

**JUDGEMENTAL ATTITUDES IN PASTORAL CARE:
SPIRITUAL COUNSELLING FOR WOMEN LIVING POSITIVELY
WITH HIV AND AIDS IN THE TOWNSHIP OF LWANDLE**

BY

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I

DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis is my own original work and that I have not previously, in its entirety or in part, submitted it at any other university for a degree.

Signature:.....

Date:.....

DEDICATION

I dedicate this work to my Heavenly Father and His Kingdom. For without Him, I would have not embarked on this journey, and without Him sustaining me, I would not have finished running this race.

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ABSTRACT

AIDS is stigma, disgrace, hatred, hardship, abandonment, isolation, exclusion, prohibition, persecution, poverty, privation. AIDS is a metaphor. It is a threat, a tragedy, a blight, a blot, a scar, a stain, a plague, a scourge, a pestilence, a demon, killer, rampant, rampaging, murderer. It is made moral. It is condemnation, deterrence, retribution, punishment, a sin, a lesson, a curse, rebuke, judgement (Pillay, 2008:21).

The above quotation represents societal perceptions, discourses and responses to the AIDS pandemic. Sadly, in the early days of this pandemic, some theologians and churches held the above-mentioned perception, creating the fear in sufferers of the disease that they might be judged. Communities, families and people living with HIV/AIDS (PLWHA) also still hold this view. The aim of this study is to investigate the judgemental attitudes in pastoral care and spiritual counselling for women living with HIV/AIDS.

One of the aspects that contribute to the spread of the HIV pandemic is the stigma attached to it as it is the stigma that causes the silence. This study aims to explore the definition of stigma and investigate its causes and results as well as looking into the judgemental attitudes of the community, church, society, family and counselling of the HIV/AIDS sufferer, their identity crisis and their question of meaning.

Furthermore, the study aims to investigate the theological reflection on the notion of God, through the doctrine of judgement (how God is presented as a judge in both the Old and the New Testaments), as well as Old and New Testaments' views on illness. Using these sources, this study investigates whether or not HIV is a punishment from God. Using case studies, the resurrection of hope and the role of hope in a person was explored. This study also investigates how pastoral care and spiritual counselling can empower and bring hope and healing to PLWHA. This was done through the use of Louw's five-phase model of counselling PLWHA, an externalising method from a narrative approach.

This study seeks to determine the judgemental attitudes in pastoral care and counselling towards women living with the HI virus in the local township of Lwandle. It is said that the people most vulnerable to the HI virus and most infected are women and especially those living in the poor townships of South Africa. Their lack of education and poverty put these

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women in a more dangerous situation than their counterparts. In the township churches, women are in the majority. This study speculates about the role of pastoral care and counselling in empowering these women, in particular those living with HIV and AIDS and seeks to explore how the faith community, society and their families judge these women. It also investigates how pastoral care can dispute irrational and unrealistic constructs applied to the interpretation of the pandemic and how the Christian community can contribute to constructive processes of de-stigmatisation.

In the early days of the pandemic, the church regarded intercourse as intended solely for procreation (Van Dyk 2008:318). Therefore, since it is well established that HIV and AIDS is a disease that is mostly contracted through sexual activity, those who contracted the disease were regarded as being not morally sound or upright members of society. This resulted in pastoral counsellors finding it difficult to counsel without discussing the causes of this disease as when they did so, they often appeared to be condemning the infected persons by judging them. This study focuses on the judgemental attitudes and stigmatisation, a theological reflection on the notion of God, as well as on women living with the HI virus in a specific context.

In order to determine the attitudes of pastoral care and counselling, an empirical study was done to assess the attitudes in the above-mentioned location to PLWHA in that community. The aim of the empirical research was not to create statistical evidence, but rather to reflect the stories of the women living with the virus in this community. For the study, a certain group of women was selected from the support group of women who are living with HIV/AIDS. The co-ordinator of the support group helped the researcher to access the people from the Ikhwezi clinic. A questionnaire was used for the findings. The study showed the pain, vulnerability as well as the bravery of these women. Through the case study, the researcher was able to demonstrate how hope can change the lives of PLWHA.

OPSOMMING

Vigs is stigma, haat, swaarkry, verlatting, isolasie, uitsluiting, verbod, vervolging, armoede, ontbering. VIGS is 'n metafoor. Dit is 'n bedreiging, 'n tragedie, 'n vloek, 'n klad, 'n letsel, 'n vlek, 'n plaag, 'n kastyding, 'n pestilensie, 'n demoon, 'n doodmaker, wild, vervloek, 'n moordenaar. Dit is sedelikheid gemaak. Dit is veroordeling, afskrikking, vergelding, straf, 'n sonde, 'n les, 'n vloek, teregwysing veroordeling (Pillay, 2008:21).

Bostaande aanhaling verteenwoordig sosiale persepsies, gesprekke en reaksies betreffende die VIGS pandemie. Tragies om te sê, in die begin van die pandemie was bostaande persepsie die standpunt van sommige teoloë en kerke, wat die vrees by lyers van die siekte geskep het dat hulle veroordeel sou word. Gemeenskappe, gesinne en mense wat lewe met MIV/VIGS (MWLMV) huldig nog steeds hierdie seining. Die doel van hierdie studie is om die veroordelende houdings by pastorale sorg en berading van vroue wat lewe met MIV/VIGS, te ondersoek.

Een van die kwessies wat bydrae tot die toename van die MIV- pandemie is die stigma wat daaraan kleef, omdat dat die stigma is wat die verswyging daarvan veroorsaak. Hierdie studie beoog om die definisie van stigma te verken, en om die oorsaak en die gevolg daarvan te ondersoek, asook as om 'n kykie te kry in die veroordelende houdings van die gemeenskap, die kerk, die samelewing, die familie en die berading van die MIV/VIGS-lyer, hulle identiteitskrisis en hulle soeke na betekenis.

Verder beoog die studie om die teologiese besinning oor die idee van God n.a.v., die leerstelling van oordeel (hoe God voorgestel word as Regter in sowel die Ou en Nuwe Testament), sowel as die Ou Testamentiese en Nuwe Testamentiese sienings oor siekte, te ondersoek. Deur die gebruik van hierdie bronne will hierdie studie ondersoek of MIV 'n straf deur God is. Hierdie studie ondersoek ook hoe pastorale sorg en berading kan bemagtig en hoop kan bring vir MWLMV. Dit is gedoen deur die gebruik van Louw se vyf fase beradingsmodel vir MWLMV-'n eksternaliseringsmetode vanuit 'n narratiewe benadering. Deur gebruik te maak van gevallestudies is die opwekking van hoop en die rol van hoop in 'n persoon verken.

Hierdie studie poog om die veroordelende houdings by pastorale sorg en berading van vroue wat leef met die MI-virus in die plaaslike dorpie Lwandle, vas te stel. Daar word gesê dat die

kwesbaarste vir die MI-virus en die mees geïnfekteerde persone die vroue is, en by uitstek die wat in die arm dorpie van Suid-Afrika woon. Hulle gebrek aan geletterdheid en hulle armoede bedreig hierdie vroue meer as hulle mans. In die dorpskerke is vrouens in die meerderheid. Hierdie studie besin oor die rol van pastorale sorg en berading in die bemagtiging van hierdie vroue, in besonder hulle wat met MIV/VIGS lewe in die studie poog om te verken hoe die geloofsgemeenskap, die samelewing en hulle gene hierdie vroue beoordeel. Dit ondersoek ook hoe pastorale sorg irrasionele en onrealistiese opvattinge rakende die interpretasie van die pandemie kan betwis, en hoe die Christengemeenskap kan bydrae tot 'n opbouende proses van destigmatisering.

In die vroeë dae van die pandemie het die kerk gemeenskap gesien as uitsluitlik bedoel vir voorplanting (Van Dyk 2008:318). Aangesien dit algemeen aanvaar word dat MIV en VIGS 'n siekte is wat meestal opgedoen word deur seksuele aktiwiteite, is hulle wat hierdie siekte opgedoen het, nie gesien as moreel, of as onkreukbare lede van die gemeenskap nie. Dit het daartoe gelei dat pastorale beraders dit moeilik gevind het om te beraad sonder om die oorsaak van die siektetoestand te bespreek indien hulle dit wel gedoen het, en het dit dikwels gelyk asof die geïnfekteerde persoon veroordeel is deurdat hulle geoordeel is. Hierdie studie fokus op die veroordelende houdings en stigmatisasie-op 'n teologiese besinning oor die idee van God, sowel as op die vroue wat met die MI-virus binne 'n bepaalde raamwerke leef.

Ten einde die houdings van pastorale sorg en berading teenoor MWLMV te bepaal, is 'n empiriese studie in daardie gemeenskap gedoen. Die doel met die empiriese navorsing was nie om statistiese bewyse te skep nie, maar eerder om te besin oor die verhale van die vroue wat met die virus leef in hierdie gemeenskap. Vir die studie is 'n bepaalde groep vroue geselekteer uit die ondersteuningsgroep vroue wat met MIV/VIGS leef. Die koördineerder van die ondersteuningsgroep het die navorser gehelp om die mense van die Ikhwezi kliniek te bereik. 'n Vraelys is gebruik vir die bevindinge. Die studie het die pyn, verwondbaarheid, sowel as die moed van hierdie vroue getoon. Deur die gevallestudie het die navorser aangetoon hoe hoop die lewens van MWLMV kan verander.

CHAPTER 1

1.1 INTRODUCTION

Although counsellors and care givers often refer to the importance of dealing with the spiritual and religious needs of HIV positive clients and their loved ones, this nevertheless remains one of the most neglected aspects of counselling within the HIV/AIDS context. The fact that spiritual counselling has been overlooked may be the result of a combination of complicated factors and negative perceptions about religious institutions and their clergy or leaders (Van Dyk, 2008:318).

HIV/AIDS is predominantly a sexually-transmitted disease; this causes many complications for spiritual and religious counselling (Van Dyk, 2008:318). A rational understanding of the origin, progress and ultimate effects of HIV/AIDS is often clouded by sexual taboos, denial, superstition, stigmatisation and the irrational fears which sexuality and sexually transmitted infections evokes in many people. Similarly, in the Christian tradition, sexuality has been connected historically to marriage (Louw, 2008:351). Within this tradition, it has been consistently maintained that sexuality belongs exclusively within marriage and is primarily meant for insemination – the means for the propagation of the species. Apart from anything else, HIV also unmasks many pre suppositions regarding the meaning of human sexuality (Louw, 2008:351).

When sexuality – with all its connotations of life, fruitfulness and fecundity - is connected to death, a short-circuit occurs in the human psyche. This contradiction is surely one of the main reasons for the terrifying anxiety that accompanies the HIV diagnosis. The possible spread of the disease becomes a battlefield : it challenges us to face up to issues here that otherwise get swept under the carpet especially since many religious communities tend to judge people more harshly for sexual transgressions. Often such judgements are based on double standards and a great deal of hypocrisy and self-righteousness (Van Dyk, 2008:319).

HIV/AIDS constitutes a crisis as an illness and creates conflict at various levels which affect our being human and our search for meaning. Yet, this crisis can also be transformed into an opportunity for growth, witnessing and a deepening of faith. People infected with HIV/AIDS have a right to human dignity. Their most profound immediate need is to be treated with respect and understanding: a suffering person needs a fellow human being who, with love,

sustains and understands (Louw 1994:61). For many people living with HIV/AIDS (PLWHA) such support remains a distant dream. Instead of fulfilling this need to be loved, respected and understood, PLWHA frequently become objects of scorn and curiosity as their fellow human beings speculate on attributing blame for the diagnosis. PLWHA cannot access the love and compassion they deserve because they cannot seem to escape the stigmatisation surrounding this disease.

The stigma surrounding HIV/AIDS is not unusual: stigma has also been linked to epilepsy, mental illness, cancer and other disabilities - all illnesses that allow the bearer to be regarded as potentially dangerous or no longer a valuable member of society.

The stress placed on those who are stigmatised only serves to exacerbate their existing condition. HIV-related stigma is particularly salient because of its relation to sexuality and human values. The moral discourse surrounding sexuality has perpetuated the stereotyping, separation, and discrimination of PLWHA (Scurry 2004:53). The issues of stigmatisation and stereotyping are closely related to negative attitudes towards sexuality (Van Dyk 2008:319). Although one would expect religious communities to be generally supportive and accepting of HIV-positive people, fears and unresolved complexes often override compassion and theological principles to bring out 'unexpected' and frequently dangerous negative reactions. (Louw,2008:425) suggests four great dangers in the religious community's reaction to PLWHA:

1. Apathy bordering on neutrality.

The apathy that readily results from viewing AIDS as a 'sinner's disease' is damaging to the Christian task, as it may be accompanied by a refusal among individual Christians to view persons in the high-risk group as the proper focus of the church's mission.

2. An attitude of smugness, hypocrisy and prejudice.

The 'good guys' are the hetero sexuals and the 'bad guys' are the homosexuals and drug addicts. A spirit of self-righteousness develops that considers HIV patients as part of that group of people who reap what they have sown. This judgmental attitude towards those nameless, generalized 'others' is readily transferred to persons living with HIV. Some ask: "Are they not merely receiving the just wages for their sinful lifestyle"?

3. Isolation and exclusion approach: Stigmatisation and labelling are synonymous with isolation. This is resulting in making HIV the leprosy of the twenty-first century. PLWHA might not be physically isolated as the leprosy, however, when the comments like, people living with HIV/AIDS should not date, let alone marry, (see chapter 4) that is isolation.

4. Scapegoating: Who is to be blamed or convicted? Normally, PLWHA are seen as

promiscuous and permissive. The question now is how did he/she get infected. That question is part and parcel of stigmatisation.(Louw:2008,426)

1.2 RESEARCH PROBLEM

Instead of experiencing an environment which promotes hope, people suffering from HIV/AIDS are frequently confronted by prejudice and criticism. They feel rejected, isolated and are frequently plagued by feelings and despair. This thesis aims to assess the ways in which women who are living positively with HIV/AIDS in Lwandle township are exposed to a hostile environment. The research asks the question: To what extent does the community of Lwandle respond with prejudice and a judgmental attitude? This research will attempt to address questions such as:

- Does the Lwandle community respond with a judgmental attitude more than with a compassionate stance?
- What is the interplay between God-images and judgmental attitudes within the churches in Lwandle, a predominantly Christian-oriented community?
- Does the notion that HIV/AIDS is God's chastisement for the promiscuous lifestyle of modern society exist within the Lwandle township?
- Does the Lwandle community think they have been failed by God-images closely related to God as Judge?
- What role can Spiritual counselling play in the deconstruction of biased and destructive prejudice.

Exploration of these questions will require examining the reference between social perceptions, the role of God images, theological language, and attitudes within communities of faith, within the HIV/AIDS debate. It will also aim to ascertain what stigma is all about. Stigmatisation of PLWHA manifests in various forms, including disapproval; rejection by family members, neighbors and faith communities; and condemnation by the church using Scriptural texts(Amanze *et al.*, 2007:29). Social prejudice thus gains a theological status (Louw, 2008:426) and robs PLWHA further of their dignity.

One negative consequence of stigmatisation is the fear of being tested and diagnosed (Amanze, 2007:28). Once diagnosed, people are reluctant to declare their status for fear that others will pass moral judgement upon them as having incurred punishment from God because of their sexual immorality. In this way a vicious cycle is entrenched which denies people from receiving the love and compassion they need.

1.3 OBJECTIVES OF THE RESEARCH

This research seeks to find a link between the physical processes of stigmatisation and the ability to rise above stigmatisation to access spiritual resources in the human quest for meaning. Particular attention will be paid to people's specific understanding of and perspectives on sexuality, self-esteem and stigmatisation.

Scripture does indeed refer to God as Judge. While keeping this in mind, what is the difference in the HIV/AIDS discourse between 'being judged by God' and the prejudice that arises from judgmental attitudes within faith communities?

This research intends to probe the features of a very specific cultural setting - the Lwandle township - and the interplay between culture and stigma that exists there. In order to get clarity on the interconnectedness of culture and prejudice, the researcher has decided to interview women living positively with HIV/AIDS within the Lwandle township.

The fact that the researcher lives within this community makes the choice of Lwandle for the focus group self-evident. The research will explore the most appropriate approach to pastoral counselling so as to also make it easier for PLWHA to re-integrate into the community. This requires holding in tension church doctrines on the one hand, whilst endeavoring to encourage those already-infected.

1.4 RESEARCH PRESUPPOSITIONS AND ASSUMPTIONS

As HIV/AIDS is a disease with undertones of sexual activity, those in religious circles frequently regard it as a disease associated with sexual promiscuity. The church has traditionally viewed intercourse as being solely for procreation (Van Dyk, 2008:318). Since it is well established that HIV/AIDS is a disease that is most often contracted through sexual activity, it is regarded as a disease that infects those who are not morally sound or upright. Those who have contracted this disease are frequently banished to the background of the church's life. For example, one of the women interviewed told the researcher that once her HIV-positive status became known she was no longer allowed to teach Sunday school. Lack of knowledge about the disease plus the link in many peoples' minds between HIV/AIDS and promiscuity makes pastoral counselling difficult. How does a counsellor speak about the

causes of HIV/AIDS without appearing to condemn and judge those infected?

The way Scripture is used in church life exacerbates the difficulties in pastoral counselling. Like any other sufferer, the PLWHA expects Bible verses to identify with their experience; they find instead that the way people use Bible verses insult them. For example, one of the women in the Masiphumelele support group (where the researcher had worked before Lwandle) believed that when the story of the Samaritan woman was preached from the pulpit, emphasis was mostly placed on the number of the men the woman had been with (John 4:7) and the promiscuous lifestyle that this woman supposedly had led.

In order to change a community's perspectives concerning HIV/AIDS issues, as well as to change the skewed perceptions about HIV/AIDS, pastoral counselling should dispute all irrational and unrealistic constructs applied to the interpretation of the pandemic, particularly God-images (Louw, 2008:439). The Christian community could contribute much to the constructive processes of de-stigmatisation if inappropriate God-images are assessed in spiritual counselling. The assumption is that the Christian perspective on God, the power of God and the fact that God is often portrayed as a Judge within the Christian community in Lwandle, could be a hampering factor in Christian spiritual life. Is such a perception of God a stumbling block in the spiritual development of PLWHA? Is it possible in spiritual counselling to link God as Judge to the Christian notion of comfort, compassion and care?

1.5 RESEARCH METHODOLOGY

Various methods are used in this research: a literature study; an exploration of the extensive documented research that has already been done in pastoral care and spiritual counselling on this topic; a hermeneutical approach is applied to interpret attitudes; and a qualitative study seeks to describe the meaning which the individuals give to their lives.

(Louw,2000:3) suggests that pastoral hermeneutics is an interpretation of existential and contextual issues in a person's encounters with God. Existential issues are the very issues with which every person who is infected and affected by HIV has to wrestle. The challenge facing pastoral counsellors is to address these existential issues from the perspective of Christian faith and hope (Louw, 2000:3). This thesis will use a literature review and empirical data gleaned from the stories of women living positively with HIV/AIDS to address the hypothesis. The empirical component is used because this research seeks to analyse the present situation of women living positively with HIV/AIDS in Lwandle community.(Smith,2008:152) The ethical clearance regarding the consent is available in the

Faculty of Theology

WHY THE LWANDLE COMMUNITY?

Lwandle was chosen for the following reasons:

- Lwandle lies three kilometres from the researcher's own neighborhood.
- In South Africa the rate of the HI-virus is said to be highest in the black communities; more prevalent in less educated and poorer communities; and it affects mostly women - a vulnerable gender (Scurry, 2004:21). Lwandle's socio-economic conditions makes it ideal for this research.
- Inhabitants of Lwandle were victims of the Apartheid evil which left many of them poor and vulnerable. These same people are now fighting the evils of the HI-virus. The research aims to probe the judgmental attitudes experienced by people in this setting.
- The majority of Lwandle residents are isiXhosa. The researcher is Xhosa-speaking and has lived in Lwandle.
- Lwandle has its own clinic that supplies PLWHA with treatment. This facilitates access to PLWHA for interview purposes.

1.5.1 Sampling

This study researches primary evidence: it works with the stories of Lwandle women living with the HI virus. The data was obtained through a questionnaire that was drawn up and shown to the women. Its purpose was not for statistical, but to gain accurate information in order to produce better quality research (Strydom & Venter, 2002:199).

The study focuses on a certain section of the population that has a high rate of HIV: black, Xhosa-speaking women living in Lwandle, a community situated near the towns of Somerset West, Strand and Gordon's Bay, South Africa . To ensure the unbiased representation of the female population of this community, the focus group consisted of young, old, married and unmarried mothers who are also all HIV-positive (Smith, 2008:238). The fact that most women - young and old – who are living with the HI-virus go to the clinic to seek treatment, gave the researcher easy access to a cross-section of the types of women who form the majority of people who visit local government clinics to seek treatment. The criteria used for selecting the women were: any black woman who is living positively with the HI-virus, living in Lwandle and who attends the Ikhwezi clinic for treatment. Lwandle is a microcosm of the wider South African context. This study aims to be a voice for this vulnerable group of people in the church.

The women who were interviewed for this study all belong to the PLWHA support groups, which meets at the Ikhwezi clinic, where they also go to receive their anti-retroviral treatments (ARVs). The co-ordinator of this support group where the pilot group came from, introduced the researcher to the women. The aim and purpose of the interviews was explained to them and their permission to be interviewed was asked.

No consent forms were given. The coordinator of the women's support group had warned the researcher that the women would not participate in the process if they were made to sign any consent form. Therefore, only their verbal consent was obtained, however the departmental ethics screening committee has the data collection forms and the consent form signed by the coordinator of the support group.

1.5.2 The interview

There were two interview processes: a pilot study and a focus group. The pilot study consisted of approximately 15 women. These women were interviewed first and were used to test the questions. They are coming from the support group of the new mothers that are living with HIV/AIDS.. The focus group comprised about five women. These women are coming from the different support group, their support group is for PLWHA, that are taking arv's (Anti-retro viral treatment) Both of these groups were required to answer the same questions. During the interviews, the pilot group were asked one question at a time, and anybody could answer. The focus group were asked questions individually and privately. They met separately from the pilot group and were not part of the pilot group. They were not part of the support group where the focus group belong. The focus group were interviewed two weeks after the pilot study.

1.6 ABOUT THE RESEARCHER

The researcher is a Xhosa-speaking woman. Like the women interviewed for this work, she came from the Eastern Cape originally, but has subsequently also lived in other South African informal settlements for many years. Like many other black South African women, she worked as a domestic worker. She has experienced the evils caused by Apartheid and has experienced physical abuse from a man.

At one time the researcher, like the women she interviewed, also felt that she had no voice. Patricia de Lille captures this vulnerability most poignantly:

A woman's struggle for a voice is often her most prolonged struggle. Sometimes

words of power rise from her belly, percolate in her heart and then stick in her throat. Often she is forced to whisper the most important words, the simple, small-type words that carry bold consequences. Many times she is cowed into silence by circumstances, suppression and fear.

(in Erasmus-Kritzinger, 2003:388)

The researcher lost three older brothers to HIV/AIDS. At that stage of her life she also thought her family were bewitched. In the process of writing this study, the researcher had to help someone very close to her to come to terms with being sick through HIV/AIDS.

As a minister of the Baptist Union of Southern Africa, the researcher spent five years counselling PLWHA and their families. During this time she formed a support group for PLWHA in the community of Masiphumelele where she worked before coming to Lwandle. This group – comprising women only – was where she gleaned some of the information regarding HIV/AIDS that is supported by scientific research. The experience of working with PLWHA in Masiphumelele made her decide to embark on this research journey. She personally witnessed the church closing its doors to PLWHA. Working in this ministry gave her an opportunity to witness the extent to which women within the church are suffering alone without anyone knowing their status. Because the church was unable to address their emotional and spiritual needs adequately, these women would come in wounded and leave wounded, perhaps even more wounded than they were at first. The HIV-positive person's need for spiritual comfort, consolation and understanding is thus not addressed at a stage in his or her life when these needs are most acute (Van Dyk, 2008:318).

As the researcher is affected herself in many ways by HIV/AIDS, her position is thus one of a participant observer in this study.

1.7 OUTLINE OF THE STUDY

Chapter One serves as an introduction to the research. Chapter Two deals with the definition, causes and results of the stigma surrounding HIV/AIDS. This chapter will also examine judgmental attitudes towards HIV/AIDS. Particular focus will be on judgmental attitudes in the general community; within the church community; in the wider society; in pastoral counselling ; and within the families concerned. The quest for truth, the quality of relationships, the identity crisis and dignity will also all be dealt with in Chapter Two.

Chapter Three deals with judgmental attitudes from a theological perspective; more particularly, a theological reflection on the notion of God's judgement. This chapter will

examine the doctrine of judgement; God as Judge from an Old Testament perspective; and the view of illness in the Old Testament. It will then examine the notion of God as Judge from the New Testament perspective; and the view of illness in the New Testament. Using what is found in the doctrine of judgement, God as Judge in the New and Old Testaments and the view of illness in both these Testaments, this chapter will conclude with the question: “Is HIV/AIDS therefore a punishment from God?”

Chapter Four will give a voice to women living positively with HIV/AIDS. As discussed above, two groups of women were interviewed – a pilot study and a focus group. This research will look at the narratives of the women interviewed for this study and provide an interpretation of their answers.

Chapter Five deals with a therapeutic approach; the human quest for empowerment in pastoral care and spiritual counselling; pastoral care and hope: “For in sadness there can be hope. And in death there can be resurrection” (De Vries, 1989:45). We will look at a definition of hope; hope in the Resurrection; and the role of hope in a person: “Since the Resurrection is not only a new perspective, but also an historic reality, it has consequences for hope. Resurrection hope then becomes hope for a collective existence” (Louw, 2008:435). The last section of chapter 5 deals with PLWHA and spiritual counselling; Louw’s five-phase model for counselling PLWHA; and a narrative approach using externalising conversations. The latter begins to disempower the effects of labelling, pathologising and diagnosing that are commonly experienced by PLWHA. Narrative conversations open up possibilities for people to describe themselves, each other and their relationships from a new rather than a problem-saturated position (Morgan, 2000:24).

The final chapter, Chapter Six, deals with the findings and the outcome of the research.

CHAPTER 2

JUDGEMENTAL ATTITUDES AND STIGMATISATION: THE QUEST FOR TRUTH

2.1 INTRODUCTION

A volunteer working to persuade South Africans not to discriminate against HIV-infected people was beaten to death last week by her neighbors who accused her of bringing shame on their community by revealing that she was HIV-positive. The killing scared other anti-AIDS activists, who said it proved what they have been saying for years that, although three million South Africans are infected with the virus that causes AIDS, nearly all are afraid to admit it because of the hostility they face. The slain woman, Gugu Dlamini, 36, was a volunteer field worker for the National Association of People Living with HIV/AIDS. She went public on World Aids Day, December 1, speaking out about her HIV infection on Zulu language radio and on television.

(New York Times, 28 December 1998)

Although the people of Gugu's own community killed her for disclosing her status, there is more to this act than meets the eye. Gugu's death illustrates clearly that stigma is a social ill as well as a personal experience, Scurry, (2004:51). AIDS was perceived as bringing shame not only to Gugu as an individual, but also to her community: her disclosure thus seemed to provoke a communal response.

The researcher links this response of Gugu's community to the fact that South African black communities still do not even call HIV/AIDS by its proper name.

More recently, the (*City Press*, 2012: 5 May) published news about the death of Minister Shiceka. The editorial points out how after so many deaths, so many funerals, even politicians still can't call HIV/AIDS by its proper name. It is called instead a 'long illness':

What did he die of? A long illness

Here lies another young lion. He defined effective communication, and helped to craft the image of one of the world's greatest leaders, he was kind and

sharp, and gone too soon.

What did he die of? A long illness.

Here lies a wonderful trade union leader, snapped away from one of the country's best worker's organisation at the tender age of 30 something.

This long illness of ours, taking our best and our brightest, turning their brains to mush, filling the grave yard too soon. This long illness of ours that has meant grannies are turned back into mothers, bringing up grandchildren and great-grandchildren. This long illness that is beatable with amazing drugs that can turn it from deadly to chronic. But first you have to say its name to know its danger, you have to acknowledge its course through the veins and into the body. First we have to accept that it is, often but not always the outcomes of choice, the choice of our imperfections, of fallibility. To say its name is to take away its power.

(‘He died of “a long illness”’ *City Press*, 2012: May, 05)

One often hears about the ‘long illness’ in township funerals. When people explain the death of the family or community member it is very seldom that the cause of death is named as HIV/AIDS. It is this secrecy that really kills, not the disease.

When something is bad, shameful or disgraceful, the black community will pretend it either does not exist, or that it is not so bad by not actually calling it by name. This is what the researcher thinks is happening in both the *City Press* article and Gugu’s case. Gugu’s disclosure was seen as a shameful disgrace to her community, made worse by the fact that she had come out and named it publicly. Her disclosure brought fear, shame and anger to the community. A similar sense of shame was evoked when a young girl falls pregnant. This is called *waphuke ibele* in isiXhosa, literally meaning ‘the breast has broken’ or she is no longer a virgin. Similarly, cancer is called ‘*isilonda esikhulu*’ - ‘the big sore’. (Stein, 2003:1) suggests that when something seems too much to handle people frequently diminish, minimise or somehow make it sound less drastic by using metaphors to describe it instead of the real name itself. Calling something by its proper name can make it seem too real.

In the townships many different metaphors are used to describe HIV and AIDS. Stein, (2003:1) suggests that the invisibility of HIV makes it particularly vulnerable to different metaphors, depending on the context:

- In some areas of Khayelitsha, when someone is infected by HIV they say, ‘*ubambe iloto*’ which means they have ‘won the lottery’;

- In other townships it is called '*amagama amathathu*', which literally means 'three names' (H, I and V).
- The Lwandle community calls it '*lento iphandlapha*' meaning 'this thing that is outside'.
- People living in some of Kwazulu Natal's townships call it '*ushaya abhuqe*' meaning 'catastrophe'.
- In some areas of the Eastern Cape they call it '*umbulala zwe*' meaning 'The Destroyer of the Nation'.

From the meaning of these words, one can see an element of attempting to push the seriousness of HIV aside or trying to deny its true danger/implications or even stigmatising it. For instance, '*lento iphandlapha*' describes HIV/AIDS as being 'outside' of me, and not 'inside' or 'of' me. Whereas the phrase, 'The Destroyer of the Nation' gives a sense of communal involvement with the virus: it is 'ours'. This sense of communal involvement begs the question of whether the strategy of combating HIV/AIDS should change when it comes to the townships. Instead of attacking it as individual thing (which seems to be easier to deny), perhaps it should be confronted at a community level? The use of these metaphoric names suggests that not only is HIV and AIDS perceived as a disease without a cure, but also one which is 'so stigmatized that it cannot be named' (Stein, 2003:3). 'To say something's name is to take away its power' (*City Press*, 2012). The researcher regards this naming as one of the coping mechanisms people use to deal with the disease as well as with a stigma. It is easier to confront it with a euphemism or metaphor. There is such anxiety, shame or stigma and an overwhelming fear of the disease - the black community especially find it difficult to name anything that they feel powerless to face - means these metaphors (such as 'a long illness') and euphemistic names for the virus have come about.

The need to name this disease in order to 'take away its power' is complicated by the fact that HIV is linked to sex. In traditional black culture, sex as a subject of discussion is taboo. Graca Machel in (Nolen, 2007:346) suggests that:

It is unthinkable for a Xhosa elder to discuss matters related to sexuality in public... Everything related to sex is private. Only some aunties and uncles can speak to younger ones about sexuality, or those who go on the initiation process - the traditional rite of passage ceremony for young men in many tribes.

But HIV cuts right through this reticence: black communities are forced to consider sex whenever they deal with HIV/AIDS. It unmasks many presuppositions regarding the meaning of human sexuality and re-opens the issues - such as the meaning of human sexuality and

how it relates to human identity, human dignity, the origin of life, marriage, family and the dynamics of human relationships - that otherwise would have been swept under the carpet or discussed only in private (Louw2008:351). In the Christian tradition, sexuality has been connected historically to marriage: it belongs exclusively within marriage and is primarily meant for insemination (Louw,2008:351). But HIV/AIDS has forced us to differentiate between marriage and human sexuality. It challenges Christian spirituality to ask the question:

‘What is meant by sexuality as a unique category and an ingredient of human existence?’ The following section will focus on stigma and HIV/AIDS; judgemental attitudes in counselling, community, church community, family; stigma towards self; and the quest for truth.

2.2 JUDGEMENTAL ATTITUDES AND HIV/AIDS

HIV/AIDS has become one of the major problems facing African societies today. According to the demographic projections made by the Centre for Actuarial Research at the University of Cape Town, South Africa has the highest number of cases of HIV infection in the world, with the black population and poorer classes, in particular, being affected. In the case of HIV/AIDS, three structural conditions seem to play a crucial role: social inequalities, gender violence and migration. These are the people who also were affected by inequalities and migration caused by Apartheid., They have found themselves in a struggle once again, though a struggle of a different sort.

HIV/AIDS is repeating what Apartheid did previously: it marginalises a section of the population and tears families apart (Greyling, 2003:120). People who are infected and directly affected by HIV/AIDS are stigmatised and discriminated against, even by their own family members. Although HIV/AIDS does not discriminate on the basis of race, age, gender or creed, as was the case during Apartheid, nevertheless women and children bear the brunt of this disease due to their vulnerability and powerlessness to fight back. This vulnerability is further exacerbated by poverty, patriarchy and violence, which they are also powerless to do anything about.

PLWHA are stigmatised because of the disease – much as the racism of Apartheid stigmatised people. But there is a major difference between racism and the HIV/AIDS stigma. In the case of racism, a person is born with physical features that may mark them as ‘black’ or ‘white. In the case of HIV/AIDS, the biological differentiation usually happens later in life (when HIV/AIDS is contracted) and people living in the same communities or families may not have the same HIV status, (Deacon,2005:11). Unlike race, gender or disability, the

physical markers of HIV/AIDS are not always visible. Even when PLWHA become sick they mostly contract other communicable diseases such as tuberculosis (TB) that are secondary markers for AIDS. This is because AIDS is not a disease in itself, but a syndrome which lowers peoples' immunity and makes PLWHA more vulnerable to contracting secondary infections. The 'invisibility' of HIV/AIDS helps PLWHA and others to deny their status - even to themselves. They use the fact that they do not appear sick with HIV to avoid both stigmatisation and self-stigmatisation at a personal level. Although such denial might seem convenient in the short term, revealing a hidden stigmatising characteristic causes greater psychological distress at a later stage thus creating problems when PLWHA begin to need special treatment or care. The invisibility of HIV infection at a social level exacerbates stigmatisation and encourages people to use secondary markers - such as wasting or the onset of illnesses such as TB - to identify who has the condition. The infected encourage the idea that HIV/AIDS affects 'other people.'

This invisibility of the HI-virus makes stigmatising it very difficult to fight. Unlike the fight for liberation from Apartheid:

[which] was very hard, HIV is much more complex, because it's not an enemy where you can say, it is there, and I am here. There is no demarcation between us and the enemy this time....This goes much deeper than the struggle for liberation, because liberation was ideological, it was political. This is a terrible human struggle. Even though HIV has an individual stigma, yet it is a communal thing.

Graca Machel in(Nolen 2007:343)

Apartheid was felt in solidarity: it had the same impact on every black person. As a result, everyone could see the impact or result of Apartheid upon everyone else. Everyone who was against Apartheid had one goal: to destroy it. It was humiliating to be discriminated against because of the colour of your skin, yet it was not something those discriminated against were ashamed to fight. Everybody talked about it, it was a known fact. But with HIV/AIDS, no one owns up to it because it is shameful:

Sometimes we wish that the enemy were just over there, so we could pick up our guns, get into position and start firing. But our worst enemy is among us. It is everywhere - between men and women, boys and girls, husbands and wives. It is in the beds of our intimacy - in the best moments of our lives. When we kiss and make love, the enemy is there. It is now in our veins, our blood, our

cells, in our fluids, in our minds. We are back in the battlefield fighting for our liberation again. This is a sobering, a critical moment. But put your guns down. Shall we shoot at ourselves?

This is the challenge of living in the age of HIV/AIDS, we have to shoot at ourselves to win this battle. We have to look closer to home, at ourselves, and question our relationships.

(Dube, 2003:85)

But the challenge to 'look closer to home, at ourselves, and question our relationships' is perhaps the hardest challenge of all. This kind of battle is more like a civil war – 'we have to shot at ourselves' - which turns one family member against another thereby making it very difficult to fight. One does not know which weapon to use when the virus is inside our homes. It is far easier to point at it from a distance and to fight it from a distance. Moreover, the stigma surrounding the disease, frequently leaves one alone on home ground in this battle. Only when this disease is right at one's door does one begin to realise the enormity of the stigma surrounding this disease. It is the invisibility of the virus that causes the stigma making it very difficult to take a closer look at ourselves.

2.3 JUDGEMENTAL ATTITUDES AND COUNSELLING

PLWHA, like most people, are very sensitive to judgemental statements or actions. This sensitivity makes them unwilling to open up until they are sure about a counsellor's attitude: When the person becomes aware of any judgement, he/she usually experiences it as pure threat. Whether positive or negative, judgement is perceived as alien, perhaps even as undeserved.

(Colston,1969:57)

This then means that people are naturally more wary about counselling if they think the counsellor is also going to judge them if they say too much.

Judgement has a tremendous impact on the growth potential of every person (Colston, 1969:21). Judgement is interpreted as the act of the self judging itself, the self giving and receiving judgement in relation to others and self-giving and receiving judgement in relation to God. The function of judgement in each instance is to develop the spirit of wisdom and prudence enabling one to know and to discern what is truly creative in attitude and action, to

become discriminating as to good and evil, right and wrong and to be directed toward what is ultimately fulfilling.

Although the task of judgement may not belong to human beings, we do indeed judge (Wise, 1966:81). This is the nature of freedom. How then do we judge? (Colston, 1969:19) suggests that any meeting of one person with another inevitably involves both persons in judgement. The degree of judgement depends upon the significance or importance of each to the other. The self-esteem and self-respect of each person hangs in the balance. This confrontation involves risk. If the positive regard of the other is highly valued, one's vulnerability to judgement is increased and the risk to one's self-regard is greater. In this manner, one measures one's worthiness. How one is valued by a person or group of persons is crucial. How one values oneself both affects this process and is affected by it.

How will this process work if the person concerned already judges her-/himself negatively? Normally, the HIV-infected person already feels worthless and condemned. Will this type of confrontation work? The intensive encounter of one person by another is in itself an act of judgement. Whether the one encountered is a worthy opponent, a valued companion, or a rough diamond, there is a challenge in the engagement, which may be an act of moving against, or moving with, the other person. Judgement is implied in both the actions and the worthiness of the other. However, if judgement is to be not merely a prudential matter, but a totally responsible one, it will be refined by the judgement of God. The ground for any decision therefore is love under *agape* (Colston, 1969:21).

How does one go about pastoral counselling respectfully, especially with PLWHA where sensitivity towards being judged can be acute? The most obvious first step has to do with our own physical presence: the pastoral care-giver's body language needs to communicate a non-judgemental attitude and the willingness to be with, and be part of, the journey. This care-giver needs to bring peace to the counsellee's space. Care must be taken when questioning because questions – especially those which seek the reason or what/who was to 'blame' for the infection - can appear as judging. The HIV dilemma is so complicated that a person may not be able to give an honest answer for fear of being judged (Louw 1998:269). The pastoral care-giver must make ensure to ask questions with constructive effect. (Louw, 2008:446) proposes the following guidelines for counselling from a pastoral perspective:

- Establish a helping relationship based on trust (being with somebody)
- Ensure a caring system (empathetic space)

- Engage in constructive or structured conversation, whether through interviews, group discussion, dialogue or one-on-one verbalisation
- Teach how to cope in a more ‘meaningful’ way with different life issues or problems
- Connect possible problems to more constructive attitudes, alternative options and preferred scenarios to look for solutions (the narrative approach calls this ‘re-authoring conversations’)
- Explore sources for appropriate and effective coping skills or management strategies
- Empower a person to take responsible decisions as well as to set goals that take action, and
- Assess and make use of appropriate God-images in the establishment of a mature, spiritual stance in life. This can promote hope and growth.

Human suffering can reveal a human being’s deepest need to us (Louw, 2008:16-17). These deepest needs include: somebody to be with, empowerment, recognition, comfort, consolation and compassion. PLWHA need to have these needs addressed, even before the onset of their illness. When these needs are not met by the community or – worse still, when the person experiences judgement and ostracism rather than acceptance - it is painful especially to an African as they know what it is to be supported by the community.

2.4 JUDGEMENTAL ATTITUDES AND COMMUNITIES

Families and communities have been so profoundly affected by the HIV/AIDS pandemic that the usual ways of African communities coping with sorrow have broken down or are inadequate:

One of the most remarkable and tangible dimensions of African Spirituality relates to the unique notion of communality and collective solidarity that the African society exhibits in all spheres of life. There is a profound sense of interdependence, from the extended family to the entire community. In a very real sense, everybody is interrelated, including relations between the living and those who have departed.

(Mthethwa,1996:24)

Why is this not the case with HIV and AIDS? Where is *ubuntu*? During the time of Apartheid, South Africans demonstrated this communality and collective solidarity – the

‘profound sense of interdependence’ that Mthethwa writes about. It seems as if the stigma associated with HIV has removed that interrelatedness. People no longer feel safe in their own communities. The community used to be a refuge where everybody knew and protected one another. One could always approach one of the Elders for solace and advice. Sadly, this is no longer the case. People are afraid to let it be known by anybody in the community that they are HIV-positive or that they have been infected by the disease, even if they do not have full-blown AIDS.

One of the women who was interviewed for this study told the researcher that she cannot go home to the Eastern Cape because she is so thin and, if her community see her like this, they might know that she is HIV-positive. A similar fear is expressed by one of (Ndhlovu’s 2008:175) interviewees:

What wears me down is that my role in society has changed. It is no longer easy to meet up, with friends especially, in the same way as before. I am aware that they are thinking about me being infected. I feel that I can live with my HIV by withdrawing. From this statement, it is not HIV itself that I am suffering from. It’s people that make me suffer.

The HIV itself is not a threat. It is the judgement from the communities in which the sufferer lives that makes it worse. Another of the women who was interviewed for this research mentioned, off the record, that she had fallen one day and was bleeding. The people coming from work walked right past her. Nobody asked why she was lying there or offered to help her up. What is the cause of this neglect? Is it HIV that has made people so insensitive? What has happened to these structures of society who used to be pillars of strength for the residents? It looks as if HIV/AIDS has alienated the black community from itself and families – instead of being ‘pillars of strength’ - have become eroded:

HIV has had a major impact on individuals and on community structures such as the families. Family has traditionally been the fundamental unit of any society but as the epidemic progresses this structure is being steadily eroded.

(Karim & Karim, 2005:351)

One of the most obvious changes has been in the increase in single-parent households. In the past, due largely to the widespread practice of migrant labour in the South African economy, women have often effectively been single parents as fathers/husbands have worked away from home. Although this practice still continues ‘skipped generation households’ - households headed by a grandmother because the mother has

died - are becoming increasingly common.

2.5 JUDGEMENTAL ATTITUDES WITHIN THE CHURCH AND COMMUNITIES OF FAITH

The average church leader's work on the African continent has doubled since the outbreak of HIV/AIDS. There are more sick people who need to be visited and prayed for, there are more grieving relatives who need to be visited and encouraged and there are an increasing number of orphans who cannot be absorbed by their overburdened extended families and who, in turn, need to be comforted, cared for, guided, loved and educated in day-care centres (Dube, 2004:1).

Sadly, there are also more funerals to attend. Any individual who lives in a black township in Cape Town knows that each Friday mini-bus taxis transport the body of someone's daughter/son/uncle/brother/sister to be buried in the Eastern Cape, where funerals take place every weekend. The church bears the burden of comforting the families during the time of death and burial. But are the church leaders/pastors aware of the cause of these deaths of mostly young people? And, if they are, what are they doing about it? Or is it because of 'the long illness' – the disease that people cannot bear to name?

To what extent is the church community a place of refuge for PLWHA? In the past the church and faith communities have played a critical role in the developing and fostering of communities of women in South Africa (Haddad,2003:16). Networks of religious women continue to be a key site of survival practice and a place where poor and marginalised women are taking control of their lives. Given this history of care it would seem that the church would be a site of spiritual support and survival for women living with HIV/AIDS (Scurry, 2004:78). But the women whom Scurry interviewed suggest that in fact there is something in the church community *per se* that makes it especially difficult to go to in order to disclose one's status. Noluthando, one of the womenwhom (Scurry, 2004:79) interviewed, said she fears judgement at church and believes that people from the church in whom she may confide will regard her as promiscuous. Scurry wonders if the judgement they fear comes from God or from the church community. (Vahakangas, 2005:54) suggests that the church communities seem only to increase the stigma of PLWHA, rather than minimising it. She relates the story of an HIV-positive person who went to her pastor and told him about her HIV-positive status. Afterwards she found that the pastor's wife had spread her story to others.

The woman had trusted the pastor which is why she had told him the truth and confided in

him, believing there would be confidentiality. But the subsequent gossip about her story to others stigmatised her. (Chauke 2000:137) also interviewed women living with HIV/AIDS. She made the following observations about church communities:

1. The church has separated itself from the people who need it.
2. Although the church will visit the sick and the bereaved from time to time, the church is so busy with its programmes that it does not take time enough to listen to the hurting.
3. The women she interviewed said very little about the church's involvement.
4. They needed someone to listen to them.
5. The women had many difficult questions.
6. In their struggle to find meaning in this confusion, women raised questions about the reality of God as well as questions about God's attitude towards those affected and infected by HIV and AIDS.
7. HIV/AIDS has exposed some oppressive cultural practices against women.
8. The church, along with its leaders, are reluctant to involve themselves because some church leaders regard HIV and AIDS as God's punishment for sin.
9. The church has forgotten that it is meant to be a messenger of God's grace to the needy in times of struggle, strife and pain.

It is a sad indictment when the church is too busy concentrating on other programmes rather than focusing on pastoral care for PLWHA. It is even sadder when the church is busy with other programmes on 1 December, International World AIDS day.

(Dube 2004:1) argues that church leaders/pastors who are serving now cannot be expected to automatically have the skills to deal with HIV/AIDS. She argues that they are faced with the challenge of having to learn a whole new way of doing ministry in an HIV/AIDS context. The answers (Chauke 2000:139) received from the pastors whom she interviewed are evidence of how challenging it is to minister in an HIV/AIDS era:

- One pastor believed that the Bible was clear on the matter. Quoting the stories of Noah as well as Sodom and Gomorrah, he concluded that God is judging the world because of the sin of immorality. For him the focus of the church's ministry must be preaching against the sin following Paul's recommendation to: 'Preach the Word; be prepared in season and out of season, correct, rebuke, and encourage with great patience and careful instruction' (2 Timothy 4:2).
- Another pastor says that some people regard AIDS as God's punishment for an evil society.

- Still others say viruses and diseases like HIV are the result of witchcraft. Because women are female women are consequently to blame for the pandemic.
- Pastors' reading and understanding of the Bible is still influenced by their culture which, in certain aspects, remains indifferent to women's well-being.
- There are pastors who believe that the church need not concern itself at all with people who choose to disobey the law. Just as the Lord punished the people of the Old Testament, so He is punishing people today for their lawlessness. Chauke comments that the unfortunate thing about this pastor's beliefs is that all he sees is God's wrath over their sin but not His love for the sinner. He does not seem to understand that, whilst God hates to see us sin, He still loves us because we are all His children whom he created in His own image.
- In their sermons pastors frequently neglect the opportunity to minister to people's need for forgiveness. (Ibrahim 2006:10)observes that, in the Sunday services, there are two elements that many people view as important. The first is 'confession', and the second is 'preaching.' In the confession, people are set free from sin before hearing the preaching of the Word of God that is meant to sustain and empower them. They believe that, by going to church, they will feel at peace in their hearts, because in the name of Jesus, a welcome is extended to those who are weary and heavily burdened (Matthew.12:28). In contrast, PLWHA experience stigma in the judgemental sermons that are frequently preached against HIV and AIDS. Their burdens are increased after hearing the sermon, rather than being helped and uplifted. In preparing a sermon on HIV and AIDS, pastors need to choose appropriate forms of expressing themselves. Pastors must be aware that they have a responsibility to many people in the church, including those who are infected and affected by HIV and AIDS: their words must be chosen carefully indeed. In addition to 'preaching', space must be made for 'confession' and absolution: this – rather than judgement – will bring comfort rather than further condemnation.

Many churches have failed to provide a supportive community for PLWHA to accompany them through their illness and to deal with the stigma they may face in their society (Scurry, 2004:110). They have not provided a space where people are encouraged to share their suffering. PLWHA have felt excluded rather than embraced. The experiences of the women interviewed suggest that HIV/AIDS is facing churches with a new challenge: ministering in this context calls for a theology of inclusion. Churches should be sanctuaries, refuges for people living with HIV and AIDS. The stigmatisation of PLWHA calls on the church to ask

itself what it means in our time to be the inclusive community that Jesus proclaimed it to be. The theology of inclusion does not merely portray an image of a 'kinder, gentler God,' it also portrays an aggressively inclusive God: Jesus' ministry was inclusive to the point of scandalising religious authorities and so-called respectable people who judged others.

2.6 JUDGEMENTAL ATTITUDES WITHIN TOWNSHIP SOCIETIES

2.6.1 Families and other relatives

Some of the women who were interviewed for this research have family members who also are infected by the virus. Frequently their experience was one of being rejected and ostracised by their siblings:

It still shames me to think that in my family, one that I considered highly educated and informed, my own brother had to suffer the indignity of having his utensils and laundry separated from everyone else's.

Mboyi in (Karim & Karim, 2005:33)

This is how PLWHA suffer judgement in their own homes. One often hears about cases like this. The researcher remembers vividly the story of a single mother with two daughters who was chased out of the house by her step-mother when she disclosed her status to the family. Because of that brutal and forceful rejection, the whole township knew her status. (Mboyi's 2005:34) autobiography testifies to a similar story. She met a man who fell in love with her. When Mboyi disclosed her status to this man, he was stressed for some hours mulling over facts and then seemed to accept it. In spite of the fact that Mboyi had taken her time to explain her circumstances to him, he seemed to keep forgetting that they needed to use condoms and she had to continually remind him to do so. As a result, he started to become abusive to, and angry with Mboyi because of her status. During their conversations he made it sound as though she had forced him into a relationship with her. He would force anal sex without a condom as he believed he could not contract HIV in that way. Mboyi felt violated and abused and, simultaneously, she felt powerless because she had disclosed her status in what she thought was a safe environment. She learnt firsthand from this experience the personal vulnerability that emanates from selective disclosure. After breaking up with this man, Mboyi then met another man and also disclosed her status to him. He then went to be tested and, although he returned with a HIV-negative result, he became obsessed with protection and went to the extreme. He would constantly check her to see if she had any cuts

or open sores anywhere on her body. Before and after sexual intercourse he would scrub his hands and genital area with disinfectant. This made Mboyi feel dirty and diseased.

Mboyi's experience is not unusual. One of the women interviewed for this study also bore the brunt of abusive and controlling behaviour from a man. The reason she stayed and took the abuse was that she did not have to explain her status to him: this man was also living with the HI-virus and she wouldn't have to worry about having to go out and meet another man who may judge her in the future.

For many women, the fact that they have to deal with the possibility of being rejected at home, by their partners, as well as by their society becomes just too much. The lack of sufficient health care in some townships places the burden of care for the infected on women as the perceived care-givers. A survey conducted by (Barnet *et al.* 2002:185), revealed that, in households affected by HIV and AIDS in South Africa, 68% of care-givers are women and/or girls. In more than 40% of the households, the primary care-giver must take time off from formal or informal employment or schooling to take care of AIDS patients, adding to the loss of household income and the girls' lack of schooling. Care-givers thus tend to suffer from emotional as well as financial strain. Mboyi, while infected herself also had to care for her sick brother. Not only was she coping with her own destiny – with little time left over to grieve for her lost healthy future – but what resources she had were also spent caring for her brother. Mboyi's experience is shared by many other women:

When the society blames these women, they internalise these fears. The stress of blame and stigma not only compromises their emotional capacity to cope with the illness, but also affects their immune system and accelerates the course of the disease.

(Link *et al.* 2003:118)

Some women and girls in these townships go elsewhere to be tested because of their fear of being rejected by their own societies. They presume that, because most of the clinic employees are from the township in which they themselves live, these employees will tell their community. The researcher heard about women who had to go to other areas to be tested. They would also go to the other clinic where nobody knew them to take the ARV treatment. Stigma discourages these women from disclosing their status to their partners, families or their communities. The researcher recalls the story of a young girl whom she approached to disclose her status on video for marketing purposes. The girl had no problem with this, on condition that the video would not be seen by anyone in her community. The researcher came across the same thing four years later. The woman she interviewed for this

research (see Chapter Four) said that she may record their interview only on condition that it would not be shown in their community, and as long as the researcher came across the same thing four years later. The women she interviewed for this research (see Chapter Four) said that she may record their interview only on condition that it would not be shown in their community, and as long as the researcher was not a member of that community. The researcher's other advantage was that she, in fact, does not live in that community.

Stigma has created a widespread fear of testing and disclosure because people fear that they will become isolated and segregated from the rest of society (Nyblade, 2003:25).

(Scurry (2004:61) interviewed a woman who said that she had lost eight friends whom she suspected had all died of AIDS because of the symptoms that she had recognised in them. Despite some of them knowing about her own HIV-positive status, none of her friends confided their own status to her. This silence not only denied them emotional and physical support when they really needed it, but may also have put their partners at greater risk of infection or re-infection.

Most of these women found it very difficult to tell their families of their status. This silence perpetuates denial as it allows some of them to behave as if AIDS does not exist.

Women are not alone in the difficulties they share. (Nolen,2007:368) interviewed a young man from Kwazulu Natal who had disclosed his status to his girlfriends and to his colleagues. His disclosure was met with silence, but after he left they scrutinised him, looking for the signs of a sick person. When he disclosed his status to his friends, some never called again and some said that this could not be true because he still looked so well. These kinds of comments create a struggle with identification.

2.7 THE TENSION BETWEEN DISCLOSURE AND NON-DISCLOSURE

2.7.1 PLWHA and the interplay between attitude and identity

We define identity in terms of bearing the image of God. We believe that any definition of human identity that does not take the image of God as a basic point of reference fails to fully portray that Biblical view of human identity (Van der Walt, 1998:105). In a theological anthropology, (Louw,2000:208) defines identity as being when people discover that God calls them to respond to their destiny, to love God and their fellow human beings. People display the quality of their responsibility and the genuineness and sincerity of their obedience to God in the way that they love. Identity is about people being called - the principle of vocation.

Identity also requires a sense of consistency: the congruence between the human I and the self. With HIV/AIDS, identity is the crucial aspect and causes conflict at many different levels in a person living with the HI-virus (Louw,2005:21).

(Louw,2008:119,168,445) suggests the following levels of conflict which illness causes within one's self:

- *The illness causes conflict within the environment.*

People become 'patients' and come into conflict with their environment. The familiar world becomes foreign, a hospital ward and a sick bed replace familiar surroundings like the bedroom. The world of medical practitioners and nurses is alien territory. Even relatives are placed in a new role. Where harmony and peace previously prevailed, tension now sets in.

- *The illness causes conflict within the community*

Community and identity are inseparable for African people. Personhood is linked to kinship, the extended family, clan and tribe. Thus alienation from the family community can be described as an identity crisis and a form of 'death.' It implies a loss of meaning and personal identity. Moreover, the human being (*umuntu*) anthropology needs to be understood from a theocentric perspective. Human beings are naturally attuned to a transcendent cosmic force, which can be called God. *Umuntu* shares in Divine qualities and is therefore fundamentally a religious and spiritual entity. To be fully *muntu* means to participate in Divine qualities, but at the same time to participate in the communality of life.

Illness and health have a communal dimension. Illness disrupts the concept of order, balance and harmony. When dealing with illness in the African community the requirement is not for a precise diagnosis, but rather an answer to the question: 'Who disturbed the societal order and why?'

- *The illness causes conflict with spirituality and with a person's quest for meaning*

A person's sense of meaning is linked to belief systems, convictions, life views and a sense of destiny. As a qualitative term, meaning refers to a specific state of being directed by life goals, determined by a sense of hopefulness and shaped by convictions, values and virtues. (Louw,2005:98-99) identifies four basic existential issues that threaten the quest for meaning: anxiety, guilt, despair and hopelessness. PLWHA are confronted on each of these issues. Whereas before faith was possibly taken for granted; now faith is no longer a given. Questions also arise about God's justice and omni potence. Hostile feelings can be projected onto God and He is blamed for the situation. Some people, however, can develop an even greater

dependence on God. Either rejection of God, or increased dependence on God on the part of the patient can provoke conflict in church communities. In addition to guilt feelings, PLWHA are overtaken by feelings of anxiety, despair and hopelessness. They are confronted by questions such as: ‘Does this situation have any meaning?’; and ‘Do I still want to live or would euthanasia be a possible way out?’ People who have been affected through promiscuous sexual relations may struggle with the question, ‘Does anybody still love me?’ Some of the questions of meaning also involve the struggle with fate, such as ‘Why did this happen to me?’ or ‘Why must I die when I don’t want to die?’

- *The illness causes conflict within oneself*

For many people, illness presents a crisis to their human self-image which often leads to an identity crisis, something PLWHA often struggle with. PLWHA ask themselves questions such as: ‘Who am I?’; ‘Am I still the same person despite my status?’; ‘Will I still be accepted by my people, especially my relatives?’; ‘Must I disclose and tell others and, if so, who do I tell?’ The crisis of meaning impacts profoundly: one is faced with the need to reorient oneself regarding one’s identity and value; uncertainty about the future creates confusion; one’s sense of purpose is eroded as what one would normally wish to do is now impossible; one’s reasoning becomes distorted. As one tries to orientate oneself rationally with the new situation, one’s sense of self is plagued by questions such as: ‘What are my chances of recovery?’; ‘Who or what caused this illness?’

At the same time, the emotional world is disturbed. Emotionally, a person with HIV may feel confused, depressed, helpless, vulnerable and weak. Loneliness and negative thoughts predominate in the mind and alter the person’s perceptions on life. Worries and uncertainty lead to a loss of self-confidence.

HIV/AIDS is not solely a personal thing: the different conflicts that PLWHA experience - both internal and external - affect their relationships profoundly as well as all aspects of their lives: cultural, spiritual, economic, political, social and psychological (Dube, 2003:1).

2.7.2 PLWHA and their relationships

2.7.2.1 Relationship with the community

The decision of whether or not to disclose one’s status and to whom continually confronts PLWHA. The stigma that still surrounds the disease contributes to the dilemma. If one remains silent, one distances oneself from possible support by neighbours and the wider

community; but if one discloses one's status one runs the risk of greater isolation and ostracism. (Van Dyk's 2007) study relates many stories about repulsing attitudes held by people towards others with AIDS and endorsement of social sanctions against them. This dilemma is clearly evident in the choice facing infected lactating mothers. Since it is widely known that infected mothers do not breast-feed their babies, but receive formula from the clinics, many infected mothers choose to continue breastfeeding to avoid the immediate assumption in the community that they are HIV positive. Non-disclosure is thus a double blow for PLWHA: not only does it create a barrier preventing them from accessing necessary support, but it also might reflect that these mother have internalised the societal stigma surrounding HIV/AIDS (Smyth, 2004:167).

Although the women interviewed in (Smyth's 2004:167) research might have felt isolated and ostracised from the community at large, many of them found refuge in the community of individuals living with HIV/AIDS. The HIV support group (as they call it) became the place where they could be themselves and speak openly and honestly about their real feelings. When they discovered that they are not the only ones living with HIV, they enabled one another to think about living positively with HIV, instead of having feelings of loneliness, loss of hope and loss of future. Interacting with others who are HIV positive gave participants hope and a sense that they could be brave and strong despite their HIV status. In place of isolation and ostracism, there was a sense of universalism and belonging in realising that they were not alone in their experience with HIV. In addition, being able to tell their stories to one another emerged as a constituent aspect of the lived experience of shared social support. They could tell their stories without fear of being judged, and discovered the amazing freedom that comes from being able to the truth about who they are and face it with solidarity (Smyth, 2004:168).

2.7.2.2 Relationship with the family

As with other diseases, the family is expected to provide support for people living with HIV/AIDS when they become ill. However, the stigma associated with this disease and the possible risk of transmission challenge the family unit. HIV can have an impact on choice of partners, availability of support, relationships with children and psychological well-being of family and friends (Bor & Elford, 1998:30).

Once again, HIV-positive individuals are frequently confronted with the question of who to tell. Some people decide to share the information with a selected few family members who will keep it confidential, others decide to keep their HIV-positive status a secret from all (Van Dyk, 2008:261). This discrepancy reflects the sensitivity which still surrounds AIDS-related issues (Bor & Elford, 1998:22). Research done with HIV-positive adults in Tanzania revealed

that PLWHA generally did not disclose their HIV status to their spouse or partner, but were more likely to tell somebody within the extended family to whom they were close. This puts a strain on the relationship. Some chose to remain silent because they felt they did not deserve the shame and blame associated with the disease. Others feared that they will be rejected. Others want to keep the secret in the belief that they should not burden their family with the knowledge that they are going to die from such a stigmatised disease. There were some – a minority – who could not think of anyone to whom they wanted to disclose (Bor & Elford, 1998:22).

The decision whether or not to disclose is costly – emotionally, psychologically and physiologically. Those who live with the fear of rejection live under constant psychological stress, a condition which may contribute to the deterioration of their health. Those who want to keep their status a secret from even their closest family members may put others in dangerous situations for HIV transmission, whether intentional or not (Bor & Elford, 1998:24).

Secrecy can have other very negative consequences: it may isolate and alienate clients from the support systems that they so desperately need (Van Dyk, 2008:261). Some people fear alienation of another kind. (Pillay, 2008:171) tells how John found it very difficult to disclose his HIV-positive status to his brother who was responsible for paying for his tuition at university. John felt ashamed because his status meant that he had been a ‘bad person’; and he feared ‘punishment’ from his brother in the form of the withdrawal of his financial support. The kind of social support generally given to families with terminally ill members cannot be given openly to families who keep the HIV diagnosis a secret. Bereavement may ultimately also be very difficult to handle in these families because bereavement will be the culmination of a long process of denial. Clearly, the decision about whether or not to disclose their status is not something that PLWHA take lightly. It is an extremely difficult choice to make, with a wide range of inherent risks.

2.7.2.3 Relationships with partners/spouses

AIDS is about relationships. It is about intimacy, sexuality, vulnerability, pain, suffering, death and stigma (Pillay,2008:164). PLWHA are affected by the all of the above-mentioned dynamics. Their sex lives have to be negotiated and that is not easy, especially for women, whose intimate sexual relationships is frequently defined by a culture of silence and submission (Smyth,2004:16). ‘Good’ women are expected to fulfil their partners’ needs and wishes, satisfy their male partners’ urge for sexual pleasure, and remain ignorant about sex. ‘Good’ women are also expected to be passive in sexual interactions: it therefore becomes impossible for some women to negotiate for safe sex In addition, many women live in a

context of physical and emotional abuse: this makes negotiation for condom use virtually impossible for many women (Scurry,2004:32). Condoms have come to imply a level of distrust or suspicion. If a woman wants to use a condom, her partner assumes that she must have betrayed him, or feels that she is unsure of his sexual fidelity. (Pillay 2008:166) tells Beulah's story. When Beulah became pregnant, she was asked to what extent the health of her sexual partner was an issue in her decision to have unprotected sex. Beulah said that while it was not her intention to have unprotected sex, when her partner refused to use a condom, she accepted that he was prepared to take the risk, since he was unaware of her status. At that stage she was not ready to disclose her HIV-positive status to her partner for fear of being judged; she also suspected that he might also have been HIV positive. Beulah's story reveals the complexities of human sexuality in general and for HIV-positive women in particular (Pillay,2008:167).

In contrast, Nosandiso, disclosed her HIV-positive status to her husband, who then accused her of bringing the virus home as she was the one who tested first Scurry, (2004:34). A different challenge confronts women who have disclosed and whose partners are also tested HIV-positive. Because they are both HIV-positive, they run the risk of re-infecting each other repeatedly with the virus, thus accelerating the course of the disease. These and other complexities that are experienced by women living with HIV/AIDS change the quality of their relationships. They are forced to lie to their partners because of the fear of being rejected and/or of being accused for bringing the disease home. Because HIV/AIDS has been identified as a behavioural disease, the issue of making choices is important when considering the challenge that human sexuality presents in the context of HIV/AIDS. The issue of decision-making and the ranking of choices involve first acknowledging the problem - and this is what people frequently are loath to do (Pillay, 2008:169).

2.7.2.4 Relationships with God

The truth of God's Word is basically relational in character. Rather than being an analysis of a system of transcendent divine mysteries, the truth of the Word is the visibility of God's eternal covenantal relationship with humankind, embodied and enfleshed in the incarnation of Christ (Louw,2004:126). In the Old Testament, knowledge was not an intellectual game, but a relationship with God based on trusting faith. (Scurry's2004:75-6) research revealed that many women who are infected and affected with HIV/AIDS, do not regard God as some distant, complicated and theological notion, but rather a personal Provider. Their notion of God – which had in fact strengthened since they became HIV-positive – added meaning and purpose to their daily life. (Scurry 2004:73) observed that when stigma places a massive blanket of silence over HIV/AIDS and creates an environment in which people living with the

disease cannot share their trials and tribulations, prayer offers the women whom she interviewed an opportunity to speak openly, and feel that they are heard. They would not reveal their anger to those around them, and certainly not to those who hurt them, but they could release their emotions before God. The notion of God served as protection for many of the women.

The impact of the HIV/AIDS diagnosis on women's relationship with God varied for those women interviewed for this study. Some acknowledged that their relationship with God had become stronger. Nontando said: "I came to the knowledge of Jesus after my HIV diagnosis." For others it created distance. One woman, who had just received news of her HIV-positive diagnosis the previous month, said that she was distancing herself from God because she could not understand how, after she had tried to be 'a good girl', her first encounter with a man brought her this deadly disease. She was angry with God. Thus the crisis precipitated by the diagnoses affected women differently: some found consolation from their faith and others did not.

2.7.3 Dignity: The meaning question

(Louw,2005:98) suggests that the search for meaning is not a physical 'thing'; rather, it a direction - a route - to be taken in the light of a sense of purposefulness, significance and alignment. One can only pose the 'For what purpose?' question if one is aware of the most basic existential issues that threaten the quest for meaning.(Louw,2005:99-100) lists these existential threats as follows, and suggests how they can be replaced by 'existential brightness':

- Anxiety:

Anxiety reflects loss; intimacy represents our basic existential need to be accepted unconditionally without the fear of rejection and isolation. Intimacy fulfils the need for acceptance, comfort and security.

- Guilt:

Guilt reflects bondage to the past; our basic existential need is to be set free. Meaning has to do with an experience of liberation, freedom, forgiveness and reconciliation.

- Despair:

Despair robs a soul of its future. Hope represents purposefulness and anticipation for the future.

- Helplessness:

Helplessness (with its concomitant feelings of being overwhelmed and hopeless) is

replaced by care. It refers to the need for support systems and somebody who can act as a 'soul guard.'

(Louw 2008:432) suggests that once the person has accepted some meaning in suffering, the question is no longer 'Why?' and 'For what purpose?' Instead, out of God's mercy and faithfulness the person discovers answers to more future orientated questions, such as 'Where to from here?'; and 'To what purpose does my life lead?'

In addition to facing the existential issues of anxiety; guilt; despair(Louw,2004: 119) the meaningful acceptance of human dignity is one of the most fundamental issues in soulfulness and our human quest for meaning. Human dignity embodies the value and quality of the human soul within the dynamic network of social relationships. An important aspect of enhancing the quality of life for PLWHA is linked to the fostering of human dignity.

2.7.3.1 The issue of human dignity in community development

The aim of community development is to create a society in which human dignity can be cultivated: it means fostering of a culture of human rights in order to safeguard human dignity and to empower humans by means of personal validation, education and sustainable development. Following Louw (2004:120), human dignity involves the following aspects:

1. *Human dignity is relational*
2. *Human dignity is not something which is found in isolation.* It is embedded within the dynamic network of social relationships. The value and quality of the human soul is nurtured within relationships.
3. *Human dignity involves mutuality and ethics*
Human dignity is not something external to our being: it is an essential part of the quality of human relationships as embedded in the processes of mutual sharing. There is an ethical dimension of our being human.
4. *Human dignity and unconditional love*
Dignity is the outcome of an experience that one is accepted unconditionally without fear of isolation and rejection. Human dignity entails identity and maturity directed as unconditional love towards the well-being and advantage of the other.
5. *Human dignity and cultural identity:*
Human dignity is linked to cultural identity, social customs and traditions as well as to the society's network of values and norms.
6. *Human dignity involves co-existence and morality*

Human dignity largely determined by the quality and morality of co-existence - a person's interrelatedness and interconnectedness with others.

The relational, interconnected, and unconditional qualities that undergird human dignity are essential components determining the quality of human relationships. The secrecy and the stigma that surrounds HIV makes it so difficult to have the kind of mutual sharing and support which is so necessary to PLWHA .

2.8 HIV/AIDS AND STIGMATISATION

2.8.1 INTRODUCTION:

The stigma that surrounds HI virus deprived PLWHA the benefit of sharing the pain with the church community. (Smyth 2004:30) observed that stigma has a major implications for social support. Being HIV positive determines that social support is needed to enable coping with mounting HIV illness stressors, however as a results of the social unacceptability of an HIV diagnosis at the time social support is most needed least may experience. This section seeks to explore the definition of stigma the belief that cause stigma and the results of stigma.

2.8.2 Definition of stigma.

Stigmatisation has been identified as a major issue in addressing the multiple and complex challenges presented by the AIDS pandemic (Pillay, (2008:164). Dube (2004:125) defines stigma as a condition that causes one to be shunned, discriminated against and even persecuted, for perceived moral, ethnic, gender, health, economic, physical, religious, class or social impropriety. The 'condition' is viewed as a threat to the community in some way; this threat can come in various forms, for instance, those who are HIV-positive and publicly confess to it, young women pregnant out of wedlock, the disabled or physically challenged. Some people are shunned and scorned for their cultural practices, for example the uncircumcised in cultures where circumcision is common practice. Stigma brings with it devastating mental, social, spiritual and economic consequences and suffering for the stigmatised person.

The stigma surrounding PLWHA is particularly complex. There are a number of different factors - for example, class position, gender, education or HIV status - that can heighten the level of discrimination experienced. Nevertheless, despite the link between stigmatising attitudes and discriminatory actions, in the field of HIV/AIDS stigma is often treated as seamless. Consequently, discrimination against PLWHA - or any other failure to access treatment - is frequently attributed to HIV/AIDS stigma without actually investigating

whether this is the case. It would seem that relatively little research has been done to determine the relative importance of HIV/AIDS stigma in comparison to other barriers to treatment and care, or other sources of discrimination (Deacon *et.al.* 2005:19 & 23). The following two definitions of the stigma surrounding disease (Deacon *et.al.* 2005:20) might help us here:

1. Disease stigma can be defined as an ideology that claims that people with a specific disease are different from 'normal' society, more than simply through their infection with a disease agent. This ideology links the presence of a biological disease agent (or any physical signs of a disease) to negatively defined behaviours or groups in society. Disease stigma is thus negative social 'baggage' associated with a disease: a person is regarded as 'abnormal' in some way as result of the disease.
2. Disease stigmatisation can be defined as a social process by which people use shared social representations to distance themselves and their in-group from the risk of contracting a disease by:
 - constructing it as preventable or controllable
 - identifying, 'immoral' behaviours that cause the disease
 - associating these behaviours with 'carriers' of the disease in other groups
 - thus blaming certain people for their own infection
 - and justifying punitive action against them.

(Deacon,*et.al.*, 2005:23) differentiates further between these two definitions by calling the second definition a 'stigmatisation process'. The first defines stigma as those negative meanings associated with disease. This definition fails to address *why* and *how* stigmatisation occurs; the relationship between stigmatisation, discrimination and social power relations; what the role of the individual is; and whether it matters who stigmatises whom. In contrast, the second definition helps us to distinguish causes, functions and effects of stigma more easily. It also shows how significant variations in the content of stigma occur. This definition helps us to create a sense of control and immunity from danger at an individual and group level, as it distances people (and their in-groups) emotionally from risk.

Since the choice of who is identified as the out-group depends on personal identities and historical power relations, it is thus highly variable. For example, some black South Africans blame Western scientists for HIV/AIDS, while some white heterosexual British men blame black Africans for it:

Stigmatization is entirely contingent on access to social, economic and

political power that allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories and the full execution of disapproval, rejection, exclusion and discrimination.

(Link & Phelan,2004:2)

(Deacon *et al* 2005:22) suggests using the word ‘discrimination’ to describe what happens the stigmatization process. The term ‘discrimination’ is preferable because it directs attention to the power relations present between perpetrators of discrimination and their victims. Discrimination involves distinguishing (discriminating) between human differences, conferring negative value on some types of differences and treating people unjustly as a result, by drawing on social and economic power.

(Louw,2008:426) links the establishment of stigma to social settings. The routines of social intercourse in established settings and first appearances enable us to anticipate a person’s ‘social identity.’ It is easy to transform how we anticipate someone’s identity into expectations and demands that are normative. These demands, in turn, create a virtual social identity. When this identity is assessed as negative, bad, dangerous, weak, even sinful, we reduce their differentness to something ‘wrong’ or ‘evil’ and the person is reduced to a tainted, discounted individual. Such an attribute becomes a stigma, especially when its discrediting effect is very extensive. Sometimes, it is called a failing, a shortcoming, a handicap. It constitutes a special discrepancy between virtual and actual social identity.

(Deacon,*et. al.*, 2005:16) disagrees with Louw’s explanation; he suggests that it is not clear how stigma specifically contributes to the reproduction of social inequalities because, even without stigmatisation, the HIV/AIDS pandemic would exacerbate existing inequalities. The social inequality that already exists in South Africa has contributed towards the spread of HIV and the pandemic, in turn, has widened the division in society between rich and poor, white and black. Not only has HIV taken advantage of entrenched fault lines in South African society – the existing inequities and inequalities - but it has also made these fault lines far, far wider. This is very apparent in ‘post-Apartheid’ South Africa, where those who have access to advanced medical care (including anti-retroviral medicines) are predominantly white and where those who have access to sub-standard care are black. In this way HIV widens the divisions that already exist. But here one must be careful: stigmatising beliefs do not always follow the fault lines of existing social inequalities, nor does stigmatisation always perpetuate inequalities. Some stigma does not lead to discrimination by others, but can instead lead to other negative effects, such as self-stigmatisation. Some discrimination is

caused by other factors and not solely by the disease; and not all stigma or discrimination actually supports the status quo. Stigmatisation could, for example, form a springboard for activism.

2.8.3 The beliefs that cause of stigma

There are certain beliefs that fuel the HIV stigma (Deacon *et al.*, 2005:26). The religious belief - that HIV is a punishment for sin - will be expanded upon in Chapter Three. Here it suffices to list the following:

- The use of condoms are a sign of promiscuity:
Cultural taboos regarding the use of condoms challenge cultural norms about procreation. One of the women who was interviewed for this work told about the reaction of the youth group when they saw condoms in her shack. They came to the conclusion that she sleeps around!
- HIV/AIDS is automatically a death sentence.
- HIV is only found in particular groups – for example, gay men - or with behaviours already labelled as deviant because they transgress moral codes, such as homosexuality, female promiscuity and unfaithfulness in marriage.
- HIV is associated with other historically stigmatised diseases, such as syphilis, leprosy or tuberculosis.
- The individual is responsible/blamed for contracting HIV. Controllability, responsibility and blame exist in an attribution hierarchy in which blame is the final step.
- HIV is viewed through the lens of ‘disease biology’: this includes mediated assessments of the biological nature of the progress, aesthetic effects, and contagiousness of a specific disease.
- HIV is viewed as an ‘epidemic’: culturally mediated assessment of the epidemiological nature of a specific epidemic (origin identified in certain groups, its differential prevalence in certain groups and its severity).
- HIV is surrounded by ‘mystery’: there are limits to medical knowledge, the degree of uncertainty, level of knowledge and efficacy of treatments associated with the disease in lay and medical contexts.
- HIV is viewed differently in different contexts depending on the person’s social status and the distribution of power. The social acceptability of expressing stigmatising beliefs towards a PWLHA is determined by certain cultural or community norms, as well as mass-media, politicians and other social and religious leaders.

- Legal rights: even where implementation of the law is not the norm, legal recognition of the rights of PLWHA and the extent of knowledge about this will affect which public reactions are considered acceptable.
- Socio-economic context: in certain resource-poor contexts where there is little state support, some beliefs about PLWHA will have greater impact (e.g. they will be a drain on resources) and create more of a focus for stigmatising ideology.

For the purposes of this research, stigma exists when the following interrelated components converge:

1. People distinguish and label human differences.
2. Dominant cultural beliefs link labelled persons to undesirable characteristics - to negative stereotypes.
3. Labelled persons are placed in distinct categories so as to accomplish some degree of separation of 'us' and 'them'.
4. Labelled people experience status loss and discrimination that lead to unequal outcomes.

(Richter,2001:11) suggests that fear, ignorance and an inability to accept any deviance from the norm constitute the main reasons for prejudice or stigma against people living with HIV. She (Richter,2001:14-18) lists some of the factors that have contributed to fuelling stigma with regards to HIV:

- Ignorance and a lack of knowledge have led to fear and irrational behaviour; the disease is viewed as a punishment for immoral behaviour from which one should disassociate oneself.
- Self interest: this includes a desire to create a chasm between healthy and 'un-healthy' people so as to reduce the possibility of personal vulnerability to HIV, and
- Media images of defenselessness and a dichotomy between those who are innocent (e.g. children infected through vertical transmission from mother to child) and those guilty (e.g. those infected through sexual intercourse).

For (Brown,2004:74) the stigma surrounding HIV and AIDS is relatively easy to explain in the African context 'because it involves sex, and sex is a no go area.' The researcher further upholds this point of view with the knowledge of her indigenous African traditional beliefs, which also tie in with the Christian ideological and doctrinal beliefs that sex is sacred and meant for marriage only. It is worth noting that, even within marriage, sexual discussions are

considered taboo:

There are many reasons for this blatant denial of the problem, not the least of which has to do with the fact that AIDS is a sexually transmitted disease. Therefore, in order to bring it to the surface for discussion is not culturally appropriate in most African cultures, particularly in groups containing both men and women. Although sex obviously is happening, if one were to judge from the discussions being held by Africans, it simply does not exist. The vast majority of Africa considers sex a very private, and off limits topic for casual conversation.

(Brown 2004:75)

2.8.4 The results of stigma

Because of stigmatisation, there has been much fear amongst societies, beginning from the core of inner family life to traditional circles, right through to small religious groupings. Due to this fear of stigmatisation, many people refrain from presenting their true health status. (Louw 2008:425) describes the stigmatisation as an ‘attitude of smugness, hypocrisy and prejudice: ... a spirit of self-righteousness develops that considers HIV patients as part of that group of people who reap what they have sown. They deserve HIV.’ This judgemental attitude towards those nameless ‘others’ is readily transferred to persons living with HIV.

As a result of this attitude, PLWHA have suffered from rejection by society:

Aids-related stigma and discrimination remain the greatest obstacles to people living with HIV infection or AIDS. Stigma and discrimination increase people’s vulnerability, isolate them, deprive them of their basic human rights, care and support, and worsen the impact of infection. Stigma and concerns about discrimination are the main reasons why people do not come forward to have an HIV test.

(Van Dyk 2008:131)

Stigma influences the choices that PLWHA make (Pillay,2008:171). Stigma also fuels the flames of the spread of the HI-virus, as people who are HIV-positive are reluctant to disclose their status to their sexual partners. Although the choice of both sexual partners to risk infecting and/or re-infecting each other cannot be condoned regardless of what forms of stigma these individuals might have experienced, it is clear, however, that individual/personal choices cannot be understood or challenged outside of the realities of life that give rise to

them – and, in this instance, the realities of stigma are stark:

In the U.S, and Western Europe, the focus on ‘risk group’ reverberated in discourse about risk and responsibility. Once placed in a risk category, individuals are separated from other sources of identity, henceforward stigmatized and degraded by definition. Creation of alterity or ‘otherness’ allows those in power to dehumanize, to scapegoat, to blame, and thus to avoid responsibility for sufferers. Accused witches, lepers and other people who are assigned the status of dangerous others, in various times and places, are believed to be morally contagious and often sexually polluting. The results are broadly similar: such people may be consigned to limbo and to social or corporeal death. The struggles of people with HIV and AIDS to resist this ‘othering’ process were charted from the beginning of ethnographic research on AIDS.

(Kalipeni *et al.* 2004:19)

Stigma not only retards the prevention campaigns, but also fosters social isolation Kalipeni *et al.*(2004:19). Infected people are more scared of isolation and rejection by society than the disease itself with its inherent effect on health. This social ostracism – and its concomitant economic consequences - have added to the suffering endured by sick people and their families:

It was only months later as I wallowed in depression that I pinned the pieces of the puzzle together, I suspect that I was fired from my job for a suspected HIV sero-conversation. Initially my manager had been quite concerned when I became ill at the beginning of the year; she had arranged for me to see the medical staff at the clinic in case I needed support to cope with my illness. Innocently I had kept her informed about my illness and that my HIV test had been negative, although I was not obliged to show her my test results. I suspect that since the organization in question did not have an AIDS policy at the time, it was easier to terminate my employment contract with them, rather than be burdened with expensive claims in the case of me getting full-blown AIDS and dying. To date I still wrestle with the pain and humiliation of my job loss because it was immediately followed by a positive HIV diagnosis.

Mboyi’s autobiography in(Karim & Karim, 2005:325-326)

HIV and AIDS have been described as ‘the ultimate biopsychosocial phenomenon’ Schider in (Lindegger & Wood, (1995:8). HIV/AIDS affects the person living with the illness at so many different levels. This multidimensional impact results in the shrinking of the person’s territory of identity and that feeling of losing touch with that valued sense of who they are (White 2007:9). The stigma surrounding HIV/AIDS is similarly multifaceted:

AIDS stigma is both a personal phenomenon, reflecting a potential threat to physical well being (that is, to one’s identity as a healthy person) and a social phenomenon, reflecting a threat to core social values involving sexual behaviour, morality and religion. Indeed, rarely has any stigma had the capacity to simultaneously threaten so many core social identities.

(White,2007:145)

Many people have died, not because of AIDS, but as a result of the fear of being judged. They have died in silence, and they have died ‘alone’ – they have felt alone although there were many people around them. They were alone in this battle of living with HIV/AIDS. Few people dared to even try and understand what they were feeling: ‘Beyond the shame of her diagnosis, Siphwe was full of fear, remembering her sister’s painful, lonely death’ (Nolene, 2007:26). Perhaps the biggest burden that the PLWHA carry is not the illness itself, but the fear of being judged, rejected and isolated.

While the multifaceted nature of the disease – and the stigma surrounding the disease –adds to the complexity of understanding HIV/AIDS, the response of infected people to the news of their status is perhaps more understandable. They are now suddenly faced with the task of making sense of what this news means for them as individuals, for their families, for their work, for their health and for all the hopes and dreams they hold for their future. Their biggest challenge, therefore, is how to live with the virus and not be overwhelmed by the multidimensional nature of the challenges that living with HIV and AIDS present.

2.9 CONCLUSION

This chapter explored the judgemental attitudes towards HIV and AIDS. These judgemental attitudes lead to stigmatisation. Stigmatisation was defined, as well as it’s causes and the impact of the stigma on the stigmatised person. . Judgmental attitudes take place within communities, within faith communities, within families and within a township society. This

chapter focused on what is happening and what should be happening in churches, what the impact of HIV and AIDS is within the families and the impact of HIV and AIDS within our township societies. Judgemental attitudes and stigmatisation have paralysed PLWHA to such a degree that disclosure of status is affected. The judgement and stigmatisation of PLWHA affects who they are, therefore this chapter also examined the identity issues and the meaning question. The following chapter investigates the theological perspective of these judgemental attitudes.

CHAPTER 3

JUDGEMENTAL ATTITUDES: A THEOLOGICAL REFLECTION ON THE NOTION OF GOD'S JUDGEMENT

3.1 INTRODUCTION

In the early years of the HIV/AIDS pandemic, some churches were not only dead silent but, when they did speak about the pandemic, they were also quite judgemental. The spiritual counselling of HIV-positive people and their loved ones raises difficult theological issues such as: 'Is HIV a punishment from God?'; 'Am I a bad person because I am HIV-positive?'; and 'Will my HIV status therefore negatively influence my karma?' (Van Dyk, 2008:322). There are Scriptures - such as Numbers 12:14 and Numbers 21:2-9 - that can be used to justify these theological positions.

This chapter focuses on getting clarity on what is meant by the notion of God's judgment. Since HIV is seen as a disease that predominantly affects those who lead promiscuous lives and is thus also seen by many as punishment from God, how to understand the link between the judgment of God and HIV. Furthermore HIV/AIDS challenges current understanding of sickness and disease. The question arise,"when is one sick, and from a spiritual and Biblical perspective what is the sickness in the HIV/AIDS pandemic. Attention will also be paid to the doctrine of judgment; the metaphors of God as Judge; and the view of illness in both Old and New Testaments. The rationale behind this approach is twofold. First, we need to hear what the Bible (both Old and New Testaments) says about God the judge; second, since HIV is seen as punishment from God, the view of illness in both Testaments will bring balance to the argument. This chapter will conclude with an examination of the question: 'Is HIV/AIDS therefore a punishment from God?'

3.2 THE DOCTRINE OF JUDGEMENT

(Parker 1973:125) argues that many people do not believe in a god who acts as our Judge. In general, people prefer to hear about God as our Father, Friend and Helper, and of a God who loves us despite all our weakness, folly and sin. If one mentions the image of God as judge, one is greeted by frowns and the shaking of heads. Scripture nevertheless does indeed contain images of God as Judge. For instance,(Genesis 19) when Abraham was interceding for Sodom, God was about to destroy the city. Adam and Eve were judged: they were expelled from the garden and curses were pronounced on their future earthly life (Gen 3). God judged the

corrupt world of Noah by sending a flood to destroy mankind (Gen 6-8). God judged the Israelites for their unfaithfulness to Him, after their entry into Canaan, (Chronicles 21) before falling under the dominion of other nations. In Babylon, God judged both Nebuchadnezzar and Belshazzar for their impiety. (Daniel 15:18-25)

(Packer 1973:127) suggests four reasons why God (and /or Jesus) is a Judge:

- *The judge is a person with authority*

In the biblical world, the king was always the supreme judge: he was the supreme ruling authority. On that basis, according to the Bible, God is the judge of his world. As our maker, He owns us, and as our Owner, He has a right to dispose of us. He therefore, has the right to make laws for us, and to reward us according to whether or not we keep them. God is both the Lawgiver and the Judge.

- *The judge is a person identified with what is good and right*

The modern idea that a judge should be cold and dispassionate has no place in the Bible. The Biblical judge is expected to love justice and fair play and to loathe all ill-treatment of one person by another. An unjust judge is one who has no interest in seeing right triumph over wrong and is, by biblical standards, a monstrosity. The Bible leaves us in no doubt that God loves righteousness and hates iniquity and that the ideal of a judge wholly identified with what is good and right, is perfectly fulfilled in Him.

- *The judge is a person of wisdom and able to discern truth*

In the biblical world, the judge's first task is to ascertain the facts of the case before him. There is no jury: it is his responsibility - and his alone - to question, cross-examine, detect lies, to pierce through evasions and establish how matters really stand. When the Bible pictures God judging, it emphasizes His omniscience and wisdom as the searcher of hearts and the finder of facts. Nothing can escape Him; nobody can fool God. He knows everybody and judges everybody as they really are. When Abraham met the Lord in human form at the oaks of Mamre, God gave Abraham to understand that He was on the way to Sodom to establish the truth about the moral situation there:

The Lord said, because the cry of Sodom and Gomorrah is great, and because their sin is very grievous, I will go down now, and see whether they have done altogether according the cry of it, which is come unto me, and if not I will know.

(Gen 18-

20)

Whatever happens, God will know. Moreover, His judgment is according to truth: factual truth as well as moral truth.

- *The judge is a person of power and able to execute sentence*

The modern judge does no more than pronounce the sentence; another department of the judicial system then carries it out. In contrast, God is His own executioner. As He legislates and sentences, so He punishes. All judicial functions coalesce in Him.

The belief that God passes judgement on the lives of his human creatures is important for Christianity, as well as for most of the world's religious traditions (*New Dictionary of Theology*, 1988: 358). In the Old Testament, Divine judgement commonly takes the form of earthly blessing (harvest). It is based on a national response to God's commands and disobedience is punished (plague, earthquake and exile). (Leviticus Chapter 26 14-46) The New Testament, however, presupposes the belief - developed further in apocalyptic literature - in a great judgment at the end of history.

In the New Testament a doctrine of judgement is based on the following elements:

(Ferguson, Packer, Sinclair and Wright 1998:358, in *New Dictionary of Theology*),

- *All people will be judged*

This includes both the living and the dead (Acts 10:42); and Christian and non-Christian (Rom 14:10-12). This future judgement relates to Christ's final coming (Mk 8:38; 1 Cor 4:5; Thes 1:5-10).

- *Judgement will be meted out by God according to works performed by His people.*

This idea is clear in texts such as Mt 16:27; Rom 2:6; and Rev 22:12. This judgement does not conflict with justification by grace through faith. Although justification is a gift of God's free grace, it involves the obligation to work out our new status in practice. Thus, at the final judgment, a person's work will be evidence of the reality of the faith through which that person will be saved.

- *The Final Judgement will be a moment of division between those who are revealed to truly belong to Christ and those who do not.*

The Final Judgement will not be arbitrarily imposed from on high. Rather, the verdict of the Final Judgement will underline and make known the self-judgement that men and women choose during their present lives.

- *People bring judgement upon themselves by the choices people make and by the way they respond when confronted by Christ and His Gospel.*

This idea of a present self-judgement is especially prominent in John's Gospel (Jn 3:19-20).

- *Salvation and condemnation are best understood in terms of relationship or non-relationship to God.*

The criterion by which people's destinies will be determined is twofold: first, their failure to worship and serve the God revealed in the created order; second, their

attitude to Christ and their relationship to Him, of which their deeds are evidence. People's ultimate destinies consist in being either in God's presence or excluded from God's presence.

(Guthrie 1981: 848) suggests that although the idea of judgement is prominent in the Old Testament, it is judgement on earth in the present life of the nations. There is little awareness of judgement after death and, where it occurs, it is restricted to Israel.

In the intertestamental period there is evidence of a development towards a more individual approach, although the collective approach is still as dominant as it was in the Old Testament. In the book of Enoch there are frequent references to judgement and the judgement day. Yet neither in the Old Testament nor in the intertestamental literature is there any specific reference to the Messiah in the office of judge, unless the passage in Daniel 7:13ff is understood in this way. In the New Testament, the gospels make a distinctive contribution to the theme of judgement in their strong teaching about individual accountability and in the way in which they portray Jesus as judge."

The motif of God as judge is thus woven throughout the Scriptures:

God discriminates between right and wrong among men and angels according to the criterion of his own law, and pronounces a verdict issuing in eternal weal or woe.

(Shepherd 1973:

357)

In the ultimate sense, God alone is lawgiver and judge (Ja 4:12; Ps 50:6). God searches the hearts (Jer 17:10); weighs people's actions (1 Sam 2:3); avenges wrong (Heb 10:30); and rewards the righteous (Mk 10:30). The scope of judgement is such that only the omniscience of deity is adequate to it. God's love of righteousness guarantees that judgement will be according to truth (Gen 18:25; Ps 96:13; Rom 2:2). Although God the Father is the Judge (1Pet 1:17), He exercises this judgement through the Son, in continuity with the promises and threats that He made during his earthly ministry and brings his mediatorial reign to a successful completion. Jesus' advent was for salvation (Jn 3:17-19), but since redemption is inseparable from condemnation of the wicked, Jesus is also said to have come for judgement (Jn 9:39). Angels and saints are associated with Christ in the Final Judgement (Mt 25:31; 1 Cor 6:2-3). All people without exception will be judged. When the Judge appears, every eye shall see Him (Rev 1:17) and all must appear before Christ's judgment seat (2 Cor 5:10). For this purpose, the earth and the sea will give up their dead (Rev 20:13).

Since God is no respecter of persons (1 Pt 1:17), there will be no preference based on social, economic, or ethnic considerations. Distinction will be made only in view of works done in the body, whether good or bad (2 Cor 5:10). For this reason, the eternal destiny of the individual is fixed at death and does not change in the intermediate state before the final judgement. And finally, both human beings and preternatural beings are subject to this judgement (2 Pt 2:4).

- *Certainty and the public promotion of judgement*

There are anticipations in this present life of the judgement to come. The Father's discipline provides an escape from the final condemnation (1 Cor 1:32). Christ's discipline, administered through the office-bearers of the church, serves similar ends (1 Cor. 5:3-5).

People receive rewards and punishments that are not be construed simply as the natural consequences of good or evil behaviour, although this Divine providence serves the purposes of moral order. God gives the wicked up to a degenerate mind (Rom 1:28), while granting prosperity with the promise of eternal life to Christ's disciples (Mk 10:30). The perplexing discrepancies observable in this life are removed in the Final Judgement. More profoundly, believers already enjoy eternal life together with peace of conscience, while the wrath of God and hardening in sin rest upon the reprobate (Jn 3:36).

As the time of Final Judgement in absolute terms is unknown (Mt 24:36), it is not a present immanent process, but takes place on a day appointed by God (Acts 17:31) at the end of calendar history. The simultaneous redemption of God's covenant and destruction of their enemies was evident in the time of Noah, Moses and the restoration of Israel in the Old Testament point to the simultaneity of the Final Judgment of the just and the unjust in the New (Jn 5:29). For believers, resurrection is public vindication of their justification secured in the resurrection of Christ (Rom 4:25). The Resurrection is coincident with the return of Jesus from heaven to visit destruction on the disobedient and for the obedient and good to be glorified together with His Saints (2 Thes 1:7-10). The appointed Day of Judgement (1 Jn 4:17) is a day of wrath (Rom 2:5) and redemption (Eph 4:30). The certainty of judgement to come (Heb 9:27) gives rise to the urgency of the call to repentance.

The Final Judgement is not to be internalised but is public; it corresponds to the public revelation of Christ, the resurrection and the cosmic cataclysm. The purpose of the Final Judgement is not to ascertain the future state of humankind but to ratify the judgement determined at death and to display the glory of God in righteousness and holiness.

Guthrie (1981: 859) draws distinctions between non-believers and believers in relation to judgement. God's judgement of the ungodly is more widely accepted and almost axiomatic.

If we look specifically at Paul's writings, we see that the majority of references to judgement are in relation to believers, and the minority to non-believers. Paul dwells on the certainty of retribution than upon the details of judgement. Although judgement may be seen to be already at work in this life, Paul never suggests that it is completed in this life. For this reason, Paul concentrates his attention on the Final Judgement. In a few cases, Paul may have regarded death itself as a punishment but, since death is universal, he evidently recognises death and judgement as separate concepts. Paul regards the judgement day as the focal point of God's judgement on sin and sinners. He says very little on the nature of judgement facing non-believers, although his teaching has been interpreted to point to annihilation or to universal salvation or to eternal punishment. What we may deduce in a general sense about the nature of the judgement of non-believers is that it involves both loss of worthwhile existence (especially in separation from God) and positive punishment, although Paul says little about the latter.

(Brown 2004:361) suggests that it is sometimes necessary to examine whether or not human behaviour conforms to a certain standard. Such examination, together with the ultimate assessment and, if necessary, condemnation, is expressed in the New Testament by the extensive word-group connected with *krino*, to judge.

How then is God viewed as Judge in the Old Testament?

3.2.1 The metaphor of God as Judge: An Old Testament perspective

(Brueggemann 1997:234-238) observes that the metaphor of Yahweh as Judge is predominant in Israel's life and speech. Yahweh is committed to a rule of just law; Yahweh is one who can be counted on to intervene on behalf of those who are treated unjustly, or against what is regarded as inequitable treatment according to Israel's radical notions of justice, which stand against the exploitative 'realism' of much self-serving, self-aggrandising justice.

3.2.1.1 Yahweh as Judge of the whole world

Yahweh's sphere of judicial administration extends to all nations. In the end, all nations are subject to Yahweh's justice. Yahweh exercises judicial control over the affairs of the nations and metes out judgement according to His own passionate justice (Amos 1-2; Is 13-23; Jer 46-51; Ez 25-32).

3.2.1.2 Yahweh the Judge of Israel

Israel relies heavily on the role of Yahweh as Judge. The law - which informs Yahweh's

judgment - is a law of well-being for all, which Yahweh enforces. Yahweh's equity does not simply mete out 'just desserts'; it includes active intervention for those who are weak and powerless (see Psalm 96:10, 13) . Yahweh's judgement has a severe side. Sometimes Yahweh is deeply affronted by injustice and will strike back at those who affront his passionate commitment to justice. Moreover, Israel's testimony regarding Yahweh's justice contains an element of danger: on occasions, Yahweh's response appears to be disproportionate to the affront. In the context of Genesis 18-19, Abraham had to intervene (Gen 18:25). The recognition that the righteous may be destroyed with the wicked indicates Israel's awareness of potential disproportion in Yahweh's severity as Judge.

3.2.1.3 *The shepherd metaphor of Judge*

The grounds for intimate personal appeal are also grounds for Israel's belief that this Judge will call to account large social forces that practice exploitation (Ez 34:17-22). Yahweh will act as a good Shepherd of his flock, Israel.

3.2.2 The metaphor of God as Judge: A New Testament perspective

Many people have the erroneous belief that the Old Testament reveals a God of wrath, whereas the New Testament reveals solely a God of love. God is a God of justice, and this is evident in both the Old and New Testaments. God's goodness and severity are both revealed in the Old and New Testaments. These two attributes cannot in fact be separated: God's love demands his wrath. God does indeed care; He is humankind's true God and He has called us into fellowship with Himself. Thus, our rejection of that fellowship leads to ruin. Jesus, as the proclaimer of the words of eternal life, reveals God's wrath. Jesus - as John the Baptist had done before Him - calls us to repent in view of the inevitable wrath to come, which would fall upon the unrepentant.

There are many other instances in the New Testament of God as Judge. For example, in 1 Peter 1:17 God is portrayed as Father, but at the same time the writer also emphasises God's as Judge before whom men must live in fear. Hebrews 12:29, echoing the words of Deuteronomy 4:24, speaks of 'Our God [meaning the God whom we Christians worship] is a consuming fire. Herod Agrippa - the murderer of the apostle James and the persecutor of the apostle Peter - so gloried in the outward apparel of his royalty and was so corrupted by human pride - was struck suddenly by a devastating mortal disease (Acts 12:22-23). Similarly, Ananias and Sapphira are punished by sudden death for tempting the spirit of the Lord, just as the Israelites had tempted God in the wilderness and were destroyed by serpents (Acts 5:9; 1 Cor 10:9).

The New Testament thus contains sayings and deeds of terrible severity. These are just as much part of God's revelation made known in Christ Jesus as those sayings and deeds of Jesus that so conspicuously display God's love and mercy. If we concentrate our attention only upon passages of the Gospel where the Divine Fatherhood is proclaimed, we preach a debilitated Christianity one which does not, and cannot, do what Christ came into the world to do: namely, to save humankind from the wrath to come. If we eliminate the wrath or disgrace of God, we also eliminate His grace. Where there is no fear, there can be no rescue. Where there is no condemnation, there can be no acquittal. Love must be based on justice, or else it degenerates into mere affection or sentimentality.

The certainty of God's judgement was a major assumption behind the sternness of John the Baptist's preaching (Mt 3:7ff; Lk 3:7ff), although absent from Mark's account. Jesus makes the same assumption when He alludes to God's future judging activity. (Mt. 7:1,2, 11:22-24). There has been a tendency to play down this aspect of Jesus' view of God, but the importance of it cannot be assessed purely on the number of times the theme occurs. In one of his parables, Jesus contrasted an unjust judge with God's vindicating judgement (Lk 18:7). Moreover, in John's gospel, he positively associated himself with God's judging activity (Jn 8:16). Similarly, for Paul, the idea of God as Judge was an integral part of his gospel (Rom 2:16). Indeed, there was no doubt in his mind that God would judge the world (Rom 3:6). Paul speaks positively about God's judgement seat (Rom 14:10) and uses it as a basis for his condemnation of Christians who were judging their brethren.

Thus in the New Testament, no questions were raised over this judgement theme, for the idea of God as Judge was assumed everywhere. But true sovereignty would be unintelligible apart from some provision for the accountability of the subjects to the king. The king concept is closely allied to that of judge (Guthrie 1981:81). It is assumed as right and proper in the New Testament that the Divine King should exercise His prerogative of judgement. Admittedly, there is a certain element of severity about this aspect of God (Pet 2, 4ff). Paul, who admits God's severe side, is nevertheless careful to link it with his kindness (Rom 11:22).

In the Apocalypse, it is God who passes judgement against the symbolic Babylon. Indeed, throughout the book it is the One on the throne who subdues all rebellious elements.

In Revelation 19:11-22, one finds various broad themes intertwined, namely:

Christ as an Agent of God as Judge

In terms of imagery, one immediately notes that in Revelation 19: 11-16, two images are brought forward from the 'inaugural vision' of Revelation 1: 14-16, having been underlined once already as to their judgemental significance in the letters to the churches at Pergamum

and Thyatira. These images are the sharp sword seen coming out of Christ's mouth and his eyes 'like a flame of fire.' Similarly, in Revelation 1:14-15, as in Revelation 19, Christ's fiery eyes are given prominence in the description of His appearance. This imagery is clearly to be interpreted as an indication of the searching gaze of the omniscient Christ: 'I am He who searches the minds and hearts' (Rev 2:23). These two elements in the description of the returning Christ are to be linked with a key Christological motif in the book of Revelation.

This motif develops Christ's role as the witness whose testimony before God is instrumental in convicting the guilty. In Revelation 5, on the basis of his sacrificial death, Christ receives the authority from God to reveal the contents of the seven-sealed document in the heavenly courtroom.

The central theme of Revelation 5-6 is that judgement is God's sovereign activity of bringing into the open (through Christ) the true character and disposition of human beings, which clearly stands as common ground between Revelation and the fourth gospel (Jn. 3:19, 9:39).

The objects of judgement

(Mealy 1992: 65-74) divided this title into two contexts:

1. The *parousia* as Judgement on Babylon

The following statements can be made about the destruction of Babylon. It will be associated with the judgemental aspect of the *parousia*, it will be at the hands of the treacherous beast and certain hostile kings (Rev. 17:16), and the 'kings of the earth' will survive both to witness and regret Babylon's destruction at their hands.

2. *parousia* as judgement on humanity at large.

In Revelation 1:5, Christ is named 'The First Born of the Dead, and The Ruler of the Kings of the Earth.' The Kings of the Earth head the list of ranks and classes of humankind who are terrified in the presence of the Enthroned One and the Lamb.

The first representation of the *parousia* as judgement assures the readers that God and the Lamb will come again and that humanity's overdrawn account of hidden sin will be revealed. This overview of the metaphor of God as Judge as evident in both the Old and New Testament should demonstrate how easily this can lead to the assumption that PLWHA are being 'punished' by God. This notion gives rise to specific theological questions for PLWHA and their immediate families. Since HIV/AIDS is an illness that is seen by many as the result of a promiscuous lifestyle, two theological questions immediately arise: 'Is HIV a punishment from God?' and 'Am I a bad person?' (Van Dyk, 2008:322) Just as an understanding of the metaphor of God as Judge was necessary, so too it is appropriate here to look at the Biblical perspective of illness/disease from both the New and the Old Testaments. Is there sufficient evidence in the Old and New Testaments to support the belief that HIV is a punishment from

God?

3.2.3 The view of disease/illness in the Old Testament

Although sickness and disease were as much a part of Biblical life as they are today, the language used to describe these conditions was different from current medical terminology. Biblical description and archaeology nevertheless do enable identification of some of the diseases that afflicted the ancient Israelites (Arnold & Williamson, 2005:895).

1. *Views of sickness and disease*

The Hebrew root word most commonly used in the Old Testament for sickness and disease is *hlh*, which carries a broad range of meanings. It can refer to standard medical conditions of ill-health, but also to states of weakness, tiredness and pain. Similarly, the historical books of the Old Testament use a Hebrew term for healing (*rp*) that refers to restoration or making whole in a variety of contexts, including healing a sick body (2 Ki 20:5), repairing a broken altar (1 Ki 18:30) and restoring infertile land (2 Ki 2:19-22). Thus, healing may be needed for various problems, deficiencies or imbalances. Unlike the modern situation, in which sickness sometimes is assumed to have only physical or possibly mental origins, the Old Testament concept of sickness was holistic: it recognised that it could also be of moral, spiritual or relational origin.

As such, sickness and disease were viewed as being interconnected with all aspects of life and health. For instance, Amnon is described as distraught to the point of illness and visibly haggard because of his lust for his sister Tamar (2 Sam 13:1-4). Modern medicine has sometimes forgotten the psychosomatic aspects of illness and has rejected spiritual aspects, but the Old Testament perspective on illness and disease is multifaceted and holistic. This understanding must be kept in mind when we examine specific instances of sickness and disease in the historical books of the Old Testament.

2. *Sickness and disease as punishment*

The Pentateuch was clear that sickness and disease could be God's punishment on Israel. God declared:

But if you will not listen to me and carry out all these commands, and if you reject my decrees and abhor my laws and fail to carry out all my commands and so violate my covenant, then I will do this to you: I will bring upon you sudden terror, wasting diseases and fever that will destroy your sight and drain away your life.

(Lev. 26:14-16; Deut. 29:22)

The historical books of the Old Testament record many instances of these curses being

fulfilled through God's affliction of the righteous. The Sovereign God of Israel was in control of sickness and health: 'The Lord brings death and makes alive, he brings down to the grave and raises up' (1 Sam 2:6).

There are many other instances of sickness and healing in the Old Testament. Joshua's farewell address reminded Israel of these curses and blessings (Josh 23:15-16; 24:20). David's sin with Bathsheba led to God afflicting his son with an illness that led to death (2 Sam 12:13-15). When King Jeroboam stretched out his hand against the prophet, God shrivelled it up, and then restored it when the king asked for healing (1 Ki 13:4-6). Other cultures also were punished. The Philistines were afflicted with tumours because they had seized God's ark (1 Sam 5:6-12). Although the cultures around ancient Israel saw health and disease arising out of a cosmic battle between good and evil spirits, Israel held that God alone had the power to heal (Ex. 15:26). For instance, when Naaman of Aram brought his request for healing from leprosy to the king of Judah, the king replied: 'Am I God? Can I kill and bring back to life?' (2 Ki 5:7). Thus throughout the Old Testament, God's power over nature extended to God's ability to inflict sickness and disease on those – both Israelite and Gentile - who transgressed His ways.

3. Sickness and disease as part of life

Although the historical books record that sickness can be a punishment for evil deeds and that health can be a reward for righteousness, they do not lend themselves to rigidly applying this principle. Such application did indeed occur in Israel, as is reflected in the book of Job and later in the Gospels (Lk 13:2,4; Jn 9:2). Many accounts in the historical books note that sickness and death occurred without any hint of censure, thus could scarcely be seen as any form of 'punishment' from God. Eli became frail and blind as he aged (2 Sam 3:2). Hearing that Israel had been defeated in battle, his sons killed, and God's ark captured, Eli fell over, broke his neck and died (1 Sam 4:14-18). The passage notes that Eli was an old man and heavy, but it does not suggest that his death was a result of Divine Judgement. Similarly, his daughter-in-law dies in labour, apparently brought on by her grief, not by God. Later, we learn that Jonathan's son, Mephibosheth, was lame in both feet due to an accidental fall (2 Sam 4:4). This misfortune is not blamed on anyone's sin - not his, or his father's or his caretaker's - it just happened. Similarly, Naomi's husband and two sons are simply reported as having died prematurely, with no mention of God's involvement (Ru 1:3-5). As David grew old, he became frail and sickly (1 Ki 1:1). Facing death, he told Solomon: 'I am about to go the way of all the earth' (1 Ki 2:2). Elisha was not under God's judgement when we read that he was suffering from the illness from which he died (2 Ki 13:14).

Just as sickness, disease and death are not always signs of unrighteousness, so also good

health and long life are not always signs of righteousness. The lack of a simple connection between sin and sickness is more fully explored in the books of Job and Ecclesiastes, but its foundation is laid in the narratives of the historical books. The lack of a simple connection between sin and sickness in the Scriptures – both Old and New Testaments – lead (Arnold and Williamson 2005: 897) to conclude:

God's grace, faithfulness and mercy led to His actions, not a simple rule of cause and effect. Sometimes as Jesus later stated explicitly, injury and death result from living in a fallen world and being in the wrong place at the wrong time (Lk. 13:1-5).

3.2.3 The view of disease/illness in the New Testament

(Thomas 2002: 297) suggests that the New Testament identifies three primary causes of illness and/or infirmity: God, the sin, and the devil and/or demons. For the purpose of this study, this work will only examine God and the sin, because HIV is seen as a disease that is caused by immoral lifestyle, and God is punishing that lifestyle through HIV.

- **God**

God is described as the direct or indirect source of infirmity by the majority of writers in the New Testament, with the exception of Mark and Matthew (Thomas 1998: 297).. The latter two writers present God as a pedagogical device, an instrument of punishment, a source of sanctification, a means of spreading the Gospel or an instrument of salvation.

Johannine literature appears comfortable assigning the origin of certain illnesses to God. Jesus attributed the condition of a man to God when he said: "Neither this man nor his parents sinned" (Jn. 9:3). Paul and James also assign illness to God: for them, some illnesses function as pedagogical chastisement of those believers who are guilty of specific sinful behaviour. Similarly, Divine intervention in the form of illness sometimes occurs in order that the Gospel might be proclaimed. For instance, , the purpose of the thorn in Paul's flesh was to aid him in his struggle against becoming arrogant on the basis of the extraordinary heavenly revelations that he received. Luke is also not reluctant to attribute an infirmity to God. In fact, the first infirmity attributed to any source in the Gospel is attributed to God. The message that Luke sends to his readers is that God has the ability and willingness to afflict. Unbelief in response to a (prophetic) word from God is the reason for the affliction that God sends upon Zechariah, an otherwise upright individual. That such a devout person could be punished in this way cautions the reader to be very careful to respond to a word from God in an appropriate manner. The book of Acts, like the other New Testament narratives, is not

reluctant to attribute the death or an infirmity to God. Saul and Elymas are blinded as a result of an encounter with God. The reasons for afflictions sent by God include an attempt to counterfeit the activity of the Holy Spirit (in Ananias and Sapphira, Acts 5) while Herod, Elymas and Saul opposed the Gospel (Acts 9)

(Thomas 2002: 298-) lists three ways in which God becomes the source of illness and death in the New Testament:

1. Infirmity and death is used as a pedagogical device

On more than one occasion, and by more than one writer, God is described as sending an illness or death in an attempt to teach those identified as part of the Christian community that sin must not be tolerated but dealt with appropriately. On these occasions, the affliction appears as God's way of calling the believer's attention to their sins. While these situations might indicate a causal relationship exists between sin and affliction, there is no suggestion that the affliction is inherent in the sin. Rather, it is either implied or stated explicitly that the affliction comes directly from God Himself as a result of the sin. The affliction's pedagogical purpose is to draw the attention of the individual or community to the sin in question and the need for repentance.

2. Infirmity and death as punishment

In cases where illness or death is the result of God's punishment, they are said to have resulted in relation to a variety of reasons. John 5:14 indicates that the infirmity of the man at the pool of Bethesda is the result of sin and the continuation of sin might result in a worse physical calamity. While Jesus' warning about "something worse" might serve a pedagogical function, there is no suggestion that the previous infirmity played such a role.

3. Affliction and the spread of the Gospel

God is presented, not only as one who sends affliction as a teaching or punitive device, but also as one who can use affliction to further the spread of the Gospel. Two New Testament texts present God as using infirmity in precisely this manner. Both the blind man in John 9, as well as Paul, who suffers from a weakness in the flesh in Galatians 4, experience infirmity in order that God might accomplish his purpose through the revelation of his message. With the blind man, the reader is told that his condition exists in order that the works of God might be revealed.

- **Sin**

Sin is depicted in several New Testament documents as an origin of illness. On each occasion (Ja 5,1; Cor 11; Jn 5), the clear assumption is expressed that the individual who suffers an infirmity owing to sin would know of the presence of sin and its nature. Despite the fact that

someone else (a leader of some sort) indicates a knowledge of the presence of sin, none of the texts examined suggests that the sufferer would be unaware of the sin or be surprised by such an identification. The individual who bears the infirmity would appear to know full well the nature of the sin and, consequently, would play a crucial role in the discernment process. Thus, the admonitions of James to 'confess', of Paul to 'examine', and of Jesus to 'stop sinning', reveal that the believer's first step in discerning the origin of an illness is to examine self to discern whether sin may be the origin of a particular infirmity. For instance, Jesus attributed the condition of the blind man to sin and warned of an additional (worse) illness if the man continued to sin: 'He said to the man at the pool: See you are well again. Stop sinning or something worse may happen to you' (Jn 5:14). Similarly, James 5:14-16 makes very clear that some illnesses are a direct result of sin. In the cases where sickness and sin are linked, the confession of that sin is required. Paul sees the connection between sinful behaviour and sickness or death.

In the light of the evidence from Old and New Testaments regarding the link between illness, sin and punishment and given that many people regard HIV/AIDS as a result of promiscuity or having lived a 'sinful life', can we conclude that HIV/AIDS is a punishment from God? Or, as (Louw 2008:428) puts it: 'Is HIV God's chastisement for the promiscuous lifestyles so evident in modern society?'

3.3 IS HIV/AIDS A PUNISHMENT FROM GOD?

The attempt to answer this question forces the entire debate back to the question of our concept of God. Who is God? (Louw 2008:428). Richards, answers the question: 'Who is God?' by pointing out that 'God is a judge, who is now judging people for their sexual immorality' (Richards 2000:340,). According to Richards, who regards the HIV pandemic as a punishment from God, Christian doctors and ministers have yielded to social pressure by attempting to leave all moral considerations outside their consulting rooms. He believes that faithful application of Biblical principles to such an epidemic will have many God-honouring benefits, whereas being blind to the spiritual implications of the epidemic has prevented our society from removing the scourge from its midst. Richards regards both heterosexual and homosexual immorality as a mark of God's judgment. Richards uses Romans 1:24-26 as evidence that HIV is punishment from God., As men and women reject God's authority over their lives, God releases them from these beneficial controls ('giving up') so that they do 'what is against the nature' (v. 26), using their bodies in shameful ways (v. 27) for which they were not designed.

(MacFague 1997:117-118) disagrees. For her, God's primarily involvement is not in the

negative business of judging wayward individuals but in the positive business of creating, with our help, a just ecological economy for the well-being of all Her (God's) creatures. God is the one who establishes justice, not the one who hands out sentences. She (God) is concerned with establishing justice now, not with condemning in the future.

(Chilton 1987:207) regards the appearance of HIV/AIDS 'a disease that is both selective in terms of abominable actions and has the demonstrated capacity to flow out into the population at large, it is a manifest signal that Someone (God) is knocking on the cosmic door.' Chilton suggests that when people reach a certain level of immorality, punishment ceases to be particular and becomes national. When the civil order has lost its ability to act for God, God then acts against that order:

We are watching an eschatological development take place in our midst, as history progresses, blessing and cursing becomes more pronounced and less common....God is God, the All-Controller, He can turn a specific judgement into a general judgement on the whole social order, if He wishes, all it will take is a sneeze.... Wherever a society refuses to exact the required death penalty, there God exacts the death penalty on that society. Societies have fallen in great numbers for their defiance of God, and they shall continue to fall as long as their violation of God's order continues.

(Chilton 1987:43)

Both Richard's and Chilton's stance call for what (Louw 2008:428), calls a 'causal explanatory model. In this model, God is automatically the callous despot who treats people like hostages. God has a computer, where everything is programmed according to the law of providence and prediction. This kind of God is one who always has a stick in His hand, waiting for somebody to make a mistake, and whose only interest is to punish.

We need to make an important distinction between punishment for an action and the consequences of an action. Consequences are the natural outcomes of certain actions - the end result - to which several factors will have contributed. The outcomes may be good or bad for the person or persons involved, but everything will have happened within the way the world goes, and in the freedom that God gave it. But to speak of an event as 'punishment' from God attributes to God a requirement for retribution - as if divine morality were based on 'an eye for an eye and a tooth for tooth' principle, and thus ready to pursue retribution by disrupting or intervening in human or natural life.

The following case study (WCC study document, 2004: 27) tries to explain the way in which

actual events always involve a complex constellation of causes and consequences, rather than a single cause and effect, and thus underscores the problems and limitations involved in labelling consequences as ‘punishment’:

A girl from the hill tribes of Northern Thailand leaves her family to find a job in the big city of Bangkok. Her parents urge her to do so, because - as subsistence farmers whose produce commands a very low price - they cannot survive without additional income. In Bangkok, the girl is put into a brothel where many girls are held in captivity by the wealthy owner. Most of the money from the clients goes to him, but the young girl does manage to send small amounts of money to her family at home. The brothel is regularly visited by rich men from Bangkok and by sex tourists from abroad who abuse the girls for their personal pleasure. The HIV infection rate among the girls is very high, as many of the clients are HIV-infected and pass the virus on to them - and they, in turn, pass it on to other clients.

Clearly, there are many factors at work here; it is not a simple process of cause and effect. Sinful structures in society are involved: economic conditions - which virtually force the parents to sell their daughters into slavery - and sinful behaviour on the part of many people, including the brothel owner, clients and tourists, who regard the girls as commodities or objects rather than as human beings. At each point in the story, relationships are broken and disrespected. This shows why it is socially, ethically and theologically impossible to link sin directly with punishment. If the girl were infected with HIV by a tourist looking for sex, that would be a consequence, albeit a bad one but, given the circumstances of her background, it cannot be regarded as ‘punishment’ for being a prostitute. On the other hand, if the tourist who was out looking for sex caught the infection from the girl, that would again be a consequence of the encounter. But what circumstances have led to his behaviour, or have discouraged him from living out his sexuality in a responsible way in a mutually faithful relationship? While this is not to say that some actions are better than others, or that, to some degree, people are always responsible for what they do, but it does suggest that once the background and all the circumstances of an individual are understood - as God does - then labelling certain consequences as ‘punishment’ for certain action is inappropriate (WCC study document 2004: 28).

It was a common inference in Jewish thought that misfortunes are always the direct results of sin (Job 47), but Jesus challenges this notion. In John 9:3, Jesus’ disciples tried to link the disability of a blind man with sin. Jesus replied: ‘neither this man nor his parents sinned, but that the works of God should be revealed in him.’ In stark contrast to condemnation of

sinners, Jesus was often seen with 'sinners': he came to save and proclaim the forgiveness of their sins. In John 8: 1-11, where a woman was 'caught in adultery', the scribes and Pharisees pointed to the law of Moses whereas Jesus points to introspection: let he who is without sin judge her. And when none did, Jesus answered: 'I do not condemn you either, go and sin no more.' (Chilton 1987:90) regards this as denying the 'sinners' the need to repent. His concern is that when the churches in San Francisco were telling the homosexuals, who were turning to the churches, not to worry, these churches were treating gay people as 'sinless', thus denying them the need for repentance. Chilton asserts that in doing so, the church has failed to speak the truth about HIV and AIDS that convicts the world of sin, and of righteousness and judgement. Instead, we have been silent about the demands of God's law over every area of life. But if we look more closely at John 8 we see that Jesus did not treat the woman as a sinner: He treated her with dignity, and, without condemning her, gently said: 'Go and sin no more.'

We nevertheless still cannot rule out the fact that God is a Judge (Louw, 2008: 431). Human beings should somehow be held responsible for their actions as there are inevitably consequences in every action. In some cases, HIV is indeed related to irresponsible and sinful behaviour. The notions of guilt and sin thus cannot be left out of the HIV discourse. For instance, when promiscuity and rape are the issue, the notion of punishment does surface and becomes vital for a theological and ethical discussion. God is indeed a Judge and, when one talks about God as judge, this brings with it the fear of being punished. (Louw, 2004: 344). But one should not 'fear' God in the sense of trepidation; rather the 'fear of God' means that at all times one should take Him into account and have awe and respect for Him. The knowledge that human behaviour is determined by God's norms and is assessed in the light of scriptural values, means that people are moral beings. Fear of God leads to responsible behaviour and an ability to discern right and wrong. God as judge means that people have received the stewardship for which they are accountable. God as judge also guarantees God's justice.

(Louw 2008:415) suggests that a market-driven culture and a theological approach that is based on cheap triumphalism is inadequate to address or cope with the HIV/AIDS pandemic. He urges us to rethink our theological paradigms. (Louw 2008: 428) suggests that, as a theological problem, HIV offers the church two possibilities:

1. *The causal explanatory model*

God is a despot who treats people like hostages. God's computer has programmed

everything according to the law of providence and prediction (Louw 2008:429)

2. *The hermeneutical, interpretive model*

What is at stake here is the essence and quality of an encounter with God in terms of the human quest for meaning in suffering. The problem does not revolve primarily around sin, but around life and its meaning. It poses questions about God's relatedness and engagement with human suffering. In this case, the fundamental theological questions to be posed are: 'How and where is God in this drama of the HIV pandemic?'; 'Is punishment the last theological word in the debate or should we move to categories of empowerment and life rather than discreditation?'; and 'Does a sin and judgemental approach reflect the fundamental understanding of God in Scripture?'

These questions raise the notion of an adequate theological anthropology. Louw (2008: 429) suggests exploring the following possibilities:

The creational paradigm: the relational Creator and the notion of acceptance

The WCC Study Document (in Louw, 2008: 429) argues that, within the theology of creation, human beings have the capacity for relationships and freedom. Within this relational model, God is not only open to the joy and flourishing of creation, but its viciousness and disasters also make God vulnerable to pain. The emphasis now switches from interpretations of God's punishment to God's creative involvement and embracing providence. If we accept the paradigm that creation and the world are the body of God, this should help the church to respond to the HIV/AIDS pandemic with acceptance rather than with stigmatisation. Acceptance moves from simple avoidance of being judgemental to embracing who we are individually. But such a paradigm is inadequate because it still leaves us with the notion that God somehow is the instigator of the problem. The creation paradigm still confronts us with question such as: 'If God is indeed the Creator, is He not, in the final analysis, still responsible for creating the virus?' and 'How do we know that the virus is not indeed the will of God?'

The theopaschitic paradigm: the compassionate and suffering God

(Louw 2008: 430) suggests that the creational approach needs to be combined with an emphasis on incarnational theology with its emphasis on God's presence. Presence embodies grace, and hence pastoral approach towards the HIV/AIDS pandemic should therefore be rooted in an incarnational theology, more particularly, the theology of the cross (*theologia crucis*). In Christ, God identifies Himself with our human suffering and becomes our Co-sufferer. A theopaschitic paradigm moves the theological discussion in the direction of passion and compassion. All suffering - the HIV pandemic included - is viewed as

fundamentally against God's will. The God-image that guides suffering people is a revealing Presence – a Companion – and thus the church should reflect this God-image as God-with-us (Louw, 2008:430).

3.4 CONCLUSION

This chapter has given an overview of the scriptures – in both Old and New Testaments – that are frequently used to judge PLWHA. Particular attention was paid to the doctrine of judgement and how the metaphor of God as Judge is viewed both in the Old and New Testaments. The suggestion that the HIV/AIDS pandemic can be viewed as punishment from God, led us to examine the views of sickness and disease from the Old and New Testaments. In the Old Testament, God's covenant relationship with Israel meant that God's judgement was based on guiding the covenantal relationship. The New Testament – where God's covenant expresses God's incarnational Presence especially (God-in-Christ) seems to suggest the need for a hermeneutical, interpretive model instead of a causal one. Here the question is more about the essence and quality of an encounter with God in terms of the human quest for meaning in suffering. (Louw 2008:429). The next chapter will reflect on the lived experience of the women interviewed in this research and will grapple with the question: 'Do they see God as a judge, or a Partner – a Companion - for life?'

CHAPTER 4

THE COMMUNITY OF LWANDLE: A CASE STUDY

4.1 INTRODUCTION

HIV/AIDS poses an enormous challenge to many South African structures: to the government, to churches, to business and industry, to non-governmental and community organisations (Nieuwmeyer, 2002:2). It is even more challenging to PLWHA, who carry a secret every day of their lives for fear of being judged. This chapter reflects the perceptions of women living with HIV/AIDS in the Lwandle community and records their narratives. We will explore questions such as: ‘Are the women trying to seek in the support group the acceptance which they cannot find in the Lwandle township’s church community?’ and ‘Is the Lwandle community really judging PLWHA – or do the judgments emanate from their own sense of guilt and shame?’ In addition to the evidence gathered from work done in Lwandle, the research will draw from the participatory research that the researcher did at Living Hope community centre as well as similar research done in other townships in South Africa. This chapter shows that women living with HIV/AIDS can indeed live positively in spite of rejection and stigma. A forum was created for the women to speak for themselves. But before we explore their stories, we need to describe the context in which they live – Lwandle – so as to obtain a better understanding of the circumstances and challenges facing them.

4.2 BACKGROUND INFORMATION ON LWANDLE

The informal settlement of Lwandle is 40 kilometres from Cape Town, near the towns of Somerset West, Strand and Gordon’s Bay. Unlike Langa, Gugulethu and Nyanga – the three large townships bordering Cape Town - Lwandle was not established as a township originally, but was designed solely to provide hostel accommodation for black male migrant workers in the Helderberg basin. As the majority of people living in the hostels were originally from the Eastern Cape, a significant proportion of the Lwandle population originates from the Transkei and Ciskei, and oscillates between rural bases there. The dominant language spoken there is Xhosa (Ramphela, 1993:31).

Living conditions in migrant hostels were appalling:

Our beds were made of concrete. We were sleeping side by side. There was no way you could bring your family here. We used a foam mattress on top of the concrete bed to cover the cement. Sixteen to eighteen men sleeping in one room.

(Zithobile Quwe, Lwandle Migrant Museum Archives)

Although Lwandle was established and regulated as a place for men only, women (and children) lived there unofficially from the 1960s. Conditions were cramped, and the threat of police raids and deportation back to the homelands of Transkei and Ciskei was daily reality:

We had to cook, wash, pray and do everything in such a small, crowded space. Some people slept under beds, or in passages. There was no privacy.

(Nontobeko Galada, Lwandle Museum Archives)

The migrant labour system placed the traditional Xhosa family unit under severe strain. The regulations governing migrant hostels clearly stated that residence in the hostels was open only to male Bantus over the age of 18 years (SA Institute of Race Relations, 1977:52). Many men soon found themselves living dual lives - they supported a wife and family in the homelands and a mistress in Lwandle. Wives were not allowed to visit their spouses officially, but gradually women began to risk joining their men and children were born in these hostels. One of the women who were interviewed by the Lwandle Migrant Museum said that she had to come to her husband as she could not have children because of her separation from her husband. Life was not easy for women in the hostels. When the wives eventually joined their husbands in the hostels, they were frequently met by a cold, indifferent and sometimes openly hostile reception by the mistress – sometimes even their husbands viewed them as intruders.

Thuli's story typifies that of many other women:

Thuli's marriage collapsed under the burden of separation. She had been married young and had supportive in-laws. Her husband stopped communicating with her after the first few happy years of marriage. In 1972 she was encouraged by her in-laws to come to Cape Town to find him and renew the relationship. She discovered that he was living with another woman in Nyanga hostel and he gave her a cold welcome. She would be left alone, while her husband went out with his girlfriend.

(Ramphela, 1993:73)

The majority of Lwandle residents are employed in the Helderberg basin, largely within the building industry, although as many as 60% are still unemployed (Lwandle website).

As Lwandle was originally designed solely for migrant labourers, no provision was made for

schools. Khanyolwethu High School was only built in 2005. The Betheli Pre-school was formerly a kitchen for migrant workers (Lwandle website). In 1993, the 'hostel to home' project was initiated: plans were drawn up to upgrade the hostels and develop family accommodation. Most of the women interviewed for this research live in Wag-'n-Bietjie, an area in Lwandle where hostels have been turned into homes as part of the 'hostel to home' project. This area has no electricity, no water and no toilets. Areas such as these are called '*ezimbacwini*,' literally meaning 'places of refuge'. The women interviewed for this work come from this background and are descendants of the hostel dwellers - the women who had to remain in the Eastern Cape while their husbands were working here. Some of them were conceived and born in the hostels. Most of the women interviewed for this work are illiterate and have never worked before.

4.3 THE EMPIRICAL COMPONENT

4.3.1 The study

This study consisted of two groups, namely: The pilot and focus groups. The pilot group is the group that was selected to test the questions. The aim was to check if the questions will give the researcher what she is looking for. This group is made by mothers that are fetching the milk formula from the clinic. These women are living with HI virus. Their support group focuses on teaching them about how to live healthily as HIV positive mothers. Their support group is run by the clinic staff, and it takes place inside the clinic.

The interviews for the pilot study took place two weeks before the focus group. The women interviewed for pilot study were not part of the focus group.

The focus group was the group of women belong to the support group of people that are taking Anti-retroviral treatment (ARV's). In this group the questions were discussed individually and privately.

The pilot group

The study consisted of two groups – a pilot study and a focus group.

The pilot study comprised about 15 women - aged between 20 to 38 years old - who had come to the clinic either to fetch their treatment and/or to fetch milk formula for their babies. They were either pregnant or new mothers. The researcher was invited into a room where all the women living with HIV/AIDS gather for their support group meetings. These 'support groups' give education about sexual transmitted diseases, breast feeding and the importance of continuing to use condoms. The room where the support group meet was over-crowded. It was also very noisy: it was also used for other purposes, such as storing patients' files. There

was a lot of bustling in and out from the staff members; the women themselves moved in and out as periodically they would be called to be seen by the sister. The particular day on which the interviews took place was considered as the most suitable. Some of the women were accompanied by their children who ranged from one month old to three years old. Our conversations were punctuated frequently by the children crying for a feed or asking to go to the toilet. The researcher had already obtained the women's verbal consent to be interviewed at the introductory meeting. The interview took a longer time than expected because the tape had to be stopped every time someone came into or left the room or one of the children cried. There was also no privacy at all. This did not seem to concern the women – as long as the interruptions were by the clinic staff. But, even though the researcher knew that there would be little privacy afforded to her in the clinic, it nevertheless made the interviewing process very difficult indeed.

The researcher asked the questions in Xhosa, one question at a time. The goal of testing the questions with this pilot study was not achieved. Because of the constant interruption – the clinic staff were continually taking the women from the group to attend to their medical needs – it made it very difficult for the researcher to test the validity of each question. Some women missed some questions; others missed parts of questions; and very few had an opportunity to answer all the questions without interruption. The interrupted and fragmented nature of the interview process made it difficult for the researcher to judge which questions needed to be adjusted, or which questions did not give her the answers she was looking for. The pilot study did reveal one aspect very clearly indeed: the researcher would definitely need a separate room in which to interview the focus group.

The focus group

The focus group was selected from a group of women who belonged to an organisation called Yabonga, which means 'Thankful.' This organisation helped PLWHA who were on treatment and encouraged them to take their treatment regularly. It operates in a two roomed bungalow at the back of the Ikhwezi clinic. Although this room was much better than the clinic – it was more spacious with a private room where the researcher could do the one-on-one interviews - there were some educational classes taking place in the adjacent room, so the room she was given was not completely quiet. As with the pilot study, the researcher obtained verbal consent for these interviews at the introductory meeting.

Only five women were selected from the support group for the focus group. These women ranged in age from the late teens to thirty-five-years-old. Two of the five ladies were employees of the Yabonga organisation – they are also living with HIV/AIDS. The other three

women are the members of this particular support group. The focus of this particular support group is on encouraging people to take the Anti-retroviral (ARV) treatment.

The researcher used the same questions which she had used with the pilot group; there was also only one questionnaire that was prepared for both groups. This interview took place two weeks after the pilot study

4.4. THE OUTCOMES OF THE STUDY

The outcomes of this study will be discussed under the following headings:

- *Disclosure and judgemental attitudes*

It is of interest to note that all of the participants – young, old and in both the pilot study and the focus group - had experienced problems with disclosure. None of them had found it easy to disclose and those who had chosen to disclose tended to disclose to either their sisters and/or their mothers. A survey of households affected by HIV/AIDS in South Africa found that 68% of caregivers in the households surveyed are women or girls (Scurry, 2004:26). When asked why they chose to disclose to other women, most of the women interviewed in the focus group believed that women are the caregivers because they are more compassionate than men.

(Nolen 2007:26) narrates the story of Simphiwe, a Zimbabwean woman, who also nursed her sister who eventually died of AIDS-related illnesses. Her dying sister did not know what she was suffering from: the doctor had only told Simphiwe, and she could not bear to tell her sick sister. Simphiwe bore this burden for her sister. Simphiwe's mother was also HIV-positive. These two women had to share this heavy and painful burden alone. Perhaps they were faced with questions such as: 'Who will nurse or care for whom first?' and 'Who – mother or sister - will die first?' When Nolen asked what sort of support they had received from the church community, none of the women she interviewed had sought refuge in the church as they feared being judged:

I am going to die. What about the church people? What will they say? What about my parents and my neighbours?

(Nolen, 2007:60)

As much as they longed to be comforted by the family of God, they could not risk being judged. (Scurry 2004:78) suggests that there is something unique to the church as church *per se*, that makes it especially difficult to disclose there. One of the women in the focus group

told the researcher after the interview that the church had removed her from the duties she was performing because ‘they saw condoms in my house when my cell group visited me and assumed that I was promiscuous.’ They said that she was defiling the church. She narrated this story to the researcher with great pain – even more pain than when she had first been diagnosed. According to her church, PLWHA should not date, let alone marry. They were being deprived of God’s blessings. Although she has not found the church as a place of refuge, other Christians living with HIV/AIDS have found in her a confidant: ‘There are a lot of people from my church who come and disclose to me; some of them I see here in the clinic.’

- Most of the women interviewed spoke of having to carry the burden of their disease alone: most of their relatives could not be trusted with this secret. When they answered question three, the majority of these women wondered what would be the reaction of their spouses, families, community and, unfortunately, the church.

Spouses’ responses

Patriarchy in a society rests authority in the hands of men. In Xhosa culture, men are the decision-makers in the household and women are subordinate (Miles, 1997:487). Living under the authority of men makes it hard for women to protect themselves sexually from the HI-virus since they do not have the power to negotiate condom use or abstinence (Nieuwmeier, 2002:41). This lack of power in sexual relations also means that women have little hope of influencing their partners to use condoms. Men decide if they need to take seriously the HIV-positive danger, or just ignore it, as they decide when, how often, with whom and in what position they will have sex (Nieuwmeier, 2002:41). This power imbalance makes it impossible for women to negotiate for safe sex.

The participants in this research shared similar experiences with regard to their spouses.

Those who had chosen to disclose to their spouses/partners were mostly met with blame or denial. Others chose not to disclose to their spouses, because they would either blame them or tell the whole community when they are drunk:

Even when women were taken into account, it was typically via discourses of blame. They have characteristically been viewed as responsible for transmitting the virus, whether as prostitutes infecting their clients or mothers infecting their children or something along the lines of... women being treated variously as vaginas or uteruses, as whores or mothers, and as vectors or vessels.

(Baylies, 2000:4)

Most responses of the participants' partners were either denial or blame. Women tend to experience stigma more than men. For example, when Prisca finally got the news that both she and their daughter were HIV-positive, she was devastated. When she eventually told her husband:

He laughed. Up until now, I can hear him laugh. He said, "There is nothing like AIDS, there is nothing of that sort, AIDS is a white man's disease."

(Nolen, 2007:59)

The women interviewed for this research shared similar experiences. When one woman told her husband she was HIV he accused her of lying. When she received news that their child was HIV negative, he became even more adamant in his denial. He did not even try to understand how the child could be HIV-negative. Her spouse's adamant denial eventually persuaded her to enter into denial too. Denial as a response to disclosure by PLWHA serves to perpetuate the spread of HIV/AIDS. A climate of denial and ignorance encourages risky sexual practices: If that man was sleeping around, he would not stop. The level of denial/ignorance amongst the spouses of the focus group was shocking. Not a single husband/partner of the women interviewed for this work had volunteered to check his status after they heard of their partner's diagnoses. This is puzzling. Is it because they already know that they are HIV-positive, but do not wish to tell their partners? Or is it because they think that this virus will disappear if they do not confront it? Would they care if they became infected? One of the women from the pilot group said that her husband was not tested until he became ill. And, even when he knew his status, he did not tell her. When one of the clinic nurses told her his status in his presence he never said a word. Such denial is costly: they had infected their daughter who is now eight years old. Another woman told of how she had asked her partner to be tested, but he refused. When she asked him: "What if we are HIV-positive?" her partner answered, "*Ayisosifo sezinja*," which means, 'This is not a dog's disease, we will live with it.' One woman's partner left her and their child when he learnt about his boy's positive status. How does this culture of denial leave women in the community? If the men – who hold so much power – respond to disclosure in this way, where will these disempowered women end up?

- *The role of faith*

Faith can play a major role in the lives of PLWHA. Believing in God, going to church, and praying were all manifestations of this critical facet of social support (Smyth, 2004: 126). All of the participants in this research - whether or not they know God or go to church - said that faith in God was their source of strength. The majority expected to receive strength from God; they saw Him as a Giver of life. They acknowledged that now, more than ever, the longevity of their lives depends on God's grace. They trusted the strength from God to enable them to live longer so they can see their children grow up. Is this not any mother's deepest heart's desire?

The helplessness of being HIV-positive had led some of these women to seek out a Higher Power. Some confirmed that, since their diagnosis, they had come closer to God, or had started to attend church. It became clear during the interviews that these women were survivors rather than victims. They demonstrate what Haddad (2001:16) calls 'survival faith.' They saw their religion literally as a means of surviving, and attributed their survival and any relative good health to God alone (Scurry, 2004:73).

'Survival faith' does not distinguish between physical and spiritual needs (Scurry, 2004:74). Does the lack of distinction between these needs demonstrate a radical dependence on God? These women know that God is a Healer, but they expected and anticipated many kinds of healing. For instance, one woman acknowledged that God could decide to heal her emotionally and spiritually, but not necessarily cure her of HIV. Another said that when she prays that God will make the virus 'disappear', she does not necessarily ask to be cured, but that the virus will be undetectable in her blood. Many of the women are realistic and patient: 'Their descriptions of prayer revealed patience and trust, as they expected their prayers to be answered, but not "tomorrow"' (Scurry,2004:74).

For many of the women, prayer was used as a means to vent or offload onto God, in addition to praising, supplicating and thanking God. God was the only One who would listen to their prayers and not say a word. In their relationship with God the women experienced unconditional acceptance, a sense of belonging and protection (Smyth, 2004:128). This very real form of spirituality enabled participants to think more positively about life and not to lose hope. None of the researcher's participants experienced God as judging them. In the researcher's opinion, they seemed to see God as their Refuge and Strength (Psalm 46:1). They all seemed to have a very positive image of God. Moreover all the women, with the exception of one, did not experience the church community as judging them either.

- *Acceptance*

The women's longing for acceptance increased their fear of disclosure. They feared that if

they disclosed, there was a very real chance that they will not be accepted. In contrast, they had found it easy to disclose to other PLWHA because they know they will be accepted. Louw (2008:446) suggests that the reluctance to disclose for fear of rejection by friends and loved ones precipitates a 'relational crisis':

The biggest disease today is not leprosy or tuberculosis but the feeling of being unwanted, uncared for and deserted by everybody.

(Mother Teresa in Nicol, 2006:31)

The need for acceptance is extremely important to PLWHA. One of the women told the researcher after the recorder was switched off that she was involved with an older man who was very controlling: 'Under normal circumstances, this is not the kind of man I would date, but I don't have a choice. After I disclosed to him he said, "I want you with the HI virus."' Even though being linked to this controlling man forced her to eventually turn against everything she stood for, "ever since being diagnosed I longed for this: to be accepted just as I am." She settled for less, just to satisfy her need to be accepted.

How can PLWHA accept their status if they themselves are not accepted?

- *The role of the support group*

The meetings, which they have every Tuesday morning in the Ikhwezi clinic, are called a 'support group.' Although living with HIV is experienced as a heavy burden, within the support groups, however, members help each other to carry the burden. This is the place where women can talk openly; where others know what they are going through and understand, as they share similar experiences. This is the place where they can talk freely about their pain and fears without the fear of being judged. They feel accepted. Here, they can be real and honest about who they are; they can look HIV in the face accompanied by people who understand. Whereas outside the support group, they always have to pretend to be something they are not; here, they are the community of individuals living with HIV.

The support group is the only place where the women do not have to hide when they get sick. They can drop the pretence and be real:

Even if I feel sick, I pretend that I am okay, I try to look good.... If I tell them about AIDS they are going to talk about it all over.

(Nieuwmeyer, 2002:130)

The realisation that they are not alone is an important facet of the lived experience of social

support (Smyth, 2004:110). Interaction with others who are HIV-positive gives participants hope and a sense that they could be brave and strong despite HIV. There is a sense of universalism and belonging in realising that they are not alone in their experience with HIV. In support groups, ubuntu at its best is practised.

4.5 The researcher's general impression of the interviews

Before examining the evidence collected from the interviews in particular, it will be helpful to first explore some of the more general findings about women and HIV – particularly black South African women.

An overwhelming majority of those living with HIV in South Africa are women. Results of the National Antenatal Survey showed that, at the end of 2002, almost three million women between the ages of 15 and 49 years were infected with HIV (Smyth, 2004:14). (UNAIDS 2003) suggests that African women are more likely to be infected than men. Several factors could contribute to this. In South Africa, great social inequalities and societal imbalances exist, and these contribute towards making black South African women are the most susceptible to infection (Walker & Gilbert, 2002: 66). Xhosa women are under enormous cultural pressure to fall pregnant. All of the women in this research went to have their status tested because they were pregnant. Pregnancy itself does not seem to have any significant effect on the progress of the HIV disease if the mother is in the early asymptomatic phase of infection. Only in those cases where women have more advanced HIV that a pregnancy may cause more rapid progress towards AIDS (Van Dyk, 2008:42).

None of the women interviewed at Ikhwezi clinic for this research showed any AIDS symptoms - they all looked healthy and pregnancy did not seem to be having any significant effect on their health. All the women acknowledged that their pregnancy was the main reason for their being tested for HIV. It would seem that their experience was characteristic of most of the women in Lwandle community: most do not know their status and only get tested if or when they fall pregnant.

None of the women interviewed regarded safe sex as a priority: they thought that there was no point in having relationships where safe sex was negotiated by either partner. One woman told the researcher that her partner did not believe her when she told him that she was infected. The degree of denial, apathy and/or ignorance greatly concerned the researcher. If, in 2010, we still get people that are not afraid of becoming infected who do not believe their partners when they tell them that they are infected, how far are we as a country with decreasing the spread of HIV? Did this man really not believe his partner, or was it easier to say "I don't believe you", rather than face up to the fact that he might be infected as well?

This denial and ignorance only serves to increase the spread of the HI virus.

Many people do not realise that they need to protect themselves against re-infection (Van Dyk, 2008:42). Each new infection can cause an increase in the blood's viral load. The person infected for a second or subsequent time may receive a new strain of virus. More concerning, any new HIV infection during pregnancy is likely to result in an increase in the viral load, and that will increase the likelihood of mother-to-child transmission.

Most of the participants in the pilot study had not disclosed their status to their spouses, as they feared that they would be met with blame. One participant said, "When he is drunk, he will shout at me, and use my status to humiliate me in public."

It is not just the humiliation and verbal abuse that they fear so much but also the fear which they harbour deep down that other people will discover their HIV status as the following example illustrates so clearly. Nomu and Zowi work as HIV-pre and -post lay-counsellors. One of them works at the clinic for an organisation that employs HIV-infected individuals only in an attempt to encourage PLWHA to take the treatment. Consequently, members of Lwandle community who go to the clinic know Nomu and Zowi as PLWHA. Even so, these two women - who have accepted their HIV diagnosis and who now work in the community to help their fellow residents - still fear the stigma deep down. After the interview, one of the women acknowledged to the researcher: "You know Sisi, I have this man that is so controlling and is older than me."

When asked why she chose to remain with the man if he was so controlling, the woman replied:

I don't have to explain myself to him as he is also infected by the HI-virus. He can't stigmatise me. I am afraid to leave him and find somebody else. If I find someone else, I will have to take the risk of disclosing to him and then he might reject me. I don't think I could handle that.

(Transcript of interview with focus group/research group)

The interviews with the women in both the pilot study and the focus group revealed the extent to which stigma - or the fear of being stigmatized as a result of their HIV status - affected their lives. The following aspects emerged:

- None of the women interviewed for this research had disclosed their HIV status publicly to the community
- Some of the women were still not ready to disclose to anybody
- The fact that they were prepared to talk openly about their status inside the support group meeting but not outside the group seems indicative of the degree to which

they are afraid of the stigma associated with HIV/AIDS

- For the women interviewed in this research – as in other research findings (Nolen, 2007:60), the real fear was not death, it was the STIGMA surrounding HIV/AIDS: “I am going to die, what about the church people? What will they say? What about my parents and neighbours?”

The participants did not show any fear of death or of the disease in its last stages; the fear they appear to carry profoundly is the fear of being stigmatised. This supports (Scurry’s 2004:59) observation that PLWHA experience the effects of the illness as much through the *stigma* associated with HIV/AIDS as through the *disease* itself. If the stigma is so alive then the current prevention campaigns will not be enough to stop the spread of this *mbulalazwe* (*Destroyer of the nation*).

Other significant findings emerged from the interviews with the pilot group and the focus group. These included :

2. God was the only Being that they were not afraid to tell their secret to. In fact, God appeared to be the ONLY hope for their situation. From the longevity of their lives so that they can see their children grow, faith in God was their survival.
2. The women could not answer the question about their deepest spiritual need. The researcher suggests that perhaps, for these women, there is no distinction. Every need which is beyond their reach or power - whether spiritual or physical - they can only access through God.
3. None of the women had experienced judgemental attitudes in pastoral care. The reason for this might be that most of them did not disclose their HIV status to their church community or seek help from the church. Only one woman did disclose her status: she did not experience any judgemental attitudes from her church community.

4.6 Questions left with the researcher after the interview

The data collected from the interview process left the researcher grappling with a number of issues. These included questions such as:

- Why is HIV/AIDS still referred to as ‘the long illness’ after all this time?
- What is it about HIV/AIDS that creates so much fear?
- Why is it so difficult for PLWHA to disclose to members of the church community?
- Is there any role that the church can play to destigmatize HIV/AIDS?
- If it is not death that they fear most, then what does that say about us?

- If - after so many funerals and deaths - people still do not care about practising safe sex how far have we really come in our campaigns to deal with HIV/AIDS?
- What is it that HIV/AIDS takes away from a person that makes a person not know who she/he is?
- What is it that makes the person lose his/her sense of ubuntu the moment HI virus enters the body of the other human being?
- Do PLWHA lose the sense of who they are with HI virus?
- Is the decision to settle for less in a relationship a sign of losing identity: does HIV create loss of identity?
- How can a Pastoral Care bring that sense of belonging/ubuntu back to the faith and residential community?
- What is the role of spiritual counselling in an identity perspective?

The researcher's attempt to wrestle with these questions led to a deeper exploration of the role of spiritual counselling to women living positively with HIV/AIDS.

4.7 SPIRITUAL COUNSELLING

Spiritual counselling plays a significant role in the lives of PLWHA. The importance of meeting the spiritual needs of PLWHA emerged very clearly during the interviews with both the pilot and focus group. The most significant need to be addressed in counselling seemed to be issues surrounding identity:

- Does HIV change who people are and, if so, how does this affect their future choices?
This question arose in a discussion which the researcher had with one of the focus group participant. The general consensus seemed to be that PLWHA should not marry.
- If PLWHA are now regarded as distributors of the HI virus, how does this affect who they are now?
This question emerged from the participant's answers as to why they do not disclose to the spouses.
- Do they lose who they really are? Does the HIV diagnosis rob them of the right to make helpful choices in their relationship – for instance, does a woman now have to settle for a 'controlling' relationship because she has HIV?
- Why is it that PLWHA might feel secure in their relationship with God, but that this security does not match how they carry themselves in their community? Who are they with HI virus in the community?

- Similarly, why are the women completely at home with who they are in the support groups meetings, but are completely different with members of the wider Lwandle community?
- Who are these women now that they have HIV/AIDS?

From the researcher's point of view, the entry point for spiritual counselling should be their identity in Christ. Spiritual counselling should make it clear that HI virus does not define them. They are defined by their identity in Christ:

...we are no longer no-bodies, but persons for whom God has released power in Jesus Christ to become sons [daughters] of God. God has not left us, but has made His home with us in Christ.

(Oates, 1961:51)

For Oates, forgiveness is key otherwise the seed of the Word falls on stony ground:

...the Incarnate Christ focuses [wo]man's identity through the forgiveness of his [her] history of sin. That happens through the encounter with Christ. This encounter bring about an agonizing and meaningful reappraisal of one's personal history that eventuated in a clear awareness of God's forgiveness and a new interpretation of one's spiritual life. This follows by the clear decision as to who Christ is, as to who Christ would have him [her] to be and what Christ would have him [her] do with his [her] life. This encounter enables the person to clarify his [her] own Christian calling.

(Oates, 1961:74)

(Louw 2012:62) suggests that a person's ability to determine her identity depends on the quality of her response to the God encounter and on the degree and quality of human responsibility. In a theological anthropology, identity means that people discover that God calls them to respond to their destiny, which is to love God and to love their fellow human beings. But even though people are called, they still have the freedom to choose how they will respond. This freedom means that people's choices are not unlimited, but are determined by the ethical principle of unconditional love. This love includes an acceptance of self founded on grace (Louw, 2012:63). True acceptance of self means that people will never underestimate themselves or their own worth. It is this kind of self-acceptance through God's acceptance that will empower PLWHA, and lead them towards healing. The following

chapter will explore this journey in greater depth.

4.8 CONCLUSION

This chapter opened up space for the voices of the women living with HI virus in Lwandle community. The two aspects are particularly significant for the researcher: first, the degree of stigma that is still attached to HIV; and second, the need to help PLWHA renegotiate and re-story their identity, which is clearly affected by virus. In counselling PLWHA, the Pastoral care giver should stress God's unconditional acceptance and God's unconditional love. If PLWHA can see themselves as acceptable before God and entrust themselves to His care, they will stand a better chance of being healed spiritually. When that happens, growth takes place. Growth does not take place in isolation, but in an environment of authentic fellowship, mutual support and encouragement (Mulenga, 2010:120).

Chapter 5 will explore how to nurture an environment where pastoral care and spiritual counselling of PLWHA can take place. Particular focus will be on hope: the role of hope in pastoral care; hope in the resurrection; and the role of hope in creating identity. Lastly, this chapter will focus on PLWHA and spiritual counselling.

CHAPTER 5

TOWARDS A THERAPEUTIC APPROACH: THE HUMAN QUEST: FOR EMPOWERMENT IN PASTORAL CARE AND SPIRITUAL COUNSELLING

5.1 INTRODUCTION

Once every generation, history brings us to an important crossroads. Sometimes in life there is that moment when it is possible to make a change for the better. This is one of those moments.

(Elizabeth Glaser, Democratic National Convention, New York, 1992:14 July. Glaser lives with HIV/AIDS)

This is indeed ‘one of those moments’: the HIV/AIDS pandemic is an invitation for the church to change their approach to pastoral care and spiritual counselling and to formulate a strategy that will help PLWHA to find acceptance and both emotional and spiritual healing. Pastoral care can assist PLWHA to rely on God’s faithfulness even - and especially - in the midst of their suffering. Pastoral care does this through helping PLWHA to reclaim God’s scriptures: these fulfil His promises; encourage PLWHA to accept their illness with gratitude; and invite them to see it as a challenge to exercise their faith. Careful pastoral care can transform the distress of an HIV/AIDS diagnosis into an opportunity to live God’s victory and to demonstrate faith, hope, love and joy (Louw, 1994:72).

Spiritual counselling nevertheless remains a challenge, especially when it comes to counselling PLWHA. The fact that HIV is largely a sexually-transmitted disease can cause many complications for spiritual and religious counselling (Van Dyk, 2008:318). Worse still, there have been many times when Scripture has been used to judge, ostracise and isolate PLWHA.

As a result, many PLWHA do not voluntarily seek spiritual intervention in their lives; they have lost all hope and their situation seems hopeless. This chapter focuses on ways of providing pastoral care and spiritual counselling to PLWHA. It looks at how hope - hope in the resurrection and the role of hope in individual lives and in the life of the community – can transform, restore dignity and provide acceptance. This latter role of hope is explored using a

real life situation. The last part of this chapter looks at PLWHA and spiritual counselling.

5.2 PASTORAL CARE AND SPIRITUAL COUNSELLING

(Clinebell 1994:25-26) defines pastoral care and counselling as the broad, inclusive ministry of mutual healing and growth within a congregation and its community, through every stage in their life cycle. Pastoral care is used to counsel people one-on-one or in small-group relationships in order to enable healing, empowerment and growth. Pastoral counselling - which is one dimension of pastoral care - makes use of a variety of therapeutic methods to help people handle their problems and crises with more maturity and thus experience healing of their brokenness:

[Pastoral] counselling [is] a facilitative process in which the counsellor, working within the framework of a special helping relationship, uses specific skills to assist clients develop self-knowledge, emotional acceptance, emotional growth and personal resources.

(Sikkema & Bisset, 1994 in Van Dyk, 2008: 219)

Pastoral therapy has a distinctive content: it communicates pastoral care in such a way that it influences, heals and changes the way in which a person lives.

Pastoral care and counselling should empower growth towards wholeness in each of the following six interdependent aspects of a person's life (Clinebell, 1994:31):

1.To enliven the mind:

The unused capacity of normal human minds is enormous. This aspect of pastoral care and counselling focuses on developing our rich, partially used personality resources for thinking, feeling, experiencing, envisioning, and creating. A wholeness-centred approach to pastoral care and counselling aims to enrich our consciousness, release our creativity, deepen our insight, sharpen our awareness and expand our intellectual and artistic horizons.

2.To revitalise the body.

We need to learn how to experience and enjoy our bodies more fully so as to be able to use it more effectively and lovingly. This aspect of pastoral care and counselling helps people to overcome their alienation from their bodies and to re-discover how to enjoy their body-mind-spirit wholeness. This frequently involves including a focus in counselling on sound nutrition, exercise, stress-reduction and other holistic health and body-wellness approaches.

3. To repair relationships

Human personalities are formed, deformed and transformed within a relational web. Healing and growth both depend on the quality of the relationships with significant others. Relational healing and growth skills – skills which help people repair, renew and enrich their network of caring relationships - are thus essential for a ministry of wholeness.

4. To restore our relationship with the environment

People become more whole, physically, mentally and spiritually when they are helped to develop and cherish a nurturing interaction with our great Mother Nature. Pastoral care and counselling liberates our relationship with the biosphere by increasing our ecological awareness, communion and caring.

5. To transform societies and institutions

It is easy for pastoral care and counselling to be seduced by the narcissistic and self-obsessed pressures of our hyper-individualistic society. But there can be no full or long-term wholeness for individuals and families in a broken world, a world that destroys wholeness by its systems of injustice, poverty, violence and exploitation. Pastoral care must thus broaden its focus to include liberation, healing and growth within societies and institutions. This will include:

- Unmasking the pervasive ways in which racism, sexism, ageism, classism, speciesism, nationalism, militarism, economic exploitation and political oppression cripple human wholeness on a massive scale in all societies.
- Consciousness raising to make people more aware of the societal roots of their individual pain, brokenness and truncated growth.
- Subverting privatised pastoral care and counselling, along with privatised religion by insisting that the pastoral care of groups and institutions must be seen as the other side of personal and relational healing and growth work.
- Liberating, motivating and empowering people to work with others to make our institutions places where wholeness will be better nurtured in everyone.

6. To nurture spiritual growth

The key to human flowering is an open, trustful, nourishing, joyful relationship with the loving Spirit of God who is the source of all life, all healing and all growth. Methods of spiritual healing and growth aim at enhancing our meanings, our guiding values, our faith, our moments of transcendence and our empowering relationship with the creative Spirit of the

universe. This spiritual dimension intersects and unites the other five aspects of pastoral care and counselling.

Pastoral caregivers have unique training and resources to enable spiritual growth. They can help people come alive at their centre, their higher self, which is their inner point of contact with God. Healing at this point can ripple out to transform peoples' lives and relationships at every other level.

(Louw 2000:258) describes the nature of pastoral counselling in terms of the following four factors:

- *It is a triologue and not a dialogue:* Word and the Spirit form a transforming third factor in pastoral counselling.
- *It is essentially a hermeneutic process:* pastoral care aims to interpret and understand the Christian faith within human contexts.
- *It has a covenantal character:* the pastoral care giver reflects the nature of God's covenantal relationship with us. Pastoral care should thus be characterised by *agape* – the grace, truth and love of God.
- *The pastoral diagnosis deals with a very specific issue:* the association between a person's God-images, faith development and growth. Pastoral care thus assesses the value of faith in the human quest for meaning.

In what ways is *pastoral* counselling thus different from counselling in a *psychological* model? (Louw2000:259) suggests the following characteristics of pastoral counselling which differentiate it from a psychological model:

- *Content:*
The content of pastoral counselling is determined by the notion of salvation and the dynamic influence of God's promises in Scripture.
- *Source:*
The source of pastoral counselling is the Spirit, who communicates God's faithfulness.
- *Anthropology:*
Pastoral care works from a *theological* anthropology. The counselees of pastoral counselling people in need people who are *created in the image of God*.
- *Motivation:*
The reason and motivation for pastoral counselling is to convey the compassion of God, the Father and Mediator to the parishioners and give them the consolation of the Holy Spirit.

- *Attitude:*
The attitude of pastoral counselling is *agape* love, as exercised through priestly compassion and real charity.
- *Objective:*
The objective of pastoral counselling is a mature faith, a vital hope and the disclosure of significance and meaning.
- *Context:*
The environment and context of pastoral counselling takes place within the fellowship of the believers (*koinonia*) as well as within the wider the social and public context.

(Oden 1989:99) insists that in Christian counsel, the active agent of change is not the human analyst or agent alone, but God's own active Spirit to whom the human spirit may respond. This aspect underlines Louw's notion of pastoral counselling being a triologue rather than a dialogue. The triologic character of pastoral care opens up the way for the human spirit to be addressed, constrained or freed by the power of God's own Spirit. Thus for Oden, pastoral counselling must to point beyond itself to God's own indwelling Spirit.

The role of the Holy Spirit - the Para clete - must be understood as the comforter: the one who comes alongside to comfort, encourage, console and equip. The Spirit *knows* what is in the human spirit; the Spirit can create insight and bring about radical change (Louw, 1998:168). The point at which the Holy Spirit and the human spirit intersect is frequently through narratives: the stories the person is telling him/herself and how this personal story relates to the overarching narrative – the Story of God's creative and re-creative power at work within our stories, past present and future:

To maintain integrity, pastoral care and counselling must be rooted in a theological anthropology that includes awareness that a person's core narratives include stories from all three dimensions of human temporality, past, present and future. More specifically, the narrative paradigm teaches us that persons can be fully understood and effectively cared for only if the pastoral caregiver attends to their future stories. The narrative paradigm guides the minister to incorporate the future dimension of time-consciousness into pastoral care. Since the future dimension provides the content and the energy for hope, a ministry that identifies the nurture of hope as a primary function must attend to the future arena of human experience. Narrative theory informs the task of pastoral assessment by reminding us that since a person's personal

identity is composed of past, present and future stories, then cutting these stories free does serious damage to a person's core narrative.

(Lester, 1995:41)

One of the greatest threats posed by HIV/AIDS is the threat to our future: those hopes, dreams, aspirations and goals that keep us from despair. Pastoral care is uniquely equipped to deal with this threat. It has the capacity to meet the anxiety, guilt, shame and fear that plague PLWHA with promises of hope and a future not because of the diagnosis, but in spite of it. It is a hope and future based on God's faithfulness to God's promises. The aim of pastoral care is thus to re-orientate people's lives from a position of despair to one of hope.

How easy is it to effect such change? (Taylor 1991:103) insists that 'the power to change our understanding is a gift of the Holy Spirit that we are called to cooperate with and appropriate.' (Louw 2005: 37) acknowledges that it is usually difficult for people to change their lifestyles, customs and personalities. But since pastoral care works that the basic assumption of a hermeneutical approach - that change is indeed possible if one is willing to change one's attitude towards the problem in the light of a new perspective - then helping someone to recognise who they are in Christ might well supply the energy and hope to risk shifting position:

The willingness to change is often in direct opposition to our very nature. Human beings do not change easily due to inner resistance, stubbornness and sinfulness. The motivation and readiness for change must come from the external factor. In the case of Christian maturity the external factor is eschatology: who we are in Christ and who we can become in the power of the Spirit are the determinants for intended and future change.

(Louw, 2005:37)

(Cavanagh 1982:240-250) lists four major reasons why people who seek help resist change:

1. *Seeking help causes anxiety and pain.* Change is anxiety-producing and painful. It involves choosing to let go of the old ways of dealing with anxieties and to facing their fears as they develop new ways of coping. Both of these activities are uncomfortable.
2. *Change is complex.* People have to both stop old behaviours and start new ones. Letting go of the old and starting the new are complicated procedures and combining them multiplies the complexity.

3. *Old behaviours are important.* The behaviours that people must give up are important to their personal dynamics. These behaviours have fulfilled psychological needs, provided distraction, created ways of venting anger and coping with guilt.
4. *Poor motives for change inhibit change.* People frequently lack sufficient motivation to change. They do not want to change enough. Instead they might use the process to gain permission *not* to change, to validate previously made decisions, to prove they are beyond help, to score points against the counsellor or to please or satisfy others.

Thus *metanoia* – true transformation/ renewal of our minds - is hard even when we want it, because there is always a part of us that does not want to be altered (Cavanagh, 1982: 249). If people are content with their position in life, there is indeed no reason for change (Louw, 2005:38). But if people are not content with their position and become aware of the connection between problematic life issues and the inappropriateness of positions, a shift in position becomes more than a challenge: it becomes a vocation. It is exactly at this point that a spiritual and Christian approach to life's issues becomes appropriate and paramount. In a spiritual approach, the assumption is that the wisdom of the Christian faith can motivate people to change. (Fryback&Reninert 1999:13) observed that, spirituality is viewed often as a bridge between hopelessness and sense of meaning. The hope for the better future can motivate people to change. That is why spiritual counselling also need to provide hope, to the hopeless situations.

5.3 PASTORAL CARE AND HOPE

5.3.1 Definition of hope

The American poet, Emily Dickinson, described hope as a 'thing with many feathers' – hope is a multi-faceted thing indeed. The *Penguin English Dictionary* defines hope as a pleasurable and confident expectation; an expectation that something desired will happen. Hope is also defined as 'a diffuse, inclusive concept, denoting a mood or an attitude in which beliefs, emotions, imaginations and purpose are all combined, characterised by a measure of confidence and affirmative expectation about the future' (Macquarrie in Lester, 1995:62). Hope has traditionally been understood as the conviction that God will judge the evil of the world and create a new heaven and a new earth with righteousness. The Old Testament prophets tell us that the whole of history is divinely ordered and interpreted, even the most hopeless hours, in light of the coming victory of God. A new age will replace the present one

putting an end to all sadness and sin (Henry, 1973:298).

(Packer 1988:321) suggests that in theology hope has two main meanings. It can define the *object* of hope - namely Christ and all that His final coming implies; or it can define a *position or perspective* on life – namely, to look forward expectantly to God’s future activity. The basis of hope is God’s past activity in Jesus Christ, who points the way to God’s purpose for his creation. Thus, the believer looks forward to the resurrection of God’s people and the arrival of God’s kingdom, confident because Jesus has inaugurated the kingdom and has been raised from death. In worship, the believer prays, “Your Kingdom come,” and celebrates the Lord’s supper in anticipation of the heavenly banquet, because he looks back to Christ’s death and resurrection, which opens the way to the kingdom (1 Cor. 11:26). In community with others, he/she experiences the Spirit as a foretaste of the eschatological kingdom (2 Cor. 1:22). Because believers expect to be like Christ in the end, they seek to be like Christ now (1 John 3:2-3). Because they long for a better country (Heb. 11:13-16), they adopt the attitude of a pilgrim. As long as believers live in hope rather than in the fullness of the kingdom, however, they walk by faith rather than by sight (2 Cor. 5:7). Their lives are marked more by suffering than by triumph (1 Cor. 4:8-13). Christians are liberated from fear about their own future in order to care about the fear of struggles of others. Hope is thus not merely a private matter, for the scope of God’s kingdom is universal. This insistence on the broader, socio-political dimension of hope has become prominent in modern Theology.

The debate has been stimulated by the recognition that eschatology is at the heart of Jesus’ message, and by philosophical interest in the phenomenon of hope as a human experience. Hope invigorates faith again and again, with perseverance. In the Christian life faith has the priority, but hope the primacy. Without faith’s knowledge of Christ, hope becomes a utopia and remains hanging in the air. But without hope, faith falls to pieces, becomes a fainthearted and ultimately a dead faith. It is through faith that man finds the path of true life, but it is only hope that keeps him on that path. Therefore it is that hope gives faith in Christ its breadth and leads it into life (Moltmann, 1993:20).

5.3.2 Hope in the resurrection

In the light of the resurrection, humans are assessed from the perspective of *life* (affirmation) and not from the perspective of *death* (destruction) (Louw, 2008:432). Resurrection hope is about the death of death: God has finally obliterated every form of rejection, stigmatisation and isolation. People suffering from HIV should therefore be empowered to start to live life positively/constructively, despite the reality of the virus.

Guthrie (1981:378) lists the significance of the resurrection as follows:

- *The Resurrection throws light on the Doctrine of God: it shapes our understanding of the person and work of Christ.*

One of the most significant factors in early Christian understanding of the resurrection is the light it throws on the doctrine of God. The act of resurrection is always the act of God. Only a strong belief in the event of the Resurrection can assure the continuity of the pre-existence of Christ. Only if the Resurrection were a real event can the doctrine of Jesus - as both God and man - be maintained. No other view of Him is possible if the New Testament evidence is to be taken seriously. If the Resurrection was not true, then a choice would have to be made between a Divine person who never really became man and who did not die and the human person who was not divine, who died, but never rose. In both cases, parts of the New Testament evidence would have to be explained away.

- *The Resurrection links the person and work of Christ.*

The Resurrection expresses God's satisfaction with what Christ has done. If Christ had not been raised, there would have been no certainty that his death had affected anything. As Paul says, humankind would still be living a sinful life.

- *The Resurrection is indispensable to humankind's salvation.*

The belief that Christ has a continued interest in the welfare of his people – that He sits at God's right hand and intercedes for them - depends on the resurrection. Christ's capacity for effectively acting on behalf of His people in his continued ministry is as unlimited as his sovereignty.

- *Being witness to the Resurrection is a qualification for apostleship.*

One of the major qualifications for the office of an apostle, as laid down by Peter when the church needed a successor for Judas, was that the person must be a witness to the Resurrection of Jesus (Acts 1:22).

- *The Resurrection made effective Jesus' claim to be the good Shepherd.*

The main idea in 1 Peter 4:1-5:10 is that suffering will give way to glory and the glory is that of the risen Christ. The reality of the Resurrection is therefore an indispensable basis for Christian hope in the future.

- *The Resurrection testifies to Christ overcoming the power of death and sin.*

The fact that Christ, through death, destroyed the devil who had the power of death, and brought deliverance to those in bondage of the fear of death, is rooted in the Resurrection. A dead Christ could never deliver us from the fear of death, because He had, himself, been delivered into death. However a risen Christ could do so, because

in Him was the power of renewed life.

Faith in the Resurrection ensures that Christian hope is not just wishful thinking or a panacea for anxiety: We do not hope because we are afraid of death. In terms of Christ's resurrection, we hope in spite of our anxiety. Louw (2000:154) insists that the theological grounds for Christian hope must rest on the following:

- Salvation, justification and Christ's mediatory work.
- The overcoming of death by the Resurrection of Christ.
- The eternal value of our bodily existence in terms of Christ's resurrected body.
- Eschatology and the promise of a radical new future.

Since the Resurrection is not only a new perspective but also an historic reality, it has consequences for hope (Louw, 2008:435). The Resurrection is not a mere psychological or existential event in the subjective memory of human beings. It is the new way in which God deals radically and victoriously with the whole of creation. The Resurrection thus has healing implications: the existential and historical fact of an empty grave and a Risen Christ point to God's transforming power and faithfulness. Our Christian hope is that the same transforming power and faithfulness that brought Jesus Christ from the dead will be present despite disfigurement, suffering and death - even within the pandemic of HIV/AIDS.

In a paper on the Resurrection and public life delivered at Stellenbosch University Faculty of Theology, on the Theological Day in 2011, Le Bruyn emphasises the link between Resurrection and hope:

Christians will remain a witnessing, steadfast and active church in the land of the Resurrection. For Christians, the Resurrection is the great symbol of their hope. The basis of Christian hope is God, and God alone. The Resurrection is the finger of God that can be seen when we put all hope and trust in God, when the dark begins to creep in. It serves as a reminder that Jesus is still at work in the world.

The whole existence of Christians revolves around the belief in the crucifixion and resurrection. Resurrection nurtures the faith that hope of resurrection will overcome all suffering from injustice and oppression. The Resurrection creates new life, revives love, promotes peace and calls for reconciliation to live together in the land. Hope is the appropriate response in our ambiguous contexts to the promise of transformed life God starts to keep in the Resurrection of Christ. Hope is the appropriate response to eschatological

blessings. It has to do with the attitude of expectancy that a good and desired transformation of everyday contexts, which has already begun, will indeed be actualised. It is an attitude oriented towards one's ultimate and proximate contexts. Jesus' resurrection eliminates the oppression behind His crucifixion and inaugurates the end time amidst such oppression. This does not do away with continuing suffering. As centres of finite power ourselves, with joyous hopefulness, we can necessarily enact our hopefulness in public spaces and times. This can not describe it in a privatising way. Hope involves a commitment to an array of practices in public - celebratory, formation, intention, emotional expression, learning, epistemological, consciousness. It is this particularity in attitude that enacts certain practices because of specific moods.

This attitude is well grounded, the possibility of such hope lies solely in the actuality of God keeping his promise. It is a resistance to chaos or oppression. A response to the promise of God. A hope for glory .

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(Louw 2000:156) suggests that the Resurrection has the following implications for a

Theology of Pastoral Care and can profoundly shape how we care for PLWHA. The Resurrection:

- It Promises victory over death and instils a vivid hope amidst the anxiety surrounding death – even death as a consequence of HIV/AIDS.
- It Enables us to become participants in the resurrection, power and life, amidst struggle and suffering. Living in fellowship with God means being empowered by the Spirit to live and to become engaged in human relationships. HIV/AIDS is thus not necessarily a death sentence, but can be an invitation to live in relationships – to self, others, God and the environment – in ways that nurture human dignity, acceptance and a sense of belonging.
- It Restores trust in life and provides security because it opens up a new hermeneutics, that is, to experience the living God in every dimension of existence, as well as in the whole of the cosmos. Life becomes an opportunity to embody God's grace and to en flesh love.

Pastoral care in suffering is a ministry which emanates from resurrection to life. Its primary task is to help believers to discover a new direction in life. Pastoral care becomes a ministry which embodies and incarnates the vivid hope of the Resurrection (Louw, 2008:437). It becomes a sign of eschatology in action(Louw 2008:437):

As victory care, pastoral care is not triumphalism (self-sufficiency), nor does it contain any notion of a *theologia gloriae* (ignoring the painfulness of pain and suffering). Victory as an eschatological reality, links the Cross and the Resurrection and addresses the painfulness of pain within the paradoxes of life.

The Cross calls for patient surrender, but at the same time for protest (lament), the Resurrection awakens a sense of victory and empowers one to face suffering. The power of the Resurrection however does not lead to resignation and passivity. On the contrary, it can even make one rebellious and assist one in one's struggle against suffering.

(Louw, 2008:438)

Pastoral care which works from the power of the Resurrection can indeed equip all who are touched by the HIV/AIDS pandemic (PLWHA, their families and caregivers, medical staff and the community) with hope:

Resurrection means that the cross is not a last word pronouncement on life. Resurrection means that the work of justice is ongoing and that everything is possible. Resurrection also means that, on the cross, the life of struggle did not end.

(Thornton, 2002:214)

5.3.3 The role of hope in a person

To be human includes the ability to hope. This ability to anticipate the future is an ontological given, perhaps the most authentic and distinctive characteristic of humanity. Hope is the driving force that enables humans to move into the future dimension of time consciousness. Hope is the engine that provides the energy that pulls humans to the future. But *how* one anticipates the future matters enormously:

How a person thinks about, and feels toward, the “not-yet” is crucial to physical, emotional and spiritual health. The attitude one takes toward the future can be placed on a continuum between hope and despair.

(Lester, 1995:59)

(Louw's(2008:11) *Cura vitae* gives us some helpful pointers in shaping the nature of our hope:

Cura vitae is about a theology of life and the healing of life from the viewpoint of Christian spirituality. It is about how new life in the risen Christ and the indwelling presence of the Spirit can contribute to the empowerment of human beings. It is about HOPE, care, and the endeavour to give meaning to life within the reality of suffering, our human vulnerability, and the ever-present predicament of trauma, illness and sickness.

The distinctive feature about *pastoral* care to PLWHA is the source of our hope – the faithfulness of God. Christian hope is ‘the refusal to accept the reading of reality which is the majority opinion’ (Brueggemann, 1978:67). Christian hope allows for an alternate reading of reality: we find meaning in suffering, not because suffering *per se* has any meaning in it, but because God is in the suffering with us:

Hope gives us the ability to recognize that we must refuse to scale down our aspirations to the level of the facts in our present situation because God is always calling us to move beyond the present to shape and mould a better tomorrow.

(Thornton, 2002:149)

Hope is empowering. Hope enables one to become an active sufferer instead of a passive sufferer. When one has hope, one's voice is heard. To qualify this statement, the researcher would like to draw from the participatory research she undertook while counselling PLWHA at Living Hope Community Centre.

The researcher met Zozo, a teenage girl, at the local hospital. Zozo was not ill, but her nine-month-old baby was really sick and was covered with sores from head to toe.

Zozo's baby cried every time she was even touched making even nappy changing very difficult. The baby was in a single ward. The child's name, *Alikho ithemba*, was written on a label above at the top of the bed. The name caught the researcher's eye and she asked Zozo about the meaning of this name. Zozo nodded in the direction of the sickly, crying baby as she said, "As you can see, there is no hope."

Zozo then narrated her story: how she had lost her mother through AIDS; how her baby's father had rejected her after she had become pregnant; and how she, herself, had tested HIV-positive. She also narrated the story of her sick child who, like herself, will die through *lo mbulala zwe* (this nation killer). Zozo voiced her despair: "What is left for her baby? Nothing. *Alikho ithemba* will also get sick and will, eventually, die. Is there hope for someone in her situation? No."

According to Zozo, there was NO HOPE. Hence the reason for her baby's name: *Alikho ithemba* means 'No hope'.

In situations such as Zozo's, people are hurting and crying out for a new horizon of hope. They need future stories that provide security, excitement and joy in the present moment. Therefore, Pastoral caregivers have a part to play in enabling despairing persons to gain the courage to lean into their future, to revise and reconstruct future stories that are connected to hope rather than despair (Lester, 1995:139). Following Louw (2000:156) pastoral care is the ministry of hope in terms of a new reality, with new possibilities for existence and a new perspective for the future. The researcher used Louw's understanding of hope to guide her as she began caring with Zozo and her baby. Hope is not limited to a spiritual dimension: realistic hope must embrace every aspect of a person's life. In Zozo's case, the nurses were not only dealing with the HI virus, they were also fighting the baby's malnutrition. The Living Hope Community Centre believes in a holistic approach. The first step in saving the life of this teenager and her child was to help Zozo feed the child nutritious food. Zozo was also advised to join the group of PLWHA where she was immediately supported and encouraged. The group helped hold hope *with* Zozo:

Hope is something too important - its effect on body and soul too significant -

to be left to individuals alone. Hope must be the responsibility of the community. Where this is so, and when this is so, radical amazement occurs. There is an abyss. Often, we can look across or we can look in. We can find ourselves in it or know others who are. When we enter the abyss, when we see it, then radical amazement is ours. Ours. Together. With hope.

(Weingarten, 2006 :4)

In(Devries 2004:451), hope is that it is something you gain from and share with others. Hope is the responsibility of the community.

Once hope has been firmly established as an emerging property of the community, a realistic hope becomes achievable. Once Zozo had gained hope, she changed the name of her child to *Lelethu*, which means Jesus is our Hope (1 Tim 1:1: ‘Paul, an apostle of Jesus Christ, by the commandment of God our Saviour and the Lord Jesus Christ, our HOPE’).

Now Zozo could begin to dream again. Zozo found employment which enabled her to support both herself and her baby. Lelethu was put on medication. Zozo married a man who - despite knowing both her and Lelethu’s HIV status - was willing to take her in with her baby. Lelethu now goes to school and is alive and healthy.

Hope gave Zozo the ability to recognise that she must refuse to scale down her aspirations to the level of the facts in her present situation. Hope gave her a voice. She is now an active sufferer who is not afraid of being rejected. Hope made her do something she never thought possible - get married and be accepted as she is.

Zozo’s story reiterates what is evident in this research: namely, how important acceptance and a sense of belonging means to PLWHA.

The kind of hope that transformed Zozo’s life was not ‘cheap optimism and superficial euphoria...hope that does not inspire people to ignore pain and suffering’ (Louw, 2008:437):

Hope is only hope in suffering. Hope and victory within suffering do not necessarily mean victory out of suffering. Victory sometimes has to embrace the hope of not overcoming that reveals the patience and long-suffering nature of hope. (Louw,2008:438)

The kind of hope which we offer PLWHA must be what (Weingarten 2006:5)

calls 'realistic' hope. Zozo's story contains four characteristics of 'realistic' hope:

- *Realistic hope accommodates doubt and despair:*
Hope is not the same as optimism. It is not the conviction that something will turn out well, but the certainty that something makes sense, regardless of how it turns out. Doubt and despair are not antithetical to hope, but rather just two feelings or experiences that arise in certain circumstances and which we can make sense of as we would any other feelings.
- *Realistic hope integrates contradictions*
Naïve hope (or wishful thinking) hope prefers a straight line, a black or white, a simple form. Realistic hope is comfortable with a mess. It accepts that chaos can sort itself into order. It embraces contradiction. Realistic hope, with its acceptance of contradictions, offers a platform on which to stand, even when one cannot stand what one must stand.
- *Realistic hope is pragmatic: it sets goals and pathways to these goals*
There is a tendency to feel buoyed and hopeful when the goal is clear, the pathway known and hopeless when the way is blocked and the goal obscure. Despair is the conviction that nothing one wants is within reach whether it be love or security or clean water or good health.
- *Realistic hope celebrates a variety of narrative forms*
Every story has a narrative form. Tragedy plunges in a downward slope, comedy rises up after a big bump, romantic sagas curve like a roller coaster. Each shape signals certain values. This is particularly true with hope's story line, invariably portrayed as a progressive narrative, a straight line up. Hope is always on an upward flight. The progressive narrative form, however, does not depict the shapes that realistic hope can take, for its shape is determined less by the outcome of events than by the responses of the communities of people who support each other through events. In communities, any narrative form - including uncertain ones - can be borne. Realistic hope celebrates that diversity.

These four characteristics of realistic hope make doing hope more feasible. *Doing* hope is not *feeling* hopeful. It is far more useful to focus on the practice of doing hope than it is to try to stimulate the feeling of hope. In the matter of hope, feeling follows action.

Zozo and her child still have a virus in their blood. As(Louw 2008:437) reminds us when he says, this is hope within suffering. The role of spiritual counselling to PLWHA help to provide this hope within suffering.

5.4 PLWHA and spiritual counselling

The aim of counselling an HIV-positive individual is to focus on life beyond infection and not to dwell unnecessarily on the constraints of the disease (Van Dyk, 2008:220). The main problem of living with HIV is fear, especially the fear of disclosure and the consequent rejection and stigmatisation (Louw, 2008:445).

(Van Dyk 2008:223-227) proposes a four stage model of counselling that can be applied to the therapeutic relationship in general:

1. *Relationship building*

This stage establishes an open and trusting relationship in which the person feels safe enough to address personal issues and to disclose information.

2. *Helping the client to tell her/his story*

This stage helps the person to explore the problem situation. During this stage the person must grapple with the first fundamental question: 'What is going on in my life?' Exploring this stage will help the counsellor to get an understanding of the person's world. It is essentially a data gathering process.

3. *Developing an increased understanding of the problem*

The goal of this stage is for both counsellor and the person to gain a deeper understanding of the problem and to form the basis for specific action. The fundamental question at stake here is 'What do I want?' The more the counsellor understands the person's world, the better they will be able to explore the story.

4. *Intervention or action*

This stage explores intervention options and helps the person to take action to manage the problem(s). The fundamental question at stake here is 'How do I make all this happen?' Intervention is not about the counsellor offering a solution; rather, it is about co-labouring with the person in a journey that will improve the quality of her/his life.

(Louw's 2008:447-449) five stage model focuses specifically on counselling PLWHA spiritually:

- *The impact stage:*

Receiving a positive HIV diagnosis might trigger an immediate reaction of shock, denial, severe anxiety and helplessness. The focus must be on meeting the person's basic need for acceptance, understanding, love and sustenance. The counsellor must incarnate the love, acceptance, understanding and sustenance of God by simply 'being there':

Presence is a primary word for pastoral care and for pastoral psychotherapy. A counsellor is pastoral when he/she is truly there for others, is fully present to others, and recognises that this presence is in the name of God, who has called the counsellor to be available at a depth beyond normal association. The pastoral therapist is one who has answered the call to be present with all of the self that can be owned by that person, the conscious experiences of being as well as the unconscious experiences as they rise to awareness. When one is truly there for another, a depth of communication occurs that is beyond words or style, or technique, or theory or even theology. It is presence gifted by Presence.

(Augsburger, 1986:37 in Louw, 2008:447)

- *The regression stage:*

Many people retreat emotionally when forced to deal with the reality of their situation. They go into a state of psychological isolation, loneliness and mourning. Internalised anger might also surface as well as a hostile approach to the social and cultural environment. The focus of counselling during this stage must be on helping the person to deal with feelings of guilt and anger. The issue of disclosure – whether or not to disclose, and to whom – also surfaces at this stage as the person wrestles with answering the question, ‘Who can I trust?’ As the person struggles with issues of trust and trustworthiness, the experience of understanding and acceptance – from the caregivers, family, friends or support group – play a crucial role. The need to experience love and compassion becomes paramount:

The central element from the perspective of the relational metaphor, is the contact achieved, the empathic feeling and understanding experienced and the genuine caring communicated. For a pastoral counsellor, such presence, acceptance and love are the core quality of grace that makes counselling authentically pastoral.

(Augsburger, 1986:362 in Louw 2008:448)

- *The internalisation stage*

During this stage the person begins to come to terms with the long-term consequences of their HIV/AIDS status and the pressure that the taking of medication puts on them. The person gradually acknowledges and accepts the reality of the situation. Whereas the question of ‘Who can I trust?’ characterised the previous stage, during this stage the focus is more on ‘How can I tell my HIV story in a way that I prefer?’ The pastoral caregiver

helps to facilitate a forum of sharing and disclosure. At a deeper spiritual level, the caregiver tries to establish within the PLWHA an awareness of the continuity, endurance and perseverance that is possible because of God's faithfulness. The notion of hope – hope in the presence and faithfulness of God - plays a vital role in fostering an attitude of growth.

- *The reconstruction stage:*

This stage is directly connected with decision making (the quality of choices), future planning, target development and meaningful actions. The person's faith and confidence in God's faithfulness to God's promises can help to restore the person's sense of dignity, respect and self-esteem and can encourage the person to start living positively with HIV. At this stage it is vital that the person discovers that they are not isolated individuals, but embedded in a network of caring relationships:

Humans are covenanting beings and their lives are created by the covenants they make with themselves, their significant others, their surrounding community and their Creator.

(Augsburger, 1986:110 in Louw 2008:448)

The constructive stage:

The focus of counselling during this stage is to develop a quality of life which uses the person's positive HIV status as a means for growth, quality decision-making and goal setting. Particular attention

- *The constructive stage:*

The focus of counselling during this stage is to develop a quality of life which uses the person's positive HIV status as a means for growth, quality decision-making and goal setting. Particular attention needs to be paid to the person's God images at this stage.

The questions of disclosure – *what* do I say about my status, to *whom*, and *when?* – will need to be faced at every stage of the person's journey with HIV/AIDS. But counselling on the issue of disclosure cannot be dealt with without first changing stereotypes and attitudes. This includes looking at the narratives people tell themselves about themselves, HIV and their relationship with HIV. If people continue to allow their lives to be shaped by the stories around HIV – especially the stories of stigma and stigmatization – they will continue to be

imprisoned by the disease, with all the concomitant despair, hopelessness and helplessness it brings with it. But if people are able to change the stories they tell about themselves – thereby transforming their attitudes about illness and healing – transformation can come. Hence the researcher's decision to combine (Louw's 2008:447) five stage approach with narrative approach to pastoral care and spiritual counselling.

Narrative therapy uses 'externalizing conversations' to separate or put distance between people and the 'problem' stories that people are telling about themselves. In the case of PLWHA, the HIV/AIDS diagnosis – with all the threats painful disease, stigma and stigmatization – can easily shape the way people view themselves. Morgan (2000:17) describes these internalizing conversations – ways of speaking that locate the problem inwardly – as having negative effects on peoples' lives, and resulting in thin conclusions or descriptions about themselves. Moreover, these internalizing conversations - the belief that the problems of their lives are a reflection of their own identity or the identity of others, or a reflection of the identity of their relationships – shapes the way people try to resolve their problems. Unfortunately, these efforts invariably exacerbate the problems. People come to believe that their problems are internal to their self, or the selves of others - that they or others are in fact the problem (White, 2007:9-10).

'Externalizing conversations' can open up space for the person to speak about HIV/AIDS in a way that allows for a richer description of self and empowers the person with some sense of agency rather than being overwhelmed by the 'totalizing' nature of the diagnosis:

Externalisation is a practice supported by the belief that a problem is something operating or impacting on or pervading a person's life, something separate and different from the person. It separates the person's identity from their problem.

(Freedman & Combs, 1996:47)

PLWHA frequently believe that their lives are defined by the virus/ diagnosis. They are frequently judged by others as 'that group of people who reap what they've sown.' This belief only sinks them further into the problems that they are attempting to resolve. This attitude results in PLWHA 'internalising' the problem. Externalising conversation can provide an antidote to these internal understandings by objectifying the problem. They employ practices of objectification of the problem against cultural practices of objectification of people. This makes it possible for people to experience an identity that is separate from the problem: the *problem* becomes the problem, not the *person*. In the context of externalising

conversations, the problem (HIV/AIDS) ceases to represent the 'truth' about people's identities and options for successful problem resolution suddenly become visible and accessible (White, 2007:10).

This separation of the person's identity from the identity of the problem does not relinquish people from a responsibility to address the problems that they are encountering. Rather, it makes it more possible for people to assume this responsibility. If the person is the problem, there is very little that can be done outside of taking action that is self-destructive. But if a person's relationship with the problem becomes more clearly defined - as it does in externalising conversations - a range of possibilities become available to revise this relationship (White, 2007:10).

The narrative approach separates the person from the problem. There is more to a person than the HI virus. The narrative approach believes that - no matter what a person has experienced and no matter how dark the problem story-line is - there is always more to a person than the problem or trauma. This holds true even in the case of HIV/AIDS. Such a conversation points to life and living with HIV/AIDS in a different way. Instead of identity being defined by the HIV/AIDS diagnosis, space is opened up to negotiate new understandings of self, and new hope to find ways of living with HIV/AIDS (Van Dyk, 2008:270).

5.5 CONCLUSION

This chapter focused on Pastoral Care and spiritual counselling. The overarching role of hope as part of spiritual counselling - hope in the Resurrection and the role of hope in a person – was emphasised throughout this chapter. If we cannot give people hope, then we might as well do nothing. It is the hope that allows people to look beyond their circumstances. It was this kind of ‘realistic’ Resurrection hope that was at work in Zozo’s life, transforming her story from *Alikho ithemba* (no hope) to *Lelethu* (Jesus is our Hope). The last part of this chapter looked at PLWHA and spiritual counselling, following (Louw 2008:447) we looked at four stages of counselling. The following chapter look at the findings and discussions, lessons learnt and possible future studies.

CHAPTER 6

FINDINGS AND CONCLUSION

6.1 INTRODUCTION

The aim of this study was to investigate the judgemental attitudes in pastoral care and spiritual counselling for PLWHA - in particular, women living in the township of Lwandle. In this context, an empirical study was conducted in order to learn from the women who are infected by HIV/AIDS. This final chapter will discuss the findings, reflect on the lessons learned, and recommend possible areas for future study.

6.2 DISCUSSION

The starting point for the exploration of judgemental attitudes in pastoral care within spiritual counselling to women living positively with HIV/AIDS was the presupposition that HIV/AIDS is a disease with an undertone of sexual deviance; within religious circles in particular, HIV/AIDS is a disease associated with sexual intercourse. The church's traditional teaching regarded procreation as the sole purpose of sexual intercourse: as such, it should only take place between legally married, heterosexual couples.

More recently, many churches have entrenched their position that HIV/AIDS is a disease that infects those who are not morally sound and upright (Van Dyk, 2008:318). Consequently, those who have contracted this disease are frequently sent to the background of the church's life at best or ostracised and abandoned at worst. These attitudes make it difficult for pastoral counsellors to counsel PLWHA without speaking of the causes of this disease and, when they do so, they often appear to be condemning and judging the infected people. This in turn frequently makes it difficult for PLWHA to disclose their status because of the stigma attached to the disease.

The stigma surrounding HIV/AIDS was found to be still alive in this community of Lwandle. The participants whom the researcher interviewed were still fearful of what the community might do when they learnt about their status. Even though they were living positively with the

disease, their deep-seated fear still paralysed them and prevented them from living their lives to the full. Many of them also lived a life of pretence: even though they felt ill, they pretended to be well so that neighbours, fellow church members and the wider community will not suspect their HIV/AIDS diagnosis (Nieuwmeyer, 2002:85). The additional stress of keeping up this type of pretence only increased their vulnerability, decreased their immunity and exacerbated their condition.

The literature defines stigma as a construction of deviations from some ideal or expectation: stigma marginalizes and excludes individuals from groups because their HIV-positive diagnosis (Smyth, 2004:28).

South Africa is not alone in stigmatizing HIV/AIDS. Throughout the world, an HIV-positive diagnosis still carries a stigma: more especially, stigma that someone who has contracted HIV/AIDS has made choices which have indelibly blemished their moral character. Throughout the world there remain in place cultural, sexual, religious and legal influences that dictate sexual practices, sexual preferences, sexual desires, the number and type of sexual partners, the practice of birth control, and the use of condoms and drugs which link individuals who are HIV-positive to undesirable sexual behaviour. Pre-marital/extra-marital sex continues to be viewed a sin that blemishes an individual's character.

The stigma connected to HIV/AIDS remains deeply entrenched for a number of reasons Herek, 1999 in (Smyth, 2004:29). Perhaps most damaging – and most intractable in church communities - is the belief that contracting HIV has been perceived to be the bearer's responsibility: it has been contracted through voluntary and avoidable immoral behaviour. Even today, three decades after the first cases were diagnosed, the word 'HIV/AIDS' still carries so much stigma, especially the tendency amongst many in church communities to see HIV/AIDS as a punishment for sin. This link is not something new. As Susan Sontag reminds us, 'plagues are invariably regarded as judgements on society' (in Ackermann, 2003: 89). This research described what stigma is and some of the beliefs that spawn stigma in the communities, the church community, and society. If we need reminding of the dangers of stigma, we only have to remember Gugu Dhlamini, the AIDS activist in Kwa-Zulu Natal, who was stoned to death in 1998 by her community because she disclosed her status publicly. Stigma is a social ill as well as a personal experience. Gugu's community perceived AIDS as bringing shame, not only to her as an individual, but also to her community at large. Her disclosure thus seemed to require a communal response:

HIV unmasks many presuppositions regarding the meaning of human sexuality. When sexuality is connected with death, a short circuit occurs in the

human psyche and this is surely the main reason for the terrifying anxiety that AIDS creates in many people. The possible spread of the disease becomes a battlefield for repression and here they must dare to face up to issues that otherwise get swept under the carpet.

(Louw, 2008:351)

Perhaps even more pernicious than individual denial has been the denial of the South African State that its citizens are being ravaged by a pandemic. Although not dealt with in this research project, the insistence by President Thabo Mbeki and his cabinet of the need to debate ‘scientific questions’ in regard to HIV/AIDS squandered precious years in the fight against this pandemic (Ackermann, 2003: 84-5). This research focused on the valuable years the church continues to squander by allowing stigmatization of PLWHA to continue.

Eradicating stigma will take bold and courageous action. HIV/AIDS forces communities (the black community in particular) to face issues that are not normally spoken about in public. Speaking about sex is still taboo in the black culture. HIV makes the black community uncomfortable because it involves sex, which is not supposed to be discussed in public. Parents even feel uncomfortable speaking to their children about issues of sex: ‘In our part of the world... everything related to sex is so private’ (Graca Machel in Nolen, 2007:346). Culturally, it is unthinkable for a Xhosa elder to discuss matters related to sexuality in public. It is no different in the township churches where teaching about sex in the church is unthinkable. That is one of the reasons why PLWHA find it so difficult to disclose their status to the church. Of the six women who attended church regularly interviewed by (Scurry, 2004:78) four of them had not disclosed their status in their religious community. Several of them spoke of going to church more often to seek solace with God, yet they did not seek, or expect, comfort from other church members. This paradox is fascinating – and deeply disturbing - given the women’s strong expressions of faith.

The church has played a critical role in developing and fostering communities of women in South Africa. Networks of religious women are a key site of survival practice and a place where poor and marginalised women are taking control of their lives (Haddad, 2001: 16). In the light of this involvement, one would expect that the church would equally be a site of spiritual support and survival for women living with HIV/AIDS. Listening to their narratives, however, suggests that there is something unique to church, as a church *per se*, that makes it especially difficult to disclose there. Fear of disclosure is not limited to church communities – this research revealed that its pervasive presence was experienced throughout Lwandle. But the continuation of stigma in church communities makes it imperative that churches begin to

wrestle with the reality of HIV/AIDS.

In the early stages of the pandemic, churches were hesitant to become involved with HIV. (Louw 2008:427) likens HIV/AIDS to the 'leprosy' of the 21st century. The pandemic has forced churches to confront it : the question of *how* they choose to confront it is as significant as choosing not to confront it at all. The real danger arises when churches apply biblical texts - such as Leviticus 13:45-46 – inappropriately.

This research began by exploring the ethical debate surrounding: 'Is HIV God's punishment for the promiscuous lifestyle of the members of our modern society?' This question forced the direction of this research towards a theological exploration of the question 'Who is God?' The doctrine of God led in turn to exploring the concept of God as Judge in both the New and Old Testaments and how illness is perceived in both Testaments.

The theological issue at stake with regards to HIV/AIDS is bound up with God-images. Questions such as 'Is God a Judge?' and, if so 'How does God judge?' were posed. The literature confirmed that, indeed, God is Judge. Thus how people interpret the *nature* of that judgment can become problematic. There is an erroneous belief that the Old Testament reveals God solely as a God of wrath and the New Testament solely as a God of love. Other theological writings revealed God's wrath in both the New and the Old Testaments. This study showed that it is not only in the Old Testament that we read stories about sudden destruction, as a divine punishment, overtaking those who thwart God's purposes or flout His mercy. Together with Old Testament stories of God's wrath – such as the fate that befell the 42 men who had taunted Elisha with the words, 'Go up, thou bald head' at Bethel (2 Ki. 12:22-24) - one must hold New Testament stories that speak equally of the 'wrath of God'. We see this in stories such as Herod Agrippa being struck suddenly by a devastating mortal disease (Acts 12:22 -23); or Ananias and Sapphira who were punished by sudden death for tempting the Spirit of the Lord (Acts 5:9).

How then do we understand the image of God – or Jesus – as Judge?

(Packer 1973: 27) identifies four aspects to the image of 'God as Judge':

- a judge is a person with authority
- a judge is a person who is identified with what is good and right
- a judge is a person of wisdom, able to discern the truth
- a judge is a person of power, who is also empowered to propose and execute sentences

In contrast to these helpful images of God as judge, people often revert to negative images of God – 'images which sometimes are provoked even by the teachings of the church' (Louw, 2008: 427). (Ackermann 2003: 89-90) rails against such teaching:

Death is certainly not a punishment for contracting AIDS. Imagine God punishing defenceless, infected women and children with death! Yet death can certainly be a result of sin. We are a very violent species. The body is implicated in the process of sin. The very context in which we live is affected by sin. Innocents suffer. Everything that is 'born' must die. It is part of our condition. The only way to get off the theological merry-go-round [we are mortal from the start] is to accept that our responsibility is to live and to die in loving solidarity with that sighing and groaning community of creatures described by Paul as waiting for 'the redemption of our bodies' (Rom 8:23).

In contrast to the attitudes so prevalent in the church, the women interviewed for this research did not regard HIV as a punishment from God. Instead, they viewed God in a positive way: their images were of God as their loving Father. One woman, who did not know God before her positive status, stated that the virus had brought her closer to God. In their quest to live longer, all the women interviewed said that they regarded God as the Giver of Life and as a source of their strength. They also regarded God as their Provider: they needed employment, and they turned to God to provide it. They literally saw their faith in God as a means of survival. (Haddad 2001:16) calls this 'survival faith.' From the interviews, the point that stood out about God is that they all see Him as their main source of survival: their dependence on God for their daily bread is real. They expected daily mercies straight from God's hand. They expected God to provide work for them so that they could feed their families.

The interesting part of this research is that – despite these positive images of God – the women still did not find the courage to disclose their status to the church. Perhaps they not regard God as a judge: they did not need to, because they already were being judged in very real terms by the church community.

If disclosing one's HIV status proved difficult in the church community, the women found it no less difficult at home. Disclosing their status to their families frequently resulted in them being a blamed for bringing the virus into the marriage. One of the women interviewed confided that, while her husband was watching an AIDS programme on television, he told her that he would leave her if she ever came home and told him that she was HIV-positive (Scurry, 2004:61).

Fear of abandonment – with the permanent change in romantic relationships that so frequently happens as a result of disclosure - is indicative of the most devastating aspects of HIV/AIDS. Women tend to experience this stigma more than men because stigma reinforces

existing forms of discrimination against women. Women, who have been traditionally viewed as 'sexually dangerous' are blamed as carriers of the pandemic. Moreover, the HIV/AIDS pandemic has unmasked the distorted power relationships inherent in a patriarchal society. This 'virus' – the virus that makes people regard women as inferior to men – is perhaps even more dangerous than the HIV virus:

This is the virus that causes men to abuse women. It is the virus that is responsible for the shocking fact that in many countries in Africa the condition that carries the highest risk of HIV infection is that of being a married woman....When the dominant religious tradition in our country (bolstered by cultures that are male centred) has a long and sad history of treating women as second-class citizens, we cannot be surprised that women are victims in a particular way in this pandemic. HIV/AIDS thrives on disordered gender relations. I know that the virus is no respecter of class, race, or gender, but it does have its greatest impact on the most vulnerable members of our society: poor women and children. If you have little education and live in a patriarchal relationship, you have little or no power to negotiate what happens to your body. Once infected, you run the risk of being beaten, thrown out, or even killed, ironically by partners who themselves are the cause of your infection. This is happening daily. So disempowered women therefore choose the path of concealment.

(Ackermann, 2003: 83)

The research explored the link between pastoral care and hope, more particularly, hope in the Resurrection and its implications for PLWHA. The Church as the Body of Christ can serve a vital role by making space for storytelling:

When people who live with the virus tell their stories, they name and claim their identities. Instead of others labelling you or speaking on your behalf, you name *your* experience of *your* reality. Telling our stories also helps us to make sense of what is happening.

(Ackermann, 2003: 86)

Zozo's story illustrates the role of hope in the Resurrection and the transformative power of storytelling. It was this kind of 'realistic' Resurrection hope that was at work in Zozo's life, transforming her story from *Alikho ithemba* (no hope) to *Lelethu* (Jesus is our Hope). Hope changed the direction of Zozo's life. But such hope is too difficult to do alone. The Living

Hope Community Centre – the outreach programme of the Fish Hoek Baptist Church – safeguarded Zozo’s hope with her. Zozo did not hope alone, but hoped with fellow HIV-positive people, who also hoped for her when she had no hope in her life. This is the Body of Christ working at its most effective to challenge and overcome the stigma and prejudices surrounding HIV/AIDS.

The church – as the Body of Christ – has a unique calling. If instead of judgement and abandonment, the church community could be a place in which women’s gifts are recognised and where they are accorded the dignity and justice that is their birthright as members of Christ’s body, it would no longer be ‘party to bolstering male-dominated structures and relationships that presently constitute death traps’ (Ackermann, 2003: 84).

Finally, One way in which the church could help provide the dignity, respect and justice which PLWHA would be through pastoral care and spiritual counselling, provided it was offered in a non-judgmental way.

The researcher found (Louw’s 2008:447) five-phase model useful in understanding the different milestones encountered on the HIV/AIDS journey. Supplementing this understanding with Narrative therapy’s practice of ‘externalizing conversations’ – conversations which separate problems from the people experiencing those problems – helped PLWHA to speak about themselves as being affected by the problem rather than the diagnosis being part of their identity. The linguistic shift from ‘I am HIV/AIDS positive’ to ‘I am living with HIV/AIDS’ can transform how a woman sees herself, her disease and her future. Instead of despair and a future that is foreclosed, women can reclaim a sense of agency, the future has many options and many possibilities, and they can begin to live with hope.

If the research revealed how judgemental attitudes can contribute to the spread of the HI-virus it also showed how pastoral care and spiritual counselling can help to destigmatise PLWHA:

Hearing and telling stories challenges stigma and prejudices. The question of stigma is particularly relevant to persons suffering from HIV/AIDS. Once you are infected, you simply become ‘an HIV positive’, a statistic whose identity is now defined by your status. Stigmas can paralyse us. They deny the active, meaningful, and contributing lives of many HIV-positive people. Through telling and hearing stories, we discover connections and then, hopefully, we

begin to care in new ways because the shared story of our faith is our sounding board. It shows not only Jesus' care and concern for the suffering but confronts us with a person whose life makes sense and gives hope even when he suffers death on a cross.

(Ackermann, 2003: 86)

6.3 LESSONS LEARNED

Perhaps one of the most important lessons learned through this research relates directly to the importance of storytelling and how crucial the kinds of questions we ask are in determining the nature of the response. This emerged very clearly during the pilot group. Because of time pressure, only a short time was allocated for explanation of the questions and subsequent discussion of the answers. This meant that not everyone had a chance to tell their story. Allowing more time for discussion after each question would have made a huge difference and would have made the participants feel more relaxed and at ease with the researcher, allowing even more information to be gathered. Having said this, the nature of the group – and the fact that the group met fortnightly and seldom consisted of the same women – added to the pressure to get the pilot study discussion completed in one interview. Similarly, a different venue could have produced different results. The venue was problematic in that the main reason for the women being at the clinic was not to be interviewed by the researcher, but to be checked by the doctors and to collect the milk formula for their babies as well. As a result, not all of their attention was being paid to the questions that they were being asked at the time.

A better and more trusting relationship with the researcher could have been possible if the women could have come to a place where they could be met by the researcher alone. But because the researcher received access to the participants through the clinic, she had no choice but to conduct the interviews inside the clinic, despite everything else that was going on inside the clinic at that time.

The focus group's venue was different. Although it was not very quiet, it was nevertheless a great deal quieter than the pilot group's venue. The relative lack of interruption enabled the researcher to witness the disadvantage of taking the questionnaires from the English script and translating this into Xhosa as the questions were being asked. The questions therefore had to be asked twice before the women were able to grasp the meaning of the questions.

In contrast to the pilot group where the questions were put to the whole group, the five women who made up the focus group were interviewed individually. After all the interviews

were completed, the researcher remained with them a little longer in order to answer their questions about why this research was being carried out. It was from that casual conversation that the most valuable input came up. The researcher came to the conclusion that in future this kind of research needs to be led by the stories that emerge from the group rather than be shaped by a formal set of questions. The conversation from the PLWHA must lead the direction of the research.

6.4 FUTURE STUDIES

If further empirical research is done on judgemental attitudes in pastoral care and counselling, it might be advisable for the researcher to interview the church pastors as well. The findings of this research did not reveal clearly whether or not the pastors were judgemental. If they were judgemental, was it because they wanted to be judgemental, or simply because they lacked knowledge of the disease or the skill necessary to handle HIV-infected people? Empowering and educating pastors is crucial for taking a stand against the stigmatization surrounding HIV/AIDS.

If pastors were able to address the pandemic of HIV/AIDS in compassionate rather than in judgemental ways, it might help to lessen the fear of speaking about sex in the church. For instance, one of the participants interviewed from the focus group told the researcher off the record that, when her fellow-members saw condoms in her house, they (falsely) assumed that she was promiscuous. To openly support and empower women living with HIV/AIDS, members of the Body of Christ need to be comfortable talking about the issues that affect living with the virus, for example, the use of condoms.

Perhaps greater clarity might have been shed on this research topic had the empirical study been more specific. This might have been possible had the focus group only included church goers belonging to one particular church and had the question (only one question) been posed along these lines of: 'How do you feel about HIV/AIDS in the church and what role should pastoral care and spiritual counselling play?'

6.5 CONCLUSION

The findings of the present research suggest that interventions aimed at destroying the stigma attached to HIV/AIDS should be taken up by the religious community. (Ackermann 2003: 91) calls HIV/AIDS our 'kairos; it is a time when the ordinary rhythm of life is suspended. It is make-or-break time for those of us who have faith. Will it be a time of doom and no hope, or will we find a new unveiling of God's presence and love for us here and now?'

This research has revealed the extent to which stigma fuels the flames responsible for the spread of the HI-virus. The church as the Body of Christ has AIDS (Ackermann, 2003: 91). We also have the promise of the God's love and faithfulness as evidenced in our Resurrection hope. The challenge facing us is enormous; but the 'realistic' hope we have in the Risen Christ means that we are not alone. The researcher would like to conclude this research with reiterating (Pillay's 2008:172) challenge:

If we allow the fire to rage out of control ... it will ravage generation after generation ... until we are no more. And we will be remembered and branded a loveless, uncaring species, responsible for 'their own extinction.' Now that is a reality to consider

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ADDENDUM

Why these questions?

The questions were asked having a culture in mind. By this it means that one get more than one bargain for, in one question. For instance, when one asked how are you doing in Xhosa culture, one get to hear about everybody else in that household and the community or neighbors. The researcher knew that, these questions will give her more than she expects. In a Xhosa culture, when ask a question, one does not get yes or no answer. No or yes answers comes with a lot of information. For example, questions 5, if the researcher would ask just half of question 5. "What were the reactions of your family"? That part is enough to get to hear with everybody else. Exactly because of that, the researcher had to ask guiding questions so that she can get only what she was needed.

Questions asked of the women of Lwandle for both the pilot and focus groups

1. What made you go and have the HIV test?
2. How was the experience? (Describe your feelings.)
3. When the news settled, what went on, in your mind?
4. Was it difficult to disclose your positive status? To whom did you disclose to first and what was their reaction? Is there anybody else to whom you disclosed?
5. What were the reactions of your family, friends, community, minister or congregation?
Answer if applicable.
6. Did you experience any form of rejection or suspicion as a result of this disclosure? If so, name it. Would you describe it as people being judgmental towards you?
7. Tell me about your relationship with God.
8. What role did your faith in God play in this situation?
9. How did you integrate your faith in God with the fact that you are HIV positive?
10. What is your deepest religious/spiritual need?