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**The implications of Stigma towards People Living with HIV/AIDS in the
Township of Dimbaza, Buffalo City Metropolitan Municipality.**

By

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DECLARATION

I, the undersigned, Sindiswa Xabendlini, hereby declare that the work contained in this dissertation is my own work, except where due acknowledgement is made with full references in the text. This document has not been previously submitted to any university or institution of higher learning for any qualification or certificate.

Signature:

Date:

DEDICATION

This research is dedicated to my parents Julius and Vivian Xabendlini, who supported me throughout my education and showed me that through hard work everything is possible. I wouldn't be here today if it wasn't for them. I would also like to express my gratitude to my nephew, Thembaletu Seti and my niece, Vuyolwethu Xabendlini for their support and for believing in me that I can do this.

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ABSTRACT

HIV/AIDS-related stigma is still a stumbling block to HIV/AIDS prevention strategies in many communities. The phenomenon of stigma affects the social functioning of HIV positive individuals and their mental state as well. This study therefore, sought to explore the implications of stigma towards people living with HIV/AIDS (PLWHA) in the Township of Dimbaza. Multiple sources of data or data triangulation were employed. The study made use of individual in-depth interviews which consisted of 10 individuals who were HIV positive from an organisation working with PLWHA in the township and a focus group discussion comprising of 8 practitioners. Thematic analysis was employed to analyse data and the strengths perspective was used as a lens for discussing the research findings.

The findings showed that PLWHA and community members had accepted HIV/AIDS through empowerment from HIV/AIDS debates, but stigma still existed among some people. It was found that mythical beliefs which were propelled by some traditional leaders were vehicles of stigma. Results also revealed that PLWHA were stigmatised by some of the practitioners who were supposed to protect them. PLWHA showed their potential and strengths in dealing with stigma but required more assistance and support to encourage them. Therefore, it was recommended that assistance from eclectic stakeholders for the sustainability of their activities to reduce HIV/AIDS-related stigma and to get strengthened would make them achieve their intended goals on their own.

Contents

DECLARATION	i
DEDICATION	ii
ACKNOWLEDGEMENTS	iii
ABSTRACT	iv
LIST OF TABLES	ix
ACRONYMS AND ABBREVIATIONS	x
CHAPTER ONE	1
1.1 Introduction	1
1.2 Background to the study	1
1.2 Problem statement	3
1.3 Aims and objectives	4
1.4 Research Questions	4
1.5 Delineation and Scope of the Study	5
1.6 Significance of the study	5
1.7 Limitations of the study	5
1.8 Chapter Outlines	6
1.9 Conclusion	7
CHAPTER TWO	8
2.1 Introduction	8
2.2 History of stigma in South Africa as a result of HIV/AIDS	8
2.3 Stigma and discrimination	10
2.3.1 Self-stigma	13
2.4 HIV/AIDS-related stigma and mental health	14
2.5 Myths and misconceptions associated with HIV/AIDS	17
2.5.1 Traditional myths and HIV/AIDS	19
2.6 HIV/AIDS and religion	22
2.7 Gender and HIV/AIDS-related stigma	24
2.8 HIV/AIDS-related stigma and human rights	27
2.9 HIV/AIDS and poverty	30
2.10 Conclusion	32
CHAPTER THREE	33
3.1 Introduction	33

3.2	HIV/AIDS and disclosure.....	33
3.3	Door to door campaigns and behaviour change	35
3.4	Enhancing support and care	36
3.5	Promoting voluntary counselling and testing (VCT).....	38
3.6	HIV/AIDS and curriculum.....	41
3.7	Theoretical framework.....	43
3.7.1	Strengths Perspective.....	43
3.8	Conclusion	49
CHAPTER FOUR		50
4.1	Introduction	50
4.2	Research paradigm	50
4.3	Research Design.....	51
4.3.1	Specific research design	52
4.3.2	Characteristics of qualitative approach.....	53
4.4	Methods of data collection and data collection instrument	55
4.4.1	In-depth interviews	56
4.4.2	Focus group discussion.....	57
4.4.3	Re-interviewing	58
4.5	Research domain.....	58
4.5.1	Historical background	59
4.5.2	Population	59
4.5.3	Politics	60
4.5.4	Economic activities.....	60
4.5.5	Health care facilities.....	61
4.5.6	Social activities.....	61
4.5.7	Social-ills.....	62
4.6	Population of the study.....	62
4.7	Specific sample size.....	63
4.8	Sampling procedure	64
4.9	Data analysis	64
4.9.1	Thematic Analysis.....	65
4.9.2	Reporting of the findings	66
4.10	Validity and reliability	66
4.10.1	Strategies to increase trustworthiness	68

4.11	Ethical considerations	71
4.11.1	Confidentiality and Anonymity.....	72
4.11.2	Informed consent.....	72
4.11.3	Voluntary participation	73
4.12	Conclusion.....	73
CHAPTER FIVE	75
5.1	Introduction	75
5.2	Theme 1: Biographical information	76
5.3	Theme 2: Perceptions of community members about HIV/AIDS	78
5.3.1	Sub theme 1: Negative attitudes from community members	79
5.3.2	Sub-Theme 2: HIV/AIDS and promiscuity	80
5.3.3	Sub-theme 3: Feminization of HIV/AIDS.....	81
5.4	Theme 3: Positive community responses	82
5.4.1	Sub-theme 1: Acceptance of HIV/AIDS	83
5.4.2	Sub-theme 2: Support and care from community members.....	84
5.4.3	Sub-theme 3: Community outreach	86
5.5	Theme 4: Self-stigma	88
5.5.1	Sub-theme 1: Misuse of HIV seropositive status	88
5.5.2	Sub-theme 2: Labeling of PLWHA	90
5.6	Theme 5: Challenges faced by PLWHA in health-care settings.....	91
5.6.1	Sub-theme 1: Stigmatizing attitudes from health-care workers	92
5.6.2	Sub-theme 2: Differentiating folders of PLWHA.....	93
5.7	Theme 6: Cultural challenges faced by PLWHA	94
5.8	Theme 7: Recommendations by PLWHA	95
5.8.1	Sub-theme 1: Support from community members.....	95
5.8.2	Sub-theme 2: Support from various stakeholders.....	96
5.9	Conclusion	99
CHAPTER SIX	100
6.1	Introduction	100
6.2	Discussion of major findings	100
6.2.1	Theme 1: Biographical profile of participants.....	100
6.2.1.1	Sub-theme 1: Gender of the participants.....	102
6.2.1.2	Sub-theme 2: Age distribution of participants.....	102

6.2.1.3	Sub-theme 3 : Marital status.....	103
6.2.1.4	Sub-theme 4: Occupation of participants.....	104
6.2.1.5	Sub-theme 5: Number of dependents.....	104
6.2.1.6	Sub-theme 6: Educational qualifications.....	105
6.2	Theme 2: Perceptions of community members about HIV/AIDS	105
6.2.1	Sub-theme 1: Negative attitudes from community members.....	105
6.2.2	Sub-theme 2: HIV/AIDS and promiscuity	106
6.2.3	Sub-theme 3: Feminization of HIV/AIDS	106
6.3	Theme 3: Positive community responses	108
6.3.1	Sub-theme 1: Acceptance of HIV/AIDS	108
6.3.2	Sub-theme 2: Support and care from community members.....	109
6.3.3	Subtheme 3: Community out-reach	110
6.4	Theme 4: Self-stigma	111
6.4.1	Sub-theme 1: Labeling of PLWHA	112
6.5	Theme 5: Challenges faced by PLWHA in health-care settings.....	113
6.6	Theme 6: Cultural challenges faced by PLWHA	116
6.7	Theme 7: Recommendations by PLWHA	117
6.7.1	Sub-theme 1: Support from various stakeholders.....	118
6.8	General Conclusions.....	119
6.8.1	The impact of HIV/AIDS-related stigma on PLWHA.....	119
6.8.2	Support and care for PLWHA	120
6.8.3	Sustainability of activities to curb HIV/AIDS-related stigma.....	121
6.9	Recommendations	123
6.9.1	Recommendations for PLWHA and community members	123
6.9.2	Recommendations for Social Work Practice.....	124
6.9.3	Recommendations for the Eastern Cape Government and NGOs.....	125
	REFERENCES.....	127
	APPENDICES	145
	APPENDIX A: INTERVIEW GUIDE FOR PEOPLE LIVING WITH HIV/AIDS (PLWHA)	145
	APPENDIX B: INTERVIEW GUIDE FOR FOCUS GROUP	150
	APPENDIX C: INFORMED CONSENT FORM	156
	APPENDIX D – TRANSCRIPTS.....	157
	APPENDIX E: ETHICAL CLEARANCE FORM.....	212

LIST OF TABLES

Table 4.1: Sample size presentation	63
Table 4.2: The comparison of trustworthiness by research approach	68
Table 4.3: Summary of strategies to establish trustworthiness	71
Table 5.1: Biographical information of participants from individual interviews	76
Table 5.2: Biographical profile of focus group	78

ACRONYMS AND ABBREVIATIONS

HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
PLWHA	People Living with HIV/AIDS
UNAIDS	Joint United Nations Programme on HIV/AIDS
STDs	Sexually Transmitted Diseases
NGOs	Nongovernmental Organisations
FBOs	Faith Based Organisations
FBI	Federal Bureau of Investigation
ARVs	Antiretroviral
MTCP	Mother to Child Prevention
USAID	United States Agency for International Development
GIP	Global Initiative Psychiatry
WFMH	World Federation for Mental Health
NASTAD	National Alliance of State & Territorial AIDS Directors
UNDP	United Nations Development Programme
BCEA	Basic Conditions of Employment Act
TAC	Treatment Action Campaign

CEDAW	Convention on the Elimination of all forms of Discrimination Against Women
MDG	Millennium Development Goals
OVCs	Orphans and Vulnerable Children
HBC	Home-Based Care
VCT	Voluntary Counselling and Testing
UNICEF	United Nations International Children’s Emergency Fund
TB	Tuberculosis
SAPS	South African Police Services
CSG	Child Support Grant
RSPH	Royal Society for Public Health
HRSC	Human Sciences Research Council
ICCPR	International Covenant on Civil Political Rights

CHAPTER ONE

GENERAL OVERVIEW OF THE STUDY

1.1 Introduction

This chapter presents the general orientation of the study. It provides the background of the study and highlights the initial interest in conducting the study. This chapter demonstrates how the research contributes to society at large in addition to how it might add knowledge to the available literature. The outline of the ensuing chapters is also presented here.

1.2 Background to the study

The present study seeks to explore the implications of stigma towards people living with HIV/AIDS (PLWHA). Parker & Aggleton (2002) identified that stigma is a continuing challenge that prevents concerted actions at community, national and global level. Stigma also goes hand in hand with discrimination because PLWHA's basic rights are violated. This chapter includes the problem statement, research aims and objectives, research questions, methodology, significance of the study; delineation and scope of the study, limitation of the study; chapter outline and conclusion.

Stigma associated with Human immunodeficiency virus and Acquired immune deficiency syndrome (HIV/AIDS) remains a barrier to effective strategies of mitigating HIV/AIDS-related globally. The Sub-Saharan Africa has a serious HIV/AIDS epidemic. It is estimated that out of 10 million HIV infected people, 62% live in Sub-Saharan Africa (Amornkul, Vandenhoudt, Nasokho, Odhiambo & Mwaengo, 2009).

Estimates of 2011 national HIV prevalence in South Africa was 29.5% and the estimated number of new infections was 1.43%. Based on the findings of 2011 antenatal survey, the province of the Eastern Cape has estimated an average of 16.02% HIV prevalence (The National Antenatal Sentinel HIV and Syphilis Prevalence Survey, 2011). It is indicated that in South Africa, cases of people stigmatizing those living with HIV/AIDS are on the increase (Human Sciences Research Council, 2008).

Throughout the history of mankind many diseases have carried considerable stigma, including tuberculosis, cancer, mental illness and sexually transmitted diseases such as gonorrhoea, but HIV/AIDS is the latest disease to be stigmatized (UNAIDS, 2008). Heymans (2008) asserts that stigma is social identity devaluation due to a characteristic mark or feature and it imposes a discredited status resulting in personal or social rejection. HIV/AIDS is stigmatized because some people view it as the most dreadful disease more than other chronic illnesses and ignore the fact that HIV is manageable. It is also indicated that stigma towards people living with HIV/AIDS in the Sub-Saharan Africa has left many individuals scared of being tested for HI virus and disclosing their statuses (UNAIDS, 2010).

Stigma related to HIV/AIDS has a gender dimension (Juma & Klot, 2011). This is because women living with HIV/AIDS are regarded as immoral compared to other women who are not HIV positive. Women, therefore, do not want to disclose their statuses to avoid being isolated. Moreover, they are perceived as transmitters of sexually transmitted diseases (STD's) more than men. Women are often culturally, economically and socially disadvantaged; they lack equal access to treatment,

financial support and education. It is argued that 60% of all new HIV infections in the Sub-Saharan Africa are contracted by women and are particularly vulnerable as a result of their biological make-up (UNAIDS, 2008). The UNAIDS (2008) attests that South African women between the ages of 20 and 24 have a prevalence rate of 23,9 percent, whereas men in the same group have a prevalence rate of only 6 percent. This explains the feminization of AIDS and also needs to be dispelled in our communities.

Ignorance about HIV/AIDS from the Township of Dimbaza motivated the researcher to come up with this study. This came into light after the researcher observed the issue of stigma related to HIV/AIDS on people living with HIV/AIDS in the Township of Dimbaza. Therefore, this study seeks to explore how stigma affects those who are infected by HIV/AIDS in the Township of Dimbaza.

1.2 Problem statement

The prevalence of stigma related to HIV/AIDS continues to spell a blow to the success of HIV/AIDS prevention globally. The UNAIDS (2005) reveals that educational programmes aimed at preventing HIV/AIDS-related stigma have been implemented to reduce stigma. Programmes and activities in a range of countries have designed strategies to tackle stigma and the approaches have worked holistically (UNAIDS, 2005). These strategies, however, need to be well implemented. This is because people take time to adapt to these strategies due to the myths surrounding HIV/AIDS. This has delayed strategies which were aimed at curbing HIV/AIDS-related stigma. It is argued that 57% of adults infected by HIV/AIDS are women and 75% are young girls in Africa (UNAIDS, 2005). These high

percentages explain the perfidious nature of myths associated with HIV/AIDS which put these young girls and women susceptible to HIV/AIDS infections. The researcher of the present study has observed that amongst the residents of the Township of Dimbaza, HIV positive individuals are stigmatized and treated unfairly because of the false beliefs held about HIV/AIDS. Women who are HIV positive in the Township of Dimbaza continue to face discrimination and violence. The present study therefore seeks to dispel the myths that lead to stigma amongst communities.

1.3 Aims and objectives

The broad aim of the study was to explore the implications of stigma towards people living with HIV/AIDS in the Township of Dimbaza. The study was guided by the following specific objectives:

- To explore how stigma affects People Living with HIV/AIDS (PLWHA) in the Township of Dimbaza.
- To explore strategies that can be applied by community members to reduce the stigma associated with HIV/AIDS in the Township of Dimbaza.
- To examine services offered by service providers to curb stigma on people living with HIV/AIDS in the Township of Dimbaza.

1.4 Research Questions

This study sought to answer the following research questions:

- How does the stigma affect PLWHA in the Township of Dimbaza?
- What strategies can be applied by community members to reduce the stigma associated with HIV/AIDS in the Township of Dimbaza?

- What services can be offered by service providers to curb stigma on PLWHA in the Township of Dimbaza?

1.5 Delineation and Scope of the Study

The study explored the implications of stigma towards PLWHA using a case study of the Township of Dimbaza in the Eastern Cape Province of South Africa. Ten PLWHA were interviewed and eight practitioners participated in a focus group discussion.

1.6 Significance of the study

The findings will help the policy makers to formulate policies which will reduce the state of stigma towards PLWHA. The Township of Dimbaza will also benefit from the study as it will acquire a broader knowledge about HIV/AIDS. That will hopefully reduce the stigma associated with HIV/AIDS disease. It will also help other researchers to acquire more information about stigma associated with HIV/AIDS. It is also important in Social Work Practice because it will help Social Workers to have an understanding about the implications of stigma associated with HIV/AIDS.

1.7 Limitations of the study

People living with HIV/AIDS may not want to speak out or to disclose the information and they may fear disclosure of their identities. The researcher, therefore, sought permission from an Non-Governmental Organization (NGO) that works with people living with HIV/AIDS. Furthermore, face to face interviews are time consuming. The researcher took some time to complete the interviews as each interview took approximately one hour. Interviews were conducted in Xhosa and some phrases

may have lost their meaning, then they were translated in English through the help of the supervisor.

1.8 Chapter Outlines

This study is made up of six chapters which are briefly described below:

Chapter One: General overview of the study

This chapter provides background information on stigma related to HIV/AIDS. It describes the current state of knowledge about stigma associated with HIV/AIDS. This chapter further provides research objectives and questions.

Chapter Two: The perfidious nature of stigma of people living with HIV/AIDS (PLWHA)

This chapter forms the discussion of literature that relate to stigma related to HIV/AIDS such as the history of HIV/AIDS-related stigma in South Africa and the myths associated with HIV/AIDS. It also shows how the study fits on what has already been done and how it will also lead to new knowledge.

Chapter Three: Strategies to curb HIV/AIDS-related stigma

Approaches to curb HIV/AIDS-related stigma are provided in this chapter as well as the theoretical framework that is applied as the lens of the study which is the strengths perspective.

Chapter Four: Research Methodology

This chapter gives a description of the research methodology employed in the study. All tools used to collect data are provided in this chapter. It also contains ethical issues and significance of the study.

Chapter Five: Presentation of the findings

This is where the results are presented and analysed an in-depth discussion of the findings is made in this chapter.

Chapter Six: Discussion of major findings, Conclusions & Recommendations

This chapter is a discussion of major findings or experimental outcomes of the findings. Recommendations for social work practice, PLWHA and community members, NGOs and FBOs as well the government are suggested.

1.9 Conclusion

It can be noted that HIV/AIDS-related stigma affects people living with HIV/AIDS on a daily basis. Some people in communities are unaware about some issues that result in jeopardy of PLWHA's well-being. This prompted the researcher to carry out the research study on the implications of stigma towards people living with HIV/AIDS. The following chapter discusses the previous literature studies on how stigma affects people living with HIV/AIDS.

CHAPTER TWO

THE PERFIDIOUS NATURE OF STIGMA ON PEOPLE LIVING WITH HIV/AIDS (PLWHA)

2.1 Introduction

This chapter provides literature that relates to the implications of stigma associated with HIV/AIDS. The literature is reviewed in more analytical ways by comparing and contrasting different views from a variety of authors. It also shows how the present study fits on previous literature about HIV/AIDS-related stigma. Firstly, the origin of stigma as a result of HIV/AIDS which is the daily problem of people living with HIV/AIDS (PLWHA) is highlighted. Myths associated with HIV/AIDS are explored because they result in people being stigmatised. This often happens within their families, communities and institutions such as schools, work places and churches. Approaches to dismiss false information about HIV/AIDS are essential. This will make people to respond positively to HIV/AIDS and adhere to strategies that are designed to curb HIV/AIDS-related stigma.

2.2 History of stigma in South Africa as a result of HIV/AIDS

In South Africa, people at first linked AIDS with gay men because it first appeared from two homosexual cases and the government at that time warned the public that HIV/AIDS is found in high risk groups such as homosexuals and drug addicts (Busiek-Johns, 2009). This author indicated that the government implied that people should be protected from the marginalised groups rather than the marginalised group being protected from the virus. In 1987, studies showed a high level of infection

amongst Malawian gold miners (Bassett-Grant, Heywood, Fine & Strode, 2001). During the apartheid era the blame shifted to terrorists coming from other African countries and presently, many people think AIDS is a black disease (Bassett-Grant et al., 2001). All these attitudes resulted in the rapid spread of HIV virus (Bassett-Grant et al., 2011). This is supported by Van Dyk (2012) who states that HIV/AIDS in South Africa was initially with homosexual men, haemophiliacs and blood transfusion only. Van Dyk (2012) further argues that some conspiracy theories believe that the Federal Bureau of Investigation (FBI) developed the virus to destroy third world countries. Van Dyk (2012) also notes that the conspiracy theories believed that it was developed by the apartheid government in South Africa.

These author's views demonstrate that although HIV/AIDS was discovered in the early 1980's, it becomes the world's greatest threat as it has killed many people worldwide. Apparently the government had an impact on HIV/AIDS-related stigma as it is illustrated by Busiek-Johns (2009) that people were protected to those who were perceived as transmitters of HIV/AIDS. Due to mythical beliefs surrounding HIV/AIDS that emerged from its discovery, HIV/AIDS prevention strategies could delay because of false beliefs about the disease. This illustrates that stigma has come a long way where certain groups of people were associated with HIV/AIDS and carried a burden of being HIV/AIDS transmitters. This is also an indication that false information about HIV/AIDS existed from its conception. These historical views lead the level of HIV/AIDS infection to rise rapidly. The state of HIV/AIDS-related stigma also rise which make people to be hesitant to seek accurate information about HIV/AIDS. Strategies to dispel these historical views need to be well implemented as

it appears that some of people in communities still hold these historical myths about HIV/AIDS.

2.3 Stigma and discrimination

Genrich & Brathwaite (2005) note that HIV/AIDS epidemic is driven by stigma and discrimination which are the major concerns of HIV infection and death from HIV-related complications. Stigma and discrimination shifted away peoples mind set from preventive measures of HIV/AIDS. This made people to compromise their response to the prevention of HIV/AIDS. This leaves South Africa having the highest number of people living with HIV/AIDS and the increasing state of HIV/AIDS-related stigma (Kang ethe & Xabendlini, 2014). This is supported by Rehle & Shisana (2009) who indicate that the total number of persons living with HIV/AIDS in South Africa increased from an estimated 4 million in 2002 to 5.26 million by 2013.

Stigma originates from ancient Greek where outcast groups were branded and marked as a permanent measure of their status which was deemed as inferior (Zachungnunga, 2012). In HIV/AIDS-related stigma literature, stigma is referred to as a mark or disgrace (Mahajan, Sayles, Patel, Remien, Ortiz, Szekeres, & Coats, 2008). According to Goffman (1963) (in UNAIDS, 2010) stigma is an undesirable or discrediting attribute that an individual possesses, thus reducing that individual status in the eyes of the society. This is supported by Shisana (2004) cited in Mlobeli (2007) who defines stigma as consigning someone to a category that attaches on him/her a label of being undesirable. These scholars explain the perturbing situation of PLWHA who are categorised to a certain group because of their HIV seropositivity

and stigma seems to be attached to PLWHA because of differentiating HIV/AIDS to other illnesses.

HIV/AIDS is a highly stigmatised health condition and people living with HIV/AIDS are most likely to be stigmatised and discriminated more than others (Deacon & Boule, 2007). AIDS has been identified as the deadly disease that can ultimately lead to death (UNAIDS, 2008). According to the statement made by the UNAIDS (2008), being a deadly disease does not necessarily portray it as death sentence; it merely suggests that HIV/AIDS is more like other chronic illnesses that are not curable but manageable. Therefore, people have to bear in mind that being HIV positive does not mean that someone is going to die instantly especially if one takes medication. The UNAIDS (2010) observed the lack of information on HIV virus as the reason that lead people to perceive HIV/AIDS as a death sentence.

Furthermore, it is indicated that people living with HIV/AIDS do not face medical problems only but they also face social problems associated with the disease (Mbonu, Van Den Borne & De Vries, 2009). These authors point out that stigma is also used to set the affected individuals or groups apart from the normalized social order and this results in the exclusion of PLWHA within their communities; for example PLWHA in some cultural and religious groups are not allowed to participate in some activities within the community, they are regarded as “dirty”. Mbonu et al. (2009) further argue that stigma is the barrier to reach those who are at risk and the ones who are infected by HIV/AIDS, meaning that stigma hinders the strategies to curb HIV/AIDS- related stigma.

A suggestion put forward by Parker & Aggleton (2002) is that stigma and discrimination in families and communities are commonly manifested in the form of blame, scapegoat, and punishment. These scholars state that PLWHA are shunned and gossiped by communities, in some cases stigma and discrimination is practised through the form of violence. This leads people not to tell their close friends and families about their status because they fear being labelled or physically abused. Mbonu et al. (2009) indicate that stigma enhances denial by PLWHA because they fear disclosing their seropositivity. Despite the negative impact of stigma on people living with HIV/AIDS, there has been a limited number of intervention studies aimed at reducing HIV/AIDS stigma (Sengupta, Banks, Jonas, Miles & Smith, 2011). This means that there is a need to fill the gap of limited intervention studies to mitigate HIV/AIDS-related stigma.

South Africa's aim of curbing HIV/AIDS epidemic and HIV/AIDS-related stigma has been confused by the controversy which came up with the former president Thabo Mbeki and the late former Health Minister towards antiretroviral (Nattrass, 2005). During his presidency, Thabo Mbeki supported the AIDS denialists who believed that HIV is non-toxic. They believed that AIDS signs are the results of antiretroviral (ARVs) and malnutrition (Nattrass, 2005). This led the Health Minister by the time the late Manto Tshabalala-Msimang to refuse the introduction of antiretroviral for mother to child transmission prevention (MTCP) until she was forced to do so by a Constitutional Court in 2001 (Mbali, 2004). The late Health Minister promoted the use of beetroot, garlic and lemon juice as immune boosters for PLWHA and people were encouraged to use them instead of antiretroviral drugs (Mbali, 2004). This pseudo-science led to a high mortality rate in South Africa during Thabo Mbeki's

presidency. Seemingly people are misled by statements that are not scientifically proven and this becomes a huge problem because people experience suffering which leads to death at times.

Strategies to curb stigma and discrimination still need to be well implemented to communities because people still believe in myths which lead to HIV/AIDS related stigma. Some of these myths are perpetrated by people who are supposed to be role models. This is elaborated in the next section.

2.3.1 Self-stigma

There is another dimension of stigma that has received less attention from researchers and programme planners which is called self-stigma or internal stigma (USAID, 2006). Self-stigmatization is a term for the shame that a person can feel over his or her own situation (Mlobeli, 2007). Zachungunga (2012) takes the argument further by maintaining that self-stigma is the shame that people living with HIV/AIDS experience and the blame they put on themselves when they internalise the negative responses and reactions of others. It is argued that self-stigma can lead to depression, withdrawal and feeling of worthless (Zamuchnunga, 2012). This explains that when a person internalise his or her feelings, the social functioning becomes impaired because of guilt that is felt by an individual who is HIV positive. Self-stigma or internal stigma can also be the survival strategy which is aimed at protecting oneself from external stigma. This can result in the reluctance of HIV/AIDS disclosure and it prevents the delivery of medical care. This can be the serious implication of increased HIV/AIDS infections because some people do not disclose their HIV positive status to their partners.

According to Parker & Aggleton (2002) self-stigma is linked with what some researchers called, perceived and enacted stigma. Parker & Aggleton (2002) point out that these types of stigma are actions from others that are discriminatory. According to Hasan, Nath, Khan, Akram, Gomes & Rashid (2012), stigma is an imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute and an enacted stigma refers to the actual experience of discrimination. External stigma is rooted mainly in fear and judgement of what is different and is an attempt to promote social order but it breaks down communities (Hasan et al., 2012). These scholars reflect that perceived and enacted stigma seem to link because people experience discrimination due to stigma, and discrimination leads to internal stigma because some of PLWHA blame themselves for being HIV positive.

2.4 HIV/AIDS-related stigma and mental health

Apparently there is a link between HIV/AIDS and mental health (The Global Initiative on Psychiatry [GIP], 2006). The GIP articulates that developing AIDS or being HIV positive has an impact on the mental health of individuals who are affected. The GIP (2006) indicates that all chronic, life-threatening conditions bring particular stressors such as long term discomfort, physical deterioration, physical and financial dependence and the prospect of untimely death. It is argued that not every person will develop mental illness, but there are factors that increase the vulnerability of mental problems, such as poverty, gender inequalities, and substance abuse are contributing factors of mental illness (GIP, 2006). This is supported by Cox (2014) who affirms that HIV/AIDS may trigger emotional trauma and manifestation of mental health disorders or engaging in addictive behaviours. PLWHA may suffer from

mental illness due to the fear of the treatment they would receive within their environments.

The GIP (2006) also suggests that these stressors influence PLWHA to hazardous behaviours such as the use of drugs and becoming sex workers. This exemplifies that HIV/AIDS stigma hampers the well-being of PLWHA because they tend to lose hope when they are not accepted within their milieu. The GIP (2006) also mentions that failing to treat mental illness can lead to decreased survival time, reduced survival time and difficulties to adhere to HIV/AIDS treatment. In a research study conducted by Freemans, Patel, Collins & Bertolote (2005), they discovered that research in mental health and HIV/AIDS is very little and this results in the rapid spread of HIV/AIDS because people are not aware about the impact of HIV/AIDS on the mental health of PLWHA.

The discussion held at the World Federation for Mental Health (WFMH) in January 2008, Cape Town, focused on themes such as poor access to mental health care for people infected and affected by HIV (Anderson, 2008). The discussion also combined themes such as poor access to HIV prevention, care and treatment for people with mental health needs. In this debate the participants revealed the issue of poorly trained providers and huge gaps in the capacities of service delivery systems which lead to undue suffering, loss of quality of life and adherence to HIV prevention, treatment and AIDS programs. Anderson (2008) and leaders from different organisations within AIDS and mental health fields explored mental health needs for all aspects of AIDS response with particular attention on the needs of care givers,

PLWHA, and vulnerable children. These leaders concluded by stating that it is clear from the grassroots partners and members that there is a demonstrated need for strengthened mental health services which will address stress management, social support and self-esteem among people living with HIV/AIDS.

In Anderson's (2008) report it is pointed out that the research presented by the South African Depression and Anxiety Group and Wits University, it found that 89% of home based care workers in North West and Mpumalanga provinces were depressed or showed signs of depression. It is also reported that a study in Zambia showed that 85% of HIV positive women had episodes of major depression with suicidal ideation and other studies conducted in the East of Southern Africa revealed the increased depression and suicide among AIDS orphans (GIP, 2006).

There is another dimension of mental disorder which is linked to HIV/AIDS. In the research conducted by the National Alliance of State & Territorial AIDS Directors (NASTAD) (2005), it is suggested that sexual compulsivity represents a discrete clinical problem. It is said that people with the condition of sexual compulsivity tend to have strong sexual desires, preoccupied with sexual thoughts, lose control over their sexual desires and also spend most of their time in sexual activities (NASTAD, 2005). People suffering from this disorder tend to show signs of mood disorders, anxiety disorders and substance use disorders. Meuch & Parsons (2004) cited in NASTAD (2005) suggest that the reason of linking sexual compulsivity and HIV risk is that these people like to have a higher number of sexual partners, they lose control over their sexual behaviours, and they like to have sexual activities with other sexual compulsive individuals. It is unfortunate that knowledge and treatment about

sexual compulsivity is yet to be integrated widely either into clinical settings or prevention programs and it is the duty of communities to learn and do researches on how to manage this disorder (Meuch & Parsons, 2004).

It is therefore important to support PLWHA to eliminate chances of mental health problems caused by the fear of stigma. This could result in positive changes on PLWHA, which include the improved quality of life, adherence to HIV/AIDS treatment and also less HIV/AIDS-related deaths (NASTAD, 2005). The gap of conducting research on how to manage sexual compulsivity needs to be filled. That will hopefully reduce the number of HIV infection and increase the level of support and care to people who have these kinds of individuals within their families and communities.

2.5 Myths and misconceptions associated with HIV/AIDS

According to Bogart, Skinner, Weinhandt, Glasman, Sitzler, Toefy & Kalichmman (2011), in South Africa the historical context of apartheid and past racist government initiatives against Black Africans together with the slow governmental response to HIV/AIDS may have had an impact on individual's beliefs and misconceptions. These authors further argue that recent South African policies promote prevention and treatment strategies, but if the South African government did not compromise by giving a positive response to HIV/AIDS pandemic earlier, the high mortality rate occurred due to HIV/AIDS would have been prevented.

Myths have been recognised to negatively impact the prevention of HIV/AIDS in different continents, regions and countries, for example in America, especially with the emergence of HIV/AIDS, the African-Americans mythically perceived HIV/AIDS as a white, gay disease (Neff, 2006, in Kangethe & Xabendlini, 2014). It is articulated by Neff (2006) that the African-American political leaders were hesitant to embrace HIV/AIDS as an African-American disease for fear of accepting homosexuality.

Myths associated with HIV/AIDS have been a huge barrier in preventing HIV/AIDS in the Sub-Saharan countries. There are myths that have been spread by some of the traditional healers. For example, in South Africa there is this belief that sleeping with a virgin can cure a man who is living with HIV/AIDS (Jackson, 2002; Juma & Klot, 2011). Kangethe & Xabendlini (2014) reflect that the myth of sleeping with a virgin has put women and young girls' rights at jeopardy and undermines their constitutional rights which are against sexual abuse and other forms of abuse. This has also undermined the country's efforts towards fulfilling Millennium Development Goal number three that envisages increasing women empowerment and equality with men (UNDP, 2004; UNDP, 2008, cited in Kangethe & Xabendlini, 2014).

Another mythical belief is that sleeping with a woman or girl with albinism can cure HIV/AIDS (Thuku, 2011). This in Southern African countries has made women and young girls with albinism targets of sexual abuse (Thuku, 2011). This myth has been practised in countries such as Zimbabwe, Swaziland, and South Africa and has contributed to the high rate of rape in these countries and also ruins the well-being and the social functioning of these women and young girls with albinism (Thuku, 2011).

Myths and stigma have been recognised as the possible cause of increased HIV/AIDS prevalence in Botswana where the epidemic of HIV/AIDS is often accompanied by stigma and discrimination that create the circumstances for spreading the virus (Letamo, 2003). In Letamo's (2003) research study on stigma, the results showed that people were unwilling to care for their family members with HIV/AIDS. This left them with no option other than being taken care of by the government project called Community Home-based Care projects whose aim is to relieve public hospitals of HIV/AIDS patients. Letamo's (2003) research findings indicated that young people and those who believed that they can get HIV infection by sharing a meal with an HIV/AIDS person had discriminatory attitudes towards people living with HIV/AIDS.

2.5.1 Traditional myths and HIV/AIDS

In South Africa, many people believe in the strength of traditional healers (Hirst, 2005). There are several types of traditional healers such as *amagqirha* (they speak to the ancestors and are diviners) or *amaxhwele* (known as herbalists) and for many years people have obtained medical advice, remedies and cures from these healers (Hirst, 2005).

On the other hand, Knor (2008) argues that there is a link between HIV/AIDS and witchcraft; this has especially been the hindrance in the prevention of HIV/AIDS. The phenomenon of witchcraft has been explained by anthropologists as an attempt to make sense to an unexplained illness (Knor, 2008). Therefore, the blame to witchcraft serves as a defence mechanism to those who do not want to accept their

HIV positive status. Witchcraft, sorcery, and magic are foundational anthropological categories describing cultural activities employed to control flows of power in a society (American Anthropological Association, 2012; Ashforth, 2005). The American Anthropological Association (2012) asserts that these concepts are not only employed for ritual purposes but also aid for diagnostic process occurring in social groups to determine whether their members' misfortunes are caused by these supernatural activities.

Ashforth (2005) describes witchcraft in the South African context as the manipulation by malicious individuals of forces in persons, spiritual entities and substances to cause harm to others. The motive of witchcraft is typically said to be jealousy. Ashforth (2005) describes the term which is used in black communities called "*idliso*" as an act of witchcraft. *Idliso* is the name that is used in black communities when someone is sick. It is believed that someone would have been given a poisonous potion by witches so that he or she dies. This aspect prevents people from being tested for HIV/AIDS; instead they are taken to traditional healers where they are given traditional herbs or medicines also known as "*umuthi*".

Myths indicating that traditional healers can cure HIV/AIDS have also affected the health of people living with HIV/AIDS in Botswana (Kang'ethe, 2011). This could also explain the fact that the environment of the traditional healers is less stigmatized than the environment of the clinics and hospitals offering HIV/AIDS services. This state of stigma associated with biomedical facilities in Botswana was found to make caregivers and their clients seek services of the traditional healers (Kang'ethe,

2010). People seek help from traditional healers because they know that nobody would see them unlike the use of health care facilities where they are seen by everyone. Other researches indicate that traditional healers in Tsabong District of Botswana have died in the hands of the healers, or resort to accessing the services of the biomedical practitioners when they are very weak (Kang'ethe, 2012).

Perhaps why there has been a treatment lapse between the biomedical practitioners and the traditional practitioners is that the latter in many countries are neither regulated nor licensed for their services (Kang'ethe, 2012). In August 2004, South Africa legalized the practice of traditional healers, largely in response to the HIV/AIDS pandemic (Flint, 2008). However, the Basic Conditions of Employment Act (BCEA) does not consider sick notes issued by healers to be valid. This creates a dilemma for employees, whose right to consult a practitioner of their choice is protected by the Constitution (Mbatha, Street, Ngcobo, & Gqaleni, 2012).

Although according to Kang'ethe (2013a) (in Kang'ethe & Xabendlini, 2014) the campaign on information dissemination appears to be weak especially in the rural areas where the role of NGOs is critically lacking, it is believed that the state of stigma and discrimination associated with HIV/AIDS deter people from gathering courage to know their status. People are anxious about mythical beliefs on HIV/AIDS especially with myths from traditional healers. This has put South African's HIV/AIDS prevention campaign process at jeopardy of being ignored (Treatment Action Campaign, 2007; Barnett & Whiteside, 2006).

2.6 HIV/AIDS and religion

According to Kelly (2009) HIV/AIDS epidemic is understood by some religious groups as a punishment from God for sexual misbehaviour or as a divine curse for an immoral act, meaning that having sex before marriage and being unfaithful to one's partner is regarded as a sinful act by some religious groups. Kelly (2009) points out that some religious leaders have an opinion that if they lay hand in helping PLWHA they could be viewed as promoting promiscuous acts therefore they stop supporting PLWHA because of these false beliefs.

Parker & Aggleton (2002) concur with Kelly (2009) indicating that HIV/AIDS related stigma and discrimination as being reinforced by religious leaders which have used their power to maintain Status quo rather than to challenge negative attitudes towards PLWHA. For example, it was noted that religious doctrines, moral and ethical positions regarding sexual behaviour, sexism and homophobia, and denial of the realities of HIV/AIDS have helped to create the perception that those infected have sinned and deserve their punishment (Parker & Aggleton, 2002).

The more fundamentalist Christian Orthodox Jewish groups have seen AIDS as a divine punishment, a chastisement from God for violating scriptural prohibitions against sexual promiscuity, drug abuse, and most particularly homosexuality (Lala, 2007; Doka, 1997). Persons with the disease are seen as touched by divine judgement. Lala (2007) suggests that the main drivers of HIV related stigma is placement of blame and accusation of moral wrongdoing on those infected. All these perceptions make people to fear to disclose their statuses because they avoid being

viewed as sinners or being promiscuous by other religious members. Earlier on in the epidemic of HIV/AIDS faith-based organisations added to the stigma associated with HIV/AIDS by blaming PLWHA for immoral and sinful acts (Lala, 2007). In Lala's (2009) research findings the faith-based organisations have been targets of blame for their delayed responses to HIV/AIDS pandemic but currently stigmatizing attitude from Christian faith-based groups have changed considerably.

On the other hand, faith-based organisations are said to have a long history in community health interventions and the provision of health services in many countries of the sub-Saharan Africa (Moyo & Keir, 2014). These scholars argue that FBOs have been central in HIV/AIDS mitigation, for example; the Salvation Army in South Africa was already caring for dozens of HIV orphans. Currently, FBOs still continue to run HIV prevention and advocacy programmes as well as care and support programmes which provide an atmosphere of acceptance and hope for millions living with HIV/AIDS in many African countries. This is supported by (Manala, 2005) who states that HIV/AIDS pandemic demands a suitable Christian response and the Christian ministry to people living with HIV/AIDS should respond positively to the demands of the gospel of Jesus Christ for justice, transformation and liberation. This explains that FBOs are doing their greatest job in mitigation of HIV/AIDS-related stigma. However, there are some gaps that need to be filled from some religious groups who perceive HIV/AIDS discussion as ungodly.

2.7 Gender and HIV/AIDS-related stigma

The UN Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), adopted in 1979, is probably the best example of a relationship between gender and human rights (Juma & Klot, 2011). The commitment to the human rights of women was further reiterated at the Fourth World Conference of Women in Beijing in 1995, its appearance in the Millennium Development Goals (MDG) illustrates that the link between gender and human rights has been acknowledged by the international community. Juma & Klot (2011) state that women continue to be denied basic human rights and one of the ways they are denied is through HIV/AIDS. Other studies have shown that women are particularly vulnerable to stigma, including violence (Nyblade, 2009). For example, violence to HIV positive women is portrayed by the death of Gugu Dlamini in 1998 who was stoned to death at her neighbourhood in Kwa-Zulu Natal after disclosing her HIV status to the public (The Center for Faculty Development and Excellence at Emory University, 2012; USAID, 2006). This highlights the challenges HIV positive women face within their communities. Juma and Klot (2011) also argue that men who are physically violent towards women are twice likely to be HIV-positive, meaning that if the woman is raped, she has one-in-four chances of contracting HI virus.

Cultural myths on sex are also reinforced by patriarchy because it is generally men who initiate sex and decide whether or not to use a condom (Kang'ethe, 2009b). This shows that many women in South Africa are coerced into sexual activity against their wishes (Vetten & Haffejee, 2005). All these aspects of sexual violence add the risk of contracting and spreading HIV infection, and many cultures mythically perceive AIDS as a woman's disease (Vetten & Haffejee, 2005). Women may be blamed by their

partners, families or community for not raising their HIV positive sons and daughters properly (Kang'ethe, 2013b). This explains the feminization of HIV/AIDS.

Due to the mythical belief and cultural norms that men are not satiated by one woman, many patriarchal norms of masculinity encourage men to have multiple and concurrent partners (Kang'ethe & Xabendlini, 2014). This has been researched and documented to increase both men's and women's vulnerability to HIV/AIDS (Kang'ethe, 2009b, 2013b; Harrison, O Sullivan, Hoffman, Dolezal, & Morrell, 2006).

According to Epstein, Morrell, Moletsane & Unterhalter (2004) many women admit that they are not assertive around issues of safe sex because they fear being assaulted by their partners. Epstein et al. (2004) continue saying that efforts to make HIV prevention campaign contribute more broadly to gender transformation and remain important. These researchers further argue that empowering women in context where gender inequalities are common makes women vulnerable to violence. However, there are organisations that oppose the abuse of women, but it seems that there is more to be done. This is because women, especially in rural areas, are not well informed about the forms of abuse they face within their households and this makes them the victims of abuse in their daily lives.

The women's prominent role in the economic and physical viability of the family is being acknowledged and children living in households with the HIV positive mother are likely to experience food insecurity, malnutrition and poor hygiene (Jackson,

2012). Jackson (2012) describes AIDS orphaned children as the ones that experience traumatic situation because after the death of the mother within the family the loss of income support reduces lifetime resources for the children. Even if the children are taken to their extended families it becomes difficult because they may have limited resources to support the children and the end results are that these children are taken to places of safety, others end up being street children (Jackson, 2012).

However, there is a gap that needs to be acknowledged or filled because it receives less attention from the researches, that is the belief that care giving is for women only. Pellizzoli (2011) demonstrates that women remain the group most severely affected by HIV/AIDS, not because there is higher incidence rate for women than men but women are often those who take care of people living with HIV/AIDS in households and in the community. Women, especially from disadvantaged areas, who are care givers of PLWHA are susceptible to HIV/AIDS, this is because they do not have insufficient equipment to take of their patients. Also this cultural belief of women being care givers contributes to HIV/AIDS-related stigma in the sense that women are overburdened with care and support roles in their households (Ganyaza-Twalo & Seager, 2005). This put women at a greater risk of being infected by HIV/AIDS; at the same time when they are diagnosed HIV positive they are the ones who are blamed as transmitters of HIV/AIDS.

2.8 HIV/AIDS-related stigma and human rights

People with HIV and AIDS have the same basic rights and responsibilities as all other citizens (Van Dyk, 2012). The HIV and AIDS Charter sets out basic human rights which should be enjoyed by all people and should not be denied to persons infected with and affected by HIV/AIDS (Van Dyk, 2012). Bassett-Grant et al. (2001) point out that some countries passed harsh laws that they thought would protect society from the risk groups; for example, making HIV/AIDS test compulsory for sex workers and gay men. This illustrates that sex workers and gay men's human rights are being violated. Furthermore, basic human rights of PLWHA are being violated by some insurance companies because they emphasise the issue of being tested for HIV before people take their insurance policies.

During the 1980s, the link between HIV/AIDS human rights was only understood as involving people infected with HIV/AIDS and the discrimination to which they were subjected (Gruskin & Tarantola, 2002). For PLWHA the concerns included compulsory HIV testing, restriction on travel, barriers to employment and housing, access to education, medical care and health insurance. These issues of being denied to human rights of PLWHA have not been resolved currently. For example, in some environments, PLWHA find themselves excluded from what is done in such environments even if there is a saying that PLWHA should not be discriminated. Some of PLWHA are denied access to the relevant information about HIV/AIDS. This often occurs in some disadvantaged rural areas where certain people who are living with HIV/AIDS are not aware of their human rights.

The effects of discrimination in the form of racism, gender-based discrimination and homophobia continue to exacerbate the impact of the pandemic on the lives of individuals and population around the world (Gruskin & Tarantola, 2002). These researchers recognised that realization of human rights is critical to protect the rights and dignity of those infected and affected by HIV/AIDS. These researchers state that the government has the responsibility not to violate the human rights of citizens including PLWHA. Gruskin & Tarantola (2002) argue that the government has three levels of considering the human rights of people and following are the three levels:

Respecting the right - this refers to the government not to violate the human rights of people. For example, if someone is denied access to education or medical care because of his or her HIV positive status this will be the violation of human right by the government.

Protecting the right - this means that the state has to prevent violation of rights by non-state actors. For example, the religious leaders should not protect the teenagers accessing reproductive health programmes. This often occurs in some churches where these programmes are referred by religious leaders as condoning sexual activities.

Fulfilling the right - here the state has to take appropriate measures such as legislative, administrative, budgetary and judicial to make sure that the rights are fulfilled. For example, if the state fails to provide essential HIV/AIDS prevention

education in enough languages and media to be accessible to everyone in the population, this would be understood as the violation of right to education.

In the post-apartheid era, the AIDS policy making process has been characterised by a well-documented conflict between AIDS activists aligned with the Treatment Action Campaign (TAC) and the government, over government denialism and access to HIV treatment (Mbali, 2005). TAC was launched in South Africa on the 10th of December 1998, International Human Rights Day by a small group of political activists. Their aim was the equitable access to healthcare, in particular medicines for HIV. The intension of the founders of TAC was to enforce the right to access of treatment through a combination of protests, mobilization and legal action. The TAC's Constitution describes its objectives includes discrimination that limits access to treatment for HIV/AIDS in the private and public sector. The TAC fought for PLWHA to have access to health care as to prevent HIV related deaths. Heywood (2009) argues that death and diseases caused by HIV have profound implications for human rights and are recognised in the South African Constitution including right to equality, dignity, access to healthcare services and education. Contemporary AIDS activists aligned to the TAC have framed their struggle for HIV treatment access in terms of the human rights of people living with HIV/AIDS. Therefore, TAC's campaign instructed the health ministry to develop a comprehensive and prevention plan.

Stigma leads to discrimination and other violation of human rights which affect the well-being of people living with HIV in fundamental ways (UNAIDS, 2005). The

UNAIDS (2005) illustrates that in countries all over the world there are well-documented cases of people living with HIV who are denied their rights. Previous studies have come up with strategies such as educating communities about the basic human rights of people living with HIV/AIDS (UNAIDS, 2005). For example, Heywood (2009) postulates that the TAC mobilized people to a campaign for the right to health using a combination of human rights education. However, there is still more work to be done because the USAID (2006) indicates that these guidelines have not been followed by many countries such as Russia, Belgium and United Kingdom. It is said that by 2006 about twenty countries required proof of HIV negative status before allowing anyone to enter the country (USAID, 2006).

2.9 HIV/AIDS and poverty

The HIV pandemic in South Africa cannot be separated from the issue of poverty (Van der Walt, Bowman, Frank & Langa, 2007). These researchers indicate that out of 44 million South Africans around 2007, the majority lived below the poverty line. Poverty line amongst black South Africans is the result of apartheid legacy, for that reason, the spread of HIV in poor or impoverished families is high and is perpetuated by several factors such as unemployment, lack of education, crime and violence. Van de Walt et al. (2007) further commend that the households with low income are characterised by a high level of malnutrition. This makes people who are infected by HIV to become more susceptible to the virus because their immune-systems do not function properly (Gillespie, Kadiyala & Greener, 2007). Gillespie et al. (2007) suggest that poverty increasingly place individuals from poor households at greater risk of exposure to HIV.

According to Van Donk (2002) there are various ways in which poverty facilitates the transmission of HIV/AIDS: for example, evidence suggests that there is a correlation between the levels of education, fertility and condom use. Van Donk (2002) continues contending that income poverty forces people to engage in survival strategies that put them at risk of contracting HIV virus. This means that if someone is earning less income she is likely to have multiple partners which put the person at a greater risk of HIV infection. Van Donk (2002) affirms that in poor communities basic health services are inadequate and such preventive treatment is not accessible.

Poverty is thought to increase sexual risk behaviours particularly to young women who may practice the risky sexual behaviours to provide their families and children. According to Booysen & Summerton (2002) poverty stands to increase the vulnerability of women to HIV infection by resulting unsafe sexual practices often due to lack of knowledge, lack of access to means of protection and inability to negotiate condom use with sexual partners as a result of gender roles and power relations.

On the other hand it is argued that in most countries, relatively rich and better educated men and women are having the tendency of changing partners because of their great personal autonomy and it is found that even though the richer and better educated these women and men the condom use is very low (Gillespie et al., 2007). It is argued that the poorer the society and lower the education, the higher the prevalence of HIV, but the data clearly show that this is not the case because more income and more education is clearly associated with more sexual partners which

increases HIV infection (Family Watch International, 2011). Tladi (2006) concurs with the Family Watch International (2011) stating that women with some primary education as well as those with secondary education were found to be likely to engage in risky sexual behaviours.

2.10 Conclusion

This chapter has given an explanation on how HIV/AIDS-related stigma affects people living with HIV/AIDS. The researcher has established that strategies of mitigating HIV/AIDS-related stigma have been implemented worldwide, but there are some areas that received less attention from previous studies: such as the issue of self-stigma where some PLWHA pretend as if they have accepted being HIV positive but internalise their shameful thoughts and fears. There is another dimension that seems to receive less attention which is mental health and HIV/AIDS. The following chapter thus, discusses strategies that can reduce HIV/AIDS-related stigma and the strengths perspective.

CHAPTER THREE
STRATEGIES TO CURB HIV/AIDS-RELATED STIGMA AND THE
STRENGTH PERSPECTIVE

3.1 Introduction

As noted in the previous chapter, apparently HIV/AIDS-related stigma still exists globally. It makes people to be reluctant to seek health services such as HIV/AIDS testing, prevention of mother to child transmission and to disclose their HIV status. This calls on for effective strategies that could reduce HIV/AIDS-related stigma. The strengths perspective was used in this study as the theoretical framework to assess PLWHA's ability to deal with HIV/AIDS-related stigma. Therefore this chapter expands on the theory and deals with strategies to curb HIV/AIDS-related stigma.

3.2 HIV/AIDS and disclosure

Disclosure is a process whereby an individual living with HIV decides to speak out about his or her status. Disclosure offers a number of important benefits to the infected individual and to the general public and it may lead to an improved access to HIV treatment, increased opportunities for risk reduction to make plans for the future (Erku, Megabiaw, & Wubshet, 2012; Norman, Chopra & Kadiyala, 2005). Norman et al. (2005) postulate that access to other forms of care such as home based care and social grants are dependent upon the disclosure of HIV status. This explains that without disclosing HIV status someone would be deprived to a lot of benefits that he or she was supposed to get.

It is indicated that lack of support from friends, family and the community decreases disclosure and generates rejection and discrimination which increases emotional distress experienced by those who are HIV positive (Mlobeli, 2007). Many individuals with HIV can recall instances in which they felt rejected or discriminated against by someone who knew about their diagnosis and these instances often are based on other's fears about how causal contact may lead to contracting the disease (Greene & Faulkner, 2002). Fear of disclosure may negatively impact the treatment adherence and it may lead to the sub-standard treatment (Loutyfy, Logie, Zhang, Blitz, Margolese, Tharao, Rourke, Rueda, & Raboud, 2012). Erku et al., (2012) state that some public health interventions focused on encouraging HIV sero-positive individuals to reveal their sero-statuses to their partners. These researchers state that the main reasons for the non-disclosure of HIV status are the lack of communication skills, fear of loss of confidentiality and fear of abandonment.

However, disclosure can help an HIV positive individual to gain support from family members and friends by being accepted and given a positive response which can lead individual to be empowered. According to Sowell, Seals, Phillips & Julious (2003) disclosure is sensitive information and is thought to have beneficial effect on an individual's health. Sowell et al. (2003) postulate that disclosure is believed to lower the stress levels and that would lead to a better psychological health. In their findings it becomes evident that HIV infected individuals who disclose their sero-positive statuses have better immune functioning, are making fewer visits to the doctors the chances of being socially excluded lessens. Disclosure of HIV positive status opens door to a dynamic response encompassing community involvement,

the support of HIV positive individuals and their families, as well as enabling a platform for public disclosure and the eradication of stigma (Norman, 2005). This illustrates that disclosure impacts a positive change in someone's life.

3.3 Door to door campaigns and behaviour change

According to Kimpuny (2011), "door to door" campaigns are vital because they access services to people who need care, support and treatment such as; with people living with HIV/AIDS, orphans and vulnerable children (OVC) and other affected families. Kimpuny (2011) further states that mobilizing people from communities helps in the behaviour change. Raising awareness about discrimination against PLWHA and OVCs also stimulates positive behaviour among individuals, families and communities in the fight against HIV/AIDS.

Behaviour change strategies tailored for the specific needs of people are termed as positive prevention (Cloete, Stiebel, Simbayi, Van Wyk, Henda & Nqeketho, 2010). These researchers indicate that in the United States of America, positive prevention is now the standard of HIV prevention and many of the interventions to reduce unsafe behaviour is being modelled by South Africa. Cloete et al. (2010) further contend that South Africa is currently estimated to have the most people living with HIV/AIDS and it is found that in South Africa people still engage in risky behaviours.

3.4 Enhancing support and care

HIV/AIDS does not affect the physical health of a person only, but the social and mental health too and this is posed by negative attitudes, discrimination and stigmatisation of PLWHA (Forouzan, Shustari, Sajjadi, Salimi & Dejman, 2013). These scholars argue that people may lose employment, financial resources and also family and friends for support and care. Forouzan et al. (2013) attest that social support is an aspect of psychological adjustment. Kang'ethe (2011) defines social support as information from others that one is loved and cared for, re-esteemed and valued.

Home-based Care plays a significant role in the care of AIDS patients in Sub-Saharan Africa where overburdened medical and welfare services are overwhelmed by the demands of the epidemic (Campbell, 2004). It is argued that most of the home-based carers are the family members or volunteers who have insufficient training or support. In Campbell's (2004) research study, Home-Based Care (HBC) is described as 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. In Campbell's research findings it was revealed that care for PLWHA is hampered by shortages of hospital beds, inadequate numbers of public sector health practitioners, lack of resources for treatment and drugs.

Psychological support and disease acceptance has been reported to be worse for people with AIDS than for patients with other diagnoses and the caregivers have

reported that caring for AIDS patient is time consuming and stressful than caring for patients with other diagnoses (Moetlo, Penpid & Peltzer, 2011). In their research study, they indicated that people living with HIV/AIDS are having high levels of psychological distress which includes denial, blame of others for the infection and hopelessness regarding their future.

The country of Botswana is one of the countries hit by the HIV/AIDS epidemic across the globe. Despite its small population of 2 million people, the 2008 statistics indicated a population of 113,000 persons were living with HIV in the country (Kang'ethe, 2011). This shows that the prevalence of HIV is increasing. Social support remains one of the HIV/AIDS mitigation factors that need to be put into practice in all the care giving process to give the care givers and the patients adequate psychological, social and emotional well-being. Kang'ethe (2011) further states that such information may come from a friend, a spouse, or other social networks such as churches, support groups, clubs or care workers who have a strong remedial and bolstering impact upon the palliative caregivers and their care giving productivity. This stipulates that if the care givers are passionate about their social support they can easily help the patients to cope with their lives. According to Kang'ethe (2011) the care givers support group promotes teamwork and communication. In addition, support groups are important because people are able to maintain good relations with other group members.

Epstein et al. (2004) are of the opinion that activism can be performed at an individual level. These researchers indicate that in South Africa there are individuals

who challenged the government to treat patients and administer antiretroviral. Other individuals are educating, mobilising and lobbying the government and the private sector to act against HIV/AIDS. The aim of these individuals is to change the behaviour and attitudes of communities towards HIV/AIDS related stigma.

In many communities new NGOs sprouted up and existing groups mobilized to provide support to families affected by the disease in an effort to fill the care gap (Ogden, 2006). Ogden further indicates that these groups were largely unable to provide clinical inputs, instead provide a range of care and support services to affected persons and families, including spiritual and emotional support and assistance with funeral expenses. Ogden (2006) also raised the issue of limited resources which resulted in helping a small portion of affected population. This illustrates that people who are infected and affected by HIV/AIDS need every kind of support that would make them cope with their situation.

3.5 Promoting voluntary counselling and testing (VCT)

The global HIV/AIDS pandemic continues to be the health problem and the cure for HIV/AIDS has not been found and the only option to reduce HIV infection is through Voluntary Counselling and Testing VCT (Kalichman & Simbayi, 2003). It indicated that the South African government has established more than 450 VCT centres with more than 800 counsellors around the country (Kalichman & Simbayi, 2003). Bassey, Abasiubong, Ekanem & Abasiatai (2007) point out that VCT can mitigate the high risk sexual behaviour and sexual transmitted infections. Kalichman & Simbayi (2003) continue saying that it is estimated that the majority of people do not know

their HIV statuses and it mostly happens in countries that are more affected by HIV/AIDS pandemic including South Africa. Young, Hlavka, Modiba, & Gray (2010) suggest that stigma has a profound effect on people's decisions, behaviours and outcomes. These researchers point out that HIV/AIDS-related stigma reduces people's willingness to engage in HIV testing, treatment and prevention. Young et al. (2010) indicate that an early diagnosis of HIV/AIDS has been related to the improved survival rate of PLWHA. This illustrates that getting tested for HIV/AIDS increases the chances of acquiring more information about HIV/AIDS and also increases the opportunity of telling others to get tested.

Kalichman & Simbayi (2003) also indicate that people in South Africa know very well about VCT services but they fear being stigmatized after the diagnosis. The hindrance of VCT and HIV treatment by South Africans is influenced by HIV/AIDS related stigma (Kalichman & Simbayi, 2003; Bassey, Abasiubong, Ekanem & Abasiatai, 2007). These researchers recommend that the fear of stigma and discrimination affects the enthusiasm of people to get tested for HIV and this aggravates the spread of new HIV infection. These scholars observed that misconceptions about the mode of HIV transmission and risky behaviours contribute to the fewer number of people who undergo VCT. Bassett & Walensky (2010) state that HIV testing uptake is also affected by various factors, which include poor access to health facilities or VCT centres, stigma, fear and practical obstacles such as transportation. In the research conducted by Zachungnunga (2012), it is stated that in countries such as South Africa and Malawi, women stop attending antenatal clinics for the prevention of mother to child transmission service, this is because women fear being beaten up by their partners.

Voluntary Counselling and Testing is an important tool for preventing the spread of HIV especially in communities with generalised epidemics and allows people to know their statuses and to evaluate their behaviour and its consequences (UNICEF, 2010). UNICEF (2010) indicates that programmes of VCT play an important role in preventing new infections and in helping individuals' access to appropriate care. Knowledge of HIV status is the gateway to HIV care and stands alone as a prevention measure and VCT centres are not designed to perform HIV testing only but provide care, support and counselling to individuals who tested positive (Bassett & Walensky, 2010).

Countries that are most affected by HIV/AIDS need to seek advice from countries which have been successful in fighting HIV/AIDS epidemic. For example, Ugandan government's HIV/AIDS awareness campaign became successful. Uganda is one of the first countries in Sub-Saharan Africa to experience the HIV epidemic and to take action to control the epidemic (Kang'ethe, 2013a). Buryama, Bunnell, Ransam, Ekwaru, Kalule, Tamuhairwe, & Mermin (2004) articulate that the high level of political commitment to HIV prevention and care, involving a wide a range of partners and all sectors of the society is crucial. Buryama et al. (2004) suggest that Uganda was the first country in the Sub-Saharan Africa to introduce the VCT services in 1990 and VCT service has been the cornerstone in HIV prevention and care activities in Uganda.

This exemplifies the results of various dedicated stakeholders from different countries in the fight of HIV/AIDS epidemic and the stigma that attached to it. Promoting VCT to community members could also assist the government's aim of

reducing the rate of HIV/AIDS infections. VCT is a foundation for mitigating HIV/AIDS, is because it gives individuals an opportunity to know their HIV/AIDS status. Therefore, it is critical for people who are conducting these campaigns to emphasise the issue of HIV/AIDS-related stigma. This would hopefully assist people to know their HIV/AIDS status because some people become hesitant to know their HIV status fearing the stigma attached to individuals who are HIV positive.

3.6 HIV/AIDS and curriculum

HIV/AIDS education in schools has been the debate for a long time in South Africa (Thaver, 2012). In the study conducted by Thaver, debates were centred on the key issues such as the right age to introduce sex and HIV/AIDS education in schools until it was introduced in secondary schools of South Africa. The policy was designed to respond to the HIV/AIDS pandemic across South Africa by creating and implementing life skills curriculum in schools. Thaver (2012) also indicates that different life skills about HIV/AIDS awareness and information have been implemented in schools but there was no emphasis on the children's physical and mental well-being. Thaver further explained that there is a need to promote healthy behaviours such as informed decision making, communication skills and positive attitudes.

However, there are a number of challenges that must be overcome in order for its implementation to be successful such as socio-economic inequalities impact the implementation of life skills in poor communities in South Africa (Thaver, 2012). The research findings in Thaver's (2012) study showed that due to inadequate training and lack of resources, educators often lack competence to communicate sexual

health education in a successful manner and the teachers find it difficult to introduce sex education in schools because there is an opposition coming from the parents, religious sects and the community at large (Thaver, 2012). Some parents believe that sex education encourages children to be sexually active and they do not want to take part in educating their children about sex and HIV/AIDS education.

In countries such as Zimbabwe, programmes for the prevention of HIV/AIDS have been implemented to address the multidimensional impacts of HIV/AIDS. These interventions have been spearheaded by various stakeholders including public and private sectors, non-governmental organisations, and formal and informal institutions (Chevo & Bhatasara, 2012). In South Africa, there is this mythical common belief that sex education should be the domain of the private sector and should not be a part of public education (Kangethe & Xabendlini, 2014).

Education is recognised as not a quick response for HIV/AIDS (Epstein et al., 2004). These researchers argue that transmission models of education and the provision of condoms are in-effective in promoting changes in sexual practices, therefore policy makers are left with sex education in schools as a major means of tackling prevention. It is argued that in most countries education provides the most accessible way of reaching young people about HIV/AIDS and many countries have implemented HIV education programmes in schools. In South Africa the curriculum includes Life Skills which include issues of sexuality and HIV/AIDS (Epstein et al., 2004). Yet, teachers in schools do not speak openly about the issue of sexuality due

to the fear of cultural and religious values in communities that view HIV/AIDS as a disgrace.

3.7 Theoretical framework

There are social models that have been developed to understand and promote behaviour change (Mlobeli, 2007). The phenomenon of stigma related to HIV/AIDS draws an attention on various explanations, where different theories complement each other to explain different aspects of HIV/AIDS environment. The researcher employed the strengths perspective.

3.7.1 Strengths Perspective

The strengths perspective in social work was proposed by Saleebey in 1996 (Guo & Tsui, 2010). Since its inception it has been applied in child welfare, substance abuse, family services and services for elderly people (Guo & Tsui, 2010). These authors note that new attitude it presents was welcomed by powerless people in disadvantaged situations; this portrays the situation of PLWHA where they become hopeless at times because of stigmatization. Guo & Tsui (2010) affirms that the strengths perspective pays more attention to the strengths and capacities of people and holds that people have their own strengths, despite their problems and their disadvantaged environments. Saleebey (2013) assumes that all humans have somewhere within themselves the urge to be heroic, i.e. a desire to transcend circumstances, overcome diversity, to shape and to realise their dreams.

The strengths perspective attempts to understand individuals in terms of their strengths (Aarti & Sekar, 2006). This involves examining survival skills, abilities, knowledge and desires that can be used to help to meet the individuals' goals (Aarti & Sekar, 2006). This could be done through examining the capabilities of individuals would hopefully help PLWHA to achieve their desires of being treated fairly within their environments. Guo & Tsui (2010) suggest that the underlying assumption of the strengths perspective model is that human beings have the capacity for growth and change. A suggestion made by Van Breda (2001) & Saleebey (2002) illustrates that human beings can still remain stronger and live positive lives despite of the circumstances that are not conducive. This explains why the strengths perspective is referred to as resilience. Goldstein (1997) views it as the "self-righting tendencies" of the person, this explains that the identification of people's strengths can help them to overcome their problems or deficits and achieve the success in their lives. An individual can expand the inherent capacity and strength for resiliency within him or herself as Werner (2009:54) indicates that resiliency incorporates the concept of emerging from the adversity stronger and more resourceful. Resiliency reflects one of social work's aims of moving away from focusing on the deficits of the clients and take into consideration the clients strengths and capacities (Saleebey, 2008; Rak & Patterson, 1996; O'Leary, 1998). This illustrates the shift from focusing on the weaknesses of an individual and the focus becomes on an individual's growth and change. The remaining part about the strengths perspective is its moving away from the pathological point of view, which focuses on the problems, weaknesses and deficiency of an individual (Saleebey, 2013).

Empowerment is described by Guo & Tsui (2010) as one of the mainstream tools of social work practice. Promoting empowerment exemplifies that individuals are able to make their own choices and decisions. Accordingly, empowerment assists the disadvantaged people such as PLWHA or the disabled to regain their strengths to overcome their disadvantaged situations (Guo & Tsui, 2010: 235). For example, the situation of stigmatizing PLWHA is traumatizing but when PLWHA get empowered with knowledge and skills they deal with the problems positively. In addition, the role of social worker is to assist powerless people to empower themselves. That would hopefully make people to realise their own power and be responsible for their own lives. Some scholars, according to Guo & Tsui, argue that the empowerment approach should be used in a range of interventions and propose that the generalist social work practice should be empowerment-centered.

Mawar, Sahay, Pandit, & Mahajan (2004) acknowledge that one of the main factors that play a role in the HIV/AIDS epidemic is the level of empowerment. These scholars indicate that the low level of education, especially in women within patriarchal communities puts women in a different position. As a result women have lesser control over their bodies and lack negotiation skills to protect themselves. This causes women to be at risk of being infected by HIV/AIDS and are being stigmatized of being the transmitters of HIV/AIDS. In this regard, the strengths perspective is critical because it constitute the principle of empowerment. For example, empowerment would encourage women to learn more about their rights to say no over their bodies and educate them about the types of abuse that might not be taken into consideration in many cultural communities. Sex discussion is being ignored in some cultural communities and this could lead to misconceptions and misinformation

about HIV/AIDS. This might pose a great risk of other people being the victims of HIV/AIDS.

Mawar et al. (2004) postulate that HIV/AIDS stigma leads to social exclusion, this could mean that PLWHA are isolated because they are referred to as “those” people. In that instance the strengths perspective would enhance the level of self-esteem that will bring hope in their lives. PLWHA are denied access to their rights and are blamed for causing the condition through their risky behaviour (Mawar et al., 2004). For example, PLWHA are receiving treatment which is not good in some health care centres, some health workers would not stick to confidentiality, they would gossip with their patients. Accordingly, strengths perspective assumes that people need to be strengthened with skills and detailed information to know what is best for them. The strengths perspective also offers the platform for PLWHA to speak up and stand for their rights. Therefore, the researcher is of the opinion that the role of the social worker is to support the individuals and communities with skills and advise them to use the strengths they have to survive HIV/AIDS-related stigma.

In the research study conducted by Pattoni (2012) it is stipulated that there are standards that constitute the strengths perspective. Pattoni (2012) attests that the strengths perspective is goal oriented. This illustrates that people set goals which they want to achieve in their lives. The central and most crucial element of the strengths perspective is the extent to which people themselves set goals they would like to achieve in their lives.

The strengths perspective seeks to enable people to look beyond their immediate and real problems and dare to conceive a future that inspires them, providing hope that things can improve. In Pattoni's study some researchers have been criticising the strengths perspective arguing that it does not pay attention to the problems of individuals. Pattoni (2012) notes that the strengths perspective does not focus on the problem or deficits, but individuals are encouraged to use the resources surrounding them to overcome the problem. In addition, other approaches such as the medical model which stresses that the pathology should be identified and treated, strengths perspective assists individuals to live more productive and satisfying lives (Orsulic-Jeras, Sheperd, & Britton, 2003). These authors further commend that the strengths perspective is designed to empower individuals and discover the considerable power within them. Saleebey (2013) cautions social work practitioners that they should be wary of getting preoccupied with the pathologies which tend to create a layer of technical and theoretical writing. Practitioners should give time for the client system to grow, develop, change directions, realize their visions, or revise their personal meanings and narratives. It is in this manner that the clients' strengths can begin to emerge and be recognized.

The primary focus of the strengths perspective is on the assessment of the clients' strengths not their deficits. This would hopefully make individuals to recognise the inherent resources they have which they can use to survive any difficulty. Anything that helps an individual to deal with challenges such as HIV/AIDS-related stigma should be regarded as strength. Strengths will vary from person to person and, as such, it can be difficult to draw up an exhaustive list of strengths (Saleebey, 2002). Many researchers note that assessment tools in the field are still too often focused on deficits and inadequacies, and whilst there have been significant efforts to create

and use assessment tools which incorporate strengths elements. Conducting an initial assessment of client's well-functioning aspects of physical, psychosocial and social areas of life is critical as illustrated by Orsulic-Jeras (2003). The practitioners should explore what is working well in the client's life and how the client has been able to maintain the positive functioning. This makes the practitioners to acknowledge the clients strengths, increase them and apply them to the challenges faced by the clients.

Strengths perspective is a collaborative process between the person supported by services and those supporting them, allowing them to work together to determine an outcome that draws on the person's strengths and assets (Pattoni, 2012). As such, Pattoni illustrates that it concerns itself principally with the quality of the relationship that develops between those providing and being supported, as well as the elements that the person seeking support brings to the process. The strengths perspective to social work is said to value empowerment of individuals seeking services and advocates a relationship of collaboration (Pattoni, 2012). This indicates that working collaboratively promotes the opportunity for individuals to identify services by themselves rather than to be the consumers of services. Also, Pattoni illustrates that every environment has individuals, associations, groups and institutions that have resources that others may find them useful and the social services practitioner s role to link them with these resources.

It is said that language use and words are powerful because they can inspire, yet they can destroy (Saleebey, 2006). The first concept that is considered to be the

best when working with clients is to believe in the client. Saleebey (2006) postulates that, believing in the client, is central to the strengths perspective. This explains that the clients become more empowered to observe that they are being acknowledged. The practitioner should believe that the clients are trustworthy when they are seeking social work services. Judging that the client is telling untruths may put the social worker a position of undermining the values of social work profession, which includes among them the non-judgemental attitude and respecting of the clients. The second concept is membership. PLWHA are sometimes socially constructed as the “others” who are different from other community members and are perceived as disgrace. Belonging and inclusion are essential to human beings (Saleebey, 2006). Individuals - especially PLWHA - need to be acknowledged and welcomed in communities to feel that they are welcomed and belong to their communities.

3.8 Conclusion

It is evident that people in communities fear disclosing their HIV positive status and some do not want to know their HIV status. This makes HIV infections to rise faster because people become reluctant to seek medical assistance due to stigma attached to HIV/AIDS. Strategies to reduce HIV/AIDS-relates stigma are critical. These strategies could be done through incorporating the clients’ strengths when conducting “door-to-door” campaigns as to reach every person in communities. Identifying individual’s strengths to overcome their weaknesses is very crucial than focusing on their problems. That would hopefully play a huge role in changing negative behaviours and attitudes of community members. The following chapter provides the research methodology used in the study.

CHAPTER FOUR

RESEARCH METHODOLOGY

4.1 Introduction

Research methodology is a strategy of enquiry which moves from the underlying assumptions to research design, and data collection (Myers, 2009). Methodology therefore refers to the methods and approaches to carry out a research. The most important concern of methodology is how researchers go about their researches or studies. Research methodology is the most significant section of the study. It has three parts which are the research design, methods of data collection and data analysis. This chapter focuses on all aspect of the methodology including, research paradigm, design, aspects of the qualitative approach, data collection and analysis, as well as ethical considerations that were used in the study. Trustworthiness of the study is also mentioned. Research methodology does not describe the techniques and methods of data collection only, but it explains why such methods were implemented as well as approving the relevance of the methods used to the study. As such, this chapter provides information which outlines what the researcher applied in order to achieve the desired objectives of the study.

4.2 Research paradigm

According to Delpont, Fouche & Schurink (2011), a research paradigm is the fundamental model or frame of reference we use to organise our observations and reasoning. These scholars further indicate that scientific activity is shaped by paradigms, which are general ways of thinking about how the world works and how to gain knowledge about the world. It is also stated that a paradigm shapes what we see and how we understand it.

The present research employed the qualitative paradigm. Fouche & Delport (2011:65) explain this as follows:

In the qualitative paradigm the researcher is concerned with understanding rather than explanation, with naturalistic explanation rather than controlled measurement, with the subjective exploration of reality from the perspective of an insider.

The qualitative paradigm aims at understanding social life and meaning that people attach to everyday life (Fouche & Delport, 2011:65). They further mention that the qualitative research paradigm in its broadest sense refers to research that elicits participant accounts of meaning, experience or perceptions.

4.3 Research Design

Babbie & Mouton (2011:74) indicate that “research design is a blueprint of how the researcher intends conducting the research”. This means that the research design is an outline of how the researcher is going to conduct his or her study. The researcher employed a qualitative research method. The qualitative research method aims at in-depth description and understanding of actions and events and it studies attitudes and behaviours of human beings (Babbie & Mouton, 2011). Based on the present study, the qualitative research was the best suitable approach because it allowed the complexity of issues, the in-depth understanding and flexibility of exploration around touchy subjects since the study is interested in the feelings and experiences of people living with HIV/AIDS (Mlobeli, 2007). According to Babbie & Mouton (2011:271):

Qualitative approach studies social actions and processes in their natural settings meaning that qualitative research is naturalistic because it attempts to study the everyday life of people in their settings.

The study attempted to view the world through the eyes of the participants themselves, meaning that the qualitative approach views human behaviour as a product of how people interpret their world (Babbie & Mouton, 2011). The qualitative research is characterised by its aims of understanding, some aspects of social life and its methods which generate words rather than numbers (Babbie & Mouton, 2011). Based on the study, underlying issues about HIV/AIDS-related stigma were explored and discovered. It is the researcher's hypothesis that there is very little that is known about HIV/AIDS-related stigma in the township of Dimbaza.

4.3.1 Specific research design

The specific research design employed in the study was a case study. The focus of case study is to understand human beings in a social context by interpreting their actions as a single group, community or single event (Fouche & Schurink, 2011). Babbie & Mouton (2011:281) postulate that "a case study is an intensive investigation of a single unit". A case study entails the exploration of a bounded system (bounded by time, context, and/or place), or a single or multiple case, over a period of time, through detailed, informed, and in-depth data collection involving a wide range of sources of information (Fouche & Schurink, 2011). This design also allows the researcher to gain insight, discovery and interpretation rather than testing the hypothesis (Kamau, 2012). Multiple sources of data are also employed in the case study approach.

The researcher employed a case study of the Township Dimbaza because narrowing the study to this case made it possible for the researcher to collect in-depth data from the participants. The case study design allowed the researcher to study the

participants in their everyday life context. The focus of the researcher was on the way people living with HIV/AIDS (PLWHA) dealt with issues associated with stigma and how HIV/AIDS-related stigma affected them. The following section explains the characteristics of a qualitative approach and how applicable it was to the present study.

4.3.2 Characteristics of qualitative approach

Kumar (2005) cited in Fouche & Delport (2011) adds the following characteristics of the qualitative approach:

- It is classified as unstructured, because it allows flexibility in all aspects of the research process. Based on the present study the researcher made sure that the questions asked were not formal. This allowed the participants to express themselves freely.
- The unstructured approach is more appropriate to explore the nature of a problem, issue or phenomenon. The implications of HIV/AIDS-related stigma were investigated systematically because the atmosphere was comfortable during the interviews and participants were given an opportunity to give detailed information.
- The qualitative approach's purpose is to describe a situation, phenomenon, problem or event and the information is gathered through the use of variables measured on ordinal levels. The analysis is also done to establish the variation in the situation, phenomenon or problem without quantifying it. The implications of HIV/AIDS-related stigma were defined by the participants in

detail and the information gathered was analyzed using the themes that emerged.

Creswell (2007) cited in Fouche & Delport (2011) gives the following characteristics of the qualitative design. These characteristics were taken into cognizance by the researcher and applied them in the current research as explained below:

- Qualitative researchers tend to collect data in the field at the site where participants experience the issue of problem under the study. The researcher chose the Township of Dimbaza because she observed the issue of stigma and ignorance associated with HIV/AIDS in the area. This formed the researcher's pre-understanding of the research area.
- Qualitative researchers as a key instrument collect data themselves through examining documents, observing behaviour and interviewing participants. The researcher collected data through interviewing the participants.
- They gather multiple forms of data rather than rely on single data. The information on the present study was gathered from multiple sources which were the individuals living with HIV/AIDS and different service providers who deal with HIV/AIDS-related stigma in their work places. This was done in order to enhance the trustworthiness of data.
- The researcher focuses on learning the meaning that the participants hold about the problem or issue not the meaning that the researcher brings to the research. The researcher did not come up with the data but she interpreted and analyzed the information gathered from the participants.

- The researcher makes the interpretation of what he or she sees, hears and understands. Data was presented according to what the researcher observed, understood and heard from the participants.
- The qualitative researcher tries to develop a complex and holistic view of a social phenomenon. The purpose of conducting the research was to come up with the full picture of the effects of HIV/AIDS-related stigma on PLWHA. This was achieved by collecting comprehensive data from the participants who were experiencing the issue of stigma on their daily basis.

4.4 Methods of data collection and data collection instrument

The current research employed different sources of data collection which are individual in-depth interviews and one focus group discussion. The use of different sources of information is called data triangulation. Guion (2011) indicates that data triangulation involves using different sources of information in order to increase the trustworthiness of the study. The researcher's intention for employing data triangulation was to increase the reliability of the study. Furthermore, using these different sources of data helped the researcher to acquire relevant information concerning the study and to corroborate the information gleaned from the divergent sources resulting in authentic data.

A data collection instrument is a tool that is used to collect data. The present study employed a semi-structured interview guide with open ended questions which guided the researcher and the participants. (The copies of the interview guides are attached as Appendix A and Appendix B). The real names of the sample were not used during

the interview process. The researcher, at the stage of analysing the data, referred to them as *Participant Number 1, 2, 3 etc.*

With semi-structured interviews the researcher would have a set of predetermined questions on an interview schedule, but the interview would be guided rather than dictated by the schedule (Greef, 2011). An interview guide provides the researcher with arranged questions to make the interviews easier and understandable. Structuring of questions was useful in that it guided both the researcher and the participants on what was required and also it allowed the participants to introduce issues that the researcher did not think of. There were open ended questions with probes; some developed during the interview which made the participants to explore their feelings.

Additionally, the researcher made use of an audio recorder to gather all the information from the interviews because it allows a much fuller record than note-taking during the interview (Greef, 2011:359). This means that the researcher focused on the interview rather than being interrupted with writing the notes.

4.4.1 In-depth interviews

In-depth interview is defined as a qualitative technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspectives on a particular idea or situation (Boyce & Neale, 2006). The primary advantage of in-depth interviews is that they provide much more detailed information than other data collection methods such as surveys (Woods, 2011). In-depths interviews provide a comfortable environment during data collection, for example,

participants feel relaxed when they communicate with the researcher (Woods, 2011).The researcher conducted in-depth interviews with 10 people living with HIV/AIDS (PLWHA). The in-depth interview technique was useful in accessing in-depth information on how people living with HIV/AIDS in the Township of Dimbaza felt about being stigmatised within their families and the community at large.

4.4.2 Focus group discussion

A focus group discussion is a discussion with a small group of people on a topic and it typically consists of eight to twelve members (Delpont & Roestenburg, 2011). According to Delpont & Roestenburg (2011:186) “focus groups are means of better understanding how people feel or think about an issue, product or service.” Focus groups are also referred to as a formal method of interviewing a group of people for a particular topic of interest and participants are chosen because they share common characteristics that relate to the topic (Delpont & Roesternburg, 2011). Babbie & Mouton (2011) suggest that the purpose of using a focus group is to find the detailed information that the researcher would not otherwise easily access. In focus groups the researcher can make some changes in the study because participants come up with unexpected information.

The same ways used by the researcher in individual interviews were the same in the focus group, for example, the researcher applied open ended question as to gain insight from the participants’ point of view. During focus group discussion the participants shared ideas and came up with new ideas that the researcher was not aware of and that gave the researcher rich data.

The focus group discussion of service providers was made of 2 social workers, 1 police officer, 1 ward councillor, 2 nurses and 2 church leaders and was conducted as to gain the insight into their perspective on the effects of stigma on PLWHA. The number of the participants was enough as to make the focus group not to fall flat because of silent members (Babbie & Mouton, 2011). Using the group work skills grounded in social work practice, the researcher made sure that there were no members who dominated the group since there were different characters within the group. In addition, the researcher gave everyone a chance to participate in the group and share their views.

4.4.3 Re-interviewing

Re-interviewing is primarily used in qualitative inquiry methodology and is defined as a process where the researcher seeks to improve trustworthiness of data that has been recorded during the research interviews (Harper & Cole, 2012). Re-interviewing process verifies the data that have been collected from the participants (Rager, 2005 in Harper & Cole, 2012). According to Harper & Cole (2012) the researcher will restate or summarise information and asks the participants to determine accuracy. In this instance, the participants either agree or disagree.

4.5 Research domain

Dimbaza is in the Eastern Cape Province of South Africa, located in the Buffalo City Local Municipality, 20 kilometres west of King William's Town on the R63 road. (Buffalo City Metropolitan Municipality, 2014).

4.5.1 Historical background

Dimbaza was established in 1967 because there were people who were coming from Middleburg, Burger'sdorp, Graham's Town, Cape Town, Colesburg, Humansdorp and Cradock. The main aim of its establishment was to settle ex-political prisoners.

The motive behind this was to form homelands, and was also reserved for labour force. The establishment of Dimbaza was based on political issues together with the uniqueness of its history.

Dimbaza was established by the unemployed people and there were no jobs, since there were few black farm owners who were doing farming for survival not for commercial purposes. Therefore, people were struggling and were living in poverty and were vulnerable to diseases since there were no health care centres. As a result, mortality rate grew up rapidly and many children died.

4.5.2 Population

The Township of Dimbaza is composed of Xhosa speaking people, Zimbabweans and few political refugees of Somalians who are business orientated. The following figures are the rough estimate of the population.

Description - 2009-2010

1. Black African -42956

2. Coloured -12

3. Zimbabweans-200

4. Somalians -100

Total-43268

The population is comprised of the Christians and the African religion (the Bantu religion) and few Islamic faiths. Most people (the Xhosas) are bi-religiously because they still perform their African religion and they are also the Christians. The Xhosa group performs the circumcision school for males, the rituals whereby they give honour to the dead.

4.5.3 Politics

The political background has influenced them to play a significant role in the establishment and expansion of Dimbaza. In honouring the fallen heroes the new community hall is named after Moses Twebe, who was one of the heroes who fought against apartheid, Richard Varha and Archie Velile Sandile, the king of the Rharhabe kingdom are also honoured, because there are two high schools which are named after them. A wall of fame is on the pipe line, the reason behind in construct such a structure is to acknowledge all those who have sacrificed all their lives in trying to bring about an end to a cruel system of the previous government. Therefore, in commemorating all the above people there was a consultation between the political organizations whereby they unanimously decided on those names.

4.5.4 Economic activities

During the early 1980's Dimbaza changed to be the food basket of the King Williams Town and the surrounding areas due to the diversion of Dimbaza into being the industrial area. Many Asian investors came and flocked into Dimbaza and they

brought about change in the economic lifestyle of the people of the area. Therefore many factories had to be built and the garment industry came into being.

By the end of the 1990's there were new labour laws and most firms moved to another countries. The closure of many firms started because of the industrial actions, workers felt that they were being exploited and the Asians did not want to adhere to the new labour laws.

Currently the Township of Dimbaza has got 4 operating firms and the 60% of the population of the Township is not economically active as they are not working. Most of the people have moved to the other provinces mostly to the Western Cape to look for greener pastures and the rest is depending on social grant.

4.5.5 Health care facilities

There are two health care centres in Dimbaza, which caters for Dimbaza and surrounding communities. They are both operating well.

4.5.6 Social activities

Some of young people and youth are committed to Gospel Music as there are about four groups. There are also two stadiums that are used for soccer players and the other one is accommodating rugby players.

4.5.7 Social-ills

The prevalence of HIV/AIDS is very high, especially among the youths, followed by the rates of TB, Hypertension, Diabetes, Epilepsy, and Mental illnesses such as stress and depression (Buffalo City Metropolitan Municipality, 2014). A high unemployment rate breeds poverty with the majority of Dimbaza households living below the poverty line. Other common social problems are alcoholism, drug abuse, promiscuity, child abuse, rape, and domestic violence. Some of the youths involve themselves in criminal activities as they are loitering on the streets.

The reason for choosing this area is because it is easily accessible and also the state of stigma related to HIV/AIDS is escalating in this area. The researcher is also familiar with this area.

4.6 Population of the study

Population refers to individuals in the universe who possess specific characteristics (Strydom, 2011:223). This means that population is a group of individuals that share one or more characteristics from which data can be gathered and analysed. The reason for choosing the population employed in the study was that people living with HIV/AIDS experience the challenge of stigma on a daily basis globally. The officials who were chosen amongst the population also deal with PLWHA who are stigmatised in their organisations daily. More so, cases of stigma related to HIV/AIDS occur frequently amongst the Township of Dimbaza.

4.7 Specific sample size

Choosing the sample from the Township of Dimbaza helped the researcher to particularize the target population. Their age group was from 18 to 45 years because this seemed to be the most infected age group and was gender mixed. This involved 10 people living with HIV/AIDS for in-depth interviews who were drawn from the non-governmental organisation (NGO) working with people living with HIV/AIDS namely “Never Give Up” (NGO). The organisation was chosen because the researcher was looking for people who have disclosed their HIV statuses. The researcher produced a letter of permission to the participants and the copy is attached as annexure 2. The sample size is presented in Table 4.1.

Table 4.1: Sample size presentation

Type of interview method	Interview sample	Samples interviewed
Individual in-depth interview	People living with HIV/AIDS	10
Focus group interview	Social workers	2
Focus group interview	Nurse	2
Focus group interview	Church leaders	2
Focus group interview	Ward councillor	1
Focus group interview	Police	1
	Total	18

4.8 Sampling procedure

There are two types of sampling techniques, probability and non-probability. The researcher employed the non-probability sampling strategy. “In the non-probability paradigm each unit in the sampling frame does not have an equal chance of being selected for a particular study” (Strydom, 2011:231). Purposive sampling, which was applied in the present study, is based entirely on the judgment of the researcher, in that a sample is composed of elements that contain the most characteristics, representative or typical attributes of the population that best serve the purpose of the study. PLWHA and eclectic officials were intentionally chosen to represent the population of Dimbaza Township since the issue of stigma related to HIV/AIDS mostly affects them.

4.9 Data analysis

Schurink, Fouche & De Vos, (2011:397) propose that “data analysis is the process of bringing order, structure and meaning to the mass of collected data”. The researcher made use of qualitative data analysis. According to Babbie (2007:378) in (Delpont & Roestenburg, 2011) qualitative analysis is the “...non-numerical examination and interpretation of observations, for the purpose of discovering underlying meanings and patterns of relationships”. It is said that the idea of analysis implies some kind of transformation. In other words, the process of data analysis begins with the categorisation and organisation of data in search of patterns, critical themes and meanings that emerge from the data (Babbie, 2007). This means that the researcher starts collecting data and then processes it by analysing the data into an understandable and trustworthy analysis.

4.9.1 Thematic Analysis

The researcher made use of thematic analysis which is explained as a method for identifying, analysing, and reporting themes within data and it minimally organises and describes data set in detail (Braun & Clarke, 2006). In thematic analysis similar codes are put together and given one term. Thematic analysis can be crucial or a realistic method which reports experiences, meanings and reality of participants. It can be a constructionist method, meaning that it examines the ways in which events, realities, meanings and experiences are the effects of a range of discourse operating within the society. Woods (2011) suggests that thematic analysis is a way of seeing as well as a process for coding qualitative information.

Braun & Clarke (2006) propose six phases of thematic analysis which are as follows:

1. *Familiarization* – here the researcher has to transcribe data, re-read the data and note down initial ideas.
2. *Generating initial codes* – interesting features need to be coded in a systematic way across the entire data set and collate data relevant to each other.
3. *Searching for themes* – collating codes into potential themes is necessary, gathering all data relevant to each other.
4. *Reviewing themes* - the researcher has to check if themes work in relation to the coded extracts.
5. *Defining and naming themes* – this is an ongoing analysis to refine the specifics of each theme.
6. *Producing the report* – this is the final opportunity for analysis. This is the selection of vivid, compelling extracts examples. The researcher has to read

peer reviewed qualitative articles and need not report facts only but provide analytic narrative (Ruggunan, 2013).

However, the researcher had preconceived themes and allowed new themes to emerge from the thick data that was elicited. The themes were based on the objectives of the research and this made it possible for researcher not to derail from the aims and objectives of the study.

4.9.2 Reporting of the findings

In this part the researcher had to write a report which is a document that includes accurate and objective information that has been collected through the research. Strydom & Delport (2011) indicate that the findings form the largest part of the study because the analysis and interpretation of data are included. The findings were presented in words to make the data understandable. Reporting the findings does not mean that the researcher has to present it, for that reason the researcher interpreted and analysed the data indicating what it means in relation to HIV/AIDS-related stigma.

4.10 Validity and reliability

Letts, Wilkins, Law, Stewart, Bosch & Westmorland (2007) assert that while in quantitative research one discusses concepts such as reliability and validity, qualitative researchers use different terminology when determining the rigour of a qualitative study. The overarching when considering rigour is trustworthiness (Letts *et al.*, 2007). Trustworthiness ensures the quality of the findings and increases the reader's confidence in the findings. To ensure reliability in qualitative research, the examination of trustworthiness is important. Lincoln & Guba (1985) in Golafshani

(2003) indicate that the idea of discovering truth through validity and reliability is replaced by trustworthiness in qualitative research. It is not easy to assess the accuracy of qualitative research findings but to ensure trustworthiness some strategies have to be applied to measure the quality of the research.

According to Babbie (2007) cited by Delport & Roestenburg (2011) validity refers to the extent to which an empirical measure adequately reflects the real meaning of the concept under consideration. Salkind (2006) cited in Delport & Roestenburg (2011) refers to validity, truthfulness, accuracy, authenticity, genuineness and soundness. Validity is also referred to the extent to which the instrument measures what it is supposed to measure. On the other hand reliability occurs when an instrument measures the same thing more than once and results in the same outcomes or will perform the same way in the future as it has in the past. Salkind (2006) attests that reliability refers to dependability, consistency, trustworthy, predictable and faithfulness of the study.

The use of reliability and validity is common in quantitative research and now is reconsidered in the qualitative research paradigm (Golafshani, 2003). Since the reliability and validity are rooted in positivist perspective they should be redefined for their use in a naturalistic approach. Golafshani (2003) states that validity and reliability are factors that any qualitative researcher should be concerned with when designing, analysing results and judging the quality of the study. Guba's (1981) model is based on the identification of four criteria of trustworthiness that are relevant to both quantitative and qualitative studies which are truth value, applicability, consistency and neutrality.

It is indicated that since there are philosophical differences between quantitative and qualitative approaches, the model defines different strategies of assessing these criteria in each type of research. The four criterion of trustworthiness to both quantitative and qualitative studies is summarised in Table 4.2.

Table 4.2: The comparison of trustworthiness by research approach

Criterion	Qualitative Approach	Quantitative Approach
Truth value	Credibility	Internal validity
Applicability	Transferability	External validity
Consistency	Dependability	Reliability
Neutrality	Confirmability	Objectivity

4.10.1 Strategies to increase trustworthiness

The two prominent qualitative researchers Guba & Lincoln (1999) cited in Schurink & Fouche (2011) proposed the four alternative constructs in which they believe that they reflect the assumptions of the qualitative approach more accurately. The quality of a research in each paradigm should be judged by its own paradigm terms (Healy & Perry, 2000; Letts *et al.*, 2007). These scholars argue that reliability and validity are essential criteria for quantitative paradigm, therefore in qualitative paradigm terms such as credibility, neutrality or conformability, consistency or dependability and applicability or transferability are to be essential criteria for quality. The four components which are used in qualitative paradigm are discussed in the next section and are summarised in Table 4. 3.

4.10.1.1 Credibility

This is an alternative to internal validity (Schurink & Fouche, 2011). Credibility refers to the true picture of the phenomenon. The ways of ensuring credibility are the collection of data over a prolonged period and from a variety of participants. The use of multiple sources to collect data is included. Triangulation, a strategy to enhance trustworthiness through the use of multiple sources and perspectives to reduce systematic biases is considered. The involvement of participants through member checking is considered (Letts *et al.*, 2007). This may consist of the involvement of participants in a variety of activities to verify data and interpretation such as the returning of transcripts to the participants for the review of interview content. The researcher re-interviewed the participants after the data analysis and interpretation to give participants the chance of correcting and confirming the analysis and interpretation of data. Credibility was achieved because the present study made use of different sources such as individual interviews and one focus group to collect data.

4.10.1.2 Transferability

Transferability refers to whether the findings can be transferred to other situations. It is analogous to external validity that is the extent to which findings can be generalized (Maxwell, 2002; Lincoln & Guba, 1999). Transferability was achieved by providing detailed, rich description of the effects of HIV/AIDS-related stigma on PLWHA to provide sufficient information to be able to judge the applicability of the findings to other settings. Schurink & Fouche (2011) suggest that designing in which multiple cases, multiple informants or more than one data gathering methods are used, can greatly enhance the study's usefulness for other settings. The researcher

provided the rich and thick description of the study to enable the readers to make their own judgement regarding the transferability of the research outcomes.

4.10.1.3 Dependability

Dependability is an alternative to reliability, that is, the consistency of observing the same findings under similar circumstances (Schurink & Fouche, 2011). Dependability can be achieved through auditing which consists of the researcher's documentation of data, methods and decision made during the research and its end products. Auditing requires the data and description of the research to be elaborate and rich. Based on the current study the researcher provided rich data and thick description.

4.10.1.4 Confirmability

Confirmability is referred to as the degree to which the research findings can be confirmed or corroborated by others (Lincoln & Guba, 1999). The researcher provides evidence that corroborates the findings and interpretations by means of auditing. Ghauri (2004) suggests that in confirmability researchers need to demonstrate that their data and interpretations drawn from it are rooted in circumstances and conditions outside from the researcher's own imagination and are coherent and logically assemble.

Lincoln & Guba (1985) cited in Babbie & Mouton (2011) suggest that enough evidence should be left so that the auditor could determine that all aspects that are included in the research can be traced to their sources and whether they are

supported by the inquiry. The researcher referenced all sources of information applied in the study to make it easy for auditors when assessing the study.

Table 4.3: Summary of strategies to establish trustworthiness

<u>Strategy</u>	<u>Criteria</u>	<u>Application in the present study</u>
Credibility	Prolonged and varied field experience	The researcher stayed in the field until she reached the purpose of the research.
	Triangulation	Individual and focus group interviews were conducted.
	Member checking	Participants verified data and interpretation during re-interview process
Transferability	Nominated sample	Purposive sampling because the sample comprised the most characteristics.
	Comparison of sample	Sample reflective of population, they possess same characteristics.
	Dense description	Full description of methodology was discussed in the text.
Dependability	Dependability audit	Participants confirmed the data analysis in the re-interview process.
	Dense description of research method	Research methodology described fully in the text.
	Triangulation	Individual and focus group interviews were conducted.
	Peer examination	Research protocol discussed with the supervisor.
	Code-recode procedure	The researcher recoded data & results were evaluated.
Confirmability	Confirmability audit	Research was done under strict supervision.
	Triangulation	Multiple sources of data were employed.

“Adapted from Krefting, 1991”

4.11 Ethical considerations

Social work research is based on a series of ethical considerations which govern the engagement between the researcher and the participants.

The term ethics implies preferences that influence behaviour in human relations, conforming to a code of principles, the rules of conduct, and the responsibility of the researcher and the standards of conduct of a given profession (Babbie & Mouton, 2011:520).

The permission to conduct research was sought from the Ethics Committee at the University of Fort Hare. The researcher made sure that there was no harm done to the participants and took into consideration the following ethical issues:

4.11.1 Confidentiality and Anonymity

Confidentiality refers to agreement between persons that limit others access to private information (Strydom, 2011:119). The researcher assured the participants that all information provided would be protected and would be kept in strictest confidentiality. Due to the possibility of intrusion into the lives of the participants, the researcher ensured that the research was not intrusive and that privacy was maintained. Lavrakas (2008) postulates that anonymity in research refers to the data collected from respondents who are completely unknown to anyone. The researcher emphasized that it was only the participants who would know that they participated in the research and the researcher could not identify the participants' identities. The participants were asked not to use their real names to protect their identities.

4.11.2 Informed consent

Researchers are expected to obtain informed consent from all those involved in research (Halai, 2006). This adheres to a larger issue of respect for the participants. Informed consent is obtained through written consent forms. Respect for a person requires that subjects be given the opportunity to choose what shall not be happening to them (Strydom, 2011:117). The researcher read out the consent form

thus giving the participants the right to pull out of the research at anytime. The informed consent revealed among other things, why the study was being carried out and the importance of the participants' involvement. The purpose of doing that was to make participants decide whether to participate or not.

4.11.3 Voluntary participation

Social research may interrupt people's daily activities and one may need to sacrifice his or her time to participate. Babbie & Mouton (2011) argue that participants should be informed that the participation is completely voluntarily; therefore they should not expect special rewards such as payment. All ethical research must be conducted using the willingness of participants, and the participants should not be forced or bribed into participation. Participation in research should at all times be voluntary and no one should be forced to participate in a research project (Strydom, 2011). Participants were not pressured to participate in the research. The researcher guaranteed that the study was voluntarily, if anyone wanted to withdraw he/she had the right to do so.

4.12 Conclusion

In conclusion the study mainly employed qualitative research method. This is because qualitative research methods are the best means of collecting in depth information from respondents. Above this, the study involved sensitive issues; therefore the researcher felt obliged to protect the participants by keeping the information provided confidential. Lastly, the researcher treated all the participants with respect and dignity they deserved irrespective of their backgrounds. The

following chapter presents the findings of the present study, gives data analysis and interpretations

CHAPTER FIVE

PRESENTATION OF THE FINDINGS

5.1 Introduction

This chapter presents the findings of the study which were collected from the participants. Data were collected by means of individual interviews and focus group discussion and central themes were drawn out which were related to the questions asked about the effects of HIV/AIDS-related stigma. Various themes were identified and were having sub-themes. Thus, the findings are presented in terms of themes hereunder, based on each of the eleven protocols. The full protocols are attached in the appendix section. The presentation of findings includes themes that were planned for exploration initially as well as other themes that emerged from the interviews. The findings, where possible, are dialogued with the literature such that “... the literature study and findings are compared to each other” (Onwegbuzie, Leech & Collins, 2012). The following are the central themes which were planned:

1. Biographical information.
2. Perceptions of community members about HIV/AIDS.
3. Positive community response.
4. Self-stigma.
5. Challenges faced by people living with HIV/AIDS (PLWHA) in health-care settings.
6. Cultural challenges faced by people living with HIV/AIDS (PLWHA).
7. Recommendations by PLWHA.

5.2 Theme 1: Biographical information

Biographical information of the participants is presented according to attributes such as gender, race, age, marital status, number of dependants, educational qualification and occupation. Table 5.1, below, depicts the biographical information of the individual participants.

Table 5.4: Biographical information of participants from individual interviews

Participant	Gender	Age	Marital status	Number of dependants	Educational qualification	Occupation
1	Female	33	Single	2	Grade 10	Unemployed
2	Female	40	Single	2	Grade 1	Unemployed
3	Female	27	Single	2	Grade 10	Self-employed
4	Male	45	Single	2	Grade 8	Unemployed
5	Female	40	Single	3	Grade 1	Unemployed
6	Male	39	Single	3	Grade 11	Unemployed
7	Female	18	Single	2	Grade 8	Employed
8	Female	25	Single	2	Grade 12	Unemployed
9	Female	30	Single	0	Grade 9	Unemployed
10	Female	43	Single	3	Grade 12	Unemployed

As indicated in Table 5.1, the findings revealed that two participants were males and eight were females. The age of the participants ranged from 18 to 45 years of age.

The findings also revealed that some of the participants started to know their HIV seropositivity when they were in their early 20's. Regarding the marital status, the findings revealed that the participants were all single parents. Further, the findings revealed that 8 of the participants were unemployed, 1 was self-employed, and 1 was employed.

Each of the six participants had two dependants, three participants each had three dependants and one participant had no children. The findings indicated that the nine of the participants were having more than one dependant. In terms of the educational qualifications, two participants had grade 12, two had grade 10, two had grade 8; the other two had grade 1, one participant had grade 11 and the last one had grade 9. The findings indicated that none had reached the tertiary level and most of the participants did not reach their grade 12 or standard 10.

Table 5.2 presents the biographical information of the focus group. As shown in the table there were eight participants, four females and also four males. The occupation of the participants ranged from one ward councillor, one police officer, two professional nurses, two pastors and two social workers.

Table 5.5: Biographical profile of focus group

Participant	Gender	Age	Marital Status	Occupation
1	Male	45	Married	Ward councillor
2	Female	45	Single	Police
3	Male	42	Married	Pastor
4	Male	40	Married	Pastor
5	Female	45	Married	Professional nurse
6	Female	39	Single	Professional nurse
7	Male	30	Single	Social worker
8	Female	37	Single	Social worker

5.3 Theme 2: Perceptions of community members about HIV/AIDS

When the participants were asked about how the community members perceived HIV/AIDS, they all responded by saying that community members knew about the disease and were well informed about it. The findings revealed that community members knew exactly how to prevent HIV/AIDS and how it is infected. The findings were confirmed by the following responses from the participants:

People from the community know about HIV/AIDS. They know that if you are not using condoms you are at risk of being HIV positive (Participant No.1).

And also:

Some community members know that if you are HIV positive you have to stick to your treatment and eat the right diet such as fruit and vegetables (Participant No. 3).

As well as:

People are aware of HIV/AIDS because we educate them about safe preventive measures (Participant No. 5 from the focus group).

Various positive responses were expressed by the participants on how community members perceived HIV/AIDS. The findings also revealed that people get educated about HIV/AIDS on a daily basis.

5.3.1 Sub theme 1: Negative attitudes from community members

Some participants revealed that community members treat them in demeaning manner, such that they feel bad and decide to stop associating themselves with others. One of the respondents reported that some of family members who were supposed to take care of them would make someone lose hope because they become the first ones to pass negative messages. The findings were corroborated by the statements made by the participants. Four participants expressed themselves saying the following expressions:

When my aunt comes from the shebeen drunk she would shout at me to the extent that everyone in my vicinity would hear what she is saying. She would insult me saying that my mother died of AIDS and I am also going to follow her. This make me feel so ashamed and sometimes I stay indoors or go out to my boyfriend (Participant No. 4).

I am no longer associating myself with the people in my area because if you are passing by they would point fingers or gossip about you. You will also find others passing remarks which are devastating; such as look now he got the lotto which means that you have AIDS (Participant No. 1).

When we attend cultural activities and given umqombothi (African beer) the other men would pour my beer in a separate container telling that I know that I have this thing so they do not want to contract my disease.(Participant No. 1)

There are some people, especially within our families, who would look at you and feel sorry or shame. For example here in this Township some people would ask you if you are paying the burial society because they can hear anything about you. These people are not aware that we can stay longer as long as we adhere to our treatment (Participant No. 5)

Participants indicated that the negative remarks from some community members discouraged them and they felt offended all the time. They also mentioned that they feared speaking openly about their status.

5.3.2 Sub-Theme 2: HIV/AIDS and promiscuity

It was mentioned by the participants that the perception of associating HIV/AIDS and promiscuity made people to regard individuals who are infected by HIV/AIDS as promiscuous. Some participants reflected that this perception in the Township of Dimbaza was also associated with adultery. This is clarified by the following responses from the sample:

When you come to Dimbaza being sick from another town especially from the big cities such as Johannesburg or Cape Town, people from this Township would gossip about you telling others that you were a sex worker (Participant No. 2).

Some of people living with HIV/AIDS, especially women, would come to us reporting cases whereby they are insulted by other women who share the same man telling them that they are dying of AIDS and calling them prostitutes (Participant No.3 the from focus group).

Me and my sister were once insulted about our HIV positive status by some ladies in our street. It was hurtful but we managed to deal with that by telling ourselves that we are better than them because we know

where we stand regarding our HIV status and for them they fear being tested for HIV so they do not know their status(Participant No. 4).

Furthermore, some participants revealed that being HIV positive is because of the risky behaviour that someone is engaged in, such as having more than one sex partner. This was explained by the participants as follows:

I know that my girlfriend infected me with HIV/AIDS because she had too many boyfriends (Participant No. 1).

There is this lady who died because of AIDS last year, she came sick from Johannesburg and rumours were saying that she was not working but she used to be a prostitute (Participant No.10).

5.3.3 Sub-theme 3: Feminization of HIV/AIDS

Some of the female participants reported that they were regarded as the transmitters of HIV/AIDS. They showed concern about that stating that it made them to be seen as irresponsible people. One of the male participants mentioned that he was not surprised that he contracted the virus from his girlfriend because he knew that women are always the ones who bring HIV to men. This is demonstrated by the responses elicited which are stated below:

My girlfriend had too many boyfriends and she is the one who brought HIV/AIDS, by the time she told me to use condom I refused telling her that real Xhosa men do not use condoms they like flesh to flesh (Participant No.1).

Here in Dimbaza we are regarded as the ones who bring HIV to our partners. There was this lady whom I was sharing a boyfriend with her, she insulted me telling me that I am the one who infected the man (Participant No.6).

Things become worse when you are an unmarried woman who is HIV positive. You are associated with promiscuity because sometimes

someone is not working so people assume that she is engaging in promiscuous activities (Participant No. 2).

The findings also revealed that most people in the support group were women. For female participants this was an unfair judgment towards them because they expressed how hurtful it is to be perceived as transmitters of HIV/AIDS. These were their expressions:

We as women should be treated the same way as men because HIV/AIDS affects us all (Participant No. 7).

It makes me angry when someone says that HIV/AIDS is a disease of women because these same men are changing partners and spreading the virus, so who is to blame (Participant No. 8)?

Women have to be treated the same way as men. The worst part is that our dignity is being put down by other women who insult others for being the carriers of HIV/AIDS (Participant No. 5).

5.4 Theme 3: Positive community responses

The study's participants indicated that members of the Township of Dimbaza responded positively to HIV/AIDS education, whereas there are some who still have negative attitudes on people living with HIV/AIDS. The positive responses of the participants are listed below:

People do respond positively because we educate them when they are waiting at the foyer waiting for consultation to respect PLWHA and we tell them that even if they are not infected by HIV/AIDS but they are affected (Participant 8 from focus group).

Here in Dimbaza Township from my experience, I would say 80 percent of people are informed about HIV/AIDS and respond positively to PLWHA and 20 percent still need education about HIV/AIDS (Participant No.2 from the focus group).

They treat me well now in the community. At first they were laughing at me because I was mentally disturbed when I started using ARVs and I was told by the nurses that I was reacting from the pills and they changed my treatment (Participant No. 2).

HIV/AIDS education was mentioned by most of the respondents as the effective tool to mitigate stigma. It was further indicated by some of the participants that people from the Township of Dimbaza responded positively to HIV/AIDS because there were awareness campaigns conducted by stakeholders such as the Department of Social Development and Special Programmes, South African Police Services (SAPS) and the Department of Health. Participants from the focus group reported that there were also NGOs which were trying their best to educate the community members about HIV/AIDS which made members of Dimbaza Township to be knowledgeable about HIV/AIDS.

5.4.1 Sub-theme 1: Acceptance of HIV/AIDS

The participants reported that they had accepted their HIV positive status and HIV/AIDS has been accepted by some people in the Township of Dimbaza. Some of the participants reported that HIV/AIDS was accepted by the community but there was still stigma attached to it. This was confirmed by the following sentiments from the participants:

I would like people from this area to fully accept us as normal people just like any other person because if you are around some of them feel sorry for you as if you are dying (Participant No. 2).

The Township of Dimbaza has accepted people living with HIV/AIDS unlike when it emerged where people were dying and were afraid of talking about the disease. There are NGOs who educate people about HIV/AIDS (Participant No 1.from focus group).

People from this community support PLWHA. At times we use to have commemoration where we light candles and remember all people who passed away because of HIV/AIDS. You will find that PLWHA are losing hope, others cry as the names of those who are remembered are called. With the support of the community you will see that they are strengthened some would smile and lift up the candles (Participant No.3 from focus group).

Some of the participants mentioned that they had accepted their HIV positive status. They also mentioned that acceptance made them stronger to the extent that they could stand firm and talk about HIV/AIDS in public. This was corroborated by the following expression from the participants.

I feel stronger now ever since I accepted that I am living with HIV/AIDS. I am living my life the way I used to live because I know that I won't die because of my HIV positive status. Those who are gossiping about us are making us stronger instead because they know nothing about their HIV status (Participant No.4)

Participants from the focus group mentioned that PLWHA need to accept their HIV status and know that they have the potential to live their lives happily. One respondent mentioned that PLWHA need to be motivated with the strengths that they have. This was stated as follows:

You know what when you are working with clients you have to identify their strengths as well as their weaknesses. By doing that you are trying to show him or her weaknesses and strengths he or she is holding. After that you have to only capitalize with the strengths that you identified from him or her so that he or she can use the strengths to overcome the weaknesses. If I am not able to identify any strength within the client, I make him or her feel stronger by his or her physical appearance (Participant No.2 from the focus group).

5.4.2 Sub-theme 2: Support and care from community members

Some participants reported that community members were supporting PLWHA in terms of strengthening them. Some participants revealed that community members

would encourage them to adhere to the treatment and some mentioned that their neighbours supported them to the extent that they gave them vegetable seeds so that they could eat healthier. Support groups were also reported as helpful in the Township of Dimbaza. Responses showing that some community members support people living with HIV/AIDS are listed below:

There are times when I do door to door campaign I find that some parents are supporting their infected children and there are those parents who isolate their children. So I usually visit those families until they accept and support their children (Participant No.2 from the focus group).

Community members do everything to support PLWHA but there are some people who would use HIV/AIDS as an insult when someone fights with a person who is HIV positive. They use this insult to demoralize them but PLWHA do not worry about that because they know that they use HIV/AIDS as a weapon to destroy them (Respondent No.3 from focus group).

Some respondents reported that they were living positively with hope and had accepted their HIV seropositivity. Most of these participants were the ones who were well informed about HIV/AIDS. They mentioned that at first it was difficult for them to accept their HIV positive status but through support and care from their families and some of community members they felt empowered.

It was mentioned by some respondents that the information they acquired from the support group and from the workshops they attended had made them live productive lives. Some participants mentioned that their stresses were relieved since they observed that HIV/AIDS was perceived as any other sickness especially within their families. Some participants expressed their feelings as follows:

My mother accepted me; she told me that I am going to live longer because being HIV positive does not mean that you are going to die (Participant No. 6).

At church my pastor tells people not to judge PLWHA, and he always asks the congregation to pray for the cure of HIV/AIDS. I feel very happy when I am at church because people know my status but they do not have negative attitudes towards me (Participant No.7).

5.4.3 Sub-theme 3: Community outreach

Mobilizing community members and educating them about HIV/AIDS was reported by the respondents that it brought change in the Township of Dimbaza. This was reported that it was because some community members responded positively to HIV/AIDS. Some participants mentioned that they sometimes conducted “door-to-door” campaign to educate community members so as to get accurate information about the disease. Participants mentioned that different kinds of people gathered when there were awareness campaigns. This was supported by the following statements from the participants:

Sometimes we as members support group reach out to the community and talk about HIV/AIDS to impact a positive change from community members (Participant No.6).

We go to the communities and we try by all means to gather different kinds of people, for instance the youth and elderly and also traditional leaders. The reason for doing that is because most of elderly people think that HIV/AIDS affects young people only (Participant No.8 from the focus group).

These findings revealed that HIV/AIDS awareness campaigns target different age groups. It was mentioned by some of the participants that there was still a lack of accurate information about HIV/AIDS from some community members, and there was an indication that community outreach has made a difference in people’s lives. It

was further stated by the respondents that some community members in the Township of Dimbaza would make diagnostic remarks on people who show some of symptoms which are related to HIV/AIDS. This was mentioned by some of the participants whose sentiments are listed below:

Community members are well informed about HIV/AIDS but what needs to be done is to stop people from diagnosing other people, for example, when someone shows symptoms such as rash on face, becoming thin and coughing they would gossip about the person saying that he or she is HIV positive (Participant No.9).

You will find that some of people view HIV/AIDS as a death sentence because some of PLWHA whom I know tend to abuse alcohol showing that they do not have hope at all (Participant No.3).

It was mentioned by three respondents from the focus group that there were some support groups in the area which were so helpful in changing the mind-set of people who are less informed about HIV/AIDS. The respondents reflected that the social workers used to conduct door to door campaigns. One of the respondents from the focus group reported that in some households, HIV positive individuals were pushed away especially by their parents, they would say negative things about the person who is infected by the virus. The following sentiment was expressed this way:

In some households you will find that you are welcomed since people respect you as a role model and from other households it becomes difficult to accept the children's HIV positive status, they sometimes call them "dogs" who were living promiscuous lives. So that is where I keep on reach to those families to change their way of thinking (Participant No.2 from the focus group).

Two participants from the focus group reported that being patient when working with the community is the best way. They reported that being patient results in the behaviour change on people who seem to be ignorant about HIV/AIDS.

5.5 Theme 4: Self-stigma

Self-stigma was indicated by some of the participants to be the contributing factor that affects some of people living with HIV/AIDS in the Township of Dimbaza. It was mentioned by some participants that some of PLWHA in the area put blame on themselves and withdrew from the society. Some participants expressed their feelings as follows:

There was this guy who is no longer attending social gatherings because he feels ashamed ever since he was insulted by one of the community members (Participant No.1).

Some of people living with HIV/AIDS whom I know fear to seek treatment because they do not want to be seen with symptoms of HIV/AIDS. So they fear negative attitudes they think they will receive from community members (Participant No. 6).

It was mentioned by the participants that people who feared to disclose their status fetched their medication surreptitiously because they feared being labelled. Some of them indicated that they fetched their medication from other clinics which were far from their community.

5.5.1 Sub-theme 1: Misuse of HIV seropositive status

Some of PLWHA are said to be exaggerating the condition of being HIV positive as a tool to threaten others. It was mentioned by one of the participants from the focus group that some people living with HIV/AIDS tend to do things which are unacceptable. Participants mentioned that some of PLWHA used HIV/AIDS as their defence mechanism and the researcher was not aware about this issue. Some sentiments showing that some of PLWHA were misusing their HIV positive status are listed below:

There are people who are violating the rights of PLWHA and there are some of those who are infected by HIV/AIDS who misuse their rights over other people (Participant No.2 from focus group).

You know what, when you are in charge at workplace you must know that you are in trouble because some of the people who are HIV positive would be absent at work maybe for three days, when you try to find out the reason for being absent they would tell you that they are sick so they have to fetch their ARVs. I always tell them that it is not fair because HIV/AIDS is like my high blood pressure or any other illness so there is no need for them not to be at work for several days (Participant No. 3 from focus group).

One of the participant from the focus group also reported that some of PLWHA were co-operative and some were not. It was reported by one of the participants from the focus group that some of PLWHA in the Township of Dimbaza went for counselling and some stopped attending counselling sessions when they saw that they were feeling well. Two practitioners from the focus group mentioned some perturbing issues.

Some of people who stop counselling sessions would end up dying because when they need help or become very sick they do not come back to me to seek help instead they would hide themselves until you hear that someone passed away (Participant from No.2 the focus group).

I would say some of PLWHA here in Dimbaza do not want to do things for themselves. They would come and ask for food parcels stating that they are diagnosed HIV positive. These people I am talking about do not show any sickness but they are only diagnosed HIV positive. We are trying to tell them to be self-reliant but still they are keeping on coming asking for food parcels (Participant No.5 from focus group).

One respondent from the focus group was discouraged by the behaviour of some PLWHA stating that some of these people were making a lot of demands using their HIV positive status. The respondent mentioned the following expression:

At times in my organization we organize something like a dinner where we invite the infected people to join us. We usually discuss issues about HIV/AIDS such as marrying with a negative person whilst you are positive, talking about pre-marital issues or how to have a child with a negative person whilst you are positive. We contribute and prepare food for PLWHA and organize transport for those who are staying far. My concern is that at the end of the day you will find that these very same people would say that we are using them to get money from Social Development and that is why we keep on inviting them to our organization (Participant No.2 from the focus group).

Some of PLWHA reported that they sometimes felt inferior such that they thought that they became suspicious. Some participants reported that some of PLWHA behaved negatively to other people because of the bad attitude they received from some community members and therefore they thought that everybody would treat them the same way they were treated before.

5.5.2 Sub-theme 2: Labeling of PLWHA

Participants mentioned that in the Township of Dimbaza, PLWHA were called by horrible names when it was known that they were HIV positive. It was reported by some participants that someone would be gossiped that he or she has “*three letters*”, or called a “*walking ghost*”. Participants mentioned that sometimes disclosure made things worse, to such an extent that some people preferred to keep quiet about their HIV positive status. Two respondents reflected that labelling PLWHA hindered the opportunity to socialize and to go for Voluntary Counselling and Testing (VCT). This is explained by the participants in the following manner:

Some PLWHA who are sick lock themselves in their homes because they are called by names such as a “walking ghost” or “they won the lotto (Participant No. 3).

At times people will just look at you and you will see the way they look at you, their eyes are talking and if someone dies due to HIV/AIDS people would say he or she had that thing (Participant No. 7).

The respondents felt so bad about some of people in the Township of Dimbaza who were labelling other people because of their HIV positive status. They expressed that at times labelling PLWHA makes people feel inferior to others because they feel differentiated.

5.6 Theme 5: Challenges faced by PLWHA in health-care settings

Participants who had not yet disclosed their HIV status reflected that they became traumatized when they heard that their HIV positive status was known within the community. It was stated by some participants who had not yet disclosed their HIV status that, this negative behaviour was perpetrated by the health-care workers who breached confidentiality. The following are testimonies of participants who felt bad about the disclosure of information at health care centres:

I heard one of the caregivers at the local clinic mentioning names of people who fetch the ARV treatment and I felt very sad. I prefer to go to other clinics although sometimes you get tired because you do not have a bus-fare (Participant No.5).

Going to your local clinic is not good because people who are working there are curious they will ask you the reason of being there and they will check the place where you are staying. The other thing is that the ARV unit is separated from other consultation rooms so it is easier for them to conclude that you are HIV positive (Participant No. 8).

Two respondents from the focus group mentioned the issue of shortage of staff in the local clinic. They reported that some of the nurses felt exhausted because of the

workload. Respondents also reported that sometimes the workload made them displace their anger on the patients. They mentioned the following statements:

When I approached the sister in charge at the local clinic by the way the patients feel about their treatment she told me that there is a short of staff and those nurses who are on duty get tired because of the large numbers of patients each and every day (Participant No.2 from focus group).

We are trying our best to attend each patient with support and care but really some of us are losing it because they always complain about the issue of recruiting more staff (Participant No.7 from the focus group).

5.6.1 Sub-theme 1: Stigmatizing attitudes from health-care workers

Some participants revealed that they got disappointed by the nurses when they visited the clinics to fetch their medication. They indicated that there were nurses who would have negative attitudes towards them. The following sentiments were expressed by some participants:

When you miss the date to fetch your medication, the nurses would shout at you in-front of others telling you that you are going to die (Participant No.7).

Some of PLWHA whom I work with tell me that they are scared of going to the clinic because the nurses tend to breach confidentiality and gossip about them in the community. I normally approach some of the nurses whom I know and talk about these issues (Participant No.2 from focus group).

Participants reported that they were not comfortable with the treatment they received from the nurses. They mentioned that some nurses were *leaking* the information of their clients and this resulted in PLWHA to be reluctant to fetch their medication. This was testified by the following sentiments:

When my medication is finished I often send my sister and tell her to say that I am at work. This is because some nurses are disrespectful; I once did not fetch my medication because I had no food to eat. When I told the nurse that I did not have food she shouted me like hell (Participant No.10).

I fetch my medication at the hospital in town, here at the local clinic there is a nurse who is my neighbour and we do not talk to each other because she spread gossip about me regarding my HIV positive status and I felt so devastated (Participant No.3).

They felt emotionally abused by health care workers whose behaviour is negative towards them. It was strongly indicated that these behaviour discouraged people to seek help at the health care centres. One of the respondents from the focus group mentioned that some of PLWHA prefer seeking help somewhere else than going to the clinic.

5.6.2 Sub-theme 2: Differentiating folders of PLWHA

Putting different stickers on the folders of PLWHA in health-care centres was described by the participants as *stigmatization*. It was mentioned by the participants that their folders had red stickers which made them different to other patients and in the clinic there was a section for PLWHA only.

When we fetch our treatment we have to go to ARV unit on the other side of the clinic that is where we will find our folders to take our treatment at dispensary. People will identify you that you are on ARVs by the red sticker that is on the folder (Participant No.9).

We have to queue just like other patients, not to be separated as if we are going to infect others (Participant No.6).

Participants reflected that if someone was coming from the antiretroviral (ARV) section from the clinic, some community members would start to behave negatively

and gossip about them, telling others that “so and so” is HIV positive without any evidence.

5.7 Theme 6: Cultural challenges faced by PLWHA

Some of the participants revealed that HIV/AIDS is perceived in cultural context as a curse from the ancestors. They explained that if someone does not follow what the ancestors want, he or she gets sick. They further reported that some of people living with HIV/AIDS were brainwashed by some of traditional healers who insisted on PLWHA to perform rituals so that their illnesses could be cured. Some expressions to illustrate this were as follows:

There was this lady who was here with us from the support group. Her mother told her that there is a traditional healer or “igqirha” who was going to do a ritual by slaughtering a goat for her and apologise to the ancestors for not responding to their calling. The lady performed the rituals and stopped taking the treatment. She went to the initiation school to become the traditional healer. You know what she did not finish even three months and we heard that she passed away (Participant No. 3).

Some people in this area do not want to test for HIV but they prefer to seek help from traditional healers who do not perform any test. This is worrisome because they continue dying and you will hear by some of their family members that it was found that the person had AIDS (Participant No. 9).

Participants expressed their emotions saying that it is not good to see that some people do not want to accept their diagnosis. These sentiments are from the participants who showed their concern about these cultural influences. The following captures their thoughts about cultural challenges:

This this tendency from people by the minute a person tests positive she or he thinks that she or he has to perform rituals, you will see that

person using traditional medicines and by that time the viral load is going up (Participant No.2 from the focus group).

There are still people who are practicing rituals and stop taking their medication but we are mobilizing cultural leaders and educate them about these things (Participant No.8 from the focus group).

Some participants mentioned that traditional healers get informed about voluntary counselling and testing before they can treat their patients. It was also revealed by two participants from the focus group that some of traditional healers know everything about HIV/AIDS. Some traditional healers were reported to make things on their own because they were looking for profit. Participants from the focus group indicated that this is a tendency of being ignorant because they are telling lies about HIV/AIDS prevention.

5.8 Theme 7: Recommendations by PLWHA

All participants mentioned that the need for mobilizing community members regularly would make a difference. They indicated that community members were assisting them but there is much that needs to be done. Participants No.3 and No.6 for instance explained the situation as follows:

Friends and families are helping us on certain things but it is not enough because there are still people who have stigmatizing attitudes (Participant No.3).

Sometimes when I am sick some of the community members show support by visiting me at home and that makes me to recover soon (Participant No.6).

5.8.1 Sub-theme 1: Support from community members

Some participants mentioned that for the people who are not well informed about HIV/AIDS, there should be some activities such as musical shows. They indicated

that these activities would make people to be interested to attend and that is where they would have a platform as PLWHA to express the agony they felt about the negative treatment they received from some community members. This was supported by some expressions from the participants saying that:

There are members of TAC here in Dimbaza who are conducting awareness campaigns about HIV/AIDS but I can see that lack of funding to conduct activities to curb HIV/AIDS-related stigma makes these activities not to sustain (Participant No. 2 from the focus group).

If we can have something like a soup kitchen here in Dimbaza and invite other people from the community I think that would work because we will not give away the soup only but we will discuss issues that are affecting us such as the issue of HIV/AIDS-related stigma (Participant No. 4).

5.8.2 Sub-theme 2: Support from various stakeholders

All of the participants mentioned that it would be better if the social services practitioners and the community leaders work hand in hand with them to curb HIV/AIDS-related stigma. The following are reflections of some participants:

I would like the social workers and other officials to gather all the members of Dimbaza Township to the community hall and organise someone who is well known. That will make people to come and listen to our voices (Participant No.4).

I will be glad if I the social services practitioners would take further steps when someone gets stigmatised or treated unfairly because of his or her HIV/AIDS positive status (Participant No. 6).

I want those who insult us to be taken to the court of law because stigma affects our self-esteem (Participant No.3).

Virtually all respondents were willing to receive a positive treatment from the entire Township of Dimbaza. They indicated that the social services practitioners and community leaders should support them by organising funding to sustain their

activities. Some participants indicated that community members and PLWHA were doing their best to curb HIV/AIDS-related stigma but lack of funding seemed to be the barrier to their activities.

Some of the participants mentioned the issue of unemployment. They indicated that they were struggling to take care of their children. They insisted that if there could be an adequate support from the social workers, it would be better for them. They reported that they were applying for food parcels but the social workers would tell them to wait for a long period which made them delay to take treatment.

I am so reluctant to go and apply for food parcels, because every time the social workers will always say wait. I am now planting vegetables in my garden so that I can take my treatment (Participant No. 7).

Sometimes I do not take my pills because I cannot take pills on an empty stomach. The social workers are ignoring us and they take their time to do these things (Participant No. 1).

The participants associated these issues with selfishness from social workers who took long time to process their applications for food parcels. They insisted that they would feel better if they could see that their complaints were taken into consideration. The participants declared that this delay needs special attention because they think that giving away food parcels to people who are not working and on treatment is known.

Some participants recommended that it would be exciting to see some of the religious groups giving support to them. They mentioned that prayers made them feel better spiritually and that made them to be able to see the meaning of life. Data from the participants also revealed that people get motivated when they are

supported by religious leader and they become stimulated by influential religious messages from them. The participants echoed the following sentiments:

I would like the church leaders to pray for us to live longer lives (Participant No. 5).

My pastor is so supportive if all the church leaders would be like that people living with HIV/AIDS will not be ashamed of disclosing their status at church (Participant No.7).

The participants also revealed the issue of being isolated when there are employment opportunities within the community. The following opinions were expressed:

Some of the community leaders are excluding us when there are projects from the municipality; they regard as sick people (Participant No. 10).

We want people to know that being HIV positive does not mean that we are different from them but the only difference is that we PLWHA are just having HIV virus in our blood (Participant No.8).

The participants indicated that PLWHA were very concerned about the way they were treated regarding community issues. Participants pointed out that some community leaders were treating the community members differently. They reported that some people need to be informed about the difference between HIV and AIDS. They mentioned that some of the people were only diagnosed HIV positive and they looked healthy and there were those who are fully blown some of them are bed ridden. Expressions of the participants were showing signs of losing hope of getting employed. This was expressed by one of the participants who stated that:

The issue of being differentiated to other people makes us feel useless and hopeless because some of people who are in charge in the community do not take us seriously (Participant No. 7).

Some participants revealed that they needed more support from these various stakeholders so that they could live positive lives. They reported that through prayers from the church leaders their spirits would be filled with joy. One participant also quoted the scripture from the bible:

*The Lord says anyone who trusts in me will never be disappointed
(Participant No. 6).*

All participants indicated that the assistance from the combination of different stakeholders would make things better and they mentioned that their activities will be sustainable.

5.9 Conclusion

Qualitative data which were collected from the participants have been presented in this Chapter. The views of the participants regarding the effects of stigma on people living with HIV/AIDS are stated directly as they were expressed by the participants. The following chapter will discuss the findings and analysis, recommendations and conclusion.

CHAPTER SIX
DISCUSSION OF MAJOR FINDINGS, CONCLUSIONS AND
RECOMMENDATIONS

6.1 Introduction

This chapter discusses the major findings that were presented in Chapter 5. The findings are corroborated by the literature and are also discussed according to the researcher's understanding. Also discussed here are the conclusions, recommendations to PLWHA and community members, social work practice, the government, NGOs and FBOs, and lastly for future research.

6.2 Discussion of major findings

Discussion of the major findings gives the researcher the opportunity to demonstrate what she understands about the effects of stigma on PLWHA by interpreting the findings and outline what they mean. The strengths perspective was employed to observe how severe HIV/AIDS-related stigma is on PLWHA and how they survive stigmatization.

6.2.1 Theme 1: Biographical profile of participants

The findings that were revealed from the biographical profile of respondents were interpreted and there are many challenges that emerged that can contribute to HIV/AIDS-related stigma. These challenges are discussed below according to the following attributes.

6.2.1.1 Sub-theme 1: Gender of the participants

The findings revealed that two participants were males and eight were females. This finding suggests that men might fear of disclosing their HIV status. According to the researcher of the present study, this could be propagated by the belief in many patriarchal societies that men should not speak out about their problems. It is said that in South Africa, gender norms continue to limit the use of condoms amongst some men who see health seeking as weak and they are reported that they are less likely to go for HIV testing (Peacock, Redpath, Weston, Evans, Darib & Greig, 2008). Men are influenced by power relations that make them believe that they are superior and have control over women. Greater risks of HIV/AIDS infection amongst men can also impression on their women because some women are less likely to use safety precautions and do what they are told by their men. This might happen more especially on married couples.

6.2.1.2 Sub-theme 2: Age distribution of participants

The findings also revealed that the age of the participants ranged from 18-45. This might show that this age group is the most infected by HIV/AIDS and this may be due to the fact that nowadays the youth starts becoming sexually active at an earlier stage. This finding confirms literature. Adolescents are likely to experience some things that are happening within their bodies' environment. Bankole, Singh, Woog & Wulf (2004) corroborate this finding stating that South Africa is said to have a high prevalence, and a large number of cases of HIV/AIDS is among adolescents. Bankole et al. (2004) further state that behavioral, physiological and socio-cultural factors make young people to be vulnerable to HIV/AIDS and this is because

adolescent stage is the time when young people naturally explore and take risks in many aspects of their lives including sexual relationships. This also puts this age group at a higher risk of being perceived as the most group to be infected by HIV/AIDS, whereas HIV/AIDS can infect anyone.

Findings of the current study also revealed that three participants started to know their HIV seropositivity when they were in their early 20's. The long survival could suggest that they are sticking to their treatment probably due to sticking to medication. This could explain why some of PLWHA have lived so long – their lengthy survival might be attributable to their adherence to treatment. This has had a positive spin-off resulting in a positive response to their HIV/AIDS condition. This becomes evident when one considers that only three of the respondents are in their 30's while the rest are in their 40s. Their zeal for life as well as acceptance of their condition could have been a motivating factor for them to realize the importance of medication. This also explains resiliency within them to survive such a long time and this may be perpetuated by the strengths they have from within.

6.2.1.3 Sub-theme 3: Marital status

All participants were found to be single parents. Being a single parent and being HIV positive may sometimes be difficult. This may be caused by the fact that it would be difficult for them to tell their children that he or she is having a chronic disease that may be fatal at some point. Murphy (2008) corroborates the findings stating that single parents, especially single mothers, are faced by the challenge of whether to disclose their HIV positive status to their children, and how best to carry out the disclosure. Murphy (2008) further postulates that single parents become concerned

about the age of their children. The respondents' concerns center on whether their children are old enough to understand or whether they will be able to keep information confidentially. This may sometimes affect their children's lives because there are some ignorant people in communities who would stigmatize these children due to their parents' HIV positive status. Their parents may also get strengthened by the situation of their children. They may adopt coping strategies for their HIV positive status with the intensions of seeing their children happy and progress without fear of the chronic illness from their parents.

6.2.1.4 Sub-theme 4: Occupation of participants

Some of the participants stated that they were unemployed. According to the researcher's analysis this might shows that the participants depend on their families' social grants to survive and to nurture their children. This might explain the perturbing issue of scarcity of job opportunities or high unemployment rate amongst the youth of Dimbaza. The situation of being unemployed may lead to dependency syndrome and high risk of HIV/AIDS infection. Bandali (2011) indicates that lack of financial security and independence may contribute to higher HIV/AIDS risk through mechanisms such as exchange of sexual favors for financial resources or inability to negotiate safe sex because of financial dependency. The high unemployment rate amongst the youth needs to be addressed by empowering them with skills that would enable them to earn something at the end of the day.

6.2.1.5 Sub-theme 5: Number of dependents

Nine participants were having more than one dependent. Having many children may lead to strenuous situations, especially to unemployed single parents. This is because these dependents need to be taken care of; for example, they need to be

fed, to be clothed and to go to school. Seemingly the Child Support Grant (CSG) might not meet all those needs because the cost of living is too high. Most of people in South Africa depend on social grants since there is a high rate of unemployment. However, social grants are criticized for breeding dependency syndrome and undermining people's self-sufficiency and motivation to climb out of poverty through their own efforts (Chronic Poverty Research Centre, 2011). The situation of Child Support Grant might put some women at risk of being infected by HIV/AIDS because they prefer to fall pregnant several times with the intention of having a lot of beneficiaries thus receiving more CSG. This action might make people to perceive women as promiscuous.

6.2.1.6 Sub theme 6: Educational qualifications

It is worrisome to find that the participants do not have tertiary qualifications and most of them left school before finishing their high school education. Lower education may put some of PLWHA in a situation where they can be ignorant about accurate information regarding HIV/AIDS. In addition, it is argued that the relationship between poverty and HIV/AIDS is complex and involves several factors such as unemployment and lack of education (Kalichman et al., 2007) (cited by Duncan et al., 2007). These factors may lead people to be more vulnerable to HIV/AIDS because of the huge burden of nurturing their children. Moreover the lower level of education may put them in a situation where they cannot find permanent jobs.

6.2 Theme 2: Perceptions of community members about HIV/AIDS

Findings of the present study revealed that community members do have information about HIV/AIDS, though the negative attitudes from some people show ignorance about HIV/AIDS. This may be caused by the belief that HIV/AIDS is a disease that is a disgrace within communities. Below is a discussion of some of the negative responses to HIV/AIDS that emerged and lead to stigma:

6.2.1 Sub-theme 1: Negative attitudes from community members

The negative treatment that PLWHA receive from community members might indicate that people become reluctant to respond to HIV/AIDS education. The findings may suggest that some of people living with HIV/AIDS become discouraged because of the negative attitudes they receive within their environments. The findings are confirmed by the Global Initiative Psychiatry (GIP) (2006) which indicates that PLWHA face a number of stressors, decision-making dilemmas, losses and transmissions that result in more chronic emotional adjustment reactions. The GIP (2006) mentions that these reactions generally subside in months after diagnosis but if HIV/AIDS is still highly stigmatized the reactions can be prolonged.

The fact that people respond differently to HIV/AIDS may have been caused by misconceptions about HIV/AIDS. The findings revealed that some people in the Township of Dimbaza know very little about HIV/AIDS and this makes them develop negative attitudes about HIV/AIDS. Krenn & Limaye (2004) found that common myths and misinformation about HIV/AIDS stand in a way of greater awareness, discussion and acceptance of individual and societal behavior change.

6.2.2 Sub-theme 2: HIV/AIDS and promiscuity

Respondents revealed that the mode of HIV/AIDS transmission is believed to be through sexual intercourse or having more than one sexual partner. These findings might show that people are becoming ignorant when it comes to the modes of HIV/AIDS transmission. Their concern might be on sexual transmission more than other modes of transmission. In South Africa and in many less developed countries, the primary method of HIV/AIDS transmission is heterosexual intercourse and most of people know that HIV/AIDS can be transmitted this way (Anderson, Beutel & Maughan-Brown, 2007).

Educational talks about HIV/AIDS should pay more attention on other ways of HIV/AIDS transmission. That would change the negative perceptions about the modes of HIV/AIDS transmission. Promiscuity in some communities is perceived as being practiced by women whereas there are men who engage themselves in promiscuous activities. This might put women who are HIV positive at jeopardy of receiving insults.

6.2.3 Sub-theme 3: Feminization of HIV/AIDS

Patriarchal societies view HIV/AIDS as a disease that is brought by women within families. This belief sometimes may lead to gender inequalities because men are regarded as the ones who should be in control in a relationship and women have to obey what they are told (Kalichman et al., 2007). Furthermore, Jackson (2012) found that women in physically abusive relationships were significantly at greater overall risk for HIV or sexually transmitted infections (STIs) because they reported having less say about having unprotected sex or the use of condoms. This could explain the

feminization of HIV/AIDS because when a woman is HIV positive, she is blamed for bringing HIV/AIDS to her husband or boyfriend. This confirms the findings of the present study where it is indicated that HIV positive women in the Township of Dimbaza are perceived as the major carriers of HIV/AIDS compared to men. This may prove that there are men who know their HIV/AIDS status but they put the blame on women and fear to disclose their HIV status. According to the researcher's observation this could lead to the high mortality rate on men who are scared of seeking medical help. It is indicated that in cultural societies it is acceptable for a man to be promiscuous and this is culturally encouraged and admired (Diamond, 2011). This confirms the findings of the present study where it was revealed that amongst the community of Dimbaza women are blamed for being the ones who infect their men. This situation is devastating as it increases the vulnerability to HIV/AIDS infections.

The research results corroborate Mbonu, Van der Borne & De Vries's contention (2009) that society is more intolerant to women living with HIV/AIDS than men. These researchers argue that much of the social control over women's movements, voice and opportunities is based on the belief that they will become promiscuous if they are granted too much freedom and could lead to the contamination of patriarchal lineage. It is also revealed by the Royal Society for Public Health (RSPH) (2012) that gender disparities such as poverty, lack of education, lack of power and gender-based violence contribute to the high risk of HIV/AIDS infections for females in the Sub-Saharan Africa.

This also could explain the fact that most women who undergo gender inequalities are those that have lower level of education, who financially depend on their partners on their partners for survival. However, women have strengths because they endure all the pains caused by cultural beliefs and they manage to nurture their families regardless of the abuse. There is a need to step up and take into consideration some of the cultural beliefs which are increasing the rate of HIV/AIDS infections and jeopardizing women's rights.

6.3 Theme 3: Positive community responses

The findings revealed that most of the community members respond positively to HIV/AIDS because of educational talks about HIV/AIDS, whereas there are some people who still respond negatively. It is evident that motivational discourses empower PLWHA to accept their excruciating situations and encourage them to live meaningful lives.

6.3.1 Sub-theme 1: Acceptance of HIV/AIDS

The findings revealed that HIV/AIDS has been accepted by some members of the Township of Dimbaza. Most participants revealed that they have accepted their HIV positive status and they are aware that HIV virus is in their blood-stream so there is nothing that can change the situation. Acceptance seemed to have a positive impact on PLWHA because the participants were empowered and they were looking forward to live their normal lives. Apparently participants have reached a point where they decided to accept HIV/AIDS. This could explain that participants have reached the final stage of Kubler-Ross's (1969) stages of grief of acceptance. Kubler-Ross applied these stages to people who suffered from terminal illnesses and catastrophic

life experiences such as loss of job. Kubler-Ross suggests that not everyone who experiences a life-threatening or life-altering event feels all the five stages, due to reactions of personal losses differing between people. The last stage of acceptance is when a person starts to face the reality and accept the situation they find themselves in.

Moreover, it was very interesting to observe resiliency from PLWHA. Resilience could strengthen people who have been through difficult times and makes them to regard themselves as conquerors. In addition, PLWHA are strengthened by the fact that they have to raise their children. PLWHA are also empowered by the support and care they receive from their families and friends which leads to acceptance.

6.3.2 Sub-theme 2: Support and care from community members

Participants revealed that community members in the Township of Dimbaza are supporting them in terms of strengthening and motivating them to live positively. The finding might show that support and care become the source of strength to PLWHA because participants indicated that they adhere to treatment with the assistance of support they receive from their families and neighbors. This could be an indicator that people in communities are now enlightened about HIV/AIDS. Support and care may also lessen fear of death from PLWHA because when someone gets diagnosed as HIV positive, he or she is likely to become depressed thinking about his or her loved ones. Forouzan, Shustari, Sajjadi, Salimi & Dejman (2013) confirm the findings of the present study stating that social support is a critical aspect that result in people to change their risky behaviors and adhere to treatment. The researcher is of the opinion that support groups should continue to operate in communities.

6.3.3 Sub-theme 3: Community out-reach

The findings further revealed that community out-reach plays a significant role in changing people's mind-sets. This finding may illustrate that reaching out to community members and educate them about HIV/AIDS has a positive impact on people's behaviors and attitudes. It was revealed that some participants did their best to change the attitudes of some parents by conducting "door to door" campaigns.

In Krenn & Limaye's (2004) research findings, it is argued that in the early years of HIV/AIDS pandemic the focus was on providing the correct information about HIV transmission to change negative behaviours and attitudes of people. In yet another study conducted by Peltser, Parker, Mabaso, Mkonko, Zuma & Ramlagan (2012), findings revealed that exposure to HIV/AIDS-related stigma communication on the media changed the stigmatizing attitudes towards people living with HIV/AIDS. These researchers seem to concur with the finding of the present study. However, it was revealed by the study participants that there is still a lack of accurate information about HIV/AIDS in some community members. The finding might indicate that informing people who are less informed about HIV/AIDS in communities minimizes the state of HIV/AIDS-related stigma. This suggests that people who conduct these campaigns should be knowledgeable about HIV/AIDS to provide accurate information.

6.4 Theme 4: Self-stigma

Findings of the study revealed that self-stigma hinders the preventive strategies of HIV/AIDS. The study participants revealed that self-stigma affects them to the extent that some of PLWHA are no longer attending social activities and this result in others fetching their medication secretly. The African and Caribbean Council on HIV/AIDS in Orantio (2006) confirms the findings stating that world-wide, stigmatization and discriminatory attitudes towards PLWHA are known to discourage them from effectively managing the disease and people fail to seek out services they need because of the risk of being stigmatized. People may fear disclosing their status to their partners because they fear rejection or gossip. Eventually the rate of HIV/AIDS infection rises faster. This is confirmed by Ragimana (2006) who notes that some people deny the fact that they are HIV positive, others are said to be suicidal under the intense stress and some act in self-destructive ways because of built up self-resentment. Denial could be their survival strategy but at the same time they need to be motivated to fully accept their condition.

Further, the findings may clarify that self-stigma amongst PLWHA is influenced by discriminatory attitudes from some of the community members. As some participants mentioned that people who fear to disclose their HIV status fetch their medication surreptitiously, this could show that self-stigma is a powerful aspect that hampers people's thoughts. Some researchers argue that some people become suicidal when they receive their first diagnosis and these tendencies are often rooted in the fear of isolation and discrimination that will come as a result of having others find out about the disease (White & Carr, 2005). This substantiates Kubler-Ross's (1969) denial phase where the person is trying to shut out the reality or magnitude of their situation

and begin to develop a false, preferable reality. The USAID (2006) indicates that some people go through a process of moving from denial to acceptance and it is said that this process may take time because it differs from person to person. Sometimes there may be no full acceptance and this may influence the development of internal stigma (USAID, 2006).

The study also revealed that some of PLWHA are misusing their HIV positive status. This may prove that PLWHA are the first ones to stigmatize themselves because of egoism. On the other hand this might be their way of surviving. Findings also show that PLWHA are so suspicious when there are activities that put them on the forefront. All the suspicions may be rooted in self-stigma; at the same time they may be using their strengths or survival skills to avoid being used by people to fulfill their needs. Self-stigma may sometimes prevent people who are infected to fully accept their situation. The reason for that might be a tendency of labeling PLWHA by community members.

6.4.1 Sub-theme 1: Labeling of PLWHA

Some of community members in Dimbaza are labeling PLWHA by horrible names as revealed by the findings. These reports may explain the fact that some people are still scared of HIV/AIDS disease, and they prefer to label HIV/AIDS by some nasty names. Ogunmefun, Gilbert & Schatz (2011) found that some people are experiencing secondary stigma such as labeling people with funny names or gossiping about people who are HIV positive and those who take care of them. Ogunmefun et al. (2011) further state that there is a need for empirical work on the ways that social norms and cultural values connect with secondary stigma.

However, being labeled and continue to survive might indicate that PLWHA have the strength and capacity to deal with HIV/AIDS-related stigma. Efforts to bring back humanity or the spirit of “*ubuntu*” and treat PLWHA with dignity that they deserve need to be considered in some environments. *Ubuntu* is the capacity in African culture to express compassion, reciprocity, dignity, harmony and humanity in the interests of building and maintaining community (Nussbaum, 2003). This concept of *ubuntu* encourages solidarity amongst communities to take care of each other. According to Spalthoff (2013) “*ubuntu*” means that people are people through other people and also acknowledges both the rights and responsibilities of every citizen in promoting individual and societal well-being. The rationale is that PLWHA face the challenge of being labeled from different settings.

6.5 Theme 5: Challenges faced by PLWHA in health-care settings

The findings suggested that PLWHA become traumatized by the way they are treated by health-care workers. This situation might make people to derail from the HIV/AIDS preventive strategies and may increase the mortality rate of HIV patients. Mahendra (2007) substantiates the findings of the present research by reflecting that health workers’ tendencies to engender and promote HIV/AIDS-related stigma are widespread throughout the African continent and across the world. Mutalemwa, Kisoka, Nyigo, Barongo, Malecela & Kisinza (2008) believe that stigma amongst health-care workers is the result of inability of health-care workers to understand and manage HIV/AIDS. This corroborates the current study’s findings which revealed that some of the health-care workers breach confidentiality of patients. Some health-care staff, especially general workers such as cleaners, has a tendency of gossiping about patients who attend health-care centers. The greatest victims of these gossip

mongers are PLWHA. This misdemeanor might be caused by lack of proper information about HIV/AIDS and failure to observe confidentiality.

Health-care workers have inadequate access to universal precautions, such as gloves and safe blood collection kits (Mutalemwa et al., 2008) as well as being grossly understaffed. These scholars point out that the inadequacies of safety measures result in health-care workers fearing contagion. This calls on for the government to provide sufficient tools to all health-care centers to prevent ill-treatment of patients especially PLWHA. As it was mentioned by the study participants that health-care workers or nurses are sometimes intolerant of PLWHA, the source of intolerance could be the strain they find themselves within their workplaces. The nurses were reported to complain about the huge burden of consulting a large number of patients per day. This could make them to displace anger caused by workload to the patients to PLWHA.

The findings of the present study could explain the lack of confidentiality from some health care centers. This could make it difficult for people to go for testing because they fear the disclosure of their HIV status by nurses and other workers. The participants reported that they prefer visiting other health-care centers rather than their local clinic. One of the participants expressed the following sentiment:

I heard one of the caregivers at the local clinic mentioning names of people who fetch the ARV treatment and I felt very sad. I prefer to go to other clinics although sometimes you get tired because you do not have a bus-fare (Participant No.5).

This may lead people to be intimidated by health-care workers who are from their neighborhood because there are chances of disclosing their HIV positive status to

their friends and families. This is corroborated by Anderson (2008) who states that in their debate the participants revealed the issue of poorly trained providers and huge gaps in the capacities of service delivery systems which lead to undue suffering, loss of quality of life and adherence to HIV prevention, treatment and AIDS program. The researcher is of the opinion that recruitment of more staff is needed to enable support and care from the health-care workers. The following testimony was expressed by the participant from the focus group:

When I approached the sister in charge at the local clinic by the way the patients feel about their treatment, she told me that there is a shortage of staff and those nurses who are on duty get tired because of the large numbers of patients [they have to see] each and every day (Participant No.2 from focus group).

Despite the ill-treatment PLWHA receive from the health workers, PLWHA might still have the strength to adhere to their treatment even if they fetch it from other local clinics. This could also show that PLWHA are able to cope in difficult situations because they are strengthened. This may indicate that PLWHA still show their passion to get their treatment for the survival despite such stumbling blocks. Furthermore, bringing an end to the differentiation of PLWHA should be considered by the Department of Health. This represents the situation where participants mentioned that they have their own section and their folders are not the same as other patients. PLWHA may feel isolated to other patients and this might make it easier for other people to label PLWHA as this is seen as stigmatization of the worst kind. PLWHA suggested various approaches from the community members, and from various stakeholders that would mitigate the state of stigma from the Township of Dimbaza.

6.6 Theme 6: Cultural challenges faced by PLWHA

It emerged in the study that some of community members and some of PLWHA are still tenaciously holding on to cultural beliefs which are propagated by some traditional healers. Maleche & Day (2011) state that culture is a shared way of living by a group of people including their accumulated knowledge and understanding. This incorporates skills and values which they perceive as unique and meaningful to them. Maleche & Day (2011) further argues that Article 1 of the International Covenant on Civil and Political Rights (ICCPR) sets out that people have the right to determine how their culture is developed. However, this right might seem to be misused by some cultural leaders because some of them are ignorant, they still perform cultural practices that lead to vulnerability of HIV/AIDS infection. These cultural taboos may result in HIV positive people to delay taking their medication or else hinder people to go to VCT centers. These tendencies may be promoted by ignorance from some traditional healers because they are telling lies about HIV/AIDS prevention.

Some people who are HIV positive are likely to deny the situation and prefer to perform rituals. According to Poss (1981: 13) denial is a healthy initial reaction to any uncomfortable and painful situation, as it allows the patient time to mobilize other more adaptive strategies. This cultural belief might be their coping strength to protect themselves from being stigmatized. Yet, this might put them in a perturbing situation where their viral load would go up because of reluctance to respond immediately to the treatment. This may show the coping mechanism that some of PLWHA adopt. It is argued that some cultural norms appear to have no structure or no local institution to which they belong (Maleche & Day, 2011). This confirms the findings of the study

that indicate that some cultural leaders tell lies on how to cure HIV/AIDS. This calls on the stakeholders to mobilize community members and educate them on how HIV/AIDS impacts some cultural practices. This does not mean that cultural activities should be banned but people should be aware of the risks of being infected or killed by HIV/AIDS.

6.7 Theme 7: Recommendations by PLWHA

The findings of the study illustrated that all study participants were willing to get assistance from the community at large. Community mobilization was seen to be the effective strategy to educate community members about how PLWHA feel about stigmatization. This could demonstrate that some of the community members do not have enough information about HIV/AIDS even though they are aware about the preventive measures. It might also show that families and friends of PLWHA are willing to offer with anything to support their loved ones, but there is an indication that community members together with PLWHA need to be empowered.

It is argued that community home-based care programmes face overwhelming challenges such as lack of properly trained personnel; lack of proper nutritional support for PLWHA and lack of resources, all are linked to the lack of funding (Pellizzoli, 2011). It seems so interesting to unearth the strengths within community members and PLWHA, such as engaging themselves in some activities to lessen HIV/AIDS-related stigma, but due to lack of funds these activities do not sustain. This could explain the potential that community members and PLWHA have. There is a need to collaborate with stakeholders to identify resources that would help them to make their activities sustainable. This attracts some stakeholders and community

leaders to link community members and PLWHA with available resource and accessible services within their environments. That would hopefully enable them to be self-reliant.

6.7.1 Sub-theme 1: Support from various stakeholders

It was found out in the study that, different stakeholders and community leaders need to collaborate and come up with strategies that would reduce the state of stigma. It is quite fascinating to see PLWHA motivated or strengthened; this exemplifies the powerful sentiments which were mentioned by some of the participants. They mentioned that the law should act against those who have discriminatory attitudes towards PLWHA. The findings also indicated that some of practitioners are reluctant to assist PLWHA. This might lead some of PLWHA to discontinue responding positively.

South Africa is said to have a chronic lack of financial resources to implement necessary programmes (Social Aspects of HIV/AIDS and Health Research Programme of the Human Science Research Council-HSRC, 2004). The lack of financial resources was mentioned by the study participants as the barrier to some strategies of curbing HIV/AIDS-related stigma. Strategies of mitigating HIV/AIDS-related stigma may be sometimes implemented, but they collapse if there is no financial assistance. In addition, different stakeholders are having a duty of offering assistance to PLWHA and the community members. It would be critical for the stakeholders to collaborate with PLWHA and community members to allow them to decide what they want. Following are the general conclusions:

6.8 General Conclusions

Following the discussion that has been provided above the following general conclusions are made.

6.8.1 The impact of HIV/AIDS-related stigma on PLWHA

Based on the discussion about the implications of stigma on PLWHA, the researcher concludes that HIV/AIDS-related stigma still exists in communities and it becomes a barrier to preventive strategies. This may be propelled by the dearth of information and myths about HIV/AIDS that some people in communities still hold. The perturbing challenge of HIV/AIDS-related stigma impacts on PLWHA's social functioning. This is because individuals living with HIV/AIDS are perceived as different to other people, which might make PLWHA exclude themselves from social events and to be deprived of their basic human rights within the communities.

The mental health of PLWHA might be affected because of the pressure they receive due to HIV/AIDS-related stigma. Service providers are encouraged to pay more attention to the way stigma affects the social functioning and the mental health of PLWHA. Social workers, in particular, should also reinforce or strengthen PLWHA by giving them support and care. This, therefore, calls on for immediate response such as, regular awareness campaigns in communities to educate those who are less informed about HIV/AIDS. All stakeholders involved in mitigating HIV/AIDS need to tackle all aspects surrounding HIV/AIDS and this can be done by going through recent studies about HIV/AIDS as to be updated about new knowledge. In other words stakeholders need to stay abreast of latest developments. The Provincial Department of Social Development has a desk that considers the extent of HIV/AIDS

and this Department could be pro-active by offering awareness campaigns in the province.

PLWHA may be affected by HIV/AIDS-related stigma in different ways. Some cultures regard women as transmitters of HIV/AIDS. This could make women perceive themselves as inferior. Programmes to empower women are of vital importance to strengthen them to overcome their inferiority. They should be well informed about cultural issues that have a negative impact on their lives. Also, there is this traditional belief that PLWHA should perform rituals to get cured from the disease. This may be their survival strategy to live normal lives but this should be dispelled to avoid high risks of HIV/AIDS infections and deaths that could have been prevented before. The Department of Health can dispel these traditional beliefs through working together with traditional healers.

6.8.2 Support and care for PLWHA

Acceptance of HIV/AIDS that was mentioned by participants leads the researcher to conclude that there are people in communities who are responding positively to HIV/AIDS. This has been influenced by HIV/AIDS education they receive from some stakeholders. PLWHA get motivated and empowered by the support and care they receive within their families and friends. Acceptance should come from within them and should have peace within; this would strengthen them to dispel and withstand all the evil spirits that are filled within a person. This casts a doubt as to whether any counseling is offered to people who are tested for the virus.

It becomes easy for PLWHA to deal with stigma because of empowerment they acquire from HIV/AIDS education which reinforces their understanding of the virus. However, it becomes worrisome to see that some people are still ignorant about HIV/AIDS. The reason for that is the little information they get about HIV/AIDS. It becomes worse to see that some professionals or people who are supposed to bring change to people's lives being ignorant about HIV/AIDS. This may be caused by some of the professionals who do not adhere to their basic codes of conduct or ethics. This calls for effective strategies that can influence and change the behavior of minorities who still stigmatize PLWHA. Also legal actions need to be taken for those professionals who seem to undermine government's efforts to HIV/AIDS pandemic and neglect their code of conduct. Furthermore, in-service training for nurses and social workers might be considered pertinent for the benefit of the client system. Mobilizing communities and educating them about HIV/AIDS may be another coping strategy because people get strengthened by the motivation they receive from these educational talks.

6.8.3 Sustainability of activities to curb HIV/AIDS-related stigma

PLWHA and community members may be engaged in some activities to mitigate HIV/AIDS-related stigma, but these activities might lack due to financial constraints. PLWHA and community members are having a potential of doing anything that would lessen HIV/AIDS-related stigma. However, participants indicated that these activities are hindered by corrupt and insensitive activities performed by local authorities who are given mandate by the government to render services to communities, but fail to do so. Community leaders were also reported to be reluctant to fully engage themselves to issues such as HIV/AIDS, thus, services that should be

received by community members end up delaying. The government's role is to assess the service delivery from local municipalities to check if these services are well implemented.

The strengths perspective begins with understanding the goals and dreams that a client has and helps the client to reflect on the possibilities and hopes that their lives hold (Saleeby, 2006). This may explain that service providers have the duty of understanding PLWHA and community members' wishes of being financially assisted and encourage them to use their strengths to achieve the desired goal of curbing HIV/AIDS-related stigma.

Saleeby (2010) affirms that operating from the strengths perspective means that everything that a helper does will be based on facilitating the discovery and exploration, and use of clients' strengths and resources in the service of helping them achieve their goals and realize their dreams. Service providers are obliged to make things easier for PLWHA and community members by assisting them to identify resources that would strengthen them. Saleeby (2006) further assumes that trauma, abuse and struggle may be harmful but they may be sources of challenge and opportunity. This may be an indication that PLWHA may be stigmatized and discriminated but through all the painful experience, there are challenges that strengthen them to survive. For example, PLWHA may be encouraged to survive HIV/AIDS-related stigma by having the responsibility of caring for their children. Therefore, children and their families at large can be seen as the strength for them to live productively and this gives them an opportunity to adopt survival strategies to maintain their loved ones. Hopefully, identifying PLWHA and community member's

strengths and encouraging them to use them could make them able to conquer the issue of stigma by themselves.

The study explored the degree to which stigma affects people living with HIV/AIDS through employing a case study of the Township of Dimbaza. The aim of the study was to explore the effects of stigma on PLWHA. This aim was critical in the sense that it gave the researcher an opportunity to make the following recommendations which can be crucial in reducing the state of HIV/AIDS-related stigma.

6.9 Recommendations

Considering the above general conclusions, the following recommendations are made for the following categories: PLWHA and community members; for social work practice; for government, NGOs and FBOs; and lastly for future research. These recommendations are four-fold and are meant for PLWA and the community members; social work practice; the government; NGOs and FBOs and lastly for the future research.

6.9.1 Recommendations for PLWHA and community members

- PLWHA and community members should be encouraged to tolerate HIV/AIDS as a condition and not a death penalty. Medical science has made it tolerable just like diabetes and hypertension. Being tolerant would mean that they can deal with every aspect that comes alongside HIV/AIDS. This means that community members should be encouraged to attend HIV/AIDS awareness campaigns to obtain survival skills that would make them to be more knowledgeable and less

damning on those infected by the virus. This can be done through doing some activities.

- Eliminating dependency syndrome should be critical for community members and especially PLWHA. This should be done through using their considerable strengths for survival and try to collaborate with community leaders to enlighten them on how to enhance the use of their strengths identified from them.
- Full acceptance of HIV/AIDS should be considered by PLWHA and community members. This does not mean that individuals should accept for the sake of coping with HIV/AIDS-related stigma. Using their strengths positively could assist them to be able to face challenges facing them.
- PLWHA and community members should hold on to support groups. That is where they could find common support for each other and set their desired goals: this could become a coping mechanism for PLWHA and a preventative measure for the community members.
- Activities to reduce HIV/AIDS-related stigma could be the first priority from PLWHA and community leaders. They could seek help for assistance by contacting all stakeholders to intervene.

6.9.2 Recommendations for Social Work Practice

- Regardless of material things or food that some of PLWHA demand, the social workers could offer assistance by counseling thus empowering those living with HIV/AIDS and inform them on how to survive HIV/AIDS-related stigma.
- Social workers should take into consideration PLWHA's complaints and try to empathize with the PLWHA's situation. They should live by the social work code

of ethics which stipulates that social workers should not discriminate or refuse to render service to any client system, including HIV/AIDS infected and affected people. This would make it easier for them to understand the situation and be able to offer assistance where it is needed.

- Social workers could need to keep abreast of developments in their field by reading and conducting research on HIV/AIDS-related matters that affect PLWHA. This would mean that the relevant information they acquire from research would be conveyed to community members and PLWHA. Misinformation about HIV/AIDS would then be eliminated.
- Casework alone might not be sufficiently far reaching. Embarking on educating the community might be a more effective intervention strategy as it would be aimed at a larger audience.

6.9.3 Recommendations for the Eastern Cape Government and NGOs

- Government of the Eastern Cape Province and NGOs should consider implementing skills development programmes that would help PLWHA and community members to acquire skills to sustain their activities and monitoring of these programmes should be considered seriously in an effort to assist the community.
- All stakeholders should work in tandem to ensure that PLWHA and community members are well informed about policies and laws that protect human rights of PLWHA.
- Other stakeholders such as the NGOs and the FBOs could initiate programmes where people living with HIV/AIDS will feel free to express themselves. This should include programmes such as women empowerment where HIV positive

women and those with low education level would be encouraged to stand for their rights.

6.9.4 Recommendations for future research

- Intervention strategies which are designed to reduce HIV/AIDS-related stigma have been well implemented worldwide, but there is a need to conduct more research on HIV/AIDS issues which affect women. Women are resilient by nature because they deal with stressful situations especially in cultural communities. Future research needs to explore further the cultural beliefs that put women in jeopardy of being abused. The area of study could be the feminization of HIV/AIDS.
- There is a gap that needs to be filled which appears to hinder HIV/AIDS prevention: these are the beliefs of traditional healers about HIV/AIDS. There are strategies aiming at dispelling these perceptions of performing rituals when someone is diagnosed HIV positive but there is less literature on that area. Future research could consider this aspect of traditional beliefs which leads to HIV/AIDS.
- It would be the advantage to PLWH if future research would delve more into self-stigma. There is much literature on self-stigma but people in communities still fear speaking out about their HIV status, even if someone accepts the situation as they internalize stigma. Future research could pay attention to the perfidious nature of self-stigma.

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APPENDICES

APPENDIX A: INTERVIEW GUIDE FOR PEOPLE LIVING WITH HIV/AIDS (PLWHA)

- I am Sindiswa Xabendlini, a Master of Social Work student from the University of Fort Hare and I am conducting a study on the implications of stigma towards people living with HIV/AIDS.
- The purpose of the interview is to explore how HIV/AIDS-related stigma affects PLWHA.
- The reason for you to be chosen for interview is because PLWHA experience stigma associated with HIV/AIDS on a daily basis.
- The information obtained here will not be accessible to someone else and I assure you that it is kept in strict confidentiality.
- Your identity will not be revealed to anyone and the researcher will only identify you by pseudo names.
- The audio tape to collect the data will be switched on during the interview.

THEMES	QUESTIONS	PROMPTS AND PROBES
<p>THEME ONE</p> <p>Personal Details</p>	<ul style="list-style-type: none"> ➤ Can you tell me about yourself? 	<ul style="list-style-type: none"> ➤ Tell me about your occupation ➤ Number of dependants ➤ Level of education. ➤ How long have you been living with HIV?
<p>THEME TWO</p> <p>Perceptions of community members about HIV/AIDS.</p>	<ul style="list-style-type: none"> ➤ How do people from your community view HIV/AIDS? ➤ How do community members treat you? ➤ What support do you get from the community members? 	<ul style="list-style-type: none"> ➤ What is their level of knowledge on: HIV/AIDS prevention; myths surrounding HIV/AIDS; how it is infected and the rights of patients? ➤ What kind of treatment do you receive from community members? ➤ How do you cope with the treatment you receive from community members? ➤ What makes you able to cope with the treatment you receive from community members? ➤ How do you feel about the support? ➤ What changes do you experience after receiving support? ➤ How do these things strengthen and motivate you?

	<ul style="list-style-type: none"> ➤ Tell me things that are done by community members to strengthen and motivate you? 	
<p>THEME THREE</p> <p>Involvement of people living with HIV/AIDS and community members to curb HIV/AIDS stigma.</p>	<ul style="list-style-type: none"> ➤ What activities are you involved in mitigating HIV/AIDS-related stigma? ➤ What goals do you want to achieve regarding your activities? ➤ What assistance do you receive to use your capacity and strength? ➤ What needs to be done by community members to assist you in reducing HIV/AIDS-related stigma? 	<ul style="list-style-type: none"> ➤ How effective are these activities? ➤ What are the positive changes that these activities bring to your life? ➤ How do you set your goals? ➤ How do you think that these goals can change your life? ➤ Where do you get help for the achievement of your goals? ➤ How are you encouraged in using your capacity and strength? ➤ What changes do you observe after using your capacity and strength? ➤ How do you support each other? ➤ What coping strategies do you apply to tolerate each other?

<p>THEME FOUR</p> <p>The role of service providers and community leaders to curb HIV/AIDS-related stigma</p>	<ul style="list-style-type: none"> ➤ What do the service providers and community leaders offer to help to you? ➤ How do you identify the strength that is within you to cope with stigmatisation? ➤ Do you work in partnership with service providers and community leaders to mitigate HIV/AIDS-related stigma? ➤ What do you recommendations for service providers and 	<ul style="list-style-type: none"> ➤ How useful is the offer to you? ➤ What is their centre of attention during the helping process? ➤ Can you tell me the way you use the strength to cope with stigmatisation? ➤ What are the outcomes of the strength you are using? ➤ Can you give me an example where you used your inner strength? ➤ What are the benefits of working together? ➤ What changes do you observe in a collaborative process? ➤ How effective would the recommendations be in boosting your self-esteem?

	<p>community leaders in order to boost your self-esteem?</p> <ul style="list-style-type: none"> ➤ What do you suggest to be done to mitigate HIV/AIDS-related stigma? ➤ How do the service providers and community leaders empower you to survive stigmatisation? 	<ul style="list-style-type: none"> ➤ What do you expect from the recommendations? ➤ What needs to be introduced to people who still have myths about HIV/AIDS? ➤ How can you introduce such things to them? ➤ The use of your inner strengths that you were born with. ➤ Identifying the resources within your surroundings. ➤ Survival skills to live productive lives.
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THANK YOU.

APPENDIX B: INTERVIEW GUIDE FOR FOCUS GROUP

- I am Sindiswa Xabendlini, a Master of Social Work student from the University of Fort Hare and I am conducting a study on the implications of stigma towards people living with HIV/AIDS.
- The purpose of the interview is to explore how HIV/AIDS-related stigma affects people living with HIV/AIDS (PLWHA).
- The reason for you to be chosen for interview is because you deal with issues such as HIV/AIDS-related stigma at your work place most of the time.
- The information obtained here will not be accessible to someone else and I assure you that the information is kept in strict confidentiality.
- Your identity will not be revealed to anyone and the researcher will only identify you by pseudo names.
- The audio tape to collect the data will be switched on during the interview.

THEMES	QUESTIONS	PROMPTS AND PROBES
<p>THEME ONE</p> <p>Personal Details</p>	<ul style="list-style-type: none"> ➤ Can you tell me about yourself? 	<ul style="list-style-type: none"> ➤ What are your duties? ➤ What experience do you have in working with People Living with HIV/AIDS (PLWHA)? ➤ What makes you passionate about your position?
<p>THEME TWO</p> <p>Perceptions of community members about HIV/AIDS.</p>	<ul style="list-style-type: none"> ➤ How knowledgeable are the community members about HIV/AIDS? ➤ How do community members treat PLWHA? 	<ul style="list-style-type: none"> ➤ What is their level of knowledge on: HIV/AIDS prevention; myths surrounding HIV/AIDS; how is it infected and the rights of patients? ➤ What kind of treatment do PLWHA receive from community members? ➤ How do PLWHA cope with the treatment they receive from the community members? ➤ What makes PLWHA able to cope with the treatment they get from community members? ➤ How do these things strengthen and motivate

	<ul style="list-style-type: none"> ➤ Tell me things that are done by community members to strengthen and motivate PLWHA? ➤ How do you think they survive the stigmatisation from community members? ➤ What kind of support do PLWHA get from the community members? 	<p>PLWHA?</p> <ul style="list-style-type: none"> ➤ Is their survival strategy effective to manage stigmatisation from community members? ➤ How do they feel with the support they get? ➤ What changes do they experience after receiving support?
<p>THEME THREE</p> <p>Involvement of PLWHA and community members to curb HIV/AIDS stigma.</p>	<ul style="list-style-type: none"> ➤ What activities are PLWHA and the community members involved in mitigating HIV/AIDS-related stigma? ➤ What assistance do PLWHA and the community members get from you to use 	<ul style="list-style-type: none"> ➤ How sustainable are these activities? ➤ What changes do these activities bring to PLWHA and the community members? ➤ How do you encourage PLWHA and community members to use their capacities and strengths?

	<p>their capacities and strengths?</p> <ul style="list-style-type: none">➤ What is done by PLWHA and community members to curb HIV/AIDS-related stigma?	<ul style="list-style-type: none">➤ What changes do you observe after encouraging them?➤ How do they support each other?➤ What coping strategies do they apply to tolerate each other?
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<p>THEME FOUR</p> <p>The role of service providers and community leaders to curb HIV/AIDS-related stigma.</p>	<ul style="list-style-type: none"> ➤ What does the idiom “clients’ strength” means to you? ➤ How do you identify the clients’ strength? ➤ Do you work in partnership with PLWHA and community members to curb HIV/AIDS-related stigma? ➤ What would you recommend to PLWHA in order to boost their self- 	<ul style="list-style-type: none"> ➤ Do you think of clients’ strengths when working with the patients or PLWHA? ➤ How do you incorporate the clients’ strengths within the working process? ➤ How do you use the strength you identify from the clients? ➤ Can you give me an example of how you used the strength you identified from one of your clients? ➤ What are the benefits of working in partnership? ➤ What changes do you observe in a collaborative process? ➤ How effective would the recommendations be in boosting their self-esteem?
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	<p>esteem?</p> <ul style="list-style-type: none"> ➤ What do you suggest to be done to mitigate HIV/AIDS-related stigma? ➤ How do you go about empowering PLWHA and community members to survive stigmatisation? 	<ul style="list-style-type: none"> ➤ What needs to be introduced to people who still have myths about HIV/AIDS? ➤ How can you introduce such things to them? ➤ The use of their inner strengths that they were born with it. ➤ Identifying the resources within their surroundings. ➤ Survival skills to live productive lives
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THANK YOU.

APPENDIX C: INFORMED CONSENT FORM

INFORMED CONSENT FORM

I hereby agree to participate in research regarding the implications of stigma towards people living with HIV/AIDS. I understand that I am participating freely and without being forced in any way to do so. I also understand that I can stop this interview at any point should I not want to continue and that this decision will not in any way affect me negatively.

I understand that this is a research project whose purpose is not necessarily to benefit me personally.

I have received the telephone number of a person to contact should I need to speak about any issues which may arise in this interview.

I understand that this consent form will not be linked to the interviews, and that my answers will remain confidential.

I understand that if at all possible, feedback will be given to my community on the results of the completed research.

.....

Signature of participant

Date:.....

I hereby agree to the tape recording of my participation in the study

.....

Signature of participant

Date:.....

APPENDIX D – TRANSCRIPTS

Transcribed data of individual participants

PPARTICIPANT: 1

Interviewer: Can you please tell me about your self

Participant 1: I am 45 years old, and I have 2 children. I am suffering from asthma; I am not working, so I depend on doing piece jobs such as gardening around the Township. I can do other job like brick laying, fix ceilings and plumbing. I have a twin brother only; he is working at the factories. My parents passed away long time ago. We were staying together with my twin but I left the house with him because I regard him as younger than me. I stayed with my girlfriend who was a street vendor in town but she passed away because of TB and she was also HIV positive. Now I do not have a stable girlfriend I catch the one I meet for that moment. Now I depend on food parcels from Social Development

Interviewer: Tell me about educational qualification

Participant 1: I left school when I was doing standard 6 (grade 8) because my parents passed away so I had to leave school earlier.

Interviewer: How long have been living with HIV/AIDS?

Participant 1: I did not know that I was HIV positive until I was sick and went to the clinic to seek medical help. The nurse told me that she was going to do an HIV test, after that I was told that I am HIV positive and it was in 2005. The nurse told me to use condoms when I am having sexual intercourse. The other thing is that I contracted HIV from my girlfriend because every time we had sex she used to say

we must use condoms but I was wondering why she was said so but I refused because I do not like condoms I like flesh to flesh [laughs louder]. She had too many boyfriends but I won her over them and I know that my girlfriend infected me with HIV/AIDS.

Interviewer: How do community members view HIV/AIDS?

Participant 1: Yhoo!! Yhoo!! Yhoo!! My sister its bad [clapping hands], they are gossiping about us people living with HIV/AIDS. If someone whom they know that he or she is HIV positive passing by, they would point fingers gossiping about his or her HIV positive status.

Interviewer: How knowledgeable are the community members about the modes of HIV/AIDS transmission, prevention and the rights of PLWHA?

Participant 1: People from the community know about HIV/AIDS. They know that if you are not using condoms you are at risk of being HIV positive.

Interviewer: How do community members treat PLWHA?

Participant 1: They treat us badly and they gossip about us, yhoo!! It is so hurtful, hey! [standing and whispers] there was this guy in the area who stabbed the other guy because whenever he met this HIV positive guy he would mock him telling him that he has this thing, this is the saying from this area when someone is infected by HIV/AIDS. They will always point others that are HIV positive whereas they do not know their HIV status. There are also a lot of people in this area who are HIV positive but they hide themselves and point fingers to those who are known to be HIV positive.

Interviewer: How do you deal with stigmatisation from community members?

Participant 1: That guy stays at home now; he isolates himself from the community.

There was this guy whom I had a relationship with his sister, he usually tease me when he was drunk, I beat him to the extent that he was injured. He went to the police to lay charges but the case was referred to the social workers. The social workers told me to ignore all those negative remarks and look after my health.

Interviewer: What assistance do you get from the community members?

Participant1: I only get support from my brother he gives me money to buy food, and clothes

Interviewer: How do you feel about the support?

Participant 1: I feel good to see that my brother still cares about me.

Interviewer: What changes do you observe after getting support from your brother?

Participant 1: My stress gets relieved, you know what the thing that stresses me is that the nurses told me that my viral load is up. They said they are going to refer me to the doctor to change my treatment because the treatment I was using makes me sick. I last went to the clinic to fetch my ARVs last month because I do not have food at home, I cannot consume pills on an empty stomach.

Interviewer: What kind of activities do you do with community members to members to curb HIV/AIDS-related stigma?

Participant 1: There is nothing done, it is just insults and gossip from community members. The members of the support group go door to door to teach community members about HIV/AIDS. We as support group visit those who are bed ridden to wash them and cook. I am no longer associating myself with the people in my area

because if you are passing by they would point fingers or gossip about you. You will also find others passing remarks which are devastating; such as look now he got the lotto which means that you have AIDS.

Interviewer: What changes do you observe after helping those who are bedridden?

Participant 1: This is so helpful because those who are bed ridden get up, the sores disappear and they look healthy now.

Interviewer: What would you like the community members to do to curb stigmatisation.

Participant 1: They should stop insulting us and regard us as normal people just like others. When we attend cultural activities and given *umqombothi* (African beer) the other men would pour my beer in a separate container telling that I know that I have this thing so they do not want to contract my disease.

Interviewer: What do the service providers and community leaders offer to help you?

Participant 1: There is nothing done except the food parcels we get from the social workers and they take time to give us, others do not get food parcels at all. Sometimes I do not take my pills because I cannot take pills on an empty stomach. The social workers are ignoring us and they take their time to do these things.

Interviewer: How do you identify the strength that is within you to cope with stigmatisation?

Participant 1: I just comfort myself and ignore people who stigmatise me. After I've done those things my stress gets relieved.

Interviewer: Can you give me an example where you used your inner strength?

Participant 1: I was insulted by someone in my area so I did not bother responding I just ignored him.

Interviewer: Do you work in partnership with the service providers and community leaders to curb HIV/AIDS-stigma?

Participants 1: Yes, the nurses are giving us support in the clinic. They tell us to stick to our treatment and eat healthy. At times social workers give us groceries and they come to the community to educate people about HIV/AIDS.

Interviewer: What are the benefits of working together?

Participant 1: We feel good about that and we get motivated when we see that there are people who are still taking care of us.

Interviewer: What do you recommend for service providers and community leaders in order to boost your self-esteem?

Participant 1: They could tell people in the community to stop stigmatising us.

Interviewer: How effective would your recommendations be in boosting your self-esteem?

Participant 1: It would be better because we will feel free from insults.

Interviewer: What do you suggest to be done by service providers and community leaders to curb HIV/AIDS-related stigma?

Participant 1: They must do something about the people who stigmatise us.

Interviewer: What needs to be introduced to people in the community who have faulty myths about HIV/AIDS?

Participant 1: They need to be told that HIV/AIDS does not kill if you stick to your treatment.

Interviewer: How can you introduce such things to them?

Participant 1: By organising meetings and educate them.

Interviewer: How do service providers and community leaders empower you to survive stigmatisation in terms of using your inner strengths, identifying resources within your environment and survival skills to live productive lives?

Participant 1: They tell us to be bold and live normally like other people and they also tell us to plant vegetables so that we can eat healthier.

PARTICIPANT: 2

Interviewer: Can you please tell me about yourself.

Participant 2: I am not working, and I have 2 children, I am 40 years old.

Interviewer: Tell me about educational qualification

Participant 2: I left school while I was doing standard 7 (grade 9)

Interviewer: How long have been living with HIV/AIDS?

Participant 2: I was diagnosed in 10 years back and I was admitted at [X] hospital for MDR.

Interviewer: How do community members view HIV/AIDS?

Participant 2: They know that when you do not use condoms you will get HIV/AIDS. They also treat me well now in the community. At first they were laughing at me because I was mentally disturbed when I started using ARVs and I was told by the nurses that I was reacting from the pills and they changed my treatment.

Interviewer: How knowledgeable are the community members about the modes of HIV/AIDS transmission, prevention and the rights of PLWHA?

Participant 2: They know everything, but there are those who are labelling us saying that we have “*three letters*”. When you come to Dimbaza being sick from another town especially from the big cities such as Johannesburg or Cape Town, people from this Township would gossip about you telling others that you were a sex worker.

Interviewer: How do community members treat PLWHA?

Participant 2: They treat us good and others very bad. Things become worse when you are an unmarried woman who is HIV positive. You are associated with promiscuity because sometimes someone is not working so people assume that she is engaging in promiscuous activities.

Interviewer: How do you deal with stigmatisation from community members?

Participant 2: I tell those who insult us that they do not have a common sense, they are ignorant because I did not apply for HIV.

Interviewer: What assistance do you get from the community members?

Participant 2: Some of them support us by giving us food. My neighbours are very supportive because they share vegetables from their garden with me.

Interviewer: How do you feel about the support?

Participant 2: I feel very strong to see that my neighbours care for me.

Interviewer: What changes do you observe after getting support?

Participant 2: Yhoo! I feel good and blessed, the support I get from my neighbours encourages me to be stronger than before

Interviewer: What kind of activities do you do with community members to members to curb HIV/AIDS-related stigma?

Participant 2: There is nothing done by community members, except the HIV/AIDS campaigns conducted by our support group.

Interviewer: What changes do you observe after conducting awareness campaigns?

Participant 2: I used to lock myself at home, but after I get encouragement I feel free to face the world and educate others.

Interviewer: What would you like the community members to do to curb stigmatisation.

Participant 2: If some of them could change their behaviour.

Interviewer: What do the service providers and community leaders offer to help you?

Participant 2: From the social workers I did apply for food parcels and since I was at hospital for a long time I did not get any response from them.

Interviewer: How do you identify the strength that is within you to cope with stigmatisation?

Participant 2: Something coming from within motivates me to wake up you have children to nurture. Maybe my children are the ones that make me strong.

Interviewer: Can you give me an example where you used your inner strength?

Participant 2: When I was from hospital [X] some of people did not even want to stay closer to me since they knew that I am HIV positive and had MDR.

Interviewer: Do you work in partnership with the service providers and community leaders to curb HIV/AIDS-stigma?

Participants 2: Yes, the nurses tell us about the importance of adhering to our treatment and healthy lifestyles.

Interviewer: What are the benefits of working together?

Participant 2: I feel strong and live happier with my children

Interviewer: What do you recommend for service providers and community leaders in order to boost your self-esteem?

Participant 2: If they can get provide us with food parcels because they take time to process our applications. I would also like people from this area to fully accept us as normal people just like any other person, because if you are around some of them feel sorry for you as if you are dying.

Interviewer: How effective would your recommendations be in boosting your self-esteem?

Participant 2: We would stick to our treatment

Interviewer: What do you suggest to be done by service providers and community leaders to curb HIV/AIDS-related stigma?

Participant 2: If they can educate people about HIV/AIDS.

Interviewer: What needs to be introduced to people in the community who have faulty myths about HIV/AIDS?

Participant 2: By gathering the community members together and educate them about the way we feel when we are being stigmatised.

Interviewer: How can you introduce such things to them?

Participant 2: These things can be introduced by getting door to door in the community as a support group and talk about issues concerning HIV/AIDS.

Interviewer: How do the service providers and community leaders empower you to survive stigmatisation in terms of using your inner strengths, identifying resources within your environment and survival skills to live productive lives?

Participant 2: As I said I was in hospital for a long time I was empowered by nurses at the hospital to finish my treatment, the only thing that I see in this area is the garden project.

PARTICIPANT 3

Interviewer: Can you please tell me about yourself.

Participant 3: I am not working, I am 27 year and I only have child.

Interviewer: Tell me about educational qualification

Participant 3: I left school at grade 10

Interviewer: How long have been living with HIV/AIDS?

Participant 3: Uhm [pause] it was 2008 so its 6 years [laughs].

Interviewer: How do community members view HIV/AIDS?

Participant 3: They know about HIV/AIDS and some of them are fine and others do not believe that I am HIV positive.

Interviewer: How knowledgeable are the community members bout the modes of HIV/AIDS transmission, prevention and the rights of PLWHA?

Participant 3: Some community members know that if you are HIV positive you have to stick to your treatment and eat the right diet such as fruit and vegetables. Some do PLWHA do not want to accept that they are HIV positive. For example; there was this lady who was here with us from the support group. Her mother told her that there is a traditional healer or "*igqirha*" who was going to do a ritual by slaughtering a goat for her and apologise to the ancestors for not responding to their calling. The lady performed the rituals and stopped taking the treatment. She went to the initiation school to become the traditional healer. You know what she did not finish even three months and we heard that she passed away.

Interviewer: How do community members treat PLWHA?

Participant 3: Sometimes they are right; me and my sister were once insulted by our HIV positive statuses by some ladies in our street.

Interviewer: How do you deal with stigmatisation from community members?

Participant 3: I told them that I am proud of myself, it was hurtful yhoo but we managed to deal with that by telling ourselves that we are better than them because we know where we stand regarding our HIV statuses and for them they fear being tested for HIV so they do not know their statuses.

Interviewer: What assistance do you get from the community members?

Participant 3: There is no assistance except when we are at the clinic we talk about HIV/AIDS and everybody feels free and we laugh. Friends and families are helping us on certain things but it is not enough because there are still people who have stigmatizing attitudes.

Interviewer: How do you feel about that?

Participant 3: I know that there are people who care about others no matter how the situation is.

Interviewer: What changes to you observe after getting support?

Participant 3: I feel good.

Interviewer: What kind of activities do you do with community members to curb HIV/AIDS-related stigma?

Participant 3: Here in this area, it is only support we get from support group.

Interviewer: How do you feel about that?

Participant 3: This is so helpful because we receive food parcels, and those who are bed ridden get up, the sores disappear and they look healthy now.

Interviewer: What would you like the community members to do to curb stigmatisation.

Participant 3: They should support us even and those who are still having stigma could learn to accept us as human beings.

Interviewer: What do the service providers and community leaders offer to help you?

Participant 3: We get counselling from the nurses

Interviewer: How do you identify the strength that is within you to cope with stigmatisation?

Participant 3: I just ignore bad thing they say about us and I tell myself that if someone still knows nothing about his or her HIV status she or he should not guarantee that he or she is safe.

Interviewer: Can you give me an example where you used your inner strength?

Participant 3: I am proud of myself whenever person tries to tease me about HIV/AIDS.

Interviewer: Do you work in partnership with the service providers and community leaders to curb HIV/AIDS-stigma?

Participants 3: Yes, especially with some nurses because we adhere to what they are telling us to do. I fetch my medication at the hospital in town, here at the local clinic there is a nurse who is my neighbour and we do not talk at each other because she spread gossip about me regarding my HIV positive status and I felt so devastated. I would not say much about social workers because they do not give us food parcels but at times they come to the community and tell people about HIV/AIDS.

Interviewer: What are the benefits of working together?

Participant 3: We feel good about that we get motivated that there are people who are still taking care of us.

Interviewer: What do you recommend for the service providers and community leaders in order to boost your self-esteem?

Participant 3: I want those who insult us to be taken to the court of law because stigma affects our self-esteem. Secondly, they can give us groceries because we are not working, we are starving and we depend on our parents Old Age Grant, there is nowhere that we can go, jobs are so scarce.

Interviewer: How effective would your recommendations be in boosting your self-esteem?

Participant 3: It would be better because we will have something to contribute to our parents Old Age Grant.

Interviewer: What do you suggest to be done by service providers and community leaders to curb HIV/AIDS-related stigma?

Participant 3: They must gather all community members and I think the church leaders should organise prayers for us so that we should be much stronger.

Interviewer: What needs to be introduced to people in the community who have faulty myths about HIV/AIDS?

Participant 3: They can get more education about HIV/AIDS so that they learn new things about the virus.

Interviewer: How can you introduce such things to them?

Participant 3: They can be educated in a show, let us say for example, organising something like a gospel show, you know that people would come in large numbers.

Interviewer: How do the service providers and community leaders empower you to survive stigmatisation in terms of using your inner strengths, identifying resources within your environment and survival skills to live productive lives?

Participant 3: I am going to talk about the nurses, because that is where I often feel good when I am coming from the clinic. The nurses are supportive they also teach us on how to live healthy life styles.

PARTICIPANT 4

Interviewer: Can you tell me about yourself.

Participant 4: I have 2 children and I am 33 years.

Interviewer: Tell me about educational qualification.

Participant 4: I left school in grade 8.

Interviewer: How long have been living with HIV/AIDS?

Participant 4: It's been 4 years, it was in 2010

Interviewer: How do community members view HIV/AIDS?

Participant 4: When my aunt comes from the shebeen drunk she would shout at me to the extent that everyone in my vicinity would hear what she is saying. She would insult me saying that my mother died of AIDS and I am also going to follow her. This make me feel so ashamed and sometimes I stay indoors or go out to my boyfriend.

Interviewer: How knowledgeable are the community members bout the modes of HIV/AIDS transmission, prevention and the rights of PLWHA?

Participant 4: They know that if you are HIV positive you have to stick to your treatment and eat healthy food, checking your CD 4 count some do not know exactly that patients or PLWHA have rights just like everyone.

Interviewer: How do community members treat PLWHA?

Participant 4: Others treat us well and others are insulting us, they would tell you that your parents died of HIV/AIDS and if you are thin like me you are going to die. They used to tell me that I am going to infect others. Some of the community

members used to call me by horrible name such as a walking ghost because I have lost too much weight and now I am thin. My aunt always insults me about those things.

Interviewer: How do you deal with stigmatisation from community members?

Participant 4: We feel so bad; I and my sister were once insulted about our HIV positive status by some ladies in our street. It was hurtful but we managed to deal with that by telling ourselves that we are better than them because we know where we stand regarding our HIV status and for them they fear being tested for HIV so they do not know their status.

Interviewer: What assistance do you get from the community members?

Participant 4: There are some elderly women at my church who always talk to me and make me feel strong.

Interviewer: How do you feel about that?

Participant 4: I feel good after that and I feel happy that m

Interviewer: What changes to you observe after getting support?

Participant 4: I talk to others now and I smile now. I feel stronger now ever since I accepted that I am living with HIV/AIDS. I am living my life the way I used to live because I know that I won't die because of my HIV positive status. Those who are gossiping about us are making us stronger instead because they know nothing about their HIV status.

Interviewer: What kind of activities do you do with community members to members to curb HIV/AIDS-related stigma?

Participant 4: We only conduct as support groups with other community members

Interviewer: What changes do you observe after the activities?

Participant 4: We feel great and appreciated

Interviewer: What would you like the community members do to curb stigmatisation?

Participant 4: If we can have something like a soup kitchen here in Dimbaza and invite other people from the community I think that would work because we will not give away the soup only but we will discuss issues that are affecting us such as the issue of HIV/AIDS-related stigma.

Interviewer: What do the service providers and community leaders offer to help you?

Participant 4: If they can assist us on our activities.

Interviewer: How do you identify the strength that is within you to cope with stigmatisation?

Participant 4: I get stronger because of support I receive at home.

Interviewer: Can you give me an example where you used your inner strength?

Participant 4: When I was diagnosed HIV positive I was so devastated but through counselling I received I was able to tell myself that I still have to live my life to the fullest.

Interviewer: Do you work in partnership with the service providers and community leaders to curb HIV/AIDS-stigma?

Participants 4: Yes, they educate us about HIV/AIDS at times

Interviewer: What are the benefits of working together?

Participant 4: We acquire information that we didn't know.

Interviewer: What do you recommend for the service providers and community leaders in order to boost your self-esteem?

Participant 4: If they can conduct more educational talks about HIV/AIDS, it would be better.

Interviewer: How effective would your recommendations be in boosting your self-esteem?

Participant 4: I think that stigmatising attitudes would be better.

Interviewer: What do you suggest to be done by service providers and community leaders to curb HIV/AIDS-related stigma?

Participant 4: I would like the social workers and other officials to gather all the members of the Township of Dimbaza to the community hall and organise someone who is well known. That will make people to come and listen to our voices.

Interviewer: What needs to be introduced to people in the community who have faulty myths about HIV/AIDS?

Participant 4: I would say that there is a need to conduct more activities to educate people about HIV/AIDS.

Interviewer: How can you introduce such things to them?

Participant 4: By involving community members to participate from these activities.

Interviewer: How do the service providers and community leaders empower you to survive stigmatisation in terms of using your inner strengths, identifying resources within your environment and survival skills to live productive lives?

Participant 4: We are empowered by their education on how to live positively.

PARTICIPANT 5

Interviewer: Can you tell me about yourself.

Participant 5: I have 3 children and I am 40 years.

Interviewer: Tell me about educational qualification.

Participant 5: I left school in grade 1.

Interviewer: How long have been living with HIV/AIDS?

Participant 5: It was in 2005.

Interviewer: How do community members view HIV/AIDS?

Participant 5: Some of them have accepted HIV/AIDS.

Interviewer: How knowledgeable are the community members about the modes of HIV/AIDS transmission, prevention and the rights of PLWHA?

Participant 5: They know all those things.

Interviewer: How do community members treat PLWHA?

Participant 5: Most of them are right and there are those who have bad attitudes on HIV positive women. Women have to be treated the same way as men. The worst part is that our dignity is being put down by other women who insult others for being the carriers of HIV/AIDS (Participant No. 5).

Interviewer: How do you deal with stigmatisation from community members?

Participant 5: We feel so bad by those who still have negative attitudes because other people stop fetching their ARVs. There are some people, especially within our

families, who would look at you and feel sorry or shame. For example here in this Township some people would ask you if you are paying the burial society because they can hear anything about you. These people are not aware that we can stay longer as long as we adhere to our treatment.

Interviewer: What assistance do you get from the community members?

Participant 5: They are telling us to be strong, some of the give us food.

Interviewer: How do you feel about that?

Participant 5: I feel normal like other people.

Interviewer: What changes to you observe after getting support?

Participant 5: I talk to others now and I smile now

Interviewer: What kind of activities do you do with community members to members to curb HIV/AIDS-related stigma?

Participant 5: There are no more activities done in this community, except educational debates from our support group

Interviewer: What changes do you observe after the activities?

Participant 5: I don't even think that I am HIV positive.

Interviewer: What would you like the community members do to curb stigmatisation?

Participant 5: I we can do some activities

Interviewer: What do the service practitioners and community leaders offer to help you?

Participant 5: I applaud the nurses because they empower us a lot, but the social workers are reluctant to help us in terms of food parcels. At church, our pastor tell us that being HIV positive is not a death sentence

Interviewer: How do you identify the strength that is within you to cope with stigmatisation?

Participant 5: I tell myself that I am going to live longer, and I won't die as long as I am taking my treatment and get support.

Interviewer: Can you give me an example where you used your inner strength?

Participant 5: I often laughs when I see people insult PLWHA, and I tell myself that they no nothing.

Interviewer: Do you work in partnership with the service providers and community leaders to curb HIV/AIDS-stigma?

Participants 5: Yes, especially with my pastor. I also disclosed at church, yhoo! [Laughs louder] they didn't believe that I am HIV positive. They support me I don't want to lie.

Interviewer: What are the benefits of working together?

Participant 5: You feel stress free

Interviewer: What do you recommend for service providers and community leaders in order to boost your self-esteem?

Participant 5: I would like the church leaders to pray for us to live longer lives. I would like them to offer us jobs, because now we are provided by our families.

Interviewer: How effective would your recommendations be in boosting your self-esteem?

Participant 5: By that I will know that I have something to do.

Interviewer: What do you suggest to be done by service providers and community leaders to curb HIV/AIDS-related stigma?

Participant 5: if they can take legal actions against those who stigmatise PLWHA.

Interviewer: What needs to be introduced to people in the community who have faulty myths about HIV/AIDS?

Participant 5: I we can gather with community members and try to resolve the issue of HIV/AIDS-related stigma.

Interviewer: How can you introduce such things to them?

Participant 5: By involving people like nurses and the police to address HIV/AIDS issues.

Interviewer: How do the service providers and community leaders empower you to survive stigmatisation in terms of using your inner strengths, identifying resources within your environment and survival skills to live productive lives?

Participant 5: They are taking their responsibilities to tell those who still stigmatising PLWHA that they should accept HIV/AIDS and treat us positively.

PARTICIPANT 6

Interviewer: Can you tell me about yourself.

Participant 6: I have 3 children and I am 39 years.

Interviewer: Tell me about educational qualification.

Participant 6: I left school in grade 11.

Interviewer: How long have been living with HIV/AIDS?

Participant 6: It was in 2005 when I was diagnosed HIV positive.

Interviewer: How do community members view HIV/AIDS?

Participant 6: They know that it is infectious but you can prevent yourself from being infected.

Interviewer: How knowledgeable are the community members about the modes of HIV/AIDS transmission, prevention and the rights of PLWHA

Participant 6: They are informed but there are some people who still label us even at clinics they are separating us. We have to queue just like other patients, not to be separated as if we are going to infect others

Interviewer: How do community members treat PLWHA?

Participant 6: The community is fine whereas I don't want to be sure about that because if someone knows your HIV positive status, you will see that person has changed a bit. Here in Dimbaza we are regarded as the ones who bring HIV to our partners. There was this lady whom I was sharing a boyfriend with her, she insulted me telling me that I am the one who infected the man.

Interviewer: How do you deal with stigmatisation from some community members?

Participant 6: That is bad, it makes people to become ashamed and others do not want to test for HIV. There is this lady who died because of AIDS last year, she came sick from Johannesburg and rumours were saying that she was not working but she used to be a prostitute.

Interviewer: What assistance do you get from the community members?

Participant 6: Sometimes when I am sick some of the community members show support by visiting me at home and that makes me to recover soon. Some of them assist by offering us piece jobs since we are not working. My mother accepted me; she told me that I am going to live longer because being HIV positive does not mean that you are going to die.

Interviewer: How do you feel about that?

Participant 6: I become happy because I am able buy food for my children since their grant is not enough.

Interviewer: What changes do you observe after getting assistance?

Participant 6: I feel good because I know that my children are going to eat and I can take my treatment properly.

Interviewer: What kind of activities do you do with community members to members to curb HIV/AIDS-related stigma?

Participant 6: I am going to talk about my mother who always there by my side when I don't feel right, and also my neighbours who visit at times and give me

advices on how to stay healthy. There are no activities done by the community at large.

Interviewer: What changes do you observe after the support?

Participant 6: I feel right and I feel loved that is why I accepted my status.

Interviewer: what would you like the community members do to curb stigmatisation?

Participant 6: Those who have little information about HIV/AIDS should try to learn more about it.

Interviewer: What do the social services practitioners and community leaders offer to help you?

Participant 6: Some of the offer us counselling and support.

Interviewer: How do you identify the strength that is within you to cope with stigmatisation?

Participant 6: The first time I was diagnosed HIV positive I managed to deal with it whereas it was difficult. I did not lose hope.

Interviewer: Can you give me an example where you used your inner strength?

Participant 6: I am always strengthened because I know that no one is going to take my responsibilities, so I try by all means to be strong and deal with challenges that come on my way.

Interviewer: Do you work in partnership with the service providers and community leaders to curb HIV/AIDS-stigma?

Participants 6: Yes, we stick on what they are telling us to do, like eating health, using condoms and take our medication. Sometimes we as members support group reach out to the community and talk about HIV/AIDS to impact a positive change from community members.

Interviewer: What are the benefits of working together?

Participant 6: I feel better.

Interviewer: What do you recommend for service providers and community leaders in order to boost your self-esteem?

Participant 6: I will be glad if the service providers would take further steps when someone gets stigmatised or treated unfairly because of his or her HIV/AIDS positive status.

Interviewer: How effective would your recommendations be in boosting your self-esteem?

Participant 6: That will make people understand HIV/AIDS better.

Interviewer: What do you suggest to be done by service providers and community leaders to curb HIV/AIDS-related stigma?

Participant 6: If they can assist us by taking legal actions for people who insult us.

Interviewer: What needs to be introduced to people in the community who have faulty myths about HIV/AIDS?

Participant 6: To stop saying bad things to us because we get devastated by that.

Interviewer: How can you introduce such things to them?

Participant 6: If we can go each and every household and talk about HIV/AIDS.

Interviewer: How do the service providers and community leaders empower you to survive stigmatisation in terms of using your inner strengths, identifying resources within your environment and survival skills to live productive lives?

Participant 6: They pray with us and that makes us better. The Lord says anyone who trusts in me will never be disappointed.

PARTICIPANT 7

Interviewer: Can you tell me about yourself.

Participant 7: I have 2 children and I am 18 years, I am working at the factory here in Dimbaza.

Interviewer: Tell me about educational qualification.

Participant 7: I left school in grade 8.

Interviewer: How long have been living with HIV/AIDS?

Participant 7: It was last year, 2013, when I gave birth to my second baby

Interviewer: How do community members view HIV/AIDS?

Participant 7: Community members know that HIV/AIDS is a disease that affects every person even if a person is not infected.

Interviewer: How knowledgeable are the community members about the modes of HIV/AIDS transmission, prevention and the rights of PLWHA

Participant 7: They know everything but others are ignorant.

Interviewer: How do community members treat PLWHA?

Participant 7: I can say that PLWHA are accepted and as I said that some pretend as if they care whereas they gossip about you.

Interviewer: How do you deal with stigmatisation from some community members?

Participant 7: I don't like it and I prefer to keep quiet about my status and say nothing to my friends at work

Interviewer: What assistance do you get from the community members?

Participant 7: Nothing except the support I get at home.

Interviewer: How do you feel about that?

Participant 7: I feel so happy to see that my family appreciates me.

Interviewer: What changes do you observe after getting assistance?

Participant 7: I can see that I have peace within me.

Interviewer: What kind of activities do you do with community members to curb HIV/AIDS-related stigma?

Participant 7: I only participate at the support group; we normally reach out and visit those who are bedridden to help them.

Interviewer: What changes do you observe after that?

Participant 7: I feel good when I see that I can give support to others.

Interviewer: What would you like the community members do to curb stigmatisation?

Participant 7: They can form other support groups just because there are only two support groups in this Township.

Interviewer: What do the social services practitioners and community leaders offer to help you?

Participant 7: They tell us to stay strong. My pastor is so supportive, if all the church leaders would be like that people living with HIV/AIDS will not be ashamed of disclosing their status at church. He tells people not to judge PLWHA, and he

always asks the congregation to pray for the cure of HIV/AIDS. I feel very happy when I am at church because people know my status but they do not have negative attitudes towards me.

Interviewer: How do you identify the strength that is within you to cope with stigmatisation?

Participant 7: The fact that I am able to help others shows that I am strong.

Interviewer: Can you give me an example where you used your inner strength?

Participant 7: It was when I was labelled at work because I was so thin; they would pass negative remarks such as she has this “*thing*”. I managed to deal with that until I recovered and I told myself that I won’t quit my job because of ignorant people.

Interviewer: Do you work in partnership with the service providers and community leaders to curb HIV/AIDS-stigma?

Participants 7: We are trying to work with them but they keep on promising us about getting funds for our activities in the support group, but we are still struggling.

Interviewer: What are the benefits of working together?

Participant 7: We always hope that one day we will get something.

Interviewer: What do you recommend for service providers and community leaders in order to boost your self-esteem?

Participant 7: To keep encouraging PLWHA to believe in themselves.

Interviewer: How effective would your recommendations be in boosting your self-esteem?

Participant 7: That will make PLWHA to recognise that they still have value.

Interviewer: What do you suggest to be done by social services practitioners and community leaders to curb HIV/AIDS-related stigma?

Participant 7: They should educate people that we as women should be treated the same way as men because HIV/AIDS affects us all.

Interviewer: What needs to be introduced to people in the community who have faulty myths about HIV/AIDS?

Participant 7: The issue of being differentiated to other people makes us feel useless and hopeless because some of people who are in charge in the community do not take us seriously.

Interviewer: How can you introduce such things to them?

Participant 7: Through education.

Interviewer: How do the services providers and community leaders empower you to survive stigmatisation in terms of using your inner strengths, identifying resources within your environment and survival skills to live productive lives?

Participant 7: They tell us that if someone is not working he or she has to do something such as searching for a plot and plant some vegetables. They always advise us to hold on to support groups. I am so reluctant to go and apply for food parcels, because every time the social workers will always say that we must wait. I am now planting vegetables in my garden so that I can take my treatment.

PARTICIPANT 8

Interviewer: Can you tell me about yourself.

Participant 8: I have 2 children and I am 25 years, I am not working

Interviewer: Tell me about educational qualification.

Participant 8: I finished grade 12.

Interviewer: How long have been living with HIV/AIDS?

Participant 8: It was in 2010, and it was my first time to engage in sexual activities

Interviewer: How do community members view HIV/AIDS?

Participant 8: They view it as a disease contracted by people who are having multiple sex partners. It makes me angry when someone says that HIV/AIDS is a disease of women because these same men are changing partners and spreading the virus, so who is to blame?

Interviewer: How knowledgeable are the community members about the modes of HIV/AIDS transmission, prevention and the rights of PLWHA

Participant 8: They focus on one mode of transmission that is sex, they know about condoms and I am not sure about the rights.

Interviewer: How do community members treat PLWHA?

Participant 8: Some do support PLWHA whereas from other households parents refuse to give support to their children.

Interviewer: How do you deal with stigmatisation from some community members?

Participant 8: I accepted myself but at times stigma makes me feel angry because it makes me weak at times being teased with something you will not change but I always walk tall and tell myself that I am not going to live for somebody else.

Interviewer: what assistance do you get from the community members?

Participant 8: I get support from others.

Interviewer: How do you feel about that?

Participant 8: I feel like an ordinary person, I do not regard myself as a sick person.

Interviewer: What changes do you observe after getting assistance?

Participant 8: Feel the happiness from within.

Interviewer: What kind of activities do you do with community members to curb HIV/AIDS-related stigma?

Participant 8: Nothing, but there were activities before which were conducted by TAC members.

Interviewer: What changes did you observe after those activities?

Participant 8: I was motivated because the activities were tackling many issues related to HIV/AIDS.

Interviewer: What would you like the community members do to curb stigmatisation?

Participant 8: If they can tolerate us I think everything would be fine.

Interviewer: What do the service providers and community leaders offer to help you?

Participant 8: They educate us at times.

Interviewer: How do you identify the strength that is within you to cope with stigmatisation?

Participant 8: Through knowing that I am unique and I won't die if I adhere to my treatment.

Interviewer: Can you give me an example where you used your inner strength?

Participant 8: I always use it when someone tries to intimidate me by negative attitude. I normally walk away from such people and find something that will make me better.

Interviewer: Do you work in partnership with the service providers and community leaders to curb HIV/AIDS-stigma?

Participants 8: I can say yes, because the police are trying to warn people about this and they come to us telling us to report cases related to HIV/AIDS.

Interviewer: What are the benefits of working together?

Participant 8: We feel protected.

Interviewer: What do you recommend for service providers and community leaders in order to boost your self-esteem?

Participant 8: They should support us to keep on going.

Interviewer: How effective would your recommendations be in boosting your self-esteem?

Participant 8: This will bring much confidence to us if we see that we are supported.

Interviewer: What do you suggest to be done by service providers and community leaders to curb HIV/AIDS-related stigma?

Participant 8: They should reach out to communities to see what is going on out there. We want people to know that being HIV positive does not mean that we are different from them but the only difference is that we PLWHA are just having HIV virus in our blood.

Interviewer: What needs to be introduced to people in the community who have faulty myths about HIV/AIDS?

Participant 8: There is a need to tell them about the rights of PLWHA, and also be informed about legal actions that can be taken if they continue with stigma.

Interviewer: How can you introduce such things to them?

Participant 8: By conducting awareness campaigns regularly.

Interviewer: How do the service providers and community leaders empower you to survive stigmatisation in terms of using your inner strengths, identifying resources within your environment and survival skills to live productive lives?

Participant 8: They tell us to live positively.

PARTICIPANT 9

Interviewer: Can you tell me about yourself.

Participant 9: I have no children and I am 30 years, I am not working

Interviewer: Tell me about educational qualification.

Participant 9: I left school in grade 9.

Interviewer: How long have been living with HIV/AIDS?

Participant 9: It was in 2004

Interviewer: How do community members view HIV/AIDS?

Participant 9: Most of them accepted HIV/AIDS, but there are those who will view you as a whore.

Interviewer: How knowledgeable are the community members about the modes of HIV/AIDS transmission, prevention and the rights of PLWHA

Participant 9: I can say that they know these things except that some of them do not want to accept it. Some people in this area do not want to test for HIV but they prefer to seek help from traditional healers who do not perform any test. This is worrisome because they continue dying and you will hear by some of their family members that it was found that the person had AIDS.

Interviewer: How do community members treat PLWHA?

Participant 9: They treat us well and as I said some mock us, especially us as women they label us.

Interviewer: how do you deal with stigmatisation from some community members?

Participant 9: I try to cope; the only thing I told myself is that I am going to take my medication properly.

Interviewer: What assistance do you get from the community members?

Participant 9: Those who do not have a problem love us and they are supporting us by giving us advises, for instance others would tell you what to use if you are sick.

Interviewer: How do you feel about that?

Participant 9: It is fascinating to see that there are people who still care for others.

Interviewer: What changes do you observe after getting assistance?

Participant 9: Its only happiness.

Interviewer: What kinds of activities do you do with community members to members to curb HIV/AIDS-related stigma?

Participant 9: We only do awareness campaigns as a support group

Interviewer: what changes did you observe after those activities?

Participant 9: We get excited to observe that we are welcomed to convey our messages

Interviewer: What would you like the community members do to curb stigmatisation?

Participant 9: If they can acquire accurate information to be well informed about HIV/AIDS.

Interviewer: What do the service providers and community leaders offer to help you?

Participant 9: They tell us to take care of ourselves.

Interviewer: How do you identify the strength that is within you to cope with stigmatisation?

Participant 9: By being able to speak out about my HIV positive status.

Interviewer: Can you give me an example where you used your inner strength?

Participant 9: When I face challenges from some people I am able to stand firm and talk about HIV/AIDS without being shameful.

Interviewer: Do you work in partnership with the service providers and community leaders to curb HIV/AIDS-stigma?

Participants 9: Yes, because when we have financial problems at the support group we contact them.

Interviewer: What are the benefits of working together?

Participant 9: We get excited because we can see that they are paying attention to our problems but now the problem is funding, we are struggling.

Interviewer: What do you recommend for the service providers and community leaders in order to boost your self-esteem?

Participant 9: They should give us wise words to keep on moving and others should stop differentiating us. When we fetch our treatment we have to go to ARV unit on the other side of the clinic that is we will find our folders to take our treatment at dispensary. People will identify you that you are on ARVs by the red sticker that is on the folder.

Interviewer: How effective would your recommendations be in boosting your self-esteem?

Participant 9: This will bring hope.

Interviewer: What do you suggest to be done by service providers and community leaders to curb HIV/AIDS-related stigma?

Participant 9: Some of them should stop sitting in their offices and reach out to communities to see what is going on out there. Some of the community leaders are excluding us when there are projects from the municipality; they regard us as sick people. That should be considered too.

Interviewer: What needs to be introduced to people in the community who have faulty myths about HIV/AIDS?

Participant 9: If they can be stopped from their ignorance by educating them about how bad is stigma on us.

Interviewer: How can you introduce such things to them?

Participant 9: There is nothing else other than education.

Interviewer: How do the service providers and community leaders empower you to survive stigmatisation in terms of using your inner strengths, identifying resources within your environment and survival skills to live productive lives?

Participant 9: The ward counsellor promised us about funding of our support group, which inspired us to work very hard.

PARTICIPANT 10

Interviewer: Can you tell me about yourself.

Participant 10: I have 3 children and I am 43 years, I am not working

Interviewer: Tell me about educational qualification.

Participant 10: I only finished grade 12.

Interviewer: How long have been living with HIV/AIDS?

Participant 10: It was in 2000.

Interviewer: How do community members view HIV/AIDS?

Participant 10: The community knows about HIV/AIDS.

Interviewer: How knowledgeable are the community members about the modes of HIV/AIDS transmission, prevention and the rights of PLWHA

Participant 10: They know exactly about those things though some of them still have stigmatising attitudes. When my medication is finished I often send my sister and tell her to say that I am at work. This is because some nurses are disrespectful; I once did not fetch my medication because I had no food to eat. When I told the nurse that I did not have food she shouted me like hell.

Interviewer: How do community members treat PLWHA?

Participant 10: Their treatment differs; it depends on how the person views HIV/AIDS.

Interviewer: How do you deal with stigmatisation from some community members?

Participant 10: It was difficult at first when I first diagnosed, now that my family cares for me and I am on support group, I deal with some of peoples negative behaviours because I am empowered by knowledge.

Interviewer: What assistance do you get from the community members?

Participant 10: Those who do not have a problem love us and they are supporting us by giving us advises, for instance others would tell you what to use if you are sick.

Interviewer: How do you feel about that?

Participant 10: I feel strong.

Interviewer: What changes do you observe after getting assistance?

Participant 10: I become able to face some difficulties such as, labelling and gossip.

Interviewer: What kinds of activities do you do with community members to curb HIV/AIDS-related stigma?

Participant 10: Nothing more other than HIV/AIDS awareness at times which is conducted by nurses at the clinic.

Interviewer: What changes did you observe after those activities?

Participant 10: I can say that we get more knowledge on how to live healthier and on how to prevent the spread of the virus. Sometimes we get information that we were not aware of.

Interviewer: What would you like the community members do to curb stigmatisation?

Participant 10: Community members can assist us on everything we like giving us support when we are doing HIV/AIDS education as support group.

Interviewer: What do the service providers and community leaders offer to help you?

Participant 10: They motivate us to be strong and to adhere to our medication, sometimes we get food parcels from Social Development and there is nothing else.

Interviewer: How do you identify the strength that is within you to cope with stigmatisation?

Participant 10: Umh [pause], I accepted my HIV/AIDS status that is why I can it is my strength.

Interviewer: Can you give me an example where you used your inner strength?

Participant 10: When I was diagnosed HIV/AIDS positive I was hopeless but I tried to convince myself to become strong because I was thinking about my children.

Interviewer: Do you work in partnership with the service providers and community leaders to curb HIV/AIDS-stigma?

Participants 10: We are working together with them in the sense that we go to them when we do have problems and they try by all means to help us.

Interviewer: What are the benefits of working together?

Participant 10: We get advises on how to stay positive as PLWHA.

Interviewer: What do you recommend for service providers and community leaders in order to boost your self-esteem?

Participant 10: All of them could assist us by encouraging some of community members who are still stigmatising us to stop that. That would hopefully make us feel better and stronger.

Interviewer: How effective would your recommendations be in boosting your self-esteem?

Participant 10: This would be helpful because there would be no one who will stigmatise us again, we will be living our normal lives without being mocked by anyone.

Interviewer: What do you suggest to be done by service providers and community leaders to curb HIV/AIDS-related stigma?

Participant 10: They should assist us in educating community members about HIV/AIDS.

Interviewer: What needs to be introduced to people in the community who have faulty myths about HIV/AIDS?

Participant 10: There is nothing else other than educating them to accept PLWHA because there is nothing different from us and them except our HIV positive status.

Interviewer: How can you introduce such things to them?

Participant 10: By conducting HIV/AIDS education at schools, communities and at churches.

Interviewer: How do the service providers and community leaders empower you to survive stigmatisation in terms of using your inner strengths, identifying resources within your environment and survival skills to live productive lives?

Participant 10: They encourage us to use everything that can make us achieve what we want. For example; the nurses and the social workers tell us to adhere to our treatment and plant vegetables, our ward councillor also refer us to the social workers so that we can get financial help or sponsors.

Transcribed data from the focus group discussion

Interviewer: Can you tell me about yourself.

Focus group: All participants had experience in working with HIV positive patients. Some of them mentioned that they offer counselling, giving them treatment and conduct awareness campaigns on HIV/AIDS education

Interviewer: How do community members view HIV/AIDS?

Focus group: They indicated that people in this community have come to a point where they have accepted HIV/AIDS as a reality. Now they are enlightened. They also indicated that few of them still have stigmatising attitudes. Some of the participants raised the issue of some PLWHA who become ignorant at times. The issue of some professionals who are ill-treating patients was reported.

Here in Dimbaza Township from my experience, I would say 80 per cent of people are informed about HIV/AIDS and respond positively to PLWHA and 20 per cent still need education about HIV/AIDS (Participant No.2)

People do respond positively because we educate them when they are waiting at the foyer waiting for consultation to respect PLWHA and we tell them that even if they are not infected by HIV/AIDS but they are affected (Participant No.8).

Some of PLWHA whom I work with tell me that they are scared of going to the clinic because the nurses tend to breach confidentiality and gossip about them in the community. I normally approach some of the nurses whom I know and talk about these issues. When I approached the sister in charge at the local clinic by the way the patients feel about their treatment she told me that there is a short of staff and those nurses who are on duty get tired because of the large numbers of patients each and every day (Participant No.2).

You know what, when you are in charge at workplace you must know that you are in trouble because some of the people who are HIV positive would be

absent at work maybe for three days, when you try to find out the reason for being absent they would tell you that they are sick so they have to fetch their ARVs. I always tell them that it is not fair because HIV/AIDS is like my high blood pressure or any other illness so there is no need for them not to be at work for several days. (Participant No.3)

People are aware of HIV/AIDS because we educate them about safe preventive measures (Participant No.5).

There are people who are violating the rights of PLWHA and there are some of those who are infected by HIV/AIDS who misuse their rights over other people. (Participant No.2)

Interviewer: How knowledgeable are the community members about the modes of HIV/AIDS transmission, myths surrounding HIV/AIDS, prevention and the rights of PLWHA

Focus group: They reported that the Township of Dimbaza has accepted people living with HIV/AIDS unlike when it emerged where lot of people were scared of speaking out about the disease. They mentioned that PLWHA are now talking about HIV/AIDS to their children. It was illustrated that there are NGOs who educate people about HIV/AIDS in the Township of Dimbaza. Some of them mentioned the issue of traditional myths surrounding HIV/AIDS.

The Township of Dimbaza has accepted people living with HIV/AIDS unlike when it emerged where people were dying and were afraid of talking about the disease. There are NGOs who educate people about HIV/AIDS (Participant No 1.).

There is this tendency from people by the minute a person tests positive she or he thinks that she or he has to perform rituals, you will see that person using traditional medicines and by that time the viral load is going up. (Participant No.2)

There are still people who are practicing rituals and stop taking their medication but we are mobilizing cultural leaders and educate them about these things (Participant No.8).

Interviewer: How do community members treat PLWHA?

Focus group: They revealed that community members are treating PLWHA well and they have come to a point of accepting HIV/AIDS. They no longer ridicule them.

People from this community support PLWHA. At times we use to have commemoration where we light candles and remember all people who passed away because of HIV/AIDS. You will find that PLWHA are losing hope, others cry as the names of those who are remembered are called. With the support of the community you will see that they are strengthened some would smile and lift up the candles. (Participant No.3)

Interviewer: How do you they deal with stigmatisation?

Focus group: They responded saying that there are few people who are stigmatising PLWHA and they are those who lack information about HIV/AIDS. It was stated that education about HIV/AIDS made PLWHA deal with every obstacle coming on their way. One respondent indicated that if someone is ridiculing PLWHA, they report those cases.

Some of people living with HIV/AIDS, especially women, would come to us reporting cases whereby they are insulted by other women who share the same man telling them that they are dying of AIDS and calling them prostitutes (Participant No.3).

Some of people who stop counselling sessions would end up dying because when they need help or become very sick they do not come back to me to seek help instead they would hide themselves until you hear that someone passed away (Participant from No.2).

Interviewer: What assistance do PLWHA get from the community members?

Focus group: They mentioned that there are community members who support PLWHA.

There are members of TAC here in Dimbaza who are conducting awareness campaigns about HIV/AIDS but I can see that lack of funding to conduct activities to curb HIV/AIDS-related stigma makes these activities not to sustain. (Participant No. 2)

Interviewer: How do they feel about the support they receive from community members?

Focus group: They mentioned that PLWHA become very motivated because they do not feel rejected.

Interviewer: What changes do they observe after getting assistance?

Focus group: Respondents reported that some of PLWHA speak openly about HIV/AIDS without fear.

Interviewer: What kinds of activities do PLWHA and community members do to curb HIV/AIDS-related stigma?

Focus group: It was said that there are support groups in the Township of Dimbaza; they usually conduct door to door campaigns educating people about HIV/AIDS. They reported that at some churches they are given a slot those who want to talk about HIV/AIDS. They also raised the issue of scarcity of activities because of lack financial constraints. They said the local municipality is misusing funds which are allocated to help needy people and one of the participant mentioned that they are in a process of still resolving those issues.

We are trying to resolve these issues with the municipality because some of the programmes which were supposed to be delivered to the community are delaying (Participant No.1).

Interviewer: What changes do you observe after those activities and how sustainable are these activities?

Focus Group:: It was indicated that people get information regarding HIV/AIDS which makes them able to accept HIV/AIDS and get inspired. Sustainability seemed to lack as they mentioned that there was no funding.

Interviewer: What assistance do PLWHA and community members get from you to use their capacities and strengths?

Focus group: PLWHA usually come to our offices for assistance, we normally tell them to be strong, to accept themselves and to know that they are loved. We encourage them to hold on doing these campaigns so that community members get educated each and every day.

At times in my organization we organize something like a dinner where we invite the infected people to join us. We usually discuss issues about HIV/AIDS such as marrying with a negative person whilst you are positive, talking about pre-marital issues or how to have a child with a negative person whilst you are positive. We contribute and prepare food for PLWHA and organize transport for those who are staying far. My concern is that at the end of the day you will find that these very same people would say that we are using them to get money from Social Development and that is why we keep on inviting them to our organization. (Participant No.2)

In some households you will find that you are welcomed since people respect you as a role model and from other households it becomes difficult to accept the children's HIV positive status, they sometimes call them "dogs" who were living promiscuous lives. So that is where I keep on reach to those families to change their way of thinking. (Participant No.2)

Interviewer: What is done by PLWHA and community members to curb HIV/AIDS-related stigma?

Focus group: They support each other through educational talks about HIV/AIDS; they also support and empower each other in terms of encouraging others to join the support groups.

Community members do everything to support PLWHA but there are some people who would use HIV/AIDS as an insult when someone fights with a person who is HIV positive. They use this insult to demoralize them but PLWHA do not worry about that because they know that they use HIV/AIDS as a weapon to destroy them (Respondent No.3).

Interviewer: What does the idiom clients' strength means to you?

Focus group: They replied saying that it is the ability of the clients to do things on their own.

Interviewer: How do you identify the clients' strength?

Focus group: They responded saying that they inform them that for the fact that they are able to speak out about HIV/AIDS it is because of the strength they have. They indicated that they make sure that PLWHA use their strengths to overcome stigma.

Whenever PLWHA come to me for help I tell them about how good is to realise that they have the power from within that can make them live stronger (Participant No.4).

Interviewer: Do you work in partnership with PLWHA and community members to curb HIV/AIDS-stigma?

Focus group: They said they all work together so that they can understand what is required to achieve their goals. The benefits of working together were said to be the achievements of their desired goals and it was further mentioned that they get

satisfied because everything is going according to their wishes. They reported that they include them in every decision they make.

We go to the communities and we try by all means to gather different kinds of people, for instance the youth and elderly and also traditional leaders. The reason for doing that is because most of elderly people think that HIV/AIDS affects young people only (Participant No.8 from the focus group).

We are trying our best to attend each patient with support and care but really some of us are losing it because they always complain about the issue of recruiting more staff (Participant No.7)

There are times when I do door to door campaign I find that some parents are supporting their infected children and there are those parents who isolate their children. So I usually visit those families until they accept and support their children (Participant No.2 from the focus group).

Interviewer: What would you recommend to PLWHA in order to boost their self-esteem?

Focus group: Accepting their HIV positive status was recommended by the focus group. They indicated that acceptance would make them to respond positively to HIV/AIDS-related stigma.

Interviewer: What do you suggest to be done to mitigate HIV/AIDS-related stigma?

Focus group: Awareness campaigns were the best suggestion from them to curb HIV/AIDS-related stigma.

Interviewer: How do you go about empowering PLWHA to survive stigmatisation?

Focus group: Education on HIV/AIDS and the use of their strengths was their centre of attention. They reported that they inform them about their considerable power within themselves that can make to live productive lives.

I would say some of PLWHA here in Dimbaza do not want to do things for themselves. They would come and ask for food parcels stating that they are diagnosed HIV positive. These people I am talking about do not show any sickness but they are only diagnosed HIV positive. We are trying to tell them to be self-reliant but still they are keeping on coming asking for food parcels (Participant No.5).

We go to the communities and we try by all means to gather different kinds of people, for instance the youth and elderly and also traditional leaders. The reason for doing that is because most of elderly people think that HIV/AIDS affects young people only (Participant No.8).

You know what when you are working with clients you have to identify their strengths as well as their weaknesses. By doing that you are trying to show them their weaknesses and strengths he or she is holding. After that you have to only capitalize with the strengths that you identified from them so that they can use the strengths to overcome their weaknesses. If I am not able to identify any strength within the client, I make him or her feel stronger by his or her physical appearance (Participant No.2).

APPENDIX E: ETHICAL CLEARANCE FORM



University of Fort Hare
Together in Excellence

ETHICAL CLEARANCE CERTIFICATE

Certificate Reference Number: SUM021SXAB01

Project title: **The effects of stigma on people living with HIV/AIDS in Dimbaza**

Nature of Project: Masters

Principal Researcher: Sindiswa Xabendlini

Supervisor: Mr A Sumbulu

Co-supervisor:

On behalf of the University of Fort Hare's Research Ethics Committee (UREC) I hereby give ethical approval in respect of the undertakings contained in the above-mentioned project and research instrument(s). Should any other instruments be used, these require separate authorization. The Researcher may therefore commence with the research as from the date of this certificate, using the reference number indicated above.

Please note that the UREC must be informed immediately of

- Any material change in the conditions or undertakings mentioned in the document
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research

The Principal Researcher must report to the UREC in the prescribed format, where applicable, annually, and at the end of the project, in respect of ethical compliance.

Special conditions: Research that includes children as per the official regulations of the act must take the following into account:

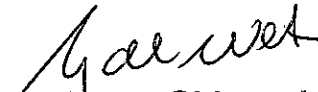
Note: The UREC is aware of the provisions of s71 of the National Health Act 61 of 2003 and that matters pertaining to obtaining the Minister's consent are under discussion and remain unresolved. Nonetheless, as was decided at a meeting between the National Health Research Ethics Committee and stakeholders on 6 June 2013, university ethics committees may continue to grant ethical clearance for research involving children without the Minister's consent, provided that the prescripts of the previous rules have been met. This certificate is granted in terms of this agreement.

The UREC retains the right to

- Withdraw or amend this Ethical Clearance Certificate if
 - Any unethical principal or practices are revealed or suspected
 - Relevant information has been withheld or misrepresented
 - Regulatory changes of whatsoever nature so require
 - The conditions contained in the Certificate have not been adhered to
- Request access to any information or data at any time during the course or after completion of the project.
- In addition to the need to comply with the highest level of ethical conduct principle investigators must report back annually as an evaluation and monitoring mechanism on the progress being made by the research. Such a report must be sent to the Dean of Research's office

The Ethics Committee wished you well in your research.

Yours sincerely


Professor Gideon de Wet
Dean of Research

22 April 2014