

**THE ROLE OF RELIGIOUS BELIEF AND
FAITH-BASED ORGANIZATIONS IN COPING WITH
HIV/AIDS.**

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ABSTRACT

The biggest pandemic that the Sub-Saharan Africa is faced with is HIV/AIDS. This research examines the experience and challenges of living with HIV/AIDS; as well as how people living with HIV/AIDS use religious/spiritual coping mechanisms and the effect on their quality of life. In addition, it examines the perceived role and effect of Faith-Based Organisations in enabling or impairing coping with their HIV challenges. A qualitative methodology was adopted and semi-structured interviews conducted with ten individuals living with HIV/AIDS. A thematic analysis of these transcripts revealed that most of the interviewees used religious/spiritual coping methods, which generally led to improved quality of life. However, results also showed that religious beliefs/practices could also be a hindrance to coping.

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DECLARATION

This dissertation was undertaken at the School of Psychology, University of KwaZulu-Natal, Pietermaritzburg. Unless specifically indicated to the contrary in the text, this dissertation is a product of the author's own work.

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CHAPTER 1: INTRODUCTION

“AIDS is a disease. It is an infection, a syndrome, an illness, a disorder, a condition threatening to human life. It is an epidemic – a social crisis, an economic catastrophe, a political challenge, a human disaster. AIDS is known. It has been analyzed assessed assayed, tested, measured, surveyed, considered, reflected, documented, depicted, exhaustively described. Its virus is primal, particular, sub-cellular, mutant, enveloped nitrogenous. Our knowledge of it is clear and precise. But the disease is also unknown. It is guessed, estimated, projected, approximated, sketched, debated, disputed, controverted, hidden obscured. Still, it is mere fact: an event, a circumstance, a happening, a reality a present as the ocean or the moon.”
(Cameron 2005, p.42)

1.1 Overview

In Sub-Saharan Africa there is an increase in the number of people infected with HIV/AIDS. HIV/AIDS has become one of the most debilitating diseases in our time, and coping with HIV/AIDS is more complicated than other chronic illness because of the associated stigma and discrimination. With the increase of antiretroviral medication and possibility of prolonging life, there is a need to investigate ways of helping HIV positive people cope and improve their quality of life.

Faith communities have a long history of supporting people in Africa by doing missionary, educational, and health work; it has been claimed that they have a significant impact not only on AIDS but also on the health consequences and quality of life of people suffering from other diseases (Chikwendu, 2004; Somlai et al., 1996; Somlai, Heckman, Kelly, Mulry, & Multhauf, 1997). Faith-Based Organisations (FBOs) seem to facilitate better coping and quality of life. According to Somlai and Heckman (2000), religiosity may mediate a positive reinterpretation of living with HIV and the psychological outcomes include positive adjustments to stressful life events or an increased commitment to improve coping and quality of life. However, it has also been claimed FBOs may be a source of stigma and discrimination (Liebowitz, 2002).

Minimal work has been conducted in Sub-Saharan Africa on coping with HIV and this research attempts to bridge that gap by looking at the experience and challenges of living with HIV/AIDS, and if and how people living with HIV/AIDS (PLWHA) use religious/spiritual coping mechanisms. In addition, the study set out to examine the perceived role and effect of FBOs in enabling or impairing coping of people who are infected with HIV/AIDS.

CHAPTER 2: REVIEW OF LITERATURE

2.1 The HIV/AIDS pandemic:

HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immune Deficiency Syndrome) have proved to be a catastrophe, worse than predicted. According to Abdool Karim (2005), “the number of people infected with HIV worldwide has increased exponentially from just a handful of cases in the early 1980’s to about 40 million by the end of 2003 and more than 20 million people have died of AIDS” (p.31).

In Africa it would be safe to accept Mandela’s statement that “the AIDS pandemic is claiming more lives than the sum total of all wars, famines and floods, and the ravages of such deadly diseases as malaria. ...it is clearly a disaster, effectively wiping out the development gains of the past decades and threatens the future.” (Abdool Karim, 2005, p.25)

South Africa is one of the hard-hit countries in the world, based on the report of the Department of Health "National HIV and Syphilis Sero-prevalence Survey in South Africa 2004", and published in 2005. It was estimated that 6.29 million South Africans were living with HIV at the end of 2004, including 3.3 million women and 104,863 babies, according to antenatal data. UNAIDS/WHO estimates that around 5.5 million South Africans were living with HIV at the end of 2005, including 240,000 children under 15 years old. The provinces that recorded the highest HIV rates were KwaZulu-Natal, Gauteng and Mpumalanga (Noble, 2006). The effects of HIV/AIDS are more devastating in South Africa, because HIV thrives in areas weighed down by unemployment, homelessness, welfare dependency, social strife, prostitution, crime and a high school drop-out rate. It is not surprising that KwaZulu-Natal has a high rate of HIV, bearing in mind its history of political conflict, violence and poverty (Kustner, 1993, in Lindegger & Wood, 1995).

2.2 Review of HIV/ AIDS stages:

The stages of HIV infection are important because research has found that people experience acute psychological distress soon after diagnosis in the asymptomatic phase and this could be related to the uncertainty of the implication of the HIV status (Mansergh, Marks & Simoni, 1998; Tross & Hirsch, 1988, in Lindegger & Wood, 1995). Consequently, it is likely that people cope differently at each subsequent stage because of being faced by various physical, economic, social and spiritual challenges.

Even though HIV has a highly variable course, according to AVERT.org (2005), HIV infections can generally be categorised into four distinct stages:

2.2.1 Primary Stage of Infection

Also known as acute stage of infection, this lasts for a few weeks, when the virus first establishes itself in the body and is often accompanied by a short flu-like illness. In up to about 20% of people the symptoms are serious enough to consult a doctor, but the diagnosis of HIV infection is frequently missed.

During this stage there is a large amount of HIV in the peripheral blood and the immune system begins to respond to the virus by producing HIV antibodies and cytotoxic lymphocytes. This process is known as seroconversion. If an HIV antibody test is done before seroconversion is complete then it may not yield a positive result. Therefore the test would have to be repeated after three to six months so as to be reliable.

2.2.2 Clinical Asymptomatic Stage

This stage may last for a number of years and is free from major symptoms, although there may be swollen glands. The level of HIV in the peripheral blood drops to very low levels but people remain infectious and HIV antibodies are detectable in the blood, so antibody tests will show a positive result.

Early care for HIV disease is highly recommended because it can give people a better chance of survival and an improved quality of life. People are asked to seek regular medical attention even though they are feeling fine, because the virus could be damaging the immune system already. They need to seek treatment before the onset of symptoms (San Francisco AIDS Foundation, 2006).

2.2.3 Symptomatic HIV Infection Stage

Symptomatic HIV infection is mainly caused by the emergence of opportunistic infections and cancers that the immune system would normally prevent. The immune system is compromised by HIV infection, many people begin to experience some mild HIV disease symptoms, such as skin rashes, fatigue, night sweats, slight weight loss, mouth ulcers, and fungal skin and nail infections (San Francisco AIDS Foundation, 2006).

2.2.4 Progression from HIV to AIDS

The immune system becomes more damaged as the illnesses that present become more severe, leading eventually to an AIDS diagnosis. This does not mean that the person will die because there is an availability of antiretroviral (ARV) therapy that helps prolong life and many opportunistic infections can be prevented and treated successfully. However, not everyone who has HIV develops AIDS, but studies have shown that untreated people do eventually become ill from HIV (San Francisco AIDS Foundation, 2006).

It is important to note that each stage may be experienced as a crisis by the individual; discovering that one is HIV positive is probably traumatic. The progression of the disease and the reduction of CD4 cells is very strenuous as one has to make a decision about medication, the changing of their label to being 'a person with AIDS' can be very frightening and stressful (Hedge et al. 1991, 1992, in Hedge & Sherr, 1995). There is almost an anxious anticipation of each stage. Unfortunately, the person never knows for sure how the disease will progress or whether they will unquestionably go through these

stages. Common to all the stages is the “difficulty of maintaining or initiating relationships” (ibid, p.207).

2.3 Impact of HIV/AIDS:

According to Kelly and St.Lawrence (1988), the consequences of HIV/AIDS on a physical level may include an extreme alteration in energy and physical health, pain, breathlessness, disfigurement or changes in the body image. On the psychological level, one is faced by intense anxiety, depression, helplessness, hopelessness, isolation, and cognitive deterioration. And on a social level it is likely that there is an indirect impact on the person’s life which is evident in the disruption of their relationships, employment, discrimination, housing, and financial status. A person’s entire well-being and life-style is affected and this effect often spreads to the family and friends as well as the community at large.

2.3.1 Direct Impact

This section highlights the direct impact of HIV/AIDS on the infected and affected individuals. It looks at how HIV affects people’s lives, how they cope physically and psychologically without the external influence of other people or factors. It shows the difficulties people experience and how they have to struggle to cope.

Depending on the stage of infection the following are physical symptoms with which some people infected with HIV are faced: Loss of up to 10% of their body’s weight, swelling of the lymph nodes, fever, night sweats, abdominal discomfort, headaches, shingles, persistent cough, recurrent oral ulcerations, neurological abnormalities, persistent and intractable chronic diarrhoea, bacterial skin infections and skin rashes plus other opportunistic infections (Van Dyk, 2001).

According to Van Dyk (2001), some people are so overwhelmed on a psychological level after being diagnosed with HIV that they use denial to temporarily reduce the emotional

stress. Some people living with HIV/AIDS (PLWHA) experience immense fear of dying alone in pain; fear of an uncertain future and worry about infecting others. They also experience loss of control over their lives, autonomy, ambitions, sexual relationships and the loss of financial stability. These individuals sometimes feel guilt and anger towards themselves for having contracted HIV and for the possibility of having infected others. This may lead to depression, which might lead some to struggle with suicidal ideation or even to commit suicide to avoid the pain or to exact control over their illness.

It is also important to consider the difficulties experienced by other people who are affected by HIV; these often include the people who have to care for the infected individual. They often experience similar feelings and difficulties as the infected people. These difficulties are highlighted by Van Dyk (2000, in Van Dyk, 2001). They struggle with the knowledge that their family member, friend or partner is HIV positive because some of them blame themselves, while others are not sure whether to accept the infected person or reject them. The affected also often experience the anxiety and fear of being infected with the virus by their partners. They are also sometimes angry at the infected person for getting infected. They may also start to anticipate the loss of the infected person. HIV also brings stress to the affected person because of the demands that the infection places on them. This may make the affected person feel helpless in dealing with the disease. For example, having to help the sick person take their medication, cleaning and dressing their wounds especially when they are in the AIDS stage and also sometimes looking after the children of the infected person. Unfortunately, because of an untimely death, some of the infected people leave behind homes headed by grandparents or even children.

2.3.2 Indirect Impact

This section looks at the response of family, friends and society to PLWHA and the consequences of their responses to the quality of life of people living with HIV. Stigma and discrimination are some of the major consequences that develop out of the people's responses to the discovery of HIV infection in others.

2.3.2.1 Stigmatisation

Much of the work on disease stigma was begun by Erving Goffman (1963). He viewed the stigma as “an attribute that is deeply discrediting” (p.13). He saw it as the construct formed by society based on what the society defines as deviant or different (ibid). He further highlighted that people who are defined by society as unacceptable because of a disease acquire a ‘spoiled identity’, which leads to them being disrespected and being discriminated against (Deacon, Stephney & Prosalendis, 2005) in that society. According to Gilmore and Somerville (1994), the stigma can also be “a response to fear, risk or a threat of disease that is incurable and can be deadly” (in Nyblade, Pande, Mathur, MacQuarrie, Kidd, Banteyerga, Kidanu, Kilonzo, Mbwambo, & Bond, 2003, p.9). Thus HIV/AIDS is a highly stigmatised disease because it is incurable and has a lot of uncertainty surrounding it. It is also associated with socially unacceptable behaviour such as sexual promiscuity, homosexuality and drug use. It is also feared to be highly contagious and is associated with complicated symptoms and premature death.

Stigma is the negative belief that people have about HIV/AIDS and PLWHA, but discrimination is not always a result of stigma because discrimination refers to people’s behaviour towards others and in the context of HIV. Thus, discrimination refers to those things people do to unfairly disadvantage PLWHA (Deacon, Stephney & Prosalendis, 2005). Therefore people could hold negative beliefs about other people but may not necessarily behave accordingly. Their behaviour may also be motivated by other factors such as racism or sexism.

People who stigmatise others assume that they cannot get infected with HIV and it is the other people that are not in their group that are infected and can get infected with the disease. As Deacon, Stephney and Prosalendis (2005) state:

“People articulate their own group identities as different in key risk-reducing ways from groups stigmatised as deviant and ‘other’. These “others” are then blamed for having risk-enhancing characteristics. A wide variety of groups have been defined as particularly at risk for (and somehow responsible for) contracting HIV/AIDS, including supposedly ‘oversexed’ black people, white people,

‘promiscuous’ gay men, commercial sex workers and women in general. Some of these stigmatising discourses become widely accepted because they are supported by powerful groups.” (p.19)

According to Deacon, Stephney and Prosalendis (2005) recently, “stigma has come to mean almost anything people do or say that stands in the way of rational responses to public health campaigns on HIV/AIDS, or that restricts the access of people living with HIV/AIDS to employment, treatment and care, testing and a reasonable quality of life.” (p.9)

People who are stigmatized not only experience direct stigma from others but there is also self-stigmatization. This is also referred to as internalized stigma. Self stigmatization is a result of people accepting some of the negative socially created judgments on disclosing that they are HIV positive. Deacon, Stephney and Prosalendis (2005) state that when PLWHA are stigmatised, they experience “the status loss and moral judgments projected onto them. This may be direct (when a person expresses stigma directly to them) or indirect (when a person living with HIV/AIDS reads a newspaper in which stigmatizing views are expressed)” (p.43). As a result of stigma being internalized it leads to “self-doubt, lower self-esteem, depression, immunosuppression and even premature death” (Deacon, Stephney & Prosalendis, 2005, p.43). These have a devastating effect on how a person copes with the illness; it reduces their motivation to challenge the stigma and affects their disclosure and treatment seeking behaviour (ibid). Nyblade et al., (2003), stress that the dynamic nature of stigma presents a further challenge because it changes as an individual progresses from HIV to AIDS, as the HIV evolves in particular communities.

2.3.2.2 Disclosure

Disclosure is one of the hardest tasks for someone who is HIV positive. People disclose depending on the accessibility and effectiveness of social support, the person’s stage of infection and their state of health. Disclosure helps an individual access practical and

emotional support, but it also facilitates a more effective coping and psychological adjustment to the disease (Holt, Court, Vedhara, Nott, Holmes & Snow, 1998). However, disclosure is often affected by stigma and self-stigmatisation. This highlights the grave need to reduce stigma in the community in order to facilitate disclosure and the normalizing of HIV/AIDS.

2. 4 Coping and Quality of Life

The subject of coping has received a lot of attention over the years in many disciplines and more so in psychology. Much research has dealt with how best to cope with stressful situations, or how people have in the past overcome these situations. According to Lazarus and Folkman (1984), coping has been explained by various theories, one from the tradition of animal experimentation and the other from psychoanalytic ego psychology. The animal model was found to be “simplistic and lacking in cognitive-emotional richness and complexity that is an integral part of human functioning” (ibid, p.190). Ego psychology became a more widely used theory and Lazarus and Folkman developed the transactional approach because of some of the deficiencies of the traditional theories.

2.4.1 Definitions

Coping is a complex phenomenon and different theorists have introduced various definitions depending on their approach. Nevertheless, two of the most widely used approaches in literature on coping are the ego psychology and the transactional approach. The ego psychology perspective focuses on “how an individual’s internal, psychological processes govern attempts to cope with the use of defence mechanisms” (Reeves, Merriam, & Courtenay, 1999, p. 345). It is defined as “realistic and flexible thoughts and acts that solve problems and thereby reduce stress” (Lazarus & Folkman, 1984, p. 190). Therefore, it is a cognitive process of dealing with stress and focuses on the person’s relationship with the environment, unlike with ego psychology where the measurements are based on classifying people so as to make predictions of how they will cope (ibid).

According to Freud (1923/1961), “the ego is armed with mechanisms for dealing with conflict. Denial, repression, projection, regression, sublimation, and reaction formation are some of the defense tools the ego has to reduce tension” (in Pargament, 1997, p.75). The defenses work by distorting the actual threat or by avoiding it in order to alleviate the fear. Denial is one of the most common defenses used. Denial has been found to be effective in the short term but may be maladaptive in the long run (Weaver et al., 2004).

Lazarus and Folkman (1984) came up with principles that specify the conditions under which denial and denial-like forms of coping might or might not be constructive:

1. When there is nothing constructive that people can do to overcome a harm or threat, that is, when there is no direct action that is relevant, denial or denial-like processes contain the potential for alleviating distress without altering functioning or producing additional harm.
2. Denial and denial-like processes may be adaptive with respect to certain facets of the situation, but not the whole. For example, patients with diabetes can deny the seriousness of the situation as long as they also continue to give vigilant attention to diet, activity level, and insulin.
3. The timing of denial and denial-like forms of coping may have major significance. Denial may be less damaging and more effective in the early stages of a crisis, such as sudden illness, incapacitation, or loss of a loved one, when the situation cannot yet be faced in its entirety, rather than in later stages.

The above is an illustration of defences using denial as an example, but Lazarus and Folkman (1984) claim that in coping:

- 1) no strategy should be labelled as inherently good or bad;
- 2) the context must be taken into account in judging coping;
- 3) principles must be developed with which to judge whether a particular coping process fits both personal and situational aspects of the transaction.

The transactional approach to coping for which Lazarus and Folkman (1984, in Reeves, Merriam, & Courtenay, 1999) are renowned defines coping as a “process that unfolds in the context of a situation or condition that is appraised as personally significant and as taxing or exceeding the individual’s resources of coping” (Lazarus & Folkman, 1984, in Folkman & Moskowitz, 2004, p.747). It therefore depends on what a person consciously “actually thinks or does in a specific context” (Lazarus & Folkman, 1984, in Reeves, Merriam, & Courtenay, 1999, p. 344). There are different stressors in daily life and they all differ in intensity depending on how an individual appraises them. The stressor also affects a person’s quality of life. Koenig, George, and Siegler (1988, in Gordon, Feldman, Crose, Schoen, Griffing, & Shankar, 2002) postulated that how a person appraises a situation and the attribution the person makes about the situation influences the coping behaviour or method of coping used. This is similar to Lazarus and Folkman’s theory.

Folkman and Lazarus (1990) stated that:

“These cognitive and behavioural efforts are constantly changing as a function of continuous appraisal and reappraisals of the person-environment relationship... Some of the changes in relationship result, in part, from coping processes directed at altering the situation that is causing distress (problem-focused coping) and/or regulating distress (emotional-focused coping), from changes in the person that are a result of feedback about what has happened, and from changes in the environment that are independent of the person” (p.210)

Therefore, this makes it difficult to generalise coping behaviour because different people react differently and individuals may not react in the same way each time they are faced by the same or a different stressor because of different appraisals. The person often determines whether he has sufficient resources to cope with the stress by assessing his time, money, the capacity of his coping skills in order to know whether he will be able to overcome the stressor (Taylor, 1990). Heller and Swindle (1983, in Pargament, Ensing, Falgout, Olsen, Reilly, Van Haitsma & Warren, 1990) summarise this by saying that the constraints on coping include the “individual’s level of competence, personality

characteristic, attitudes and beliefs, financial status, physical health status and social networks” (p. 795).

Overall, the transactional approach has the following basic working assumptions (Lazarus, 1993; Lazarus & Folkman, 1984a, in Zeidner & Saklofske, 1996) firstly, coping strategies should not be prejudged as adaptive and maladaptive because the coping process is embedded in context and changes in accordance with life conditions, secondly, coping effectiveness must be empirically demonstrated, finally, coping efforts should not be confounded with outcomes.

Lazarus and Folkman (1984, in Maes et al., 1996) believe that when people are confronted with a stressor, the way they evaluate the stressor determines how they react emotionally or behaviourally. They have identified two evaluation or appraisal processes, these are primary and secondary appraisal processes. The primary appraisal process assesses the personal meaning of the event for the individual to determine whether it is a positive or a negative event. This means that if a person sees a condition or situation as a positive experience, he is likely to have positive emotions, unlike when a person perceives the condition or situation as negative, signifying that it threatens the physical and psychological self, negative emotions such as anger or anxiety are likely to come forth.

In secondary appraisal, the individual normally asks “what can I do about it?”. The person tries to evaluate coping capacity and resources in order to be able to deal with external and internal demands. According to Lazarus and Folkman (1984, in Maes et al., 1996; Reeves et al., 1999; Taylor, 1990) the external demands refer to the event or condition, which leads to problem-focused coping, while internal demands refer to the emotional reaction, which leads to emotion-focused coping. Problem-focused coping attempts to solve or ward off the problem (Reeves et al., 1999) and it is usually employed when a person believes they can influence the situation, they view the stressor as controllable (Taylor, 1990). On the other hand, emotion-focused coping attempts to

decrease negative emotions (Reeves et al., 1999) and Taylor (1990) says it is useful for managing uncontrollable stressors.

The transactional approach is widely used in studies dealing with life threatening issues, for example, coping with chronic illness (Maes, Leventhal, & de Ridder, 1996, in *ibid*). The popularity of this approach could be partly due to easy data collection as it relies largely on “measures of self report (usually retrospective), such as the Ways of Coping Questionnaire (WCO)” (Reeves et al., 1999, p. 346). Even though the method is efficient when collecting data from a large sample, it is problematic to study chronic illness in this manner because the coping process is ever changing and hence it is difficult to capture how it unfolds over time (*ibid*).

2.4.2 Coping with Chronic Illness

Stress is deemed to affect different spheres of a person’s life, both physical and mental health; it also affects people financially, socially as well as their environment at large. One of the major stressors is poor health especially when faced with chronic illness, due to its unpredictability and high mortality rate. Chronic illness is a “long-term or permanent illness that interferes with a person’s ordinary physical, psychological, or social functioning” (Hymovich & Hagopian, 1992, in Gordon, Feldman, Crose, Schoen, Griffing & Shankar, 2002, p.162). Cancer, diabetes, arthritis, cardiovascular disease and rheumatic diseases are examples of chronic conditions.

There are differences in the way the same condition afflicts individuals and the effect it has on their life span, but what is clear is that the chronic conditions are unstable and change over time (Maes, Leventhal, & de Ridder, 1996). Therefore, people are usually in a constant state of trying to cope because the chronic illness affects their long term planning and family relationships and this is why coping is seen as an ongoing process. As Sidell (1997, in Gordon et al., 2002) says “the ultimate goal of a person who has been affected by a chronic illness is to adjust and adapt” (p. 163). The chronic illness also affects the individuals’ quality of life, more care and support that may not be readily

available is required; the individual may have financial constraints which may affect the quality of medical support received. The extended duration of the disease exacerbates an increase in stressful factors such as job loss, divorce or disability which affects a person's coping (Maes et al., 1996).

Adjustment to a chronic illness means learning to live with the disease on a daily basis. Some personal factors such as a person's attribution of the illness and individual personality traits also influence how a person copes with a chronic illness (Gordon et al., 2002). Some people may deal with chronic illness by denial or the use of other defences while other people attempt to accept the disease so as to reduce their anxiety. For example, Charmaz (1995, in Gordon et al., 2002) proposed a three stage process by which individual adapts to chronic illness:

1. experience and assessment of the initial impairment
2. recognition of the probable impact of the illness on one's future
3. acceptance of the illness

2.4.3 Coping with HIV

HIV is a chronic illness due to its irreversibility. It also manifests itself differently in different individuals and at different stages. Being diagnosed as being HIV positive is a very devastating and traumatic experience for the individual, who is faced with the possibility of reduced life expectancy and possible stigma associated with the virus. A person living with HIV is faced with "various psychological challenges caused by multiple losses, fears and anxieties, uncertainties, feelings of shame, guilt, self-blame, and social stigmatisation" (Plattner & Meiring, 2006, p. 241). The individual has to find a way of dealing with the above challenge in order to improve the quality of life.

Burish and Bradley (1983) stress that the biological, psychological and economic stressors are not unique to HIV as they are also experienced by people faced with other chronic life-threatening illnesses (in Holt et al. 1998; Hedge & Sherr, 1995). However, certain difficulties such as stigmatization and discrimination are more common to HIV

and thus complicate the coping process. Disclosure is especially difficult for PLWHA because they risk suffering discrimination (Hedge & Sherr, 1995).

Research has found that people cope in different ways, but largely attempt to make meaning of their present circumstances (Plattner & Meiring, 2006). For example, Pakehan, Dadds and Terry (1994) proposed that a person copes differently depending on the stage of infection. Therefore emotionally-focused coping in the symptomatic stages because the infection seems to be more uncontrollable is used, unlike in the asymptomatic stage when a more problem-focused way of coping is preferred (in Reeves et al., 1999). Therefore the support and care needs should be determined according to the stage of the individual's disease because different symptoms of the disease are developed at each stage (Burry et al., 1992; Department of International Development, 1998, in Nashandi, 2002).

Being diagnosed as HIV positive poses a major challenge to the individual. Even though the person is faced with similar problems as other people such as “separation, loss, life adjustment, relational conflict, or search for meaning – HIV + persons experience these issues with a higher level of intensity and a greater sense of urgency” (Landau-Stanton et al., 1993, p.267). This challenges how a person has learned to cope in the past with other stressful situations in their life. According to Jenkins and Guarnaccia (2003), HIV stressors bring about appraisals and coping patterns that differ from other conditions. This is because the stressors “include not only fatality, specific symptoms, treatment, side effects and other physical features, but also secondary social concerns, such as lifestyle stigma, impoverishment and relational implications of getting and passing on the infection” (p. 409).

In South Africa there is a particular challenge to coping with HIV/AIDS because in the past the extended family often assisted with emotional and financial assistance, but because of the high prevalence of HIV a lot of family members have passed away and the “traditional coping mechanisms are stretched to the limit” (Rugalema, 1999, in Nashandi, 2002, p. 29). These stressors are often chronic (Weaver et al., 2004) in nature and

difficult to cope with. There needs to be an effective way of coping because this brings about a better quality of life and reduction of risk-taking behaviour.

2.4.3.1 Ways of Coping/Pathways:

As we have seen above, for behaviour to be defined as coping, a person must be in a process of trying to manage the demands on them and must not perceive these as exceeding available resources (Lazarus & Folkman, 1984). This is because coping is “a subset of adaptation activities that involves effort and does not include everything that we do in relating to the environment” (ibid, p.199). As a result people cope differently and use a variety of coping strategies so as to manage the stressor(s).

The strategy that a person uses is influenced by how the person appraises a situation and what she or he believes would be most effective because a person evaluates his/her resources and determines whether they are sufficient and whether he has the necessary capabilities and skills to overcome the harm, threat or challenge (Taylor, 1990). A person decides whether they can deal with the stressor by themselves or whether they need the assistance of others or assistance from a Supreme Being in order to cope.

Another factor that seems to influence coping is perceived control. According to Taylor (1990) psychological control has been found to be important in interventions to improve coping with stressful events. This is because “those who believe that they can exert some controlling behaviour in response to a stressful event, whether behavioural or cognitive, appear to adjust better to those stressful events than those without such feeling of control” (ibid, p.45). Pargament (1997) also had similar findings in religious coping. Therefore there is a question of whether people choose a pathway depending on what helps them to attain and exact control over the stressful situation or whether they choose a pathway that is most familiar to them, or both.

Pargament (1997) suggests that people choose religious coping methods depending on:

- 1) Personal level: greater religious coping is found in people who have more religious commitment and involvement, for example, the poor, the elderly and women, as well as those who are troubled.
- 2) Situational level: religious coping is more common in situations that are more threatening, serious and harmful than in other situations.
- 3) Contextual level: religious coping is greater in certain congregations and cultures that are more involved in their religious contexts.

2.5 Religious Coping:

2.5.1 Definitions

Religion is defined differently from person to person and across cultures. According to Pargament (1999), traditionally religion has been called “the supernatural, the ultimate, the institutional, the creedal, the ritual, the experiential, the ethical, the temperamental and the directional” (p.4). He further adds that religion seems to have evolved to a narrower definition of being seen as institutionalized and formalized belief that is static.

For Pargament religion is a “search for significance in ways related to the sacred” (1997, p.32). He further explains his definition by saying that by search he means “efforts not only to find significance but to conserve significance once found or transform significance where necessary”. By significance he means “whatever people value in their lives-be it psychological, social, physical or spiritual; be it good or bad” (1999, p. 11). However, he makes it clear that not all searches are religious. For it to be religious it has to be related to the sacred, the sacred is normally viewed as the common endpoint or destination in most religions, for example, Nirvana or the Kingdom of God, but what is important is that a religious pathway is taken regardless of the destination. Some examples of sacred pathways that people can take in search of significance are “attendance at religious congregations, religious beliefs, involvement in prayer and

rituals, religious coping ...these pathways may or may not lead to sacred destinations” (Pargament, 1999, p. 12).

However, the destination could be sacred because people are often in search of different destinations. They could be in search of God or a church community or religious rituals, all of which could be found through traditional or non-traditional means, they can also be found through “personally created pathways or established pathways created by institutions, through healthy or unhealthy behaviours” (p.12).

According to Pargament (1999) spirituality is a “search for the sacred” (p.12). He stresses that spirituality without a sacred core has no centre. It involves how people’s thoughts, emotions, actions and their relationships as they search, conserve, and if necessary change the sacred in their lives. It is important to note that “the sacred encompasses concepts of God, the divine, and the transcendent, but it is not limited to notions of higher powers” (ibid). Spirituality therefore seems like a flexible and dynamic concept and the definition changes depending on the context.

The above could be summed up with Lorenz et al. (2005) who define religiousness as “a social context that facilitates and validates spirituality; spirituality has been defined as the feelings, thoughts, experiences, and behaviours that arise from searching for the sacred” (p. 775).

2.5.2 Nature of Religious Coping

When people were asked how they cope with a crisis or disease, a number of people mentioned religion. For example, in a study conducted by Siegel and Schrimshaw (2002) on the perceived benefits of religious and spiritual coping among older adults living with HIV/AIDS, it was found that even people who had stopped attending religious services sought out some kind of spiritual/religious involvement on being diagnosed with HIV to help them adjust to their illness. In an earlier study by Koenig, George, and Seigler (1988, in Pargament, Ensing, Falgout, Olsen, Reilly, Van Haitsma & Warren, 1990) a

sample of a hundred adults were asked to describe the coping behaviours they used to deal with specified stressful events. 45% of the sample identified religious coping. The most commonly employed activities were trust and faith in God, prayer and help and strength from God.

Religion is cited more than any other coping resource, in particular by elderly people, minorities and individuals faced with life-threatening situations (Pargament 2004; Pargament, Koenig & Perez, 2000; Somlai & Heckman, 2000). Global indicators of measuring religiosity (e.g., frequency of prayer, congregational attendance, and faith in God) have been few and limiting, they have not answered the question of the role of religion in coping (Bahr & Harvey, 1979; Sherkat & Reed, 1992, in Pargament, Koenig & Perez, 2000). Considering that religiosity is multidimensional, most of the global indicators are mainly related to religious coping but also measure more general modes of coping, making it difficult to identify specific religious effects.

In the late 1990s, Pargament and his colleagues developed the RCOPE (Pargament, Koenig & Perez, 2000), which was used to examine how the individual uses religion to deal with and understand their life-threatening situation (ibid). Folkman and Moskowitz (2004) report that the RCOPE was designed to assess five religious coping functions:

- 1) Finding meaning in the face of suffering and battling life experiences,
- 2) Providing an avenue to achieve a sense of mastery and control,
- 3) Finding comfort and reducing apprehension by connecting with a force that goes beyond the individual,
- 4) Fostering social solidarity and identity, and
- 5) Assisting people to give up old value objects and find new sources of significance.

Pargament, Koenig and Perez (2000) stress that even though the RCOPE method of assessment is efficient, it does leave some questions about the functional roles of religion in coping unanswered. This is because “it is not enough to know that an individual prays, attends church or watches religious television. Measures of religious coping should

specify how the individual is making use of religion to understand and deal with stressors” (ibid, p.521).

The subjective experience is important in order to know how an individual appraises illness in order to cope. As Mathews et al. (1998, in Somlai & Heckman, 2000) concluded,

“ religiosity is an effective support mechanism in coping with psychosocial stressors; that religious coping efforts are multidimensional and often involve a search for spiritual meaning and personal support; that faith congregations provide important social networks and support that facilitate personal coping and adjustment efforts; and that these congregations provide an array of instrumental, informational, and emotional support resources” (p.58).

Pargament (1997) believed that people turn to religion because its pathway leads to many different destinations and helps people find what they value in their lives. Some people are in search of meaning. Others search for comfort and solace from pain and worry; assurance, hope and strength to continue with a life of chronic illness and to have a better quality of life. Therefore, people are in search of psychological, social and physical nourishment, and this is often achieved through prayer or following a prescribed lifestyle such as avoiding drugs and alcohol, abstinence before marriage, or being a vegetarian. Finally, he believes that people are usually in search of a community in order to have a sense of belonging; however, this may also have an alienating effect because people who do not belong to that religious community may face hostility as they do not fit into what may have narrowly been defined as a community.

In summary, religion is involved in coping in three main ways according to Pargament (1990):

1. It can be a part of each of the elements of the coping process. Religious appraisals are used to explain the life events which are at least in part religious in nature such as baptism, marriage and divorce.

2. Religion can contribute to the coping process, for example Spilka, Hood and Gorsuch (1985) found that religious involvement decreases the likelihood of some behaviour including drug and alcohol abuse and non-marital sexual activities.
3. Religion can be a product of the coping process especially through attribution. For example, research by Pargament and Hahn (1986) examined the religious responses of college students to four types of imagined life events: positive, negative, just world and unjust world. The results showed that unjust world events were more likely to trigger attributions to God's will; positive outcome events were attributed most often to God's love and negative ones to God's anger.

Pargament and his colleagues (1997, 1998) developed an instruments typology focusing on a several methods of coping rather than just on one. This was guided by "breadth rather than depth" (Pargament, 1997, p. 298). The patterns were positive and negative coping. Positive religious coping methods are based on a secure relationship with God, a belief in a greater benevolent purpose in life and a sense of spiritual connectedness with a religious community (Pargament et al., 1998).

The forms of religious coping that are part of this pattern are the following:

1. Benevolent religious reappraisals – stressor redefinition through religion benevolent;
2. Collaborative religious coping – seeking control through problem solving with God;
3. Seeking spiritual support – searching for comfort and reassurance through God's love and care;
4. Spiritual connection – seeking a sense of connectedness with transcendent forces;
5. Religious purification – searching for spiritual cleansing through religious actions;
6. Seeking help from clergy or church members – searching for comfort and reassurance through the love and care of congregation members and clergy;
7. Religious helping – attempting to provide spiritual support to others;

8. Religious forgiveness – looking to religion for help in letting go of anger, hurt, fear associated with an offence;
9. Reappraisals of God's powers – redefining God's powers to influence the stressful situation.

Negative religious coping methods are a product of religious struggles in an insecure relationship with God and a sense of disconnectedness with the religious community. The following are religious coping methods that are part of this pattern:

1. Punitive religious reappraisals – redefining the stressor as a punishment from God for the individual's sins;
2. Demonic religious reappraisals – redefining the stressor as the act of the Devil;
3. Spiritual discontent – expressions of confusion and dissatisfaction with God;
4. Self-directing religious coping – seeking control through individual initiative rather than help from God;
5. Interpersonal religious discontent – expressions of confusion and dissatisfaction with clergy or church members.

Pargament (1997) stresses that people do not use one religious coping method during a stressful situation, but rather use a combination of religious coping methods. For example, in the study by Pargament, Smith and Koenig (1996, in Pargament 1997) on victims of the Oklahoma City bombing, they found that several religious coping methods were used in combination. The positive pattern of coping consisted of several religious coping methods such as: seeking spiritual support, religious forgiveness, collaborative religious coping; while the negative religious coping involved: spiritual discontent, punishing God reappraisals, interpersonal religious discontent and many more.

Pargament further looks at two possible ways that people use religion depending on their religious orientation to achieve their goals. He defines orientations as “general dispositions to use particular means to attain particular ends in living” (1997, p.59). The two religious orientations were a brain-child of Gordon Allport (1954), who was interested in the paradox of religion and tried to understand how people used their

religious orientations for both good and bad. For example, he highlighted that “one minister in war-torn Europe martyrs himself to protect the Jews in his village while another wraps his anti-Semitism in the cloak of religion” (p. 61, in Pargament, 1997). Allport and Ross (1967 in *ibid*) came up with the two religious orientation categories that people ascribe to in order to achieve their goals, which may have a positive or a negative end.

On the negative side is the extrinsic religious orientation:

“A person with an extrinsic religious orientation is using his religious views to provide security, comfort, status, or social support for himself – religion is not a value in its own right, it serves other needs, and it is a purely utilitarian formation. Now prejudice too is “useful” formation: it too provides security, comfort, status, and social support. A life that is dependent on the support of extrinsic religion is likely to be dependent on the supports of prejudice.” (p. 441, in Pargament, 1997, p. 61)

On the positive end is the intrinsic religious orientation:

“The intrinsic religious orientation is not an instrumental device. It is not a mere mode of conformity, nor a crutch, nor an overarching religious commitment. In internalizing the total creed of his religion the individual necessarily internalizes its values of humility, compassion, and love of neighbour. In such a life (where religion is an intrinsic and dominant value) there is no place for rejection, contempt, or condescension toward one’s fellow man.” (p. 441, in *ibid*)

Therefore, the person with an extrinsic orientation attempts to control future outcomes by means of prayer or prescribed rituals, while the intrinsic person gives up the need to be in direct control of the event and believes that God is in control and they will be able to cope (Spilka, Shaver & Kirkpatrick, 1985). The orientations describe the two relationships individuals could have with religion that might determine the pathway they are likely to take in crises. As Pargament (1997) put it: “the orienting system is generic, one step removed from the specific coping methods the individual uses in particular situations” (p. 283). The orientation does not tell us what the outcome will be because this depends on the religious coping method used in the particular situation.

Nevertheless, religious coping has been found to have a close connection with mental health depending on the religious coping methods used by individuals (Pargment et al., 1998, 2004). The use of positive religious coping methods, such as spiritual support and benevolent religious appraisal of negative situations leads to greater well-being and improved mental health status, reduced rates of mortality, stress-related growth, and spiritual growth. On the other hand, greater use of negative religious coping methods, such as attributions of situation to a punishing God and dissatisfaction with clergy, is linked to more psychological distress such as depression, anxiety and poor resolution of the negative life event.

2.5.3 Religious Coping with Chronic Illness

There are different reasons why people turn to God in a time of disease. For some it is because he is reliable and accessible (Kirkpatrick, 1992, in Siegel & Schrimshaw, 2002), some people search for comfort and solace from pain and worry, therefore needing assurance and hope to have the strength to continue living with a chronic illness (Pargment, 1997); while others are able to see the meaningfulness of their suffering which is for a higher purpose. According to Abraido-Lanza, Vasquez, and Echeverria (2004, p. 91) religious coping involves “the use of cognitive or behavioural strategies that are based on religious beliefs or practices (e.g., praying, seeking comfort or strength from God)”. These are all activities that a person engages in with a particular goal in mind to curb the disease or stress in the person’s life.

When in crisis, the individual may react behaviourally or cognitively. According to Dull and Skokan (1995, in *ibid*) there are two cognitive processes that are applied when dealing with chronic disease such as arthritis, depending on the individual’s religious beliefs. These are: a) religion increases a sense of control over stressful situations; b) religion gives a sense of purpose and meaning for the adversity. In finding meaning with religious coping it is possible to accept the illness because of the belief that God has a greater plan for them.

Mathews et al. (1998) concluded that:

“religiosity is an effective support mechanism in coping with psychosocial stressors; that religious coping efforts are multidimensional and often involve a search for spiritual meaning and personal support; that faith congregations provide important social networks and support that facilitate personal coping and adjustment efforts; and that these congregations provide an array of instrumental, informational, and emotional support resources” (in Somlai & Heckman, 2000, p.58).

This kind of support is critical for a person suffering from a chronic illness because they are often dealing with physical pain, disability, faced with the possibility of death, financial difficulties as well as other problems.

2.5.4 Religious Coping with HIV

Some of the concerns for PLWHA are related to their “physical and neurological deterioration, loss of financial resources, the prospect of an early death, significant changes in social relationships, disruption of existing relationships, and barriers to the formation of new social ties” (Heckman et al., 1996, in Somlai and Heckman, 2000, p.59). These concerns make HIV/AIDS a unique chronic disease to deal with as compared with most of the others, because people tend to move away from the HIV infected person, rather than draw closer to support the person, as is common with most other diseases.

As a result, coping with HIV becomes a major challenge to individuals and their families. If the person is brave enough to disclose their status, they are often rejected. The majority of people usually lack sufficient social support and may turn to a Higher Being or to religious communities for support. For example, Somlai et al. (1996) found that “persons living with HIV/AIDS were more likely to participate in prayer practices and formal religion than their non-infected counterparts” (in Somlai & Heckman, 2000, p.58). HIV also possesses a challenge because of its multifaceted dimensions that create an unpredictable and uncertain environment as people struggle with their deteriorating

health. Their previously held spiritual beliefs are also challenged and this may affect their mental health and coping (Somlai, Kelly, Kalichman, Mulry, Sikkema, McAuliffe, Multhauf & Davantes, 1996).

According to Pargament et al. (2004), the following are examples of religious and spiritual coping methods used by individuals with HIV: a) spiritual transformation when the past spiritual significance can no longer be conserved, b) belief in a higher power, c) prayer, d) belief in miracles, e) collaboration between themselves and God/Higher power.

As stated by Somlai and Heckman (2000), “religiosity may mediate a positive reinterpretation of living with HIV; psychological outcomes may include positive adjustments to stressful life events or an increased commitment to improve one’s coping” (p.59). Religious coping strategies may be intrinsically or extrinsically seeking comfort and well-being in the adjustment to the uncertainty of living with HIV/AIDS.

Most studies have found that religiosity and spirituality are more important to patients with HIV as compared to the general population (Lorenz et al., 2005). Religion and spirituality may facilitate coping and may enhance the patient’s experience of living with HIV. This may be because the person is able to explain his/her illness and no longer feels alone or lost. There is also a renewed sense of hope especially if the appraisal of the situation is positive. There may be a greater ability to deal with AIDS if they no longer view it as punishment (Somlai & Heckman, 2000). Research among people with HIV suggests that “spirituality occupies a significant role; often providing them with a context in which they can find meaning in their lives and stimulating psychological and spiritual growth” (Pargament et al., 2004, p.1203).

Nevertheless, there have been very few studies done on the role of religious/spiritual coping among PLWHA and even fewer have “systematically investigated links among quality of life and spirituality among people living with HIV/AIDS” (Somlai & Heckman, 2000, p.59). Recently, some studies have been done to examine the role of religion and spirituality in PLWHA and their adjustment to the illness. For example, in a

study of 106 HIV-infected gay men, Woods and Colleagues (1999b, in Siegel & Schrimshaw, 2002) found that religious items such as ‘put my trust in God’ or ‘find comfort in religion’ and not religious attendance or practices such as prayer, were associated with lower levels of depression.

Similar findings were noted in a study of 33 HIV- Seropositive African – American women (Woods, Antoni, Ironson, & Kling, 1999). Research has established that people with HIV/AIDS are more at risk of suicide, but religious coping helps the individuals find a renewed sense of purpose in life (Pargament et al., 2004) and hopefully this may also reduce the incidence of suicide by PLWHA.

Pargament et al. (2004) further says that “negative religious coping occurs when major life stressors pose a threat or challenge, not only to the physical and psychological health and well-being, but also to the individual’s religious and spiritual world view” (p.1201).

There is a unique variable that may affect the religious and spiritual response to HIV/AIDS and this is self stigmatisation and perceived stigma. According to Deacon, Stephney and Prosalendis (2005) self stigmatisation is when a person accepts the negative social judgments about their identity, while perceived stigma is the stigma one expects to receive from others when one tests HIV positive. People’s perception of stigma has a great impact on how differently the illness affects the individual and affects their coping. PLWHA expect to be stigmatised because HIV is a sexually transmitted disease that is stereotypically expected to infect gay men, prostitutes and poor people. As a result people blame themselves, feel guilty and expect to be discriminated against. This leads to PLWHA isolating themselves and not disclosing their status due to their internalized stigma. This unfortunately becomes a barrier to their coping as they are not able to receive support and medical attention. The church communities’ views on HIV as a result of sin further perpetuate stigma and self-stigmatisation.

2.5.5 Response/Influence of FBO's to HIV/AIDS

Faith communities have a long history of supporting people in Africa by doing missionary, educational, and health work; they have a significant impact not only on AIDS but also on the health consequences and quality of life of people suffering from other diseases (Chikwendu, 2004; Somlai et al., 1996; Somlai, Heckman, Kelly, Mulry, & Multhauf, 1997). According to Parry (2004):

“Faith-Based Organisations are an integral part of life and society in most parts of Africa. They are to be found within every community and hold much credibility with the people because of their presence at grassroots, their involvement with the people at every aspect of their lives and for the many services they offer. They have the widest network coverage in the continent, the largest constituency of people, and an enviable infrastructure, extending from the international community, to the most marginalized” (p. 13-14).

The minimal work that has been done about Faith-Based Organisations (FBOs) and HIV has concentrated on the responses of FBOs to PLWHA and the effects of FBOs on coping. As stated by Liebowitz (2002), “research on the impact of FBOs on HIV/AIDS remains a very small part of a much more extensive literature on HIV/AIDS ...this limited attention to religion stems partly from the prominence of biomedical research methodologies in any studies” (p.4). Therefore the research attempts to look at the experience of PLWHA and the influence of FBOs on their coping and Quality of Life (QOL), because, as discussed earlier, people tend to turn to religious institutions when in crisis.

According to Liebowitz (2002), FBOs have extensive networks of people, institutions and infrastructure especially in the rural areas. They seem to step in where government services have failed or are over burdened. FBOs seem to demonstrate more commitment to society as compared to many other political, social and economic institutions. He also goes further to say that their area of influence includes morality, beliefs about the spiritual bases of disease and rules of family life and sexual activity. As a result of most FBOs being independent bodies, not directly involved or assumed to have a political

agenda, they are believed to be in a unique position to deal with HIV/AIDS because PLWHA can more easily trust them.

Due to the complex nature of FBOs, Liebowitz (2002) believes that their successful functioning depends on the following:

- 1) The level of strength of an FBO in a given community will affect its ability to promote meaningful change whether behaviourally or cognitively;
- 2) Each FBO has different strengths and weaknesses in the areas of institutional structure, religious practices, system belief, and international connections. These strengths and weakness can determine to what extent an FBO is willing and able to deliver successful interventions in the area of HIV/AIDS;
- 3) Within each FBO internal dynamics between clergy and laity or between youth groups and older church members can either undermine or support efforts in disease prevention and mitigation;
- 4) The changing impact of particular FBO on class, gender, culture and intergenerational relations can lead to certain trends in HIV/AIDS and also delineate a particular intervention strategy's results;
- 5) How an FBO influences beliefs about disease causality, sexuality, and medical practice has direct relevance on its ability to generate meaningful programs;
- 6) The social mission and engagement of an FBO in a country's political and historical context also has an important effect on the ability to mobilize their congregations in preventative efforts.

However, FBOs are not all similar and they react differently depending on core beliefs about HIV (Somlai et al., 1996, Somlai, Heckman, Kelly, Mulry, & Multhauf, 1997). As a result they have also been accused of being:

“A ‘sleeping giant’; of promoting stigmatising and discriminating attitudes based on fear and prejudice; of pronouncing harsh moral judgements on those infected; of obstructing the efforts of the secular world in the area of prevention; and of reducing the issues of AIDS to simplistic moral pronouncements, that have not made Churches or Mosques places of refuge and solace, but places of exclusion to

all those ‘out there’ who are but suffering the consequences of their own moral debauchery and sin”(Parry, 2004, p.3).

The different responses may be due to the FBOs different orientations; the extrinsically orientated faith groups whose focus is on an external and formalised religion may offer spiritual assistance in a structured environment to a person who is coping with HIV related emotional distress. The intrinsically orientated groups, due to their emphasis on the development of an individual’s inherent mental or moral nature may benefit people living with HIV by supporting a more personalized spiritual life and identity (Somlai et al., 1996; Somlai, Heckman, Kelly, Mulry, & Multhauf, 1997).

2.5.5.1 Role of FBOs in Stigma against HIV Positive

Stigma is socially constructed and therefore supposedly changeable. Stigma hinders the prevention of HIV/AIDS, coping with HIV and the provision of quality care. Religion has also been responsible for lot of stigmatization and discrimination of PLWHA. It has been viewed as a hindrance to the prevention and eradication of HIV/AIDS. As highlighted by Chikwendu (2004) and Liebowitz (2002) some religious organisations and leaders resist the use of condoms; perceive AIDS as an immoral disease and limit open discussion about sexuality, gender relations and intergenerational relations. According to Kopelman (2002), there is sometimes the belief that God punishes people in order to castigate, encourage virtue, warn, rehabilitate, or maintain some cosmic order (punishment theory of disease). As a result, HIV/AIDS has sometimes been viewed by religious people as a deserved disease due to people’s immoral behaviour.

While some FBOs still hold on to the notion of AIDS as punishment for sin, other congregations believes that HIV is there to bring people closer to God. This was put forth by MAP International, (1996, in Shorter & Onyanacha, 1998). They state that HIV/AIDS offered the whole world opportunities for repentance in order to receive grace from God not because of what people have done. HIV is also an opportunity for clergy to get involved and show love and compassion to others, especially those infected and affected

by HIV/AIDS. FBOs operating from the second school of thought seem to respond faster to the needs of PLWHA and there is less denial among the congregation (ibid).

According to Shorter and Onyancha (1998) there is a great need to overcome the fears and eliminate prejudice if progress in eliminating the epidemic is to happen. This can be done through education to address the fears and misconceptions concerning the spread of HIV to change people's attitudes (Parry, 2004; Poindexter, Linsk, & Warner, 1999; Somlai et al., 1997).

2.5.5.2 Role of FBO's in Facilitating Disclosure

Stigma influences the likelihood of disclosure and people weigh the pros and cons associated with possible disclosure before disclosing their status (Armistead et al., 2001, Black & Miles, 2002; Serovich, 2001, in Ostrom, Serovich, Lim, and Mason, 2006). On the one hand, in disclosing there is a possibility of receiving emotional or instrumental support, on the other hand it could lead to rejection or second-hand disclosure (this happens when confidentiality is not maintained and the trusted individual discloses to someone else) (ibid). This makes disclosure very difficult, especially in religious organisations, because of the stigma around HIV/AIDS, due to "the constant fear of being ostracized and expelled from the church" (Shorter & Onyancha, 1998, p.64). Therefore, PLWHA may not access the social support offered by the clergy and church community, while attempting to avoid potential rejection.

Failure to disclose may exacerbate HIV symptoms due to lack of support, but also because of being faced with the stress and burden of keeping a secret (Hays et al., 1998). This affects PLWHA psychologically by heightening their feeling of guilt and self-stigmatisation. Many studies (Liebowitz, 2002; Poindexter et al., 1999; Shorter and Onyancha, 1998; Somlai et al, 1997) have shown that the church is a place for solace for PLWHA; as a result it is important for the church to create an environment that people can feel free to disclose their status without being afraid of discrimination.

2.6 Conclusion

Testing HIV positive is likely to be a traumatic experience and from the review of literature it is evident that some people may resort to religious and spiritual coping and turn to FBOs when they discover that they are HIV positive for support. Different pathways may be used to make sense of the experience, cope with HIV and improve their quality of life. Some people may opt for religious pathways and use religious coping methods, either problem-solving or emotional religious coping methods, which may lead to better mental and physical health. The outcome of the coping may be affected also by the religious orientation. Whether it is intrinsic (God is in control of everything) or extrinsic (religious beliefs are used to achieve one's needs), the goals achieved may be different and have a different effect on the individual's way of adapting to the situation.

However, there is a gap in the research, religion is an important part of peoples' lives especially in Southern Africa and it would be likely that when faced with the HIV/AIDS pandemic, some people might turn to a religious institution for support, even when their response is negative. Unfortunately, little if any work has been done in Africa on how religious coping influences the quality of life of PLWHA. Most of the research done has been in the United States and has identified religious coping as an important factor for PLWHA. Therefore there is a great need for further research to be conducted on religious coping and how FBOs influence the quality of life of PLWHA due to the large influence that faith communities have in Southern Africa. This research attempts to minimise the gap by looking at whether PLWHA resort to religious coping methods as a way of coping with HIV and improving their quality of life. It also looks at whether the FBOs are a source of support or hindrance in coping with HIV/AIDS.

CHAPTER 3: METHODOLOGY

3.1 Rationale for the Study

The review of literature has shown that HIV/AIDS is one of the most debilitating diseases of our time, and coping with HIV/AIDS is more complicated when compared to other chronic illnesses, because of the stigma and discrimination associated with it. This research has shown that when people are diagnosed as being HIV positive, some of them will turn to religion as a way of coping, offering a sense of comfort and solace from pain and worry, as well as reassurance to continue living with the disease (Pargament, 1997). This means that religion gives them a sense of purpose and meaning (Dull & Skokan, 1995, in Abraido-Lanza, Vasquez, & Echeverria, 2004). This enables them to accept the illness as part of God's plan or punishment.

The review of literature has also shown that while there has been previous research on religious coping with HIV/AIDS (Pargament, 1997; Pargament, Koenig, & Perez, 2000; Somlai et al., 1997; Somlai and Heckman, 2000), the research has mainly used structured and quantitative designs to measure religiousness, limiting the possibility of exploring the more subjective and novel aspects of religious and spiritual modes of coping.

The review of literature has shown that FBOs are also a source of support for PLWHA as they are able to turn to the church clergy and church community, but this can also be a hindrance to coping. This is often due to stigma that is sometimes perpetuated by the churches view of HIV as punishment from God and a result of sin, because it is a sexually transmitted disease. This may result in self-stigmatisation and discrimination by the church community members. However, there has been little research on the role played by FBOs in enhancing or impairing the process of coping with HIV/AIDS.

3.2 Aim of this Study

In light of these limitations, this study aims to explore if and how PLWHA use religion/spirituality as a means of coping. It further attempts to explore the perceived role of FBOs in enhancing or impairing the process of coping with HIV/AIDS. The research tries to answer the following questions:

1. What were the perceived effects of the HIV infection?
2. Do PLWHA use religious/spiritual coping and if so what form does this take?
3. How does religious coping help people with HIV/AIDS?
4. What is the perceived impact of religious coping on the quality of life of PLWHA?
5. How do FBOs influence coping and the quality of life of PLWHA?

3.3 Research Design.

Because this study aimed at an in-depth exploration of the subjective use of religious/spiritual coping, and at an exploration of the perception of how FBOs enhance or impair coping, qualitative methodology was chosen. Qualitative research is viewed as a debate rather than fixed truth (Banister, Burman, Parker, Taylor & Tindall, 1994). This is because it involves “exploring, describing and interpreting the personal and social experiences of participants” (Smith, 2003, p.2). A qualitative design also allows the possibility of an in-depth understanding of coping strategies (Bogdan & Biklen, 1998; Merriam, 1998; Patton, 1990, in Reeves, Merriam & Courtenay, 1999). This is because the qualitative process “examines interrelated events along a temporal or developmental continuum” (Struwig & Stead, 2001, p.12). According to Marks, Murray, Evans and Willig (2000) qualitative methods such as structured interviews are better suited for measuring stress and coping. More qualitative studies on coping with HIV need to be conducted.

Qualitative research is contextually sensitive, persuasive and relevant (Henwood & Pidgeon, 1992). On the other hand, quantitative methods impose meaning and rarely take into consideration the uniqueness of human experience. It was for this reason that a qualitative design was chosen for this study. Flexibility is an added advantage of qualitative methodologies (Braun & Clarke, 2006; Henwood & Pidgeon, 1992; Struwig & Stead, 2001), allowing the research to be conducted in an open and unstructured manner, rather than being strongly informed by theory or prior research. However, it is acknowledged that all research is value laden and value driven so that it is often difficult to be objective (Struwig & Stead, 2001).

In qualitative research data is collected in its naturalistic form through interviews or written material (Smith, 2003) and language is very important. Due to its close resemblance to 'real' life, the findings are often faced with the challenge of reliability, validity and objectivity because "they are fragile and mutable as real life is" (Baniser et al., 1994, p.11).

The qualitative methodology seems better suited to examine the experience of PLWHA because coping is a continuous adjustment and adaptive process, as people are usually in a constant state of trying to cope with the chronic illness that affects their long term planning and relationships. The method would be able to assess on a continuum how the people are coping, as the participants are allowed to tell their stories in an open and unstructured format. The analysis also attempts to maintain the participants' meaning of their coping in their specific context.

3.4 Sample

The sample was drawn from people living in Pietermaritzburg, KwaZulu – Natal. Given the difficulty in gaining access to PLWHA, convenience sampling was seen as most relevant to my study. As it is not a comparative study, only people living with HIV/AIDS were used. I telephonically contacted a number of FBOs working with PLWHA. They

referred me to support groups that they directly or indirectly operate, as this would be the prime area in which I would be able to obtain people who might be willing to be interviewed. The respondents were recruited on a convenience basis because I relied on the willingness of the participants to volunteer and consent to be interviewed. Ideally, I would have liked to have roughly equal numbers of male and female, black and white, and young and older respondents, in order to ensure a maximum variability of accounts, but this was practically impossible.

Due to the difficulty of gaining access to PLWHA, I only interviewed ten participants. Three of the interviews were discarded because they were not up to standard as they did not answer the research questions.

Pseudonym	Gender	Age	Year Tested	On Antiretroviral(ARV) medication or Not
Participant 1	Female	34 years	1999	Not on ARV
Participant 2	Female	-	1997	No longer taking
Participant 3	Female	56 years	2000	On ARV
Participant 4	Female	24 years	1998	On ARV
Participant 5	Male	32 years	2002	Not on ARV
Participant 6	Female	50 years	1999	On ARV
Participant 7	Female	33 years	1992	On ARV
Participant 8	Female	-	1998	No longer taking
Participant 9	Male	-	1999	-
Participant 10	Female	34 years	2002	-

3.5 Procedure

I met the prospective participants on a day when they had a support group meeting, because it was easier to brief a large group. I explained to prospective participants that they were under no obligation to participate and there would be no repercussions for not

participating. They were also informed that their consent was very important. People interested in participating were asked to put down their names and phone numbers on a piece of paper. I later contacted each person to confirm if they still wanted to participate in the research and what venue suited them. Some participants were later unavailable for interviewing due to health problems or time constraints. Those who accepted were interviewed at the support group venue.

Other participants were obtained through the help of the support group leader. With their consent, I was given their phone numbers and I contacted them directly. Some difficulties encountered were people not being willing to be interviewed because there was no monetary gain. This was a major concern for them because most of them were unemployed and came from poor social-economic backgrounds. Outside of the support group it was difficult to find participants, as people do not openly disclose their status due to the stigma. The other challenge was getting English-speaking participants, as I did not want contamination of the text by the use of translators. Each respondent was required to sign a consent form and/or the interview was tape-recorded with the participant's permission. The interview normally lasted for thirty to forty-five minutes.

3.6 Data Collection

With the participants' consent, the interview was audiotape recorded. The participants were made aware of the purpose of the research. A semi-structured interview format was used (See Appendix B). Some predetermined questions were posed to each participant but the participants were allowed to freely discuss issues beyond the questions' confines (Berg, 1995, in Struwig & Stead, 2001). Open-ended questions were used, with prompting only where necessary. The participants were asked to give a narrative account of their lives and their experience of living with HIV/AIDS, what some of the challenges were and what has helped them cope. People have a natural impulse to narrate their stories (White, 1989, in Riessman, 1993) and as a result the account of their experience was allowed to unfold naturally and take a format they found most comfortable.

According to Riessman (1993), “Respondents (if not interrupted with standardized questions) will hold the floor for lengthy turns and sometimes organize replies into long stories” (p.3). Only towards the end were the participants asked more structured question about FBOs, faith and stigma, if they had not already spontaneously elaborated on it in their narrative.

3.7 Data Analysis

The analytic qualitative method used is thematic analysis, which in this research leans towards a constructionist perspective. The qualitative methodology seems better suited to examine the experience of PLWHA because coping is a continuous adjustment and adaptive process, as people are usually in a constant state of trying to cope with the chronic illness that affects their long term planning and relationships. The method would be able to assess on a continuum how people are coping as the participants are allowed to tell their stories in an open and unstructured format. The analysis also attempts to maintain the participants’ meaning of their coping in their specific context.

The data was analyzed using thematic analysis. Thematic analysis is a “process of encoding qualitative information” (Boyatzis, 1998, p.vi). It involves identifying, analyzing and reporting themes within data (Braun & Clarke, 2006). Themes describe, organize, and interpret possible observations and certain aspects of phenomenon. The themes can be identified at a manifest level (directly observable in the information) or latent level (underlying the phenomenon) (Braun & Clarke, 2006; Boyatzis, 1998). Thematic analysis has been described as a bridge between qualitative and quantitative methods, that is, “ a translator for those speaking the language of qualitative analysis and those speaking the language of quantitative analysis” (Boyatzis, 1998, p. vii).

According to Boyatzis (1998) there are three obstacles to the effectiveness of thematic analysis. Firstly, projection, this is when a researcher imposes or reads into raw material their own values, thoughts, feelings and competencies. Secondly, the sampling process

becomes problematic if the raw information a researcher is analyzing is full of contamination from factors or variables that he/she is not aware of, thus one must critically evaluate their sampling procedure. Lastly, because qualitative research is subjective, a researcher's fatigue and/or sensory overload, frustration with raw information, or concepts, or confusion as to the unit of analysis or unit of coding may decrease his/her capacity to effectively conduct a thematic analysis.

A thematic analysis process of analysis information is used and according to Braun and Clarke (2006) it involves moving back and forth between texts because it is not a linear process. I used Braun and Clarke's phases of conducting a thematic analysis:

1. Familiarized myself with the data: Interview audiotapes were transcribed verbatim. The transcripts were read and re-read in order to get initial ideas of the participants experience and how they coped with HIV/AIDS.
2. Generated initial codes: codes related to each of the aims were developed in a systematic way across the entire data set. The coding was done manually, using coloured highlighters to identify and code text.
3. Searched for themes: codes were collated into potential themes, using all the data relevant to each potential theme. A table was used to list the codes and potential themes in order to see the main overarching themes and sub-themes. The themes were developed by examining the codes emerging from the data, and by relying on the review of literature.
4. Reviewed the themes: checked whether the themes worked in relation to the coded extract and the entire data set. It became evident that some themes could not be used as they did not have enough data to support them or they were too diverse. Some themes were collapsed into other themes, whilst some themes had to be broken up, as they were too broad. I also re-read the entire data to ascertain that the themes fitted the data set.
5. Defined and renamed themes: identified the 'story' that each theme told and considered how it fitted into the broader 'story' in the data and in relation to the research questions. I also generated clear definitions and names for each theme.
6. Finally, I reported the results.

3.8 Ethical Considerations.

The aims and purpose of the research was explained in detail, and participants were invited to ask questions about the research. Following this, each participant was asked for their consent before being interviewed. They signed consent forms or in some instances the consent was tape-recorded, with them in agreement. The interviews were tape-recorded with their consent. Confidentiality was assured, in that their names would not be divulged but they were also given the option of using pseudonyms. They were assured that the researcher would keep the tapes in a secure place and the only other person who would have access to them would be the supervisor. They were also assured that details that would clearly identify the participants would be omitted.

Due to the sensitive nature of the material discussed during the interview, the participants were told that they were free to contact the interviewer to discuss issues that may have been upsetting or distressing to them after the interview. A follow-up phone call was also made a week later to be sure that the participants had not suffered any undue stress due to the interview.

3.9 Reflectivity

Research is always conducted from a particular standpoint and it is almost impossible for the researcher's subjective feelings not to affect the research process. Due to the sensitivity of the research topic, I was aware of not wanting to cause the participants any harm or discomfort as I felt they were already experiencing a lot of difficulty. The interviewing and analysis process was emotionally laden and draining, hence I had to be aware of my own response to the material and its potential impact on the analysis because the analysis process required re-reading the text several times. Regular discussions with supervisor and colleagues helped overcome some of these issues, in order to reduce bias in the analysis.

CHAPTER 4: RESULTS

4.1 Introduction

In this section I will report on some themes that surfaced in the transcribed interviews. The interviews aimed at exploring at how HIV infected participants attempted to cope after testing HIV positive. To understand how some PLWHA coped, it is important to examine what the participants had to cope with. The participants experienced several challenges and used different pathways to cope with the direct and indirect effects of HIV/AIDS. The findings are illustrated with extracts from the transcribed interviews, where the participants express in their own words their experiences and how they attempted to cope with the numerous challenges of HIV/AIDS.

4.2 Effects of HIV

4.2.1 Physical Effects of HIV/AIDS

One of the most commonly reported effects of HIV infection was the physical effect. Participants also had to cope with the physical side effects of antiretroviral (ARV's). As a result participants were often fearful of testing because of the physical difficulties they expected their bodies to experience, such as losing weight, having sores, being helpless, not being able to look after themselves or even going to the toilet. These were very degrading and isolating for some of the participants. The side effects of antiretroviral often lead to dilemmas about taking ARV's, because with or without the medication they still got sick. Some participants seemed to prefer the sickness to take its natural course rather than take medication, as they were already aware of potential side effects, even though they were aware that the medication could make them better. For example, one participant explained her experience of prophylaxis. In the beginning she had refused to take the ARVs until her family convinced her, but she suffered severe side effects and was given different treatment, which she still did not respond to well. She eventually refused to take any ARV mediation and as a result she said that her health improved:

I took prophylaxis about two and a half months after that I became very ill. I could not move my hand even my body, I couldn't move anything on me. I couldn't feed myself even wash myself, go to toilet... (int. 2, p.1)

4.2.2 Psychological effects of HIV/AIDS

One of the commonly reported difficulties for the participants was the psychological experience that HIV/AIDS threatens to take away life. The participants saw HIV as a silent killer, a thief that comes to steal away life and opportunities. Some describe it as “that thing” because it is not acceptable and outside of them. The participants could no longer make plans for the future because they had to prepare themselves for death, as some of them thought they would die immediately after testing HIV positive. The other difficulty was that the individuals did not know when they would die, and they reported waiting anxiously and looking for possible clues that might indicate they were dying. This often became very distressing and some said they would prefer to die immediately rather than wait, as they felt they no longer had anything to live for. Some even felt they had started to die emotionally because they felt hopeless and helpless, as they faced the likelihood of reduced life expectancy. As one participant explains:

It's that coz your life when you are not HIV positive, you just know I will do everything and when you HIV, then I can't do everything now. Life it's finished. ...when you find out your HIV positive you think all my future, it is finished. It's that thing that will kill the people. (int. 1, p. 10)

The participants reported often becoming ambivalent about life. Their physical pain, combined with the emotional pain, became unbearable for them. They feared and dreaded death but it now became a welcome alternative to enduring the pain. HIV/AIDS seemed to be depicted as an enemy, with the individual in a battlefield, but this enemy already seemed to have an upper hand in the situation. Some felt as if they were fighting a losing battle, in which they would rather surrender to death than wait for HIV to defeat them. One participant said:

Let me just die because I cannot cope with anything I just feel empty, I just feel it's enough. I have done all that I could so if now I can keep on suffering like this because I was sore; my body was sore, so sore, sore, sore!! (int. 3, p.4)

For some participants being HIV positive was overwhelming and as a result they contemplated suicide. They wanted to find an immediate way of dying rather than wait for the slow and painful death of HIV/AIDS. Some participants were afraid of attempting suicide and not succeeding because that would have been more of a disappointment than living with HIV. One participant shared her thoughts:

I was saying to myself that if I could have something like a gun, something that I won't hurt myself only, something like, you know drinking poison sometimes you know you cannot die but sometimes you will live, this kind of horrible things. Then I was just saying something that I will know that it can cut me and die (int. 4, p. 4)

Another psychological effect was loneliness. Participants felt alone and isolated because of the stigma, having no one with whom to share their experiences and pain. Some participants felt even more alone because the person who had infected them was not there to share the pain of being infected with the HIV virus. Some participants reported losing friends and family on testing HIV positive, while some lost their friends to death from HIV or from committing suicide because they could no longer cope with the disease. Some participants felt that those friends were fortunate to have death come so soon for them. On the other hand they were also scared that their loneliness would lead them to take their lives and as a result they sought out new relationships.

...some left and some have killed themselves. And then most of us said ah, ah, am not sitting alone where some people will just say something and then the problem that I will have without sharing with other people... (int. 4, p.7)

Shame was a common experience reported. The participants felt ashamed on testing HIV positive because they felt that they or their spouses were to blame for their status. HIV was also seen by people in general to be the result of sexual immorality, which increased the sense of shame. The shame made it difficult to cope with being HIV infected because of the constant self-blame. Below was a participant's reaction:

What is this? How are we going to handle this? It was a very sad moment for us and there was no like counselling, we were ashamed, we were afraid, we didn't know how to confront, we couldn't think about the future, our young children and we say how is life going to be like? ...because of the shame we could not go to church anymore. We had to hide from our friends. (int. 6, p. 2)

Some also felt that they had lost their reputation and as a result hid away from people and avoided disclosing their status to prevent the risk of being ridiculed by others. The shame led to self-stigmatisation because of the perceived stigma and as a result the people isolated themselves from people because they felt unworthy. One participant explains:

It was just the shame of being HIV positive and we look at our friends, you know you look at your friends, you look at yourself, it was just; what will people think? And my husband did not want to face the congregation being HIV positive. So it was a self-imposed like situation to say we cannot face the people. (int. 6, p.5)

4.2.3 Effects of HIV/AIDS on Relationships

One of the social effects of HIV is the disturbance of faith in relationships because of sexual infidelity. When one person in the relationship had tested HIV positive, and they knew that they had not been unfaithful, it was clear that their partner had been unfaithful and that was how they had acquired the HIV virus. The women especially had entrusted their lives to their male partners and they believed that they would not do anything to jeopardise their lives. They had not expected their male partners to be unfaithful because some women participants thought they were in secure relationships. The mistrust also

affected other relationships because the participants were not able to get involved in other relationships for fear that their partners would be unfaithful to them.

...I trusted him so much because I felt that he was the one who was learned, who knew about this thing that he wouldn't like put me to risk and then, well even if his ways were like not faithful enough, I thought that he would use a condom and prevent himself from contracting deadly virus like HIV. (int. 6, p.1)

The other difficulty for participants was being accused of being unfaithful when they disclosed to their partners that they had tested HIV positive. This often resulted in the end of the relationship and the breaking up of the family unit. Being blamed was difficult for some participants because this had been the only relationship they had been involved in. One participant chose to end the relationship as a way of preserving herself and her children because she did not want to continue being infected by her partner.

And then after that my husband came back from work, find me crying, why you crying? 'Its coz it was you not faithful to me'. Aibu, what is happening? 'Am HIV positive', he says, "not me you". Au! Eh! That is shock me. Aibu, I think where did I get this coz it's only you my husband. 'Not me, you, you are HIV positive, not me'. So I say go out! Am staying. (int. 1, p. 1&2)

4.3 Religious or Faith-Based Coping with HIV/AIDS

In the face of various challenges of being HIV infected the participants in this research reported different coping mechanisms. This section will examine how the participants in this study coped with the various aspects of HIV/AIDS reported above. Many participants reported using religious coping, where God and religious figures were a central part of their coping, as described below.

4.3.1 Belief in God as Strengthening against Threat and Fear

Many participants viewed God as a source of strength in the face of the overwhelming experience of being HIV infected. God as a Higher Being was seen as having great power. Participants reported that when they felt weak they were able to give their lives to God and let him take control. As a result of their faith they believe that He gives them strength to deal with the effects of HIV. PLWHA were able to draw energy from God whose strength was infinite in order to get through their stressful daily circumstances, arising from being HIV infected. As one of the participants explained, God was both a mother and father to him. He was able to comfort him and helped him feel safe and secure at a time when he felt that people and the world had let him down. The participant felt that he was no longer alone and had someone to depend on and talk to. God was seen as a guardian or parent that had the best intention for the person and would not hurt him, like human beings would. God also had the power to influence their circumstances in order to help them cope.

When I first discovered my HIV status, I looked at God as a mother. I remember every evening I pray and cry physical tears. In mind it was just that I was being embraced by this mother, sitting on your mother's lap helpless and she has all the power to alter things whether psychologically or physically. Then as I developed psychologically with the disease I looked at God as a father figure and go to him every evening and report. There are times now and again when I see him as a friend after I would have given a talk in hospital or to young people; I just report to him as a friend and thank him as a friend (int. 5, p.2)

This quote is also interesting, describing God as mother, father, friend and companion, which was very important, given the feeling of loneliness described by many participants. This issue carries on in the next quote.

A female participant reported that God also helped her cope with her daily challenges. God helped her feel in control of her very overwhelming circumstances because her husband was no longer there to help her bring up her family. God was also faithful to her, unlike her husband who was not faithful. She trusted that God would not let her down or

leave her to handle the difficulties on her own. God once again became a reliable and faithful companion, which is an important source of coping because of the many reports of breaches of trust in relationships of HIV infected people.

...as a single mother, one salary, one child in varsity, one in high school, one is at home with a baby, who needs also to go to college and I have got a son, my eldest son is thirty years this year, but he is out there, he is like a delinquent, he is drinking out there, he doesn't really have his way out. Ahh, in all this as one mother, plus the status, the struggle of being HIV, I think my strength to handle all these pressures at all, can only come from God. This is why I say my God, in a few words had been faithful to me. He has seen me through each and every obstacle. (int. 6, p.6)

The participants also reported that they received strength from God through prayer. Prayer was seen as a way of communicating with God and maintaining a relationship with him. The participants believed that through prayer they could ask for what they wanted at anytime because God is always available and always listening. A participant said, "Prayer conquers anything and everything". Once again there were no limitations on what God could do, unlike with human beings. Prayer also strengthened their relationship with God and he was seen as a confidant.

...we prayed and prayed and prayed and I feel that, that prayer is going, going to heaven, serious. Coz when we finished praying I just feel strong. (int. 1, p.2)

It was earlier described that a fear of loss of life and impending death is a major consequence of HIV infection. On the other hand, the findings show that belief in God and a relationship with God also took away the participants' fear of dying because God is perceived as being in control over life and death.

I can tell you is that am not afraid of anything because the greatest fears of HIV/AIDS is people focus on death, that they are going to die and on my part I have told myself that, as much as am going to die, but what I know is that everybody else living today with or without HIV is gonna die. Nobody who is human is going to live forever, but if my way

to death is going to go through HIV, well I will go, but I have also told myself that as a child of God, God knows my time, its not a mistake, God knew this time for me and when my time comes for me to go, it will be an appointed time. This is what I tell myself all the time and my relationship with God in fact is more now than ever before, it's growing daily (int. 6, p.4)

4.3.2 Religious Faith and Disclosure of HIV Status

Disclosure of one's status to others is often very difficult for anyone who tests HIV positive; this is because of the fear of rejection and stigmatisation. However, the participants reported that God helped them to disclose their status to their family members. Their belief in God seems to have given the participants courage to disclose because they no longer felt that they were alone; while they feared that disclosure might lead to hostile reactions from the family, friends and the community, they also felt that God was there to support them as they disclosed. This sense of a relationship with a non-judgemental God eased the fear of being rejected. One participant explains she had to 'expose' herself, almost like someone who had done wrong and now she was caught out. As a result she may have had the difficulty of facing her family for the guilt she might have felt, but God's forgiveness helped her feel more acceptable and strong enough to disclose her status.

I prayed for three months to be strong to tell everyone especially to my family (int. 1, p.3)

I think my Lord helped me to be strong to expose myself to my family (int. 3, p. 5)

4.3.3 Healing of HIV/AIDS by Faith in God

Some participants described God as also being a healer of their HIV related disease itself. God was viewed as being very powerful and in control of their disease. As one participant explains:

After disclosing my status I see God as a healer and unfortunately some of the Christians limit God in healing. I see God coming every evening and adding up my CD4 cells. I see God within me through the Holy Spirit catching the virus not to multiply because I am aware that there are possibilities that I can lead the whole of my life with the virus. I see God as a great healer (int. 5, p.1)

This person describes his experience of God as directly intervening in his body, “catching the virus” and preventing the HIV virus from further replicating, as he later said that his CD4 count had remained the same for a long time, something that seems to him that medicine cannot easily do. So God does not only give him courage from a distance to continue living with the disease, but God was there with him physically to “count his CD4 cells”. Something that no one else could do for him and it gave him a lot of assurance and security because God, who was viewed to be so powerful, could meet him in his time of need.

Some participants also reported that because of their belief in the power of God to heal their disease, there was no need to take medication, such as ARVs. In fact some people viewed use of medication as a betrayal of God, an expression of lack of trust in God. This led some people to feel that they needed to choose between use of medicine and faith in the power of God to heal them. One participant reported that improvement in her CD4 count is evidence of the healing power of God, as follows:

I said if there is God, why should I take treatment. I talked to God and asked him to make me alive without taking any treatment ...I have go for a CD4 count test, the result shocked me also because it was 492 (*it had been 84 before*), it was unbelievable, ...when I got that am HIV positive I thought God betrayed me, then I backslidden, but when it comes to my illness I started talking to God, “God I repent now, I have sinned a lot please forgive me in everything I did”. Then he replied spiritually and told me that, “you will never die, you will wake up and tell my people about me”. And I am, and I ended there to take treatment. (int. 2, p.1&2)

What is interesting in the above extract is that on testing HIV positive the participant thought that God had betrayed her. This same participant felt that her body had let her down in getting the virus and her partner had also let her down by infecting her. The ultimate person she could have turned to, God, had also let her down. Her certainty that God would heal her led this participant to make a decision to stop the use of medication.

4.3.4 Faith as a Means to Reattribution and Meaning

Some participants seemed to cope by changing their thoughts about the disease and death through their faith in God. One of the reported effects of testing HIV positive was that participants assumed that they were going to die shortly and as a result they had little hope for the future. However, the participants reported that through their faith in God their fear and anxieties around death were reduced and they were able to cope more effectively. Rather than focusing on dying, they were more easily able to focus on living. This was partly through a reattribution process, which allowed them to interpret physical symptoms differently. For example, one participant described.

Even if you're coughing you have got something serious in your body, but you will not think you are going to die now. You don't think this is AIDS now. You just say its flu, yeah, you will just take it easy, you not take seriously this disease it can kill me now. No! as I am saying to my sister one day, don't worry if I say I have got flu because why? Ehh, my life is in the hands of God and ehh, I won't die now. I will die when my time is coming. (int. 1, p.10)

Participants also showed an additional aspect of coping with the fear of death, through the reattribution process, which was apparent when people thought about the possibility of dying. They reported that they had the faith that they were leaving this world for a better world, and that death comes as a relief because in the after life they believe there is no pain or suffering. This means that they would no longer be HIV positive with all the difficult consequences. From this perspective death almost becomes something that is celebrated rather than feared.

I believe that one day I will see Jesus and I will sit with him and enjoy. So though my life is complaining here and there, but there is life after death. Which I think is eternal life and should be a good life, so I am focussed on that and it helps me. (int. 3, p.3)

Religious faith also gave HIV infected people a new sense of meaning in the midst of the challenges of being HIV infected. There were some participants who experienced that getting HIV was a way of God giving them a purpose. This sense of purpose in their suffering enabled them to have the hope and desire to live. These people reported that they felt that they had a particular role to play in their community, as a result of HIV. Some of the roles the participants felt that they could play were, being a source of support to other people infected and affected by the HIV virus, speaking to the community members about HIV/AIDS in order to try and prevent other people from being infected with HIV and/or telling people how God had been their source of strength. This enabled them to feel a greater sense of confidence and value, in the face of a disease that made them helpless. Their faith in God boosted them to feel that they could still contribute to society and they are able to begin a new phase of their lives. In the extract below a participant quotes a response that she believes God said to her to encourage her to continue living.

“You will never die, you will wake up and tell my people about me” and I am. (int.2, p.2)

4.3.5 Religious Belief Enables People to Cope with Discrimination and Lack of Support

Participants reported feeling that God was available to those who felt abandoned by family and the church community because of their HIV status and who were not receiving any form of support from the church. Thus a sense of relationship with God enabled the participants to deal with the discrimination, which they experienced as a result of their HIV status. As described earlier in this chapter, awareness of being HIV infected was very difficult for people to bear because of feeling isolated and unacceptable because of the disease, so when the individual was rejected by the church community it served as a confirmation of what he/she already believed about themselves. This was

especially the case as the church community was expected to be more compassionate and understanding compared to other people or communities. So when the church did not accept the participants, they lost all hope of ever being accepted in society. In fact, religious faith even enabled HIV infected people to understand those who were discriminating against them. One of the participants had the following to say:

I just think the Lord is helping me to understand them because I was born in this church and I know their attitude. ...what comforts me is that I know that they are ignorant (int. 3, p.7)

For some participants finding greater support in their relationship with God was an important way of coping with discrimination. This was because God is dependable and does not let them down or reject them. They believed that God has the capacity to accept them fully unlike their family or friends, who rejected them for being HIV positive. As a result they did not mind losing their relationships with other people, because they felt that they were in a relationship with someone who understood and cared for them.

Some of them because I think it is the lack of education, HIV/AIDS education that's why they are acting like this but I do not care about them what I care about is my life and the communication between me and God. (int. 2, p.4)

4.4 Faith-Based Organisations' Response to HIV/AIDS.

A second aim of this research study was to understand the perceived role of FBOs in dealing with the experience of being HIV infected, and in facilitating or impairing coping with HIV/AIDS. The FBOs have been at the forefront of a lot of controversy in terms of HIV/AIDS issues. In this research the participants also had ambivalent reactions towards the church and the clergy. This section will report on participants' experiences of how FBOs helped them cope with HIV and/or how FBOs hindered their coping.

4.4.1 Role of Clergy in Coping

One means that participants used in order to cope with their HIV status was through pastors. Religious leaders, such as pastors or priests in the church were seen as people who are God's representation on earth, chosen by God and allowed to do his work because they are able to easily reach the people. There was a mixed perception of the response they received from the pastors or priests. Some thought that they were supportive and able to deal with HIV/AIDS, whereas others had negative experiences. For example, one of the ways that the participants felt that the leaders helped them cope was through praying with them and for them. They approached the pastors to pray for them, seeing them as the intermediaries between God and themselves. As the participant below says:

I was thinking that because he is a servant of God he will be, his prayer will be heard than mine and I said if myself and praying for myself but if other people they are praying for me it will be something powerful. (int. 4, p.6)

The findings suggest that the mediation of pastors/priests was seen as especially important for people who felt unworthy or ashamed and therefore not able to approach God directly or were afraid that God might not listen to them. It was expected that the prayer of the pastor would be heard or listened to unlike the participant's. Through this route, pastors were described as playing an important role in facilitating the relationship of these people with God, the importance of which in coping with HIV/AIDS, has already been described earlier in this chapter.

The pastors also acted as mediators among family members. They helped deal with discrimination in families against HIV infected family members and facilitated communication and forgiveness among the members. For example, the participant below was not on good talking terms with her husband because she was angry with him and held him responsible for infecting her. The pastor was able to bring them to a point of

reconciliation, which helped the participant cope with the disease and improved her quality of life.

I opened up to the pastor and the pastor had to make time, he came home and then we had to speak about it, we spoke like myself I had to come to a level where I had to forgive him if I had to go on with my life. The thing I did and he confessed to say he was sorry to each one of us (int.6, p.3)

Interestingly, the pastors also played an important role in facilitating health protective behaviour, enabling people to cope by improving their health status. A few participants reported that the pastors advised them not to continue engaging in sexual activities as this would compromise their health further and encouraged them to abstain from sex. They were also encouraged to eat healthily and avoid alcohol. This demonstrated to the participants that the pastors did not only care about their spiritual growth but were concerned about their long-term health.

Then he start counselling me, you are not going to die now, the life is going on you must start now to know that life is different, it is not the same before because you were doing what you want to do, now you know getting clean body, eat healthy food, not doing sex. (int. 1, p. 2)

In contrast to the supportive role of pastors, other people felt that the pastors were not supportive and were not able to handle the disclosure of the participants. Some pastors reacted in shock to people revealing their HIV status, while others tried to prevent the participants from disclosing this to other people. This was especially stigmatising to the participants, because they expected to receive support from the ministers but the reaction of the latter made them assume that other people would also not be able to bear the knowledge that the participants were infected with HIV. This also made the participants lose confidence and hope of being able to cope, because, as compared to the participants who are infected by HIV, the pastor was expected to be stronger and to have the capacity

to handle any devastating news. One participant explains the pastor's reaction to disclosing her status:

Shooo!!! Got a shock, he was really got a shock, he nearly fell down. You know and I said, 'no do not worry, things happen, things like this do happen'. ...and he hasn't said anything about this since then. He has never, even asked me, 'how are you doing, are you coping? No! I have had lots and lots of challenges but he would never ask me about my disease. (int. 3, p. 7)

The above participant also reported being left in despair after disclosing her HIV status to the pastor and getting this reaction. Ironically, she had to console the pastor and try to make the issue more bearable and understandable for him, while he should have been the one reassuring her. He also never spoke about the disease thereafter and this reinforced the stigma of HIV that it was something unspeakable and this often led to some participants not disclosing their status to the church community. Contrary to their expectations about the pastor and the church, such people were not able to access support, which in turn made it more difficult to cope with being HIV infected. One participant had the following to say when asked whether her church knew her HIV status:

I was thinking, thinking of maybe even if I was like in church being like this other person, I would be like touched (*by God*) or something, I was thinking that I will be judged from there, people will just say, oh shame she is crying or she is feeling or this kind of thing, ...because of her HIV status. So I said it will hinder me to worship and praise God and I just said ah, ah, I would rather not tell them. (int. 4, p.9)

Similarly, the participant below had difficulty disclosing her status to the pastor. She had approached the pastor because she felt she could no longer face the disease alone and needed someone to support her spiritually and to be a mediator between her and God. Unfortunately, the pastor was overwhelmed by the news and did not react as expected, even swearing at her. This shows that HIV was something that the pastor did not know how to deal with and was clearly threatened by.

I am HIV positive and am saying this because I feel I am not coping and I think maybe the strength from God can, can show me, it when I can be able. And he was so scared and it was as if am telling him something? And I said God! This pastor and he was like swear and I was like am not saying am going to disclose. He was like okay, but do not even tell anybody and disclose and what not. Then I just said okay. Then I was really to become like, you know down... (int. 4, p. 10)

Some participants reported that the reason why the pastors did not want them to disclose, was because they could not bear the thought of having HIV positive people in their congregation as they felt that this would stigmatise the church and he would lose church members.

4.4.2 Reactions of Church Members

Some participants coped with being HIV positive because of the support they received from their church members. The participants reported that the church members prayed with and talked to them, and some even offered them material support. Some participants felt much more comfortable to disclose their status to the church members because they would not be judged. As one of the participants said, “church is like a family” and as a result they received the emotional and physical support that one would expect from their own families. The church members also offered support by praying for the participants. This was important to the participants especially in times when they felt they were not coping and were not strong enough to pray for themselves. Therefore, they seem to derive strength from knowing that a number of people are praying for them. As a result the participants feel that they are not bearing the disease alone.

The congregation was the first people to know before I even told my family. After I disclose my status the people were very supportive and they came forward and immediately they prayed for me. They came back to ask me when did I find out and how I found out. (int. 5, p.1)

Some participants also reported that disclosure to the church community gave them a sense of freedom to access support from church members. It also helped them to come to terms with their HIV status, because they no longer had to hide that they were HIV positive. They could discuss it openly and even pray openly about it. This was an important change for the participants because usually in the church people could pray openly for people with other diseases or problems, but not for people infected with HIV.

Being able to feel a part of the church community helped the participants cope because it gave them a sense of belonging. One participant explained his experience of disclosure in the church:

When I pray in church for example I don't hide. I pray for my viral load, CD4 count and I don't hide it. I said it openly for myself of which that has helped me not to carry the burden on my own. The members of the church have the ability or access to call my name and say Lord we are praying for ** that he may be healed. I am looking at the broader perspective of healing whether emotional, spiritual, and physical or any other aspect of healing. That has strengthen me that they are not pretending as if I am invisible and pretending as if am not infected. (int. 5, p. 1)

The participant seemed to feel whole and part of the community because he no longer had to hide his status, and he felt free enough to even mention his CD4 count and not fear rejection. The church community was also free to pray for him and talk to him about his status. This helped the participant cope because it normalised his disease and he felt that he could receive help from the church and God like anyone else.

In contrast to this, some participants reported that when HIV was mentioned in prayer and sermons in the church, apparently reference was normally made to 'those people', talking about them as people who were not part of their church. This also suggested that they would not be having people who were HIV positive in their churches, because of the assumption that people who do not have a relationship with God were the ones that got infected with HIV because of their immoral behaviour. This further suggested that these people were not acceptable in the church.

CHAPTER 5: DISCUSSION

5.1 Introduction:

This research aimed at looking at the experience and challenges of HIV/AIDS, and if and how PLWHA use religious/spiritual coping mechanisms. In addition, the study set out to examine the perceived role and effect of FBOs in enabling or impairing coping with their HIV challenges. Below are some of the questions that the research attempted to answer:

1. Do PLWHA use religious/spiritual coping and if so what form does this take?
2. How does religious coping help people with HIV/AIDS?
3. What is the perceived impact of religious coping on the quality of life of PLWHA?
4. How do FBOs influence coping and the quality of life of PLWHA?

5.2 Do PLWHA Use Religious Coping and if so what Form Does this Take?

Most of the people living with HIV/AIDS interviewed reported turning to religion to help them cope. Some people said they turned to God and he was the only person they felt helped them carry on with their lives especially at a time when they felt that their internal and external resources were depleted and that the problem that they faced was beyond their control.

One of the most commonly reported religious coping methods was prayer. The participants used prayer as a means of communicating with God and maintaining a relationship with Him. They could ask for what they wanted and they could express their feelings to God freely and in private and feel that God was listening to them.

Some participants saw God as a healer. Some participants even reported that God cured some of their ailments, including improving CD4 counts and made them feel better and even live longer, to the extent that some participants believe that they no longer needed ARV medication. Some participants reported that God also helped them to disclose their HIV status, as they no longer felt alone and afraid of the reactions of family members and others, because God helped them to deal with the anticipated discrimination. Some participants said that God gave them a purpose in life, a reason to continue living.

These findings were in accordance with studies conducted by Linsk and Warner, (1999); Pargament, (1990); Pargament et al., (1998); and Pargament et al., (2004), who found that people do turn to God in times of crisis and reported finding comfort and solace from God. They also found that the most commonly reported way of coping was through prayer. According to Hood, Spilka, Hunsberger and Gorsuch (1996) one of the ways religious people who are HIV positive cope is by praying; prayer may be a way of a person finding new means to solve their problem, but prayer can also be a maladaptive coping mechanism, by preventing the individual from actually dealing with the problem. This was evident from this research when some participants said they were coping through prayer and trusting in God and as a result no longer taking any medication.

According to a study by Siegel and Schrimshaw (2002) on the perceived benefits of religious and spiritual coping among older adults living with HIV/AIDS, religious and spiritual beliefs and activities often played a central role in their lives, especially when they were faced with ill health. They found that religion facilitated adjustment to stressful situations by influencing the cognitive appraisal of the situation (Pargament, 1997; Siegel & Schrimshaw, 2002). The form of coping used with stressors, such as being HIV positive, depends on how the individual appraises the situation. The primary appraisal is followed by a secondary appraisal, which is concerned with what they can do about the situation. According to Lazarus and Folkman (1984, in Maes et al., 1996) the individual initially uses primary appraisal processes that assess the personal meaning the event or experience has for the individual. The person determines whether it is a positive or negative event and reacts accordingly. The severity of the event or situation is usually

determined by how threatening the situation is. "A person can view what is happening as an intentional action of God to teach a lesson or possibly to reward or punish via everyday successes or failure" (Hood et al., 1996, p.378).

Therefore, as PLWHA are struggling to deal with their diagnosis, they are confronted by two issues; one, the problem itself and two, the emotions that are aroused by the threat posed by the HIV disease (Hood et al., 1996). Hence the form of coping used can either be problem-focused or emotion-focused.

It is evident from the findings that religious coping is important for PLWHA. Therefore, it needs to be taken into account when making policies and determining how best to treat and manage people who are infected with HIV. However, there is evidence that religious coping can introduce major complications such as non-compliance with medication and other safety behaviours, further complicating management of people with HIV infection. Thus these considerations need to be taken into account in the care of HIV positive people.

5.3 How Does Religious Coping Help People with HIV/AIDS?

The findings show that religious coping had a number of effects: i) reduced the sense of isolation and anticipated rejection from disclosure; ii) facilitated disclosure because of a reduction in fear of anticipated consequences such as discrimination; iii) increased their sense of personal strength and resilience, and gave a sense of mastery; iv) enabled them to reframe their fear of death.

The increased strength and sense of mastery experience through religious coping is in accordance with the two major cognitive functions discussed by Dull and Skokan (1995, in Abraido-Lanza, Vasquez & Echeverria, 2004): firstly, people acquire a sense of control, for example, through prayer, because they are able to feel that this provides some influence over their difficult situation. Prayer also helps them to gain strength to tolerate

their hardships. In this study a sense of control was important for some participants because they were able to overcome the physical and psychological hardships of the illness with a range of religious activities, such as prayer; secondly, religion provides a sense of purpose and meaning during stressful events and chronic adversity. This reattribution is important as is evident from this study. We see that PLWHA are able to accept their HIV status because they believe that God has a greater plan for them and that is why they are infected with the virus. People who cope through such positive attributions have been found to cope better as compared to people who believe that the disease is a punishment from God (Abraido-Lanza, Vasquez & Echeverria, 2004; Spilka, Shaver, & Kirkpatrick, 1985; Pargament, 1997; Pargament et al., 1998). Therefore, religious beliefs/practices can be a source of self-esteem and self-efficacy, but if one believes in a punitive God these beliefs can threaten a person's sense of meaning, control and self-esteem.

This finding is also supported by findings from a study done in Namibia on PLWHA (Plattner & Meiring, 2006) that found that when people attributed their HIV infection to God, their religious belief in God made their HIV status more meaningful to the participants and brought a purpose to their lives because they had hope for the future and were able to reframe their fear of death. Therefore, religious faith enabled PLWHA to cope with the suffering of being HIV positive and the fear of impending death, through a process of reattribution of meaning, for example, seeing death as a gateway to a better life.

Nevertheless, there has been debate about the usefulness of religious coping. For example, Freud (1933, in Weaver & Flannelly, 2004) and later Lazarus (1983) regarded religious coping as a defence mechanism and the main defence being denial. Denial is helpful when a person cannot do anything about the stressor or threat. It is also useful when used to deny some difficult aspects; for example, they were able to accept that they were HIV positive but not able to accept the seriousness of the HIV infection, and that it would lead to death if proper treatment was not undertaken (Lazarus & Folkman, 1984). However, prolonged denial becomes a maladaptive coping mechanism because it could

have unfortunate consequences such as delayed medical attention and other people getting infected or the person infected with HIV getting re-infected (Reeves et al., 1999). This was evident in this study, as some participants reported not taking medication or delaying getting medical attention, while some participants were re-infected by their partners.

5.4 What is the Perceived Impact of Religious Coping on the Quality of Life of PLWHA?

The participants reported being faced with several challenges such as prospects of early death, financial hardships as a result of job loss, difficulties in their relationships and concerns about their physical health. The challenges were similar to findings by Heckman et al. (1996, in Somlai & Heckman, 2000) which were “concerns regarding physical and neurological deterioration, loss of financial resources, the prospect of early death, significant changes in social relationships, disruption of existing relationships and barriers to formation of new social ties” (p.59).

There is considerable evidence that religious beliefs and practices play a positive role in enhancing mental health and perceived psychological well being (Flannelly & Inouye, 2001; Somlai & Heckman, 2000; Woods et al., 1999). Some participants’ reported their quality of life improved because of their religious beliefs. For example, some participants were able to disclose their HIV status and seek medication attention because of their trust in God. The participants reported a better health status due to positive religious coping. A study by Tarakeshwar, Vanderwerker, Paulk, Pearce, Kasl and Prigerson (2006) on religious coping and Quality of Life (QOL) in patients with advanced cancer, found that greater use of positive religious coping was related to better overall QOL, while greater use of negative coping was associated with worse overall QOL.

The participants reported that religious coping helped them begin a new life because they had hope of a better lifestyle; they felt empowered to take control of their lives rather than wait to die. They were also able to join support groups and form new relationships;

the participants also felt more confident and no longer blamed themselves for the HIV infection. This was similar to findings from a study by Lin and Bauer-Wu (2003, in Tarakeshwar et al., 2006) on psycho-spiritual well-being among individuals with advanced cancer, which highlighted that religion/spirituality, contributed the following to the well-being of the patients: self-awareness, relationships and connectedness with others, a sense of empowerment and confidence and living with meaning and hope.

Even though little research has been done on the relationship between religion and QOL (Somlai & Heckman, 2000; Weaver & Flannelly, 2004) and even fewer on their influence on PLWHA, QOL is becoming increasingly important for patients, as advances in treatment prolong life (Flannelly & Inouye, 2001; Weaver & Flannelly, 2004). This is even more important for PLWHA. Thus there need to be more studies conducted on the QOL as this has great implications for the treatment and livelihood of PLWHA. This study only assessed the subjective QOL and it would be important to have a study that assesses the objective QOL.

5.5 How do Faith-Based Organisations (FBOs) Influence the Coping and QOL of PLWHA?

In addition to the personal, private religious coping, the findings also showed that FBOs played a potentially important role and had a significant impact on coping and QOL of PLWHA. Some studies (Linsk & Warner, 1999; Somlai et al., 1997; Weaver & Flannelly, 2004) have also found that FBOs played an important role in the lives of PLWHA.

Participants often turned to FBOs because they offered them a sense of belonging and were also the most familiar institutions to some of them. According to Somlai and Heckman (2000) PLWHA seek environments that are both familiar and accepting of them. The participants reported finding solace and support (Somlai et al., 1997) among the church community. Siegel and Schrimshaw (2002) stated that some studies found that participating in religious community activities gave participants a sense of acceptance

and self-worth. This might explain why some participants continued going to church even after the pastor had rejected them. Hence, the social support received from the FBOs was important, not only because it gave the participants a sense of belonging, but also because they did not feel they were any different from the church members because of their HIV status, as they were treated like everyone else and were able to relate to church members about other issues other than HIV. Therefore this positively impacted on their quality of life.

The participants reported receiving different responses from different FBOs; some were supportive, while other FBOs were not. This was in accordance with findings from a study by Somlai et al. (1997) on the response of religious congregations to the spiritual needs of PLWHA, which stated that the difference in responses was a result of different core beliefs about HIV/AIDS. Some congregations have the tendency of blaming the infected person, because they believe that the person is infected as a result of their sinful behaviour. Viewing HIV/AIDS as a result of sinful behaviour and thus a punishment from God leads to self-stigmatisation in the participants and their being discriminated against. Some researchers (Chikwendu, 2004; Liebowitz, 2002) have argued that religion can be a hindrance to the prevention and eradication of HIV stigma.

This is because stigma has an influence on the likelihood of disclosing one's HIV status (Ostrom et al, 2006). Some participants reported that they were afraid of being stigmatised and as a result did not disclose their HIV status. Lack of disclosure makes it difficult for PLWHA to receive any form of support from FBOs, such as emotional support, being helped to find a means of earning an income, food parcels and receiving training on safety behaviours and how to adopt a healthier lifestyle.

Unfortunately, very little research has been conducted on the impact of FBOs on HIV/AIDS and the QOL of people infected with HIV/AIDS (Liebowitz, 2002). More work needs to be done on the influence of FBOs, as they are an integral part of society, especially in Africa and have quite a large coverage and infrastructure extending even to the most marginalised (Parry, 2004). This suggests that FBOs and other vehicles of

religious faith may have a major role to play in optimizing the quality of life of PLWHA. It also suggests that even secular Organisations concerned with the PLWHA need to involve FBOs in the treatment, management and support of people living with HIV/AIDS. The influence and contribution of FBOs should also be taken seriously during the policy-making processes with regards to HIV/AIDS.

CHAPTER 6: CONCLUDING REMARKS

6.1 Implications

The findings of this study show that in the South African context religious coping and FBOs probably play an important role in coping with HIV/AIDS. This suggests that FBOs need to be more involved in improving the quality of life of PLWHA, and in the management and treatment of HIV positive people. They also seem to have an influence on the families of the PLWHA.

The findings also suggest that training programmes for HIV positive people and their families need to be developed that not only offer coping skills but also help PLWHA develop deeper religiosity or spirituality so as to be able to cope with the devastating effects of HIV/AIDS. Psychologists and pastoral counsellors need to work together to support the people infected and affected by HIV/AIDS. There should also be training offered to the clergy so that they are in a better position to deal with disclosure and other issues surrounding HIV/AIDS.

However, it is important for professionals working with PLWHA to be aware that religious beliefs play a major role in coping and may have specific effects on disclosure, discrimination and stigma, also enabling people to cope with the fear and anxiety of the disease and death.

While the findings of his study point to the important positive effects of religious coping, they also highlight some of the potential negative effects, for example, stopping to take ARVs. In the light of this, careful attention should be paid to the pathways by which religious and spiritual experience impacts on coping with HIV/AIDS.

The study has also shown that FBOs are a useful resource for PLWHA that needs to be tapped as they may offer a sense of security and solace that enables them to cope with HIV/AIDS.

6.2 Limitations

Firstly, the small convenience sample cannot be used to make generalizations about religious coping of PLWHA. A small sample was used as it was difficult to find participants due to lack of monetary incentives and the language barriers.

Secondly, participants' stories may have been influenced by social desirability because the participants came from religious organisations and support groups; hence they may not have felt free to report other experiences of FBOs. Sampling in future studies should include people from the general population so as to be able to make a comparison of coping mechanisms among the people involved in religious organisation and those that are not.

Lastly, data was collected through the use of interviews. It may have been difficult for some participants to talk about their experiences of being HIV positive, due to the sensitive nature of the experience. In addition, participants could only give subjective reports of their quality of life. In future studies it would be essential to consider other methods of measuring the quality of life and coping mechanisms.

6.3 Future Research

More research is needed in this field. There needs to be research that compares religious coping to other forms of coping. Future research also needs to be conducted with a larger sample in order to be able to generalise the findings and make comparisons. It would also be interesting to examine whether the coping methods used change, depending on the stages of HIV/AIDS.

It would also be interesting to see if there are differences in how people, who attended different churches cope: for example Catholics vs. Protestants, or people of different faiths such as Muslims vs. Hindus.

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APPENDIX A

Interview Guiding/Prompting Questions:

- Please can you share with me the story of your life from the time that you discovered that you were HIV positive.
- How did you feel at the time you discovered and afterwards?
- Did your life change after the discovery of your HIV status? How?
- Did you share your HIV status with others?
- What were the effects of being HIV positive?
- What were some of the most difficult aspects or times of being HIV positive?
- Please share with me how you managed to cope with being HIV positive?
- Were there things that made it easier to cope?

- Are you a religious person? Are you a member of a church?
- Please share with me your religious beliefs and experiences in your life generally.
- Have your religious beliefs changed since discovering your HIV positive? How?
- Since discovering your HIV status, has your religious belief or church played any role in coping with HIV?
- What is the attitude or response of your church to HIV?
- Do they know that you are HIV positive? How have they responded?
- Has being religious helped you to cope with HIV? Please explain.
- Has your church helped you to cope with HIV?
- Do you pray? Has it been helpful?
- Are there other religious rituals that you do such as fasting, reading the bible that have helped you cope with HIV?

APPENDIX B

Letter of Consent

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I accept to voluntarily participate in a research about the experiences of people living with HIV/AIDS and how the response of Faith-Based Organisations has influenced their coping and quality of life.

As a participant I am aware that the information I provide will be treated confidentially and am not obligated to divulge private information. I am also at liberty to withdrawal at anytime from the research with no consequences for doing so. It is to my knowledge that the interviewer will attempt to minimise any risk or discomfort that may arise.

I am aware that the interview will be tape recorded and anonymity will be observed. The data will be securely stored and the research findings would be available at my request.

Sign.....

Date.....