

**STIGMATISATION AND DISCRIMINATION OF PEOPLE LIVING WITH HIV
AND AIDS AT ELIM IN VHEMBE DISTRICT: A JUNGIAN
PHENOMENOLOGICAL STUDY**

by

Olivia Kensani Nkuna

DISSERTATION

Submitted in fulfilment of the requirements for the degree of

PhD in Psychology

in the

**Faculty of Humanities
(School of Social Sciences)**

at the

UNIVERSITY OF LIMPOPO

Promoter: Associate Professor Kathryn A Nel

2016

Declaration

I declare that the Doctor of Philosophy in Psychology thesis hereby submitted to the University of Limpopo, for degree PhD in Psychology has not previously been submitted by me for a degree at this or any other university; that it is my work in design and in execution, and that all material contained herein has been duly acknowledged.

NKuna,O.K. (Mrs)

Date

08.09.2016

Acknowledgments

I would like to thank my promoter Professor Kathryn Nel. I would like to thank my friends and family for their love, devotion and unwavering support. My religion is important to me and I would like to acknowledge it as a source of inspiration. Importantly, I would like to thank the participants for sharing their narratives with me.

Abstract

Exploring the lived experiences of People Living with HIV/AIDS in relation to stigma and discrimination was the purpose of this qualitative research underpinned by Jungian Phenomenology. The study was qualitative in nature with a non-probability sample of fifteen participants aged from twenty tree to sixty four years. The setting was a rural and the research took place at a designated HIV/AIDS clinic in Limpopo. Semi-structured interviews, in the vernacular, were constructed so that the in-depth, lived experience of the participants relating to stigmatisation and discrimination could be ascertained. The participants' responses were organised through the application of the Jungian metaphors and presented as themes which were presented in English. The archetypes of the Self, Shadow and Persona were highlighted as dominant metaphors with the Animus playing an important. These were followed by archetypes which represented more marginal roles in the participants' personality development namely, the Anima, Hero, Caregiver, Innocent and Orphan. Everyone has the desire to develop a well-rounded socially acceptable and fulfilling personality, whose development process is accompanied by the generation and maturation of various archetypal traits. Once this is achieved, the process of personal individuation is completed and an individual is able to experience their true Self and live a fulfilling and authentic (honest) life. HIV infection and HIV related stigma generate archetypal traits which tend to impede the personality development of individuals. As a result they were not able to merge their personality development into an integrated unit and emerge as spiritual and deep-thinking beings.

TABLE OF CONTENTS

Declaration	i
Acknowledgement	ii
Abstract	iii
Table of contents	iv
List of tables	ix
List of abbreviations and acronyms	x

Chapter 1: Introduction to the study

1.1	Introduction	1
1.2	Background to the study	2
1.3	Research problem	3
1.4	Aim of the study	5
1.5	Study objectives	6
1.6	Significance of the study	6
1.7	Summary	6

Chapter 2: Literature Review

2.1	Introduction	7
2.2	Global research on HIV/AIDS stigmatisation and discrimination	7
2.3	Causes of stigmatisation	9
2.4	Effects of stigmatisation	12
2.5	Traditional African culture and HIV/AIDS in South Africa	15
2.6	Contending with discrimination and stigmatisation	17
2.7	The role of the media in the HIV/AIDS pandemic in South Africa	19

2.8	Stigmatisation of PLWHA in South Africa	22
2.9	Preventing the stigmatisation of PLWHA	25
2.10	Coping mechanisms of PLWHA	29
2.11	HIV/AIDS stigma prevention internationally	31
2.12	HIV/AIDS stigma prevention in South Africa	32
2.13	Cultural perception of HIV/AIDS stigma	33
2.14	Social aspects of HIV/AIDS stigma	35
	2.14.1 Orphans and child-headed households	35
	2.14.2 Psychosocial community needs in South Africa	37
2.15	Religion and HIV/AIDS	39
2.16	Stories of lived experience of PLWHA	42
2.17	Summary	44

Chapter 3: Theoretical framework for the study

3.1	Introduction	45
3.2	Definition of key terms	45
	3.2.1 Stigmatisation	45
	3.2.2 Discrimination	45
	3.2.3 People Living with HIV/AIDS (PLWHA)	46
	3.2.4 HIV/AIDS	46
3.3	The phenomenological approach	46
3.4	Jungian phenomenological theory	50
	3.4.1 Description	50
	3.4.2 Phenomenological reduction	51
	3.4.3 The search for essences	52
	3.4.4 Intentionality	52
3.5	Summary	53

Chapter 4: Research Methodology

4.1	Introduction	54
4.2	Research design	54
	4.2.1 Research Approach	54

4.3	Area of the study	54
4.4	Population	54
4.4.1	Sampling method	55
	4.4.1.1 Inclusion criteria	55
	4.4.1.2 Exclusion criteria	55
4.5	Research Instrument	56
	4.5.1 Entry Negotiation	56
	4.5.2 Pre-testing	56
4.6	Data collection	57
4.7	Trustworthiness of study (Quality criteria)	58
4.8	Data analysis	59
	4.8.1 The Self	59
	4.8.2 The Shadow	60
	4.8.3 The Anima	60
	4.8.4 The Animus	61
	4.8.5 The Persona	61
	4.8.6 Other archetypes	61
	4.8.6.1 The innocent	61
	4.8.6.2 The orphan	62
	4.8.6.3 The hero	62
	4.8.6.4 The caregiver	62
	4.8.7 The formulated statements	62
	4.8.8 Participants' responses	62
4.9	Study research questions	63
4.10	Bias in the study	63
4.11	Ethical consideration	63
	4.11.1 Informed consent	64
	4.11.2 Participants' withdrawal rights	64
	4.11.3 Confidentiality and anonymity	63
4.12	Summary	65

Chapter 5: Presentation of results and analysis

5.1	Introduction	66
-----	--------------	----

5.2	Demographic information of participants	66
5.3	Experiences, presented as themes, of participants' understanding of discrimination and stigmatisation underpinned by Jungian Phenomenology	70
5.3.1	Theme 1: Identity	70
5.3.1.1	Summary of theme 1: Identity	82
5.3.2	Theme 2: Feelings before Voluntary Counselling and Testing (VCT)	82
5.3.2.1	Summary of theme 2: Feelings before Voluntary Counselling and Testing	91
5.3.3	Theme 3: Feelings after testing HIV positive	92
5.3.3.1	Summary of theme 3: Feelings after testing HIV positive	96
5.3.4	Theme 4: Fear related to HIV infection	96
5.3.4.1	Summary of theme 4: Fear related to HIV infection	101
5.3.5	Theme 5: Perspectives of death	101
5.3.5.1	Summary of theme 5: Perspectives of death	104
5.3.6	Theme 6: Anxiety related to being HIV positive	105
5.3.6.1	Summary of theme 6: Anxiety related to being HIV positive	109
5.3.7	Theme 7: Stigmatisation	110
5.3.7.1.1	Sub-theme 7.1: Discrimination as experienced by Participant	118
5.3.7.1.2	Sub-theme 7.2: Deliberate bullying associated with Stigmatisation	122
5.3.7.1	Summary of theme 7: Stigmatisation; Sub-theme: 7.1: Discrimination as experienced by participants and Sub-theme 7.2: Deliberate bullying associated with Stigmatisation	124
5.4	Tabular summary of themes and sub-themes emerging from participants' responses	125
5.5	Participants' suggestion about reduction of HIV/AIDS stigmatisation	125
5.6	Participants' conscious coping strategies pertaining to external HIV/AIDS Stigmatisation	126
5.7	Summary	128

Chapter 6: Research conclusions and research limitations, strengths and recommendations

6.1	Introduction	129
6.2	Study conclusions	129
6.2.1	What individual effects do PLWHA experience because of stigmatisation and discrimination?	129
6.2.2	What effect does HIV/AIDS stigma and discrimination have on PLWHA in their socio-cultural context?	129
6.2.3	What kind of stigmatisation and discrimination do PLWHA experience?	130
6.2.4	Overall study conclusions	131
6.3	Research strengths	131
6.4	Research limitations	132
6.5	Research recommendations	132
	References	133
	Appendices	
	Appendix 1: Semi-structured interview guide	145
	Appendix 2: Letter to the Department of Health	150
	Appendix 3: Letter to the CEO of Elim Hospital	151
	Appendix 4: TREC ethics forms	152

List of Tables

Table 1: Key demographics of participants	69
Table 2: Summary of emerging themes	125
Table 3: Participants' suggestions about reduction of HIV/AIDS stigmatisation	126
Table 4: Participants' conscious coping strategies pertaining to external HIV/AIDS stigmatisation	127

List of abbreviations and acronyms

AIDS – Acquired Immune Deficiency Syndrome

ART – Ante-retroviral Therapy

AVERT – Averting HIV and AIDS

DosD – Department of Social Development

HST – Health Systems Trust

HIV - The Human Immune Virus

HRSA – Health Resources and Services Administration

HTLV111 – Human T-Cell Lymphotropic Virus

IPPF – International Planned Parenthood Federation

LGBTI – Lesbian, Gay, Bi-sexual, Trans-sexual and Intersex

LAV - Lymphadenopathy associated virus

NGO – Non-Governmental Organisation

PLC – People Living Close [to them]

PLWHA – People Living With HIV/AIDS

PMT – Protection Motivation Theory

SAMRC – South African Medical Research Council

SANAC – South African National Aids Council

STI – Sexually Transmitted Infection

SaDoH – South African Department of Health

TAC – Treatment Action Campaign

UN – United Nations

UNAIDS – United Nations Aids Programme

VCT – Voluntary Counselling and Testing

WHO – World Health Organisation

CHAPTER 1: INTRODUCTION

1.1 Introduction

The Human Immune Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) has become one of the most feared pandemics of the 21st century, with an estimated sixty million people having been infected with the virus (World Health Organisation [WHO], 2012). Acquired Immune Deficiency Syndrome (AIDS) was first identified in 1981, when clusters of gay men in Los Angeles and New York were diagnosed with Kaposi's sarcoma and pneumocystis carinni pneumonia (Partington-Nel, 2003). At first, on the African continent, sporadic cases occurred which were predominantly heterosexual thus they were not associated with the outbreak of the illness amongst gay men in North America. The illnesses were given different names like *slim* disease in Ghana, Africa (WHO, 2012). It was later established that a sexually transmitted infectious agent was causing the disease. According to Barolsky (2009) in May 1983, this new virus believed to be the causative agent of AIDS was isolated at the Pasteur Institute in France. The disease was initially called lymphadenopathy associated virus (LAV). Barlosky (2009) reported that the National Cancer Institute (2009) also isolated a similar virus and called it human T-cell lymphotropic virus (HTLV111). Both names were dropped in 1986 and Human Immuno-deficiency Virus (HIV) was adopted and the illnesses that stemmed from it were named Acquired Immune Deficiency Syndrome (AIDS).

There are around forty million people worldwide living with the human immune-deficiency virus (HIV), of these; eighteen million are women and just over two million children (United Nations Aids Programme [UNAIDS], 2012). Almost twelve percent (4.9 million) of those infected become newly infected yearly (UNAIDS, 2014). The global pandemic has shown itself capable of triggering responses of compassion, solidarity and support, bringing out the best in people, their families and communities. However, the disease is also associated with stigma, repression and discrimination, since individuals infected and affected by HIV/AIDS are often rejected by their families, their loved ones and their communities. This rejection holds true in both rich and poor societies in South Africa and the rest of the world. The pandemic is ranked as the third leading cause of death in the South Africa (Statistics South Africa, 2012).

It is postulated that HIV/AIDS is as much about social phenomena as it is about biological and medical concerns. A key supposition in phenomenology is that people seek to create meaning of their life world and social environment by the use of narratives that use common symbols or archetypes (Bray, 2012; Harambalous, Holborn & Heald, 2006). Symbols in Jungian

phenomenology are common to all peoples and can be used in the in-depth interpretation and understanding of the experiences and feelings of people living with HIV/AIDS (PLWHA). As programmes and interventions for HIV/AIDS are usually designed on the basis of large scale surveys they may not always be appropriate, particularly in African social contexts (Nyblade, 2016; Nqojane, 2009; Weston, 2006).

1.2 Background to the study

The first priority in mitigating the effects of HIV/AIDS is to enable the person living with the illness to stay healthy through interventions such as antiretroviral therapy, nutritional assistance and treatment for opportunistic infections. Comprehensive programmes involving the community and family members together with appropriate legislation, which provides protection against all forms of discrimination, as well as psychosocial and financial support are likely to provide the best results in alleviating the impact of the pandemic on individuals and communities (Nqojane, 2009; Nyblade, 2016; UNAIDS, 2013).

The stigmatisation of HIV/AIDS was highlighted in 2008 when it was described by the then United Nations Secretary-General Ban Ki-Moon as, “the chief reason why the AIDS epidemic continues to devastate societies around the world” (UNAIDS, 2013, p.3). A major concern, more than three decades into the pandemic, from both public health and human rights perspectives is that stigmatisation has negative effects across the treatment continuum. Stigmatisation means that individuals are less likely to access testing and counselling services which, in turn, suggest that there is probably more mother-to-child transmission than there should be. According to Winskell, Hill and Obyerodhyambo (2011), this scenario aggravates the psychosocial effects of HIV/AIDS infection. This again adds to the psychological burden of PLWHA.

Stigma and discrimination can arise from community-level responses to HIV/AIDS (AVERT, 2015). The harassment of individuals who are perceived as being HIV infected, or belonging to a particular group for instance, homosexuals or prostitutes, has been widely reported (Nqojane, 2009). According to the author these groups are wrongly thought, in African society, to be the main source of the infection. Stigmatisation and discrimination are often motivated by the need to blame and punish, and in extreme circumstances, can extend to acts of violence and murder. Further, HIV/AIDS related murders have been reported in countries as diverse as Brazil, Colombia, Ethiopia, India, South Africa and Thailand. It is reported that PLWHA in the United States of America (USA) have been the targets of stigma since the first cases were diagnosed in the nineteen eighties (Health Resources and Services Administration [HRSA], 2012). Since then, discrimination

in the workplace and social settings has created problematic circumstances PLWHA in the USA. Research by Kalichman and Simbayi (2006) on aids related stigma in South Africa, found that more than one in five respondents reported that they would not trust people who are HIV positive to look after their children. Generally, participants in the survey felt that people who were HIV positive could not be trusted in any sphere of life. These findings suggest that HIV/AIDS stigmatising beliefs are widely held in South Africa and pose a substantial barrier to HIV prevention efforts. In South Africa studies throughout the pandemic indicate that stigmatisation and discrimination occur, but most do not document the in-depth lived experience of the individual who is stigmatised (Maponyane, 2012; Mogotsi, 2009; Weston, 2006).

The South African National AIDS Council (SANAC, 2015) in research relating to challenges associated with HIV/AIDS indicated the stigma index for South Africa. The survey found that although HIV related stigma and discrimination was still prevalent, it was lower than previously estimated and lower than in most countries. The study further observed that stigma and discrimination to the pandemic are driven by the instinctive reaction people have when they face death. It was suggested that when individuals confront a person infected or dying from any disease their initial reaction conjures up their worst fears and prejudices. It was concluded that the HIV/AIDS and tuberculosis (TB) related stigma is a multifaceted problem in South Africa and that one in three PLWHA experienced some form of discrimination or stigma in their encounters with family members, peers, neighbours and community members generally.

Haughey et al. (2012) report that nearly fifty percent of people infected with HIV will eventually develop some form of brain damage that, although mild, can affect the ability to drive, work, or participate in many day-to-day activities. It has long been assumed that the disease was causing the damage, but according to the author, Johns Hopkins medical school researchers report that the drug efavirenz may play a key role in causing neurological impairment. People infected with HIV may take a cocktail of psychopharmacological drugs that suppress the virus and these drugs are taken during the individual's lifespan. The author reports that this can cause psycho-social and possible neurological problems for PLWHA. This information has been reported in the media and has caused some PLWHA not to adhere to medication schedules.

1.3 Research problem

According to Herek (2007), HIV/AIDS stigma is expressed around the world in a variety of ways including ostracism, discrimination, rejection, violence against, and avoidance of PLWHA. It can also lead to compulsory HIV testing without prior consent or protection of confidentiality. Whatever

its form, HIV/AIDS stigma inflicts suffering on people and interferes with attempts to fight the pandemic. AVERT (2015) reports that it is important to understand the context in which stigmatisation occurs, and how the experience of stigma and the individual's ability to cope with the stigma as determined by the social, historical and economic context of a region. It was noted that being poor, young and female increases an individual's vulnerability to stigmatisation, particularly if the individual has full blown AIDS. It is further postulated that HIV/AIDS related stigma and discrimination refers to prejudice, negative attitudes and abuse directed at PLWHA. In over thirty percent of countries available data indicates that over fifty percent of men and women report having discriminatory attitudes towards people living with HIV/AIDS. The consequences of stigma and discrimination are noted as wide-ranging for instance, the experience of verbal and physical abuse and isolation from family and community. It is further reported that one in every eight people living with HIV/AIDS does not attend clinics because of fear of stigma and discrimination.

The majority of the research on HIV/AIDS stigmatisation has focused on various factors such as the frequency and nature of stigmatisation and Knowledge, Attitude, Perception and Belief (KAPB) studies for instance, (Maponyane, 2012; Nqojane, 2009; Partington-Nel, 2003). Sources of stigma according to the South African Medical Research Council (SAMRC, 2013) include fear of illness, fear of contagion and fear of death. Fear of illness and fear of contagion are a common reaction amongst health workers, co-workers and care givers, as well as the general population. Stigmatisation of PLWHA is one means of coping with the fear that contact with a member of an affected individual will result in contracting the disease. This leads to PLWHA being discriminated against in all social settings.

Katz et al. (2013) concluded from their qualitative research on the impact of HIV related stigma on treatment adherence, that stigma and discrimination compromised the participants' ability to successfully adhere to ante-retroviral treatment (ART). Further, they observed that interventions to reduce stigma should target multiple levels of influence (intrapersonal, interpersonal and structural) in order to have maximum effectiveness on improving ART adherence. They noted that research should provide a window into the intra- and interpersonal dynamics that need to be appreciated in order to shape programmes that facilitate adherence in improving the lives of PLWHA.

In another qualitative study Flowers, Davis, Larkin, Church and Marriott (2011) concluded that in Scotland, where HIV/AIDS prevalence is low and where no accessible HIV positive sub-culture exists, there is on-going psychological distress amongst gay men testing HIV positive. They determined that the HIV/AIDS related policies in the country did not address the psychological and

psychosocial needs of PLWHA. It was recommended that interventions were needed to reduce the psychosocial and cognitive trauma associated with an HIV positive diagnosis. This research highlighted the psychosocial and intrapersonal costs associated with an HIV/AIDS diagnosis.

Subramoney (2015), in a phenomenological study on the lived experience of Indian women with HIV/AIDS in South Africa, observed that this type of qualitative research is very limited. It was suggested that further phenomenological investigations are needed in the country using participants from different economic backgrounds, cultures and at different geographical locations. Furthermore, they concluded that future research on the lived experiences of South African women with HIV, regardless of race or location was essential both from a phenomenological knowledge perspective and a therapeutic one, in the discovery of new in-depth information related to PLWHA. This is supported by McQuillen (2014) who carried out a phenomenological study of the experience of ageing for PLWHA. This population of long term survivors, and those diagnosed later in life, is predicted to increase. Scholarly literature suggests that knowledge of the lived experiences of this population is lacking and that programmes and policies do not meet the needs of this group. The author concluded that continued research, using a phenomenological framework, is needed.

As the phenomenon under scrutiny is flexible and challenging in nature (stigmatisation and discrimination) and continuously shapes the lived reality of individuals, the research process has to be flexible and iterative. The researcher, in the present research, decided on a qualitative approach using Jungian phenomenology as both a framework and a system for analysis, rather than a quantitative approach which would have given a broader rather than an in-depth description of the phenomena under investigation. In this study it was deemed critical that the methodology adopted was able to fulfil the requirements of the research. No Jungian Phenomenological research with participants who were living with HIV/AIDS could be found when the study was designed. The study thus used a qualitative approach, underpinned by Jungian Phenomenology, as it provided a set of resources and criteria that shaped the investigation's design and interpretation (Chisaka, 2006). This identified gap in the literature, as identified in the previous paragraphs, suggested that the approach to the topic which gives a detailed description of occurrences, events, experiences and an in-depth understanding of individual meanings would be appropriate.

1.4 Aim of the study

The aim of the study was to describe the effects of HIV/AIDS stigma and discrimination on the individual within his or her socio-cultural community context using a Jungian Phenomenological explication.

1.5 Study objectives

The study objectives are:

- to determine the effects of HIV/AIDS related stigma and discrimination on PLWHA;
- to investigate the in-depth, individual meanings attributed to stigma and discrimination of PLWHA;
- to determine the in-depth perceptions of PLWHA in terms of how they understand stigma reduction and coping within their socio-cultural environment..

1.6 Significance of the study

HIV/AIDS affects many people in South Africa therefore effective management of the pandemic is critical to reduce its impact. On-going HIV/AIDS stigmatisation and discrimination presents serious challenges to interventions aimed at managing the pandemic. A number of studies (AVERT, 2016; Florom-Smith & De Santis, 2012; Karamouzian, Akbari, Haghdoost, Setayesh & Zolala, 2015; Schatz, Madhavan & Williams, 2011) have provided evidence that stigma is associated with socio-economic contexts and poverty. It is posited that this has caused an escalation in the incidence and prevalence of the pandemic (UNAIDS, 2013). The in-depth experience of PLWHA, relating to discrimination and stigmatisation, provided by a phenomenological explication, helps in exposing some of the hidden characteristics of stigmatisation and discrimination. The research also explored the conscious coping mechanisms of participants and their understanding of how stigma reduction could best be achieved. The study is distinctive, in that it strives to understand HIV/AIDS related stigma from the perspective of an individual in a rural setting within a Jungian Phenomenological framework which provided a unique, in-depth understanding of the individual's understanding and awareness of their circumstances.

1.7 Summary

This chapter introduced the topic and presented the research problem, background, aims, and objectives and noted the significance of the study. The following chapter gives an overview of relevant literature related to the study topic.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

An overview of the literature related to HIV/AIDS is presented in this chapter. It covers various aspects of HIV/AIDS discrimination and stigmatisation. The review covers older and contemporary literature. There is also some overlap in the reported findings which are presented to show the similarity of research results (in different international and South African studies) in terms of HIV/AIDS related stigma and discrimination.

2.2 Global research on HIV/AIDS, stigmatisation and discrimination

Nachege et al. (2012) observed that little is known about the perspectives of PLWHA on perceived HIV/AIDS related stigma and its consequences. In a global survey in 2015 of HIV/AIDS infected adults, thirty seven percent of the respondents reported loneliness as a result of their status. Depression was reported by twenty seven percent while ninety six percent reported disclosing their HIV/AIDS status to at least one person. Seventeen percent of the respondents, who reported being in a long-term sexual relationship, had not disclosed their status to their partners. It was concluded that more than forty years into the HIV pandemic, perceived HIV stigma, isolation and discrimination persist and are associated with loneliness and depression amongst PLWHA.

An early study by Herek, Capitani and Wideman (2002) reported that the prevalence and magnitude of stigma amongst adults is significantly greater than those found in national surveys related to other chronic illnesses in the USA. Most adults (over ninety percent) in the survey expressed some degree of negative behavioural intentions or stigmatising attitudes towards PLWHA. Furthermore, twenty nine percent of the adult sample expressed moderate to high levels of discriminatory attitudes to HIV/AIDS infected individuals. This concurs with findings, in the same era, that ninety seven percent of young adults participating in a survey in Cape Town, South Africa expressed some degree of discrimination and stigma and forty six percent expressed moderate to high levels of stigma (Maugham-Brown, 2004). It was also found that the prevalence and magnitude of stigma varied according to which dimensions of stigma were being measured. Symbolic and instrumental stigma was expressed more often, and to a greater degree, than negative behavioural intentions towards PLWHA. The aforementioned studies are supported by a recent study by Stangl, Lloyd, Brady, Holland and Baral (2013) which indicated that HIV related stigma and discrimination continues to impede efforts to prevent new infections and engage people in HIV/AIDS treatment and intervention programmes. In many emerging countries HIV/AIDS stigma is still high (+70%). This is problematic as the identification of effective interventions to reduce stigma and

discrimination that could be integrated into national responses is crucial to the success of the global HIV/AIDS response. Their study revealed that although there was some progress in the stigma-reduction field, critical challenges and gaps remain which impedes the identification of effective stigma-reduction strategies in historically disadvantaged countries. It was suggested that the development, validation, and consistent use of globally relevant scales (for developed and developing countries) of stigma and discrimination are a critical step in advancing the field of research in this area.

Yuh, Ellwanger, Potts and Senyonga (2014) indicated that by the end of 2011 Africa had over twenty three million HIV infected people and over seventy percent of the new HIV/AIDS infections globally. It was noted that the mainly sexual transmission of HIV, in the African context, is associated with stigma especially amongst women. This stigma includes negative behaviours such as denial, secrecy, fear and self-blame related to the disease. The stigma is associated with sexual promiscuity, hinders disclosure of sero-status and affects individuals seeking treatment. Though there is an acknowledgement of the negative effects of HIV/AIDS stigma it was noted that there was relatively little research on the topic in the African context. According to the United Nations Aids programme (UNAIDS, 2013), prevention of new HIV/AIDS infections requires acknowledgement of the fact that stigma and discrimination is attached to disclosure of HIV positive status yet sero-positive people still engage in risky sexual behaviours. It was posited that there is a need to design strategies to counteract the negative effects associated to HIV/AIDS stigma and discrimination at all levels.

South Africa is recorded as having the largest number of PLWHA in the world with nearly six million persons infected with the retrovirus (UNAIDS, 2014; World Health Organisation [WHO], 2014). The estimate was derived from ante-natal data which the South African Department of Health (SADoH) collects annually through sentinel sites located in each of the nine provinces (SADoH, 2012). In this regard the stigmatisation of HIV/AIDS is problematic.

Mall, Middelkoop, Mark, Wood and Beker (2013) conducted a study on changing patterns in HIV/AIDS stigma and use of Voluntary Counselling and Testing (VCT) service in South Africa. The study indicated that overall basic knowledge of HIV/AIDS increased from 2004 to 2008 and stigmatisation towards HIV positive individuals decreased over the same period. Increasing knowledge scores were significantly associated with a lower stigma score while decreasing stigma scores were associated with knowing someone who was HIV infected, or who had died from HIV/AIDS. The proportion of participants who had undergone HIV testing increased from 2004 to

2008 (forty to seventy percent respectively) and, in particular, VCT increased from twenty six to forty three percent. A reduction in levels of HIV/AIDS associated stigma was noted in a community with a high HIV prevalence, as was an increase in reported VCT. It was concluded that these findings may be the result of the various interventions such as governmental and other programmes.

2.3 Causes of stigmatisation

Link and Phelan (2006) posited that stigma involves the social expression of negative attitudes and beliefs that contribute to processes of rejection, isolation, marginalisation and harm to others. It is largely related to judgmental notions about others, whilst discrimination involves some form of direct enactment which may be verbal or physical that is likely to hurt and/or be harmful to the individual to whom it is addressed (Herek et al., 2002; Maponyane, 2012; Parker & Birdsall, 2008). Stigma is a process that occurs at an individual level, but it is also influenced by social processes related to assumptions, stereotypes, generalisations and labelling people as falling into a particular category on the basis of an association. It is part of an identity that has to do with prejudice, the setting apart of individuals and or groups through attachments of negative perceptions and values (Gaynair, 2013; Herek et al., 2002; Parker & Birdsall, 2008).

According to Avert (2016), stigma is defined as a shame or disgrace attached to something regarded as socially unacceptable. People who are stigmatised are marked as being different and are blamed for that difference. In this regard stigma is often attached to things people are afraid of. Stigmatisation leads to people not being treated with dignity and respect. In this study HIV/AIDS stigma is attached to people who are perceived as being infected with HIV/AIDS. It must be noted that stigmatisation stigma enhances fear, prejudice and is a key factor in discriminatory and negative attitudes towards those who are perceived as HIV infected. It can result in insults, rejection, being gossiped about and excluded from all social activities.

Furthermore, stigmatisation can be defined as the act of branding and condemning those who are HIV positive. It is characterised by discreditable and humiliating behaviours to those who are perceived to be HIV positive or have full-blown AIDS. Fear and stigmatisation in the context of the HIV/AIDS pandemic is widespread amongst people in Africa and South Africa (AVERT, 2016).

Stigmatisation arises due to lack of awareness and knowledge about HIV/AIDS, fear of acquiring HIV through everyday contact with infected people and linking people infected with HIV with behaviour that is considered improper and immoral (UNAIDS, 2013). According to Turan and Nyblade (2013), self-stigmatisation indicates that PLWHA are worried about being condemned to illness and death. It is believed that this type of negative thinking shortens their lives as it becomes a self-fulfilling prophecy. Some PLWHA contemplate suicide, thinking that it is better to be dead

than alive and to continue being stigmatised. It is noted that PLWHA often have depression which is a direct result of the social isolation caused by stigmatisation. Swartz (2007) defined an idea about the disease as a lived experience of suffering. He postulated that it is not enough to understand the physical disease of an individual person and that it is equally important to understand the individual's experience of the illness. He further proposed that an individual's experience of illness determines how the individual behaves, the intervention he or she seeks and his or her reaction to the intervention.

AVERT (2016) in an investigation about why there is stigma related to HIV/AIDS, reports that fear is the main cause. They reported that after many decades the fear surrounding the HIV epidemic still persists. This fear is related to the fact that HIV/AIDS was (and is) still perceived as a death sentence and associated with sexual risk-taking behaviours. As HIV/AIDS is transmitted through sex, which is a taboo subject in many traditional cultures, infection was seen as the personal irresponsibility or moral fault (such as infidelity) of PLWHA, thus deserving of punishment. This type of belief system causes much unnecessary judgment and suffering for PLWHA on the African continent which has a traditional, patriarchal culture.

Turan et al. (2011) conducted a large cross-sectional study, with a sample size of over a thousand women, attending antenatal clinics in Kenya. Associations of stigma measures with HIV testing refusal were examined using multivariate logistic regression. Rates of anticipated HIV/AIDS stigma were high, thirty two percent anticipated a break-up of their relationships and forty five percent anticipated losing friends. The study demonstrated quantitatively that anticipation of HIV/AIDS stigma is likely to be a barrier to the acceptance of HIV testing by pregnant women. It also highlighted the need for the development of interventions that address pregnant women's fears of HIV/AIDS stigma and violence from male partners.

Gaynair (2013) reports that challenges related to stigma and discrimination occur when individuals devalue an individual or group of people because they are associated with a certain disease, behaviour or practice. Those who stigmatise PLWHA falsely believe that the virus is highly contagious and that they can be easily infected. When that happens there is a snowball effect and individual's opinions influence other community members, who start to view HIV/AIDS positive women and men as a threat. As a result PLWHA become isolated within their homes, in public and/or in their workplaces. Those who experience this type of discrimination are further stigmatised by the assumptions that community members hold about their moral integrity. Essentially, the individuals who stigmatise PLWHA believe that it is the individuals own fault they are HIV positive as it was their own risky sexual behaviour that exposed them to infection. This is supported by

information on the AVERT (2015) website which listed six factors that are responsible for fear which creates the majority of HIV related stigmas and discrimination. It was noted that the majority of people perceive HIV/AIDS as a life-threatening condition associated with certain death. It was also associated with behaviours that many people disapprove of namely homosexuality, sex work and infidelity, even though the main mode of transmission on the African continent is heterosexual.

It must be noted that in Africa there has been a rise in accusations of witchcraft with the onset of the HIV/AIDS pandemic. This has been observed in many rural areas where traditional cultures exist for instance, in rural Zambia and South Africa (Colson, 2006; International Planned Parenthood Federation [IPPF], 2014). Fundamentally, stigma begins and ends with individuals. A combination of ignorance, prejudice and fear create fertile ground for the continued spread of HIV discrimination. Openness, acceptance and accessible sexual and reproductive health information and HIV services are key to the reduction of stigma worldwide (IPPF, 2014).

Early research by Boehene (2007) postulated that HIV/AIDS has four characteristics that account for it being highly stigmatised. First, it is a disease that is perceived as the bearer's responsibility because the primary mode of transmission of the infection is behaviour that is considered voluntary and avoidable (that is, unprotected sexual intercourse). Secondly, it is perceived as fatal. Thirdly, it is noted that conditions that are contagious, and have to do with sexual transmission, always have greater stigma attached to them. Lastly, it was noted that conditions that are apparent to others, such as an individual in the advanced stages of AIDS, are more stigmatised.

Research by Bharat, Aggleton and Tyrer (2008) in the same era suggested that three different types of HIV/AIDS related stigma can be identified. 1) Self-stigma which is internal stigma that is manifested in self-blame and self-deprecation. Individuals feel they are responsible for becoming infected and even killing their spouses, children or partners. Sometimes they indicate to counsellors that they want to die; 2) Perceived stigma. This is manifested in the fear that PLWHA have about being stigmatised when they have to disclose their status. This is noted as fear of rejection by a spouse, family or friends or the fear of being labelled a failure, a disappointment or a burden. Individuals also fear losing their self-worth and thus their self-identity. 3) Enacted stigma or external stigma. This is the actual experience of discrimination. It is when people actually discriminate against those that they think, or know to be HIV positive. They gossip, call them names, reject them, isolate them, chase them away and/or restrict their participation in day-to-day activities such as school, work and other social activities.

Additionally, Visser, Makin, Vandormael, Sikkema and Forsyth (2009) proposed that sources of stigma include fear of illness, fear of contagion, and fear of death. Fear of illness and fear of contagion is a common reaction amongst health workers, co-workers, and caregivers, as well as the general population. Stigma is one means of coping with the fear that contact with a member of an affected group (for example, by not sharing utensils with PLWHA) which they think will result in contracting the disease. HIV/AIDS stigma is often layered on top of many other stigmas associated with groups such as homosexuals and commercial sex workers and behaviours such as drug abuse (by sharing needles). These behaviours are perceived as controllable and are therefore assigned more blame, receive less sympathy, but instead, more anger thus PLWHA are less likely to receive assistance.

More recently a study by Florom-Smith et al. (2012) proposed that HIV/AIDS related stigma can be experienced by individuals externally and internally or may be experienced externally or internally separately. Participants responded to felt stigma by choosing to either not disclose their HIV positive status or to devise systemic methods for disclosure (when, how, and whom to disclose to). Participants reported being rejected and blamed for their positive status and felt shame, loneliness and anger in response to discrimination and stigmatisation from others. In this study medical doctors also revealed to researchers that they feared HIV infection from patients. For instance, one medical doctor revealed that a colleague who performed a hip replacement on a PLWHA sustained a needle prick. He received treatment and did not become HIV positive. However, it was further reported that the doctor who received the needle prick revealed this to his patient who then felt as if he had to apologise for the incident. This indicates that medical doctors may also show discrimination to PLWHA.

2.4 Effects of stigmatisation

Dosier (2010) indicates that disease stigma is a very common phenomenon with a diversity of causes and effects. The impacts of stigmatisation on PLWHA can be understood from individual, social and healthcare perspectives. From an individual perspective, people may be discouraged from taking HIV tests, sharing results and complying with treatment because of fear of discrimination, rejection and violence even when they are aware of the advantages of early detection. Their sense of shame about the condition impacts on their ability to take preventive actions. Furthermore, HIV related stigma hurts people directly because they lose community support due to their real or supposed HIV infection. Individuals may be isolated within their family, hidden away from visitors or made to eat alone. These repercussions can be noted as acts of insensitivity but are directly related to stigmatisation and discrimination of PLWHA (Haughey et al., 2012).

Cultural identity defines forms of social interactions that allow people to understand health behaviour within different historical and political spaces and times (Airhihenbuwa, 2007). According to UNAIDS (2014), there is extensive evidence that PLWHA, who are women, or non-heterosexual men, are more likely to be badly treated than children and heterosexual men. Evidence from around the world indicates that attacks on men who are assumed to be gay have increased, and that sex workers (often blamed for HIV transmission) have been singled out for abuse. In some countries it has been reported that HIV/AIDS related murders have increased, mostly in developing countries. The social exclusion of PLWHA begins in the family and extends into the community. The effect of stigma is mediated by gender and it is experienced more by women than men. This is rooted in current social constructions of sexuality and sexual relations which accept male promiscuity and blame women for the spread of HIV. Therefore, HIV infection not only means that a woman has to face living with, and managing a chronic health condition, it also means that they are likely face social stigma that may fundamentally change the way they perceive themselves (Lliamputtong, 2013). This is supported by AVERT (2015) who report that HIV related stigma and discrimination exists worldwide, although it can manifest differently across countries, communities, religions and individuals. However, countries with traditional, patriarchal norms are more likely to have a higher incidence of stigmatisation and discrimination.

Weston (2006) suggests that in health care settings, the most extreme forms of stigmatisation are towards people who are thought to be infected with HIV/AIDS. Treatment of these individuals includes denial of drugs and treatment, being left in the corridor, being dealt with last, being labelled or called names and being subjected to degrading and inhumane treatment. It is also reported that in some hospitals, patients who do not have HIV infection put a physical distance between themselves and individuals they think are infected with HIV/AIDS. In health care settings, people who do not have HIV/AIDS are observed as not shaking hands, not sitting next to, not sharing food and drinking utensils with individuals they think have HIV/AIDS. This signals rejection as a form of stigmatisation. In schools, HIV/AIDS stigma manifests itself in the form of rejection, gossip and taunting. Scholars taunt other scholars whose parents (they think) died as a result of HIV/AIDS related diseases. This leads to the bullied scholars becoming reluctant to go to school. These views are supported by Visser et al. (2009) who suggest that the consequences of stigma can be viewed along a range of reactions ranging from mild (for instance, silence and denial), to ostracism and eventually to violence. The way in which individuals discover and disclose their HIV status to others, as well as how they cope with their HIV status, is influenced by cultural and community beliefs and values regarding causes of illness, learned patterns of response to illness, social and economic contexts, and social norms. The author notes that discrimination against

PLWHA can be expressed as subtle or overt punitive behaviour that infringes negatively on their human rights and dignity. Some of these actions include compulsory HIV testing without prior consent or the protection of confidentiality. Violence against persons who are perceived as having HIV/AIDS often takes place. This can take the form of physical assault, maiming and in extreme cases the murder of individuals thought to be living with HIV/AIDS. However, whatever the form of stigmatisation or discrimination, it inflicts suffering on people and interferes with attempts to fight the epidemic. In this regard it was concluded that this is why some individuals prefer not knowing their HIV status.

According to SAMRC (2013), the impact of HIV/AIDS on women is particularly challenging in Africa where women are economically, culturally, and socially disadvantaged and lack equal access to treatment, financial support and education. It has been found that in a number of African societies women are mistakenly perceived as the main transmitters of sexually transmitted diseases (STIs) which results in HIV positive women being treated differently (more punitively) than HIV positive men. Men are likely to be excused for the sexual behaviour that resulted in their infection, whereas women are not, which is consistent with patriarchal norms. In general, literature in South Africa suggests that PLWHA, particularly women, are stigmatised and discriminated against by the health care system and its workers. Stigmatisation ranges from withholding treatment to non-treatment of patients by hospital staff.

In healthcare settings in some countries on the African continent, according to Engender Health (2011), PLWHA report that doctors and nurses often refuse to see them. As a consequence of this kind of discrimination minimal or poor quality of care, scares away individuals in need of care, and undermines effective HIV/AIDS prevention efforts. As HIV/AIDS treatment programmes become increasingly available in resource-poor countries, access to, and use of, these lifesaving services depends on the degree to which health workers in these facilities welcome and respect the rights of PLWHA. According to UNAIDS (2013) stigma and discrimination are the chief barriers to individuals seeking HIV information, treatment, care and support. Their research indicates that stigma and discrimination undermine HIV prevention efforts. This is so because individuals are afraid to seek HIV information and services as these actions may raise suspicion about their HIV/AIDS status. Fear of stigma and discrimination has also been shown to discourage PLWHA from disclosing their status, even to family members and sexual partners, which undermines their ability and willingness to access and adhere to treatment.

Blose (2015), in a recent study, reported that the HIV Stigma Index indicates that just under half of HIV positive South Africans suffer from internalised stigma (which is noted as a sense of shame and inferiority) resulting in them retreating from society and thus not living an authentic or full life. External stigma, which is enacted towards PLWHA, is still high at over a third of the population. It was noted that some parents living with HIV infection or full blown AIDS have reported that their children are stigmatised by other children because of their (parents) status. This results in these children becoming withdrawn and less self-confident. As stigmatisation and bullying infringes on the constitutional rights of individuals, it is extremely important for PLWHA to choose the right time to disclose their HIV/AIDS status. They need the time to build up self-confidence in order to deal with any unwanted consequences of disclosure. It should also be noted that disclosure is a confidential matter and the person confided in does not have the right to disclose the information to others. It was concluded that disclosure of HIV status must be treated with confidentiality and sensitivity.

According to Sedibe and Goosby (2013) HIV related stigma and discrimination continue to compromise PLWHA socially. It prevents many people coming forward for testing and for prevention and treatment services. The authors report that it is likely that up to sixty percent of PLWHA are unaware of their status and that many others choose to hide a positive HIV status. It was reported that gay and transgender people are highly stigmatised, even though HIV prevalence remains low in those groups. It was concluded that these individuals and their families are often unable to exercise their right to basic health, non-discrimination and freedom from violence.

Chipangura (2013) indicates that the HIV/AIDS pandemic has brought out both the best and the worst in people. The disease brings out the best when individuals group together in unity to fight the consequences of HIV/AIDS discrimination and to support and care for PLWHA. The pandemic however, also brings out the worst in people when PLWHA are stigmatised and ostracised by their families and communities and discriminated against individually, socially and in the workplace. The author concludes that stigmatisation and discrimination have a negative impact on HIV/AIDS prevention and treatment efforts.

2.5 Traditional African culture and HIV/AIDS in South Africa

In South Africa there is a strong traditional African belief, particularly in the Xhosa cultural group, in a mythical creature known as the Tokoloshe. The creature is described as small, hairy with very long arms and a large penis, and is known for its sexual appetite and ability to abduct children (usually female adolescents). Interestingly, it is linked to the time in an adolescent female's life when she begins to experience sexual awakening. It is very common for young South Africans

from this culture to pass the blame for sexual irresponsibility from themselves onto this mythical creature. A newspaper circulated in Paterson, a small town in the Eastern Cape of South Africa, had an article written by a journalist blaming the Tokoloshe for the molestation of children, as well as the spread of HIV/AIDS. It has been suggested that this cultural belief has presented African men an opportunity to deflect responsibility for their sexually irresponsible acts (SexInfo online, 2013).

According to Mswela (2009) specific customary practices and habits facilitate the spread of the virus in South Africa. These are, for example, resistance to the use of condoms as a result of specific sexual and cultural norms and values whereby individuals believe that the use of a condom promotes unfaithfulness between partners. This belief is iterated by stating that if an individual is faithful to his or her partner then a condom should not be used. Social norms on the African continent allow or promote high numbers of sexual partners, particularly amongst men, which also facilitates the spread of HIV and other sex STIs and unwanted pregnancies. Patriarchal culture, which is predominant in South Africa, also plays a role in preventing the dissemination of reproductive knowledge for instance, the preference for a male child (son), the practice of polygamy, bride price or lobola (which is perceived as conferring ownership of a woman to her husband) and wife inheritance (levirate) where, in the event of a husband's death, the brother or male cousin is pressured to marry the widow. These patriarchal beliefs and adherence to a culture of silence where myths (for instance, the Tokoloshe of the Xhosas and the Xidajani (a ghost which is linked to sexual behaviours) of the Tsongas and various mythical beliefs amongst the Vendas, Pedis and Sothos are powerful constructs that influence understanding and behaviour among people, often in a negative manner when linked to STIs and HIV/AIDS.

However, some cultural traditions do not seem to have had a negative impact on the HIV/AIDS pandemic. For instance, in the Eastern Cape (EC) in South Africa, Xhosa speakers, who traditionally circumcise, have lower prevalence rates of HIV (around eleven percent) than Zulu speakers, who do not practice circumcision (a prevalence rate of sixteen percent). However, the difference is not great and the prevalence rates in the Eastern Cape are still very high by international standards. On the other hand, the Western Cape, which does not have a tradition of circumcision, has the lowest HIV prevalence rate at six percent in the country. According to one national survey ten to twelve percent of circumcised men were HIV positive and twelve percent of intact men were similarly HIV positive (Nqayiyana 2011).

The cultural taboo about talking about HIV/AIDS in rural African communities appears to be worsened by the taboo on talking about all things related to sexuality. This is related to patriarchy which is associated with men controlling all things related to the family. Beliefs, underpinned by

patriarchy, reinforce the stigmatisation of PLWHA (for instance, HIV is highly contagious, associated with promiscuity, commercial sex work and homosexuality) are worsened and perpetuated by silence, denial and taboos related to sexuality, within these communities (Stutterheim et al., 2012).

2.6 Contending with discrimination and stigmatisation

Schatz, Madhavan, and Williams (2011) suggest that HIV/AIDS has significantly altered the household organisation and challenges African households' capacity to cope with day-to-day living. This effect is partly due to the extensive economic and emotional shocks to households, and broader social networks, related to individuals within families being infected with HIV/AIDS. Relatives who are not sick (or sometimes older children from a family) function as the primary locus of care for the sick and children orphaned by the pandemic. These households face great emotional and financial strain, for instance, from the costs related to illness, funerals, and care for the orphaned children. The social grant and pension payout system in the country does help relieve the burden on these household to some degree, but they are not adequate as they do not provide for all eventualities.

Lekas, Siegel and Leider (2011) observe that despite advances which have transformed HIV/AIDS into a more manageable chronic disease, it remains highly stigmatised and contributes to the social marginalisation of those infected which undermines their mental and physical well-being. Most individuals who became infected with HIV and or full blown AIDS have been exposed to stigma and discrimination. An HIV diagnosis conferred on groups already wrongly associated with the spread of the pandemic in Africa (for instance, homosexuals and sex-workers) face more discrimination and stigmatisation than other groups which means they often face multiple layers of stigma. This shapes their internal picture of themselves and results in low self-esteem, depression and sometimes suicide and they find it hard to cope with any forms of stigmatisation.

Jewkes and Morrell (2010) contend that intervention at an individual level and those that address community norms around gender and HIV have been developed in many African settings. Some of these are gender sensitive in that they recognise the specific needs and realities of men based on social construction of gender roles. Many of these interventions seek to transform gender roles and promote more gender equality and thus address how men and women view themselves in a changing world.

Mnisi (2014) suggests digital story telling as a means of exploring HIV related stigma. Stigma, the author notes, is contextual and how the individual is stigmatised is associated with the language

used, the meaning given in a specific language and the meaning and thoughts that a community constructs around a specific stigma. In the context of the author's research, digital storytelling enabled individual stories of high school learners' experience of discrimination and stigma, associated with HIV/AIDS, in the context of a school in a rural community, to be heard. Digital storytelling in itself assists in changing the meaning attached to language which changes thoughts around specific types of discrimination and stigma as experienced by a community. Digital storytelling involved sharing stories about experiences of HIV/AIDS related stigma and the use of these stories as an intervention in informing and educating communities about stigma. The stories thus became a part of the solution in lessening stigmatisation and discrimination.

The SAMRC (2013) reports that eliminating stigma, in South Africa, completely remains unlikely for many decades however, an overview of much research does suggest that something can be done to help eliminate stigma through a variety of interventions. These interventions include, focused information dissemination, counselling, learning appropriate coping skills and direct contact with someone that is living with HIV/AIDS.

The Health Systems Trust (HST, 2013) indicates that possible activities to promote workplace stigma-reduction include training for managers, peer educators, and counsellors, and devising strategies to address stigma. The commonly reported interaction between workplace and community-based stigma calls for a coordinated response, such as offering workers and their family members a choice of using VCT services in their community or workplace. Because gender differences are also important, couples counselling should be emphasised to reduce blame directed to women.

Ekstrand (2010) indicates that PLHWA use stigma avoidance strategies that include the following.

- a) Implying that they have a different disease such as tuberculosis (TB). Through this approach the PLHWA finds privacy, refuge and secures some support for being sick. The PLWHA tends to feel guilt when using this approach as he or she feels guilty about being dishonest with family and friends.
- b) Adopting a *do not ask* personal information stance. It is a less appealing approach that may result in the PLWHA being isolated. Anger is often associated with this approach, and as it is a consuming emotion which is frequently accompanied by other physical complaints, it impacts negatively on the immune status of PLWHA.

- c) Being dishonest about their HIV status. Fabricated lies and stories are used by PLWHA to deflect attention issues relating to their true status. This approach presents a challenge because the PLWHA is always on guard in case he or she forgets the lie.
- d) Seeking treatment at a hospital far away from home. Through this approach the PLWHA perceives a greater confidentiality by reducing chances of an encounter with familiar people. This is a temporary measure that may prove useful in giving the PLWHA time to consider when he or she can appropriately disclose their status.
- e) Refusing to explain written medical documents to illiterate family members. It is similar to the *do not ask* personal-information stance. The PLWHA finds security in not explaining medical documents to family and friends thus not disclosing their status.

Becoming pregnant is a complicated decision for HIV positive women. They must contend with various symptoms and the possibility of vertical (mother-to-infant) transmission. Many of these women often have problematic life contexts such as poverty and substance abuse. They are also aware that if their status is known, and they become pregnant, that discrimination and stigma may compromise their parenting abilities. Few differences have been found between the reproductive beliefs, attitudes and behaviours of HIV negative and HIV positive women. Infected women are just as likely to become pregnant as sero-positive women however; they are also no more likely to terminate a pregnancy. A survey assessing the fertility desires of a large sample of HIV positive men and women in the USA, revealed that twelve percent of all infected women and twenty six percent of those younger than thirty years conceived after becoming sero-positive. An additional ten percent, who were diagnosed as HIV positive during pregnancy, carried to term and gave birth to healthy babies (Kirshenbaum et al., 2006; UNAIDS, 2014).

2.7 The role of the media in the HIV/AIDS pandemic in South Africa

Creel, Rimal, Mkandawire, Bose and Brown (2011) report that HIV/AIDS related stigma has been recognised as a significant public health issue and that there is much still to be done in terms of reducing stigma. Radio Malawi features a programme that encourages PLWHA to tell their stories. Thirty villages with ten participants in each village took part in the intervention. Post intervention surveys revealed that casual discriminatory contact was reduced by the intervention. Shame was also reduced, but only for those reporting prior exposure to the radio programme and for those who did not have a close friend or relative with HIV. The intervention helped HIV infected young males and females reduce their own self-blame but not older male and female participants. To some degree this supports early research by Bray (2003) who posited that educational messages can help

unify PLWHA who are discriminated against. The first step to ensure cohesion is to explain what HIV is, and how it is and is not transmitted, so as to dispel myths and associated fears. These messages can be communicated through printed materials, newspapers, magazine articles and phone hot lines.

Bekalu, Eggermon, Ramandhant and Viswanath (2014) suggest that HIV/AIDS related stigma hinders prevention efforts. Media use was generally associated with low levels of HI/AIDS related stigma, and diminished the gap between individuals with high and low educational levels. However, the effect of mass media was found to be stronger among those living in urban areas, rather than amongst those living in rural areas. The authors suggest that this could lead to a widening gap between these groups in terms of endorsing HIV/AIDS related stigma (with those living in rural areas more likely to discriminate and be discriminated against). The implication in respect of media use related to HIV/AIDS stigma in sub-Saharan Africa is the following: a) the mass media may have the potential to minimise the gap in HIV/AIDS related stigma between individuals with high and low educational levels thus future efforts in reducing HIV/AIDS related stigma in the region may benefit from utilising the media in an appropriate manner; b) as there is low media penetration in rural sub-Saharan Africa thus mass media could have the unintended effect of widening the urban-rural gap unless more customised and rural-focused communication interventions are put in place.

Madoori (2015) observes that despite progress made in efforts to de-stigmatise HIV/AIDS the mainstream media has not fully joined the fight. In some cases, the media's coverage of HIV criminalisation becomes the source of stigma. A new case under an out-dated HIV criminalisation law in Illinois, USA, demonstrated the media's inability to handle sensitive information. According to a police press release, a twenty five year old man was arrested at his place of employment in Chicago's Lakeview neighbourhood district based on accusations of his not disclosing his HIV/AIDS status while engaging in intimate contact without protection. This type of reporting is problematic as the whole picture is not given and it leads to further discrimination of PLWHA.

In South Africa Herek and Mitnick (2002) reported that the mass media played a central role in providing information about AIDS and HIV to the public. As with the law, the media has both engendered HIV/AIDS stigma and helped to combat it. It is postulated that the challenges of the HIV/AIDS pandemic reinforces the view that it is a mistake to define illness and mental health too narrowly. The only way the pandemic can be properly contained is by helping people change and/or modify their behaviour. This includes sexual behaviour and social behaviour (such as stigmatisation). This was supported by Park (2012) who stated that the media, in reporting the facts

about South Africa's early HIV/AIDS epidemic, played an important role in advocating for those who are stigmatised. The author also indicated that the South African press took a strong position against the denialism era under President Thabo Mbeki. The attitude of denialism was generally characterised by the highest office in the land stating that the HIV did not cause AIDS. As a result all efforts to deal with the HIV/AIDS pandemic were wilfully ignored by the government of the time. The advisers to President Thabo Mbeki's office were, it seems, misinformed about HIV/AIDS. In that period, when interventions should have taken place, there were under a million PLWHA in the country. As a result of the lack of proper interventions the pandemic grew exponentially and by 2011 there were more than five million PLWHA in the country. During the denialism period up to four hundred thousand PLWHA lost their lives as they were denied access to life giving antiretroviral therapy [ART] (Park, 2012). In this regard Simelela, Venter, Pillay and Barron (2015) state that for nearly 10 years, the South African government's response to the HIV epidemic was denialist, which was estimated to have resulted in the deaths of more than three hundred, or more, thousand people because lifesaving ART was not provided. However, over the past several decades South Africa has emerged as a leader in ART roll-out as over 3 million people are on ART, which is the largest number in the world (Park, 2012).

A television programme in South Africa reported that the sterilisation of HIV positive women, without their consent, was taking place. The South African Department of Health (SADoH) in the country did not have a policy aimed at sterilising HIV positive woman without their consent, as this would be both unconstitutional and against the law. The programme indicated that twenty-seven HIV positive women had been sterilised without consent. It was noted that this should not have taken place and that the women had been denied their constitutional and Human Rights. The procedure was also unethical in terms of medical science. It appeared that the women did not understand the forms they signed as the information was not given to them properly. Fundamentally, they did not understand that they would not be able to give birth after they were sterilised. It was posited that by bringing this information to the media, it was unlikely that this practice would continue (Matheza, 2015).

According to SANAC (2015), the late Nelson Mandela used the media in a positive manner when he addressed HIV/AIDS related stigma in 2005. He disclosed to journalists, who had gathered at his Johannesburg home, that his son Makgatho had died of HIV/AIDS. It was a clear message to the nation that AIDS is an illness that all levels of society can die from. The prevailing message was that a family should not feel shame if a family member is infected with HIV and/or dies from HIV/AIDS. Mandela could have remained silent but decided to take the broader picture into

account. He used his own family challenges as an opportunity to educate the nation. He remarked that it was an ordinary illness that people were misinformed about. After this he famously wore a Treatment Action Campaign (TAC) t-shirt when he visited the country's first public sector ART site in Khayelitsha in December 2003. The impact of Mandela's equal treatment and physical contact with PLWHA, together with the kind of public HIV disclosure, through print and television media of Judge Edwin Cameron, has had a major influence on the levels of stigma reduction in the country.

In 2014 the media in South Africa reported that World AIDS Day focused on 'Zero Discrimination', without losing sight of the other zeroes namely, 'Zero new HIV infections,' and 'Zero AIDS-related deaths'. South Africans were called upon to join the campaign. In 2015 World AIDS Day in the country was targeted, through the media, at stigmatisation and discrimination with the slogan, 'I can't change my HIV status but you can change your attitude.' This message reinforced previous global and South African efforts to highlight and reduce HIV related stigma (UNAIDS, 2015).

2.8 Stigmatisation of PLWHA in South Africa

Stigma continues to be a seriously neglected issue, particularly in sub-Saharan Africa regardless of the fact that it has detrimental effects on public health and human rights (UNAIDS, 2013). Negative attitudes towards PLWHA in South Africa can also be attached to people assumed as being HIV positive and those close to PLWHA such as partner, family member or caregiver. When these negative attitudes turn into acts which result in unjustified treatment it is discrimination which leads to the stigmatisation of PLWHA. The stigma results in PLWHA feelings of shame and self-blame and a range of protective behaviours, including the inability to disclose HIV status (Siyam'kela Stigma Project, 2007). The government of the USA announced, in March 2013, that their financial support to South Africa for dealing with HIV/AIDS will be cut in half by 2017 (due to the struggling American economy) however, they noted that money that is given should support the reduction of HIV/AIDS stigma. This is obviously problematic in funding the fight against the pandemic in South Africa.

At present, the primary mode of HIV transmission in South Africa is heterosexual. According to Matheza, (2015) most HIV positive people in South Africa find out about their status only when they have repeated incidents of TB, the main opportunistic infection. When they finally seek help their CD4 count (which measures the strength of a person's immune system) is very low. They are often too weak to start ART treatment. Research focusing on other groups for instance, homosexual males in the country, is scant. Currently it is unknown how many people living with HIV/AIDS in

South Africa are men sleeping with men (MSM). However, it is reported that many MSM experience social isolation, stigmatisation and discrimination due to their perceived HIV status. There is no doubt that mental health interventions are needed for HIV positive South African MSM although they are a minority group in terms of HIV infection (Inter Press Service News Agency [IPSNA], 2010).

Stigmatisation and problems resulting from it are rife in South Africa. On the third of December 2012 at 21h30 an incident of stigmatisation, discrimination and bullying occurred which resulted in the death of Sibulele Sibaxa's parents. The parents of Ms Sibaxa were killed by the community because they were thought to be HIV positive. An earlier death was that of Gugu Dlamini, who was stoned and beaten to death by neighbours in a township near Durban in 1998. This occurred after she spoke about her HIV status in the media (AVERT, 2015).

In a Knowledge, Attitudes, Perceptions and Behaviour (KAPB) study conducted by Nqojane (2009), using a sample of a thousand students in KwaZulu Natal, it was found that general knowledge about HIV/AIDS was good. However, many students still reported stigmatisation of those known to be HIV positive or who had full-blown AIDS, particularly in rural communities. In research in the Eastern Cape, Weston (2006), in a study underpinned by the Health Belief Model (HBM) and Protection Motivation Theory (PMT), indicated that university students view themselves as being separated from the retrovirus and not easily infected. They separated themselves from the pandemic for a number of reasons including the desire to be away from being stigmatised or discriminated against.

Gilbert and Walker (2010) investigated stigma at a clinic in Johannesburg, Gauteng where they researched fear and rejection experienced by HIV positive individuals who attended the clinic. It was found that stigmatisation and discrimination in terms of HIV/AIDS still remains highly significant in the context of the pandemic in South Africa. They suggest that there is a wide consensus that HIV/AIDS related stigma compromises (negatively) the well-being of people living with the disease. In the clinic where the research was conducted HIV/AIDS was regarded as a chronic condition which is well managed by contemporary ART therapy. However, this approach was not shared by many family members, neighbours and employers who held highly stigmatised views and tended to discriminate against these individuals within their own families.

Ogenmefun, Gilbert and Schatz (2010) looked at how secondary stigma affects care-giver women in rural South Africa. They indicated that the HIV/AIDS epidemic in South Africa poses a public health threat with multi-faceted and harmful and which has socially complex outcomes. They

suggest that some of these outcomes are a result of the fast paced, individualistic environment that shapes contemporary society's attitudes. Due to negative attitudes towards PLWHA, stigmatisation often extends to close family member, particularly caregivers. Many caregivers in South Africa are older women. Their narratives revealed that they attribute high rates of death of PLWHA in their communities to lack of care and respect for African social norms and traditions. The types of secondary stigma experienced by the caregivers included isolation, separation from family members, voyeurism and social-isolation, finger-pointing and jeering.

On the 11th June 2015, the Daily Maverick (newspaper) carried a report about HIV stigma being an unspoken issue. It reported that confronting stigma is a major task in confronting the country's HIV/AIDS challenges. The author reported on the first HIV-related stigma survey in the country which noted high levels of discrimination and stigmatisation. The Deputy President, Cyril Ramaphosa, was asked to comment in the article and he stated that:

“Sometimes discrimination is not overt. It could be a glance, a whispered remark, a social snub. There are times when PLWHA internalize the stigma undermining their own sense of self-worth and dignity” (Nicholson, 2015, p.6).

Cloete et al. (2010) in research on HIV/AIDS in Cape Town found that HIV/AIDS related stigma was still pervasive in local many communities. This was associated with the difficulty of disclosure of HIV/AIDS status and fear of rejection. It was also noted that the role of risky sexual behaviour, such as not using condoms was considered as secondary to daily life stressors like poverty, unemployment, gender-based violence, stigmatisation and bullying.

According to Velloza et al. (2015), research conducted at different venues that served alcohol in Cape Town to investigate the impact (of drinking alcohol) on HIV disclosure, testing, and treatment-seeking behaviours. It was considered that, as alcohol generally makes individuals more talkative, patrons would be likely to talk more openly about HIV. They indicated that many patrons knew other patrons living with HIV/AIDS. The visibility of HIV impacted on how these individuals expressed HIV related stigma. The participants noted four forms of HIV related stigma, namely, fearing PLWHA, fearing becoming HIV positive, blaming others for spreading HIV and isolating PLWHA. Their exposure to HIV positive individuals and knowledge of HIV related stigma, particularly fear of isolation, influenced the participants' willingness to disclose their own status in a negative manner. The results suggest that efforts to change norms and reduce expressions of HIV related stigma should take place in all types of social settings using specifically tailored

interventions. The inference is that programmes tailored to a specific environment might increase an individual's willingness to go for HIV testing and promote help seeking behaviours thus reducing stigmatisation and discrimination of PLWHA.

Zuch and Lurie (2011) investigated the effect of ART on HIV related stigma in rural South Africa, their research focused on the connection between ART and HIV-related stigma. From interviews conducted with HIV positive adults they identified two implications for the role of ART in reducing HIV related stigma. Firstly, they found that ART can reduce stigma through weakening HIV/AIDS link with death and secondly, they found that ART enables the establishment of spaces for support, which helps reduce stigma and discrimination through normalisation of the disease.

Maugham-Brown (2010) surveyed over a thousand participants residing in Cape Town in 2003, 2006 and 2009. The collected data was used to evaluate three distinct dimensions of stigma namely, behavioural intentions towards people living with HIV/AIDS, instrumental stigma and symbolic stigma. The author found that stigma had increased in spite of public centred campaigns to try and reduce discrimination and stigmatisation. These findings indicate an imperative for renewed efforts to reduce stigma, perhaps through interventions that weaken association between HIV/AIDS and death. The author postulates that this may well reduce fear of HIV/AIDS and recast the pandemic as a chronic manageable disease.

Among South African youth aged fifteen to twenty four years the development of HIV/AIDS stigma is increasing. Young people and their behaviours have been cited as being an important contributing factor for self-stigmatisation and stigmatising others who are known to be living with HIV/AIDS. However, it was also reported that the media in South Africa have played an important role in advocating (particularly amongst the youth) for those who are stigmatised because of HIV infection or AIDS related illnesses (SAMRC, 2013).

2.9 Preventing the stigmatisation of PLWHA

According to Herek and Mitnick (2002) in the early years of the pandemic, a consensus among public health officials in many countries believed that HIV/AIDS must be approached differently from other sexually transmitted diseases. This is because they wanted to avoid stigma and mistreatment that could drive the pandemic underground. This, it was considered, would compromise access to care and services, deter or delay HIV testing and undermine the effectiveness of HIV/AIDS prevention efforts. Leading experts were brought together in the USA to identify key issues in addressing HIV/AIDS stigma. It was postulated that a comprehensive approach to HIV/AIDS stigma using interventions and services in applied settings, including training for clinical

and non-clinical providers, consumer education, social marketing, approaches for community wide education and awareness, and support for consumer complaints would be effective in stopping the exponential spread of the pandemic.

The majority of HIV/AIDS campaigners state that the law can, and must, be used to establish a protective and supportive framework for people affected by the pandemic and not a punitive one. This is a critical element in an environment of collaboration and mutual support that emphasises the community of interest between the infected and the uninfected and between governments and individuals. Without proper legislation, which makes people feel secure, PLWHA will feel fear. Studies in Zambia have highlighted how stigmatisation, and the fear that it provokes, can impede efforts to work effectively with pregnant women in reducing mother to child HIV transmission (Maugham-Brown, 2010; Nyblade et al., 2003).

According to UNAIDS (2013), in its document on the Strategic Framework on Partnership with Faith-based Organisations (FBO) key roles identified in ending the marginalisation of PLWHA and HIV related stigma included designing faith based frameworks, policy and programmes that were culturally relevant. The organisation was involved in the implementation, research, monitoring and evaluation of programmes underpinned by the policy document. They were also included in decision-making processes which advocated for universal access to HIV prevention, treatment, care and support services. The framework noted that all human beings should be equally respected and are equally worthy of health, dignity and care. Furthermore, it was suggested that if PLWHA were included in policy making and equally treated by all countries HIV/AIDS related stigma and discrimination could be significantly mitigated.

Efforts to reduce HIV/AIDS stigma must target multiple levels as reported below (adapted from Ekstrand, 2011).

- 1) Law and policy: Reforms are needed globally to prohibit discrimination of PLWHA and to protect those who are most vulnerable (for example, sex workers, women, and substance abusers, ethnic and racial minorities).
- 2) Social level: Community-based programmes, including media (as appropriate in each setting) need to report on matters that broach HIV/AIDS stigma. Work through local NGOs should focus on highlighting the scourge of HIV/AIDS stigma.

- 3) Institutional level: Military, schools, prisons, hospitals, religious institutions and leaders should have inclusive programmes and policies that discuss issues related to HIV/AIDS stigma.
- 4) Families: A family provides support thus must be educated in terms of HIV/AIDS. Families that are well informed on HIV/AIDS stigma provide security of support with improved understanding to members who are affected.
- 5) Couples: In whatever setting that couples can be reached, including testing and counselling, couples represent a powerful social structure in terms of efficiently dealing with stigma issues.
- 6) Individuals: During health care visits, testing, counselling and in other appropriate settings, individuals must be educated about HIV/AIDS. An individual is a powerful change agent of self so educating and changing individual perceptions towards HIV/AIDS will ultimately help change other individual's perceptions (friends, colleagues and/or peers).
- 7) Support groups: Those who are HIV positive should be mobilised to get involved in issues of advocacy. The approach of sharing and empathy among PLWHA presents a vehicle that generates coping skills, reduction of fear and assuagement of guilt feelings among members.

In December 2013, at the launch of the UNAIDS Zero Discrimination campaign, the Nobel Peace Prize recipient Daw Aung San Suu Kyi described discrimination as a violation of human rights. She indicted that discrimination and stigmatisation is illegal, immoral, hurtful and dehumanising. She iterated that too many people around the world face unequal treatment because of their race, religion, nationality, sexual orientation, or identity, disability, gender or age or if they have some form of affliction that is seen as their own fault. She further observed that discrimination can happen anywhere for instance, at work, at school, at home and in the community. She concluded that discrimination hurts everyone and called for an end to discrimination by sharing and disseminating knowledge. Furthermore, she noted that there are many things which can be done to counter discrimination and encourage acceptance for instance, speaking up when something is wrong, raising awareness, supporting people who have been discriminated against and promoting

the benefits of diversity (UNAIDS, 2013).

Furthermore, on the 1st March 2015, Michel Sidibe, UNAIDS Executive Director, stated that sixty five years after the Universal Declaration of Human Rights, discrimination still blemishes societies around the world. He stated that discrimination provokes prejudice, limits the life chances of millions of people and is responsible for the physical and mental abuse of millions around the world. He further commented that stigmatising PLWHA discourages individuals from getting tested which results in them not receiving life-saving health care and treatment. In offering a solution, he suggested that the world adopt the measures noted by Daw Aung San Suu Kyi in 2013 namely, speaking up when something is wrong, raising awareness, supporting people who have been discriminated against and promoting the benefits of diversity (UNAIDS, 2013).

AVERT (2015) reports that a community participation intervention to reduce HIV/AIDS stigma was conducted in North East Thailand. In the intervention the authors investigated whether an integrated socio-economic and community participation intervention could be used to reduce HIV/AIDS stigma. The intervention worked well, resulting in a significant improvement in HIV/AIDS knowledge and a significant reduction in HIV/AIDS stigma in the subject village as compared to the control village. The results suggest that community interventions which empower the community, combined with a socio-economic intervention to reduce resource constraints, are useful and effective means of increasing positive interaction between PLWHA and other community members. This leads to increasing tolerance and reduction of stigma.

Some interventions to prevent HIV/AIDS stigma, according to the HST (2013), include educating PLWHA about their basic human rights so that they can develop confidence and assert their rights. They can learn how to enforce these rights through legal processes. This may help in order to mitigate the effects of discrimination and stigma. Public and private institutions should implement their HIV/AIDS policies based on sound information and take into account the rights of all individuals. HIV negative people need to be educated in order to create an environment free of fear of HIV- biased social attitudes and no stereotypes towards HIV (Tswelopele Project, 2011).

Famoroti, Fernandes and Chima (2013) in a study on stigmatisation of PLWHA by healthcare workers at a tertiary hospital in KwaZulu-Natal, South Africa, highlighted the importance of continuing education among Health Care Workers (HCWs) in minimising the impact of stigmatisation and discrimination when dealing with PLWHA. Continuing professional education and counselling for HCWs, it was suggested, will lead to them having better coping mechanisms. Moreover, it was suggested that educational activities should highlight teaching on ethics and healthcare law with a clear understanding of patient's rights. Further, it was suggested that

gossiping amongst HCWs may have the effect of compromising patient confidentiality and could interfere with the doctor-patient relationship. Educational interventions noting the negative effects of gossiping were also suggested.

2.10 Coping mechanisms of PLWHA

According to Makoe et al. (2008), in a study on coping with HIV-related stigma in Lesotho, Malawi, South Africa and Tanzania, observed that PLWHA and their families are subjected to prejudice, discrimination, and hostility related to the stigmatisation of HIV/AIDS. Coping strategies used by PLWHA in dealing with HIV-related stigma were differentiated. A total of seventeen different self-care coping strategies were identified as follows: restructuring perceptions of the illness, seeing oneself as *Okay*, letting go of self-negativity, turning to God, seeing hope for the future, changing negative behaviours, keeping active, using humour, joining a support or social group, disclosure of HIV status, speaking to others with the same problem, getting counselling, helping others to cope with the illness, educating others, learning from *others*, acquiring knowledge and understanding the disease plus getting help from others. However, the authors concluded that these mechanisms appeared to be self-taught and only marginally helpful in managing perceived stigma.

According to Snyder et al. (2014) perceived stigma and self-stigma, voluntary and involuntary disclosure, positive and negative coping, and demographics were assessed by trained interviewers in a study of inter-relationships amongst stigma, disclosure, coping and adherence in PLWHA. The study indicated that perceived stigma is primarily related to involuntary disclosure, whereas self-stigma is related to voluntary disclosure. Religious coping positively relates to acceptance, whereas perceived stigma is related to high levels of denial of HIV/AIDS status. Adherence was negatively affected by alcohol use, self-stigma and denial. It was concluded that substituting maladaptive coping mechanisms like denial and alcohol use with a more adaptive coping style may be an important strategy to improve long-term ART adherence and well-being of PLWHA.

Grodensky et al. (2015) in their study on the roles of relationships, spirituality, disclosure, stigma, and shame for older women living with HIV/AIDS discussed three types of relationships that were sources of potential or actual support in their lives: (a) family and platonic relationships, (b) romantic partnerships, and (c) relationships with a church community and with God. Within each type of relationship, salient themes emerged that reflected two general issues: (a) the types of support received, and (b) factors that helped or hindered accessing that potential source of support. The authors noted that isolation and inhibition stop PLWHA from seeking social connections and

the reason most participants were reluctant to disclose their HIV status. Disclosure was perceived as being even more shameful if participants, particularly women, were middle-aged. Those receiving social support did so mainly through relationships with family and friends, rather than romantic relationships. All participants noted that they drew greater support from spirituality than friends or family. It was also reported that community-level stigma-reducing programmes may help older HIV positive individuals, particularly women, receive support.

A regional consultation on stigma and HIV/AIDS in South Africa noted that responses should focus on the following groups and areas: children (who face different challenges compared to adults); community involvement through participatory approaches (rather than communities as passive recipients); PLWHA (recognising their relatives social dis-empowerment, and potential to participate in stigma reduction activities); research (to ensure that stigma and discrimination are adequately understood). It is worth noting that some of the strongest responses to non-stigmatising and non-discrimination practices in relation to HIV/AIDS have been led within rural South African traditional communities (Human Science Research Council [HSRC], 2012).

French, Greeff, Watson and Doak (2015, p. 6) in a case study of a comprehensive HIV/AIDS stigma-reduction and wellness-enhancement community intervention, conducted in the North West Province of South Africa, indicate that the PLWHA reported gaining knowledge on how to cope with stigma and discrimination. The research looked at various groups and conducted various activities to arrive at how to reduce stigmatisation. Some of the comments from the participants were as follows: “I learnt how to cope with stigmatizing behaviour” and “I learned how to handle people who are stigmatising and learned how to cope.” The children reported on gaining knowledge regarding HIV stigma: “I was having a lack of knowledge about the stigma” and “The workshop gave me more knowledge about HIV and stigma”. The comprehensive HIV stigma-reduction and wellness-enhancement community intervention described showed that empowering PLWHA and people living close to them (PLC) to target HIV stigma on a community level was much more effective than targeting it on an individual level.

Snyder et al. (2014) note that preliminary results from Hlanganani (Coming Together), a structured support group for HIV/AIDS infected adolescents piloted in Cape Town, South Africa, indicated that the social mechanisms that were observed in, and amongst, the groups were likely to hold the most potential for the programmes health promoting effects. This pilot study suggested that ‘safe spaces’ may provide a critical platform for HIV management competence. Despite initial concerns about stigma, participants described finding Hlanganani a safe, trusting environment in which they

were able to share concerns and experiences with others. They were also able to share and augment one and others strengths, particularly when it came to disclosing their HIV status to partners, friends or family.

Wouters, Masquillier, Ponnet and le Roux Booyesen (2014) indicate that families that form tight units and that are adaptable to external changes form the ideal environment for community-based support initiatives, while dysfunctional families that have difficulty adapting to external changes, are not able to show support in any positive manner. The authors note that coping with HIV/AIDS stigma is a serious challenge. Over and above other subtle social and personal stigmata that people have to contend with in their daily living, the added burden of having to cope with HIV related stigma presents a difficult paradigm shift. It was concluded that there has to be, over and above individual coping mechanisms, community and nation-wide interventions and support structures to assist PLWHA in coping with the stigmatisation and discrimination associated with HIV/AIDS.

2.11 HIV/AIDS stigma prevention internationally

According to Enah, Piper and Moneyhan (2014) HIV/AIDS stigmatisation should be considered amongst the most severe human rights violations and demonstrably punishable by law. They note that African Americans in the rural Southern United States continue to experience disproportionate increases in new HIV/AIDS infections. They found that using games which told a story for the reduction of HIV/AIDS stigma and prevention, in this community, was found to be appealing and acceptable. Such games it was stated should be designed to reflect the daily lives of the target population and should involve a sample of potential players of the game at every phase of the development process. This research is supported by Jacobi et al. (2013) who described an HIV/AIDS stigma reduction programme in schools in Cameroon. This programme adopted educational strategies (including storytelling and games) aimed at reducing stigma and facilitating acceptance of people living with HIV/AIDS. The interventions appeared to work quite well and children were more accepting of PLWHA.

In Nigeria HIV/AIDS related stigma constitutes an impediment to public health as it hampers efforts to control the pandemic. To address the complex problems of increasing HIV/AIDS infection rates, widespread misinformation about the infection and rising levels of HIV/AIDS related stigma, the various tiers of government in Nigeria are working with local and international non-governmental organisations (NGOs) to develop and implement strategic communication programmes. Exposure to HIV/AIDS related communication in the media is associated with increased knowledge about the pandemic, which is in turn a strong predictor of accepting attitudes.

Communication exposure also has a significant and positive association with accepting attitudes towards people living with HIV/AIDS. The findings strongly suggested that media-based HIV/AIDS programmes constitute an effective strategy in combating the pandemic related stigma. It was recommended that such programmes and interventions should be intensified in the country (Babalola, Fatusi & Anyanti, 2009).

Sedibe and Goosby (2013) report that United Nations (UN) Member States at the 2011 UN High Level Meeting on HIV/AIDS committed themselves to the goal of reducing stigma, discrimination and violence related to HIV. Countries were asked to intensify their actions to build effective stigma-reduction programmes and policies, protective laws and protocols and appropriate legal, social and policy frameworks that will eliminate stigma, discrimination and violence related to HIV. It was suggested this could be carried out using governmental, NGO interventions and the media. However, Grossman and Stangl (2013) indicate that current stigma and discrimination reduction approaches in the international arena are varied and measurement, in order to compare and contrast these interventions, is difficult. They further observe that it is critical for the research community to clearly link intervention activities to the areas of stigmatisation and discrimination which need to be changed. They concluded that assessment of stigmatisation and discrimination domains in a clear, coherent and consistent manner will help with the reduction of HIV stigma and promote HIV prevention, care and treatment outcomes.

2.12 HIV/AIDS stigma prevention in South Africa

As noted previously the 2014 World AIDS Day in South Africa was branded 'Zero Stigma and Zero Discrimination.' South Africans were reminded that it is the duty of everyone to continue fighting prejudice, stigma and discrimination related to HIV/AIDS. This was built on the UNAIDS theme for the period 2011 until 2015 which was, 'Getting to Zero,' that is zero infection, zero HIV/AIDS related deaths and zero stigmatisation and discrimination of PLWHA (SANAC, 2015).

South Africa's HIV/AIDS national plan was announced by President Jacob Zuma on the 1st December 2011. Prevention is the core of the National Strategic Plan for HIV, Sexually Transmitted Infections (STIs) and Tuberculosis (TB). The strategic plan aims to reduce new infections by fifty percent by taking a holistic approach. The plan has another goal which is the reduction of stigma related to HIV/AIDS and TB by fifty percent. Another strategic objective is to protect the human rights of PLWHA mainly through ending stigmatisation, discrimination, stopping human rights violations and gender inequality (South Africa.info, 2015).

A package of anti-stigmatisation interventions to be undertaken by South African National AIDS Council (SANAC) in partnership with development agencies and civil society organisations was announced by the Deputy Minister of Health, Dr Joe Phaahla (SANAC, 2015). It includes the following points.

1. A National legal assistance programme for individuals who are discriminated against on the basis of having HIV or TB. This service will be administered by Legal Aid South Africa through the national system of legal aid centres.
2. A National communication programme which will be designed to challenge attitudes related to stigmatisation. It is hoped the campaign will help those without HIV infection to have a better understanding of PLWHA, who will share their stories on a national platform.
3. A project on stigma reduction, which was started in the Eastern Cape, will be expanded to the national stage.
4. Empowerment of PLWHA through the aforementioned programmes and/or campaigns (adapted from SANAC, 2015).

At the economic level PLWHA in the past were stigmatised and discriminated against by life insurance institutions. These institutions required a medical test to check for HIV positive status, which if found, would compromise the individuals chance of getting insurance (often it was not granted). However, as individuals who are HIV positive are now expected to live a full life with ART the position of these insurers has changed. It must also be stated that previously it was argued that insurers were violating the human rights of PLWHA. The positive shift in insurance policy coverage of HIV positive individuals by South African insurers has stopped this form of discrimination (SANAC, 2015).

2.13 Cultural perceptions of HIV/AIDS stigma

Airhihenbuwa (2007) states that stigma is considered a major obstacle in terms of controlling the HIV/AIDS pandemic. However, the author notes the church can be a major player in reducing stigma.

“Spiritual leaders within organised religions are considered to be key gate keepers in reducing and/or eliminating HIV/AIDS related stigma. Central to the debilitating force of stigma is the moralization of behaviour (particularly sexual behaviour) and the condemnation of persons living with HIV/AIDS as religious and sexual deviants. The common spiritual doctrines in

which stigmatisation have been problematic are mostly Christian and Islam. However, a doctrine conspicuously absent from this discourse is that of African spirituality and culture” (Airhihenbuwa, 2007, p.139).

Even though HIV/AIDS is experienced as an illness it has various interpretations relating to stigma depending on the cultural setting. According to Winskell et al. (2011) genre is regarded as a measure of the cultural resources available to people as they try to make sense of a new phenomenon. They note that the Nigerian narratives are distinguished by an unforgiving moral agenda, dominated by conservative Christian doctrine on sexuality which tends to focus on the misdeeds of characters (primarily female) that lead to their infection. The narratives from high-prevalence Swaziland are, in contrast, more diverse and are more positive. *Othering* (othering refers to the purpose of highlighting differences on which stigmatisation and discrimination against individuals that are different from self is based) and preoccupation with the circumstances of infection are more common in lower prevalence countries but vary substantially depending on the cultural context. The authors note that social representations from the highest prevalence countries, Swaziland and Namibia, and from lower prevalence Burkina Faso offer potential models for the framing of HIV/AIDS in ways that serve to counteract symbolic stigma (Mofolo, 2010).

Karamouzian, Akbari, Haghdoost and Zolala (2015) in a study on HIV/AIDS related stigma in Iran observed the following themes a) shame and isolation; b) feeling miserable; c) avoidance, rejection and anger; d) treated as an outcast; e) being shunned in the workplace; f) being refused care by healthcare providers; g) physical distancing of people not HIV positive; h) negative verbal and non-verbal communication. As Iran is a family orientated, collective society in which an individual and collective experience is not fully separated PLWHA experience much psychological trauma. The themes derived from the experience of PLWHA are, the authors note, related to traditional notions of religiosity where illnesses related to perceived sexual misconduct exacerbate the levels of stigma and discrimination in the country.

Wong (2013) in a cross-sectional nationwide study in Malaysia indicated that HIV/AIDS transmission knowledge is not associated with self-stigma. The author notes that priority should be given to interventions that are directed towards de-stigmatising HIV/AIDS. It was further reported that ethnic, demographic, and socio-economic disparities contribute to negative or more positive perceptions of PLWHA. It was further suggested that, in this regard, socio-cultural tailored interventions at specific groups (classes) are more effective.

2.14 Social aspects of HIV/AIDS stigma

According to Lowther, Selman, Harding and Higginson (2014) advances in HIV/AIDS care have resulted in increasing numbers of PLWHA receiving antiretroviral therapy and achieving viral control. This has led to a focus on the biomedical aspects of care, leaving the data on psychosocial and social problems relatively neglected. The authors conclude that if unmanaged, psychological and social problems, such as stigmatisation and discrimination, which are associated with unnecessary suffering and non-adherence to medication, have potentially serious clinical and public health consequences.

AVERT (2015) reports that community levels of stigma and discrimination towards PLWHA is found globally. People Living with HIV/AIDS are often forced to leave their homes, change their daily activities such as shopping, socialising or schooling, face rejection and verbal and physical abuse. This happens in heterosexual and homosexual communities. Studies have indicated that within some Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) communities' segregation exists between HIV positive and HIV negative men, where men associate predominantly with those of the same status. Lesbian women do not make this distinction. Other members of LGBTI communities have reported stigma based on physical changes due to the side effects of ART treatment, which can lead individuals to delay seeking and initiating treatment.

2.14.1 Orphans and child-headed households

Sowa (2008) reported that in Ethiopia, in one specific instance he found two children living in a home that consisted of one and a half small dark rooms. They were living alone in the house after their father and mother died from HIV/AIDS related illnesses. The eldest child helped her mother nurse her father and then did her best to nurse her mother. Since their deaths, she had been looking after her younger brother. The outlook for the children was poor as they had no interested relatives and neighbours, although concerned, had their own problems. The author concluded that the Ethiopian state needed to address issues related to HIV/AIDS orphans and child-headed households.

Mogotlane, Chauke, Van Rensburg, Human and Kganakga (2010) found that the rights of HIV/AIDS affected children were compromised in South Africa. Those heading households (because of paternal deaths) were often not at school and were responsible for domestic chores. The household needed food, clothes, money, shelter, and education. Government, in attempting to address these needs, requires clear, coherent policies which provide a distinction between orphaned and vulnerable children and child-headed households. The authors recommended that a collaborative approach (for instance, government, NGOs and religious groups) between all

stakeholders was needed to help such children as no single model of best practice could appropriately and effectively address the needs of child-headed households.

In sub-Saharan Africa UNAIDS (2014) reported that while twenty percent of Zimbabwean children have lost one or both parents to HIV/AIDS, this estimate rises to twenty four percent among children in the poorest income groups compared to only five percent in the richest, suggesting that orphanhood and poverty are strongly linked. The authors suggest that monetary grants are necessary for child-headed households, particularly in the poverty stricken group. South Africa offers one of the largest cash transfer initiatives on the continent, with two grant types oriented specifically to child headed households. The child support grant (CSG), a means-tested cash transfer targeted to low-income individuals providing primary care for a child under the age of eighteen years, was directed to more than eleven million beneficiaries in 2013. Fewer recipients, about half a million, in 2013, were receiving a foster child grant (FCG). It was noted that many of the child headed households had parents or a parent who died from HIV/AIDS (Thurman, Kidman& Taylor, 2014).

AVERT (2015) indicates that worldwide around eighteen million children under eighteen years old have been orphaned by HIV/AIDS. This could rise to twenty five to thirty million by 2015. Around fifteen million or eighty five percent of these live in Sub-Saharan Africa. In 2012 an estimated four hundred and ten thousand children aged from one to fourteen years were living with HIV/AIDS in South Africa. In South Africa the number of children orphaned by one or both parents due to the pandemic is about two and a half million, accounting for sixty three percent of the total number of orphans in the country. Nigeria is second with just over two million children orphaned by HIV/AIDS constituting nineteen percent of the total orphans in the country. A total of just over one million children orphaned by HIV/AIDS can be found in Asia. It is the highest number of HIV/AIDS related orphans outside of Africa. As these children do not have adult role models their future prospects are likely to be reduced.

Furthermore, according to AVERT (2015) children whose parents are living with HIV/AIDS often experience many negative changes in their lives and suffer neglect, including emotional neglect, before they are orphaned as their parents are very ill and cannot give them the support they need. Eventually, their parent(s) or caregiver(s) die and they suffer emotional trauma. In this case, they have to adjust to their new situation, often with little or no support. These children are vulnerable and can become victims of exploitation and abuse. The majority of children who have lost a parent continue to live in the care of a surviving parent or family member, but they usually have the responsibility of doing many chores and have to look after siblings while caring for an ill or dying parent.

Thorsteinsson (2015) reports a case study of two girls aged twelve and sixteen years who were orphaned because of HIV/AIDS in Ethiopia. They were initially cared for by their paternal aunt, who lived next door. She taught them to cook and provided guidance to them on a day-to-day basis. However, she had to leave for other responsibilities and the girls had to fend for one and other. The rest of the extended family lived far away and were too poor to send money for food and school. Through a world renew project, funded by an international organisation the girls became part of a project where fifteen hundred children received food, assistance with their education, and support from a social worker. This was a successful project and all the children who were helped in this manner have done well academically and socially in the short to mid-term.

In Zimbabwe, a staff reporter (no name given) of the New Zimbabwe Newspaper (2015), reported that the Minister of Health and Child Welfare in Zimbabwe, Mr David Parirenyatwa stated that more than three quarters of a million orphans and vulnerable children are in urgent need of various forms of support including educational help, health and child care in Zimbabwe. Furthermore, he indicated that the economic decline in Zimbabwe has culminated in economic hardships that have affected many families. The pandemic, he stated, has added to this burden with some children losing both parents resulting in child-headed families. He further noted that some of the orphaned children have resorted to prostitution, risking their lives in the process. The minister also stated that The National AIDS Council in Zimbabwe has a major role to play in addressing the consequences and impact of the pandemic.

2.14.2 Psychosocial community needs in South Africa

The Speaker of the South African Parliament, Mbete (2015) in her letter dated the 26th February 2015, addressed to the Chief Executive Officer (CEO) of the South African National AIDS Council (SANAC) indicating that the National Assembly agreed to a motion recognising ‘Zero Discrimination Day.’ The day was the 1st March 2015. This promoted recognition of difference and the fact that discrimination and stigmatisation are contrary to the spirit of the South African constitution. The day aimed at eradicating the deeply rooted stigma and discrimination faced by HIV infected groups. SANAC and other organisations were commended for contributing to the first National Stigma Index Survey among people living with HIV/AIDS in South Africa which it is perceived will help highlight causes of stigmatisation and thus help eliminate discrimination of PLWHA in the country.

Wu and Li (2013) looked at community-based HIV/AIDS interventions in promoting psychosocial well-being among PLWHA. They reported that community-based interventions are an effective

approach to improve the well-being of PLWHA, no matter what their age or gender. The volunteer home-visiting approach was effective in strengthening the psychological well-being of PLWHA through support services such as advice, therapy and counselling, HIV/AIDS education and medical referral. Support group meetings for caregivers provided an opportunity for individuals facing similar challenges to meet and thus support each other on a weekly or monthly basis. Children were also invited to peer group sessions run by an older trained facilitator. This proved to be a popular and worthwhile approach and encouraged communities to accept and integrate orphaned and vulnerable children.

In a qualitative study of community home-based care and antiretroviral adherence in Swaziland, Root and Whiteside (2013) reported that care supporter practices which facilitated adherence to ART played a crucial role in community home based care. This was particularly relevant in rural areas with few governmental support structures (for instance, hospitals and clinics). Care supporters were noted as being actively engaged in the client's experiences of sickness and experience of stigma and discrimination which made them a key part in the client's support structure. The research concluded that care supporters need on-going training and support.

In striving for zero discrimination in health care, Hirnschall (2016) indicates that while many healthcare workers are among the most inspiring advocates for providing decent and stigma-free care there are also others that do not (they still stigmatise and discriminate). The author notes that one important issue is a move away from specialised HIV services to a model of de-centralised, integrated health services. It was noted that this is welcomed as it roots HIV/AIDS services firmly in day-to-day healthcare which is a cost saving measure as well as being able to deliver services to more communities and is a people-centered approach.

The World Health Organisation (WHO, 2012) reported that the advent of HIV/AIDS related stigma had stimulated sectors of South African society to engage in joint and individual strategies to combat stigmatisation and discrimination. It stated that since South Africa has the highest incidence and prevalence of HIV/AIDS infection, innovative psychosocial interventions should be pioneered in the country. In research conducted by the organisation a comprehensive approach was used focusing on the varied facets of HIV/AIDS psychosocial afflictions that PLHWA suffer from in South Africa. The research concluded that existing school health programmes should be strengthened to focus on HIV/AIDS related stigma and discrimination. Furthermore, it was suggested that national sport activities, particularly codes like soccer, rugby and cricket should lead the way in fighting HIV/AIDS related stigma. The use of music and songs that shun HIV/AIDS

related stigma was noted as having the ability to encourage a stigma-averse society and thus promote the mental health of PLWHA. For practicing Christians it was suggested that all South African churches should hold provincial interdenominational congregations twice a year, to discuss issues related to HIV/AIDS stigma and promote awareness of the discrimination that PLWHA face. It was further suggested that the print, digital and electronic media provide wide coverage of these events.

The Department of Social Development (DoSD, 2014) reported that psychosocial support may include a range of actions for instance, love and affirmation through foster parenting, adoption and for instance, living in a place of safety. Children should also have their basic rights realised (protection, nutrition, development, health care and participation). It is also important that children are listened to and that caregivers assist them when they find it difficult to cope. Caregivers should also ensure that children have peer friendships and mix socially which helps them develop life skills. The department also asserts that as there are many orphaned children in South Africa therefore the need for psychosocial support is great and should remain one of the key priorities of government and civil society groups.

2.15 Religion and HIV/AIDS

According to Reyes-Estrada, Varas-Diaz and Martinez-Sarson (2015), the physical and emotional health of many people suffering from chronic illnesses is influenced by religion. Furthermore, the use of religious beliefs and practices (for instance, praying) in nurse-patient interventions has been documented as being an important factor in the well-being of patients. Conversely when serving highly stigmatised populations, such as PLWHA, health professionals need to be aware of the potentially harmful effects of religion on HIV/AIDS stigma. The religious socio-cultural phenomenon has been shown by many studies to play an important role in the manifestation of HIV/AIDS stigma, for instance, some religions perpetuate blame in terms of those who are perceived to have many different sexual partners. If this reality is overlooked it could have detrimental effects on the well-being of PLWHA such as low adherence to treatment and poor physical and emotional health.

Muturi and An (2010) in their qualitative study of HIV/AIDS and religiosity among African American women observed that many negative attributions were involved related to HIV/AIDS and stigma surrounding PLWHA. They further observed the influence of religious leaders to the stigma surrounding HIV/AIDS infection was often, in terms of Christianity, viewed to be a result of sinful acts and immorality. The individual is seen as becoming sick with HIV/AIDS as a consequence of

such behaviour. Those who are infected with HIV are described with words such as ‘unclean’ and ‘impure’, which results in their stigmatisation. Religious and moral values lead other people to conclude that having HIV/AIDS is a result of moral fault and thus worthy of punishment. Religious teachings that support such perceptions are many in the Bible, for instance, verses like “the wages of sin is death” (Romans, 6:23, New Testament, 2013) or “for all have sinned and come short of the glory of God” (Romans, 3:23, New Testament, 2013). However, other interventions reflect the role of faith-based organisations and religious leaders in dealing with AIDS related stigma in a positive, compassionate and empathic manner (Fonchingong, Mbuagbo, & Abong, 2009).

A study was conducted on the prevention of transmission of HIV/AIDS through local social organisations in the Jember fishing community in Uganda. The study revealed that increased knowledge, awareness, and supportive behaviour related to HIV/AIDS in Islamic study group members is higher than Christian group members in this community. This is because the Islamic study group is purely a religious association and members are mentally and qualitatively better prepared for dealing with PLWHA than Christian or non-Christian members of the community. It was noted that conditions that existed in the Islamic community in particular were consistent with previous research which indicated that the involvement of religious leaders helped in destigmatising HIV/AIDS (Hanizar, Adzkiyak, & Swastika, 2014).

According to Kagimu et al. (2012), individuals who are not religious are more likely to become infected with HIV/AIDS. The authors looked at the following dimensions of religiosity in their study which they propose could account for this finding. Participants who were not HIV positive felt their religiosity played a part in this (morality). They reported to feeling guided by God; feeling thankful for God’s blessings; praying privately; trying hard to be patient in life and trying hard to love God. Higher infection rates were associated with having multiple life-time sexual partners, drinking alcohol, and using narcotics for recreation. The authors concluded that utilising religion norms could have an important role in HIV/AIDS prevention.

However, Kagimu et al. (2012) reports that many Christian and other religious leaders are as susceptible to discriminatory behaviour as lay people although they hold more power (in terms of authority in a church and/or religious setting). This imbalance of power is facilitated by such structured inequalities within churches such as the pre-eminence of clergy over laity, of men over women, and even by the presumed superiority of the more spiritual over the less so. Under the influence of western missionaries many South African Christian organisations still promote evangelical formulae in which, it is taught, creation was originally good, but then the fall of humankind occurred, which is bad, and finally, redemption is available only for the chosen. This

theological approach warrants stigmatising people as saved or sinner which strengthens the broader social groups within which stigma flourishes. This can also add to stigmatisation of PLWHA in communities where this type of religiosity exists.

Marshall (2015) quotes Archbishop Desmond Tutu as referring to the HIV/AIDS pandemic as a new apartheid (because of stigmatisation and discrimination) on a global scale. The Archbishop said the virus works in close alliance with poverty, ignorance, complacency, discrimination and inequality. The pandemic's devastating impact is the greatest in areas where inequality exists. The Health Minister of South Africa echoed the sentiments of the Archbishop when he referred to the new Sustainable Development Goals (SDGs) that the United Nations General Assembly passed in September 2015. Partnership is central to the SDGs with critical roles for faith-based organisations. The Minister suggests the following roles for faith – based organisations: support for access to universal health care; dealing with the challenges of stigma, especially discrimination in relation to HIV/AIDS, Tuberculosis (TB), Leprosy and albinism; promotion of palliative care; spreading the message of healthy lifestyle; reduction of interpersonal violence; help governments in caring for the poor, giving dignity and assist the destitute.

Churches occupy an important social and cultural position in Madagascar. The sexual transmission of HIV is controversial. Many Christian church leaders in the country could become important players in HIV/AIDS prevention if they improved their knowledge of the illness and their commitment to international recommendations. They also need to interact with PLWHA and with individuals who are most at risk of contracting the retrovirus. Essentially, they need to let go of any stigma and discrimination they might feel, which have been influenced by traditional morality and bigotry in the Christian churches in the region (Rakotoniana, Rakotomanga & Bareness, 2014).

According to AVERT (2015) there are many reports in Africa of PLWHA receiving discriminatory treatment, including ostracism from faith organisations because of their status. Airhihenbuwa (2007) states that this has sometimes resulted in PLWHA being summoned for special prayers or confessional sessions before congregations, often based on fraudulent and persistent claims about miracle cures for AIDS. Exaggerated fears of contagion have led to PLWHA being ordered to be last when taking Holy Communion in churches, or being excluded from religious rites altogether. Spirituality encompasses beliefs and value systems that range from organised religion to individual and/or collective values which represent guiding principles on which meanings are based. These values have proven relevant for HIV/AIDS prevention, care and support. The author suggests that obvious neglect of African spirituality, in terms of prevention and interventions related to the pandemic makes the discourse on spirituality and health incomplete.

Religious institutions have displayed a wide variety of responses to the HIV/AIDS pandemic, with most expressing condemnation of HIV/AIDS stigma. Nevertheless, because HIV is transmitted by behaviours that are condemned by many religions, the religious response to AIDS has often been ambiguous (Herek & Mitnick, 2002; Nqojane, 2009). There is also evidence that religious leaders can be sensitive to the needs of PLWHA and can play a major role in promoting a culture of acceptance and respect for PLWHA, including notions of responsibility and tolerance (Maponyane, 2012). Provision of spiritual and moral care to those infected and affected by HIV/AIDS is necessary because they may experience a range of difficult emotions, including fear of death, depression, suicidal ideation, guilt, anguish, anger, denial, shock, rejection, and isolation arising from stigmatisation (Herek & Mitnick, 2002; Maponyane, 2012).

2.16 Stories of lived experiences of PLWHA

The stories and lived experiences of PLWHA who experienced stigma and discrimination were narrated by several individuals under the auspices of SANAC (2015). One story is that of fifty six year old Cindy Pivacic who was infected by her partner, who knew he was HIV positive. She noted that it took her six years to reveal her status. She was afraid that if she told people she was HIV positive she would be rejected. After six years she decided to reveal her status with the thought that if people did not want to be around her because she was HIV positive, then she did not need them in her life. After coming to terms with the fact that some individuals would reject her she was able to disclose her positive HIV status and stated that she would be resilient to all forms of stigmatisation.

Twenty three year old Koketso Mokhetso reported that she was born HIV positive. In 2015 she turned twenty four and reported that she was now the mother to a healthy HIV-negative baby. When she was first diagnosed she stated that doctors told her she would not live beyond thirteen and that she would not be able to have children. Her partner knows about her positive status but did not take it well at first. After doing a couple's test, he could not believe that he was HIV positive as well. His attendance at support groups has helped him cope and accept the challenges associated with being HIV positive (SANAC, 2015, p.3).

Another story belongs to Mongezi Sosibo, a twenty three year old student who loves writing. He reported that he accused one of his girlfriends of infecting him with the retrovirus after testing HIV positive. However, soon thereafter he came to the understanding that he lacked knowledge and understanding of the pandemic when she was tested negative (on several subsequent occasions). He disclosed his status to his mother by telephone and to his father by text message as he felt his mother would be more understanding (thus spoke to her). Mongezi's belief is that people stigmatise

others due to ignorance and that this applied to him before he became knowledgeable about the pandemic. True to his belief, gossip about his personal life soon surfaced, he heard that he was gay and now tries to educate other people about HIV/AIDS facts and myths (SANAC, 2015).

Nomasimo Limako is a forty year old disabled person. She went for Voluntary Counselling and Testing (VCT) as soon as she suspected she was HIV positive. She was very distressed when her HIV positive status was confirmed. She confronted her boyfriend about this as she was sure it was his fault. She was astonished to learn that he knew he was HIV positive and had picked her as a girlfriend because she was disabled. He thought that having sex with a disabled person would cure him of his HIV infection. She now lives as a single parent to her children and after four years of knowing her positive HIV status felt secure enough to reveal it to her family and others. Her greatest wish, as a disabled person, is to represent women on challenges related to HIV infection (SANAC, 2015).

Phindile Nomasimo Madonsela, a blood donating Traditional Healer, was issued an envelope and refused permission to donate blood when she went to do so in 1997. After following the advice of the technicians at the venue she went to see a doctor. The doctor opened the envelope and told her that she was HIV positive. This was quite shocking at the time and the news was not related in an empathic manner as VCT was not commonplace where she lived (and in that year). She has come to terms with her status and helps those infected with the retrovirus as a traditional healer (SANAC, 2015).

Thirty four year old Simphiwe Dlamini became HIV positive when she was in Grade 12, after giving birth. She became severely depressed and took medication belonging to her grandmother in a suicide attempt. Her grandmother, who was aware of Simphiwe's status, managed to wake her up which resulted in her being treated and not dying. The grandmother then asked Simphiwe if she wanted to live for her child. Since that day Simphiwe developed a strong purpose in life, to live for her child. Her grandmother and father support her unreservedly. However, she endured discrimination and rejection from the family of her boyfriend. Unfortunately, her boyfriend did not get tested and later became sick and finally died. His family make statements about wanting her dead even though they do not know who became HIV positive first (SANAC, 2015).

The story of Yvette Raphael is enlightening. In 2001, after she had a baby she lost weight. She went for VCT and the nurse counselled her after informing her she was HIV positive. She reported feeling dazed, confused and helpless after she left the hospital. She was taken home by a Taxi driver who she did not know and yet she told what had happened. He offered to help her. Her supervisor

at work asked her to organise AIDS day which entailed finding a guest speaker. She did not find a speaker so she decided that she would become the speaker. She disclosed her status to eighty fellow workers who had assembled in the hall. Intimate questions were asked by her peers and she was confident enough to respond to them. Afterwards, it was a friend, who she least expected to be discriminatory, that hurt her the most. This 'friend' would not share cups at work. However, the majority of her fellow workers were supportive as were her family members (SANAC, 2015).

2.17 Summary

This chapter presented an overview of the global and South African research on HIV/AIDS related stigma and discrimination. Literature covered broad aspects of stigmatisation and discrimination relevant to the present study. For instance, contending with discrimination and stigmatisation, traditional African culture and HIV/AIDS in South Africa, the effects and causes of HIV/AIDS, prevention and coping with HIV/AIDS stigmatisation, cultural, social and religious aspects of HIV/AIDS stigmatisation and stories related to the lived experience of PLWHA. It was noted that the causes of HIV-related stigma are many, and are internal or external. Contending with stigma is noted as a challenge for PLWHA. Coping mechanisms vary from individual mechanisms to socio-legal approaches. It was further noted in the review that prevention of HIV-related stigma is critical to HIV management. The advent of orphans and child-headed homes as generated by HIV/AIDS has led to a challenging change in social structure demographics. Psychosocial communities' needs were addressed in the literature as was the effect of religion on HIV/AIDS related stigmatisation and challenges.

CHAPTER 3: THEORETICAL FRAMEWORK FOR THE STUDY

3.1 Introduction

For the purpose of this study Jungian Phenomenological theory was applied as a framework. This theory is suitable for qualitative research which was the approach used in this study. Phenomenology has four overlapping characteristics: description, phenomenological reduction, the search for essences and intentionality. The framework is explained in this chapter.

3.2 Definition of key terms

3.2.1 Stigmatisation

The concept of stigmatisation is often used interchangeably with that of discrimination even though the meanings differ. One of the better, although older, definitions come from Goffman (1963), who states that stigma relates to reducing a person in our minds from a whole and usual person to a tainted, discounted one. He further stated that certain kinds of disease carry more stigma than others. Diseases associated with the highest degree of stigma share the following common attributes: a) The person with the disease is seen as responsible for having the illness; b) the disease is both progressive and incurable; c) the disease is not well understood by the general public; d) the symptoms cannot always be concealed and e) the illness that is associated with sex.

Parker and Aggleton (2003), suggest that the dominant definition of stigmatisation as an undesirable difference ignores the fact that stigma is socially constructed. They oppose the idea that stigma is a static individual characteristic, and argue in favor of stigma as a social process. Ultimately stigma creates and is reinforced by social inequality within a societal context (UNAIDS, 2012).

3.2.2 Discrimination

According to Parker and Birdsall (2008), discrimination involves some form of enactment of stigma which may be verbal or physical and which is likely to be hurtful and/or harmful to the person to whom it is addressed. Discrimination involves practices such as prejudice in the workplace (which is often illegal). The stigmatised person is seen to possess a spoiled or polluted identity which is considered different or deviant to societal norms. Furthermore, Adrionasolo, Rakotoarivelo, Randiarimanana, Angjiro and Randria (2011) describe discrimination of PLWHA in term of medicine as the refusal of health professionals to manage or treat them.

3.2.3 People Living With HIV/AIDS (PLWHA)

People living with HIV/AIDS (PLWHA) are those people who are HIV infected or who have full blown AIDS (Nqojane, 2009).

3.2.4 HIV/AIDS

The acronym AIDS stands for Acquired Immune Deficiency Syndrome. Acquired means you can get infected with it. Immune Deficiency means a weakness in the body's system that fights diseases. Syndrome means a group of health problems that make up a disease. AIDS is caused by a virus called HIV, the Human Immune-deficiency Virus (HST, 2013).

3.3 The phenomenological approach

Daidsen (2013) indicates that phenomenology is the study of structures of consciousness as experienced from the first person point of view. The central structure of an experience is its intentionality, its being directed towards something, as it is an experience of or about some object. An experience is directed towards an object by virtue of its content or meaning (which represents the object) together with appropriate enabling conditions. Phenomenology as a discipline is distinct from but related to other key disciplines in philosophy, such as ontology, epistemology, logic and ethics. Phenomenology has been practiced in various guises for centuries, but it came into its own in the early 20th century in the works of philosophers such as Husserl (1859 – 1938), Heidegger (1889 – 1876), Sartre (1865 – 1945), Merleau-Ponty (1908 – 1961) and others. Phenomenology is often restricted to the characterization of sensory qualities of seeing and hearing and understanding what it is like to have sensations of various kinds. However the experience is normally much richer in content than mere sensation. Accordingly, in the phenomenological tradition, phenomenology is given a much wider range, addressing the meaning things have in our experience, notably the significance of objects, events, tools, the flow of time, the self, and others as these things arise and are experienced in people's life. Basically, phenomenology studies the structure of various types of experience ranging from perception, thought, memory, imagination, emotion, desire and volition to bodily awareness, embodied action, and social activity, including linguistics activity. The structure of these forms of experience typically involves what Husserl described by Smith (2013) as intentionality, which is the directedness of experience toward things in the world, the property of consciousness that is a consciousness of or about something.

Phenomenology is an umbrella term encompassing both a philosophical movement and a range of research approaches (Finlay, 2009). The author further states that applied to research, phenomenology is the study of phenomena; their nature and meanings. The focus is on the way things appear to us through experience or in our consciousness. Langdrige (2007), defines phenomenology as a discipline that aims to focus on people's perceptions of the world in which they

live in and what it means to them. Phenomenology has been conceptualized as a philosophy, a research method and an overarching perspective from which all qualitative research is sourced. According to Merleau-Ponty (1962) phenomenology is essentially a method for studying the essences of phenomena, and the method has four overlapping characteristics: description, phenomenological reduction, the search for essences (eidetic reduction), and intentionality. Berrios (1989), indicates that the term phenomenology refers to a set of philosophical doctrines loosely sharing assumptions as to what the world is like (ontological) and what it can be known (epistemological) and strategies for the descriptive management of the mental entities relating to such a world. A more simplistic definition about phenomenology is offered by Grbich (2007) and Van Manen (1997), who suggest that phenomenology as an approach to understand the hidden meanings and the essences of an experience together. Van Manen (1997) considered phenomenology as the most appropriate method to explore the phenomena of pedagogical significance. He elaborates phenomenology as a response to how one orients to lived experience and questions the way one experiences the world. According to Langdrige (2007) the hermeneutic turn of phenomenology resulted in the opinion that our experiences can be best understood through stories we tell of that experience.

Phenomenology is commonly understood in either of the two ways: as a disciplinary field in philosophy, or as a movement in the history of philosophy. It is the study of subjective experience. The goal of phenomenological research is to almost accurately describe the lived experience in what is being researched. Revealing questions that could be used to gain an in-depth understanding of the individual's feelings that query the participants' feelings (Balls, 2009).

Daividsen (2013) indicates that a whole family of qualitative methods is informed by phenomenological philosophy. When applying these methods, the material is analysed using concepts from this philosophy to interrogate the findings and to enable greater theoretical analysis. However, the phenomenological approach represents different approaches, from pure description to those more informed by interpretation. Phenomenological philosophy developed from a discipline focusing on thorough descriptions, and only descriptions, toward a greater emphasis on interpretation being inherited in experience. An analogous development toward a broader acknowledgement of the need for interpretation, the influence of the relationship and the researcher, and the co-construction of the narrative is mirrored in qualitative analytic theory and the description of newer analytical methods as, for example, Interpretative Phenomenological Analysis and Critical Narrative Analysis, methods which are theoretically founded in phenomenology.

The phenomenological approach was started as a movement in philosophy. It deals with the

essences of objects, or phenomena as they present themselves in human consciousness. The founding father of phenomenology, Edmund Husserl (1859 – 1938), argues that through rigorous examination of objects, as they are presented in individual consciousness, the essence of those objects' realities can intuitively be known (Brooke, 1993). It is a tradition with a focus on the essence of lived experience. Those engaged in phenomenological research focus in-depth on the meaning of a particular aspect of experience, assuming that through dialogue and reflection the quintessential meaning of the experience will be reviewed. Troy, Wyness and McAuliffe (2007) in their application of the phenomenological approach, observe that qualitative approaches are associated with subjective descriptions of life experiences, in order to develop a greater understanding of the issues being considered. The goal of phenomenological research is to describe the world as experienced by the participants in the study in order to discover the common meanings and underlying empirical variations of a given phenomenon.

Dunkley (2012) indicates that epistemologically, the phenomenological approach could be said to be based in a paradigm of personal, subjective knowledge. The purpose of the phenomenological approach is to identify phenomena, as they are perceived by the perceiver, to highlight the specific, gain insight, or understanding of research participants' experiences, and emphasise the significance of a personal perspective and interpretation. This would translate into gathering in-depth information and perceptions through inductive, qualitative methods such as interviews and participant observation and representing it from the perspective of the research participants. Thus, a phenomenological approach is well suited to a qualitative method of enquiry.

Balls (2009) indicates that Brook (1993) takes the fundamental concepts of analytical Psychology and re-interprets them within a phenomenological framework in order to provide a new understanding of Jung's writing. Phenomenology as outlined by this author supports the re-examination of a taken-for-granted experience, and through examining the qualities of the experience to identify its essence. The purpose of the Phenomenological approach is to illuminate the specific, to identify phenomena through how they are perceived in a situation.

When phenomenologists investigate the imagination, they approach it by examining how objects are experienced when they are imagined (rather than, for example, perceived) and what the experience of imagining is like (as opposed to, for example, the experience of perceiving). Their inquiries into the imagination are thus part of the greater phenomenological project of clarifying the different modes in which we can experience, or be conscious of, the world (or some objects in the world) and the correlation modes in which the world (or some objects in it) can appear to us. Mostly, phenomenologists consider what is often called 'sensory' imagination, that is, the

experience in some sensory mode (such as visual or the aural) of something not actually present. Phenomenologists may, for example, investigate how our beliefs in the reality or unreality, or in the presence or absence, of things are themselves founded in different modes of experience (such as perception or imagination) and motivated by different ways in which things appear to us that is , as perceived, as imagined (Jansen, 2015).

Okoli and Uhembe (2014) posit that the purpose of the phenomenological approach is to illuminate the specific, to identify phenomena through how they are perceived by the actors in a situation. In human sphere, this normally translates into gathering ‘deep’ information and perceptions through inductive, qualitative methods such as interviews, discussions and participant observation, and representing it from the perspective of the research participant. Put simply, the phenomenological approach is an investigative method that interrogates phenomena based on human perception and experience. In effect, a phenomenological inquiry seeks to understand reality as it is perceived or experienced without reference to the question as to whether what is perceived or experienced is objectively real.

Churchill and Wertz (2013) indicate that as individuals move from simple experiential acts to more extended social, life-historical involvements, they continue to find meaning through the transcendence to the lived world. These meanings are different for each unique individual, although they can be seen to embrace many common socio-cultural structures, such as language. An authentic interrogation of any human experience shows that it is not an isolated event but rather is, according to its immanent structure, a moment of ongoing social relation between a whole ‘personality’ and the world that can be spoken about or revealed through language. The larger-order unity, outside of which no single human activity can be understood, is referred to by phenomenologists as the *lifeworld* (Lebenswelt), which provides the foundation for all scientific enquiries.

According to Lester (2013) the phenomenological approach is particularly effective at bringing to the fore the experiences and perceptions of individuals from their own perspectives, and therefore at challenging structural or normative assumptions. It is concerned with the study of experience from the perspective of the individual, ‘bracketing’ taken-for-granted assumptions and usual ways of perceiving. Epistemologically, phenomenological approaches are based in a paradigm of personal knowledge and subjectivity, and emphasise the importance of personal perspective and interpretation. As such they are powerful for understanding subjective experience, gaining insights into people’s motivations and actions, and cutting through the clutter of taken-for-granted assumptions and conventional wisdom. Fundamentally, man’s negativity is most critically present

in death. For death is not only the ultimate limit to natural life; but man can consciously anticipate, and indeed may freely choose death. For Hegel not only the life-and-death struggle and the slave are marked by the stark evidence of mortality, however, but also unhappy consciousness, the ethical order, absolute freedom and terror and revealed religion.

3.4 Jungian Phenomenological Theory

In this study a Jungian phenomenological approach was used as a frame work of the study. According to Brooke (1993), Jungian phenomenology is primarily and thoroughly descriptive and real, as it presents within life. It is the core of the phenomenological approach. The collective unconsciousness describes the psychological experience of human beings, as a pattern of responses that reach into past experience. An advantage of the approach is that it provides an understanding of self and experience from those who have lived it. According to Brooke (1993) Jung used the term instinct referring not to food, sex and warmth but to any action or psychological tendency that is not a function of an individual's consciousness. The self is the totality of one's potentialities given in a unique blend which forms each individual's personality.

The Jungian phenomenological approach allowed the researcher to explore the essence of human experiences concerning a phenomenon as described by participants in their own interpretation. It examined human experiences through detailed descriptions of people being evaluated. The approach assumes the perspective that human behaviour is not as easily observable and measured as a phenomenon in the natural sciences. Human motivation is shaped by factors that are not always observable, for instance, inner thoughts (Brooke, 1993). The following aspects of Jungian Phenomenology were taken into account (adapted from Brooke, 1993).

3.4.1 Description – phenomenology is mainly and methodically descriptive. “Theoretical and scientific hypotheses and accounts are distrusted if they have come to be generally accepted as the unquestioned prejudices of the community at large” (Brooke, 1993 p. 31). The psychological experience must be described in its own terms that access a spiritual experience in a non-reductionist manner. Through description, the phenomenologist aims to see beyond what is physically observable. The description has to be conducted repeatedly and each experience would be a deeper expression of what was appreciated before. Finally the real description of the observed phenomenon will emerge and even that may not necessarily be the final account of the phenomenon. What is certain to the phenomenologist is that through careful, meticulous, repeated appraisal, and description of a phenomenon, a phenomenon's true and original aspects would be unraveled.

According to Giorgi (2012) a large part of phenomenology is descriptive but this does not rule out phases where interpretation also takes place. Phenomenology does not dictate to phenomena but rather it wants to understand how phenomena present themselves to consciousness and the elucidation of this process is a descriptive task. Description is the use of language to articulate the intentional objects of experience. The process of describing is similar to what takes place when one interprets but in the former case the analysis takes into account noetic (acts) factors that are usually not referred to by interpretive theorists working in the realm of the social sciences (but they could be).

3.4.2 Phenomenological reduction – when interpreting a phenomenon, phenomenologists have to give up or put aside their philosophical prejudices. According to Brooke (1993, p. 33), this involves a “mental leap known as phenomenological reduction which involves the bracketing of being or the epoch which means the disconnection from the researchers natural attitude.” A natural attitude pre-disposes an individual to conscious or unconscious prejudice. The reduction will thus ensure that the phenomenological interpretation is descriptive and that the meaning should present itself to the researcher (and reader) and not be a prejudiced assumption of the researcher.

In scientific psychology research, a hypothesis is put which represents an anticipated biased outcome of the researcher. Even at the end of the result presentation, the bias of the researcher is almost always referred to when considering the final outcome of the research. In phenomenology, the bias is reduced as a precondition, so that the final result should be devoid of its influence. The bias referred to may emanate from earlier experience, accumulated knowledge and or informed opinion. A high toll is thus anticipated from the phenomenologist to revert to a pure natural position of being non-judgmental, open, and intuitively intrusive towards the original behaviour being observed (Giorgi, 2012).

According to Giorgi (2012) the researcher who wants to employ the descriptive phenomenological psychological method has to begin by assuming the correct attitude. First, the researcher has to assume the attitude of phenomenological reduction which means she must resist from judging as existing whatever object or state of affairs is present. The researcher still considers what is given to her but treats it as something that is present to his or her consciousness and refrains from judging that the way it is presented is the reality. In addition, the researcher refrains from bringing in non-given past knowledge to help account for whatever is present. The researcher concentrates on the given as a phenomenon and

everything that is said about the phenomenon is based upon what is given. Since the analysis is intended to be a psychological one the researcher also assumes a psychological attitude toward the data. Finally, the researcher's adopted attitude must also include special sensitivity toward the phenomenon being investigated.

3.4.3 The search for essences – the following points concerning the eidetic (process of discrimination and articulation) reduction can be noted. “The essence of a phenomenon is within the thing itself and must not be confused with empirical contingencies” (Brooke, 1993, p. 37). Essentially, one must not confuse empirical possibilities (what you know or judge as likely) with the principles of the phenomena as they reveal themselves. The essence is discovered by bracketing one's attitude or prejudices and allowing meanings to be naturally discovered. These essences or meanings are revealed in the researcher's consciousness which is not passive but attempts to transcend any judgments or biases s/he has (Brooke, 1993). The phenomenologist looks for the indisputable quality of the phenomenon, the pure psychological and “phenomenological extract of the phenomenon akin to the final product of the process of quintessential wine distillation” (Brooke, 1993, p. 350).

3.4.4 Intentionality: According to Brooke (1993), intentionality is not an aspect of the phenomenological analysis. It is a characteristic of consciousness that is presupposed in any phenomenological analysis. Consciousness is a consciousness of something. This level of consciousness is the ontological ‘there’ of world-opening which makes it possible for a thing to ‘be’ and consciousness to be appropriated as ‘someone's’. Intentionality means that consciousness is always focused and necessarily directed towards an object that is other than consciousness itself. In short, consciousness is that irreducible, non-optional occurrence within which the world comes into being. Brooke (1993, p. 150), notes that:

“From nothing, in the early times, something as colossal as the universe emerged, today. Intentionality, as propounded by Jung, emanates from this epoch changing reality. It presents intentionality as the initial consciousness that gave birth to the simplified consciousness as experienced by an individual. It is the mother consciousness that binds all that constitutes the existential consciousness in psychology. It is an element of the larger purpose of the master plan that led to creation as broadly as we know it today.”

3.5 Summary

Phenomenology was explained as was the Jungian phenomenological approach which is used in this study as a framework. The framework has the potential to penetrate deep to the human experience and trace the essence of a phenomenon and explicate them in their original form as experienced by individuals. Jungian phenomenological theory has wide spread recognition and was deemed appropriate for use in the present research.

CHAPTER 4: RESEARCH METHODOLOGY

4.1 Introduction

This chapter outlines the research design and approach used by the study. The population, sampling, data collection and analysis are presented and ethical matters outlined.

4.2 Research design

The research design for the study utilised a qualitative approach underpinned by Jungian phenomenology as a theoretical framework and tool for analysis of data.

4.2.1 Research approach

A qualitative approach was used in this study because it allows a rounded explanation of individual behaviours and attitudes. A qualitative approach allows the participant's thoughts and feelings to be expressed as themes which give in-depth, rich information. This is in contrast to a quantitative approach which uses hypotheses and presents a systematic view of phenomena by specifying relations amongst variables as explanations for natural phenomena (Creswell, 2003). However, this does not allow for an understanding of the views and perceptions of people (Creswell, 2003). In this study the researcher wanted to gain an understanding of participants' feelings thus a Jungian phenomenological approach which details in-depth experience through the use of metaphors and archetypes was considered appropriate. This considered more appropriate by the researcher than for instance, a psychoanalytic or psychodynamic approach as the feelings and experiences of the participants developed naturally through narratives which allowed the emergence of metaphors which are consistent with storytelling metaphors used in an African context.

4.3 Area of the study

The research was conducted at Elim in Makhado municipality within Vhembe district. The area is populated largely by Xitsonga and Tshivenda speaking people. The people live an agrarian lifestyle characterised by informal subsistence agriculture. The majority of the families in the area live in poverty.

4.4 Population

A population refers to all members of an identifiable group (Welman, Kruger & Mitchell, 2006). It refers to a group of people, from a population, which has the characteristics the researcher wants to study (Castillo, 2009). The population sample was drawn from individuals who are HIV positive or already suffering from AIDS at Elim, under Makhado municipality, in the Vhembe District and who attended the HIV/AIDS clinic at Elim Hospital in Makhado municipality, under the Vhembe

District of Limpopo Province during the period of study. This population was deemed appropriate as recent statistics indicate an HIV/AIDS prevalence of nearly forty percent in the area (Magadzi, 2013).

The upper-bound poverty line in the area according to Statistics South Africa (2011) was R623 per month and the lower-bound poverty line was R321. In terms of the study this is a largely disadvantaged area where there is much poverty which is often linked to high prevalence of illness such as HIV/AIDS (UNAIDS, 2014).

4.4.1 Sampling method

According to Welman, Kruger and Mitchell (2009) and Terre Blanche, Durrheim and Painter (2009) sampling is used in research when the researcher is unable to investigate the total population which is involved. Non-probability sampling was used, in this case purposive sampling, in which the researcher made judgments as to whether the sample matched the characteristics required by the research. The interviews were conducted with fifteen PLWHA who were members of the Elim community. HIV positive males and females aged eighteen years and older were approached to participate. The semi-structured interviews took place until saturation of answers to the questions (individual testaments) was reached. Essentially, this meant that if no new information was forthcoming after interviewing ten HIV positive individuals, no more interviews would be conducted. However, if new information was forthcoming, interviews would continue until saturation was reached. In the present research, after fifteen interviews, no new information was forthcoming as saturation was reached.

4.4.1.1 Inclusion criteria

An inclusion criterion was:

Individuals eighteen years of age or older, who were HIV positive or who had full-blown AIDS and who attended the clinic at Elim hospital.

4.4.1.2 Exclusion criteria

Exclusion criteria included individuals:

- a. who attend the clinic at Elim hospital but who are not HIV positive or do not have AIDS;
- b. further exclusions were individuals who are HIV positive or who have AIDS but were under 18 years of age;
- c. And/or people who were HIV positive and had AIDS but were too ill to take part.

4.5 Research instrument

A semi-structured interview protocol underpinned by Jungian Phenomenology was used (See Appendix 1). A semi-structured interview is a method of research used in the social sciences. While a structured interview has a rigorous set of questions which do not allow one to divert, a semi-structured interview is open, allowing new ideas to be brought up during the interview as a result of what the interviewee says. The interviewer in a semi-structured interview generally has a framework of themes to be explored (Lilienfeld, 2008; Terre Blanche et al., 2009).

The protocol was translated into the relevant vernacular and respondents were able to choose if they wanted to be interviewed in Tshivenda, Xitsonga or English. The interview protocol was used with the aim of obtaining insight and an in-depth understanding of the phenomena under investigation. The focus of the interview specifically dealt with the effect of HIV/AIDS stigmatisation on PLWHA, and their experience of stigmatisation and discrimination. As the topic needs some direction a semi – structured interview guide was constructed however, it must be noted that probing for in-depth information was undertaken. This allowed for the feelings and experience of individuals to emerge naturally and allowed freedom of participation by the participants. It also allowed the researcher to gain an in-depth understanding of the lived experience of the individual participant.

4.5.1 Entry Negotiation

The researcher is a Clinical Psychologist who visits clinics in the area. Entry was negotiated through the hospital management that the clinic falls under and the Department of Health in Limpopo Province. The nurse/manager in charge of the clinic was also approached in this regard and permission was granted through her auspices. Ethical guidelines through the Health Professions Council of South Africa (Psychology Board) were followed as were ethical procedures through the University of Limpopo ethics committees.

4.5.2 Pre-testing

The data collecting instrument (questionnaire) used was underpinned by a reading of the literature in the field. The questionnaires were pre-tested on two individuals, who attended the clinic, and any bias, double meanings or other problems with questions were rectified. This data was not used in the study. The research design and its implementation was planned and accomplished at a considered level as were the operational details of the data collection. As the aforementioned were given in detail and the procedures decided on were carried out in the field the reliability of the qualitative study was ensured.

4.6 Data collection

An exploratory interview was conducted using a schedule constructed from a combination of guide questions derived from reading of relevant literature underpinned by Jungian Phenomenology. The researcher was placed at Elim Hospital. She visited the local HIV/AIDS clinic which was operating within the hospital to collect data when permission from the university and hospital committees was granted. An audio recording of the interviews took place after the participant gave permission for the recording. The researcher also took notes during the interview sessions with the approval of the participant. The interviews were about an hour long per individual with an extra 15 – 30 minutes for debriefing. Debriefing was applied to deal with the patient's emotions and other possible trauma that each participant went through during the interview, as a result of re-living unpleasant experiences (debriefing was conducted after each interview).

Debriefing is a process of receiving an explanation of a study or investigation after participation is complete. Debriefing is a semi-structured process by which the facilitator, once a certain activity is accomplished, makes a series of progressive questions in this session, with an adequate sequence that let the participants reflect what happened, giving important insights with the aim of that project towards the future, linking the challenge with the actions and the future. Debriefing is a one-time semi-structured conversation with an individual who has just experienced a stressful event. The purpose of debriefing is to reduce any possibility of psychological harm by informing people about their experience or allowing them to talk about it (Green, Friedman, & de Jong, 2007). Furthermore, in psychological research, debriefing is a short interview that takes place between researcher and research participants immediately following their participation in a psychology experiment. The debriefing is an important ethical consideration to make sure that participants are fully informed about, and not harmed in any way by their experience in an experiment (Bisson, Foa, Keane, Friedman & Cohen, 2009). It is further noted that participants must be thoroughly debriefed at the end of the study. They must be given a general idea of what the researcher was investigating and why, and their participation in the research should be explained. They must be told if they have been deceived and given reasons. They must be asked if they have any questions and those questions should be answered honestly and as fully as possible.

A follow up interview took place which was thirty to forty minutes long. In the follow up interview participants were asked to verify meanings the researcher found through analysing the data from the original transcripts. If these meanings were incorrect the participant was allowed to clarify the meaning. This collaboration resulted in the researcher gaining an in-depth understanding of the phenomenon under investigation. Interviews were conducted in Xitsonga and/or Tshivenda since

these are the dominant languages at Elim. English was used if the participant preferred that language. The following steps were used in the introductory phase to the interviews: a) the researcher arrived at the Elim clinic, by car, half an hour before the scheduled interview to ensure the venue was set up appropriately; b) warm greetings according to the Xitsonga and Tshivenda cultures were observed to ensure the participants felt respected and welcomed; c) to facilitate rapport and observe courtesy, inherent to the Xitsonga and Tshivenda cultures, the researcher asked how participants arrived at the clinic and how they felt; d) a time limit was set for each interview; e) the participant was told about the reasons for the research and its value to the participant and the community and lastly f) clarification was given by the researcher to any areas that the participant identified as contentious or problematic.

4.7 Trustworthiness of the study (Quality criteria)

- Credibility was established as follows: Frequent de-briefing sessions were held between the researcher and her promoter. These sessions were used by the researcher to discuss alternative approaches, ideas or meanings inherent to the data. The meetings also provided a soundboard for the researcher to test her developing ideas and interpretations. Probing from the promoter helped the researcher to recognise her own biases and preferences (Porter, 2007; Terre Blanche et al., 2009).
- In terms of transferability the Psychology Department and relevant University of Limpopo committees' scrutinised the proposed research before permission was given to carry it out. The researcher used the feedback to fine tune the proposed research. This enabled the researcher to polish the proposed methods, develop the research design and strengthen the arguments made in the proposed research (Terre Blanche et al., 2009; Shenton, 2007).
- The researcher, in respect of dependability, had follow up interviews with the participants in which transcripts of the collected data were discussed. This was to verify that the in-depth experiences as expressed by participants during the interview process were the same as those that were revealed during data interpretation (Gallagher & Zahavi, 2014; Terre Blanche et al., 2009).
- In terms of conformity the researcher studied both quantitative and qualitative findings on discrimination and stigmatisation of PLWHA. This was an examination of previous research findings, as recorded in relevant literature, which ensured that she had an excellent grasp of the phenomena under investigation (Shenton, 2007; Terre Blanche et al., 2009).

4.8 Data analysis

Gale, Heath, Cameron, Rashid and Redwood (2013) indicate that phenomenology sits within a broad family of analysis methods. These approaches identify commonalities and differences in quality data, before focusing on relationships between different parts of the data, thereby seeking to draw descriptive and/or explanatory conclusions clustered around themes. In this investigation data, from participants responses will be presented in themes related to archetypes found in Jungian Phenomenology.

Phenomenology seeks to create meaning of individual life-worlds by drawing on commonly held individual beliefs or world views (Haralambos, Holborn & Heald, 2006). This knowledge principally involves an individual's consciousness of the world around him or her and the meaning they attribute to it. Phenomenology therefore seeks to interpret and understand the meaning of things. It does not try to explain how the *things* or *phenomena* came about. In the data analysis a Jungian phenomenological viewpoint will be used to highlight the in-depth emotions of the participants with reference to how *they feel* and how *they experience* their emotions. HIV/AIDS and the stigma associated to it have a devastating impact on individuals both physically and emotionally. It is this impact the study seeks to understand. Phenomenology is thus an appropriate method to help with an in-depth understanding of the foundations of knowledge in everyday life. Jungian phenomenology uses symbols and archetypes as an interpretative framework. In this study they will be used to interpret data gleaned from participants. Jung (Brooke, 1993) postulated that humanity had a collective unconscious, which consists of pre-existent forms or archetypes which are not individual but part of the consciousness of humanity and which give definition to specific psychological content. For instance, archetypal figures such as the Hero, the Innocent and the Orphan are archetypal images which are the archaic remains of archetypes or primordial images. There are five main metaphors, used in Jungian phenomenology (adapted from Brooke, 1993) which will be used as a basis with which to support and interpret data from the in-depth interviews.

4.8.1 The Self is the centre of the psyche which helps the individual become the person they can become. The Self helps individuation. The individual is a collection of archetypes. It is that part of an individual which changes throughout life and is what an individual aspires to be. The self is an archetype that represents the unification of the unconscious and conscious of an individual. The creation of the self occurs through a process known as individuation, in which the various aspects of personality are integrated. Jung often represented the self as a circle, square or

mandala (Brooke, 1993). The Self is the regulating centre of personality and mediates between the conscious, unconscious and collective unconscious (Hall, 2007). The true Self cannot emerge until other system of the personality has fully developed when the individual moves from sole reliance on the conscious ego to a middle ground between the conscious and the unconscious. The emergence of a more spiritual, philosophical self is the result of an optimal blending of conscious and the unconscious (Nystal, 2009).

4.8.2 The Shadow is something within all of us that we can either choose or not choose to know. It lies beneath the surface and is often associated with negative impulses or sides of an individual's character. The shadow is an archetype that consists of the sex and life instincts. The shadow exists as part of the unconscious mind and is composed of repressed ideas, weaknesses, desires, instincts and shortcomings. This archetype is often described as the dark side of the psyche, representing wildness, chaos and the unknown. These latent dispositions are present in all of us, Jung believed, although people sometimes deny this element of their own psyche and instead project it onto others. The shadow is the antithesis of the persona. It is the reservoir of those characteristics we find most repugnant in ourselves and attempt to disavow. The shadow is manifested by the defence mechanism of projection. The Shadow can be acknowledged as the integral part of the individual's personality development that requires considerable moral effort because it challenges the positive image the individual wishes to present to the world (Nystal, 2009).

4.8.3 The Anima is a representation of femininity that does not represent the female per se but helps us connect (within our dreams) with femininity in all of its aspects. It allows males to have a better connection to females and femininity. Anima is the feminine side archetype in men. It is responsible for certain characteristics stereotypically associated with the opposite sex. The anima may behaviourally manifest itself as tenderness in the man. The anima is the feminine image in the male psyche. These opposite sex characteristics allow each sex to understand and react appropriately to the other. Jung believes that these archetypes come from millennia of generations of men and women living together and slowly picking up parts of each other's personalities (Cherry, 2011).

4.8.4 The Animus is similar to the anima but represents masculinity and helps females to understand and communicate with a man and things masculine. Animus is the masculine side archetype in women. It is also responsible for certain characteristics stereotypically associated with the opposite sex. The animus is manifested as aggressive behaviour in the women. The animus is a male image in a female psyche. Both represent the “true self” rather than the image we present to others and serve as the primary source of communication with the collective unconscious (Cherry, 2011).

4.8.5 The Persona is what we, as individuals, present to the world. It is sometimes referred to as a mask which helps protect us from negatives. Problematically, if the mask or Persona becomes ingrained, the image we have of ourselves (and which we may present to the world) is not entirely true. The persona is the thick shield that covers the ego. It develops during childhood and is the public image that the individual allows others to see. It is the compromise that one must make between personal desire and those of society. Persona is the conscious everyday component of the self and is reflected in various roles, such as work, family, leisure and social settings. The goal of individuation is inversely related to one's persona. That is the more one is aware of the social, personal self and operates on it, the less one is able to understand the act on the private, personal self. The persona is how we present ourselves to the world. The word Persona is derived from a Latin word that literally means 'mask'. It is not a literal mask, however. The Persona represents all of the different social masks that we wear among different groups and situations. It acts to shield the ego from negative images. According to Jung, the persona may appear in dreams and take a number of different forms (Cherry, 2011).

4.8.6 There are many other Jungian archetypes which display patterns of behaviour referred to in Jungian psychology however, other ones, which are referred to within the ambit of an interpretation of Brooke's (1993) Jungian Phenomenology, in terms of this research are noted below.

4.8.6.1 The Innocent – is an archetypal pattern of naivety which is exemplified as a saint, romantic, dreamer or a traditionalist who wants to do things in a correct manner and fears being punished for doing wrong (Stevens, 2006).

4.8.6.2 The Orphan – a characteristic pattern of wanting to be equal and is characterised by a lack of pretense. The archetypal pattern denoting this character is a realist who is scared of not being able to connect with others or being left out and/or standing out in anyway (Stevens, 2006).

4.8.6.3 The Hero – a pattern of courageous acts through a desire to prove self-worth who fear vulnerability but can be arrogant (Stevens, 2006).

4.8.6.4 The Caregiver – an archetypal pattern displaying a desire to protect others who fear selfishness and ingratitude. Is inclined to martyrdom but can be known a saintly and altruistic (Stevens, 2006).

4.8.7 Formulated statements were attached to meanings which were integrated into a narrative description commensurate with Jungian Phenomenology. The statements were used as a basis for understanding the individual in his or her authentically expressed lived experience or psychological life as interpreted by the researcher who bracketed (put aside) her biases. In the statements of interpretation the researcher attempted to indicate how some challenges to the participants' integrated statements could be overcome and, where appropriate, contextualised the background to their responses. When participants' answers to questions reached saturation of content a selection of responses was presented in order to prevent repetition. However, some comparable responses are presented in order for the similarities of experience presented in the data, which undoubtedly relates to the comparable traditional socio-cultural context and educational levels of the participants, to be understood by the reader.

4.8.8 Participants' responses related to HIV/AIDS stigma reduction and their conscious experience of coping mechanisms are also presented by interrogating the transcripts. This was carried out in order to give an indication of the lived reality of their experience (coping) and how participants' constructed responses to HIV/AIDS stigma reduction.

4.9 Study research questions

The study had the following research questions.

- What individual effects do PLWHA experience because of stigmatisation and discrimination?
- What effect does HIV/AIDS stigma and discrimination have on PLWHA in their socio-cultural context?
- What kind of stigmatisation and discrimination do PLWHA's experience?

4.10 Bias in the study

According to Welman et al. (2009), bias can range from errors in using measuring systems to the prejudices and opinions of the researchers involved. Silverman (2006) and Gallagher and Zahavi, (2014) state that the concept of self, as a researcher, in relation to the topic of the research is a pre-condition for coping with issues related to researcher bias. The researcher focused on the purpose of the study, which is the effect of stigmatisation and discrimination amongst PLWHA.

To minimise bias in the current study, the researcher undertook the following: a) she was careful in making interpretations according to the research findings and *put aside* any existing judgments; b) she ensured ethical practice when conducting the research; c) she engaged in constant reflections of her own opinions and prejudices in terms of the data; d) the researcher ensured there was an audio recording when (or if) the participant gave permission and ensured that accurate, detailed field notes were taken. These notes included reflections on the researchers objectivity which was discussed with her promoter so that any subjective interpretations were identified; e) she engaged in *bracketing*, which involved putting aside pre-conceived notions so that the researcher was as objective as possible and; f) the researcher had regular, scheduled meetings with her promoter who acted as a mirror in reflecting the researcher's biases, feelings and prejudices in order to *bracket* personal bias.

4.11 Ethical considerations

The researcher arrived on time at the designated place. Permission to conduct the research was gained from relevant bodies of the University of Limpopo. Ethical guidelines, as laid down by the Health Professions Council of South Africa, Psychology Division were followed.

4.11.1 Informed Consent

Informed consent means that research participants have the right to be informed about the nature of the research and the right to withdraw at any time (Gallagher & Zahavi, 2014; Silverman, 2006). Informed consent was sought from each participant. The researcher took active and positive steps to maximise the possible benefits for participants, show respect, reduce possible harm and encourage participant's freedom of thought and actions. Participants reserved the right to participate or not to participate in the study so that they felt respected and thus able to follow research requests, answer truthfully and were keen to return for follow up interview. Participants were informed about the significance and relevance of the study. The nature and aim of the research were explained to the participants and it was ensured that participants understood the information. According to Shaughnessy and Shenton (2007) researchers obtain informed consent from participants to ensure that they explicitly express a willingness to take part in the research after having been informed about the nature of the study (see appendix 4).

Gallagher and Zahavi (2014) indicate that the most important goal of informed consent is that the individual has an opportunity to be an informed participant in any research decisions. It is generally accepted that the informed consent includes a discussion of the following elements: The nature of the decision/procedure; any relevant risk, benefits, and uncertainties related to each alternative and the acceptance of the research intervention by the participant.

4.11.2 Participants' withdrawal rights

The researcher explained to the participants that their participation in the research project was entirely voluntary and that they were free to withdraw at any time. If they chose to withdraw, their information would not be used anywhere in the study. If participants were overwhelmed or distressed in any manner by the questioning it would cease immediately and they would be referred to an appropriate psychologist or counsellor for debriefing.

It must be stated that the participants who needed referral, because of their state of mind or because they needed other help, were referred appropriately. This is stated in some of the cases, in the interpretation, but not necessarily all. All participants who needed help were referred appropriately.

4.11.3 Confidentiality and anonymity

Confidentiality was maintained in all activities of the research study. Confidentiality means a person knows but will not tell and anonymity means that a person's name is not known and is not made public. According to Terre Blanche et al. (2009) and Gallagher and Zahavi (2014) information

obtained from the research must be confined to certain well-defined scientific uses that should be clear to the participants at the time of informed consent. Such information shall not be made generally available in any way that could harm or embarrass the participants. To ensure that both confidentiality and anonymity were not compromised the researcher recorded and stored data using pseudonyms rather than participant's actual names. This preserved participants' anonymity.

Ethical guidelines, as recommended by the Health Professions Council of South Africa (Psychology Division) were adhered to. A written letter of permission to conduct the research was sought from the Limpopo Province Department of Health and Social Development, and the permission was granted. Permission from the University of Limpopo, Turfloop campus, Research and Ethics Committee (TREC) was also granted to conduct the research. The Chief Executive Officer of Elim Hospital was also contacted and permission to do the research at that hospital was granted.

4.12 Summary

A qualitative research design was selected and a purposefully selected non-probability sample of PLWHAs was used in the research. A semi - structured interview underpinned by Jungian phenomenology was used for data collection and analysis. Bias, validity and reliability were reported as relevant to the study. Permission to conduct the research was obtained from the University of Limpopo ethics committee. Ethical issues relating to the study were addressed.

CHAPTER 5: PRESENTATION OF RESULTS AND ANALYSIS

5.1 Introduction

This chapter presents the results of the research in relation to the literature review and the Jungian phenomenological approach. It further provides an analysis in terms of the Jungian metaphors.

5.2 Demographic information of participants'

The participants, to preserve anonymity and confidentiality, were given numbers and not named. A table is presented (See table 1: Key demographics) at the end of this section so that the main demographics of participants are clear to the reader. It must be noted that poor educational qualifications, poverty and unemployment impact on PLWHA as they often do not have the financial capacity to attend clinics or buy nutritious food and in some cases do not understand information provided about the pandemic (UNAIDS, 2014).

Participant 1 was a female who was a thirty six year old and Tsonga speaking. She was born on the 6th April 1979 at a village in Tzaneen. She currently resides at Magangeni portion of Elim village in Limpopo Province. She is single and has passed grade 12. At the time of the interviews her son was six years old and her daughter nine years old. She did not have a partner nor was she dating anyone. She was employed as a municipal clerk when the research was undertaken.

Participant 2 was a Tsonga speaking female who was fifty one years old at the time of the study. She was born on 25th February 1965 in the rural village next to Bandelierkop in Limpopo Province. She resides at Mpheni village adjacent to Elim in Limpopo Province. She has two daughters one, at the time of the research, was twenty years old the other twenty five years old. She is a widow who only schooled up to Grade 12. She had no partner and worked for herself as a vegetable hawker.

Participant 3 was a Tsonga speaking female who was fifty two years old at the time of the investigation. She was born on the 3rd February 1964 at Chavani village about five kilometers from Elim village. She currently resides at Elim village. She is married and only schooled up to Grade 3. She has two sons and five daughters. Her eldest child, a male, is 25 years old. Her last born child is ten years old. At the time of the research she reported a platonic relationship with her husband and was unemployed.

Participant 4 was a Venda speaking female who was twenty six years old. She was born on the 15th April 1989 at Mashamba village about 10 kilometers from Elim village. She resides at Mpheni

village adjacent to Elim. She was single and schooled up to Grade 8. Her only child is female (three years old at the time the research). She was unemployed.

Participant 5 was a Venda speaking female who was twenty nine years old. She was born in 1987 at Chiawelo in Soweto (Johannesburg) in Gauteng Province. She resides at Mpheni villa adjacent to Elim vilage. She is single and only schooled up to Grade 11. Her two sons were aged five and eight years old. When the investigation took place she had a partner, who worked in another province. He provided her with money as she was unemployed.

Participant 6 was a Tsonga speaking female who was fifty two years old. She was born on the 25th December 1953 at Majosi village about 10 kilometers from Elim village. She resides at Mpheni village adjacent to Elim village. She is widowed and did not go to school. She has five children. The eldest is a male (thirty five years old), the rest are female the youngest of whom was twenty five years old. At the time of the research she did not have a partner and sold home brewed beer to support her family.

Participant 7 was a Tsonga speaking female who was fifty years old. She was born on the 1st January 1966 at Shikuhele village at Elim. She resides at the Magangeni portion of Elim village. She is widowed and had never been to school. Her children are all males, the eldest of whom was thirty years old and the youngest twenty four years old. She had no partner and was unemployed.

Participant 8 was Tsonga speaking female who was 50 years old. She was born on the 5th May 1965 in Mozambique. She resides at the Mabobo portion of Elim village. She is married and had never been to school. She has seven children of which five are males and two females. Her eldest child is a female who was thirty two years old and the youngest a male of twenty years old, at the time of the research. She was unemployed.

Participant 9 was Tsonga speaking male who was fifty five years old. He was born on the 2nd February 1961 in Mozambique. He resided at the Mabobo portion of Elim village. He is married and had never been to school. He has seven children, four males and three females. His eldest child, at the time of the research was a male of thirty three years and the youngest a female of nineteen year. He was unemployed.

Participant 10 was a Tsonga speaking female who was twenty nine years old. She was born on the 24th March 1987 at Elim. She resides at the Mutshimbila-nga-dzebu portion of Elim village. She was cohabiting with a male partner when the investigation took place. She schooled up to Grade 12. Her only child is female and six years old. She was unemployed.

Participant 11 was a Venda speaking female who was fifty years old. She was born in 1965 in Johannesburg. She resides at Mpheni village adjacent to Elim village. She is single and had never been to school. Her three children are one male and two females. Her oldest son was thirty two years old and her youngest, a daughter, twenty seven years old at the time of the research. She was unemployed.

Participant 12 was a Venda speaking female who was twenty one years old. She was born on the 5th April 1995 at Ndzhelele village about 150 kilometers from Elim village. She resides at Mpheni village adjacent to Elim village. She was single at the time of the research and reported going to school until Grade 9. She had no partner or boyfriend and was unemployed.

Participant 13 was a Venda speaking female who was thirty four years old. She was born on the 18th June 1981 at Nthabalala village about 10 kilometers from Elim village. She resides at Mpheni village adjacent to Elim village. She is single and schooled up to Grade 11. Her two children are male and female and are ten and twelve years old respectively. At the time of the investigation she had no partner and was unemployed.

Participant 14 was a Tsonga speaking female who was sixty four years old. She was born on the 21st January 1952 at Albasin village about 5 kilometers from Elim village. She resides at Elim village. She is widowed and had never been to school. She has seven children, six females and one male. Her eldest child is a male who was 42 years old while her youngest is a female who was 28 years old when the investigation took place. She has no partner and is a pensioner (does not work).

Participant 15 was a Tsonga speaking male who was sixty four years old. He was born on the 2nd February 1951 at Mbhokota village adjacent to Elim village. He resides at Elim village. He is a widower who went to school up to Grade 12. He has eighteen children, ten of whom are females and eight of whom are males (not all from his deceased wife). His eldest child is male who was forty one years old and his youngest a male of twenty nine years old at the time of the research. He has a partner and is a village headman.

Table 1: Key demographics of participants

Participant	Age	Female (F) or Male (M)	Married/partner/ Single or widowed	How long known about +HIV status	Children at time of research	Education	Occupation
1	36	F	Single	7 years	2	Grade 12	Municipal clerk
2	51	F	Widowed	7 years	2	Grade 12	Vegetable hawker
3	52	F	Married	10 years	7	Grade 3	Spaza shop
4	26	F	Single	2 years	1	Grade 8	Unemployed
5	29	F	Single	3 years	2	Grade 11	Unemployed
6	52	F	Widowed	4 years	5	Not Schooled	Sells beer at home
7	50	F	Widowed	3years	3	Not schooled	Unemployed
8	50	F	Married	10 years	7	Not schooled	Unemployed
9	55	M	Married	10 years	7	Not schooled	Unemployed
10	29	F	Partner	11 years	1	Grade 12	Unemployed
11	50	F	Single	5 years	3	Not schooled	Unemployed
12	21	F	Single	3 years	1	Grade 9	Unemployed
13	34	F	Single	5 years	2	Grade 11	Unemployed
14	64	F	Widowed	11 years	7	Not schooled	Pensioner
15	64	M	Widowed	5 years	18	Grade 12	Headman

5.3 Experiences, presented as themes, of participants' understandings of discrimination and stigmatisation underpinned by Jungian Phenomenology

The experiences of the participants are presented in themes, as this is a coherent way of narrating their lived understanding. The thematic narration of the participants' experiences is further underpinned by relevant literature and supported by an analysis, using Jungian Phenomenology as described by Brooke (1993). When participant's responses are overwhelmingly similar not all of them are provided to avoid repetition. However, many are provided which are fairly similar to indicate how the participants' experiences are *shared* or very similar in nature. This, although qualitative results cannot be generalised, does indicate that archetypal experience is part of humanities collective unconscious. Essentially, we all live with archetypes which make up our personalities, thus our lived experience of them is likely to have certain connections.

According to Jungian Phenomenological theory, within the aspect of description, the phenomenologist conducts a careful, meticulous, repeated appraisal and description of a phenomenon and thus unravels the true and original aspects of the phenomenon (Brooke, 1993). When interpreting a phenomenon, phenomenologists have to give up or put aside their philosophical prejudices. According to Brooke (1993, p. 33), this involves a "mental leap known as phenomenological reduction which involves the bracketing of being or the epoch which means the disconnection from the researchers natural attitude." The researcher, in addressing the theme of stigmatisation, applied the Jungian phenomenological metaphors (the self, shadow, anima, animus and persona) to describe the responses of the participants.

The participants' responses will be presented in English after translation from the vernacular. As a result English grammatical constructs are not always adhered to so that the reader has a real sense of how the participant related his/or her narrative. It must also be stated that, if a construct in the vernacular does not have an exact meaning in English, a similar one is given.

5.3.1 Theme 1: Identity

All fifteen participants expressed a diversity of views on their identity in relation to HIV/AIDS and stigmatisation. Winskell and Obyerodhyambo (2011) suggest that identity is related to HIV/AIDS stigma in terms of negative coping behaviours such as denial, secrecy, fear and self-blame related to the disease. Furthermore, as noted by Turan and Nyblade (2013), PLWHA self-stigmatise as being guilty which becomes a self-fulfilling prophecy which in some cases can lead to suicide. Self-stigma and internal stigma is manifested as self-blame and self-deprecation which is noted when people refer to themselves negatively (Bharat et al., 2008) alternately self-acceptance and a positive

identity occur when PLWHA accept themselves (Nqojane, 2009).

Participant 1(F):

“At first I felt bad after disclosing my status. As time went on I adjusted and felt free to talk about it. I feel accepted by the community in which I live now I have accepted my condition. I feel like I used to, no difference and I often address people in public. I really didn't think I would be one of them [a person who was HIV positive]. I feel good because my family has accepted me and my positive status. My family supports me. I do blame myself because I did not live a safe life. I have accepted that I am HIV positive because of my old lifestyle.”[not using condoms and sleeping with different partners].

In terms of Jungian Phenomenology the participant's first responses refer to the Animus. The Animus is a male image in a female psyche (Cherry, 2011). The participant seems to have bravery (an attribute or archetype of males) to face up to the challenge of living with HIV/AIDS. The participant has the courage to be a Hero (archetype of bravery) and to face her status and resultant stigmatisation. Through the Siyam'kela Stigma Project (2007) it was realised that HIV/AIDS stigma results in feelings of shame and self-blame and a range of protective behaviours, including the inability to disclose HIV status and discuss it in public enabled PLWHA to accept their status and become self-confident. Her acceptance in the community has helped her to find a balance and adapt to her new identity. The Animus within her psyche has allowed her to be heroic. However, she still refers to PLWHA as *them* which indicate she still has some ambivalence, albeit unconscious, about her positive status. This indicates that her Shadow is lingering in her unconscious and that she has not fully accepted either herself or others living with HIV/AIDS. She needs to reflect on this and integrate this archetype into her consciousness to fully individuate. The participant does have the support of her family and community which should help her in this regard Wouters et al. (2014) indicate that families that form tight units are more adaptive to external changes and form an ideal environment for community based support initiatives. The participant seems to have a supportive family environment which helps provide her with positive adaptive mechanisms to external challenges such as her HIV positive status.

Participant 2(F):

“I feel good now because my daughter supports me. When people look at me I look like any other person I am not thin and do not have any AIDS symptoms. My weight is not on and off like before [becoming thin and then fat]. I now live a normal life. I have accepted my condition. I no longer fear stigmatisation because of the knowledge I have. I can even advise people about HIV/AIDS and tell them they should go for testing. Now I feel fine I don't have to think about HIV. I get support from the hospital staff, and I adhere to the treatment, I have no problems. I have disclosed to my daughter only. I feel that my disease is like cancer and diabetes because they are chronic diseases.”

The first responses refer to the Animus when applying Jungian Phenomenology. The participant seems to have garnered the courage to be heroic (a manly attribute) in facing her HIV positive status and any discrimination it may bring. She has accepted how she is perceived in terms of her body-weight and has the desire to participate in public education on matters related to HIV. Cherry (2011) indicates that the Animus is responsible for certain characteristics stereotypically associated with the opposite sex. Aggression, assertiveness and the drive to survive are frequent characteristics displayed by men in terms of the Hero archetype. In this case, instead of hiding, being isolated and withdrawn, we see a participant who emerges with boldness the only possible downfall maybe that she may become overly arrogant and think her experience is ‘everyman’s’ understanding of HIV/AIDS and her life world (Lebenswelt).

However, in terms of her Persona she may have developed a mask in which she is overly accepting of her predicament. This is related to heroic arrogance particularly when she makes statements like she has ‘no problems.’ She also states she looks like anyone else (as in not thin or fat) which suggests that she does not want people to discriminate against her for having HIV/AIDS symptoms which is congruent with her having developed a public mask (what she wants people to see). This is linked to her only disclosing her status to her daughter. According to Cherry (2011), the goal of individuation is related to the individual’s own ‘Persona.’ In this case it is apparent that the strong heroic persona experienced by the participant, and her lack of reflection (not having to *think about HIV*, is likely to negatively affect her individuation process. Makoae, Greeff, William and Holzemer (2008) reported that one of the coping strategies used by PLWHA was as seeing themselves as ‘okay’ which, in the long term, can result in denialism and inability to individuate to become the best person they can.

Participant 3(F):

“I know.... it is my secret. The secret helped me accept my condition plus the fact that I look healthy like other people. I even talk about HIV [not disclosing my status]and advise people to go for treatment. This helps me to accept my condition. I also attended all the campaigns and workshops to help others. I feel happy and I do not want to condomise because I have told myself that I will not be living [having sex] with men anymore. What makes me happy is that I am HIV positive and no-one knows about it since I do not have the symptoms. I have not disclosed to anyone. People do not stigmatise against me because they don't know about my status. I have accepted my condition and I adhere to treatment. It helps me to feel that I am helping others when I do this. It seems like we [the whole community) are all preparing ourselves to accept HIV/AIDS. To date I do not have feelings for my partner. We are a couple living without having sex.”

In terms of Jungian Phenomenology the first responses refer to the Persona. The participant seems to have perfected her mask through denialism and seems determined to continue in this manner. She has behaved like this for ten years. The participant presents as comfortable in her mask (denialism) and does not want to upset her status quo. The coping mechanism applied by the participant is one described by Ekstrand (2011) as being dishonest about HIV status (because of fear of stigmatisation). She tells herself that having a *secret* is fine and that she is happy as she accepts her status and she attends HIV workshops and/or campaigns to help others. This approach presents her an ongoing challenge as she is always on guard in case she forgets her lie and her Shadow dominates. She cannot experience herself truthfully and cannot accept a true image of herself as HIV positive. She states she does not have to condomise and later reports she does not have sex with her husband who she has no feelings for (here there is an element of blame which she has not worked through with her partner). Although she seems to ‘care’ about PLWHA she displays a characteristic pattern of martyrdom in not being willing to properly reflect on her HIV status.

The last response refers to the Self. The participant seems to have adopted a life path devoid of love and passion. Her process of personality development has brought forward a phase that could be expected in extreme old age or (at the time of the research she was fifty two years old). Lliamputong (2013) indicates that stigma also means that women are likely face social stigma, in terms of the pandemic, in ways that fundamentally change their self-perception. This participant’s current self-perception seems oriented towards a lifestyle devoid of love or intimate relationships.

This is supported by the research findings of Grodensky et al. (2015) who note that some PLWHA seem to want platonic (rather than sexual) relationships. However, as a woman who is still relatively young it would seem likely that in future frustration and anger, unless addressed, are likely to hinder the process of individuation.

Participant 4(F):

“I was diagnosed with HIV and have just managed to disclose to my mother and will disclose to others soon. I have started to identify with others who are HIV positive. I have learned to accept it. I do believe that HIV/AIDS exists, I didn't always believe it did...and that I have it. That has helped me to deal with my feelings and understand that AIDS is like any other disease. Now I am sick but I know that AIDS does not kill. I am confident now that will die of something else and not AIDS. If I disclose to others and they stigmatise me it will not bother me since I have already accepted my condition. I really have accepted my condition. I have learnt not to worry a lot about my condition. I think I need to focus only on my health, particularly how I am improving on a daily basis. Coping with the condition has proved very challenging but I have found adherence works.”

Through the application of Jungian Phenomenology the first response refers to the Persona. The participant has dealt with her status through limited disclosure to her mother because of fear of stigmatisation. At this stage she wears a mask and conceals her true self to the majority of individuals she interacts with. However, she is going to disclose her status soon and her narrative seems to indicate that she is building up to doing this. Snyder (2014) refers to the creation of safe spaces as being critical for HIV positive individuals especially when it came to disclosing their status to others. It is apparent that the participant has not found the space, but is looking for it, hence her limited disclosure. Other responses refer to the Animus. Even though the participant has disclosed, to a limited extent her status, she has not totally adjusted to her HIV positive status. Turan et al. (2011) indicate that rates of anticipated HIV/AIDS stigma are high because of anticipated loss of relationships. This participant is probably fearful of disclosure and is delaying it because of this.

The last two responses refer to the Self. The participant seems to have faced the reality of a changed life orientation. She has adopted a different development path and has factored in the reality of her status to her personality development. The Self archetype involves the participant's acceptance of her status, with which she seems comfortable which relates to Zuch and Lurie's (2011) finding that

adherence to treatment regimens reduce HIV/AIDS stigma by weakening the pandemics link with death. They also noted that ART enables the construction of spaces for support, which helps reduce stigma through normalisation of the disease. The participants experience underpins this belief. To fully realise the development of her personality she will have to find the heroism to fully disclose and thus have an integrated 'Persona.'

Participant 5(F):

"I eventually accepted my status. I disclosed to my family and was encouraged by the accepting behaviour of my family and nurses and the social workers and people at the church. This helped me to accept my condition as I want to stay with my family. Finally, I accepted my condition through the support I received. I understand that when I am on treatment with this support I will live longer I have learnt this from workshops at the hospital. It is true that when you are HIV positive, and you do not listen to the nurses and doctors, you will become sick ...you must listen and accept advice because AIDS can kill. I try to attend everything about HIV."

In applying Jungian Phenomenology the first three responses refer to the Animus. The participant shows the courage and strength of a Hero (a manly archetype) in facing her situation by accepting it, disclosing her status (in spite of possible stigmatisation) and allowing people to support her. She has been living with HIV infection for three years. In striving to reduce stigma, Ekstrand (2011) refers to efforts that should target institutions for instance, schools, hospitals and religious institutions and leaders. It appears that the participant is benefiting from intervention programmes at the hospital she attends.

The last response refers to the Self. The participant seems to have a personality development path which has factored in the reality of HIV. She is a realist and has factored in that her family could be orphaned. Death awareness is a focal of her personal development. She appears vigilant in terms of her own health. This indicates an archetypal adjustment pattern that has a profound impact for integration into her personal development and individuation. However, she must beware that she is not too compliant in trying to be involved in 'everything' because she fears being alone or orphaned herself. She needs to reflect on her position in life to be able to individuate and experience her lifeworld.

Participant 6(F):

“I do not blame myself. It was not my choice to be HIV positive. I had to accept it however and now I am used to it. Stigmatisation happen you know this because when you talk about HIV it is not the same as talking about flu. Now I feel better. Adherence is the best approach. I feel healthy but I am not ready for another partner as I fear being infected again. Even though I have accepted that I am infected I do fear the unknown. What happens if I get really ill? It is not easy to change what people perceive about HIV/AIDS. When I talk about it, it feels like I am relieving myself of something from my body. It felt very good to talk to the researcher today. It was like therapy to me. Since I am on treatment I can see the improvement of my CD4 count so I will do the right thing and keep on taking the medication because of this I do not think I will die of AIDS.

The first three responses refer to the Animus, according to an interpretation using Jungian Phenomenology. The participant seems aware that she has to summon up her heroic (manly) courage to be able to cope. By accepting her condition she has reached a key step in adapting her life and consciousness to a functional state. She does not blame herself but does *fear the unknown* which relates to her Shadow and both conscious and unconscious repressed ideas, weaknesses, desires, instincts and shortcomings (Brooke, 1993). Although Turan and Nyblade (2013) report that blaming, discrimination and self-stigmatisation suggest that PLWHA may worry about being condemned to illness and death, the participant has learnt to deal with this and does not self-stigmatise but fear exists through her Shadow. She displays insecurity in stating that she does not *think* she will die from AIDS. Overall it appears that she does not want to appear vulnerable as heroes do not like to show weakness. However, to completely fulfill her true self in terms of individuation she will have to come to terms with displaying some vulnerability.

In terms of Jungian Phenomenology the third, up to the last responses refer to the Self-archetype. The participant seems to have accepted an individuation process that accommodates and promotes ART adherence. Lliamputong (2013) asserts that women face social stigma that changes their self-perceptions. The participant seems to perceive herself as not needing sexual relationship which infers she is fearful of disclosing her HIV positive status to a new partner. Nystal (2009) observes that the emergence of a spiritual, philosophical self is related to an integrated conscious and unconscious within an individual. In the case of the participant, optimal unification of archetypes within the participant's personality appears stifled as she is not willing to 'share' an infected self with a partner. She displays characteristics of the Innocent. Her responses suggest that she thinks

the right thing is to take medication thus she will live and that punishment (not taking ARTs) will result if she does not comply. To an extent this is correct but taking ARTs extends life in most case but not always and medication can be linked to physical side effects which the participant does not seem to have factored in. Individuation, in her case, is likely to be delayed until she reflects on, and integrates, all factors into her personality development.

The last response, in terms of Jungian Phenomenology, refers to the Shadow as she seems to be hiding her fear of death through discussing it as *fear of the unknown*. Visser et al (2009) suggest that sources of stigma include fear of illness, fear of contagion, and fear of death. The participant has, to an extent, masked, the true possibility of death posed by HIV/AIDS by fearing the unknown on a conscious and very likely unconscious level.

Participant 7(F):

“This disease does not kill if you listen to the nurses and the doctors who I have found very supportive. Adherence is the best solution. I was depressed but when I became an ambassador for HIV I helped many people to understand the disease. This helped me understand myself and other people’s reactions to it. I liked the acting in the dramas we presented during campaigns....when we did this every day I became comfortable with accepting my status.”

The first two responses refer to the Self in relation to Jungian Phenomenology. The participant seems to have factored in the reality of her status in her processes of individuation and future personality development. Hirschall (2016) indicates that there are many healthcare workers who are advocates for providing stigma-free care for PLWHA, which the participant appears to have experienced. This supportive environment plus her adherence to ART treatment has helped the participant combat depression (a common negative effect of HIV infection and related stigma). This is important as some depressed PLWHA commit suicide due to stigmatisation and an inability to accept their new reality Nachege et al. (2012) fundamentally their new Self and life world.

The last response from this participant is consistent with the Animus archetype as she had found the courage or heroism to accept and live with her condition. The HIV status has inspired her archetypal masculine traits (the Hero) in order to cope with her lived reality. In keeping with findings by Makoae et al. (2008) the participant used strategies such as teaching others (through interventions such as workshops and drama) to cope with HIV/AIDS in order to live a fulfilling live. Constant reflection will be required by the participant, to ensure that she does not develop an

overconfident or arrogant Persona or become depressed again. If she does this she should fully individuate in terms of her Persona.

Participant 8(F):

“My worry now is that I forget easily” [since I was diagnosed as HIV positive].

In terms of Jungian Phenomenology this refers to the Self. The participant is not able to integrate all aspects of the archetypes which constitute her personality and ‘forgets’. She cannot recognise her own Shadow and thus chooses not to remember her true self. The hallmark of her identification with her HIV status is the insipient memory loss. It is apparent that her personality development is going to be impacted negatively by this reality. There is some neurological imperative for memory loss for instance, Haughey et al. (2012) report that nearly fifty percent of people infected with HIV will eventually develop some form of mild brain damage that which can affect PLWHAs ability to participate in day-to-day activities. However, in this case the participant ‘forgets easily’ which may point to a more defensive coping as she reported no trouble in coping with day to day activities. As the Self regulates the centre of personality and mediates between the conscious, unconscious and collective unconscious (Brooke, 1993), participant 8 is unable to reflect on the reality of her positive status which is easier to ‘forget.’

Participant 9(M):

“Actually I am helpless.....I feel so helpless, so helpless.”

The participant is experiencing a regression in his process of individuation to his true Self which takes him back to a state of dependency. The dominant archetype that a positive HIV status seems to bring up in this participant is not congruent with his cultural expectations as a male (who would be expected to be heroic). In terms of traditional culture he is supposed to be depended on not being dependent and ‘helpless’ (which she reiterates emphasising his ‘orphanhood’ or aloneness). Blose (2015) suggests that internalised stigma is a challenge for HIV positive South Africans. They develop a sense of inferiority, guilt and shame hence they retreat from society and lead a non-fulfilling life. Helplessness is experienced as a result of stigma and the participant’s inability to cope with his new Self. He will not be able to individuate and emerge as a spiritual, philosophical self as he will be unable to optimally blend his conscious and unconscious (Nystal, 2009). This participant needs to accept his new Self and embrace and integrate the different archetypes which are part of his developing personality.

Participant 10(F):

“I feel energetic. I have accepted my condition and pretend that I am not HIV positive. I have not disclosed my status to family members. It is only my mother who knows about my status. My partner also knows about my status. Both have accepted me and are supporting me. My life was not risky [sexually]. I will not die of AIDS. Because of adherence I feel healthy and strong now. I have accepted my condition.”

The first three responses refer to the Persona. The participant seems to have a mask which she is ready to continue wearing as she ‘pretends’ that she is not HIV positive. She is hiding from her status which is inferred by her very limited disclosure. The participant seems to want to protect her ego in the face of clear indications that she is at risk. The task of disclosure is not easy as it has to be integrated into her Persona, with the possible adoption of new archetypal characteristics. Disclosure needs a conducive and supportive environment as concluded by Snyder (2012). The participant masquerades as if she is not HIV positive to most of the world and hides from the fact that there was some risk in her life (as she became HIV positive). Since this mask appears set to be deep-seated, the participant is fundamentally experiencing a false image of herself thus will not be able to fully individuate.

The fourth response refers to the Self in terms of Jungian Phenomenology. The participant seems to have factored in adherence as part of her personality maturation factors. The life-saving treatment, in this case, seems to support her pretense and it appears that she may fear death which is linked to the pandemic (Zuch & Lurie, 2011). Although, at first glance, she seems to have removed the link of death to the illness her pretense and inability to disclose effectively displays her fear. Although she notes to ‘accepting her condition,’ her pretense indicates she has not which infers her Shadow, (which will not allow true individuation and an authentic Self) has come to the fore. The Shadow reflects those characteristics we find most unacceptable in ourselves and those which we attempt to deny (Nystal, 2009).

Participant 11(F):

“I feel like I am losing my sense of belonging because I am discriminated against by my son, my mother and everyone has turned their back on me. What makes me happy is that I get support from the nurses and doctors at the hospital. This helps me to accept my condition. I had expected stigmatisation from community members but now that it is family, I realise its seriousness. I am helpless and hopeless”.

These responses predominantly refer to the Self in terms of Jungian Phenomenology. The participant reports some happiness as she has factored in the care of hospital personnel but feels helpless and hopeless because those closest to her have abandoned her. Her happiness is transitory as she has been orphaned by her family that is she left alone and left out. She is a realist and understands the seriousness of the problem but does not appear to be ready to accept all facets of her personality and integrate all stereotypes and thus self-stigmatises. Her Shadow looms large and she is unable to reflect on her situation and thus is unable to fully individuate. Lekas et al. (2011) observe that stigma can shape the internal picture of PLWHA to result in low self-esteem, depression and sometimes suicide. The participant is in danger of gravitating to these psychological realities as helplessness coupled with hopelessness are related to suicidal ideation and ultimately suicide. Her Shadow is suppressing her conscious and unconscious integration of archetypal characteristics and her authentic Self.

Participant 12(F):

“I am infected. Nothing will change. The best thing is for me to accept it. It is a factYes, I am HIV positive. My understanding is that I will live like anyone else and get to a very old age.”

The Animus is the metaphor captured by the first response when applying Jungian Phenomenology. The participant seems to be heroic in stating the truth. Her reiteration of this truth about her lived reality could point toward some aggression (a masculine feature). It infers that she has some way to go before she faces genuine acceptance of her positive status. At present she states that her understanding is that she will live like anyone else. This denotes a conditional acceptance as her condition needs monitoring and treatment and there are things that change for instance, diet, exercise and her ability to comply with a medication regime. She needs to integrate knowledge of HIV/AIDS and unconditional acceptance before she can become self-accepting and integrate all facets of her personality into her true Self. If she does this she will be able to individuate if not she will find no true self-acceptance and her personality development will remain in a state of limbo (that is, not fully integrated) and not reflect her life world.

Participant 13(F):

“After counselling I felt that I could live with the HIV.”

In terms of Jungian Phenomenology this refers to the Self. The participant seems to have assimilated her condition in the course of her personal development. Reconciling herself to the reality of being infected paves the way to emotional restoration that should ensure a positive

balance in her personality development. Snyder et al. (2014) encourage the substitution of maladaptive coping mechanisms with adaptive ones, such as counselling and self-acceptance. They are noted as key strategies in improving long-term adherence to treatment and the related physical and psychological well-being of PLWHA.

Participant 14(F):

“Nobody knows about my status presently. There is nothing wrong with me so I am not easily seen as someone with HIV. There is no difference between me and other elderly people.”

In terms of Jungian Phenomenology the abovementioned responses refer to the Persona. The participant seems to have established a mask in order to protect herself and does not appear to have the ability to genuinely reflect on her positive status. As she is past middle age, and her social values are related to the patriarchal socio-cultural norms of her culture she is likely to find it very difficult to disclose her HIV positive status. This is underpinned by Grodensky et al. (2015) who concluded that older African women found HIV positive status and disclosure as shameful. Furthermore, the authors concluded that older women who disclosed that they were infected with HIV were far more likely than younger women and men to be stigmatised. The participant was, at the time of the research, sixty four years old, thus it is likely that her ingrained sense of morality related to cultural norms are very likely to hinder her from integrating all aspects of her true-self into an integrated and individuated personality.

Participant 15(M):

“I pretend to be HIV negative because I do not have symptoms. No one suspects that I am HIV positive. Even though I have a girlfriend, I miss my wife [who died reportedly from HIV related illness]. I do not have a problem [meaning the participant did not display any signs of ill health]. I look very healthy.”

The Persona is the predominant metaphor captured by all three responses when interpreted in terms of Jungian Phenomenology. The participant has developed a resilient mask that may be difficult to break down. His heroic qualities appear steeped in arrogance. He did not answer the question when probed about disclosing his status to his girlfriend (even though this was asked several times). The inference is that he has probably not disclosed that he is HIV positive to his girlfriend. His self-deception is so strong that he states he has ‘no problems.’ Wearing such an ingrained and deceptive mask which is related to his Shadow displays maladaptive coping skills that will deprive him from

experiencing his true self. According to Cherry (2011), an individual who has an entrenched Persona experiences a stunted individuation process. In relation to this Brooke (1993) relates that in order to discover one's true essence an individual needs to bracket his or her attitudes or prejudices which would allow meanings related to their true self to reveal themselves naturally. As an African male who feels that he should protect and lead and have a manly posture, which is related to traditional cultural norms, it is questionable whether the participant will ever individuate fully (and recognise his true Self).

5.3.1.1 Summary of theme 1: Identity

The researcher, in analysing the theme of identity in relation to HIV/AIDS stigmatization underpinned by Jungian Phenomenology, looked for their true meanings or essences in the various responses articulated by the participants. The Jungian phenomenological metaphors the Self, Shadow, Anima, Animus, and Persona, were all interpreted from the participants responses.

In relation to the representation of their Persona most participants could not cope with their true or authentic identity (true Self) which incorporates their HIV positive status. Their masks were inflexible (a negative quality of the Hero) into their personality projection. As this is probably related to the socio-cultural norms of the traditional culture within which they live it will be difficult for them to become self-reflective. This, of course, may also be related to their broader understanding of the world which is negatively impacted by their educational disadvantage underpinned by schooling in the Apartheid era.

The Jungian metaphor of Animus was also seen amongst the responses. The intentionality of identity seems to display an overly heroic posture indicated by some anger. The process of personality development and individuation is therefore going to be adversely affected. At present their Shadow dominates and will not allow self-reflection and conscious and unconscious integration of all archetypes into their personalities.

5.3.2 Theme 2: Feelings before Voluntary, Counselling and Testing (VCT)

Out of the fifteen participants only one did not respond to the question related to the participant's feelings before going for VCT. It is likely that this participant does not want to remember these feelings which are probably inexorably linked to *guilt* and *shame*, plus the related fear of discrimination and stigmatisation. Those who stigmatise PLWHA falsely believe that the virus is highly contagious and that they could be easily infected. When the belief takes root, it generates a snowball effect whereby their opinions influence others in the community start to view HIV

positive individuals as a threat to their well-being. Fundamentally, individuals who stigmatise PLWHA believe that it is the individuals own fault and blame them for becoming HIV positive as it was their risky sexual behaviour that exposed them to infection this can also lead to the PLWHA self-stigmatising (ICRW, 2015). This type of stigma is referred to by Bharat et al. (2008) as perceived stigma, which is the fear that PLWHA commonly experience as being discriminated against if their positive status becomes known. This is experienced as fear of rejection by a spouse, family or friends or the fear of being labeled a failure, a disappointment or a burden. Individuals also tend to lose their feelings of self-worth and self-identity.

Participant 1(F):

“I never thought I would be infected. I lived a care free life before I knew my status. I used to live a care free life. I thought people were just talking like they would about any other disease. I was not involved in safe sex. I was ignorant about how HIV infected people.

The Shadow is the predominant metaphor referred to in these responses in terms of Jungian Phenomenology. The participant seems to portray the archetype in a manner which is related to low self-vigilance, poor observations about sexuality and a general indifference to readily available information about the pandemic. Her response suggests a general lack of self-control when it comes to sexual relationships. According to AVERT (2016), HIV stigma emanates from incorrect assertions that HIV is associated with personal irresponsibility or moral fault (such as infidelity) that deserves to be punished. This participant is thirty six years old and it is difficult to imagine that she was not exposed to HIV information and government and media campaigns which would have imparted HIV/AIDS knowledge. It is likely that as a teenager she was given to archetypal portrays of the Innocent and naively carried on with her life. The participant is older now and it is likely she fear being blamed for her HIV positive status and further fears punishment for ‘doing wrong.’ As a result she cannot recognise her own Self and come to terms with the different archetypes which make up her personality. She needs to reflect on her ‘ignorance’ in a manner that will allow her to individuate.

Participant 2(F):

“I was one of those who stigmatised and discriminated against PLWHA. I could not face a positive test I knew deep down I could be positive but I put it out of my mind. I never thought I would get AIDS. I was afraid when I heard that you get it through sexual interaction. Before I was tested I felt like any other person. I heard people

talking about HIV/AIDS and it was just talk like any other disease they said what I thought, I just didn't take any notice."

This participant's overall response refers to the participant's Shadow. The participant understands that she stigmatised others before becoming infected. At the time she was not HIV positive but stigmatised and discriminated against PLWHA. Her Shadow is something that she does not choose to know and her responses indicate that she does not know it on either a conscious or unconscious level. It lies beneath the surface and is habitually connected to negative impulses in an individual's personality. The Shadow is an archetype that consists of the sex and life instincts and is made up of repressed ideas, weaknesses, desires, instincts and inadequacies. This archetype is frequently described as the dark side of the psyche, demonstrating chaos and the unknown. The International Planned Parenthood Federation [IPPF] (2014) suggests that stigma begins and ends with individuals and that a combination of ignorance, prejudice and fear create productive ground for the continued spread of HIV stigma. The candidate, for some reason, either ignored information that HIV was spread through sexual contact or unconsciously ignored the message. At fifty one years of age she turned a 'blind eye' to this message thus was unable to sexual and reproductive health information which would have reduced her chance of infection and stigma reduction. It is thus apparent that her Shadow is regulating her personality integration and she will need to reflect on this to fully individuate. At present she appears to mirror her own responses while transferring them to others (*they said what I thought*) which will not allow her to become her true Self.

Participant 3(F):

"I was one of those who used to talk negatively about HIV/AIDS as I did not want anyone to think I might have it. As soon as I knew that he was HIV positive [her husband], I got angry with him and stopped having sex with him. I got angry because I had little information about HIV/AIDS. I suspected my husband was having affairs...These men they do not think about themselves they don't want to use condoms. I used to be one of the gossips who talked badly of HIV positive people...."

This participant's response refers to the Shadow. Her negative behaviour relating to PLWHA before she knew she was HIV positive indicates that she was willing to gossip so that she would not be considered *as one of them* thus she wanted to be seen as an Innocent. The participant seems to expose the weakness in her personality in stigmatising others by transferring (projecting) her flaws onto others. Makoae et al. (2008) report that the acquisition of knowledge and understanding about HIV/AIDS are adaptive strategies linked to getting help from others in order to cope with HIV. This

participant has consciously and unconsciously ignored freely available information. She also blames her husband and accepts no responsibility in her HIV positive status as she did not insist on safe sex or stop having sex with her husband when she knew (or suspected) his infidelity. Her Shadow did not allow this and her anger will stop her from fully realising her true Self until she reflects on, and accepts her own part in her HIV status. Her responses suggest that she feels guilty about gossiping about PLWHA but she does not state that she is sorry about this which underpins how her Shadow is representative of her present personality development.

Participant 4(F):

“It was difficult for me to be tested since I did not want to know my status. I was not aware about the precautions I needed to practice because, at that time, I did not know how HIV was transmitted.”

The Persona is the metaphor related to this response in terms of Jungian Phenomenology. The participant seems to be intent on assuming a position of self-preservation (coping) based on *not* knowing and thus innocence. Fear of punishment (for doing wrong) is connected to this archetype (punishment by self as well as others). She presents a mask which will not benefit the healthy development of an integrated personality. Sedibe and Goosby (2013) report that many PLWHA do not know their status fear of stigma (punishment) prevents them from going for testing. Visser et al. (2013) asserts that the way in which individuals discover and disclose their HIV status to others, as well as how they cope with their HIV status, is influenced by cultural and community beliefs and values pertaining to causes of illness, learned patterns of response to illness, social and economic contexts, and social norms. The participant’s response suggests that she feared testing due to fear of stigma which underpins how her Shadow has taken (and took) over her personality not allowing individuation through an integration of all her personality archetypes.

Participant 5(F):

“People do not know that HIV does not kill. I did not exercise safe sex. It was not easy for me to live the life style I lived (of having many sex partners). I did not have sexual boundaries and needed presents. In spite of my awareness of HIV I failed to take precautions. I did not want to be infected but I did not help myself. I was one of those who was at high risk....I should have known that.”

In terms of Jungian Phenomenology this refers to the Self and the Shadow. The participant in terms of these archetypes displays weaknesses and shortcomings particularly related to sexual self-control. Her responses appear to affirm the finding by Gaynair (2013) that stigmatisation instills fear by presenting HIV/AIDS as a life-threatening condition (death) associated with behaviour that people disapprove of for instance, sex work, infidelity and women designated as sex workers as they have had many sexual partners. She presents herself as not being able to help herself and having many sexual partners. It is likely she was looking for a stable partner but did not find one and slept with many men because she needed *resents*. These were probably money, food and or things she wanted to live a reasonable lifestyle. She will have to factor in that she engaged in sex work as she received some sort of payment for sleeping with men. This will be difficult as her Self is presently dominated by her Shadow which will not allow her to recognise the darkness in her psyche thus individuation to her true Self will be difficult.

Participant 6(F):

“I didn’t give HIV a thought and because of this I did not bother to take any precautions. I was afraid that I could be infected but I trusted my husband. I had a suspicion that he was unfaithful to me because he was never at home. I suspected it but there was nothing I could do about it....I blame myself.”

The Shadow is the predominant metaphor in terms of this participant’s response. It is also related to the Innocent archetype. Even though the participant seems suspected that her husband was not faithful she still states that she *trusted* him. This statement is contradictory and she uses it so that she does not have to face her own behavioural shortcomings (she could have insisted on using condoms or not having sex, for instance or confronted him about his possible infidelity). However, the vulnerability of women in a patriarchal society is problematic as highlighted by AVERT (2016) who report that HIV related stigma and discrimination exist worldwide, and is higher in countries with traditional, patriarchal norms. The Tsonga culture is strongly traditional and patriarchal thus women have little room to maneuver, particularly in the realm of conjugal rights. This suggests that the participant self-stigmatises as she blames herself as a punishment (the Innocent). It is difficult but the participant will have to accept that she allowed traditional cultural norms to impact on decisions which resulted in her becoming HIV positive. This will allow her to accept her Shadow archetype and integrate it into her overall personality development.

Participant 7(F):

“No-one told me how to take care of someone who was HIV positive. Through ignorance one can be a victim of a serious disease. Due to lack of knowledge, I had no fear at all. I thought it was just like any other illness. When people associated HIV with sex I thought I was protected because I was not sexually active. Ignorance and lack of knowledge can put one in a serious position.”

In terms of Jungian Phenomenology the first two responses refer to the Shadow. The participant seems to project her anger at society as she blames her lack of knowledge on *not being told*. Fundamentally, she is using this as a justification as advice about HIV/AIDS care is given out at hospitals and clinics plus there have been many programmes and media interventions. Fundamentally, the mask of innocence creates a convenient mask or Persona. Mall et al. (2013) state that overall basic knowledge related to HIV/AIDS increased exponentially from 2004 to 2008. It is also extremely rare for individuals to become infected with HIV when caring for those with the disease. It may be that she was infected years previously through sexual intercourse but is not willing to look at that part of her life. The participant’s true Self cannot be revealed through individuation until she properly reflects on her life and accepts who she truly is.

Participant 8(F):

“People believe that they are safe and healthy if they have not tested for HIV. Before I was tested people thought I was HIV positive...I only tested because I was sick. I didn’t want to know” [because I had symptoms and was ill for a while].

These responses refer to the Shadow in terms of Jungian Phenomenology. The participant did not want to know her true status which relates to feelings of fear. She did not go for VCT until she was sick and people in the community already thought she had the disease. The participant’s ‘Shadow has not allowed true integration of all the archetypes in her personality development as she has consciously chosen to ‘own’ it. According to Nystal (2009) to integrate the Shadow with other archetypes requires considerable moral effort because it challenges the image an individual wishes to present to the world (their mask). It is also true that HIV stigma (internal and external) seems to have precluded the participant from going for VCT. The last statement is supported by a study by Sedibe and Goosby (2015) who found that both types of stigma were involved in inhibiting individuals from VCT.

Participant 9(M):

“I strongly believed that my wife was positive, as she had other partners, but that I was not. I just did not bother. Before I was tested I felt anxious but thought I must be negative as I was not ill. I had fear but I did not know what I feared. I had mixed feelings of whether I should go or not. I was not ready to know my status. Actually, I was not ready to receive an HIV positive result. I used to live a care free life. My wife and I used to abuse alcohol we did not even think of HIV as a result of having different sexual partners....I miss her.”

The Persona and Shadow archetypes are reflected in the participant’s responses in terms of Jungian Phenomenology. In terms of the Shadow the participant displayed weaknesses and desires he did not want to control (the use of alcohol and many sexual partners). He believes that the Persona, he displays to the world through his mask (not displaying illness, thus not being HIV positive), must be accurate. However, the anxiety in his responses indicates that, just below the surface, on a conscious level his anxiety (fear) was apparent but could not fully emerge because of his entrenched Shadow. His desire for easy living and pleasure revolved around the consumption of alcohol and sex which he has started to recognise. He reports that both he and his wife shared this lifestyle and it is interesting that he projects being HIV positive onto her (but not himself). The participant’s first wife died and he is left alone (although he does have different partners) and throughout the interview session he reported missing her which indicates regret and sadness. It is apparent that below the surface of his consciousness he wants to accept and integrate the Shadow into his personality development (not let it dominate) but this will take considerable moral effort (Nystal, 2009). He does not report stigma (towards himself), as such here, but as a male in traditional society it is likely that blame is apportioned to his wife which, is inferred, by his first statement where he *strongly* believed his wife (not him) was HIV positive. This is linked to Gaynair’s (2013) findings that promiscuity, particularly in females, is related to their being stigmatised.

Participant 10(F):

“I thought people who got infected were the ones who did not look after their health. I was careful about my life. I thought I would not be infected because I used to listen to my parents and I was not sexually active. I didn’t think about or fully understand the illness, and at that at that stage. I knew very little about HIV/AIDS. I didn’t worry about mixing with positive people or anything like that.”

In terms of Jungian Phenomenology this refers to the Shadow. As noted in other interpretations much knowledge about HIV has been in general circulation through workshops, programmes and the media thus it would be unusual for someone to not know about sources of infection. Although the participant states she was not sexually active she does not state how she became infected. It is likely that although she was not sexually active when her positive status became known she has not related her status to previous sexual encounters. She cannot find her true Self as she has not been able to integrate or recognise elements of her Persona (Nystal, 2009). The participant chooses not to know that which lies beneath the surface and, until she does, she will not be able to fully individuate.

Participant 11(F):

“It did not occur to me that I could be diagnosed with HIV as I didn’t think about my life...I had no direction or aims in life. As long as the sun was up and night came I felt I was living well. I did not bother to find out what they meant when they talked about HIV/AIDS and did not want to know.”

The responses refer to the Shadow and the Self in terms of Jungian Phenomenology. In reference to the participant’s Self she had no direction in her life which indicates that the archetypes in her psyche were not well integrated. She was not moving on with her life and aspiring to be what she had the possibility to be. Her Shadow enabled her to mask her true identity, in terms of her Persona, and she was not able to unify her unconscious and conscious psyche. Nystal (2009) indicates that individuals with dominant expressions of the Shadow need extensive psychological redirection since the Shadow obstructs positive self-image.

Participant 12(F):

“I heard people talking about HIV/AIDS. Because I was young, I didn’t think I could be infected. I do not know much about HIV/AIDS. I used to take life as it came and I thought HIV/AIDS was for the sick in hospital. I focused on my friends we moved around and had many boyfriends [sexual partners] and did not think about the future.”

In terms of Jungian Phenomenology the participant has a dominant Shadow which allowed a carefree mask to dominate her conscious personality presentation or Persona. As the participant is twenty one years old it is not possible that she was not exposed to HIV/AIDS programmes, workshops and campaigns during her school career however, it is probable that she did not *want to*

know thus did not actively listen or absorb knowledge imparted by these interventions. As she was untroubled she did not want to recognise her Shadow as it displays the characteristics which we do not like within ourselves (Brooke, 1993). She found it easier to embrace them but not consciously recognise them. In her future she will have to develop her Persona and individuate to become her true Self as she is to live a fulfilling life and experience her authentic life world.

Participant 14(F):

“I am presently a pensioner I looked after my children all my life. How could I be infected? I kept asking myself how I could have become infected. They never explained anything to me nor gave me anything to protect myself. I believed it was a disease for the sexually active. I did not know it could infect you when you bath with someone HIV positive. I believed that older people would not be infected. I did not think about it to me it seemed a disease of the sexually active youth.”

The participant's dominant archetype is denoted by the Shadow metaphor in terms of Jungian Phenomenology. The participant is in denial and as she blames 'them' (*they*) for not telling her anything. As she has attended the hospital and clinic for some time her file indicates that she has certainly been counseled and advised in terms of HIV/AIDS but has 'forgotten' this. Her role as a Caregiver through the years also suggests that she is inclined to martyrdom which is an integral part of that archetype. She does not recognise that sexual intimacy at any age can lead to infection with sexually transmitted infections (STIs) or that it can be many years before an individual becomes symptomatic (if HIV positive). The participant may have more knowledge about HIV than she states because she does know that it occurs when an individual is sexually active. As she is sixty four years old and a traditional matriarch of the Tsonga culture she is likely to be ashamed of her status and her replies indicate that she is angry and wants to transfer blame. The participant did not go to school at all thus her educational level is likely to have made her vulnerable to not understanding some aspects related to the pandemic. At this point she has to try and assimilate archetypes into her personality that are difficult both consciously and unconsciously. This is underpinned by Stutterheim's (2012) research which noted many cultural taboos when thinking and talking about HIV in rural African communities. It will be difficult for this participant to become a truly fulfilled personality in terms of her true Self owing to her age, traditional background and educational levels.

Participant 15(M):

“I refused [VCT], fearing that people would know about my status. Before I was infected, I knew about HIV/AIDS but I did not take precautions. I just thought it was curable like TB, so what does it matter. I used to live a care free life which I know was not responsible.”

The Persona is reflected as the prevailing metaphor in the participant’s response. He was care free which reflects a mask characteristic of apparent self-preservation. The participant did not want to take the test as he was scared that people would know about his status. As testing is confidential this also relates to his lack of trust or suspicion of health professionals which is also related to his Shadow, that darkness within her own psyche which did not want him to end his carefree existence. He only tested because he displayed some symptoms but would have preferred not to, as underpinned by the study by Sedibe and Goosby (2013), who found that people prefer to remain ignorant (unconscious) about their status because of perceived stigma and discrimination. It must be stated that his position as traditional Headman of the village put him in a level to enjoy specific excesses such as having many sexual partners and drinking alcohol without being branded as immoral and reflected the Shadow in his personality. At the time of the research he was sixty four years and has come to the realisation that his previous carefree life was not a responsible one. This suggests that he may be on the cusp of integrating the various archetypes which make up his Persona, into a new more integrated Self.

5.3.2.1 Summary of theme 2: Feelings before going for Voluntary Testing and Counselling (VCT)

The researcher, in addressing the theme of feelings before testing HIV positive, applied Jungian phenomenological metaphors in interpreting the responses of the participants. The Jungian metaphors Shadow and Self were equally dominant in the participant’s responses followed by the Persona metaphor. The feelings of the participants before HIV testing, as interpreted through Jungian Phenomenology, talk to the structure and intentionality of their experience. It appears that negative instinctive drives are galvanised and brought to the fore through the participant’s Shadow. Reconciliation of the participant’s conscious and unconscious psyche and commensurate archetypes indicate that a few are beginning to reflect on, and integrate, their archetypes into their true Self while others are not yet at this point in their personality development.

5.3.3 Theme 3: Feelings after testing HIV positive

All fifteen participants expressed their perceptions related to how they felt after they tested HIV positive. These feelings are similar to those related by participants in SANAC (2015) research where individuals, did not react in a constructive way at first, blamed others and were shocked but eventually came to accept support and some of the challenges associated with being HIV infected. However, many participants felt ambivalent about their positive status and although they often stated they accepted it, at other times still resorted to feeling guilty and blaming others. Not all participants' responses were presented, to avoid repetition, as some responses were very similar.

Participant 1(F):

“I felt bad at first. Later I felt better.....but sometimes I feel guilty and want to blame others and myself.”

The response captures the Self-metaphor in terms of Jungian Phenomenology. The feeling expressed by the participant is congruent to the situation. At this stage her feelings seem reconciled to the reality of her status although her Shadow sometimes comes to the fore and she wants to blame someone for her HIV status. The participant also blames herself; this is consistent with self-stigmatisation as suggested by Kalichman and Simbayi (2006). She does appear to be making a start to integrating the Shadow archetype into her true Self which will allow her a path to individuation and a fulfilling life in terms of individuating in a Jungian Phenomenological framework.

Participant 2(F):

“I felt bad. I thought I was dying. Hence I was afraid as well. After being tested I felt bad and guilty. At first I could not accept my condition. I was afraid. I thought I was going to die because my husband was dead already.”

The Shadow metaphor is prominent in terms of the darker side of the participant's psyche. She experienced fear and non-acceptance of her condition and thought she would die (as her husband died from the disease). The participant is self-stigmatises which is indicated by her feelings of guilt. According to Turan and Nyblade (2013) this is a common reaction of PLWHA. The authors also report that worrying about illness and death can become a self-fulfilling prophecy. At this point in her personality development the participant has not been able to integrate the different elements of her personal archetypes and her lack of acceptance points towards a dominant Shadow. She will

have to find the moral strength to reflect on her understanding of Self in order to individuate and live a life where her potential is fulfilled.

Participant 3(F):

“I used to be afraid of it and did not want to think about it. Immediately after testing positive, I did not have a problem. Since I had pre-test counselling, I understood everything I was told by the nurses. After a time I was worried about how I was going to live my life...it was difficult to change the way I lived but I did.”

The Self and the Animus are metaphorical representations of the participant’s personality development. She displayed heroic qualities, as part of the masculine side of her psyche, in accepting her positive status (*I did not have a problem*). However, even though she understands the knowledge she has received she does admit to anxiety about the changes she had to make in her life. The participant appears to have been able to accept her status and integrate her different archetypes into her true Self. Her responses indicate that her heroism is positive in terms of self-worth and she has the ability to emerge as a more spiritual, philosophical self through the optimal blending of her conscious and unconscious archetypes (Nystal, 2009).

Participant 5(F):

“When I found out about my HIV positive status it was a problem. It was not easy for me to accept it at first. I was anxious and did not know what to do. However I found the strength to go forward and I am alright [okay].”

The participants’ responses refer to the Shadow, the Animus and the Self in terms of Jungian Phenomenology. Although at first her Shadow representing the darker side of her psyche and the unknown wanted to deny her true feelings. However, she was ultimately able through her Animus archetype, to act in an heroic manner and accept her new reality. Her conscious and unconscious psyche has been able to integrate the aforementioned archetypes into her personality development which will enable her to individuate into her true Self. She will be able to fulfil the promise of her personality, in all its aspects. The participant’s initial anxiety was likely related to perceived stigma and psychological anxiety which resulted in self-stigmatisation (Blose, 2015). This, in turn is linked to Swartz’s (2007) notion about the disease as a lived experience of suffering where an individual can only ‘see’ the negative images HIV invokes thus anxiety is a normal reaction. However, this was replaced by a coping strategy reported by Makoae et al. (2008), which suggests that an intra-personal acceptance of being ‘okay’ allows PLWHA the ability to accept their positive status.

Participant 6(F):

“At first I felt bad, frustrated and angry with my husband I had looked after him and the family all the years. He infected me as I was faithful and he had other partners. After I attended a group session at the hospital, I started realising that I was in danger [when we had sex]....I still blame him but have learnt to live with it. What else can I do?”

In terms of Jungian Phenomenology this refers to the archetypal Shadow, the Caregiver, the Self and the Persona. Her instinctual Shadow which consists of sex and life (and thus death) instincts allows anger to others and a repression of her own shortcomings. She did not challenge her husband about his infidelities or try and discuss this with him which is also related to her cultural norms as a traditional African woman. She denies the Shadow and ultimately projects it onto her husband as it contains all the characteristics which she cannot recognise and finds unacceptable in her ‘Self.’ Nystal (2009) indicates that the Shadow lies just beneath our consciousness and need much moral effort to overcome. At this point she displays characteristics of the Caregiver who although she looked after her husband selflessly is inclined to martyrdom as she can do nothing else. This infers that she is not yet ready to reflect on her own part in the position she finds herself in (HIV positive) thus her Self is presented through her Persona as one who has been self-sacrificing in the past and who is now martyred.

Participant 7(F):

“Surprisingly, when they told me I was HIV positive, I denied it. I did not trust them because I could not understand how I could have contracted the disease. I did not want to. I was very scared and I had the worst shock of my life.”

Denial, in terms of Jungian Phenomenology is often associated with the Shadow and the Persona metaphors. Denial emanates from disbelief and is associated with negative coping mechanisms (Nqojane, 2009). She reports to not understanding how she contracted HIV/AIDS however, in the unrecognized parts of her conscious psyche she does. This is inferred by the statement that she *did not want to* recognise it. Denial is also related to the Persona in terms of the masking of her actual Self and wanting to present herself as not being HIV infected. This is related to her lack of trust of health professionals and the likelihood that she did not want to be seen as HIV positive to them as she *scared* of stigmatisation and death. This is underpinned by a report from UNAIDS (2013) which indicates that people fear acquiring HIV and link people infected with HIV to sexual behaviours that are considered immoral which causes them to be stigmatised. Individuation through

integration of the archetypes in her personality will require self-reflection and the ability to recognise all parts of her true Self.

Participant 8(F):

“I was shocked. I thought I was going to die because people told me that AIDS is a killer disease. I used to cry a lot and could not sleep. I did not believe that that I would live for more than a few months...but I did.”

The response refers to the Shadow and the Self in terms of Jungian Phenomenology. Her Shadow dominated her personality development at first and her thoughts of death related in an experience that is akin with depression. She did not die thus her personality has the ability to begin to integrate all the archetypes into her true and authentic Self. This is likely to be a long journey as her understanding of the disease needs to be broadened as it is a chronic as opposed to an acute disease today. Fundamentally, it does not kill if an ART programme is adhered to. Depression is linked to self-stigmatisation, which can be overwhelming. Nachega et al. (2012) reported that depression was reported by around thirty percent of PLWHA as a result of external and self-stigmatisation. The participant, during the interview, reported some symptoms that are consistent with clinical depression which she is being treated for. However, she will have to recognise her true Self and integrate the archetypes, including the Shadow into her conscious psyche if she is to truly individuate.

Participant 11(F):

“I was depressed. It felt like it was the end of the world and I would die. I felt helpless and useless to my family how would I look after them?”

This participant’s response is indicative of participant 8s response in terms of the Shadow and Self-metaphors in terms of Jungian Phenomenology. It seems she experiences her reality through her archetypes in a very similar manner. However, in this case she self-stigmatises more as she reports to feeling *helpless and useless*. This means she experiences her lived reality as the Caregiver, which suggests she could self-stigmatise and present her Persona as a martyr. Her reality in thinking that she might *die* indicates depression and possible suicidal ideation. According to Turan and Nyblade (2013), this type of negative thinking can result in suicide because PLWHA believe it is better to be dead than to be stigmatised. In this instance, the participant will have to stop self-stigmatising and thinking of death through integrating the different parts of her psyche and individuating to become her true and authentic Self.

5.3.3.1 Summary of theme 3: Feelings after testing HIV positive

According to Giorgi (2012) a large part of phenomenology is descriptive but this does not rule out phases where interpretation also takes place. Phenomenology does not dictate to phenomena but rather it wants to understand how phenomena present themselves as part of lived reality and everyday consciousness. It is this process through which the researcher has used the language of Jungian Phenomenology to articulate the intentional objects of the participant's lived experience. The dominant Jungian Phenomenological metaphors, in relation to participant's feelings after testing positive are the Shadow, and the Self. The inter-relation of other archetypes such as the Persona and the Animus are also noted.

An HIV positive diagnosis truly shocks the participants' sense of being and affects their identity in terms of how they have previously experienced their authentic Self. Their archetypal experiences are largely mediated by the Shadow or the dark side of the psyche. The essence of an HIV positive status seems to be experienced as a profound re-evaluation of an individual's Self and integrity. Overall, participants will need to find a way in which to experience themselves as HIV positive in an authentic manner in order to become properly individuated.

5.3.4 Theme 4: Fear related to HIV infection

All fifteen participants gave responses related to fear of HIV infection. It is estimated by UNAIDS (2015) that there are around forty million PLWHA worldwide, of these, around nineteen million are women and three million are children. Almost twelve percent of these become newly infected each year. Individuals infected and affected by HIV are often rejected by their families, their loved ones and their communities and are thus fear infection as they are discriminated against. To contextualise this statistic in South Africa HIV/AIDS is ranked as the fourth leading cause of death in the country (Statistics South Africa, 2012). According to Abdullah (2015), when people are faced with people who are dying from disease, including HIV/AIDS, their initial reaction summons feelings of fear and prejudice which causes them to discriminate against PLWHA. Not all participants' responses are presented as saturation was reached.

Participant 2(F):

“I thought my husband would get it, not me. Before testing I was not worried and I didn't think I would get it so I was not scared.”

The participant's Shadow is the archetype related to her response. This archetype reflects the dark side of her psyche which pushes characteristics which she does not want to recognise into her unconscious. She is practicing conscious denial and cannot integrate the Shadow (which is the opposite of the Persona) into her personality development. The participant wears a mask of *not being* worried and thus *not being scared*. In reality if her husband was at high risk then by inference so would she. However, she does not want to identify this and she cannot recognise that part of her psyche, dominated by the Shadow, which acts a defence mechanism. If she is to recognise her authentic Self and fulfil her true potential she will have to acknowledge all the archetypes within her psyche. This will require much effort as she will have to challenge elements of the Persona that she presents to herself and the world.

Mall et al. (2013) reported that overall basic knowledge of HIV/AIDS increased from 2004 to 2008 and that stigmatisation towards HIV positive individuals decreased over the same period. However, by stating that she was not *worried* even though she thought her husband would test positive it appears that the participant made no conscious effort to actively engage in understanding the pandemic.

Participant 3(F):

“Since I knew the lifestyle my husband led, I thought [suspected] that he might be infected though he used to hide his symptoms. He did not want to talk about it. He also did not want me to know that he was on treatment. If you are married, you do not have any choice, you look after your family, you are infected by your husband and that is that. I did feel scared.”

The Shadow metaphor is reflected in the in the participants responses in terms of Jungian Phenomenology. There is also an element of the Caregiver who selflessly cares for her family and husband but accepts that he will infect her and thus becomes a martyr. Conservative, patriarchal Tsonga culture plays a key part in this participant's acceptance of her HIV positive status. This, together, with low educational levels, has played a significant role in how she perceives her place in society. Mswela (2009) describes customary practices, for instance lobola, that contribute to the spread of HIV among South Africans. There is, for example, resistance to the use of condoms as a result of traditional African sexual and cultural norms and values. Africans, particularly those who have low educational levels believe that condom use promotes suspicions of unfaithfulness between partners. He states that lobola is seen as a binding agreement between the wife and husband's families and that a wife, when the designated payment has been made, is often seen as belonging to

her husband (thus must follow his direction in all things). The participant did not speak to her husband about his infidelities nor did she make any effort to protect herself against STIs because of her interpretation of cultural norms. She needs to interrogate this understanding and reflect on her responsibilities, in terms of herself and her family, and try to come to terms with the changing place of women in traditional societies. This is difficult, but for her to individuate and lead a fulfilling life, she needs to try. She has to integrate her fear (Shadow) and mask (Persona) and find the courage (Animus) to do this and still behave in a feminine manner appropriate to her culture (Anima).

Participant 6(F):

“Yes, I thought I could become infected because my husband was not often at home and I knew he was unfaithful. I didn’t protect myself though...he would not have allowed it...because of this I was scared.”

The interpretation of this participant’s response is similar to the aforementioned although the dominant metaphor is the Shadow. In this response however, the participant states that her husband would not have *allowed* her to take precautions against STIs. As noted previously conservative ethnic groups like the Tsonga have restrictive cultural practices and customs that make women vulnerable to HIV infection. Her age group and educational level increase her cultural vulnerability. Mswela (2009) makes the observation that promotion of many sexual partners, particularly amongst men, seems to be considered usual on the African continent. This practice facilitates the spread of HIV and other STIs. This is a difficult situation but the participant will have to confront traditional practices in her culture as noted in the previous interpretation to individuate to her true Self. It is difficult to know if this will occur however, all participants attend the Elim clinic and see counsellors and/or psychologists, as well as other health professionals, there is a chance they will be able to interrogate their lived reality and recognise their authentic Selves.

Participant 7(F):

“In fact, I never thought I would be infected. No. I never thought I would get infected since I was not very sexually active. I thought it was a disease for young people...not older people who only had sex with their partners. I knew my husband had other women but still was not scared as I didn’t think it would happen to me even when I cared for my husband when he was sick. I didn’t want it to become known and when it did I was no longer included in community events. That was when the fear started.”

The metaphoric representation of the response is seen in terms of the Persona and to some extent the Shadow. The participant has turned a *blind eye* to her husband's infidelity and her mask is one that projects an image of believing it a disease for only the young (not the old). Her Shadow has allowed this to permeate her consciousness thus she *did not want to know* the truth of her lived reality. She did not have fear as the dark side of her personality dominated both her conscious and unconscious thus she could not *see* the obvious that any sexual activity could result in an STI. Ogenmefun et al. (2010) report that secondary stigma towards care-givers in rural South Africa, often extends to close family members and caregivers who are often middle aged women. Their narratives revealed they were discriminated and stigmatised against and were often scared of how people would react to them. This participant was fifty years old at the time of the research and was not educated at all thus her ability to understand everything about the pandemic is probably limited. However, she needs to make a conscious effort to understand HIV/AIDS and integrate all parts of her psyche if she is to truly individuate into her authentic Self.

Participant 12(F):

“I was afraid that I would get it since I was sexually active...but I didn't do anything to protect myself because men must take care of that.”

The Shadow and Animus archetypes are dominant in the participant's responses in terms of Jungian Phenomenology. She was scared of HIV infection, but her Shadow dominated and she allowed her behaviour, consistent with cultural norms, to continue. The Animus archetype in her psyche, which may have allowed her to behave in a more assertive manner (masculine), was dormant. Nystal (2009) indicates that a strong Shadow presents an impediment for an individual to know his or her true self. An intensive regenerative effort is needed to redirect the participant to a path that would assist her to develop and enjoy a true reflection of her Self. As she is young, twenty one years old, it is possible that her personality development will follow a positive path and she will be able to individuate in future.

Participant 13(F):

“Yes, I was scared because I am still young and pregnant...I do not know how I was infected...I still do not know the status of my boyfriend...we still have sex.”

The participant is HIV positive, young and pregnant and *does not know how she was infected*. This response can be attributed to her Shadow as she has certainly been exposed to many HIV/AIDS knowledge campaigns at school and in her community. Her Shadow does not want her to know anything related to HIV/AIDS thus she consciously and unconsciously blocks knowledge and experience through the dark side of her psyche. She has not asked her partner his status and continues to have sex with him which is very risky for both her and her baby (if he is not wearing condoms). At present she chooses her the dark side of her psyche which, in this case, represents the unknown. These hidden characteristics help her deny elements in her psyche (Nystal, 2009) thus she is not yet ready to integrate all her personality archetypes into an integrated, individuated Self. It is also likely that she fears being left alone by her boyfriend, if she challenges him in terms of his HIV status, and losing any funding he might provide. This is underpinned by research which indicated that African women are seriously impacted by HIV/AIDS since they are economically, culturally, and socially disadvantaged in terms of traditional socio-cultural norms and patriarchy (SAMRC, 2013).

Participant 15(M):

“I did not think I would be infected, so I was not scared of HIV, because I was not so young even though I was unfaithful to my wife. I did not think it would happen to me, a man.”

Mswela (2009) indicates that patriarchy associated with African social norms allows males to have many sexual partners without it being considered wrong both on a cultural and moral level. He further notes that the paradigm of patriarchy plays a role in preventing the dissemination of reproductive knowledge. The participant has allowed his Persona to reflect an entrenched mask displaying no fear in an arrogance manner, not as a true Hero. His Shadow has allowed this to happen as he has consciously and unconsciously ignored the reality of HIV/AIDS. At the time of the research he was sixty four years old and it would take the huge moral regeneration of his psyche for him to integrate all the archetypes which exist in his psyche. To reach his full individuation potential and become his authentic Self he would have to reflect on traditional cultural practices and understand how they have negatively impacted on his own life, and the spread of HIV/AIDS in South Africa. Owing to his age and low educational levels this may not occur. However, he may gain some insights into Self through his continued attendance at the Elim clinic where he receives advice and counselling.

5.3.4.1 Summary of theme 4: Fear related to HIV infection

The researcher, in addressing the theme of fear of getting infected found that the dominant Jungian phenomenological metaphors the Shadow and Persona were dominant the Self, Animus, Hero and Caregiver were all represented. The essence of fear related to HIV infection is seen by the dominance of the Shadow archetype interpreted from participants' responses. In terms of phenomenology this suggests that the structures of consciousness, as experienced by participants, was directed away from their true Self to their dark side or Shadow which has not allowed them to experience their authentic or true Selves and thus experience their authentic life world.

5.3.5 Theme 5: Perspectives of death

Fourteen participants gave their perspective or understanding of death and one, who was unable to reflect on, or face this issue, did not. According to Turan and Nyblade (2012), people who worry about illness and death self-stigmatise which, in turn, leads to more worry and guilt which can become a self-fulfilling prophecy (essentially, they live shortened lives).

Essentially, people who stigmatise PLWHA believe that it is the individuals own fault they are HIV positive as it was their risky sexual behavior that exposed them to infection. This becomes internalised by PLWHA (ICRW, 2015). This is supported by information from AVERT (2014) in who suggest that HIV/AIDS is a life-threatening condition associated with death which is often internalised by PLWHA. The following responses underpin the theme perspectives of death. Not all responses are provided as saturation of content was reached.

Participant 1(F):

“When I saw people dying I felt bad...but I didn't want to think of dying and didn't think about it or admit I thought I could die to anyone.”

In terms of Jungian Phenomenology this refers to the Shadow and the Persona. The participant has a mask that relates to suppressing thoughts of death. She does not admit she might die to herself and her Shadow attempts to keep it out of her psyche. However, her response indicates that thoughts of her own death to creep into her consciousness and she has to keep repressing it through not admitting the possibility. The dark side of her psyche did not allow her to integrate the possibility of death and dying into the archetypes that exist in the characteristics which contribute to her personality development. Yuh et al. (2014) indicate that HIV/AIDS stigma includes negative behaviour, denial, secrecy, fear and self-blame related to the disease. Her denial of the possibility of death can accentuate self-stigma can lead to depression and more seriously suicide. The participant

needs to integrate the realities of life and death into her true Self to truly understand her own mortality and to complete her process of individuation.

Participant 2(F):

“Death is natural. I do not think about it now....I did at first but my status won’t affect how long I live.”

The response reflects the Persona in terms of Jungian Phenomenology. The participant seems to have developed a mask in relation to her condition. Putting the reality and possibility of death because of HIV/AIDS out of her consciousness (or trying to) is a negative coping behaviour (Yuh et al. (2014) which will not allow her optimum personality development as noted in the previous interpretation. Her Shadow allows the dark side of her psyche to dominate and mask her true Self. The stigma that links HIV to death is persuasive and tenacious and very difficult to expunge from an individual’s consciousness. Masking it is a temporary coping behaviour that is used by some PLWHA. Internalised self-stigma facilitates this type of coping according to the SAMRC (2012), as fear of contagion and fear of death are prevalent amongst PLWHA.

Participant 3(F):

“Death happens. In my family my brother died of AIDS. My sister died following a motor accident. What difference does it make...death? I don’t think I will die of HIV probably something else. Death is death. We are all going to die one day. I do not have any fear of dying because I might die of anything not just HIV.”

The Persona metaphor is reflected in the response in terms of Jungian Phenomenology. The participant seems to have built a strong mask that protects her from issues related to death for instance, ‘*What difference does it make?*’ Her mask is ingrained and stops her from feeling grief, despair and empathy thus the ability to be human. Her Shadow blocks this from her consciousness and has enveloped her unconscious thoughts. This effectively stops her integrating her personality characteristics and individuating to become her true Self. According to Cherry (2011) individuals with ingrained Personas have a compromised their goal of individuation. This participant seems to be at this stage. At the time of the research she was fifty two years old and it may be that her deeply ingrained mask may prevent her from experiencing her true Self. She notes that *death is death* but does not want to recognise that HIV/AIDS could cause her death which is likely related to self-stigmatisation which PLWHA experience through feeling guilty because of their illness (SAMRC, 2012). To individuate she will have to recognise that PLWHA often face shorter life expectancy

than those who are not HIV positive even when treated with ARTs which also has side effects (SAMRC, 2012).

Participant 4(F):

“I used to be afraid of death before, but now I understand it differently. Everyone dies...what can I do? It does cause me to think about it but I try not to.”

The response refers to the participants Self and her Shadow in terms of Jungian Phenomenology. At the time of the research she was twenty six year old and, at that age, an individual does not usually think much about it. Her HIV status seems to have brought cognitive restructuring regarding her perception of death. Death's reality and possibility is understood differently as a PLWHA. Her response moves death away from herself to everyone this projection displays aspects of her Shadow. Turan and Nyblade (2013) indicate that PLWHA worry a lot, particularly about illness and death and sometimes this self-fulfilling prophecy becomes true. The participant needs to understand death and life as an integrated continuum and not to worry about what is inevitable and thus individuate to find her true Self (without living a life trying to consciously suppress fear).

Participant 5(F):

“It is difficult I am a Christian and I should have lived a long life...but I fear death coming sooner because of HIV.”.

In terms of Jungian Phenomenology this refers to the Self. The participant seems to have factored the reality of her condition into her system of personality development but the Shadow in her psyche lets her fear death coming sooner because of her positive status. This participant is young (twenty nine years old) and, as noted in the previous interpretation people at this age do not usually think about death (although it is always a possibility in life).For her to fear it suggests that she worries about its proximity. The participant *should have lived a long life* which she associates with her Christianity which infers she feels guilty and is self-stigmatising. This internal stigma is related to fear and self-blame related to the disease (Yuh et al. 2014), which can result in a self-fulfilling prophecy (Turan & Nyblade, 2013)

Participant 10(F):

“I will continue to adhere to the treatment until I die like any other person, not because I fear AIDS...my baby died because of the illness and I have accepted that and although it was bad and I thought I would not be able to carry on I did.”

In terms of Jungian Phenomenology this refers to the Self. This participant has realised that she will die at some point but not because she fears HIV/AIDS. She appears to recognise her true Self and does not fear HIV/AIDS (and thus the Shadow) because she adheres to a treatment plan. The reality of death has been factored in to the archetypes that make up her personality and her Shadow is not dominant. Although this participant is also young (in her twenties) her HIV positive status has made her face the realities of death and dying before she usually would (in terms of personality development). She has had to face the tragedy of death as her baby died thus has shown great moral strength in being able to individuate to be an authentic Self she recognises. It is likely that this participant will continue on a path of optimum personality development as her response suggests she does not self-stigmatise and blame herself.

Participant 15(M):

“I do not think I will die since I am using ARTs, particularly because I neither drink nor smoke. No, I am not scared because I won’t die now.”

In terms of Jungian Phenomenology this refers to the Persona and the Shadow. The participant has developed a mask in order to cope with death if it is caused by HIV/AIDS. His mask allows him to state confidently that ‘*I won’t die now.*’ This is unrealistic and perversely heroic as the participant is sixty four years old and (even though using ARTs) his health has been severely compromised (he has been symptomatic for specific AIDS related illness). It is unlikely that owing to his socio-cultural status and the Persona he presents to the world as a man (Heroic in a negative sense) that he will be able to truly individuate and experience his real self. According to Cherry (2011), an ingrained Persona is inversely related to authentic individuation.

5.3.5.1 Summary of theme 5: Perspectives of death

The Shadow and the Persona emerged as the dominant Jungian Phenomenological metaphors in the theme pertaining to the participants perceptions of death. The Self and the Hero archetypes were also represented. The essence of the participants’ perspective on death is reflected in the dominant Shadow which does not want the participants to consciously reflect on death’s reality and the life-death continuum ever present in the every-day life of humanity. Only one participant was able to indicate that she was able to recognise her authentic self. This was the participant who suffered the tragedy of death as her baby died. Others, though experiencing the death of loved ones were not able to truly reflect on death. Their masks facilitated by their Shadows allowed a false image (Persona) to dominate their lives. It is apparent that their responses, through a Jungian Phenomenological interpretation, indicated that their intentionality, on perspectives of death, is

expressed through conscious and unconscious expressions as one of fear. It is also worth noting that fourteen of the participants' experience of their Self, as the mediator between their conscious, unconscious and collective unconscious, is undoubtedly adversely affected by their perspectives on death. This means they will require much moral courage to face the dark side of their psyche (colloquially their *demons*) in order to fully individuate.

5.3.6 Theme 6: Anxiety related to being HIV positive

Out of the fifteen participants, only one did not discuss any significant anxiety related to being HIV positive. According to Kamen et al. (2015), women reported greater anxiety about being infected with HIV and experienced more HIV related stigma and self-stigma. As there were only two male participants, and the study could not be generalised, comparisons could not be made. However, the women in this study did display anxiety about their illness related to care-giving, money and their lives in general. The one participant who did not discuss significant anxieties related to the positive diagnosis was male. Not all the participants' responses are presented owing to saturation of content.

Participant 1(F):

“I do not have a problem now. I was anxious and worried at first but I have got over that. Sometimes I worry a bit because of my family.”

In terms of Jungian Phenomenology this refers to Animus. The participant has become brave and heroic in confronting her lived reality. It appears that her Shadow allows her recognise her anxiety but is not dominant in her archetypal mix. Equilibrium seems restored so that she is able to move forward with her life and follow the process of individuation. She has lived with her HIV status for seven years and has carried on with her everyday life, which entails caring for her two children and staying employed. Cherry (2011) refers to the 'Animus' as if integrated in a positive manner reflective of the individuals true Self. In this case the participant seems to have found the courage to follow an authentic path to individuation and recognition of her true Self.

Participant 2(F):

“I have ulcers and flu. I sometimes cough the doctor tells me it is because I worry too much [about my condition].”

The Shadow metaphor is reflected in the response in terms of Jungian Phenomenology. The participant seems to be worried about co-morbidities that aggravate her health in the face of HIV infection. The participant seems to have an enhanced vigilance towards the possibility of death which her Persona masked in her response towards perspectives on death motivated by the dark side

of her psyche (Shadow). Constant worry is the genesis of pathology such as ulcers and vulnerability to minor viral infections often underpins AIDS symptomology (Nqojane, 2009). This is supported by AVERT (2014) who confirm that HIV/AIDS has many comorbidities associated with the onset of full blown AIDS.

Participant 3(F):

“My womanising husband has rejected our family and lives in Johannesburg. My worry is about having to look after my seven children alone. I am unemployed. My neighbours also know about my status thus I worry about my children being stigmatised.”

The Animus and Shadow archetypes are reflected in the participant’s response in terms of Jungian Phenomenology. The participant is angry and has adopted a male role in being heroic and fending for her family. This heroism has a negative slant as it is, in her case, associated with aggression and hostility through representations of the Hero through her dark side (Shadow). The participant has lost her husband and reported to the researcher that her brother had died of HIV/AIDS and is now confronted with unemployment and caring for her children. Her life is very difficult. The worry about her children being stigmatised is a relevant one as it is well documented that men experience less stigmatisation than women and children when they are known to be HIV positive (SAMRC, 2013). The effect of stigma is mediated by gender and it is experienced more by women who are blamed for spreading the disease than men. This is rooted in traditional social constructions of sexuality and sexual relations which accept male promiscuity and blame women for the spread of HIV (UNAIDS, 2012). To fully individuate the participant will have to allow her archetypes to integrate and consciously reflect on her anger. This will be difficult as her lived reality is challenging however, if she can do this she will be able to fully develop her personality which will allow her to see opportunity (and light) not just darkness.

Participant 4(F):

“I worry about what other people say and how other people think about those who are HIV positive and those who have AIDS.”

The participant responds in a way which reflects the Shadow in terms of Jungian Phenomenology. The participant does not refer to herself when worrying about what others will say she speaks about *those who have AIDS*. This is denial as her response suggests that she has not truly accepted being one of those who is infected with HIV. Her denialism means that she will be unable to integrate all elements of the archetypes which make up her personality. She needs to integrate and acknowledge

her Shadow to individuate which will require much effort and what Nystal (2009) refers to as moral courage so that she can recognise that she herself is *one of those* PLWHA.

Participant 5(F):

“I am unemployed and unmarried. I am expected to adhere to the treatment and get a balanced meal. I cannot do this so I worry about my health which makes everything worse. I don’t tell others though I want to be strong.”

In terms of Jungian Phenomenology this participant’s response is indicative of a dominant Persona archetype with elements of the Hero (*wanting to be strong*). Her lived reality dictates that she cannot always eat balanced meals thus her worry over her diet is well founded. This is the reality that many PLWHA live with however; worrying about her health is likely to have a negative effect as that may aggravate her condition through becoming a self-fulfilling prophecy (Turan & Nyblade, 2013). The participant needs to drop her mask and become truly heroic by telling her family and/or close friends about her worries so that she can get help. This should also be discussed with her counselors at Elim clinic who have access to particular programmes (through NGOs) who could help her [the participant was given information in this regard]. This would help her experience her true Self and help her on her path to individuation. Schatz et al. (2011) suggest that the HIV/AIDS pandemic has significantly changed the household challenges in everyday African life which this participant has experienced.

Participant 6(F):

“I do not have enough money to buy food. My worry is about my HIV status and hypertension. I do not know who will look after my family when I die. I feel guilty.”

The response reflects the Shadow in terms of Jungian Phenomenology. The participant does state she does not have enough money to buy food. She did not appear under-nourished and when questioned reported to buying fresh vegetables and offal which are good sources of nutrients however, she thinks of good food as red meat and processed foods (such as cereals and white bread). It is likely, however that she does not have money to provide properly for her five children since she was widowed (her husband died through HIV/AIDS related illness). The harsh reality of her everyday life plus her HIV positive status worries her as, if she dies, the children will be orphaned. This is a reality thus her anxieties are real. She is fifty two years old and also has hypertension which worries her more. When questioned she states that she takes her medication most of the time but not always as she sometimes forgets when she is busy. She knows that she needs to take all her medication to stay healthy however, the dark side of her psyche allows her to

forget (denial) thus she worries more making her self-stigmatise by feeling guilty Her anxieties and self-stigmatisation could result in a self-fulfilling prophecy relating to her early death (Turan & Nyblade, 2013). The researcher discussed nutrition (and referred the participant to one of the clinic sisters) to help her understand that some of her worries may not be correct. However, she will have to recognise that self-stigmatisation will enable her Shadow to dominate her personality which will impinge on her ability to individuate to her true Self (thus be able to recognise possibilities in the future not just negatives).

Participant 7(F):

“My family discriminated against me I feel guilty about this. I try to act in a happy way but when I look at my son and how he treats me I feel very sad. I could see my son was in pain and could not stand it but he did not treat me well.”

In terms of Jungian Phenomenology this refers to the Persona. The participant displays a *happy* mask to her family and others which is not how she truly experiences her Self. She is trying to integrate a *happy* mask into her conscious behaviour which is not truly successful. Her family has discriminated against her which is very sad but she has not (reportedly) tried to inform them about her condition (through information and pamphlets from the clinic or asking a social worker to visit her at home). She experiences this as pain that she *could not stand* and states her son treated her badly. Her *happy* mask is heroic in a negative manner. She displays characteristics of the Caregiver in that she is inclined to martyrdom that is, accepting her situation and not doing anything to overcome it (possibly because of depression). When the research took place she was fifty years old, had never been to school and was unemployed. It is likely that her guilt and self-stigmatisation could lead to her becoming depressed and possibly suicidal (Turan & Nyblade, 2013). Her state of mind was noted and she was referred to one of the psychologists at Elim Clinic.

Participant 12(F):

“I see myself without a future. I am worried about my lost youth and being discriminated against by my mother. I am worried about the way my mom handled my status.”

The response reflects the Shadow in terms of Jungian Phenomenology. The participant reports that she does not see herself as having a *future*. Her process of individuation is presently interrupted as she has no vision of a life path. As she is only twenty one years old she has time to reflect on her lived reality and come to terms with the archetypes which make up her authentic Self. Her mother does not seem to offer empathy and support (previously it was stated that her mother disclosed her

daughters HIV status to neighbours). This lack of empathy and discrimination from her mother has allowed her to dwell on *her lost youth* which is interpreted as her lost innocence. This infers that as well as experiencing discrimination she self-stigmatises as loss of innocence implies guilt. Blose (2015) suggests that internalised stigma results in PLWHA retreating from society and not experiencing a full life. The participant needs to discuss her HIV status with her mother, however she reacts, and realise that she has the potential to live a life. This will help her on her journey to true individuation.

Participant 15(M):

“I am worried about my children because I am the bread winner and my wife has since passed on. Many of my children are still young. I would be happy if they finish school before I die. I cannot get used to living alone without my wife. I miss her a lot.”

In terms of Jungian Phenomenology this refers to Anima. The participant seems to be displaying the feminine side to his nature by wanting to nurture his children. He also refers to missing his wife (who died from AIDS related illness) and not being used to living alone. His deep concern for the future of children, whilst it is a male capability, is inextricably linked to femininity. According to Cherry (2011), the Anima is about the feminine tenderness in a man. It is about showing the female in the mind of a man. It represents the extent to which the man has picked up parts of the female personality. However, he needs to be heroic in by being courageous and accepting his loss and being alone while concentrating in integrating the Anima, Animus and Shadow (previously mentioned in this participant) into his personality development. It is unclear whether he will be able to do this however, as his Anima has come into play this may indicate that his Shadow will become less dominant and he will consciously and unconsciously be able to properly reflect on his life thus far and enable him to recognise his true Self.

5.3.6.1 Summary of theme 6: Anxiety related to being HIV positive

The most dominant metaphor in terms of Jungian Phenomenology identified in this theme was the Shadow with representations of the Persona, Self, Hero and Caregiver. Significant anxiety has an impact on the conscious mind of an individual hence the Self (which has the consciousness as an element) is negatively affected by dominance of for instance, the Shadow (Cherry, 2011). In this research the participants indicated that the intentionality of their experience of anxiety impacted negatively on their personal development processes and individuation. The Self as the regulating

centre of personality that mediates between the conscious, unconscious and collective unconscious has been destabilised by the anxiety that the participants report.

5.3.7 Theme 7: Stigmatisation

Among the fifteen participants, thirteen were female and two were male. Eleven of the participants reported to experiencing various forms of stigmatisation. There were more women than men who 1) attended the clinic at Elim hospital and 2) were willing to come forward to describe or narrate their experiences. Fundamentally, this endorses the social construct where women are largely blamed for promiscuity and being infectious, hence females are more stigmatised than men. This is reported by UNAIDS (2012). Furthermore, health care services are underpinned by stigma meted out by health care workers towards PLWHA. This has a negative impact on programmes in combating the spread of HIV as observed by Weston (2006). According to Stangl et al. (2013) the identification of effective interventions to reduce stigma and discrimination that can be integrated into national responses is crucial to the success of the global HIV/AIDS response.

The theme also supports the narrative which denotes that in a display of self-stigma some PLWHA choose to hide away from the public, isolating themselves from others as reported by Shirimba and Nyamaze (2006) and Dosier (2010). This is further supported by research conducted by SANAC (2015) where PLWHA in South Africa show high internalised stigma which constitutes feeling shame, guilt, self-blame, blaming others, low self-esteem, suicidal and the need to be punished.

The experience of stigmatisation felt by the participants is supported by the following statements.

Participant 1(F):

“I was afraid that you [the researcher] were going to see me at work because you came in a Health Department car. If this had happened I would be worried about what my fellow workers would think [that there was something seriously wrong with me perhaps HIV].”

In terms of Jungian Phenomenology (Brooke, 1993) this participant has some disquiet at being HIV positive. She struggles with what Jung refers to as the Persona. She copes by hiding her true status and by hiding behind the mask she has developed (to protect herself). Problematically, the longer an individual portrays a mask and not the true self, the harder it becomes for an individual to regulate their true self which means they cannot individuate (Sedgwick, 2009). Essentially, the participant cannot aspire to what she could be as her unconscious and conscious are not unified. The search for her true essence continues as she continues on her path to individuation (Brooke, 1993).

Participant 2 (F):

“I had a problem consulting at the clinic because people suspected that I was HIV positive. I did not want my children to know that I am HIV positive. I used to hide my treatment. I thought it was wrong to have HIV and people would discriminate against me and my family. I was worried that when people talked about HIV/AIDS they were talking about me. I thought they knew about my status. They like to talk and discredit others because they have nothing else to do.”

The participant's responses in terms of the Jungian Phenomenological approach are dominated by the Shadow and Persona archetypes. The participant's narrative is consistent with false self-preservation through projection. She thinks others are talking about her and she projects negative thoughts onto them regarding her positive status. She also thinks people know that she is HIV positive. In terms of the Persona, the participant wanted to preserve an image that is acceptable to her family thus she keeps her true HIV positive Self- hidden and presents a mask to the community. Her mask indicates that she is HIV negative. As she is fifty one years old and was raised in the traditional, patriarchal, conservative Tsonga culture she is likely to experience embarrassment and guilt at being HIV positive. The participant's predicament is explained by Blose (2015) who indicates that HIV positive South Africans suffer from internalised stigma which is noted as a sense of shame and inferiority. This results in them retreating from society and thus not living an authentic or full life. Her responses infer that she self-stigmatises through feelings of guilt. In some senses this relates to the archetypal pattern of the Caregiver as she wants to protect her family however, she hides her positive status and tries to carry on her life and thus 'martyrs' herself for their sake.

Participant 3 (F):

“It makes it easy for me [not speaking about my own status] because I only feel guilty when people talk about HIV/AIDS.... even though I know they are not talking about me.”

A Jungian Phenomenological interpretation according to Brooke (1993) would be that the participant seems to have succeeded in masking (hiding) her HIV status and is thus not able to reveal or experience her true Persona. As she is fifty two years of age, raised in conservative Tsonga culture, with seven children she would feel embarrassed and ashamed if her status were known, in spite of having lived for ten years with HIV. All individuals naturally attempt to individuate so that they can achieve a balanced personality without individuation their journey to a true self is not

possible. This process is well captured by Nystal (2009) when he indicates that the emergence of a more spiritual, philosophical self is the result of an ideal blending of the conscious and the unconscious. A deep-seated mask, such as the one worn by the participant, interferes with this process significantly. The person may be seen as archetypically orphaned as she does not want to stand out in any way, in this case be recognised as HIV positive.

Participant 4 (F):

“I was really scared about how other people would see me. It dawned on me that I have joined other people who are not healthy and that my disease is HIV. I did not feel good at all.....but this is me..... now and I am used to it.”

This is interpreted as referring to the Self. The participant seems to have successfully factored in her HIV positive status within the process of her individuation. The participant is no longer scared of her status and appears to have reconciled herself to the reality of HIV infection. At the time of her statement she had been living with HIV for two years and had learnt to cope. The participant has accepted her true self and had acknowledged her HIV positive status. French et al. (2015) state that in order to individuate an individual must recognise all his or her personality characteristics in order to secure a stable personality through integration of the various archetypes, which is the basis for further positive personality development and recognising one’s true Self (individuation) and life world.

Participant 5 (F):

“I was not happy. I asked myself many questions like why did this happen to me. I could not believe that I was infected. It felt like it was the end of the world for me. I did not know who to blame. I was depressed because I had a few [sexual] partners. I blame myself for not being vigilant. I blame myself for being irresponsible”.

In terms of Jungian Phenomenology, according to Brooke (1993) the participant appears to be referring to the Self. Her perception of Self seems not to be congruent to the one she envisaged as it seemed to be the ‘end of the world.’ Nystal (2009) asserts that the Self cannot emerge until other characteristics of the personality have fully developed. An individual moves from sole reliance on the conscious ego to a middle ground between the conscious and the unconscious. In the case of the participant, there seems to be an internal cognitive revolution that will at some point restore balance and that will generate a new middle ground which will allow her to accept herself and her positive status.

In terms of Jungian Phenomenology the second, third and fifth sentences refer to the Shadow. The participant seems to be stifled in projecting her shortcomings and weaknesses to herself and to others. She is conscious of her weakness related to her sexual behaviour which was unchecked and she feels socially unacceptable (given that in the Tsonga culture discussion about sex are taboo). She seems to concede that her inner drives were not well controlled in terms of existing social norms in her community. Winskell, et al. (2011), found the same in Nigerian narratives which are illustrated by unforgiving moral agendas and dominated by conservative Christian doctrine on sexuality, which tends to focus on the misdeeds of individuals (primarily female) that leads to their infection.

Participant 6 (F):

“I found myself in a situation where I was infected and felt helpless as I depend on others. When I am alone I am pre-occupied with my HIV status and hypertension [which I also have]. I am easily fatigued and persistently worry. If people do not listen and understand you... do not talk.”

Brooke's (1993) Jungian Phenomenology is used to interpret these sentences as referring to the 'Self.' The participant seems to regret that her envisaged Self will not be realised. She seems to be experiencing a regressive state where dependence seems to be the hallmark of her life. The participant experiences helplessness that is expressed as fatigue and incessant worry. She has been living with HIV for four years. According to Sedgwick (2009) the creation of the Self occurs through individuation, in which the various aspects of personality are integrated. If persistent worry and fatigue do not diminish she will not be able to integrate aspects of these archetypes into her personality. Fundamentally, she is showing patterns consistent with being a martyr in terms of protecting herself and her family from community prejudice, but not in a care-giving or altruistic manner.

The last sentence refers to the Shadow in terms of Jungian Phenomenology (Brooke, 1993). The participant has developed an attitude that people 'do not listen,' thus 'do not talk.' Her projective assessment of others suggests that many do not understand thus she should not talk. Her shortcomings and weaknesses are expressed through this projective tendency. Nystal (2009) indicates that the Shadow can be acknowledged as an integral part of an individual's personality development and that it requires considerable honest effort because it challenges the positive image an individual wants to present to the world. In this regard the participant projects (transfers) a negative attitude onto others in terms of them not understanding thus not wanting to talk she is therefore underpinning a position of being reclusive and martyrdom.

Participant 7 (F):

“People will not stop talking about AIDS and gossiping about those who are HIV positive which makes me feel helpless. Someone should advise people not to discriminate against those with the disease and that they should not laugh at them or hate them.”

These responses refer to the Self when analysed using Brooke’s (1993) Jungian phenomenology as a template. The participant seems to express helplessness and resignation in terms of her perceived reality that people will continue to talk and gossip about PLWHA. In expression of the subtle Shadow, she seems to project her dissatisfaction with her image as an HIV positive person who is being discriminated against, laughed at and [even] hated. This position is in keeping with the assertion by Nachega et al. (2012) that thirty years into the HIV pandemic, perceived HIV stigma, isolation and discrimination persist and are associated with loneliness and depression amongst PLWHA.

Participant 8 (F):

“I did not want to be ‘one of them. I am helpless’. At first I refused to take treatment since I was stubborn. The stubbornness was because of those who stigmatised me. I grew up in the church but now I have lost interest in Christianity. If you understand this condition you would not laugh at others. Many people do not understand that when you are HIV positive it was not your choice. You weren’t asking for it either. When I talk people mocked me and they thought I was not aware they were discriminating against me. I was fully aware at the way they were looking at me and the comments they were making about me. They laughed at them thus aggravating my pain and suffering. How can you laugh at someone who is sick? They seemed to enjoy making me suffer.”

In terms of Jungian Phenomenology the first four and last two sentences refer to the Self. The participant reported losing her religious beliefs which may infer that her individuation will be delayed as her spirituality may not be fully congruent with her true Self. This participant still feels the impact of HIV stigma in spite of having lived for ten years with HIV. This significant religious (and probably spiritual) re-organisation is underpinned by Lliamputtong (2013) who asserts that HIV infection not only means that women not only have to face living with, and managing a chronic health condition, it also means that they are likely face social stigma that may fundamentally change the way they perceive themselves. The participants psyche is impacted by her

HIV positive status to the point of feeling helpless. Turan and Nyblade (2013) indicate that some PLWHA contemplate suicide, thinking that it is better to be dead than to continue being stigmatised. They also report that PLWHA often have depression which is a direct result of the social isolation caused by stigmatisation. Helplessness, as experienced by the participant, is a serious sign of severe depression which maybe a forerunner to suicidal ideation. Her current reality is to be reconciled with her status. She does not like the image she projects to people. In terms of Jungian Phenomenology the participant's fifth to ninth responses refer to the Shadow. She is angry that people are mocking her HIV status. Her suppressed negative feelings and ideas come to the fore as she projects her frustration. Nystal (2009) indicates that the Shadow is that aspect of an individual's personality that lies beneath the surface and is displayed as a negative impulse which the individual always attempts to hide.

Participant 11 (F):

“I regret having disclosed my status to my family. They even told our neighbours that I am HIV positive and because of this I am discriminated against by community members. I have mixed feelings I don't know who I am. I didn't go out to catch HIV on purpose. If you are stigmatised by your mother and son, there is not much you can do about it”.

The participant describes a problem with her sense of identity and belonging which refers to the 'Self.' This affects her psyche and her overall personality development. The lack of family support poses a serious threat to the participant's ability to cope and adapt to her HIV status. Self-blame and shame seem to creep into the participant's responses as she states that she did not look for the disease and does not know who she is. Grodensky et al. (2015) in their study on the roles of relationships, spirituality, disclosure, stigma, and shame in older women living with HIV identified family support and platonic relationships (with males) as important sources of support. In this instance, the participant is not only experiencing stigmatisation from her nearest family but also from the community. She has thus not been able to find her true Self and thus is unable to individuate.

Participant 12 (F):

“My mother disclosed my status to her friend. My mother and her friend disclosed my status to other people. There was nothing I could do I felt like a small child. It disturbs me to know that my mom does not support me. I wasn't sure whether to disclose or keep it to myself, I wish I hadn't. I thought I was going to die. I am

severely stigmatised because of my poor background as well. Stigma seems to go [hand in hand] with poverty.”

The third to the last sentence of the participant's response refer to the Self with regard to Brooke's (1993) Jungian Phenomenology. The participant seems to have stalled in the process of individuation because of lack of empathy and support from her family. Helplessness is manifested in her responses. In a study by Grodensky et al. (2015) disclosure was perceived as being even more shameful if participants, particularly women, were middle-aged. Those receiving social support do so mainly through relationships with family and friends, rather than romantic relationships. The lack of family support received by the participant interferes with her efforts to assimilate her status, and thus adjust to her lived reality. She seems to have no anchor for her trust. At present she cannot integrate archetypes into her personality as she is not able to envisage them either consciously or unconsciously. The participant needs to encourage her family to read stories such as the one told by the late President Mandela, when he disclosed that his son, Makgato, died of HIV/AIDS. If her family becomes more understanding and empathic she may be able to resolve her inner conflict.

The first two responses (sentences) refer to Shadow. She blames her mother (and thus projects anger) and her mother's friend for disclosing her status to the community. The participant has repressed desires related to her poor socio-economic status. Realistically, since she is unemployed, she is dependent on her unsupportive family for all her needs. Visser et al. (2009) found that HIV/AIDS related stigma is often layered. In this instance, poverty is one of the layers of stigmatisation. In support of this Lekas et al. (2011), observed that the blame for HIV conferred on groups wrongly associated with the spread of the pandemic in Africa (for instance, those who live in poverty) is often associated with them facing more discrimination and stigmatisation than other groups meaning they experience multiple layers of stigma. This is instrumental in shaping this participant's internal picture of herself and is likely to have resulted in low self-esteem and depression.

Participant 13 (F):

“I was not happy about myself because I suspected [thought] people knew that I was HIV positive. Lack of knowledge can cause stigmatisation and discrimination ...you know I only feel guilty about my status when I hear people talking about HIV/AIDS.”

The first response refers to the Shadow. The participant seems to transfer her own feelings onto others in terms of them knowing that she is HIV positive. She clearly has repressed negative feelings and thoughts since she concedes that she is not happy with herself. Building on the finding by Nystal (2009) it seems that the participant needs to reflect on her intra and inter personal self as

her words do not reflect a positive image of her true Self. She does not want to be *suspected* as being HIV positive. In terms of the Persona in Jungian phenomenology the participant has masked her HIV status and feels guilt when she hears discussions about HIV/AIDS which involves her Shadow. Her guilt in relation to her HIV positive status however, is situational (only when people talk about HIV/AIDS). Cherry (2011) indicates that the goal of individuation is inversely related to one's Persona. It is apparent that the participant because of her inability to accept herself and recognise her feelings of guilt on an every-day-basis will, at this stage, not be able to realise optimal individuation and an authentic life world.

Participant 15 (M):

“You want to think that they are talking about another person [not oneself]. If only I lived with my wife, with one woman, I would have been HIV negative...I regret this not being the case...I feel guilty and alone.”

The first sentence refers to the Shadow when applying Jungian Phenomenology. The participant regrets his past when he behaved in a manner which he perceived was consistent with the cultural norms for males in his traditional society (having more than one sexual partner). Nicholson (2015) stated that subtle discrimination is not always overt and can be conveyed through body language as well as word. This participant looked down, moved around a lot and, at one part of the interview, looked into space without speaking. It is likely that he has self-stigmatised as being guilty which has undermined his own sense of self-worth and dignity. To individuate fully and become self-accepting and develop his true Persona, he will have to reconcile his cultural norms with more contemporary acceptance of monogamy and the place of women in society.

The second sentence refers, in part, to the Anima metaphor. The true loving aspect of what a woman should be is revealed through the second response. It is likely that he is beginning to understand that monogamy is the general preference of women in traditional cultures (Nqojane, 2009). The HIV/AIDS pandemic has motivated this understanding in some culturally traditional Tsonga men, who used to believe in polygamy and/or multiple sexual partners. In terms of Jungian Phenomenology the second response refers in part to Self. Currently the archetypes that come to the fore are those encompassing regret, dissatisfaction and lack of fulfillment with life which he seems to experience as being orphaned.

5.3.7.1.1 Sub-theme 7.1: Discrimination as experienced by participants

All fifteen of the HIV positive participants were able to describe how they had experienced discrimination. This has been widely reported in the literature and is frequently motivated by the need to blame and punish and can lead to acts of violence and murder (AVERT, 2013). Yuh et al. (2014) indicate that HIV/AIDS discrimination is associated with negative behaviours which include violence and taunting. This discrimination is associated with perceived sexual promiscuity and hinders disclosure of HIV status and is also linked to the self-stigmatisation of PLWHA (AVERT, 2013).

Participant 1(F):

“I do experience poor behaviour from others. The discrimination I experienced was when I was rejected by the community who heard about my status. I was not invited to any events and was isolated. The community rejects you when they know your status. After you are diagnosed, they blame you saying you asked for it so I felt guilty because it was my fault.”

In terms of Jungian Phenomenology the dominant metaphor in this response is the Shadow. The participant has experienced external discrimination by being isolated by her community when they found out her HIV positive status. This sense of isolation is reinforced by her self-stigmatisation in perceiving that being HIV positive is indeed her own *fault*. This, together with the external discrimination, may lead to her to further feelings of guilt, sadness and depression (Nystal, 2009). Mbete (2015) the Speaker of the National Assembly in South Africa, indicated that the 1st of March 2015 was recognized as ‘Zero Discrimination Day’ by the National Assembly. This was a National effort to make all South Africans conscious of the damage that discrimination does to PLWHA and their families. External discrimination is difficult to deal with however, the participant must not allow the dark side of her psyche (Shadow) to dominate her Self. She must allow all parts of her personality archetypes to integrate through a reflective process if she is to full individuate to her authentic Self.

Participant 2(F):

“When people talk about HIV/AIDS amongst themselves and when I am not part of the conversation, I feel bad. I always think they are talking about me. When I joined such conversations I felt they were laughing at me [inwardly]. It is true that people

do a lot of gossiping when they know that neighbours are HIV positive and they don't invite them to their houses."

The response reflects Shadow in terms of Jungian Phenomenology. The participant projects her self-stigmatisation onto others [as she cannot be sure if they are discussing a specific person or HIV/AIDS generally]. Her feelings of guilt are projected through these thoughts. The participant was fifty one years old at the time of the research and had been diagnosed as HIV positive for seven years. She notes that when people know *neighbours* are HIV positive they do not get invited to homes in the community. The participant does not state that she does not get invited. This suggests she has not fully accepted her status and that her Shadow is dominant. The participant will need much moral effort (Nystal, 2009) in order to integrate her personality archetypes into an authentic Self (and thus individuate). Much of the discrimination experienced by PLWHA is internalised and experienced as self-stigmatisation (Blöse, 2015). This is the case with this participant who needs to integrate her lived reality into her conscious and unconscious psyche.

Participant 3(F):

"I experience guilt all the time because I feel guilty. I think it was my fault that I became infected. People can be discriminated against when they go to fetch their treatment. People talk for the sake of gossiping about others. I used to gossip, laughing at those who were HIV positive not knowing that I would be one of them."

The participants Shadow and Persona are reflected in her responses in terms of Jungian Phenomenology. In the past she gossiped about PLWHA and now experiences that gossip herself, interestingly she does not state she was sorry about her behaviour. This participant also reports that *people* are discriminated against when they go to the clinic she does not state that she is discriminated against in this manner. Essentially, this is a form of denial where full acceptance of an HIV positive status has not been attained. The dark side of her psyche or Shadow is also revealed when she does not express sorrow at laughing at PLWHA, she merely states that she did it. Her responses suggest the Persona she presents to the world is entrenched in a mask of denial as she cannot accept her lived reality. As a result of this she discusses discrimination in the third person, as if it is not directed or connected to her in anyway. The participant has experienced people gossiping as discrimination but she has also been directly involved in discriminatory behaviour associated with gossiping. Her Shadow is dominant in this regard as she does not want to recognise all of the archetypes in her personality development and allow them to integrate to become her true Self. This infers she know that this type of behaviour is ethically wrong and morally wrong. Statistics South

Africa (2012) report that the advent of HIV on a global scale triggered responses of empathy in dictating that PLWHA should be treated with dignity and care and conversely it also triggered discrimination and stigmatisation towards those known to be HIV positive.

Participant 4(F):

“People were talking about me. They discriminated against me. They would ostracize me and not involve me in activities. I was conscious of their gossip. I was felt unwanted. Gossiping about people and mocking them because they are HIV positive is wrong. People say you asked for it so you deserve it.”

In terms of Jungian Phenomenology this refers to Shadow. The participant experienced both external and internal stigma. The external stigma seems to be mainly at community level. The internal stigma was through personal feelings of being unwanted, belittled and disliked. The projection she shows indicates hidden negative impulses, instincts and shortcomings. At the age of 26 and having a bad school record the participant seems to need moral intervention lest she will not get to experience her true self. Nystal (2009) indicates that Shadow represents the opposite of a masked personality. It represents the dark side of a person, chaos, wildness and the unknown.

Participant 6(F):

“They gossiped about me when they realised that I was sick and they thought I had HIV/AIDS. Others start talking about HIV/AIDS when they saw me coming. When I talked to my customers, they accused me of being too noisy and then they said it is because of my HIV positive status. They also accused me of killing my husband. Others said I infected him [not that he infected me]. When they accuse me they talk about my status and say it is my own fault. I used to worry a lot but, you know, people talk about others every day....they gossip and discriminate. I am used to it.”

The Shadow archetype is the most dominant in the participant’s response as she has *got used* to the discrimination that she experienced. She was accused of killing her husband, being too noisy and blamed for her positive status. At first sight she may be considered heroic in doing this but the response *I am used to it* infers that she is prepared to be martyr. Her Animus motivated by the Shadow archetype allows her to experience the dark side of her psyche as martyrdom. This will not allow her to fulfil her true potential in terms of her personality development (true Self). At the time of the research she was fifty two years old and worked in a Shebeen where she served mostly male customers. It is likely that she has internalised the traditional, patriarchal norms of her culture.

Nystal (2009) suggests that the Shadow needs a serious moral effort if an individual is to present their true Self to the world and follow the path of authentic individuation. This participant needs to reflect on her place in society in the contemporary world which because of her age and ingrained mask she might find it hard to do.

Participant 7(F):

“I was not allowed to use cutlery and crockery in the house. They [others in my family] gave me a plate to use and soap and bleach to wash my plates. I was not allowed to touch things in the house. If I did touch something, it would be cleaned thoroughly so I was isolated I felt I was to blame.”

The responses reflect the Shadow and the Self in terms of Jungian Phenomenology. The participant experienced external stigma sadly perpetuated within her family. At the time of these discriminatory behaviours the participant was fifty years old and in the eyes of traditional African culture should have been respected as an elder in her community. Instead she was discriminated against and isolated by her own family. Her Shadow dominated and she felt guilt (*blame*) and thus self-stigmatised and did not experience her true Self. Gaynair (2013) reported that individuals who discriminate against others do so because they fear infection and contact with the PLWHA could expose them to infection. The participant displayed signs of depression [she was referred to the psychologist at Elim Clinic). She will have to make a great effort to recognise all archetypes in her personality so that she can allow them to integrate and therefore be able to experience her true Self. As aspects of her Persona indicate a mask of self-suffering and martyrdom she will have first come to terms with an understanding of her Self as she experiences it now. The participant will also need to gain a proper understanding and knowledge about HIV/AIDS infection and ensure her family is properly educated (in this regard she was further referred to a social worker). Coming to terms with who you are in terms of Jungian archetypes and your lived reality is not an easy undertaking and as Nystal (2009) suggests takes a great deal of moral effort.

Participant 9(M):

“Most of my neighbours talk and laugh at people who are HIV positive. They don't laugh at me and I am not discriminated against. I don't feel bad about this.”

In terms of Jungian Phenomenology this refers to the participant's Animus, Persona and Shadow archetypes. He knows that his neighbours discriminate against PLWHA but has not experienced this himself. The participant consciously does not allow himself to feel about others experiencing

discrimination. The participant projects his condition to others. At the time of the research he was fifty five years old and his Animus dictated by the Hero has allowed him to become arrogant in his non-empathic response to discrimination experienced by others. As a male he has not been seen as someone who infects others because of many sexual partners but rather as a Hero (for behaving as a man in his traditional culture). His Persona thus presents as a rigid mask in presenting him as heroic and righteous. His Shadow dominates and to achieve personality development and recognition of his true Self he will need break down his mask by emphasising with others and reflect on a man's place (be truly heroic) in African society in the new century. If he does not do this he may never experience a truly fulfilled self-identity.

5.3.7.1.2 Sub-theme 7.2: Deliberate bullying associated with stigmatisation

All fifteen participants responded to the theme related to the participant's view on whether stigmatisation is related to deliberate bullying or not. Most participants experienced stigma as deliberate bullying while a few did not. The process of bullying through stigmatisation occurs at an individual level but is also influenced by social processes related to assumptions, stereotypes, generalisations and labeling people as falling into a particular category on the basis of an association (ICRW, 2015). The researcher, to ensure clarity, has presented the parts of the participants' responses which are indicative of whether they think stigmatisation is associated with deliberate bullying.

The participants' whose responses indicated that they feel that bullying is deliberate stigmatisation have transferred and projected their feelings onto others and are likely to self-stigmatise (thus their guilt is projected onto others). The Jungian Phenomenological archetypes related to these internal mechanisms are the Shadow which means that the participants' are internalising the darker side of their psyche and do not want to (or fear) recognising their lived reality. Those who do not think that stigmatisation is deliberate bullying are more likely to recognise their true Selves (or be in the process of doing so through individuation). They do not project their feelings of guilt onto others and have accepted or are in the process of accepting their lived reality. These participants are moving away from their sole reliance on the conscious ego to a middle ground between the conscious and the unconscious. They are thus much more likely to emerge as more spiritual, philosophical selves with an optimal blending of their conscious and the unconscious archetypes (Nystal, 2009).

Participant 1(F):

“Yes, it happens deliberately because before testing they live peacefully with you. Everybody interacts with you freely.”

Participant 2(F):

“Yes I understand stigmatisation and bullying as deliberate.”

Participant 4(F):

“Yes, I think it happens deliberately. It is deliberate. I think they say it so no one will talk about them.”

Participant 5(F):

“They are dealing with their fears by stigmatising others deliberately.”

Participant 7(F):

“It is deliberate; they are scared so talk as if it could not happen to them.”

Participant 8(F):

“Yes, it happens deliberately....they are bullies....they don't look to themselves.”

Participant 10(M):

“Yes, I think it is deliberate but they don't talk about men because women are guiltier if I understand the gossip correctly.”

Participant 12(F):

“Yes, it is deliberate because they want to make people laugh at others not at themselves. They don't want others to look at them as they might be HIV positive.”

Participant 15(F):

“Sometimes I think they just start talking and being nasty when they see someone they know who HIV positive is so they can hide away from their own status. It is deliberate.”

Participant 3(F):

“It is people's second nature to just talk and to join in [thus possibly not deliberate].”

Participant 6(F):

“I think people just talk and then join in and they don’t think before they speak and such a thing is not deliberate.”

Participant 9(F):

“You know I did it myself before I was positive. I didn’t do it to bully it was just talk....now I understand it is not right.”

Participant 11(F):

“People just talk about anything; they don’t mean to be nasty, they don’t understand how we feel.”

Participant 13(F):

“I think about myself and how I talk about things to others...I think people don’t understand how we feel and just talk because they can. I don’t think they are bullies.”

Participant 14(F):

“Even at church people talk and gossip about things they don’t think about what they are saying and don’t understand that many in the church are HIV positive...it is fear not bullying.”

5.3.7.1 Summary of themes 7: Stigmatisation; Sub-theme: 7.1: Discrimination as experienced by participants and Sub- theme 7.2: Deliberate bullying associated with stigmatisation

In terms of Jungian Phenomenological archetypes the Shadow, Self, Persona, Animus and Hero are represented in these themes. Generally, there was no clear path to individuation for any of the participants who did not recognise their true Selves and had not achieved integrated personality development. Dosier (2010) indicates that HIV-related stigma removes PLWHA from their communities by eroding their support and isolating them. As they often blame themselves which leads to self-stigmatisation many are in danger of becoming depressed and ill which can become a self-fulfilling prophecy (Turan & Nyblade, 2013). Females in this research experience more stigma and discrimination than their male counterparts which is underpinned by research by Lliamputtong

(2013) who reports that females experience more HIV related stigma than males. He also adds that they also have to deal with altered perceptions of themselves as a consequence of stigmatisation.

5.4 Tabular summary of themes and sub-themes emerging from participants' responses

The narrated themes are summarised in the following table to help clarify the aforementioned interpretations (see table 2).

Table 2: Summary of emerging themes

Themes	Brief description	Dominant Jungian Phenomenological archetypes
1.Identity	How the participant experiences their identity in terms of stigma and self-stigma	The Shadow, Self and Persona
2. Feelings before VCT	How the participants' expressed their feelings before an HIV positive diagnosis	The Shadow, Self and Persona
3. Feelings after testing HIV positive	How participants experienced their feelings after an HIV positive diagnosis	The Shadow, Self, Persona and Animus
4.Fear related to HIV infection	Feelings of fear (or not) experienced by participants in relation to the HIV retrovirus	The Shadow, Persona, Animus, Hero and Caregiver
5.Perspectives of death	How participants perceived death in relation to HIV/AIDS	The Shadow and the Persona
6.Anxiety related to being HIV positive	Significant anxiety experienced by the participants	The Shadow, Persona, Self, Hero and Caregiver
7. Stigmatisation	Various experiences of stigmatisation faced by participants	The Shadow, Self, Animus and Hero
Sub-theme 7.1: Discrimination experienced by participants	Various types of discrimination as experienced by participants	The Shadow, Self, Animus and Hero
Sub-theme 7.2: Deliberate bullying associated with stigmatisation	Participants perceptions on whether stigmatisation was deliberate stigmatisation	The Shadow, Self, Animus and Hero

5.5 Participants' suggestions about reduction of HIV/AIDS stigmatisation

In this section participants' ideas of how stigmatisation of PLWHA could be reduced are presented. Thirteen of the participants felt that stigma could be reduced and two did not express any views in this regard. Fundamentally, stigma reduction begins and ends with individuals. A combination of ignorance, prejudice and fear create a context for the continuance of HIV related stigma while

openness, acceptance and accessible sexual and reproductive health information and HIV services are the key to stigma reduction worldwide (IPPF, 2014). Their suggestions are presented in a tabular format with a response supporting that idea (see table 3).

Table 3: Participants suggestions about reduction of HIV/AIDS stigmatisation

Participants	Suggestion as to how stigma can be reduced	Example of participants response
1(F);2(F);10(F);3(F);5(F)	More workshops and discussions about stigma reduction in hospitals, clinics, churches and community halls	<i>“More workshops in different places should be organised which only discuss stigma and how it can be reduced.”</i>
5(F);8(F);9(M);7(F);4(F)	Support groups that educate about stigmatisation.”	<i>“Discussing HIV/AIDS and stigma helps me deal with stigmatisation and also there must be many more support groups.”</i> <i>“Many people need to be educated about stigmatisation in order to stop it.”</i>
13(F);12(F);11(F)	Campaigns organised by PLWHA in the community	<i>“Campaigns organised by the government and others do not always talk to us. They should get PLWHA to be more involved.”</i>
14(F)	Dietary campaigns	<i>“More education about what is a good diet is needed for us [PLWHA].</i>
15(M)	Campaigns about alcohol abuse	<i>People should be given more information and know that they should avoid alcohol abuse if they are HIV positive and about alcohol abuse in the community and problems it can cause.”</i>

5.6 Participants’ conscious coping strategies pertaining to external HIV/AIDS stigmatisation

Thirteen participants reported how they coped with external stigmatisation while two did not express any views in this regard. In this regard Makoae et al. (2008) identified different self-care strategies in PLWHA, which included: cognitive restructuring, turning to God, hoping, changing behaviour, keeping active, using humour, joining a support or social group, disclosure of HIV status, learning from others and acquiring knowledge and understanding the disease. The authors concluded that these mechanisms appeared to be self-taught and not always helpful in managing external stigma. French et al. (2015), in a study of stigma-reduction and wellness-enhancement in a community intervention conducted in South Africa, indicated that PLWHA reported gaining knowledge on how to cope with stigma and discrimination overtime and that coping occurred

gradually. Their conscious coping mechanisms are presented in a tabular format with a response that underpins their coping process (see table 4).

Table 4: Participants' conscious coping strategies pertaining to external HIV/AIDS stigmatisation

Participant	Conscious HIV/AIDS Coping mechanism	Example of participants response
1(F)	Reported people to the Law and village Headman	<i>"I went to the Chief and to the magistrate. I went because I was stigmatised by community members this helped me cope...nothing happened to the people I reported but they were more careful around me in."</i>
2(F)	Acceptance	<i>"If you have accepted and know about your status you can cope with stigmatisation."</i>
3(F)	VCT	<i>"People must go for testing. It helped me gain insight into myself and understand more about HIV/AIDS. This helped me with all the things people said about me."</i>
4(F)	Adherence	<i>"If you comply with your treatment you will cope and your body will improve this will help you with stigmatisation."</i>
5(F); 11(F); 12(F)	Support	<i>"From my understanding you can cope if you are HIV positive if you comply with your treatment and know that you are supported by the hospital and your family. You must try to focus on your health and listen to those who help and support you. You must adhere to treatment and you must accept your condition."</i>
15(M)	Not abusing substances	<i>"Avoid abusing substances like alcohol, dagga and cigarettes this will help you cope as you won't get ill and then no one will stigmatise you."</i>

5.7 Summary

This chapter presented the participants' responses in themes. Jungian Phenomenological metaphors were applied to analyse the data underpinned by relevant literature. It also presented participants ideas on how to reduce stigma in their communities as well as how they perceived their conscious coping mechanisms. Tables were used to clarify themes, suggestions and coping mechanisms. The following chapter concludes the research and describes the methodological strengths and limitations plus it gives recommendations for future research.

CHAPTER 6: RESEARCH CONCLUSIONS AND RESEARCH LIMITATIONS, STRENGTHS AND RECOMMENDATIONS

6.1 Introduction

This chapter presents the research conclusions, methodological limitations and strengths and recommendations for future research emanating out of the investigation.

6.2 Study conclusions

The study conclusions are presented with reference to the interpretations in chapter five and the research questions as follows.

6.2.1 What individual effects do PLWHA experience because of stigmatisation and discrimination?

The participants, who were all PLWHA, experienced negative in terms of their personality development and were unable to individuate properly because of their experience of stigmatisation and discrimination. They were unable to integrate all the Jungian archetypes into their authentic Selves. In most cases their psyches were dominated by the Shadow and Persona. Only one response indicated the person was fully accepting of her lived reality and had integrated conscious and unconscious elements of her true Self into her personality structure. The Persona or mask the participants' presented to the world was often deep-seated and they did not want to recognise their lived reality (the dark side of their psyche or Shadow). Fundamentally they lived in fear and denial of their HIV/AIDS status because of stigmatisation and discrimination. There was much self-stigmatisation because of self-blame, guilty and unsupportive peers and family units. This stigmatisation which was internal and external was experienced by many participants as depression which resulted in feelings of vulnerability which was frequently masked by arrogance (a negative of the Hero archetype). The ability to live an honest, self-fulfilled or authentic life was thus not (at the time of the research) possible.

6.2.2 What effect does HIV/AIDS stigma and discrimination have on PLWHA in their socio-cultural context?

The participants' responses indicated dominant metaphors of the Shadow and Persona in the context of stigmatisation and discrimination with other archetypal representations such as the Persona, Hero, Anima and Animus. The participants' live in a socio-cultural context which is best described

as traditional, patriarchal and African. Females in this context are expected to take a subservient role while the male is supposed to take the lead in all things, particularly those related to sex and finances. Many men still have polygamous relationships, if in a position of power, or have many sexual partners (if they do not have the money to keep many wives). This has resulted in problems with identity for both men and women which is identified in the responses of the female and male participants. For instance, females do not accept responsibility for HIV infection as her male partner does not use condoms (as he may feel this is not appropriate) or confront her partner about infidelities she knows (or suspects). The payment of lobola to a woman's family seems to exacerbate this as both males and females infer that this means the woman belongs to the man and his family unit. The male participants in the study were less likely to experience stigma or discrimination however, both were lonely and one missed his wife profoundly. The socio-cultural environment affects men negatively as they must act as the Hero (heroic and courageous) at all times. This becomes a negative as they struggle to experience their feminine side (Anima). Effectively, the socio-cultural environment in which both male and female participants live has a negative impact on their ability to experience ongoing personality development. They are unable to integrate all their personality archetypes into their overall personality structures and experience their self-fulfilled authentic Selves.

6.2.3 What kind of stigmatisation and discrimination do PLWHAs experience?

The Jungian archetypes the Shadow, Self, Persona, Animus and Hero are found in the participants responses related to HIV/AIDS stigmatisation. The participants experienced both external and internal stigmatisation and overt discrimination. Many of the participants experienced some form of internal stigmatisation related to guilt and feelings of self-blame which resulted in many feeling depressed. External stigmatisation was reported by the females in the study but not by the males (although only two). This is related to the findings that females, in the African context, experience the brunt of stigmatisation by being blamed for spreading the pandemic. The males in the study did not experience external stigmatisation or discrimination as their sexual behaviour is condoned by traditional, patriarchal African norms which dictate it is acceptable for them to have many sexual partners. However, this reinforced their heroism which is negatively expressed as arrogance (although there was some indication of a breakthrough in terms of recognising the Anima in both males responses to specific questions however, it was not reflected in all their responses). All the female participants experienced some form of discrimination either by not being invited to community gatherings, not being able to use household appliance and/or not being accepted by their family and/or friends. HIV related stigma isolates women from their communities and as a result they self-stigmatise and blame thus are likely to become depressed and/or ill. Females in this

research experienced stigmatisation and discrimination which meant they had to deal with altered perceptions of self (as well as how they experienced community perceptions of their new Self). This makes their journey to finding their true Self extremely difficult and needing considerable effort. One response by a female participant indicated that she was finding her way, through understanding her psyche, to a journey towards individuation however, at this point the majority had not found that road. The males in the research had not managed to integrate, or reflect on, their personality archetypes in terms of newer more contemporary socio-cultural norms thus had not made the effort needed to become self-fulfilled, authentic Selves.

6.2.4 Overall study conclusions

This study explored the stigmatisation and discrimination of PLWHA using Jungian Phenomenology and Jungian archetypes in order to give an in-depth explication of the experience of participants in terms of these metaphors. The archetypes of the Self, Shadow and Persona were highlighted as dominant metaphors with the Animus playing an important role followed by marginal roles, in terms of the participants personality development, by the Anima, Hero, Caregiver, Innocent and Orphan. Everyman has the desire to develop a well-rounded socially acceptable and fulfilling personality, whose development process is accompanied by the generation and maturation of various archetypal traits. Once this is achieved, the process of personal individuation is completed and an individual is able to experience their true Self and live a fulfilling and authentic (honest) life. HIV infection and HIV related stigma generate archetypal traits which tend to impede the personality development of individuals. This study underpins this as the Shadow and Persona tend to dominate participants ability to integrate other archetypes, that make-up their personalities, into an authentic Self. As a result they have not been able to merge their personality development into an integrated unit and emerge as spiritual and deep-thinking beings. Their conscious and unconscious have not been optimally blended and their maladaptive archetypes could be embedded in their psyche forever which could lead to a personality which does not match their wishes, expectations and values and the ability to experience their authentic life world.

6.3 Research strengths

- The participants in the study were all willing to participate and were socially and intellectually mature.
- The researcher was able to speak to the participants in their own language which enabled a good communication process.

- The interview questions were well understood thus provided a mechanism through which the participants could express themselves properly.
- To gain an in-depth understanding of the experience of the participants an appropriate research method was used, in this case a qualitative approach using Jungian phenomenology.
- The research was undertaken within a specific locale meaning that although findings cannot be generalised it is possible that people in the given community have similar experiences.

6.4 Research limitations

- There were more females than males in the study which may have led to a gender bias.
- The level of education of the participants was not high which means other participants with more education may have had a different type of experience.
- As the study was qualitative in nature none of the findings could be generalised.
- The ethnic groups who participated in the study were not inclusive of all ethnic groups in South Africa. It is possible that other groups perceive the phenomenon differently.
- All participants were heterosexual and it is likely that HIV positive individuals who are from the Lesbian, Gay Bi-sexual, Transgender and Intersex (LGBTI) communities have differing experiences.

6.5 Research recommendations

- A quantitative study investigating stigmatisation and discrimination should be conducted in the same area.
- Similar research on different ethnicities and the LGBTI community is undertaken.
- More interventions utilising narratives in the area of HIV/AIDS should be utilised.
- More workshops and interventions targeting HIV/AIDS stigmatisation should be carried out in the vernacular in areas of South Africa.
- Prevention and intervention workshops using community based chiefs to stress the prevention of stigmatisation and discrimination amongst those with HIV/AIDS

References

- Airhihenbuwa, C.O. (2007). *Healing our differences: The crisis of global health and the politics of Identity*. Plymouth, UK: Rowman and Littlefield Publishers Inc.
- Adrionasolo, R.L., Rakotoarivelo, R.A., Randiarimanana, D., Angijiro, P.G., & Randria, M.J. (2011). Discrimination of HIV infected persons in medical settings in Madagascar. *Medecine et Maladies Infectieuses*, 41(11), 2-6.
- AVERT. (2015). *Stigma, discrimination and HIV: AVERTing HIV/AIDS*. Retrieved from [http:// www.AVERT.org](http://www.AVERT.org)>...>Social issues.
- Babalola,S., Fatusi, A., & Anyanti, J. (2009). Media saturation, communication exposure and HIV Stigma in Nigeria. *Social Science Medicine*, 68(8), 1513 – 1520.
- Balls, P. (2009). *Phenomenology in nursing research methodology*. Norfolk, UK: NHS Foundation.
- Barolsky, V. (2009). *AIDS review 2009*. Pretoria, SA: University of Pretoria Centre for the study of AIDS. Pretoria: University of Pretoria.
- Bekalu, M.A., Eggermont, S., Ramanadhan, S., & Viswanath, K. (2014). Effect of media use on HIV related stigma in Sub-Saharan Africa: A cross-sectional study. *PLoS ONE Journals*, 9(6), 43 – 48.
- Berrios, G.E. (1989). What is phenomenology? A review. *Journal of the Royal Society of Medicine*, 82(7), 425-428.
- Bharat, S., Aggleton, P., & Tyrer, P. (2008). *HIV/AIDS related discrimination, stigma and denial*. Retrieved from <http://www.unAIDS.org/en/media/unAIDS/contentassets/documents>
- Bisson, J.L., Foa, E.B., Keane, T.M., Friedman, M.J., & Cohen, J.A. (2009). *Psychological debriefing for adults*. New York, USA: Guilford Publications.
- Blose, S. (2015, June 15). Forty three percent of HIV positive South African suffer from internalised stigma. *Stigma@702Podcast*. Podcast retrieved from <http://www.702.co.za/podcast>>internalised-stigma

- Boehene, K. (2007). The Internalised stigmatisation among people living with HIV/AIDS. *AIDS Care*, 8(5), 1-7.
- Bray, R. (2003). Proceedings from the CSSR 2003. Third international conference on HIV/AIDS. Cape Town, SA: University of Cape Town Centre for Social Science.
- Brooke, R. (1993). *Jung and phenomenology*. London, UK: Routledge.
- Castillo, J. J. (2009). *Sampling methods*. Retrieved from <http://www.experimentresources.com/stratified-sampling.html>
- Chipangura, S. (2013). *An Investigation into the manifestation of stigma and discrimination and its consequences on HIV/AIDS prevention and treatment efforts among People Living with HIV/AIDS*. (Unpublished masters dissertation). Stellenbosch University. Cape Town, South Africa.
- Chisaka, J.K.C. (2006). *Women living with AIDS a phenomenological interpretation of their Experiences*. (Unpublished masters dissertation). Rhodes University, Grahamstown.
- Churchill, S.D., & Wertz, F.J. (2013). *An introduction to phenomenological research in psychology: Historical, conceptual, and methodological foundations*. Retrieved from <http://www.academia.edu>>Cloete, A.
- Creswell, J.W. (2003). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. (2nd ed.). University of Nebraska –Lincoln, CA: Sage.
- Cherry, K. (2011). *Archetypes and Jung*. Retrieved from <http://psychology.about.com/od/archetypesandjung>
- Cloete, A., Strebel, A., Simbayi, L., van Wyk., Henda, N., & Nqeketo, A. (2010). Challenges Faced by People Living with HIV/AIDS in Cape Town, South Africa: Issues for Group Risk Reduction Interventions. *AIDS Research and Treatment*, 10(1), 2 – 9.
- Colson, J. (2006). *Oxford handbook of clinical specialties*. Oxford, UK: Oxford University Press.
- Creel, A.H., Rimal, R.N., Mkhawire, G., Bose, K., & Brown, J.W. (2011). Effects of mass media intervention on HIV related Stigma. *Health Education Research*, 26 (3), 456-65.

- Davidson, A.S. (2013). Phenomenological approaches in psychology and health sciences. *Qualitative Research in Psychology*, 10(3), 318-339.
- Department of Social Development. (2014). *Psychosocial support for orphans and other children made vulnerable by HIV/AIDS*. Retrieved from [http://www.dsd.gov.za>Nacca1>index21>index2](http://www.dsd.gov.za/Nacca1>index21>index2)
- Dosier, B. (2010). *Effects of stigmatisation on people who are HIV Positive in relation to physical disability* Retrieved from <https://barbaradozier.wordpress.com>effe...>
- Dunkley, J. (2013). *Parenting adolescents: A phenomenological approach*. (Unpublished doctoral dissertation). University of the Free State: Bloemfontein, SA.
- Ekstrand, M.L. (2011). *Health Consequences of AIDS related stigma*. San Francisco, USA: University of California Center for AIDS Prevention Studies.
- Enah, C., Piper, K., & Moneyham, L. (2015). Qualitative evaluation of relevance and acceptability of a web-based HIV prevention game for rural adolescents. *Journal of Pediatric Nursing*, 30(2), 321-328.
- Engender Health. (2011). *Reducing Stigma and Discrimination Related to HIV/AIDS*. Retrieved from <http://www.engenderhealth.org/pubs/hiv-AIDS-sti/reducing-stigma>.
- Famoroti, T.O., Fernandes, L., & Chima, S.C. (2013). Stigmatisation of people living with HIV/AIDS by healthcare workers at a tertiary hospital in KwaZulu-Natal, South Africa: a cross-sectional descriptive study. *BMC Medical Ethics*, 14(1), 5 – 6.
- Finlay, L. (2009). Debating phenomenological research. *Phenomenology & Practice*, 3(1), 6-25.
- Florom-Smith, A.L., & De Santis, J.P. (2012). Exploring the concept of HIV related stigma. *Nurses Forum*, 47(3), 153-165.
- Flowers, P., Davis, M.M., Larkin, M., Church, S., & Marriott, C. (2011). Understanding the impact of HIV diagnosis amongst gay men in Scotland: An interpretative phenomenological analysis. *Psychology and Health*, 26 (10), 1378-1391.

- Fonchingong, F. Mbuagbo, S., & Abong, A. (2009.). The role of faith-based organisations and religious leaders in dealing with AIDS related stigma. *Qualitative Research in Psychology*, 10(3), 250 - 257.
- French, H., Greeff, M., Watson, M. J., & Doak, C. M. (2015). A comprehensive HIV stigma-Reduction and wellness-enhancement community intervention: A case study. *Journal of the Association of Nurses in AIDS Care*, 26(1), 81-96.
- Gale, N.K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013).Using the Framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13, 117 - 20.
- Gallagher, S., & Zahavi, D. (2014). *Phenomenological approaches to self-consciousness*. Stanford,USA: Stanford University.
- Gaynair, G. (2013). *Reducing HIV related stigma in India*. Mumbai, India: ICRW.
- Gilbert, L., & Walker, L. (2010). My biggest fear was that people would reject me once they knew My status: stigma as experienced by patients at an HIV/AIDS clinic in Johannesburg, South Africa. *Health and Care in the Community*, 18(2), 139-146.
- Giorgi, A. (2012). The descriptive phenomenological psychological method. *Journal of Phenomenological Psychology*, 43(1), 3-12.
- Goffman, E. (1963). *Stigma, notes on the management of spoiled identity*. Harmondsworth, UK: Penguin books.
- Grbich, C. (2007). *Qualitative data analysis: an introduction*. London, U.K: Sage Publications Inc.
- Green, B.L., Friedman, M.J., & de Jong, J. (2007). *Trauma interventions in war and peace: prevention, practice and policy*. Boston, USA: Kluwer Academic Publishers.
- Grodensky, C. A., Golin, C. E., Jones, C., Mamo, M., Dennis, A. C., Abernethy, M. G., & Patterson, K. B. (2015). I should know better: The roles of relationships, spirituality, disclosure, stigma, and shame for older women living with HIV seeking support in the south. *Journal of the Association of Nurses in AIDS Care*, 26(1), 12-23.

- Grossman, C.I., & Stangl, A.L. (2013). Global Action to reduce HIV stigma and discrimination. *Journal of the International AIDS Society*, 16 (3), 2 – 8.
- Hanizar, E., Adzkiyak, P., & Swastika, K. (2015). Prevention of transmission of HIV/AIDS through local social organisations on jember fishermen community. *Procedia Environmental Sciences*, 23(10), 136-141.
- Haralambos, M., Holborn, M., & Heald, R. (2006). *Sociology: themes and perspectives*. London, UK: Harper Collins.
- Haughey, N. J., Luis, B., Romo, T., Avery, L. B., Sacktor, N., & McArthur, J. (2012). *Popular HIV Drug May Cause Memory Declines*. Retrieved from http://johns.hopkinsmedicine.org/meia/releases_
- Health Systems Trust. (2013). *HIV/AIDS related information*. Retrieved from <http://www.hst.org.za/about-health-systems-trust>
- Herek, G.M., Capitanio, J.P., & Wideman, K.F. (2002). HIV related stigma and knowledge in the United States 1991 – 1999. *American Journal of Public Health*, 92(3), 371-377.
- Herek, G.M., & Mitnick, L. (2002). AIDS and stigma: A conceptual and research agenda. *AIDS and Public Policy Journal*, 13(1), 36-47.
- Herek, M.H. (2007). Thinking about AIDS and stigma: A psychologist's perspective. *Journal of Law, Medicine and Ethics*, 30(4), 594-607.
- Hirnschall, G. (2016). Striving for zero discrimination in health care. Unite to end TB. Retrieved from <http://www.who.int/hiv>
- Health Resources and Services Administration. (2012). *Providing HIV/AIDS care in a changing environment*. Retrieved from [http://www.hab.hrsa.gov/publication/august 2012.htm](http://www.hab.hrsa.gov/publication/august%202012.htm)
- Human Sciences Research Council. (2014). *South African national HIV prevalence, incidence and behaviour survey*. Cape Town, SA: HSRC Press.
- International Planned Parenthood Federation. (2010). *Reducing HIV related Stigma*. Retrieved from [http://www.ippf.org/...>HIV and AIDS](http://www.ippf.org/.../HIV%20and%20AIDS)

Inter Press Service News Agency. (2010). *HIV/AIDS and discrimination*. Retrieved from <http://www.ips.org/institutional/get-to-know-us-2/our-mission/>

Jacobi, C.A., Atanga, P.N.J.I., Bin, L.K., Mbome, V.N., Akam, W., Bogner, J.R., Kropf, S., & Malfertheiner, P. (2013). HIV/AIDS related stigma felt by PLWHA from Buea, Cameroon. *AIDS Care, 25*(2), 173- 180.

Jansen, J. (2015). *Imagination - phenomenological approaches*. Retrieved from <https://www.rep.routledge.com>articles>.

Jewkes, R., & Morrell, R. (2010). Gender and sexuality: emerging perspectives from the heterosexual epidemic in South Africa and implications for HIV risk and prevention. *Journal of the International AIDS Society, 13*(6), 1758-2652.

Kagimu, M., Guwatudde, D., Rwabukali, C., Kaye, S., Walakari, Y., & Ainomuqisha, D. (2012). Religiosity for HIV prevention in Uganda. *Africa Health Sciences, 12*(1), 17-25.

Kalichman, S.C., & Simbayi, L.C. (2006). HIV testing attitudes AIDS stigma, and voluntary HIV counselling and testing (VCT) in a black township in Cape Town, South Africa. *Sexually Transmitted Infections, 79*(6), 442-447.

Kamen, C., Arganbright, J., Kienitz, E., Weller, M., Khaylis, A., Shenkman, T., Smith, S., Koopman, C., & Gore-Felton, C. (2015). HIV related stigma: implications for symptoms of anxiety and depression among Malawian women. *African Journal of AIDS, 14*(1), 67-73.

Karamouzian, M., Akbari, M., Haghdoost, A.A., Setayesh, H., & Zolala, F. (2015). I Am Dead to Them: HIV related stigma experienced by People Living With HIV in Kerman, Iran. *Journal of the Association of Nurses in AIDS Care, 26*, 46-56.

Katz, I.T., Ryu, A.E., Onuegbu, A.G., Pasros, C., Weiser, S.D., Bangsberg, D.R., & Tsai, A.C. (2013). Impact of HIV related stigma on treatment adherence: systemic review and meta-synthesis. *Journal of International AIDS Society, 16* (Suppl 2): 18640

Kirshenbaum, S.B., Hirky, A.E., Correale, J., Goldstein, R.B., Johnson, M.O., Rotheram-Borus, M.J., & Ehrhardt, A.A. (2006). *Perspectives on Sexual and Reproductive Health, 36* (3), 106-113.

- Langdridge, D. (2007). *Phenomenological psychology: theory, research and methods*. London, U.K: Pearson Education.
- Lekas, H.M., Siegel, K., & Leider, J. (2011). Felt and enacted stigma among HIV/HCV co-infected adults. The impact of stigma layering. *Quality Health Research, 21*(9), 1205-1219.
- Lester, S. (2013). *An introduction to phenomenological research*. Retrieved from <http://www.slester@devmts.co.uk>
- Lilienfield, S.O. (2008). *Debiasing*. Retrieved from <http://bps-research-digest.blogspot.com/?2007/09/can-psychology-save-the-world.html>
- Link, B., & Phelan, J. (2006). Conceptualization of stigma. *Annual Review of Sociology, 27*, 363-385.
- Lliamputtong, P. (2013). *Stigma, discrimination and living with HIV/AIDS: a cross-cultural perspective*. New York, USA: Springer.
- Lowther, K., Selman, L., Harding, R., & Higginson, I. J. (2014). Experience of persistent psychological symptoms and perceived stigma among people with HIV on antiretroviral therapy (ART): A systematic review. *International Journal of Nursing Studies, 51*(8), 1171-1189.
- Madoori, S. (2015). *Media-driven stigma continues with new HI criminalisation case*. Retrieved from <http://www.huffingtonpost.com>suraj-madoori>
- Magadzi, D. (2013). *Elim Hospital Reports and Statistics, Jan – March 2013*. Polokwane. SA: Limpopo Department of Health.
- Makoe, L. N., Greeff, M., Phetlhu, R. D., Uys, L. R., Naidoo, J. R., Kohi, T. W., & Holzemer, W. L. (2008). Coping with HIV related stigma in five African countries. *Journal of the Association of Nurses in AIDS Care, 19*(2), 137-146.
- Mall, S., Middelkoop, K., Mark, D., Wood, R., & Beker, L.G. (2013). Changing patterns in HIV/AIDS stigma and uptake of voluntary counselling and testing services: The results of two consecutive surveys conducted in the Western Cape, South Africa. *AIDS Care, 25*(2), 194 – 201.

- Maponyane, E. (2012). *An investigation into the HIV/AIDS knowledge, attitudes, behaviour and beliefs of University of Limpopo (Medunsa campus) undergraduate students*. (Unpublished masters dissertation). University of Limpopo (Medunsa Campus), Ga-Rankuwa.
- Matheza, D. (Producer). (2015, March 22). *Rights and Recourse* [Television broadcast]. Auckland Park, Gauteng: South African Broadcasting Corporation.
- Marshall, K. (2015). *Health care and religion in South Africa and beyond*. Retrieved from <http://www.m.huffpost.com>entry>.
- Maughan – Brown, B. (2004). *Measuring HIV/AIDS stigma*. Cape Town, SA: University of Cape Town Centre for Social Science Research.
- Maughan-Brown, B. (2010). Stigma rises despite antiretroviral roll-out: A longitudinal analysis in South Africa. *Social Science & Medicine*, 70(3), 368-374.
- Mbete, B. (2015). *Motion of the South African National Assembly on HIV/AIDS*. Retrieved from <http://www.parliament.gov.za>
- McQuillen, J. L. (2014). *A phenomenological study of aging with HIV/AIDS: in the words of those who really know*. (Unpublished doctoral Dissertation). The University of Nebraska, USA: Nebraska.
- Merleau-Ponty, M. (1962). *Phenomenology of perception*. London, U.K: Routledge & Kegan.
- Mnisi, T. (2014). HIV/AIDS Stigma Explored through digital story telling. Retrieved from <http://www.ndabaonline.ukzn.ac.za>Ukzndaba Story>.
- Mofolo, T. (2010). *The Role of culture in contributing to the spread of HIV/AIDS*. Pretoria, SA: African Institute of South Africa
- Mogotsi, M. (2011). *An investigation into alcohol use by students at the University of Limpopo - Medunsa Campus*. (Unpublished Masters Dissertation) University of Limpopo, Ga-Rankuwa.
- Mogotlane, S.M., Chauke, M.E., van Rensburg, G.H., Human, C.M., & Kganakga, C.M. (2010). A situation analysis of child-headed households in South Africa. *Curationis*, 33(3), 24 – 32.

- Mswela, M. (2009). Cultural practice and HIV in South Africa. A legal perspective. *Potchefstroom Electronic Law Journal*, 12 (4).
- Muturi, N., & An, S. (2010). HIV/AIDS stigma and religiosity among African American women. *Journal of Health Communication*, 15(4), 388-401.
- Nachege, J.B., Morrioni, C., Zuniga, J.M., Sherer, R., Beyrer, C., Solomon, S., Schechter M., & Rockstroh, J. (2012). HIV related stigma, isolation, discrimination, and Sero-status disclosure. *Journal of the International Association of Providers of AIDS Care*, 11(3), 172-178.
- New Testament. (2013). *The new English Bible*. Oxford, UK: Oxford University Press.
- Nicholson, G. (2015, June 11). The Great Unspoken Issue. *Daily Maverick*. Pp. 3-4.
- Nqaiyana, D.J. (2011). The illusive promise of circumcision to prevent female-to-male HIV infection: not the way to go for South Africa. *South African Medical Journal*, 101(11), 775-776.
- Nqojane, A. (2009). *Attitudes, knowledge and perceptions towards HIV/AIDS, condom use and voluntary counselling and testing (VCT) amongst University of Zululand students during the HIV/AIDS pandemic*. (Unpublished masters dissertation). University of Zululand, Kwadlangezwa.
- Nyblade, L. (2016). *HIV/AIDS stigma*. Retrieved from <https://www.rti.org/newsroom/news.cfm?obj=A4798826-9D07-3EEB-51E710D5AEF8BD06>
- Nyblade, L., Pande, R., Mathur, S., MacQuarrie, K., Kidd, R., Banteyarga, H., Kidanu, A., Kilonzo, G., Mbambwo, J., & Bond, V. (2003). *Disentangling HIV/AIDS stigma in Ethiopia, Tanzania, Zambia*. Washington, D.C: International Centre for Research on Woman.
- Nystal, A. (2009). *The emergence of a phenomenological self. is the result of an optimal blending of conscious and the unconscious*. Oxford, UK. Routledge.
- Ogenmefun, C., Gilbert, L., & Schatz, E. (2010). Older female caregivers and HIV/AIDS related secondary stigma in rural South Africa. *Journal of cross-cultural gerontology*, 26(1), 85 -102.

- Okoli, A. C., & Uhembe, A.C. (2014). Of cult and power: a political phenomenology of the Ombatse cult in Nasarawa State, Nigeria. *International Journal of Liberal Arts and Social Science*, 2(7).
- Park, A. (2012). *Thabo Mbeki and AIDS Denialism*. Retrieved from <http://www.healthland.time.com>> 2012/08/21 > slide
- Parker, R., & Aggleton, P. (2003). HIV/AIDS related stigma and discrimination: A conceptual framework and implications for action. *Journal of Social Science & Medicine*, 57(1), 13-24.
- Parker, W., & Birdsall, K. (2008). *HIV/AIDS, stigma and faith-based organisations-a review*. Centre for AIDS Development, Research and Evaluation (CADRE). Grahamstown, SA: Rhodes University.
- Partington-Nel, K. (2003). *A survey of students' knowledge, behaviour and resultant attitudes towards HIV/AIDS on the University of Zululand campus*. (Unpublished masters dissertation). University of Zululand, Kwadlangezwa.
- Porter, S. (2007). Validity, trustworthiness and rigour: reasserting realism in qualitative research. *Journal of advanced nursing*, 60(1), 79 – 86.
- Rakotoniana, J.S., Rakotomanga, J. D. D.M., & Barennes, H. (2014). Can churches play a role in combating the HIV/AIDS epidemic? A study of the attitudes of Christian religious leaders in Madagascar. *PLoS ONE*, 9(5), 7 -13.
- Reyes-Estrada, M., Varas-Diaz, N., & Martinez-Sarson. A. (2015). Religion and HIV/AIDS stigma: considerations for the nursing profession. *The New School Psychology Bulletin*, 12(1), 52-53
- Root, R., & Whiteside, A. (2013). A qualitative study of community home-based care and antiretroviral adherence in Swaziland. *Journal of International AIDS Society*, 16(1), 17 - 20.
- S.A.info Reporter. (2012, June 17). *South Africa's HIV/AIDS Battle Plan*. Retrieved from <http://www.southafrica.info>>AIDS-prevention.
- South African Department of Health. (2012). *HIV/AIDS/STD strategic plan for South Africa*. Retrieved from <http://www.siteresources.worldbank.org/INTHIVAIDS/Resources/>

- South African National Aids Council. (2015). *Tackling HIV related discrimination: The South African Stigma Index*. Retrieved from <http://sanac.org.za/resouces/stigma-and-discrimination-campaign-resources>.
- Schatz, E., Madhavan, S., & Williams (2011). Female-headed households contending with AIDS related hardship in rural South Africa. *Health & Place*, 17(2), 598-605.
- SexInfo online. (2013). *Risks of HIV/AIDS and gender inequality in Sub-Saharan Africa*. Santa Barbara, California: University of California.
- Sedibe, M., & Goosby, E. (2013). Global action to reduce HIV stigma and discrimination. *Journal of International AIDS Society*, 16(3 Suppl 2), 18893.
- Shenton, A.K. (2004). Strategies for ensuring trustworthiness in research projects. *Journal of Education for Information*, 22, 63–75.
- Silverman, D. (2006). *Interpreting qualitative data: methods of analysing talk, text and interaction*. London, UK: Sage Publication.
- Simelela, N., Venter, W.D.F., Pillay, Y., & Barron, P. (2015). A political and social history on HIV in South Africa. *Current HIV/AIDS Reports*, 12(2), 256 – 261.
- Siyam'kela National Aids Project (2007). *Measuring HIV/AIDS related stigma. HIV/AIDS stigma indicators: A tool for measuring the progress of HIV/AIDS stigma mitigation*. Retrieved from <http://www.hivhealthclearinghouse.unesco.org>siya...>
- Smith, D.W. (2013). *Phenomenology*. Retrieved from <http://www.plato.stanford.edu>entries>phenomeno...>
- Snyder, K., Wallace, M., Duby, Z., Aquino, L. D. H., Stafford, S., Hosek, S., & Bekker, L. (2014). Preliminary results from Hlanganani (coming together): A structured support group for HIV infected adolescents piloted in Cape Town, South Africa. *Children and Youth Services Review*, 45(0), 114-121.
- South African Medical Research Council. (2013). *HIV/AIDS and Stigma*. Retrieved from <http://www.mrc.ac.za/public/facts17.htm>

- South African National AIDS Council. (2015, July 03). *Update on stigma campaign*. South African Stigma Index. Retrieved from www.sanac.org.za/news/item/227-
- Sowa, T. (2008). *Global HIV/AIDS medication*. Retrieved from https://books.google.co.za/books?hl=en&lr=&id=fNU62HhYFT0C&oi=fnd&pg=PR11&dq=Sowa+%282008%29+hiv+aids+research&ots=r2xJnQNCCa&sig=nyGBpMGtWzpjUBlyWOc4ItaCRGo&redir_esc=y#v=onepage&q&f=false
- Staff Reporter. (2015, August 27). 700 000 Orphans in Urgent Need of Help. *New Zimbabwe*. pp. 6-7.
- Stangl, A.L., Lloyd, J.K., Brady, L.M., Holland, C.E., & Baral, S. (2013). A systemic review of interventions to reduce HIV related stigma and discrimination from 2002 to 2013: how far have we come? *Journal of the International AIDS Society*, 16(Suppl 2), 18734.
- Statistics South Africa. (2012). *Mortality and causes of death in South Africa, 1997-2003. findings from death notification reports*. Pretoria, RSA: Statistics South Africa.
- Statistics South Africa. (2011). The poverty line. Retrieved from <http://www.statssa.gov.za/publications/Report-03-10-06/Report-03-10-06March2014.pdf>
- Stevens, A. (2006). *The archetypes. The handbook of Jungian psychology*. New York, USA: Routledge
- Stutterheim, S.E., Bos, A.E.R., van Kersten, N.M.C., Shiribandi, I., Pryor, J.B., de Bruyn, M., & Schaalma, H.H.P. (2012). Beliefs contributing to HIV related stigma in African and Afro-Caribbean communities. *Netherland Journal of Community and Applied Social Psychology*, 22, 470 – 484.
- Subramoney, R. (2015). The Lived Experiences of Indian women with HIV/AIDS in South Africa: A phenomenological inquiry. *International Journal of Health Sciences*, 3(2), 61-121.
- Swartz, L. (2007). *Culture and Mental Health: A Southern African view*. Cape Town: Oxford press.
- Terre Blanche, M., Durrheim, K., & Painter, D. (2009). *Research in practice: applied methods for the social sciences*. Cape Town, South Africa: University of Cape Town Press.

- The National Cancer Institute (2009). Viruses and Retroviruses. Retrieved from <http://www.cancer.gov/>
- Thorsteinsson, A. (2015). *Orphaned and living alone, sisters look to the future*. Burlington, Canada: World Renew.
- Thurman, T.R., Kidman, R. & Taylor, T.M. (2014). Bridging the gap: The impact of home visiting programmes for orphans and vulnerable children on social grant uptake in South Africa. *Children and Youth Service Review*, 48, 111-116.
- Troy, P.H., Wyness, L.A., & McAuliffe, E. (2007). Nurse's experience of recruitment and migration from developing countries: a phenomenological approach. *Human Resources for Health*, 5(15), 5-15.
- Tswelopele Research Project Report. (2011). *HIV/AIDS Stigma and Human Rights*. Centre for the Study of AIDS. Pretoria. University of Pretoria.
- Turan, J.M., Bukusi, E.A., Onono, M., Holzemmer, W.L., Miller, S., & Cohen, C.R. (2011). HIV/AIDS stigma and refusal of HIV testing among pregnant women in rural Kenya: results from the MAMAS Study. *AIDS and Behaviour*, 15(6), 1111-1120.
- Turan, J.M., & Nyblade, L. (2013). HIV related stigma as a barrier to achievement of global PMTCT and maternal health goals: a review of the evidence. *AIDS and Behaviour*, 17(7), 2528-2539.
- United Nations Aids Programme (2012). *Global AIDS report 2012*. Retrieved from <http://www.unAIDS.org/en/media/unAIDS/contentassets/documents>
- United Nations Aids Programme (2013). *Global AIDS update*. Retrieved from <http://www.unAIDS.org/en/media/unAIDS/contentassets/documents>
- United Nations Aids Programme (2014). *HIV/AIDS stigma and discrimination*. Retrieved from <http://www.unAIDS.org/en/media/unAIDS/contentassets/documents>
- Van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy*. Ontario, Canada: The Althouse Press.

- Velloza, J., Watt, M.H., Choi, K.W., Ablner, L., Kalichman, S.C., Skinner, D., Pieterse, D., & Sikkem, K.J. (2015). HIV/AIDS related stigma in South Africa alcohol serving venues and its potential impact on HIV disclosure, testing and treatment seeking behaviours. *Global Public Health, 10*(9), 1092-1106.
- Visser, M.J., Makin, J.D., Vandormael, A., Sikkema, K.J., & Forsyth, B.W.C. (2009). *HIV/AIDS Stigma in a South African community. AIDS and Behaviour, 21*(2), 197-206.
- Welman, C., Kruger F., & Mitchell, B. (2009). *Research methodology*. Cape Town, South Africa: OUP Southern Africa.
- Williams Institute of Law Institute of Law (2011). *HIV/AIDS research*. Retrieved from <http://williamsinstitute.law.ucla.edu/category/research/health-and-hiv-aids/> hiv aids research
- Weston, R. (2006). *An exploratory study of Rhodes students' attitudes and perspectives towards HIV/AIDS*. (Unpublished masters dissertation).Rhodes University. Grahamstown.
- World Health Organisation. (2012). *Information on HIV/AIDS-Zero infection*. Retrieved from http://www.who.int/topics/hiv_AIDS/en/
- World Health Organisation. (2014). *Stigmatisation of PLWHA*. Retrieved from http://www.who.int/topics/hiv_AIDS/en/
- Winskell, K., Hill, E., & Obyerodhyambo, O. (2011).Comparing HIV-related symbolic stigma in six African countries: Social representations in young people's narratives. *Social Science & Medicine, 73*(8), 1257-1265.
- Wong, L. P. (2013). Prevalence and factors associated with HIV/AIDS related stigma and discriminatory attitudes: A cross-sectional nationwide study. *Preventive Medicine, 57*, Supplement (0), S60-S63.
- Wouters, E., Masquillier, C., Ponnet, K., & le Roux Booyesen, F. (2014). A peer adherence support Intervention to improve the antiretroviral treatment outcomes of HIV patients in South Africa: The moderating role of family dynamics. *Social Science & Medicine, 113*(0), 145-153.
- Wu, L., & Li, X. (2013). Community –based HIV/AIDS intervention to promote psychosocial well-being among people living with HIV/AIDS: a literature review. *Health Psychology and Behavioural Medicine, 1*(1), 31- 46.

Yuh, J. N., Ellwanger, K., Potts, L., & Ssenyonga, J. (2014). Stigma among HIV/AIDS patients in Africa: A critical review. *Procedia - Social and Behavioural Sciences*, 140(0), 581-585.

Zuch, M., & Lurie, M. (2012). A virus and nothing else: the effect of ART on HIV related stigma in rural South Africa. *AIDS and Behaviour*, 16(3), 564-570.

Appendix 1 - Semi structured interview guide

Preliminaries

1. Introduction
2. Explain the purpose and nature of the study
3. Ethical issues:
 - Obtain verbal and written consent to take part in the study
 - Confidentiality – research information will be kept secure. The participants will be told that pseudonyms will be used to ensure anonymity.
 - The participants will be asked if the interview can be tape-recorded and then transcribed.
 - It will be explained that this is academic research and that the researcher will experience no direct financial gain from the study.
 - The participants will be made aware of their right to abandon the interview if they feel like discontinuing.

Guiding themes of the interview questions

The interview guide is semi-structured to allow for in-depth probing of the participants narrative as required (English, Xitsonga and TshiVenda)

1. Biographical information, e.g. date and place of birth.
 1. Mahungu-ntiviso, xikombiso. Siku na dzhawu yo velekiwa (Xitsonga)
 1. Mafhungo-ndivhadzo, tshumbo, duvha na fhethu ha mabebo (TshiVenda)
Date of birth; Gender; Place of birth; Residence; Level of education; Maritalstatus; Education; Ethnic group and number of children.
 2. Experiences of being victimised or stigmatised.
 2. Matimu ya ku xanisiwa kumbe ku hlekuriwa (Xitsonga)
 2. Divhazwakale ya u tambudziwa kana u semiwa (TshiVenda)
 3. How the participants see their identity in terms of HIV/HIV/AIDS.
 3. Leswi vahlamuri va ti twisaka xi swona mayelana na HIV/HIV/AIDS. (Xitsonga)
 3. Zwine vhafhinduli vha dipfisa zwone malugana na HIV/HIV/AIDS (TshiVenda)
 4. What were your initial feelings when you tested HIV-positive?
 4. U ti twice ku yini ro sungula loko mbuyelo wu vula ku ri u na xitsongwana xa HIV? (Xitsonga)
 4. No di pfha hani lwa u thoma musi ndingo dzi tshi amba u ri ni na tshitshili tsha HIV? (TshiVenda)
 5. What were your feelings about HIV/AIDS before you knew you had it?
 5. A wu ti twa njhani mayelana na HIV/AIDS loko u nga si tiva leswaku u na yona? (Xitsonga)
 5. No vha ni tshi khou di pfa hani nga HIV/AIDS ni sa thu divha u ri ni nayo? (TshiVenda)
 6. Were you afraid that you would get it?
 6. A wu chava ku ri unga ngeniwa hi HIV? (Xitsonga)
 6. No vha ni tshi ofha u ri ni do dzheniwa nga dwadze? (TshiVenda)

7. What is your understanding of death? In this context, what are your feelings about the possibility of dying young?

7. U twisisa yini hi rifu? Eka xiyimo lexi, u ti twisa ku yini hi ku fa wa ha ri ntsongo?(Xitsonga)

7. Ni pfesesa mini nga lufu? Meadana na hezwi, ni di pfha hani nga u tshinyala kana u lovha ni tshi kha di vha mutuku?? (TshiVenda)

8.What worries you the most about your present situation?

8. I ncini lexi xi ku vilerisaka ngopfu mayelana na xiyimo xa wena xa sweswi?(Xitsonga)

8.Ndi mini tshi no ni vhilaedza nga maanda nga nyimele yanu ya zwino?(TshiVenda)

9. How can you describe stigmatisation according to your understanding?

9. U nga swi hlamusela hi ndlela yihi ku hlekuriwa hi ku twisisa ka wena xana? (Xitsonga)

9.Ni nga zwi talutshedza hani u semiwa/koleliwa nga ndila ine na zwi pfesesa ngayo? (TshiVenda).

10.How do you reduce stigmatisation if you think it happens naturally in terms of the following attributes: a person with HIV/HIV/AIDS is responsible for the illness; HIV/AIDS is progressive and incurable; the illness is not well understood by people; symptoms cannot be concealed and illness is associated with sex?

10.U nga hunguta nhlekulo hi ndlela yihi loko u tsundzuka leswaku nhlekulo wu humelela hi ntumbuluko hikwalaho ka leswi swi landzelaka? Munhu loyi a ngana xitsongwatsongwana xa HIV u lo tivangela vuvabyi lebyi; ,HIV/HIV/AIDS ya ndlandlamuka na kona a yi tshunguleki; Vuvabyi lebyi a byi twisisiwi hi vanhu; Swikoweto a swi tumbeteki na kona vuvabyi lebyi byi yelana ni timhaka ta masangu.(Xitsonga)

10.Ni nga fhungudza hani u semiwa/koleliwa samusi zwi tshi itea nga mvelele nga ndila dzi tevhelaho? Muthu a ne a vha na tshitshili o to zwi toda nga ene mune; HIV/AIDS I ya hula na hone a yi alafhei; Vulwadze uvu a vu pfesesiwi nga vhatu; tshumbo a dzi dzumbeyina hone uvu vulwadze vu tshimbizana na zwa dzekisano (TshiVhenda)

11.Can you mention ways of dealing with stigmatisation?

11.U nga vula tindlela to lwisa nhlekulo? (Xitsonga)

11.Ni nga amba ndila dza u lwa na u semiwa/koleliwa?(TshiVenda)

12.According to your understanding, does stigmatisation happen deliberately?

12. Hi ku twisia ka wena xana nhlekulo wu humelela hi vomu?(Xitsonga)

12.Nga u pfesesa hanu u semiwa/koleliwa zwi itea nga khole? (TshiVenda)

The closing of the interview

A tone of empathy will be maintained throughout the interview process. As well as being empathic, the researcher will be respectful and courteous. A de-briefing and follow up session will be arranged to check the interpreted meanings with the participant(s).

Appendix 2 – Letter to the Department of Health in Limpopo Province requesting permission to conduct the study

From: Mrs O.K. Nkuna

Student no: 88057800

Department of Psychology

University of Limpopo (Turfloop campus)

E-mail: oliviakhensani@gmail.com

To The Director of Health, Limpopo Province (Permission to conduct a research study)

Dear Director,

I am currently registered for a PhD in Psychology by dissertation at the University of Limpopo (Turfloop campus). My research is titled: **A JUNGIAN PHENOMENOLOGICAL STUDY: STIGMATISATION AND DISCRIMINATION OF PEOPLE LIVING WITH HIV/AIDS AT ELIM IN VHEMBE DISTRICT.**

I would like permission to conduct the aforementioned research at Elim hospital which falls under your auspices, in Vhembe District. I hope that the department will allow me to conduct this research. Due to the nature of the study I want to recruit the participants with full confidentiality following proper ethical guidelines, as laid down by the Health Professions Council of South Africa (Psychology Board) and the University of Limpopo (Turfloop campus). Participants who are interested in participating in the study will be asked to sign a consent form and it will be explained to them that they may withdraw from the research at any time. A copy of the proposal and consent form is attached.

Your approval to conduct this study will be greatly appreciated as it is seen as an important addition to research on the psychological impact of HIV/AIDS stigma. I will make constant follow up with the department and am happy to answer any questions or concerns that you may have. After the research has been completed and due process at UL completed, a copy of the Journal article (written to summarise the research) will be sent to you. The name of the clinic and area plus the names of participants will not be disclosed in the study.

You may contact me at my email address: oliviakhensani@gmail.com or my promoter Prof K A Nel at the following address: Kathryn.Nel@ul.ac.za

Yours faithfully,

Mrs Olivia Khensani Nkuna _____ (Date)

Prof K A Nel (Promoter) _____ (Date)

Department of Psychology (University of Limpopo, Turfloop campus)

Appendix 3: Letter to the Chief Executive Officer Elim Hospital requesting permission to conduct a study.

From: Mrs O.K. Nkuna

Student no: 88057800

Department of Psychology

University of Limpopo (Turfloop campus)

E-mail: oliviakhensani@gmail.com

To The Chief Executive Officer Elim Hospital requesting permission to conduct a study

Dear Sir/Madam

I am currently registered for a PhD in Psychology by dissertation at the University of Limpopo (Turfloop Campus). My research is titled: A JUNGIAN PHENOMENOLOGICAL STUDY: STIGMATISATION AND DISCRIMINATION OF PEOPLE LIVING WITH HIV/AIDS AT ELIM IN VHEMBE DISTRICT. I would like permission to conduct the aforementioned research at Elim hospital of which you are CEO. Due to the nature of the study I want to recruit the participants with full confidentiality following proper ethical guidelines, as laid down by the Health Professions Council of South Africa (Psychology Board) and the University of Limpopo (Turfloop campus). Participants who are interested in participating in the study will be asked to sign a consent form and it will be explain to them that they may withdraw from the research at any time. A copy of the proposal and consent form is attached.

Your approval to conduct this study will be greatly appreciated as it is seen as an important addition to research on the psychological impact of HIV/AIDS stigma. I will make constant follow up with the department and I am happy to answer any questions or concerns that you may have. After the research has been completed and due process at UL completed, a copy of the journal article (written to summarise the research) will be sent to you. The name of the clinic and area plus the names of participants will not be disclosed in the study.

You may contact me or my research project (Promoter) Prof K.A. Nel at the following address: Kathryn.Nel@ul.ac.za

Yours faithfully,

Mrs Olivia Khensani Nkuna

Date.....

Prof K A Nel (Promoter)

Department of Psychology, University of Limpopo (Turfloop campus)

Appendix 4 – Ethics forms (Turfloop Research Ethics Committee)

Date:.....

FORM B – PART I

PROJECT TITLE: A JUNGIAN PHENOMENOLOGICAL STUDY: STIGMATISATION AND DISCRIMINATION OF PEOPLE LIVING WITH HIV/AIDS AT ELIM IN VHEMBE DISTRICT

PROJECT LEADER: Mrs Olivia Khensani Nkuna

DECLARATION

I, the signatory, hereby apply for approval to conduct research described in the attached research proposal and declare that:

1. I am fully aware of the guidelines and regulations for ethical research and that I will abide by these guidelines and regulations as set out in documents (available from the Secretary of the Ethics Committee); and
2. I undertake to provide every person who participates in this research project with the relevant information in Part III. Every participant will be requested to sign Part IV.

Name of Researcher: Mrs Olivia Khensani Nkuna

Signature:.....

Date: 20.11.2013

For Official use by the Ethics Committee:

Approved/Not approved

Remarks:.....
.....
.....
.....

Signature of Chairperson:.....

Date:.....

FORM B – PART 11

PROJECT TITLE: A JUNGIAN PHENOMENOLOGICAL STUDY: STIGMATISATION AND DISCRIMINATION OF PEOPLE LIVING WITH HIV/AIDS AT ELIM IN VHEMBE DISTRICT

PROJECT LEADER: Mrs Olivia Khensani Nkuna

Protocol for conducting research using human participants

1. Department: Psychology
2. Title of project: **A JUNGIAN PHENOMENOLOGICAL STUDY: STIGMATISATION AND DISCRIMINATION OF PEOPLE LIVING WITH HIV/AIDS AT ELIM IN VHEMBE DISTRICT**
3. Full name, surname and qualifications of project leader:
Olivia Khensani Nkuna
B.A. Social Work Honours
B.A. Honours in Psychology
M.A. in Clinical Psychology
4. List the name(s) of all persons (Researchers and Technical Staff) involved with the project and identify their role(s) in the conduct of the experiment:

Name:	Qualifications:	Responsible for:
Olivia Khensani Nkuna	B.A. Social Work Honours	Research
B.A. Honours in Psychology		
M.A. in Clinical Psychology		
5. Name and address of principal researcher: Olivia Khensani Nkuna: P.O. Box 694; Malamulele; 0982
6. Procedures to be followed:
Exploratory interviews will be conducted using a schedule constructed from a combination of guide questions derived from a reading of relevant literature underpinned by Jungian Phenomenology.
Informed consent will be sought from each participant.
7. Nature of discomfort:
The interview could trigger sad memories that could cause flashbacks with depression, anxiety and anger. Affected participants will be referred to clinical psychologist for intervention.
8. Description of the advantages that may be expected from the results of the study:
 - a. The study could provide an avenue for catharsis to some participants. This could bring resolution to repressed anger.
 - b. Other undisclosed matters could be exposed and these could receive attention in terms of psychotherapy
 - c. A higher level of understanding of HIV/AIDS stigma could be exposed which would lead to more effective ways of dealing with it.
 - d. The body of knowledge regarding HIV/AIDS stigma would be embellished.

Signature of Project Leader:.....

INFORMATION FOR PARTICIPANTS

PROJECT TITLE: A JUNGIAN PHENOMENOLOGICAL STUDY: STIGMATISATION AND DISCRIMINATION OF PEOPLE LIVING WITH HIV/AIDS AT ELIM IN VHEMBE DISTRICT.

PROJECT LEADER: Mrs Olivia Khensani Nkuna

1. You are invited to participate in the following research project: **AJUNGIAN PHENOMENOLOGICAL STUDY: STIGMATISATION AND DISCRIMINATION OF PEOPLE LIVING WITH HIV/AIDS AT ELIM IN VHEMBE DISTRICT.**
2. Participation in the project is completely voluntary and you are free to withdraw from the project, without providing any reasons, at any time.
3. It is possible that you might not personally experience any advantages during the project, although the knowledge that may be accumulated through the project might prove advantageous to others.
4. You are encouraged to ask any questions that you might have in connection with this project at any stage. The project leader and the researcher will gladly answer your questions. They will also discuss the project in detail with you.
5. It may be that you feel discomfort when discussing stigmatisation and/or discrimination. However, I will ensure that this is discussed properly with you and if you do find that you have any problems (such as feeling traumatised or depressed) after our interview I will ensure that you have proper referral to a professional counsellor/psychologist. The advantages of talking to me may be that you may be better able to understand the position you are in. The research may also help others in the same position as well.
6. Should you at any stage feel unhappy, uncomfortable or concerned about the research please contact Ms Noko Shai-Ragoboya at the University of Limpopo, Private Bag X1106, Sovenga, 0727, tel: 015 268 2401

PART IV - CONSENT FORM

PROJECT TITLE: A JUNGIAN PHENOMENOLOGICAL STUDY: STIGMATISATION AND DISCRIMINATION OF PEOPLE LIVING WITH HIV/AIDS AT ELIM IN VHEMBE DISTRICT

PROJECT LEADER: Olivia K Nkuna

I, _____, hereby voluntarily consent to participate in the following project: **A JUNGIAN PHENOMENOLOGICAL STUDY: STIGMATISATION AND DISCRIMINATION OF PEOPLE LIVING WITH HIV/AIDS AT ELIM IN VHEMBE DISTRICT.**

I realise that:

1. The study deals with the effects of HIV/AIDS stigmatisation and discrimination on PLWHA and their families.
2. The research may hold some psychological risk for me that cannot be foreseen at this stage.
3. The Ethics Committee has approved that individuals may be approached to participate in the study.
4. The research project (that is, the extent, aims and methods of the research) have been explained to me.
5. The project sets out the risks that can be reasonably expected as well as possible discomfort for persons participating in the research. It also sets out an explanation of the anticipated advantages, for myself or others, that are reasonably expected from the research and alternative procedures that may be to my advantage.
6. I will be informed of any new information that may become available during the research that may influence my willingness to continue my participation.
7. Access to the records that pertain to my participation in the study will be restricted to persons directly involved in the research.
8. Any questions that I may have regarding the research, or related matters, will be answered by the researcher and her promoter.
9. If I have any questions about, or problems regarding the study, or experience any undesirable effects, I may contact Ms O Nkuna (oliviakhensani@gmail.com) or Prof K.A. Nel (knel@ul.ac.za)
10. Participation in this research is voluntary and I can withdraw my participation at any stage.
11. If any medical/psychological problem is identified at any stage during the research, or when I am vetted for participation, such condition will be discussed with me in confidence by a qualified person and/or I will be referred to my doctor.

12. I indemnify the University of Limpopo and all persons involved with the above project from any liability that may arise from my participation in the above project or that may be related to it, for whatever reasons, including negligence on the part of the mentioned persons.

SIGNATURE OF RESEARCH PARTICIPANT _____

SIGNATURE OF WITNESS _____

SIGNATURE OF PARTICIPANT _____

Signed at _____ this ____ day of _____ 2013