)*

*When we visited homes, they will shut their doors and say, "Here comes these nuisance". (Organisation C)*

#### **4.4.3 Stigma from the community and nurses**

##### ***4.4.3.1 Ridicule, name-calling and gossip from the community.***

When talking about the experiences and the kind of stigma and discrimination they receive from the community, participants reported that they are being called names and their work is looked down upon. Name calling and ridicule was reported by all focus group discussions. Some people

in the community ridicule and laugh at the work they do, particularly because caregiving is not a paying job. They are viewed by community members as having a low social status. Some members would even belittle them in public. There are a number of demeaning words that volunteer caregivers shared on how they are referred to by the community and even nurses in clinics. The names that community members use to refer to volunteer caregivers are *onesi bophaqa* (nurses with sandals), *ostandard two* (standard twos), *abasula izinga zogogo* (people who wipe grannies butts), *abakhuluma izindaba* (gossipers) and *abaklina amakaka* (those who clean faeces). The dominant themes from these names are more to do with the perception that caregiving is for people who are not educated and that the work they do is lowly esteemed.

*We were very much discriminated in the community because all they knew was that we clean people who have soiled themselves. People would criticise me and say my work is nonsense and I clean people's faeces.* (Organisation D)

*The work we do is just a joke to some of the people in the community. Even when you are going to Pinetown you hear people talking and saying "look at her, she wipes people's backs." It is just not good to hear that.* (Organisation E)

*They call us 'people who wipe grannies butts' or 'nurses of sandals'. That name is offensive and painful.*

#### **4.4.3.2 Name calling from nurses**

A lot of caregivers complained about the ill-treatment they receive from nurses. They do not feel supported by the nurses at all. They reported that nurses call them with derogatory names and treat them with disrespect when they communicate with them. All participants in this study reported continuing tension between nurses and volunteer caregivers. Volunteer caregivers seemed bitter and angry when they spoke about the poor relationship they have with nurses in community clinics and the kind of treatment they receive. They believed nurses should be the very people giving them support since they contribute so much to ease their work load. Derogatory words that nurses use when referring to volunteer caregivers are 'onesibophaqa' (nurses with sandals), 'onesibakaZuma' (Zuma's nurses), 'iziqhaza' (the uneducated), 'onesi abangaholi' (unpaid nurses), 'omatrons' (matrons) and 'abangazilutho' (those who know

nothing). Even though the nature of discrimination that volunteer caregivers received from nurses was not directly because they take care of PLWHA, they were still devalued, belittled and insulted by nurses because they looked down on the HIV/AIDS caregiving work they did as well as their level of education. They do not fully embrace them as part of health care workers.

*In clinics we are still looked down upon. Nurses see us as unintelligent. I brought a patient to the clinic and the nurse called me unesikaZuma (Zuma's nurse). Some nurses speak harshly to us. (Organisation A)*

*Nurses call us 'Zuma's nurses', 'iziqhaza' (the uneducated), 'abangazilutho' (those who know nothing), 'standard twos', 'those who clean faeces' or 'nurses with slippers.' (Organisation C)*

*....Nurses were the worst! They do not give us any respect. They even ask you in a sarcastic way how much you get for spending your time helping people. You get confused whether they hate you or they just hate the job you do. (Organisation F)*

#### **4.4.3.3 Caregivers are perceived as being HIV positive.**

Participants reported about a common perception that they are also living with HIV simply because they care for PLWHA. A lot of caregivers said that some family members and community think that the reason for their volunteering is that they themselves are living with HIV/AIDS. For some caregivers, they played along with this perception because they wanted to show the community that you can be HIV positive and still look healthy.

*Some said to me it is impossible that you can be a volunteer if you yourself are not HIV positive. For me I didn't worry about it. I just agreed and said yes I do have it. They were pointing fingers at us saying these people running up and down are HIV positive. (Organisation E)*

*When I first started, others would say we give care to PLWHA because we also are infected with the disease. They think the reason you volunteer is because you yourself are HIV positive and you want to teach others about it. (Organisation F)*

## **4.5 Feelings of alienation from government**

Volunteer caregivers felt that they were neglected and undervalued by the government. A lot of caregivers were disgruntled that they have worked for a long time with the hope that the government will eventually employ them formally like other health professionals. Some felt like they are just being studied, but their lives are not developing in relation to possible career or formal employment within the health sector.

*You should speak to the government about us. You always come here to listen to us, but our lives are still the same. (Organisation C)*

*The government is not taking us seriously, our work is not appreciated. We have been working for a long time, but we are still volunteers. I was hoping that by this time the government would have employed us formally. (Organisation B)*

## **4.6 The effects of Stigma on Caregivers**

### ***4.6.1 Attrition of caregivers***

It is not unusual for volunteer caregivers to not stay longer in their job. Due to the pressure of being stigmatised and discriminated by the community, some caregivers left work. Participants reported that some of their colleagues could not withstand the ridicule and unpleasant treatment they received from the community and decided to stop doing caregiving work.

*What I can say is that it really depends on you and your heart. If you are not a person who is patient, you will not have the love of this job. I say this because I had a lot of other colleagues I used to work with who are no longer working. A few of us are still here from the time we started. They left because they were troubled by the disrespect and ridicule of the community. (Organisation B)*

### ***4.6.2 Decrease in morale***

The kind of ill-treatment and discrimination that volunteer caregivers received, particularly from nurses, discourages them from doing their work with ease. Other caregivers dreaded going to the clinic because they wished to avoid interacting with nurses. This poor working relationship also impacts on the daily work of caregivers, making it more difficult to perform their duties

effectively. In all focus group discussions, volunteer caregivers reported a poor relationship with nurses and felt discouraged about the work they do, especially when they need to come into direct contact with the nurses. Not only did they lose courage due to discrimination, but also because of the unpleasant treatment and disrespect from nurses.

*I have to sign at the clinic every morning. I hate going there! If I had a choice I wouldn't put my foot there. Nurses do not like us. We are not being treated well. It is painful to come to work where you are not treated well. Nurses do not treat us well in clinics. There is no good relation between us and them.* (Organisation D)

*Nurses treat us very badly. When you go to the clinic you receive a letter of confirmation from our organisation. When you show it to the nurses, even when you are wearing this uniform, they tell you to wait like any other patient. They do not recognise and respect the work we do. They disrespect us.* (Organisation E)

#### **4.6.3 Discrimination from nurses impedes volunteer caregivers' daily work.**

Volunteer caregivers work closely with nurses almost on a daily basis. Sometimes they are sent by nurses into communities to look for patients who have not been attending clinic regularly to get their medication. Poor working relations and discrimination from nurses impedes the daily working of volunteer caregivers. Participants report having to wait in long queues at the clinic (if they have to collect their patients' medication) and this delayed caregivers to do home visits on time. This lack of cooperation from the nurses affected how volunteer caregivers did their daily work.

*It is even a struggle to get a wheelchair from the clinic so you can transport a patient who cannot walk. You have to explain and plead with the nurses. At this one time I went as far as borrowing a wheelchair from one patient so I can transport another patient of mine who could not walk.* (Organisation B)

*When we are standing in a queue, nurses don't take any notice of us. We even hear nurses say here comes 'these people'. They take us for granted. At times, when we do stand in the queue, it is the patients that say 'you are not supposed to be standing in line because you still have to go out and visit homes'.* (Organisation F)



#### **4.6.4 Emotional Burden**

Discrimination and secondary stigma adds more burden on top of the physical work that volunteer caregivers do. Participants reported feeling distressed and emotionally hurt by the negative comments they receive from the community. Some participants reported to crying and feeling less worthwhile. During the focus group discussion about how stigma affects volunteer caregivers, caregivers displayed emotions of resentment and being overwhelmed.

*Wherever you go around the community, they will say 'there is the one who cleans people's faeces'. It is painful when people say that. You feel like you are nothing. (Organisation B)*

*We feel hurt. They want us to stand in the queue like patients. They can see my uniform and they know I am a caregiver. It's painful. Sometimes I would cry. (Organisation A)*

*Field work is very strenuous, and when we get to the clinic, nurses add more stress. The community gives you a burden, the patient gives you a burden, family gives you a burden, as well as the nurse. As a result you get stressed (Organisation F)*

#### **4.7 Volunteer Caregivers' way of dealing with stigma**

Although caregivers display agency and resistance during their work, especially against stigmatisation, the fight to eliminate HIV/AIDS-related stigma and secondary stigma is still far from being over. The themes below show the effort of volunteer caregivers in responding to the challenges of stigma and the discrimination they come across. A lot of work still needs to be done on interventions to eliminating HIV/AIDS-related stigma and promoting awareness and acceptance of HIV/AIDS home-based caregivers.

##### **4.7.1 Counselling**

Volunteer caregivers reported that they had to find a way of fighting stigmatisation from the community as well as family members of PLWHA who refused to accept them in their homes. They used counselling as a way of combating stigma and reducing ignorance about HIV/AIDS. They insisted on educating people about their work, and counselling patients and their families about HIV/AIDS. They also used counselling to encourage patients who resisted their help and were not willing to visit clinics because of the fear of being stigmatised. Caregivers showed strength and creativity in their work and in dealing with stigma. They were able to teach and

explain to patients and their families about HIV/AIDS and caregiving work. However, not all families of PLWHA were able to listen to and give volunteer caregivers a chance to speak about their work. And not all caregivers were patient enough to break through families who were unwelcoming.

*Sometimes it is still difficult though to talk to people. But because we are trained, we are able to sit the person down and put them at ease about their illness. You need to have a way of talking to a sick person whom you are seeing for the very first time. (Organisation F)*

*What makes patients to be closer to us than the nurses is that we are able to sit down with the person and not just say “you see how sick you are, you must test.” We teach them and explain to them the dangers of what will happen if they don’t go to the clinic.*

(Organisation E)

#### **4.7.2 The use of name badges**

The introduction of name badges by the Department of Health has made a positive effect in reducing secondary stigma towards volunteer caregivers and making them more accepted and credible in the face of the community. This has helped to boost the image of caregivers and has made HIV/AIDS caregiving more appealing. During focus group discussions, volunteer caregivers say that name badges make them to appear more professional and trustworthy. Some community members are now able to approach volunteer caregivers and ask about their work and how they can get help from their services. Not all volunteer caregivers have name badges, but those that have them attest that it has made their work significantly easier.

*Name badges have helped a lot. We now have dignity. People can see that we are under the Department of Health. They no longer undermine us. They understand we are employed. When you come into the house people are able to give you their time and listen. Previously, people would say you are wasting their time. (Organisation A)*

*We now have name badges from the clinic. After these name badges, the community respects me so much. They never held me in high regard before. But now a lot of people are coming to me to inquire about what I do and to ask for assistance. (Organisation F)*

### **4.7.3 Persistence and Perseverance**

Even though stigmatisation kills the morale of volunteer caregivers and leads to attrition, a lot of volunteer caregivers showed a strong character of persistence against being stigmatised and discriminated. Overtime, they have developed the tenacity to withstand ridicule, insults and discrimination they encounter in their work with community as well as nurses. They emphasized the importance of love for the patient and perseverance. By responding affectionately and professionally to insults, they seemed to have won a lot of people from the community. This has yielded positive results and a change in how the community perceives HIV/AIDS caregiving.

*My colleague is right. We really endure a lot. It depends on how you handle the community. If you change every time they say something bad, you make them to continue. If they do those things and call you names and find that you remain the same, they eventually stop. (Organization B)*

*In our training as caregivers, we are taught patience and humility. We are taught to disregard negative comments from people. You cannot be a caregiver and be easily disgusted, angered and short tempered. You must have love and patience. (Organisation F)*

*We try not to put it into our heart. It is easy to give up when you are forced to do something. But when you are committing and doing something wholeheartedly, you are able to persevere. No one was forced to come here. We are able to endure this because we love our job. (Organisation A)*

### **4.7.4 Testimonies of patients helped to reduce the stigma towards caregivers**

As much as the secondary stigma is still high in the communities they work in, volunteer caregivers do acknowledge that there is a growing positive perception of HIV/AIDS caregiving work. Caregivers reported that as more patients were getting better from their work of caregiving, the community became more accepting towards their work. They received respect and high regard as they were perceived in a positive light. Some in the community are now able to refer other patients who need help to volunteer caregivers. Almost every caregiver agrees that the amount of stigma and discrimination they encounter is gradually decreasing and there is a growing positive attitude towards volunteer caregivers. Access to antiretroviral treatment has also made a significant impact in reducing stigma, thus reducing secondary stigma upon

caregivers. People are now living longer and taking ARVs, which results in the HIV/AIDS being seen as a chronic and manageable disease. On all focus group discussions volunteer caregivers say this has therefore led to a more welcoming attitude by the community. It has also helped to decrease the burden of care for volunteer caregivers.

*The community did not like our work in the beginning. As time went on they realised the impact we are making. They so how hopelessly sick patients were restored to health again. Some of my patients are now married. It is funny that some of those who detested our work are now with us. Like this one (pointing at a fellow caregiver, and they all laugh). (Organisation E)*

*There was a lot of discrimination we faced before. When we visited homes, they would shut their doors and say here comes these nuisances. As time went on, those who allowed us to help them were the ones preaching to others about our good work and the love for people. (Organisation B)*

*ARVs have decreased the level of discrimination we get from people. Before there were ARVs, a lot of patients had open sores. So people assumed we would be infected. Now ARVs are making the lives of patients better. They are not as ill as the ones we used to care for when we started. (Organisation E)*

## **Chapter Five: Discussion of Results**

### **5.1 Introduction**

The discussion of the findings is presented using the *Model of the Dynamics of HIV/AIDS Stigma* which has the 3 contextual factors of stigma: Environment, Healthcare sector and the Agents. This section discusses the findings in relation to the stigma process of the model (stigma triggers, stigmatising behaviours, type of stigma and stigma outcome), bearing in mind the research questions regarding the 1) nature of secondary stigma and discrimination experienced by volunteer caregivers, 2) its effects on them and their daily work, 3) the ways they deal with it. However, the aspect of the stigma process will not be discussed exclusively, but will be incorporated into the 3 contextual factors of stigma since they tend to overlap and connect to each other.

### **5.2 Environment**

The community perceptions and beliefs about HIV/AIDS, home-based care, and volunteer caregiving affect the everyday work of HIV/AIDS caregivers. The healthcare system and policy on HIV/AIDS also has an influence on the environment that volunteer caregivers work under. Initially, home-based caregivers worked in a period where ARVs were not yet introduced. This means they encountered a lot of bed-ridden patients. At that time, HIV/AIDS was mostly perceived as a death sentence and it was highly stigmatised in the community. Knowledge about HIV/AIDS in the community was still low. This resulted in an increased burden of care for volunteer caregivers, where HIV/AIDS-related stigma and discrimination towards caregivers was very dominant. This is the kind of environment that caregivers originally worked under. They reported about the difficulties of facing HIV/AIDS-related stigma, work-overload and caring for patients who were chronically ill. When one looks at the 2002 HIV and AIDS Household Survey in South Africa, it shows that during this year, levels of HIV stigma were still high. About 94.5% of people responded that they would not talk to someone who is HIV positive, whilst 80.8% said they would not sleep in the same room with someone who is HIV positive. This concurs with the study done in 2004 by Akintola where families of patients were just waiting and expecting their sick family member to die. It is worth mentioning that volunteer caregivers were mostly middle

to old age women with an average experience of about 6-7 years. This however, did not seem to be a factor on the findings.

Although volunteer caregivers worked in communities where HIV/AIDS-related stigma is still prevailing, it should be acknowledged that the introduction of (ARVs) in South Africa has made a difference in the fight against HIV/AIDS-related stigma. The findings of this study revealed that unlike when they started caregiving work, volunteer caregivers are now encountering less bed-ridden patients than before, and patients are recovering sooner than before. This has made people in the community to be more accepting of volunteer caregivers, thus reducing the secondary stigma they faced. These findings indicate that there is a decline in the HIV/AIDS stigma, as it has been seen in the literature (IPPF, 2014; Shisana et. al, 2014; UNAIDS, 2012b).

In a study done in Nigeria on home-based care for PLWHA, participants reported that some people would say that HIV positive people should be injected with poison, not ARVs (Agbonyotor, 2009). In this instance, the introduction of ARVs did not result in the reduction of stigma towards PLWHA. A study done in Zimbabwe on volunteer caregivers' motivation and concerns, Rodlach (2009) reports that the availability of Antiretroviral Treatment (ART) assisted in the reduction of HIV/AIDS-related stigma. Though it was apparent that stigma was still rife in the community, ARVs helped to empower PLWHA to face stigma with dignity and retain a positive sense of self. It also increased their social status as they regained their health and were able to earn income by going back to their work. This shows that ART can make a difference in empowering PLWHA and reducing secondary stigma towards caregivers, thus changing the environment that caregivers work under. This was the case in our study.

The findings of this study show that the very nature of caregiving work, and that it is an unpaid job were the main reasons for the discrimination that volunteer caregivers received from the community. The community saw the act of caring, bathing and cleaning ill people as low-valued, particularly because volunteers are unpaid. Also, volunteer caregiving was seen as a job for the uneducated. All of this resulted in the community ridiculing, gossiping and calling them names. These findings are in line with the work of Akintola (2008a) which was exploring the everyday challenges faced by volunteer caregivers in KwaZulu-Natal in South Africa. The study showed that volunteer caregivers received ridicule and insults from the community they worked in, and some people detested that they worked without pay. Whilst the unpaid aspect of caregiving may

not be the primary reason for stigmatisation of volunteer caregivers, evidence from the study shows that it is a major cause of stigma from the community.

Volunteer caregivers often work in communities where there are high levels of HIV/AIDS stigma (Akintola, 2006; Mieh, Airhihenbuwa & Iwelunmor 2013; Mwinituo, 2006; Rodlach, 2009). The findings of this study showed that some family members of patients refused to accept the services of volunteer caregivers. Some responded harshly, denied or hid their family members due to the fear of suffering stigmatisation from the community. Volunteer caregivers had to use creative ways to get through family members who were a barrier to reach to the sick person. They sat the family members down to counsel them about HIV/AIDS and home-based care. This is in line with other studies done in South Africa and Zimbabwe which showed that volunteer caregivers were chased away or blocked when they were visiting homes of patients living with HIV/AIDS (Akintola, 2008a; Orner, 2006; Rodlach 2009). Also, these findings affirm studies done by Akintola (2008a) and Hangulu (2012) which revealed that volunteer caregivers had to use counselling and their negotiation skills on families in order to gain access to their potential patients and overcome HIV/AIDS-related stigma.

HIV/AIDS stigma is still a barrier on caregivers in providing HIV/AIDS home-based care services to communities. In order to reduce HIV/AIDS-related stigma and secondary stigma towards home-based caregivers, there needs to be a good relation between HBCOs, government, community leaders and the community itself. HBCOs and volunteer caregivers have already made a significant effort in combating stigma and discrimination through effective home-based care services. From the findings of this study, it is clear that community awareness of home-based care and HIV/AIDS helps to reduce the stigma environment and leads to the acceptance of volunteer caregivers. HBCOs can improve awareness by giving out educational pamphlets about HBC and volunteer caregiving. Also, leaders of the community could use their influence in working with the community and HBCOs through community *imbizo* (gatherings) to improve home-based care awareness and de-stigmatise HIV/AIDS.

### **5.3 Healthcare System**

The relationship of volunteer caregivers and nurses is crucial in ensuring an effective HIV/AIDS home-based care programme and a strong healthcare system. All volunteer caregivers

participating in focus groups indicated that there were tensions between them and nurses in community clinics. Volunteer caregivers discussed a number of instances where they were discriminated and ridiculed by nurses. The most common acts were those of being called derogatory names or being ridiculed for their work. This study also found that nurses were sometimes not co-operative with volunteer caregivers. They were made to wait in long queues in clinics to get their patients' medication when they still had home-visits to do. Like the community perceptions of volunteer caregivers, nurses also seemed to view carers and their caregiving work as of less value. They were seen as uneducated people who hold a low social status in the community.

Although Rodlach (2009) in a study done in Zimbabwe found that some volunteer caregivers felt discriminated by nurses who excluded them from healthcare workers' meetings in clinics, the study however did not report any overt stigmatisation or discrimination like the one reported in this study. On the contrary, Rodlach reports that nurses worked together with volunteer caregivers in deciding on which patients needed home-based care services. Judging from the participants' comments in our study, it does not look like there is a clear understanding of what the nurses and volunteer caregivers should expect from each other. This speaks to the poor relationship that volunteer caregivers have with professional health workers like nurses. And the main reason for this is that volunteer caregivers are not formally integrated into the health care system, hence it is easier for nurses to discriminate and treat them like outsiders. This discrimination is not based on HIV/AIDS, but it is the competitiveness of nurses and them looking down upon the caregiving work that volunteers do. Also, this tension between nurses and volunteer caregivers seems to emanate from nurses marking their professional territory, as the derogatory words they use towards volunteer caregivers emphasize that they are not nurses and therefore are non-professionals.

The findings on the discrimination of caregivers by nurses are in line with the work of Schneider, Hlophe & Rensburg (2008) where nurses were discriminating volunteer caregivers. In this study, it was reported that nurses excluded volunteer caregivers in their meetings and did not allow them to enter certain rooms. They did not approve of the suggestion that caregivers should wear uniform. Caregivers felt that they were treated like outsiders and were not welcomed as part of the health care team. Unlike our study, the study by Schneider and colleagues did not report that



nurses used any derogatory words to belittle the work that volunteers do or to emphasize that they are uneducated and unprofessional. However, nurses did demarcate their professional space as they were offended when people referred to volunteer caregivers as nurses.

This study adds new knowledge about the poor treatment and discrimination that volunteer caregivers receive from nurses in clinics. This calls for a great need to develop a good professional relationship between HBCOs and community clinics. This can be done through having a clear guide or policy on how volunteer caregivers and nurses work as a team in facilitating a better home-based care programme. Also, there could be ongoing meetings between caregivers and nurses since they interact with each other almost on a daily basis. This will eliminate the existing tension between volunteer caregivers and nurses and strengthen the relationship between HBCO and the Department of Health.

#### **5.4 Agents**

In this study, the main agents of stigma towards volunteer caregivers were 1) their own families or relatives, 2) families of patients 3) community (neighbours) and 4) nurses. Apart from the HIV/AIDS-related stigma they received, volunteer caregivers were also discriminated against due to the fact that their work was perceived as being of low-status and insignificant. Most volunteer caregivers reported that their families did not approve of the work they do. Some warned them of the possibility of being infected, and others ridiculed the work they do particularly because it was unpaid. All participants reported experiencing gossips, name-calling or ridicule from the communities they worked in. Throughout this study, the main themes that have been dominant in these discriminatory words used by both the community and nurses is that of volunteers' nature of work, it being unpaid and their level of education.

Due to HIV/AIDS being a highly stigmatised disease in the community, families of patients hid their sick members or denied that someone was ill when they were approached by volunteer caregivers. This was to avoid being discriminated by neighbours or other people in the community. Also, some family members did not trust volunteer caregivers and felt that they will go around gossiping about the ill person in the community. This is in line with the findings of Akintola's (2008a) study which revealed volunteer caregivers' persistence against the challenges of their work which include ridicule and stigmatisation. In Akintola's study, volunteer caregivers

also encountered resistance from families of patients who did not want to give them access to members of their families who were ill. Other studies have also reported similar findings on the behaviour of patients' families who refused help from volunteer caregivers (Campbell, Ann Foulis, Maimane & Sibiya, 2005; Hangu, 2012; Mills, 2006; Rodlach, 2009).

In this study participants reported being insulted by friends and acquaintances who were especially angered by the unpaid work that they did. The study further showed that volunteer caregivers worked in an environment where HIV/AIDS-related stigma towards PLWHA and carers was high. Some participants reported that members of their community perceived them as HIV positive because they cared for PLWHA. Dageid, Akintola & Saeberg (2015) also reported similar findings of people perceiving home-based caregivers as HIV positive. In a study done by Haber, Robyn and High-George (2011) which used both the qualitative and quantitative approach to explore the associate stigma on HIV/AIDS health care workers, it was other health care workers who assumed that their colleagues who work with PLWHA were also HIV positive. In this study which was conducted in the Eastern Cape Province in South Africa, participants included doctors, nurses, community health workers, counsellors as well as HIV/AIDS home-based caregivers.

The impact of secondary stigma on volunteer caregivers affects the quality and effectiveness of HIV/AIDS home-based care services. The discrimination and lack of co-operation from nurses also hinders caregivers' daily work. When caregivers are forced by nurses to stand in long clinic queues, they do not make it on time to do their home visit work which includes caring and preparing food to ensure that their patients adhere to taking medication. Some patients do not receive the kind of help they need when family members deny them access into their household due to the fear of being stigmatised by the community. The insults, discrimination and stigmatisation of volunteer caregivers destroy the love they have for their work. Volunteer caregivers reported that some of their colleagues decided to quit their work because of the discrimination, name-calling and insults they received from the community. The stigma and ridicule also resulted in an emotional burden and decreased morale for carers who were still doing their caregiving work. A South African study done in the Eastern Cape province on stigma by association revealed that associate stigma was one of the reasons mentioned by the 39% of healthcare workers (doctors, nurses, counsellors, home-based caregivers, community health care

workers) who reported contemplating leaving HIV/AIDS work (Haber, Roby & High-George, 2011).

Although studies have documented that volunteer caregivers suffer ridicule from friends and community members, this study has added to the literature by identifying the derogatory names used towards carers and has extended knowledge about the poor relationship that they have with nurses. Uys et al., (2005) have documented series of phrases which were mostly derogatory, used to refer to PLWHA. Also, Mills (2006) found that some people used hand signals to secretly refer to someone who is HIV positive. These derogatory words from these studies were directed to PLWHA, and not volunteer caregivers. No studies have explored specifically the kinds of derogatory names used by people to discriminate and stigmatise HIV/AIDS volunteer caregivers. The dominant themes that were carried by these derogatory terms were that volunteer caregivers are uneducated and that their work is of low status and detestable, particularly since it is unpaid. This confirms studies by Akintola (2008a) and Dageid, Akintola & Saeberg 2015 which revealed that volunteer caregivers were ridiculed and belittled because of the nature of caregiving work and that it is unpaid. A study done by Naidu and Sliiep (2012) on the agency of HIV/AIDS volunteer home-based caregivers in the rural community of KwaZulu-Natal indicates that the community saw volunteer caregiving as a work for the poor and desperate. These findings seem to be evidence that the general perception of volunteer caregivers held by the communities they work in is that of low-status and low regard. There is a great need to challenge this perception and portray HIV/AIDS volunteer caregiving as a dignified work within the health care sector. This may demand volunteer HIV/AIDS home-based caregiving to move from just being volunteerism to being a career (Akintola, 2015).

In order to change the communities' attitude towards volunteer caregivers, there needs to be a change in how HIV/AIDS volunteer caregiving is generally perceived. The incorporation of volunteer caregivers into the formal health system may significantly change perception about HIV/AIDS volunteer work, thus reducing the stigma and discrimination burden from caregivers. This was seen in this very study when volunteer caregivers reported to being respected and given time by the people they visit after they received name-badges from the department of health. HBCOs can also employ this creation of name-badges for their volunteers who are not yet under the department of health. Some caregivers also reported that after the introduction of stipends,

people started to inquire about home-based caregiving. This shows that if home-based caregiving can be a paying job, and have a more professional appeal, it could change people's perception of home-based care, thus reducing the stigma and discrimination that caregivers have to endure. This is why the integration of home-based caregivers into the formal health system through the policy of 're-engineering' PHC system is such a progressive attempt from the government. This could help improve the status of volunteers and in turn lead to them being treated with respect and dignity by both the communities they work for as well as other health care workers. This is likely going to improve volunteer caregivers' professionalism and create a positive appeal in their communities. It could also build a strong relationship between nurses and volunteer caregivers, thus reducing the discrimination they receive.

Volunteer caregivers mentioned that they see lack of information about HIV/AIDS and HBC as a reason behind the stigmatising behaviours they receive from the community and families of patients. This is why they sat the families of their patients down to counsel them about HIV/AIDS and HBC. This concurs with a study by Nyabblade et al., (2003) which showed that a lack of in-depth knowledge about HIV/AIDS was a cause for stigma towards PLWHA. Another study on the negative attitudes and perceived acts of discrimination towards PLWHA revealed that a lack of information about ARVs was associated with high negative attitudes towards PLWHA (Genberg et al., 2009). This signifies the importance of knowledge and information in fighting HIV/AIDS-related stigma. If communities are constantly empowered with such knowledge and awareness about HIV/AIDS, it could reduce HIV/AIDS-related stigma and secondary stigma towards volunteer caregivers.

## **Chapter Six: Conclusion and Recommendations**

### **6.1 Conclusion**

This study explored volunteer caregivers' experiences of secondary stigma, how it impacts on their daily work, and the ways they use to deal with or overcome HIV/AIDS secondary stigma. It also looked at the discrimination they receive just because they are volunteer caregivers. Apart from the psychosocial burdens of caring for PLWHA, this study reveals that volunteer caregivers worked in a context of high HIV/AIDS-related stigma. Most of them did not get support from their families as they disapproved of their work and were concerned that they are putting themselves at risk of being infected with HIV. Friends, community members, families of patients and nurses were the main agents of stigma and discrimination towards HIV/AIDS volunteer caregivers.

Gossips, ridicule, insults and name-calling were the discriminating and stigmatising behaviours that they had to face in their daily work of caring. The presence of volunteer caregivers in households was seen as a subsequent disclosure that someone is HIV positive. This resulted in some families denying volunteer caregivers access into their homes because of the fear of being discriminated. It was evident that volunteer caregivers held a lower social status within the community they worked in. The kind of ridicule, insults and name-calling from members of the community indicate that their work is devalued because they are unpaid and are perceived to be uneducated, and that they simply take care of people who are ill. Whilst the literature expounds that stigma towards volunteer caregivers is a heavy burden that is a cause for concern, this study adds knowledge about the perceptions and reasons behind the stigmatising attitudes as well as the discrimination that the community and nurses have towards volunteer caregivers. HIV/AIDS caregiving is seen as a low and insignificant work done by people who are uneducated, especially since it is unpaid. This is evident from the meaning laden derogatory words used by the community and nurses towards caregivers. The study also adds new knowledge about the poor work relationship between volunteers and nurses, and the kind of discrimination and mistreatment they receive from nurses in clinics.

This study found that the discrimination of volunteer caregivers by the nurses in community clinics was highly common. Participants reported that nurses insulted and called them names,

and were sometimes not co-operative with the work that they did. This affected the effectiveness of their work. Though the environment they worked under is still saturated with HIV/AIDS-related stigma, volunteer caregivers reported that compared to the time they started caring for PLWHA, secondary stigma and stigma towards PLWHA is steadily diminishing. They attribute this to the introduction of ART which has eased their burden of care and has made HIV/AIDS to be seen as a manageable disease. HBC work has also contributed in the education of communities about HIV/AIDS, thus reducing HIV/AIDS-related stigma and increasing volunteer caregivers' acceptance in the community. However, there exists a need to explore more effective strategies related to HIV/AIDS stigma since a lot of community education has been taking place with little results. Volunteer caregivers were able to withstand the insults and discrimination they encountered by ignoring and letting it pass. They also used education, counselling and negotiation skills as their weapon against families of patients who were denying them access to care for their sick family members. This was also another way to curb HIV/AIDS stigma. The introduction of name-badges were also effective in reducing stigma towards volunteer caregivers and increasing their professionalism, and hence their social status in the community. Yet, more interventions are still needed to create a conducive working environment for volunteer caregivers and to reduce the burden of HIV/AIDS-related stigma they face each day of their lives.

## **6.2 Recommendations**

- HIV/AIDS Home-based care organisations and volunteer caregivers are playing a crucial role in the fight against HIV/AIDS-related stigma. Education and information about HIV/AIDS and HBC helps to reduce the stigmatising attitudes and behaviours held by the community. In order to improve this, HBCOs can have educational pamphlets (defining who they are and what they do) that they can give to the community and family members of their patients or potential patients. This could increase awareness of HIV/AIDS and HBC, thus decreasing stigma towards volunteer caregivers. There is a gap to also use more effective alternative strategies for education in communities.
- There is a huge need for nurses, HBCOs and volunteer caregivers to work together in improving home-based care services. Due to the discrimination that volunteer caregivers receive from nurses, there is a need for nurses to be trained on HIV/AIDS-stigma, the importance of HBC and the significance of volunteer caregivers. There should also be a

clear understanding and expectation between nurses and volunteer caregivers regarding the work they do and how it collaborates. This will improve the poor working relationship between nurses and volunteer caregivers. The anticipated integration of volunteer caregivers into the formal health care system could be a huge step in bringing their dignity, as well as strengthening relations with other health care workers like nurses. This will give home-based caregiving a more professional appeal and a higher social status. As a result, it could reduce the secondary stigma as well as the discrimination that they experience in the hands of nurses and the community as a whole.

- Due to the stigmatisation volunteer caregivers receive from the communities they work in, it is important for HBCOs to collaborate with community leaders. This will influence the behaviour of community members to be less stigmatising towards volunteer caregivers and can increase their acceptance in the community.
- The improvement of volunteer caregiving to be seen as more professional is important in reducing discrimination and secondary stigma. It is recommended that volunteer caregivers should have name badges and uniforms (whether from the department of health or HBCOs). This will increase their social status and reduce the insult and discrimination they receive from the community, as seen in the findings of this study. Although this is already happening, it is only so in some of the caregivers.
- The proper remuneration of volunteer caregivers will increase their social status, thus decreasing secondary stigma. This is evident in the literature as well as this study. Currently, only a few volunteer caregivers are receiving stipends. This could also eliminate their feelings of being excluded from the formal health sector
- It is worth noting that the very presence of volunteer caregivers in communities increases empathy for the stigmatisation of PLWHA. Thus their on-going community home-based care work will continue to actively break down HIV/AIDS-related stigma.

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## Appendix A: Interview Questionnaire

### Demographics

- What is your age?
- How long have you been working as a volunteer caregiver?
  
- What does your family say about your work as a caregiver?
- How do family members of the patients you care for respond to the help you offer? How do they treat you?
- How is your relationship with the nurses from the clinic?
- What is the attitude of the community towards HIV/AIDS caregivers?
- How do they (community) treat volunteer caregivers?
- How often do you experience stigmatization and discrimination because of the work that you do?
- Can you give me experiences where you were discriminated against because of being associated with PLWHA?
- How has this affected you and your daily work?
- How do you deal with secondary stigma and discrimination that is directed towards you?

## **Appendix B:**

### **Introducing the Study to Participant before the interview**

#### **Experiences of Secondary Stigma on HIV/AIDS Home-based Caregivers and how theyCope**

Good Morning, /afternoon/evening, my name is PhephelaniZondi. I am an honours student School of Psychology, University of Kwa-Zulu Natal, 4041, Durban, South Africa. I am conducting research on home-based caregivers' experiences of secondary stigma and how they cope. I would like to speak to you only if you agree to speak to me.

This discussion will take about 40 minutes-1 hour. I will ask you about your personal experiences regarding the stigma and discrimination you have encountered in your care-giving. I will need your permission to use audio-tape recorders to capture our discussion.

All information that you give will be kept confidential. The information collected will be stored in my 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 department and government in carrying out effective home-based care/ the problems that your organization has in accessing support for home-based care

Your participation in this study is voluntary and you have the right not to talk to us if you do not want to. 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 0835711509 (PhephelaniZondi) or Dr O. Akintola (supervisor) on 031 2607426.

**Informed consent**

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)

**IsiZulu Version**

IncwadiYemvume

Mina,

\_\_\_\_\_ Sengifundilemayelananokuqukethweyinhlolovofuthingiyaqondaizincazelo zenhlolovonjengobangazisiwefuthingachazelwangazongomlomo.

Isiphendulekileimibuzoyamingalenhlolovo, ngakhongiyaqondaukuthiyinielindelekekiminaumangibayingxenyeyalenhlolovo

Signature \_\_\_\_\_ Usuku: \_\_\_\_\_

**Informed Consent for the use of voice-recorders**

I \_\_\_\_\_ agree to the use of a voice recorder during the focus group interviews.

**IsiZulu Version**

**Imvume yokusetshenziswa kwesiqo-phamazwi**

Mina \_\_\_\_\_  
ngiyavumaukubakusetshenziswe isiqophamazingesikhathisengxoxoyenhlobo.