

**THE ROLE OF SPIRITUALITY IN THE LIFE OF  
PEOPLE LIVING WITH HIV/AIDS**

**BY**

**MEIKO JOSEPHINE DOLO**

**A dissertation submitted to the School of Nursing,  
University of KwaZulu-Natal (Durban), South Africa**

**In fulfillment of a Master's Degree in  
Psychiatric/Mental Health Nursing**

**Supervised by Dr. Sarah Nomalizo Mahlangu**

**2006**

## ABSTRACT

The purpose of the study was to explore the role of spirituality in the lives of people living with HIV/AIDS, which was aimed at exploring the different spiritual beliefs held by that group of people and the importance of those beliefs in helping them to live with HIV/AIDS. A qualitative approach, using an exploratory research design was undertaken using twenty-five purposefully selected participants from the support group of people living with HIV/AIDS at Philani Clinic in King Edward VIII Hospital in Durban. Data were collected by utilizing focus-group interviews followed by one-on-one individual interviews. An audio tape recorder was used to record the interviews. Field notes and memos were also kept to strengthen the data and to ensure trustworthiness.

The socio-demographic characteristics of participants were analyzed using the Statistical Package for Social Sciences (SPSS 11.5) for Windows; the results are displayed in the form of tables, graphs, percentages and presented in the methodology section of chapter three. The qualitative data were transcribed and analyzed manually by assembling the transcript from each interview and utilized to form major themes, sub-themes, categories and sub-categories that emerged from the data. In this study spirituality was described as a four-dimensional cognitive (mental) relationship with the transcendent being/higher power/ultimate reality, a relationship of love, forgiveness and connectedness that is reinforced by one's belief system. The result of this relationship is the achievement of inner peace, which produced a general sense of wellness that is usually subjective. General wellness could be physical health, mental health, acceptance of things that one cannot change and quality of life. Common themes identified from the sample included spirituality, defined as a personal relationship with God or a higher power that facilitates love, forgiveness and connectedness; taking precaution, respecting the elders and believing in God for everything. HIV/AIDS was found not to be a curse from God, but an ordinary illness, even though other participants believed that it was God's plan to bring humanity back to Him, while others believed that it was a blessing. The study also found

that HIV/AIDS could be prevented through the continuous use of condoms, faithfulness in marriage and abstinence, but some believed that its cure could only come from God after the accomplishment of the purpose for which He allowed the infection. However some study participants believed that the cure would be discovered through research. The benefit of the spiritual belief that helped participants to cope with the infection was the achievement of inner peace, which was achieved through restoration of relationships.

## ACKNOWLEDGEMENT

I would like to acknowledge the Godhead: Father, Son and the Holy Spirit for the entire research. He is the author and the finisher of my faith. I would like to express my sincere thanks and appreciation to my parents who taught me to fear the Lord and to my family at large for their love and support. I would also like to thank Dr. Melvin J. Mason for his mentorship. My profound gratitude goes to the World Health Organization for their financial support that enabled me to acquire a higher education.

I would like to acknowledge and thank the following individuals who helped me along the way and whose assistance made me complete this study. This research would not have been successful without your support.

1. Dr. Sarah Nomalizo Mahlangu was my research supervisor, whose hard work enabled me to come this far. You were the fore-runner. That is, you did your PhD research in Spirituality; otherwise I would not have known that this topic can be done academically. You always made kind comments to me concerning my research results.
2. The School of Nursing support staff for your love and support for the difficult days. You always reassured me that I would make it no matter the difficulties.
3. Mary Spry was my friend from South Africa. She has a very good heart and knows when her friends are in need.
4. Lungi Mkize was my mental health lecturer who stood with me through thick and thin. Lungi, you never left me alone. You were always there for me.
5. My research participants and the social workers at Philani Clinic. Without you I would not have been able to complete this work.
6. Griphin Chirambo was my classmate who was very helpful to me in many ways. Thank you for your help.
7. Ingrid Ussher is my friend from South Africa. You were such an inspiration to me.
8. Nomphilo and Tanya were from the HIV/AIDS support unit on campus. They helped me in so many ways. You provided me with relevant resources when I needed them.
9. Jacquie Metz and her family who edited this work.

## DECLARATION

I, Meiko Josephine Dolo declare that:

This dissertation, The role of Spirituality in the life of People living with HIV/AIDS is my own work and it has not been submitted to any other university other than the University of KwaZulu-Natal (Durban). All sources of information that have been utilized or quoted have been acknowledged by a complete reference.

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Meiko J. Dolo

Date: January 10, 2006

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## **CHAPTER ONE: INTRODUCTION TO THE STUDY**

### **1.1 Introduction**

Acquired immune-deficiency syndrome (AIDS) is unique in human history in its rapid spread, its extent and the depth of its impact. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS, 2004) Report on the Global HIV/AIDS Epidemic, since the first AIDS case was diagnosed in 1981, the world has struggled to come to grips with its extraordinary dimension. Now, more than twenty years later, twenty million people are dead and 37.8 million (34.6-42.3 million) people worldwide are living with HIV; and still AIDS expands relentlessly, destroying the fabric of societies as a cure remains elusive (UNAIDS, 2004). The executive Director of the Joint United Nations Programme on HIV/AIDS (UNAIDS) argued that AIDS demands that we do business differently: not only do we need to do more and do it better; we must transform both our personal and institutional responses in the face of a truly exceptional global threat to security and stability (Piot, 2004).

Past research has shown that because HIV/AIDS has been so stigmatized, that individuals living with the infection have difficult spiritual questions that confront most people with life-threatening illnesses: Did I bring this on myself? What is life about? Why is there pain and suffering? Does God love me (Health Resources and Services Administration) (HRSA, 2002)? During these critical points in life, such rather difficult questions are asked, which may reveal the inner working of the individual's mind and the psychological distress associated with the disease. There is a growing realization that for

many clients, spirituality is a personal strength that can be used for oneself and in clinical settings to ameliorate problems associated with chronic diseases such as HIV/AIDS (Barker, 1995; Carroll, 1997; Pagament, 1997; Richards & Bergin, 1997; Sermabeiklan, 1994). Spirituality may play a critical role because the relationship with the transcendent being or concept can give meaning and purpose to people's lives, their joys and their sufferings (Puchalski, 2001). Research suggests that individuals who are spiritually well and able to find meaning and purpose in their lives were found to be happier (Carson & Green, 1992). As cited in the study of Mahlungulu and Uys (2004) there is scientific evidence from North America and British studies and literature that the spiritual well-being of a person can improve the quality of life lived and the general response to life's crises of illness, suffering, pain and even death (Ross, 1994 in Mahlungulu & Uys, 2004).

Similarly, research studies prove that beliefs have the power to transform and maintain enormous changes in one's perceptions, values, and behaviours. It can be a personal source of strength in coping with physical, emotional, or environmental stress (Anderson & Worthen, 1997; Aldridge, 2001). In a cross-sectional study, Bergin & Jensen (1990) and Hodge (1996) indicated that spirituality is the most important aspect of personal ontology for many people. Spirituality is described as the crossroads of empiricism and rationalism, which provides philosophers a point from which to begin a search for meaning (Slife & Williams, 1995). Empiricism is a path to knowledge through sensory experience (Slife & Williams, 1995). In contrast, the rationalist approach maintains that there are innate ideas and that general propositions can be known to be true in advance or in the absence of empirical verification (Feinberg, 1985 in Neid, 2000). Spiritual beliefs

involve assumptions about reality in the absence of evidence. Whichever belief system we embrace, rationalism or empiricism will come to bear upon our values, goals, actions and the interpretation of our experiences (Neid, 2000). One of the most philosophical and essential questions one can ask is, “What is the meaning of life?” The sincere attempt to answer this inquiry reveals the most basic assumption about who we are, what our relations are, and what are our beliefs. This question becomes intensified by our awareness that although life is brief, it can be meaningful. With this realization, we seek to find or make meaning out of life (Neid, 2000). Against this backdrop, it is of interest for nurse researchers to explore the role of spirituality in the lives of people living with HIV/AIDS (PLWHA) in order to encourage verbalization of their thoughts, expression of their feelings and beliefs.

### **1.2 Background to the Problem**

The role of spirituality in human lives, a once disregarded dimension, is emerging in research and clinical care as a relevant factor, not only in the nursing profession, but also in politics, business, mental health, education, theology and other health related professions (Salmasy, 2002). The recent attention to matters of spirituality is due to the fact that research findings have demonstrated that spirituality plays a key role in one’s illness and wellness (Salmasy, 2002). In the absence of a medical cure for AIDS, HIV-infected individuals may seek alternative treatment therapies and folk healing practices which may include some aspects of their spirituality. In South Africa and in other parts of Africa and the world, some individuals and communities understand HIV/AIDS to be caused by magical and spiritual forces, although others draw on the scientific reasoning and many apply both models (Malala, 2001). Salmasy (2002) however argued that

ancient peoples readily understood sickness as a disturbance in relations, because healing was a spiritual act that consisted of the restoration of relationships between peoples and their gods.

Illness disrupts families and workplaces. It shatters pre-existing patterns of coping and it raises questions about a relationship with the transcendent God as understood by the person (Salmasy, 2002). A growing body of research shows that people are now beginning to live many years following an HIV/AIDS diagnosis (Ross, 1997). According to the Health Resources and Services Administrators, there is a strong connection between the way people define the meaning of their illness, the strength of their immune system, and their ability to cope with illness (HRSA, 2002). Contemporary scientific healing also consists of homeostatic relationship of the patient as an individual organism. Literature reveals that in Britain the comprehensive treatment programmes for people living with AIDS include the spiritual welfare of the patient and its influence on their well-being (Hall, 1998; Holt, Houg & Romano, 1999; Sowell & Misener, 1997).

Spirituality has been positively associated with life satisfaction, psychological adjustment, self-control, personality functioning, self-esteem, internal locus of control, purpose in life, and adjustment and morale in the elderly (Wulff, 1997). Spirituality has also been found to play a significant role in positive outcomes in alcoholism and substance abuse treatment, while it has been negatively associated with death, anxiety, depression, and maladaptive narcissism. Spirituality has been found to play a role in the lives of those who are now surviving for longer periods of time with HIV infection (Hodge, 2000). Solomon et al. (1987) in Ross (1997) described an intensive Psycho-

immunologic Study of Long-Surviving Persons with AIDS that was conducted to understand how long-term survivors are different from people who follow the expected course of the disease. Among other factors thought to be significant to long-term survivors were described as a “belief” that they:

- Understood and accepted the reality of HIV/AIDS diagnosis, but also refused to believe that the syndrome was an automatic death sentence.
- Believed that they could cope actively with the disease, and refused to succumb to a helpless-hopeless state and more.

Clay (2003) recorded that researchers have confirmed an association between surrendering one’s will to a higher power and the use of prayer and meditation, to improve one’s relationship with Him and to seek spiritual awakening. Clay (2003) also said that “given the Bush administration, a recent creation of a US \$ 600 million voucher program has made it possible for Federal dollars to support faith-based treatment. With this grant and other initiatives, psychologists are finding that spirituality can play a role in preventing and treating alcoholism and substance abuse in vulnerable populations such as adolescents and minorities” (Clay, 2003 p. 1). Spirituality has been found to have implications for prevention efforts. Goggin (2001) developed the Alcohol-Related God Locus of Control Scale to measure whether adolescents believed that God controls their drinking behaviour. Through this scale, Goggin (2001) discovered that the more adolescents believe that God played a role in their lives; the less likely they were to drink. Clay (2003) argued that spiritual belief can be protective, but what is not known is why it is a protective factor and how it works. A study of sex workers in Hillbrow,

Johannesburg, showed that sex workers consulted both medical doctors and traditional healers because they believed that traditional doctors uproot the disease, while biomedical doctors cured it (Malala, 2001). In taking an ecological perspective that considers the sufferer and the caregivers, Cooke (1992) argued that the care of HIV-infected patients is physically demanding as well as emotional. Thus, the emotional concerns and spiritual welfare of caregivers as well as that of the patients, should be directly addressed.

### **1.3 Problem Statement**

A number of studies cited in professional journals of nursing, social work, psychology, psychiatry and medicine show a positive correlation between spirituality and mental/physical health (Ross, 1997, 1997; Dossey, 1993; Goldstein, 1995; Leonard, 2001; Halstead & Fernsler, 1994; Oxman, Freeman & Manheimer, 1995; Sullivan, 1993). However, the role of spirituality in the life of people living with HIV/AIDS has not been well documented. Evidence suggests that more and more people are living longer with HIV-infection. Whether this can be associated with the roll out of antiretroviral or the use of alternative medicine such as spirituality, is yet to be discovered. For now, there is no cure for AIDS; spirituality could be a possible alternative management for the condition, considering its potential benefits in chronic illnesses.

The researcher has decided to explore and validate the role of spirituality in the life of people living with HIV/AIDS (PLWHA) due to the current emphasis on improving the quality of life of PLWHA. Furthermore, information specific to spirituality from the perspective of PLWHA is scanty in literature. From experience, the researcher has

observed that prayer is used in Liberia to cure many illnesses. Forgiveness and social connectedness is a means by which many people overcome depression. The researcher has also experienced a period of exposure to spiritual healing as part of an intercessory prayer group, as well as administering nursing care to client and patients with chronic diseases.

#### **1.4 Purpose of the Study**

The purpose of the study was to explore the role of spirituality in the lives of people living with HIV/AIDS. The study further aimed at exploring the different spiritual beliefs held by that group of people and the importance of those beliefs in helping them to live with HIV/AIDS.

#### **1.5 Research Objectives**

In order to achieve the purpose of this study, this research study was conducted to address the following objectives:

- To describe the role of spirituality in the lives of people living with HIV/AIDS.
- To explore the different beliefs about the cause, prevention and cure of HIV/AIDS.
- To describe how spiritual belief can help people living with HIV/AIDS to cope with the infection.

#### **1.6 Research Questions**

The study was guided by the following three research questions:

1. What is the role of spirituality in the lives of people living with HIV/AIDS?
2. What are the different beliefs about the cause, prevention and cure of HIV/AIDS?

### 3. How does spiritual belief help one to cope with HIV/AIDS?

#### **1.7 Significance of the Study**

Identifying the role of spirituality in the lives of people with HIV/AIDS has several implications for nurses and health care workers. Exploring and validating the different beliefs and their importance to this group of people could suggest a framework for the education and training of nurses regarding spiritual aspects of a patient's wellbeing. The study could provide a new direction for nursing education, practice and research, and also provide a clear conceptualization for students and practitioners who are unfamiliar with spiritual beliefs of clients and patients entrusted to their care. Health is defined as the complete state of mental, physical, emotional and spiritual wellbeing and not merely the absence of disease or infirmity (WHO, 2003). In the era of the HIV/AIDS pandemic, addressing the role of spirituality in the lives of PLWHA through an empirical study will create an awareness of the need for a clearer understanding of the phenomenon. There is the need for nurses to identify the spiritual needs of patients in order to render a more holistic approach to care that includes all aspects of life. The role of spirituality in the lives of patients with chronic diseases, which now includes HIV/AIDS, cannot be underestimated.

The need to conduct an empirical study that provides a scientific rationale and basis for nursing practice is important especially at a time when HIV/AIDS is stigmatized in many societies. An evidence-based practice promoted in present day nursing practice is one that includes a scientific rationale or basis for nursing actions. Nurses are urged to encourage

PLWA to seek the spiritual support of others. Ellison & George (1994); Levin (1998) and Perry (1998) found that the level of support individuals experience in spiritual venues is frequently qualitatively and quantitatively superior to social support in other forms. Due to shared experiences, values, mission, commitment and goals, a richer, deeper, more pervasive of support can occur. For example, Maton and Salem's (1995) multilevel, longitudinal examination of Evangelical congregation revealed an empowering, supportive, strengths-based atmosphere. A potent sense of community existed which stressed the significance of each participant. On the other hand, Dossey (1993) has summarized a number of studies, many of which randomized clinical trials, which demonstrate the affects of mental processes such as prayer, meditation, and other spiritual rituals. This study will therefore serve to provide documentation on the support group studied for future reference. Exploring and validating the role of spirituality becomes useful at a time when the cure for AIDS is yet to be found, and can contribute to improving the lives of clients and patients on a spiritual level. More over, this neglected area in nursing care practice can be suggested as a possible alternative management in the care of patients who hold such beliefs based on findings of the study, as global efforts are now geared towards improving the lives of PLWHA. It is expected that findings in this study will enrich the knowledge base of health care providers on the role of spirituality in caring for people living with HIV/AIDS as well as in other chronic diseases.

Lastly, the findings of the study could be useful for further research to deepen knowledge and improve practice because it may offer direction for empirical measurement (i.e., the strength of a belief system). Such an empirical measurement would create opportunities

for research to investigate the relationship between spirituality and other variables, including physical health, mental health, aging, and life satisfaction. Studies could also investigate what kind of interventions could increase the strength of spiritual beliefs.

### **1.8 Operational Definition of Terms**

**Spirituality:** Mahlunqulu and Uys (2004) viewed spirituality as an aspect of the total being inseparably integrated to all other aspects of the being. Spirituality has to do with how the person experiences himself or herself in relationship to what he or she considers as a source of ultimate power and the meaning of life. Spirituality is the integration of one's experiences of God (as understood by the person) in relationship to one's self and the effects this relationship has on individual's value system and the total philosophy of life (Kretzschmar, 1995 in Mahlunqulu and Uys, 2004). Spirituality is a broader concept than religion; the two terms are not synonymous (Golberg, 1998 in Mahlunqulu and Uys, 2004).

In this study, spirituality is defined as a four-dimensional cognitive (mental) relationship with the transcendent being/higher power/ultimate reality, a relationship of love, forgiveness and connectedness that is reinforced by one's belief system. The result of this relationship is peace/serenity/altruism, which produces a general sense of wellness that is usually subjective. General wellness could mean physical health, mental health, acceptance of things that one cannot change and quality of life.

**HIV:** Human immunodeficiency virus is a retrovirus that causes AIDS by infecting the T-helper lymphocytes of the immune system. The most common serotype HIV-1 is distributed world-wide, while HIV-2 is confined to West Africa. HIV lives in blood and other body fluids that contain blood or white blood cells (Walker, Reid & Cornell, 2004).

**AIDS:** Acquired immune-deficiency syndrome is caused by HIV (human immunodeficiency virus). It is not a single disease, but a group of illnesses and conditions, ranging from yeast infection (Candida) to cancer and pneumonia. While some of the AIDS defining conditions can be fatal, many of them are not (Walker et al., 2004).

**People living with HIV/AIDS (PLWHA):** PLWHA for this study are HIV-positive individuals who are members of the support group at Philani Clinic in King Edward VIII Hospital.

**Role:** A role exists in context. It is a state and behaviour of an entity with respect to a particular context. A role does not exhibit all the states or behaviour of the entity, but the role will exhibit state and /or behaviour that is relevant to its participation in the context. The role of spirituality is therefore the function, office, purpose or use of it (<http://www.wordnet.princeton.edu/perl/webwn>. October 15, 2004).

**Belief:** It is a cognitive/mental act, condition, or habit of placing trust or confidence in one's higher power or another; any cognitive content held as true; a persuasion of the truth of religious faith (Hodge, 2000).

**Spiritual belief** is the assumption about reality in the absence of tangible evidence.

**Patient** referred to any person sick or well who benefits from nursing care. In this study the concept of “patient” was used to refer to the person who is sick and undergoing some medical treatment and subjected to nursing care in a clinical setting.

**Support group** referred to a group of people living with HIV/AIDS that are sometimes led by a social worker or a therapist that meet on a regular basis to provide each other with moral support, information and advice on problems relating to some shared characteristics or experience.

## 1.9 Conceptual Framework

The spirituality model proposed for this study is a modification of a model of spirituality developed by Randy Neid, a study conducted under the auspices of the University of Georgia’s School of Social Work, which is a synthesis and elaboration upon the cognitive-behavioural approach to spirituality (Neid, 2000). This approach fits well with a behaviour-cognitive orientation in which human behaviour is predicated on a cognitive interpretation and evaluation of a stimulus. This framework explains spirituality as a function of beliefs, values, behaviours and experiences. It is a circular relationship in which beliefs give rise to values, which inform our behaviours, resulting in an experiential impact upon the spiritual belief system. There is no beginning or end to this circle, at different times any of the phases may be the catalyst toward a change in the belief system.

Beliefs are the core component of the spirituality framework. Spiritual beliefs are driven by a humanistic innate need for seeking meaning and purpose (Maslow, 1968 in Neil, 2000). In a qualitative study, Canda (1988b in Neil 2000) examined the spirituality of “helpers” across major religious orientations. An area of agreement was in the belief that there is an innate need for humans to search for meaning and purpose in their lives. A spiritual person has been on a quest for meaning and purpose, and emerges with confidence that life is deeply meaningful and that his or her own existence has purpose (Elkins et al., 1988). While behaviour may be more easily measured than beliefs, it would be difficult to quantify different types of spiritual acts (e.g. Prayer). Another obstacle towards measuring the spirituality of behaviour is that within a cognitive/behaviour framework the spirituality of an act is grounded in reference to the individual’s own belief system. The model of spirituality proposed for this work is developed within the framework of the cognitive-behaviour theory. The model is a circular process of cognition, meaning it is a relationship. The double headed arrows signify that the relationship has two dimensions-giving and receiving (feedback). Spirituality has a different meaning to different people of diverse philosophies of life, profession, cultural background and religion. Depending on the individual, spirituality would mean a relationship with a transcendent being/higher power/ultimate reality; a relationship of love, forgiveness and connectedness. A relationship with a transcendent being/higher power/ultimate reality could be God for Christians; Allah for Muslims; for Buddhists, Buddha; for Hindus, Shiva, amongst others. This relationship may be expressed through prayer, meditation, reciting a rosary, or baptism.

- A relationship of love can be for oneself the ultimate reality, environment/nature, family friends and loved ones.
- A relationship of forgiveness (resolution/coming to terms with) is a powerful force that could be for oneself, environment/nature, family, friends and love ones.
- A relationship of connectedness could be with oneself, the ultimate reality, environment/nature, family, friends and love ones.

However, at every level, spirituality is reinforced by one's belief system, which is represented by single-headed arrows around the circle of spirituality. Considering that all things are equal, the person in this relationship reaches a level called Peace/Serenity/Altruism with the ultimate reality, others, oneself, environment/nature, family, friends and loved ones. This is the level of equilibrium, where there is love, forgiveness and connection with each other (Daniels, 2003).

The person at the level of peace experiences a general sense of wellness that is always subjective. At this level, all things are possible. The possibilities are physical health, mental health, acceptance of things that one cannot change (death) and quality of life. Belief gives rise to behaviour. The behaviour that one exhibits is the result of his/her belief system. The Bible says (St. Mark 9:23) that "all things are possible to them that believe".

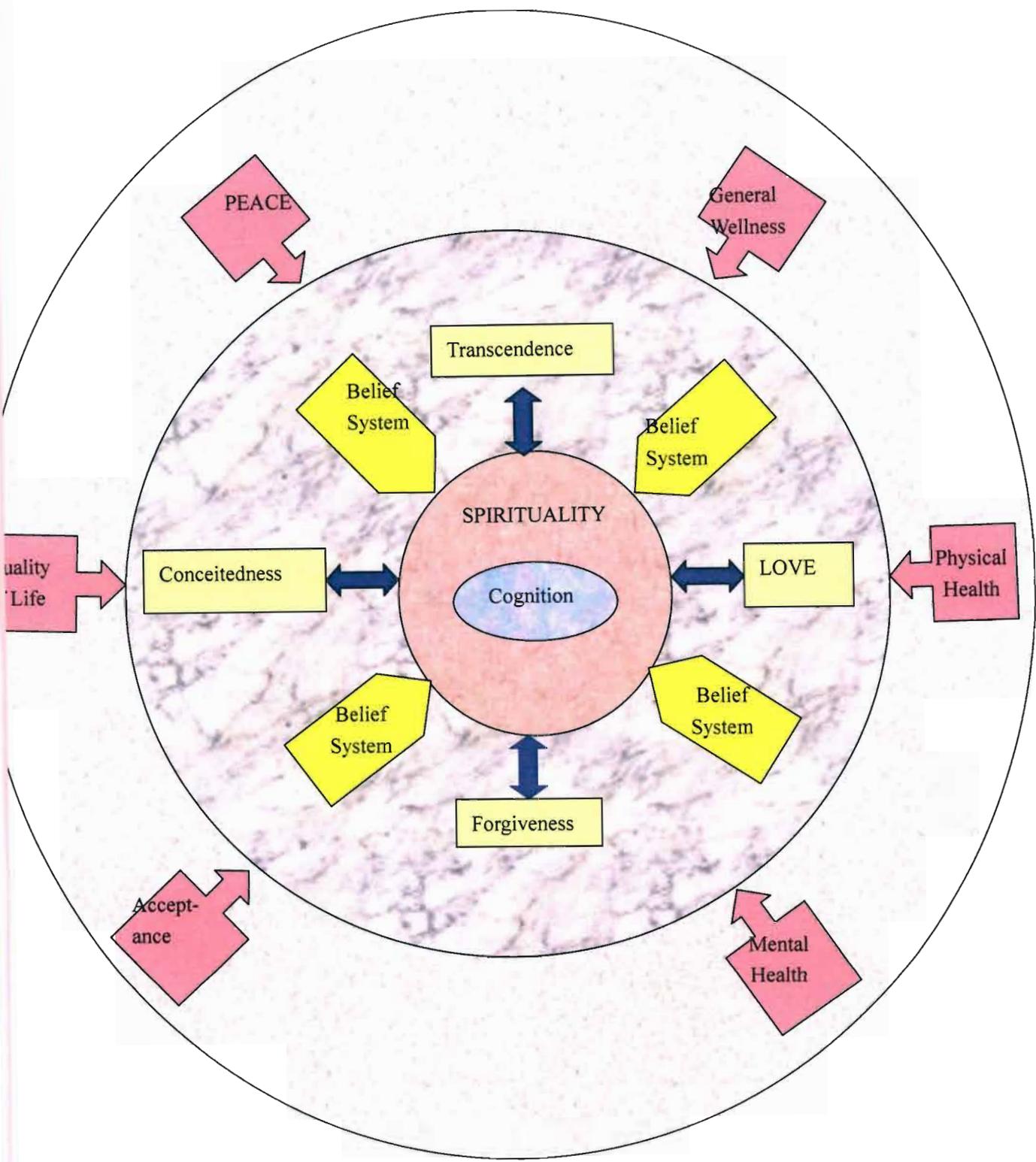


Figure 1: The Cognitive-Behaviour model of Spirituality is diagrammatically explained as follows.

### **1.10 Conclusion**

This chapter had outlined the background to the research problem, the purpose and objectives of the study. The role of spirituality in illness and wellness has been speculated. The research has been conducted to describe the role of spirituality in the life of people living with HIV/AIDS. Due to the reported potential benefits of spirituality in chronic illnesses and in considering the current emphasis on improving the quality of life for people living with HIV/AIDS, the researcher decided to explore and validate the role of spirituality in the life of people living with HIV/AIDS. It was hoped that the findings would be suggested as an alternative management for the infection. The conceptual framework proposed for this study was a modification of the cognitive-behaviour model of spirituality developed by Randy Neid. This framework was chosen because a person's belief helps him/her to make meanings of life experiences.

## CHAPTER TWO: LITERATURE REVIEW

### 2.1 Introduction

Although nursing has its roots in spirituality, the link between these two elements has become less obvious since modern medicine began to make its impact on health care at the turn of the 19<sup>th</sup> century. Since the 1980s nursing began to return to its original roots in spirituality, with a steady flow of interest in the topic (Narayanasamy & Owens, 2001), resulting in a variety of traditions and perspectives. Despite this variety there is a consensus in the literature that spirituality is an important facet of humanity (Narayanasamy, 1999 in Narayanasamy & Owens, 2001). The literature equates a state of well-being with the harmonious balance between these three interrelated, but distinct entities: body, mind and spirit. Distress in any one of these areas affects the others and therefore a holistic approach in restoring the harmonious balance between these three components of humanity is paramount (Narayanasamy & Owens, 2001).

Tanyi (2002) found that rhetoric about spirituality and the human search for spiritual answers has been part of human history for many years. Tanyi (2002) also found that humans have a profound need to understand their spirits, which is the core of human existence and the most elusive and mysterious constituent of our human nature, because being spiritual is part of being human (Wright, 1998 in Tanyi, 2002). The life patterns for people living with HIV/AIDS are already known, and the way they answer spiritual questions has profound implications for both their physical and mental health. How people find meaning and purpose in life in the midst of suffering varies.

This chapter reviews relevant literature on the role that spiritual beliefs play in the lives of people living with HIV/AIDS, as well as in the lives of people with other conditions. This literature suggests that spiritual beliefs can help patients cope with the uncertainty of illness, restore hope, bring comfort and support from others, and resolve the problem of existence, particularly the fear of death.

## **2.2 The Role of Spirituality as Described by Nursing and Researchers**

Spirituality may have different meanings to different people in other professions. Nursing research reveals that there is a plethora of definitions which include: a need for meaning and purpose in life, a need for hope, trust, faith in self, others and in the power beyond self, a need for forgiveness, a need to establish and maintain a dynamic relationship with self, others and the ultimate other (Golberg, 1998; Sardina, 1990; Goddard, 1995).

Furthermore, research suggests that spirituality can be a relationship with a transcendent being (or whatever is considered ultimate), informed by a certain spiritual tradition, which fosters a sense of meaning, purpose and mission in life (Hodge, 2000). In turn, this relationship produces faith, such as altruism, love and forgiveness, which has a discernible effect upon one's relationship to creation, self, others and the ultimate reality (Carroll, 1997; Musick, Koenig, Larson & Matthews, 1998; Spero, 1990). Spirituality provides a context in which a person strives for transcendental values, meaning, experience and development; for knowledge of an ultimate reality, for belonging and relatedness with the moral universe and community; and for union with the imminent, supernatural powers that guide people and the universe for good and evil (Bhagwan, 2002).

Writing in more personal terms, Bhagwan (2002) expressed that spirituality is the transcendental relationship between the person and a Higher Being, a quality that goes beyond specific religious affiliation. Thus, spirituality is not contained by theological walls of any specific ideological system, nor is it considered as equivalent with religion, religiosity or theology (Cowley & Derozotes, 1994).

For the purpose of this research, a clear distinction is made between “religion” and “spirituality,” as the following quotation indicates: “Spirituality can occur in or out of the context of organized religion, and not all aspects of religion are assumed to be spiritual” (Hutchison, 1997, p. 3). Hodge (2000) stated, “Spirituality is not a religion; it has to do with experience. Religion has to do with the conceptualization of that experience. Spirituality focuses on what happens in the heart, religion tries to codify and capture that experience in a system (p. 2)”.

As of 1998, over several hundred empirical studies on spirituality have been conducted, covering a broad range of outcomes (Ellison & Levin, 1998). As McFadden and Levin (1996) noted, the results of these studies have been remarkably consistent. Largely positive effects have been found across populations, regardless of gender, race, ethnicity, age, national origin, study design and religious affiliation.

Additionally, the importance of spirituality has been especially notable. For example, Donahue and Benson (1995) found that self-reported measures of spirituality were frequently better predictors of attitudes and behaviours among adolescents than such

widely regarded predictors as gender and single parent status. In the purview of psychological well-being, it has been widely assumed that one's health is the best predictor of well-being, yet Levin (1995) found that spirituality is at least equal to health itself in terms of predicting well-being and may in fact be a better predictor. A similar importance has been found in the purview of physical health (Martin, Manor & Blondheim, 1996; Oxman et al., 1995).

Spirituality, an integral dimension of human life, is also an essential factor in health and well-being. Skokan & Bader (2000) argued that although all people have spiritual desires and a need to fulfil them, they feel this especially strong when ill. Spirituality can bring an ill person three benefits: hope, strength and emotional support, and as the result of meaningful spiritual experience, the person will often have a sense of peaceful satisfaction with life and satisfaction even with the illness. Salmasy (2002) referred to spirituality as an individual's or group's relationship with the transcendent, or a search for transcendent meaning. This is based on the notion of the human person as a being in relationship, and sickness is understood as a disturbance in relations. Gallup (1997 in HRSA, 2002) wrote that studies have found that patients with advanced HIV/AIDS who found comfort from their spiritual beliefs were more satisfied with their lives, were happier and had diminished pain compared with those without spiritual beliefs.

### **2.3 Spirituality and Alternative Treatment**

Seeking alternative treatment therapies and folk healing practices is common among individuals with HIV/AIDS. According to Walker et al, (2004) there are two broad types

of African healing practitioners in South Africa: faith healers and traditional healers. Both draw on a range of diverse traditions and can be further divided into subsets. In South Africa we find the sangoma, who is possessed by spirits and who has been initiated into a healing cult, and the inyanga (herbalist) who is simply a person knowledgeable about African medicinal herbs. The sangoma is distinguished from the inyanga primarily by the sangoma's belief that he or she is possessed by one or several spirits, and by the sangoma's having experienced some life-threatening illness that had been cured through their apprenticeship to a senior sangoma (Walker et al, 2004).

Pretorius (1999) estimated that there are between 150 000 to 200 000 traditional healers in South Africa, and it is believed that as many as 80% of African people consult traditional healers and they do so for a number of reasons: the absence of hospitals and clinics in many regions (particularly in rural areas), and understaffed and overcrowded health facilities (where they do exist). Yet when health services are accessible, millions of people still choose to confer with traditional healers. This decision is because traditional healers provide a 'psychological' and a physical diagnosis that relates to the complaint and the social milieu of the client (Thornton, 2002). Traditional healers usually take a holistic approach, dealing with all aspects of the patient's life and provide culturally familiar ways of explaining the cause and timing of ill health and its relationship to the social and supernatural worlds. Healers provide medicine for the affairs of daily life and they also provide a conceptual framework that helps many of their patients to understand their illnesses (Reuher, 2001).

In inner-city New Jersey, HIV-infected Hispanics aged 23-55 and primarily of Puerto Rican origin or descent receiving care at an HIV/AIDS clinic, believed in good and evil spirits and that such spirits have a causal role in their infection (Suarez, Raffaelli & O'Leary, 1996). They sought such spiritual folk healing for physical relief, spiritual relief, and protection from evil.

In a two-year ethnographic study that focused on the use of alternative therapies by HIV-positive gay men of West Hollywood, USA, Furin (1995) found that 62.9% of the men in the study were currently using alternative treatment for their HIV disease. A majority of them also used some type of western biomedical treatment as well. The types of alternative therapies used ranged from acupuncture and herbal treatments, to ozone therapy and bitter melon (Furin, 1995).

#### **2.4 The Role of Belief**

Beliefs have the power to transform and to maintain enormous changes in one's perception, values, and behaviours. It can be a personal source of strength in coping with physical, emotional, or environmental stress (Neid, 2000). In Dual Recovery Anonymous (DRA) (2000) it is recorded that members use belief to recover from many physical as well as mental illnesses. Accordingly, members are required to identify a higher power(s) of their choice, and then begin to believe that with the new source of help, they can change their thinking and actions and learn to keep their disease in remission (DRA, 2000).

On the other hand, patients have belief systems that are sometimes not stated, but may have a profound impact on their physical health as well as on their health care providers.

HRSA (2002) found that for many people with HIV infection, the belief system may have something to do with God and punishment and why they are in the position they are in. The stigma associated with HIV/AIDS has led many people to believe that AIDS is a kind of divine punishment for their behaviour by a very angry God, who is just waiting until you mess up and will punish you. Such belief can cause some patients not to take their medications because they think that if HIV is a God's punishment for the type of life they live, then who are they to frustrate God's plan (HRSA, 2002)? However, the demand for care of the whole person as strenuously adopted by nursing, reminds us that in caring for the patient, there is a need to include spiritual belief and their expressions (Clark & Dawson, 1996; Dossey, 1993). Within these approaches, there is a core of opinion which accepts that suffering and pain are part of a larger life experience, and that they can have meaning for the patient (Aldridge, 2001); the emphasis is placed upon the person's concept of God, sources of strength and hope, and their belief system. Patients' beliefs play a significant role especially at the end of life. For example, Greisinger, Lorimor, Aday, Winn & Baile (1997) interviewed 120 terminal cancer patients and found that their most important concerns were existential, spiritual, familial, physical and emotional issues. This implies that patients' way of understanding should be taken seriously.

### **2.5 Belief, Cultural Practice and the Spread of HIV/AIDS**

The influence of belief on sexual behaviour is complex at both individual and societal levels. From the onset, the first known victims of HIV/AIDS were gay men. As a result the infection was associated with stigmatized minorities in the United States and elsewhere. However, the demographic difference between the first diagnosed case in June,

1981, and the present, is that the disease now overwhelmingly affects poor heterosexuals in the developing world (Walker et al, 2004). Marks (2002) reported that the first AIDS cases in South Africa were reported in 1983. At first, the epidemic had its greatest impact among minority groups: intravenous drug users, prostitutes and gay men, and those who did not belong to these high risk groups believed that they were immune to the infection. The understanding of HIV/AIDS at that time was strongly influenced by moral judgements and those who were infected were believed to be the victims of their own immoral or antisocial behaviour.

In apartheid South Africa, racial and political attitudes strongly influenced people's beliefs and attitudes to AIDS. Some blacks argued that whites had deliberately spread the disease and that the promotion of condoms use was a racist device to curb the African population (Walker et al., 2004). These beliefs were encapsulated in a popular expression at the time that AIDS stood for "American invention to destroy sex or Afrikaner invention to deprive us of sex" (Walker et al, 2004). Many African men may have failed to wear condoms as the result of such belief.

On the other hand, men are encouraged to wear condoms and women to insist that they wear them. Walker et al (2004) further explored that for some men and women, the exchange of fluids during sexual intercourse is linked to strong cultural belief about maintaining good health, and condom use is a cultural taboo. Men's greater social power places them in a position of vulnerability regarding HIV infection. Many men are under social pressure to behave in a domineering and sexually aggressive way (Marks, 2002).

For men, norms of masculinity which dictates that young men should be knowledgeable and experienced about sex, prevent them from seeking information and practicing safe sex. Some of them may even be coerced into experimenting unsafe sex to prove their manhood (Jewkes, 2001).

In some countries, initiation rites held at puberty may involve sexual intercourse, and at some major transactions like the death of a husband, sexual rites may be performed. Jackson (2002) wrote that different cultural practices and traditions that once fulfilled important functions in the past may today pose serious health and welfare risks. Some of these practices include:

- The practice of the levirate (inheritance of a wife by the deceased husband's brother), even though her husband may have died of HIV/AIDS and she is infected. The widow has sex with the brother of her deceased husband in a linked cleansing ceremony.
- Initiation rites in parts of Malawi involve adolescent girls being scheduled for training to be a wife. This includes having sex with an anonymous man selected from the community.
- Hampton (1991) described how certain aspects of cultural practice may have contributed to HIV spread in Krobo District in Ghana. This practice is an initiation ceremony into womanhood and it involves sexual activities with anonymous men.
- Polygamy that is practiced by many men throughout the world is risky if men have many girlfriends and seeking other wives without using condoms; or if

wives seek extramarital relationships. If any partner becomes infected, the others are at high risk of infection.

- The practice of dry sex is also common in parts of Africa because the vagina is expected to be dry, tight and hot for the man to really enjoy sex and to ensure that the woman is clean.
- The view that a boyfriend must use force in the first sexual encounter with a new girlfriend so that he can prove that he is respectable. In both cases, the abrasiveness of the sexual activities and the fact that the girl is not aroused increases the risk of vaginal tearing and hence of infection, and condoms are highly unlikely to be used.
- The idea that sex is something to do and not to talk about and the view that sex is for male pleasure and it is not respectable for women to enjoy sex. Enjoyment implies that a woman is “loose”.
- The belief that the first sexual act with a new partner cannot cause infection or pregnancy, and the view that a wife cannot contract sexually transmitted infections (STIs) from an unfaithful husband because STIs do not affect “nice” women. Fear that condoms actually cause HIV, or that they can become stuck in the vagina (Hampton, 1991)

The president of South Africa, Thabo Mbeki, had openly said that HIV does not cause AIDS due to his personal convictions or due to his belief system. The researcher thinks that such a pronouncement is dangerous because it tends to cause people to further neglect the use of condoms, and further increase the spread of HIV.

## **2.6 Relationship between Spirituality and Psycho-biological Outcomes**

There are several studies supporting a positive relationship between the ability of the mind to modulate mental and physical illness. As cited in Neid (2000) the field of psycho-neuroimmunology, which emerged in the 1940s, has established that there is a brain-body connection in which the mind can impact the immune system in its fight against the body's foreign invaders (e.g. bacteria, viruses). Psycho-neuroimmunology explains a brain-body connection in which the limbic-hypothalamic system of the brain converts electrical neural impulses into the hormonal messengers of the body. The hypothalamus is the brain's control centre for all the major regulatory systems of the body: the autonomic, endocrine, immune systems, and the neuropeptide psychosomatic network (Ross, 1988 in Neid 2000). Thus, psycho-neuroimmunology offers one possible explanation for the link between spiritual belief and psycho-biological phenomena such as consciousness, emotion, moods, and memory, and is the knowledge of the world of cause and effect (Aldridge, 2001).

Although the AIDS epidemic has destroyed millions of lives worldwide, it can be perceived as a beautiful experience to some people. Dixon (1997) suggested that AIDS is a saviour because it returns a sense of reality to a world mired in hyper reality. The major part of his work considers how AIDS has influenced a number of creative artists, with a concentration upon novelists and playwrights. Dixon (1997) argued that before AIDS, Paul Monett was personally contented but professionally unsatisfied as a writer of film novelizations. In works such as "Borrowed Time" and "Becoming a Man", he catalyzed a renaissance in a deeply personal style of American Literature. Similar positive

transformations occur with playwrights such as Larry Kramer, Harvey Fierstein and Robert Chesley. However, Dixon (1997) concluded that these transformations are temporary as most of the writers eventually died of AIDS.

Depalo (1997) identified levels of spirituality, hopelessness, coping and multidimensional fear of death in sixty-five gay men with AIDS and found out how individuals dealt with their illnesses. Spirituality and aspects of fear of death emerged as strong predictors of key variables. An individual's ability to cope positively via cognitive or behavioural strategies, or negatively via avoidant strategies can predict his/her reliance upon spirituality and fear associated with dying (Depalo, 1997).

Simonton et al. in Neid (2000) demonstrated a relationship between spirituality and physical illness among a group of patients diagnosed with medically incurable malignancies. The average survival time of participants still living at the time data were being collected, was 24.4 months, twice that of national norms for persons with similar conditions. The average survival time of the subjects who had died was 20.2 months, one and a half times the national norm. A qualitative study by Sullivan (1993) examined the relationship between spirituality as associated with relapse and receptiveness among individuals with severe mental illnesses. The criteria for inclusion in this study were that individuals be free from psychiatric hospitalization in the preceding two years, reside in at least a semi-independent setting, and engaged in a vocational activity. Of the 40 respondents interviewed 48% identified spiritual beliefs and practices as essential to their success (Sullivan, 1993).

Aldridge (2001) studied the relationship between spirituality and psychological mood states in response to life change. Spiritual well-being, existential well-being, and spiritual outlook showed a strong inverse relationship with negative moods, suggesting that spiritual values may influence psychological well-being. Koss in Neid (2000) compared the effects of community mental health services in Puerto Rico to that of a spiritual leader in the treatment of patients with mental health complaints. She found that the outcome ratings of the spiritualist's patients were significantly better than those of the therapist.

### **2.7 Prayer and Spiritual Healing**

Prayer and spiritual healing have been researched over the past years. Aldridge (2001) found that spiritual awareness, a neglected aspect of much research, is finding its way into clinical practice in the treatment of a variety of problems. It is a challenge to use spiritual healing in a holistic and ethical manner. The use of prayer is related to specific health outcomes (Dukro & Magaletta, 1994; McCullough, 1995) and its acceptance within medical practice (Magaletta & Dukro, 1996). Although initial clinical research into the benefits of prayer was inconclusive (Aldridge, 2001), more recent studies, from a broader medical perspective have shown that intercessory prayer is beneficial (Magaletta and Dukro, 1996; King et al, 1999). Prayer is becoming increasingly used in approaches of healing (Aldridge, 2001).

Saudia, Kinney, Brown, Young & Ward, (1991) investigated the helpfulness of prayer as a direct-action coping mechanism in the use by patients before and prior to having cardiac surgery, and found that out of ninety-six subjects, 70 gave it the highest possible

rating on the helpfulness of prayer scale. In the treatment of alcoholism there has been an historical influence of spiritual considerations being included in treatment plans (Bergmark, 1998; Carroll, 1993; Eisenbach-Stagl, 1998). Such treatment for alcohol abuse was often composite packages that included spiritual techniques of prayer. This procedure is still used today, and has been extended into the realm of chemical dependency and substance abuse (Green, Fullilove & Fullilove, 1998; Miller, 1998; Peteet, 1993). For individuals suffering from substance problems it has been found that spiritual engagement appears to be correlated with recovery (Miller, 1998) while religiosity may be an advantageous coping factor (Kendler, Gardner & Prescott, 1997).

Medical help seeking and prayer are not mutually exclusive (Bearon and Koenig, 1990), as prayer is considered to be an active coping response in the face of stressful medical problems. A study of 160 physicians found that physicians believe that prayer has positive effect on physical health, and that religious issues should be addressed (Aldridge, 2001). Prayer is not the only one form of healing that is regarded as spiritual. There are a variety of other forms of spiritual healing Dossey (1993).

The National Federation of Spiritual Healers in England (NFSH) (1999) defined spiritual healing as restoring the balance of body, mind and spirit in the recipient with the intention of promoting self-healing, to bring a sense of well-being and peace to the recipient. A further description concerns itself with finding an inner peaceful core, connecting with a universal source of peace and love that is channelled for the benefit of another. This connection with a universal force is also at the centre of therapeutic touch and belies its connections with ancient systems of healing (Fisher & Johnson, 1999).

While the state of mind necessary for healing has been elusive to research there has been quite extensive research into the physical sequel of spiritual healing phenomena which has included investigations using controlled trials (Aldridge, 2001). Enzymes and body chemicals in vitro have been studied, as have the effects of healing on cells and lower organisms (including bacteria, fungus and yeasts), human tissue cells in vitro, the mortality of simple organisms and plants, on animals and on human problems. While spiritual healing is often dismissed as purely a placebo response, the evidence from studies of lower organisms and cells would indicate that there is direct influence (Aldridge, 2001).

At the level of daily practice some general practitioners have been willing to entertain the idea of spiritual healing and incorporate it into their practice, to use spiritual explanations for some of their patient contact, or as part of their referral network (Aldridge, 2000; Brown, 1995; Dossey, 1993). Cohen (1990) emphasized the value of touch, time and compassion which the healer can offer, and the benefits of referral. In Brown's (1995) study of chronic problems in an English general practice of six doctors, adult patients with chronic complaints were referred by their general practitioner to a healing clinic. In choosing the patients, the general practitioner included those who had had a problem of six months duration and had not responded well to usual interventions. Treatment sessions lasted 20 minutes once a week for an eight week period. The spiritual healing used a "laying on of hands approach" to channel healing energies. There were significant changes after eight weeks in what was a group of patients with poor health status in role limitations, social function, pain, general health and vitality (Brown, 1995).

In Liberia, a similar technique of “laying on of hands” is used in the management for many medical as well as social conditions. Medical conditions that are usually prayed for are those for which medical practitioners have no medical explanations as well as those that do not respond to medical treatment. In many cases, the researcher has observed that healing was immediate or gradual. However, depending on your belief system, prayer is applicable to every health condition. On the other hand, many social problems are resolved through prayer. Many people who have marital problems in Liberia ask for prayer and there is almost always a peaceful resolution. Parents of problematic children will submit their children’s names for prayer and there are always positive solutions.

## **2.8 Spiritual Awakening**

Nursing has a long history of spiritual influence through the recognition of humans as spiritual beings. However, despite this recognition, many nurses are reluctant to develop and use skills in spirituality (Wright, 1998). Three reasons for this reluctance are:

- Lack of knowledge that illness/wellness is a spiritual issue
- Lack of knowledge of cultural/spiritual diversity
- Failure to do a spiritual assessment/history

### **2.8.1 Lack of Knowledge that Illness/Wellness is a Spiritual Issue**

Nurses have embraced a holistic concept of persons, and therefore have the ethical obligation to seek the spiritual well-being of their patients. However, many nurses are not convinced that illness and wellness are spiritual issues (Wright, 1998).

Sulmasy (2002) wrote that ancient peoples readily understood sickness as a disturbance in relationships between humans and their gods. Thus, healing was a spiritual act which consisted of the restoration of right relationships. Contemporary scientific healing also consists of the restoration of homeostatic relationships of the patient as an individual organism. Much of medical/nursing training has to do with finding a cure or fixing a problem (Puchalski and Sandoval, 2003). In HIV/AIDS and in end of life care, this is no longer possible. This situation is where spiritual well-being becomes more critical because it allows us to care for our patients even when cure is not possible.

### **2.8.2 Lack of Knowledge of Cultural/Spiritual Diversity**

Wherever nurses work in any health care system, they care for patients that are culturally diverse. Campinha-Bacote (2003) argued that in order to provide quality and cost-effective care in a diverse culture, health care professionals need to strive to achieve cultural competence. Cultural competence is used to describe people and organizations that work effectively within their own culture and cultural groups different from their own, which involves a set of attitudes, practices, behaviours and policies that enable a person, agency, or system to work effectively in multi-ethnic, pluralistic, and linguistically diverse communities.

The lack of knowledge of cultural diversity can lead to attitudes such as fear, ethnocentricity, cultural blindness, racism and discrimination (Leonard, 2001). The biomedical health care “culture” must accommodate not only persons from diverse cultures, but also diverse systems of care, rather than require them to assimilate into the

system's "culture." This fundamental shift requires nurses to move quickly to develop cultural competency as individuals and to provide leadership for this system-wide change (Leonard, 2001).

### **2.8.3 Failure to do a Spiritual Assessment/History**

Spiritual assessment is the process of gathering relevant information from a patient about spiritual values, religious beliefs, spiritual needs and concerns, and whatever gives the patient's life meaning (O'Brien, 1999). Current nursing theories address the spiritual dimension of the person. For example, Newman in Carroll (1997) stated that spirituality permeates all aspects of a person, regardless of whether spirituality is acknowledged or developed. According to Newman, people are energised through "spirits," resulting in movement toward wellness and enthusiasm in relationships. When illness, loss, grief, or pain strike a person, energy is depleted and one's spirit is affected, resulting in spiritual needs and concerns (Newman, in Carroll, 1997).

## **2.9 Conclusion**

The literature has explored the role that a patient's belief plays in his or her health and illness. Puchalski and Sandoval (2003) noted that if the patient is religious, it is helpful to ascertain if he or she believes in God or a higher power, and to know their unique perspectives. If he is not religious, it is important to find out other spiritual beliefs and practices that may affect his or her illness. In both cases, spiritual or religious, what may ultimately give a patient a sense of meaning and purpose may be within the context of a particular identified belief or outside of that context (Puchalski and Sandoval, 2003).

Literature was revised around specific areas of relevance according to the focus of this study. The review of the literature has therefore provided background information regarding the role that spirituality play in the life of people living with HIV/AIDS as well as the role of beliefs in diverse life situations. Furthermore, it has demonstrated the role that belief and cultural practices play in the spread of the infection, the importance of prayer and spiritual healing and the need for spiritual awakening among nurses.

## **CHAPTER THREE: RESEARCH METHODOLOGY**

### **3.1 Introduction**

In this chapter the researcher gives an overview of the research process that was followed in exploring the role of spirituality in the lives of people living with HIV/AIDS. The research methodology section includes discussions on the research design, setting, sampling and sampling procedure, sample description, socio-demographic characteristics of the sample, instrumentation, data collection, data analysis, and ethical considerations.

### **3.2 Research Design**

A qualitative approach, using an exploratory research design was deemed appropriate for this study. The purpose of exploratory research is to explore and describe phenomena for the generation of new knowledge about concepts or topics about which little is known (Burns and Grove, 2001). This approach was followed in order to explore the role of spirituality and examine different spiritual beliefs in the lives of PLWHA. Exploratory or informative research is conducted to gain new insights, discover new ideas and/or increase knowledge of a phenomenon. Exploratory studies are undertaken when a new area or topic is being investigated. This design enabled the researcher to investigate the full nature of the phenomena under investigation, the manner in which it is manifest and other factors with which it is related (Polit and Hungler, 1999).

Exploratory qualitative research is designed to shed light on and explore the full nature of a little-understood phenomenon (Streubert & Carpenter, 1999). Burns and Grove (2001)

argued that exploratory studies are conducted in areas about which nursing has little knowledge, theoretical or factual, and the researcher explores the field in order to learn what is there, what meanings are attached to the discoveries and how the meanings can be organized. Intuition and insight play important roles in this process. The researcher must feel free to follow through on a new lead and move the study into new areas in the middle of the study process. Therefore exploratory studies tend to have less design structure than other types of studies (Burns and Grove, 2001). The design is very flexible; enabling the researcher to function somewhat as an investigator, searching out clues to factors in the situation that may be significant. Due to the flexibility of the design, Burns and Grove (2001) suggest that the researcher must rigorously design the study to maximize the accuracy (reliability/trustworthiness) of the evidence collected and minimize bias and threats to the validity of the findings. These actions increase the probability that if the study were repeated, similar findings would result, thus adding credibility to the study (Burns and Grove, 2001).

Exploratory designs can be either qualitative or quantitative depending on whether the data are numeric or in words, and whether the intent of the study is to develop theory or to develop the knowledge of a field to the point that more quantitative approaches can be used (Burns and Grove, 2001). Due to the scarcity of empirical research in this area within the South African context, it was necessary for this study to follow an exploratory design or an information gathering exercise that could provide pointers and insight into the role of spirituality in the lives of people living with HIV and AIDS. The exploratory research or information gathering design was used because the role of spiritual belief is a

new area of study. This method is utilized in order to build a foundation of general ideas which can be explored more rigorously at a later date (Polit & Beck, 2004).

### **3.3 Research Setting**

The study was conducted at Philani HIV Family Clinic in Durban. The word Philani means 'to get well' in the African language of Xhosa. The Philani clinic is an out-patient HIV clinic located within the compound of King Edward VIII Hospital, located on Sydney Road, Congella, Durban. The program was started in 1979 in an informal settlement of Crossroads near Cape Town as a mobile pediatric clinic for feeding malnourished children. However, over the years, Philani has grown and has centres in many parts of the country. One of the clinic's activities is to manage and treat sexually transmitted diseases (STDs), AIDS and tuberculosis. This aspect of Philani started in Durban in 2001. This setting was chosen because the researcher believed that she would be more likely to access the target population that is, people infected by HIV/AIDS. The setting was also chosen because the emphasis of care is holistic, which includes the spiritual dimension of the person and is aimed at giving hope to people who are infected with HIV/AIDS (<http://www.hivan.org.za/details.asp?id=1034&netid=400>.) November 10, 2005.

### **3.4 Study Population**

The study focused on the adult (18 years and above) population of people living with HIV/AIDS in the support group at Philani Clinic in Durban, as participants for the study.

### **3.5 Sampling and Sample Procedure**

The sampling technique used was the purposive or judgemental sampling procedure. Purposive sampling method is a type of nonprobability sampling method in which the

researcher selects participants on the basis of personal judgement about which one will be most representative or productive (Polit and Hungler, 1999). In this design, the researcher is guided in his or her choice of participants by previous answers received from the participants, and the need to fill the gaps in the emerging categories (Burns and Grove, 2001). This meant that the researcher would not begin with a fixed number of participants, but would continue selecting and adding participants until data is saturated. This means, who to sample next depends on who has been sampled already and what information has been obtained (Polit and Hungler, 1999). The participants were selected on the basis that they were living with the infection and that they were adults (18 years and above) who could give a voluntary consent, were well oriented, fully conscious, mentally sound and aware of the clinical prognosis of their illness. This group was selected for the study because research has revealed that infection with HIV raises difficult spiritual questions that confront most people with life-threatening illnesses. Particularly, those with HIV infection have the belief that it may have something to do with God and punishment and why they are in the position they are in (Forsarelli, 2001 in HRSA, 2002). In addition, studies done in the United States and Britain have shown that spirituality or spiritual beliefs have been found to play a role in providing strength to those who are now surviving for longer period of time with HIV infection (HRSA, 2002); and patients are more likely to seek a relationship that is beyond the material realm (Ross, 1994).

### **3.6 Sample Description**

The sample composed of twenty-five (25) participants drawn from the Philani Clinic support group for the study, from a population of thirty-five (35), which represents the

total number of people that were once in the support group. The researcher did not make any prior decision about the number of participants to sample. However, she continued to collect data until data saturation was achieved. The support group at Philani was not very large. Initially there were 35 members of the support group as mentioned, who met each week. However, due to individual member financial constraint, they no longer met as a support group. All patients attending the clinic are usually seen individually during visits to the clinic.

Nineteen participants were interviewed in four (4) focus groups: three (3) consisted of five (5) participants each, and one (1) consisted of four (4) participants. Six (6) participants were interviewed on one-on-one basis. A total of ten interviews were conducted. The participants were all interviewed at Philani Clinic in King Edward VIII Hospital because they were all members of the Philani Clinic Support Group. The interviews yielded a response rate of 100% because all 25 sampled were willing to participate in the study. Data were collected until saturation was reached and new information was no longer forthcoming.

Participants from the first focus group were all females, between the ages 20 to 45. In the second focus group, the participants were all females between the ages of 21 to 33. The third focus group had three (3) females and two (2) males, between the ages 20-37 and the fourth focus group participants were all females between the ages 22-25. The individual one-on-one participants were all females between the ages 21-48.

All the study participants were Zulu-speaking Africans, but also spoke English fluently. They were given the option to respond in the language of their choice (English or Zulu), and they responded in English, except for members of the second focus group who responded in Zulu. The researcher does not speak Zulu. Therefore, a Zulu-speaking nursing student served as a translator for this group. The responses were then translated into English and later transcribed into a rich text. The data for the focus-group discussions were collected in March, 2005, followed by individual one-on-one data collection which occurred in June and July of 2005 from the same support group. Respondents of the focus groups were different from those of the individual one-on-one interviews. The same questions were asked to all the respondents in the study, that is, the focus groups and the one-on-one participant interviews.

### 3.7 Socio-demographic characteristics of study

The socio-demographic characteristics of the participants in the study are displayed in the form of tables, graphs, and pie chart.

#### Age

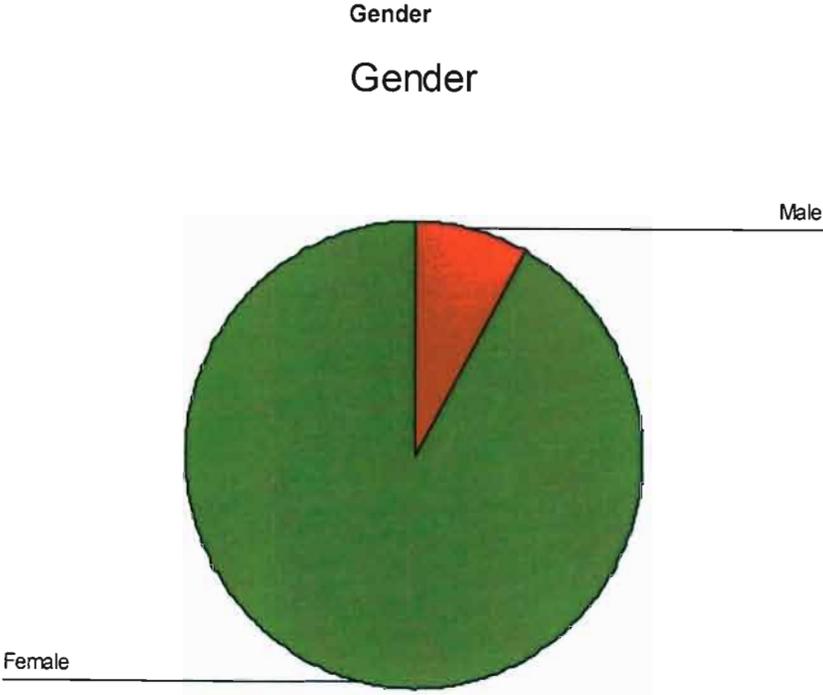
Age was categorized into six groups. There were 12 (48%) participants between ages 18 - 25; 6 (24%) between the ages 26-30; 3 (12%) between the ages 31-35; 2 (8%) between the ages 36-40; 1 (4%) between the ages 41-45; and 1 (4%) 46 and above. The majority of the respondents (12) in the sample were young, between the ages of 18 and 25 (**Table 1**).

Age in years	Frequency	Percent
18-25	12	48
26-30	6	24
31-35	3	12
36-40	2	8
41-45	1	4
46 and above	1	4
Total	25	100.0

**Table 1: Showing Age distribution of all participants (N=25)**

**Gender**

Females dominated the sample. Of the total sample of 25 respondents, 23 (92%) were females and 2 (8%) were males (**Figure 2**).



**Figure 2: Gender Distribution of Respondents (N=25)**

### **Marital Status**

The marital status distribution shows that 22 (88%) respondents were single, 2 (8%) were married and 1 (4%) was a widow (**Table 2**). The statistics shows that the majority of the respondents were single.

Marital status	Frequency	Percent
Married	2	8
Single	22	88
Separated	0	0
Divorced	0	0
Widow	1	4
Total	25	100

**Table 2: Marital Status Distribution of respondents (N=25)**

### **Level of Education**

Of the total respondents, 21 (84%) completed matric and 4 (16%) had some tertiary education (**Table 3**). The statistics show that the majority of the respondents did not have any tertiary education.

Educational Level	Frequency	Percent
Primary	0	0
Secondary	0	0
Matric	21	84
Tertiary	4	16
Other	0	0
Total	25	100

**Table 3: Level of Education of respondents (N=25)**

### **Religious Affiliation**

The religious affiliation distribution of respondents revealed that 22 (88%) respondents practiced Christianity, 2 (8%) ascribed to ancestral worship, but also identified with Christianity and (1) (4%) respondent had no religious affiliation (**Table 4**). This respondent stated that he ascribed to Christianity in the past, but lost his faith

Religious Affiliation	Frequency	Percentage
Christian	22	88
Muslim	0	0
Hindu	0	0
Buddhist	0	0
Ancestral Worship	2	8
No religion	1	4
Total	25	100

**Table 4: Religious Affiliation Distribution of respondents (N=25)**

### **3.8 Data Collection and Instrumentation**

The data for the data were collected over a period of five months (March 2005 to July 2005), using a semi-structured interview schedule, which was developed by the researcher (Annexure E). The instrument was utilized to solicit rich descriptions of the role of spirituality in the life of people living with HIV/AIDS. The instrument was structured through open-ended questions. Polit and Hungler (1999) listed the advantages of open-ended questions that include the following:

- Open-ended questions are flexible
- They allow the interviewer to probe so that he/she may go into more depth if he/she chooses, or to clear up any misunderstandings
- They enable the interviewer to test the limits of a respondent's knowledge on the topic under study.
- They encourage cooperation and rapport; and they allow the interviewer to make a more accurate assessment of what the respondent really believes.

The disadvantages of open-ended questions lie in the possibilities of loss of control by the interviewer, and in particular in being more difficult to analyze than close-ended questions. During these interviews, however, the participants were always brought back to the interview focus.

The instrument was developed in English. The researcher was aware that the target population spoke both Zulu and English. Therefore, there was no need for translation of the instrument because participants were literate in both English and Zulu. The

instrument consisted of two sections: Section (A)-(questions 1-7) was used to obtain demographic data from the participants and section (B)-(questions 8-14) was the section of the interview schedule, which was utilized to gather information on the role of spirituality in the life of people living with HIV/AIDS. The following are the sub-sections of Section B of the instrument:

- Questions 8 – 12 focused on the role of spirituality in terms of participants' descriptions and definitions of their own spirituality and the role of interpersonal relationships (love, forgiveness and connectedness) in their lives.
- Question 13 focused on the different beliefs about the cause, prevention and cure for HIV/AIDS;
- Question 14 focused on the benefits of spiritual beliefs that help people living with HIV/AIDS to cope with the infection.

### **3.9 Pre-testing of the Instrument (Pilot study)**

A pre-test was done on two clients who were not part of the study in order to test the trustworthiness of the instrument. Pre-test is a “small scale study on a limited number of subjects from the same population group as that of the intended participants for the eventual project” (Polit and Beck, 2004, p. 196). This is done in order to investigate the feasibility of the study and to detect any problems with the instrument for data collection. The pre-test was also done in order to identify parts of the instrument that are vague or offensive to respondents (Polit and Beck, 2004).

As already mentioned, the participants were interviewed in focus groups and individually. The interviews were conducted among those who volunteered to participate in the study. The rationale for focus group interviews is to enable the researcher to obtain the viewpoints of many participants in a short time. In focus groups, the researcher is able to probe more on the responses generated by the clients (Polit and Hungler, 1999). The researcher also conducted six individual interviews on a one-on-one basis. The one-on-one participants were not the same as those of the focus group. Before commencing each interview, the purpose, objectives and significance of the study were read to the participants and they were given the opportunity to ask questions and clarifications were made. Later, the participants signed the voluntary consent, permitting the researcher to interview them. Permission was also obtained for audio-taping the interviews. The interviews were audio-taped and later transcribed by the researcher and her assistant. Each focus-group interview lasted for approximately 45 minutes to 1 hour due to the size of the group. However, each individual one-on-one interview lasted for 20-25 minutes.

When using a semi-structured interview guide, probing questions were used to clarify the meaning of responses in some cases and to elicit more information. The researcher's aim was to encourage the respondents to talk freely about what they were asked. Burns and Grove (2001) stated that interviewing is a flexible technique that can allow the researcher to explore more information. The other advantage of the interview is that it ensures that all questions have been answered and when in doubt, the interviewer can reassure and encourage the respondents to answer.

### 3.10 Data Analysis

The socio-demographic data were analyzed using the Statistical Package for Social Sciences (SPSS 11.5) for Windows; the results are displayed in the form of tables, graphs, percentages and were presented earlier in chapter three in the methodology section.

The main section of the instrument, the interview guide, focused on the role of spirituality in the lives of people living with HIV/AIDS. The findings are presented in chapter four. The interview guide was divided into three sections: 1) the role of spirituality in the lives of people living with HIV/AIDS; 2) the different beliefs about the cause, prevention and cure of HIV/AIDS; and 3) the benefits of spiritual beliefs in helping people living with HIV/AIDS cope with the infection. The interview guide was utilized to obtain rich descriptions of the role of spirituality in focus group interviews and individual one-on-one interviews and yielded the qualitative results.

The qualitative data were transcribed and analyzed manually by assembling the transcript from each interview and utilized to form major themes, sub-themes, categories and sub-categories that emerged from the data. The interview guide developed for this study served as a template in categorising the data. According to Polit and Beck (2004), in this style, the researcher develops a template or analysis guide, to which the narrative data are applied, constantly reviewing the data as more data are gathered. The analysis of the resulting data, once sorted according to the template, is interpretive. A template can emanate from theory or pre-existing knowledge (Polit and Beck, 2004). In this study the

template emanated from the interview guide and assisted with the identification of meaningful units or parts that were categorized into major themes. The interview guide was then applied to the data collected and major themes and sub-themes as well as categories that emerged are discussed. The different sub-categories that were observed in some of the categories are also presented in chapter four.

### **3.11 Trustworthiness**

The academic rigor for qualitative studies is measured by their trustworthiness or by their being true to the data and their context (Polit and Beck, 2004). Trustworthiness is the procedure used by qualitative researchers to evaluate and qualify their data and findings. The potential strength of qualitative research may be lost if appropriate strategies are not followed to reduce careless handling of data and researcher's biases (Khalifa, 1993). According to Lincoln and Guba (in Polit and Beck, 2004), there are four criteria for establishing the trustworthiness of qualitative data: credibility, transferability dependability and confirmability.

#### **3.11.1 Credibility**

Credibility is one of the processes through which qualitative data is evaluated, referring to the truth of the data. Polit and Hungler (1999) point out that the credibility of an inquiry involves two aspects: first, carrying out the investigation in such a way that the believability of the findings is enhanced, and second, taking steps to demonstrate credibility. In order to achieve credibility, the researcher utilized several measures. She first utilized prolonged engagement and persistent observation. The researcher interacted with the study participants for the period of five months (March – July, 2005). The aim of

this initiative was to have an in-depth understanding of the views of the participants and to test for misinformation and distortions of any information (Lincoln and Guba, 1985 in Polit and Hungler, 1999). Prolonged engagement was also used to build trust and rapport with study participants.

Secondly, the researcher employed a method of triangulation; this means that she used more than one method of data collection: one-on-one interviews and focus groups interviews. The purpose of using triangulation is to provide a basis for convergence on the truth by using multiple methods and perspectives.

Thirdly, the researcher also utilized member check which is the researcher's ability to check back with the participants to validate the accuracy of the information given and recorded. The researcher validated the information by allowing participants to read the transcript of the data. Peer debriefing was also done in order to achieve credibility. The data analysis process was discussed with other colleagues and with the research supervisor at regular intervals to ensure credibility.

### **3.11.2 Transferability**

The second aspect of trustworthiness is transferability (Lincoln and Guba in Polit and Beck, 2004). In order to ensure transferability of the study the researcher provided a thick description or sufficient information about the phenomenon under study in order to permit judgements about its contextual similarity. Transferability refers essentially to the generalizability of the data; that is, the extent to which the findings from the data can be

transferred to other settings or groups (Guba and Lincoln in Polit and Beck, 2004). To ensure transferability, the researcher provided a significant description data in the research report so that readers can evaluate the applicability of the data to other contexts.

### **3.11.3 Dependability**

The third aspect of trustworthiness of qualitative study is dependability. Dependability of qualitative data refers to the stability of data over time and over conditions. Polit and Beck (2004) identify stepwise replication approach to assessing the dependability of data. This approach involves having a research group of two or more people who can be divided into two teams that deals with data sources separately and conduct essentially, independent inquiries through which data can be compared (Polit & Beck, 2004). To ensure dependability, the process of data collection, analysis and interpretation were monitored by the research supervisor. The dependability audit technique was also utilized whereby the data and other supporting documents are scrutinized by an external reviewer.

### **3.11.4 Confirmability**

Confirmability is the fourth aspect of trustworthiness. Confirmability refers to the objectivity or neutrality of the data, such that there would be agreement between two or more independent people about the data's relevance or meaning (Polit and Hungler, 1999). The focus of confirmability of qualitative data is on the characteristics of the data (are the data confirmable?). Inquiry audits can be used to establish both the dependability and confirmability of the data. In order to ensure confirmability of the data, the researcher developed an audit trail in which she collected materials (audio recordings of the interviews) and documentation (letters of permit from the Department of Health of KwaZulu-Natal and from the institution where data were collected), that will allow

independent auditors to come to the conclusion about the data. The researcher also has the transcript that was utilized for the analysis of the data.

### **3.12 Dissemination of Findings**

The researcher is obliged to inform the participants about the research findings. A copy of the findings of the research was therefore sent to the Administrative Office of King Edward VIII Hospital and Philani Clinic where participants were recruited. Secondly, the findings will be submitted to the School of Nursing of the University of KwaZulu-Natal in a written report form.

### **3.13 Ethical Consideration**

The research proposal to conduct this research was submitted to the University of KwaZulu-Natal Research Ethics Committee for ethical approval and clearance was given for the data to be collected. Written permission to conduct the research was obtained from the Department of Health of KwaZulu-Natal. Permission to conduct the research was also obtained from the authorities of King Edward VIII Hospital by presenting a copy of the research proposal to the appropriate authority. When humans are used as study participants – as they always are in nursing research, care must be exercised in ensuring that the rights of those humans are protected (Polit and Beck, 2004). For this reason, permission to enter the support group was also sought from the social worker as well as from the participants of the study. The participants for the study were all contacted from the support group for their permission to participate in the study. A letter of permission was read to them, stating the goals and objectives for the study. Later,

clarifications were made regarding participants' concerns. Those who volunteered to participate in the study signed the consent page of the letter of permission.

Some participants did not feel comfortable to be interviewed in a group format. As a result, some of them were interviewed on a one-on-one basis, while others were interviewed in group format. All the participants were assured that confidentiality would be respected and their names not mentioned anywhere in this document.

Because of the nature of the methodology, issues may emerge in the interview for which both participants and researcher were not prepared. It is acknowledged that because of the open, emerging and unpredictable nature of qualitative research, informed consent is problematic (Robley, 1995). As a way forward, consensual decision-making or process-informed consent was utilized, in which consent is re-evaluated throughout the research process (Streubert & Carpenter, 1999). That is, participants were free to quit whenever they wished or not to answer any question that they felt were sensitive to them.

### **3.14 Conclusion**

This chapter provided an overview of the approach that was used during the data collection phase of the study. Details of the processes involved in an empirical study have been discussed in an attempt to give a systematic flow of information considering the purpose of the study. The information derived from the first part of the study was also presented to give an idea of the sample description and socio-demographic data. Ethical consideration was observed throughout the study as the nature of the study required an atmosphere of trust, openness and confidentiality. In the next chapter, results from the

data collection on the interview guide are presented separately under the appropriate themes, sub-themes, categories and sub-categories based on results obtained on analyzing the transcripts.

## **CHAPTER FOUR: RESEARCH RESULTS**

### **4.1 Introduction**

The purpose of the study was to explore the role of spirituality in the lives of people living with HIV/AIDS. The study was aimed at exploring the different beliefs held by this group of people about the cause, prevention and cure of HIV/AIDS and the benefit of these beliefs in helping them to cope with the infection. This chapter presents the findings of the research. The social demographic characteristics of study participants are displayed in the form of tables, graphs, percentages and paragraphs in chapter three.

### **4.2 Presentation of findings**

This section presents the qualitative research findings obtained through focus-group discussions and individual one-on-one interviews held in Philani Clinic Support Group at King Edward VIII Hospital in Durban. The findings from the interviews are presented following the interview guide that was developed around the three research questions for the study. These three research questions were utilized to form most of the major themes of the study. Four major themes emerged from the study:

- Definition of spirituality
- The role of spirituality in the life of people living with HIV/AIDS
- Beliefs about the cause, prevention and cure of HIV/AIDS
- Benefits of spiritual belief in helping people living with HIV/AIDS to cope with the infection.

### 4.3 Theme 1: Definition of Spirituality (how respondents defined spirituality)

Spirituality was defined by the study participants in a variety of terms, which included a belief in and a relationship with God, oneself and others, as illustrated in the following quotes:

*“The belief a person has that there is a God”*

*“The awareness that each person has a spirit that one needs to connect with and nurture”*

Participants who ascribed to Christianity defined spirituality in the following terms:

*“A relation with God through Jesus Christ and the Holy Spirit”*

*“A relationship with God that facilitates love, forgivingness and connectedness”*

Two participants provided a definition which went beyond a personal view and included the community in a deep helping relationship as illustrated below:

*“Spirituality means advocating for others to get ARVs.”*

*“Spirituality encompasses our relationship with God, each other, and the entire society”*

*“Spirituality means doing the right things, forgetting your own needs and sorting out the needs of others and making their needs the first priorities”*

In trying to explain spirituality, one participant referred to it as a mystery of life as stated in the following quotations:

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*“There is an inherent mystery in life and our spirituality enables us to put our trust in a loving God who gives us hope and shows us how to transcend our difficulties and look beyond to a good future”*

*“Spirituality is taking precaution, respecting the elders and believing in God for everything”*

Most participants initially expressed difficulty in providing a definition for spirituality because they said that the word was difficult to define. However, they continued to define spirituality in terms of:

*“Spirituality means a personal relationship with God that includes a relationship with each other and the church.*

One sub theme developed from the definition of spirituality:

- Spiritual expressions

#### **4.3.1 Sub-theme 1: Spiritual Expressions**

Participants reported that they expressed their beliefs in several ways. Those who ascribed to Christianity said that they expressed their beliefs in God through prayer, meditation, reading the Bible and attending Church services. However, some respondents reported using more than one form of spiritual expression. The following quotes are illustrative:

*“I always pray to my God in everything that I do.”*

*“I need to read the Bible always because God speaks to me through it.”*

*“When I meditate, I can feel the presence of God all around me.”*

*“I always read my Bible and pray when I’m having my quiet time.”*

Other participants reported that helping other people was the way through which they expressed their spirituality. They believed that the way people relate and treat others was a very important aspect of expressing spirituality:

*“For me, the way you relate and treat your friends, family and people that are around you are just what makes your life the way it is.”*

*“For me, I believe in serving other people.”*

*“For now, I am not sick, so I help those that are sick and no longer strong to help themselves; I share what I have with other people and that’s the way I am.”*

#### **4.4 Theme 2: The role of spirituality in the life of people living with HIV/AIDS**

Participants reported that spirituality played significant roles in their lives. They reported that a belief in God, in themselves or in others, as well as in the ancestors help them in living daily with HIV/AIDS. The following quotes are illustrative:

*‘Spirituality helps me to do my work.’*

*“My belief in God is helpful because it makes me to feel strong; sometimes when I feel I cannot make it, or I feel like giving up, it makes me feel strong each and everyday.”*

One participant who was a seamstress reported that spirituality was giving her strength in her sewing as illustrated in the following quote:

*“God helps me in my sewing; He keeps me physically strong always.”*

Six sub-themes emerged from the role of spirituality in the life of people living with HIV/AIDS:

- Spirituality provides strengths to deal with stigma and discrimination
- Spirituality provides strength for positive living
- Spirituality provides hope for the future
- Spirituality facilitates interpersonal relationship
- Spirituality provides protection

#### **4.4.1 Sub-theme 1: Spirituality provided strength to deal with stigma and discrimination**

Living with HIV/AIDS was expressed as challenging. The challenges were related to coping with the shock and social stigma that surrounded a diagnosis. Participants expressed different ways in dealing with stigma. Some participants expressed that they did not publicize their HIV-status, but only told people who were close to them. They believed that the people who were close to them were those who supported them through prayer by which God strengthened them to carry on with their lives. The following quotes are illustrative:

“The way I deal with stigma is that I did not publicize my HIV status, I have only told a few close people to me because those are people who supported me through prayer and that helped me to carry on with life.”

Others reported that they dealt with stigma by simply ignoring those who stigmatized them and by praying because they believed that God did not discriminate against any body. The following quotes are illustrative:

*“When people point fingers at me, I simply ignore them, and move on with my life because I trust in God.”*

*“You know it is difficult when people stigmatize you, whenever it happens, I usually go in my room and pray to my God.”*

*“There is someone who will never betray you or discriminate against you, I am talking about God.”*

One category emerged from this sub theme:

- Spirituality provides emotional strength to overcome the difficulties related to HIV/AIDS.

#### **4.4.1.1 Category 1: Spirituality provided emotional strength**

One particular emotional challenge that was reported by all participants was guilt, which they said required as much attention as the infection itself. Participants reported that they felt guilty about the way they treated their relatives and friends who tried to help them live better lives. They also felt guilty about the way they were negligent with their lives.

The following quotes are illustrative:

*“I used to feel guilty about the way I treated people in the past, how I treated members of my family, how I treated past girlfriends and those kinds of things.”*

*“I am guilty because I went through a time in my life that I did not have much focus about what I was doing with my life, and I think that I was basically living just negligently and to me, HIV infection came as a consequence of that negligence.”*

In order to cope with these challenges, participants expressed that they prayed and asked God to forgive them. They reported that their actions were taken in ignorance and being assured of God’s forgiveness supplied emotional strength to carry on. The following quotes are illustrative:

*“But now, there is a verse in the Bible that says there is no condemnation to those who are in Christ Jesus; on the basis of that verse, I really don’t feel guilty any more because God tells me that he has forgiven me and there is no condemnation for my actions because they were taken in ignorance.”*

Another emotion that participants commonly expressed was anger. Some participants reported being angry with themselves because they blamed themselves for the infection, realizing that it was irreversible. The following quote is illustrative:

*“At some point in time, I was angry with myself due to the circumstances that I was faced with; I believe I was stupid because I cannot reverse the situation.”*

Participants reported that they forgave themselves in order to stop being angry with themselves as illustrative in the following quote:

*“I cannot continue to live with anger; I had to forgive myself in order to move on with my life.”*

#### **4.4.2 Sub-theme 2: Spirituality provided strength for positive living**

Participants reported that positive living was significant in their lives. They reported that they were aware about the influence that their thoughts have on their lives and health, and as the result, they reported that the strength to live positively with HIV/AIDS came from positive self-talk and determination. The following quotes are illustrative of this sub-theme:

*“I am HIV-positive, but nothing can stop me in doing everything that I want to do in life.”*

*“HIV/AIDS, listen to me, you cannot do anything to me, you cannot kill me, I must move on with my life.”*

Another participant believed that she is determined to fulfill her many life dreams and HIV/AIDS cannot stop her. She believed that her determination is helping her to overcome the weakness associated with the infection.

*“I have so many determinations in life; I can just feel within myself that I will make so many discoveries in life and show the very youth that when they are determined to do something, they can make it as well.”*

*“I am determined to be a role model to prove something to those people who think that life is bad and short when you are HIV-positive.”*

#### **4.4. 3 Sub-theme 3: Spirituality provided hope for the future**

Participants expressed that they were aware that there was no cure for HIV/AIDS, but their belief reassured them that there was a way out of the infection; this helped them to face the future with confidence. The following quotes are illustrative:

*“I have faith that something good is going to come my way because I have so many hopes in life.”*

*“I think that HIV is not just the end, it is the beginning and I am going to live and see what life is holding for me.”*

Participants reported that they do understand that there is no cure for HIV/AIDS, but their belief in God sustains them. The following quotes are illustrative:

*“My belief in God helps me to understand that although there is no cure for the virus, I have hope that I can still make it no matter the difficulties.”*

*“I understand that there is no cure for the infection and it is difficult to live with it each and every day; however my belief in God gives me the hope that one day, there will be cure a for it.”*

Others reported that their trust in God transcends the worries associated with the infection. Such trust was expressed in the following quote:

*“Basically, I like to involve God in everything that I do, that is I put everything that concerns me in the hands of God and I leave them there believing and hoping that it will be well with me.”*

#### **4.4.4 Sub-theme 4: Spirituality facilitated interpersonal relationship**

Participants believed that amidst the challenges posed by HIV and AIDS, spirituality enabled them to establish and maintain interpersonal relationship with themselves, God and others, thereby giving them peace of mind. Relationship, especially love was reported to be important in the lives of people living with HIV/AIDS, but due to personal experiences, many participants reported of living with constant hatred. For many of them, love was mainly limited within very few family members, but there was a general agreement that only God can help people to love each other. This understanding is illustrative in the following quotes:

*“I don't believe in love, but I have to show love to my parents, my siblings and my kids, that's all.”*

*“I have hatred all the time, I hate too much, but I do pray and sometimes ask God to help me to love other people”*

One participant reported that she does not understand love due to her childhood experience. This participant felt that her mother did not love her, as illustrated by the following:

*“You know when we talk about love, I do feel uneasy because in my family, there were so many of us; my mother had nine children, so there was this thing of competition among us.” “You don’t love me, you love him or her instead of me, there was that kind of competition among us.” “I do know that my mother loves me because she gave birth to me, but sometimes I think that she set me aside.”*

Participants believed that love does not stand alone, it exists alongside forgiveness. That is, in order to establish and maintain a relationship of love, one has to always be willing to forgive and then God will enable you to love as illustrated by the following quotations:

*“When you forgive, then God will give you that love so that you can love other people.*

*“Through prayer, God enables you to forgive people who offend you and love them as well.”*

*“Love has to do with forgiveness because we have to understand that everyone makes mistakes.”*

Three categories emerged from this sub-theme:

- Spirituality facilitated love
- Spirituality facilitated forgiveness

- Spirituality facilitated connectedness

#### **4.4.4.1 Category 1: Spirituality facilitated love**

Study participants felt that love was a difficult topic of discussion because they believed that there was no true love in the world, even among parents and children as well as among married couples. As the result, they expressed mixed opinions about love, yet believed that only God possess true love for people and he alone can enable people to truly understand and love one another, thereby giving them peace of mind. The following quotes illustrate the category:

*“Loving is a difficult thing for me because I do not love and forgive easily.”*

*“The only love that I understand is God’s love because I have done so many wrong things in my life; if those things were done against human beings, maybe I won’t be here today.”*

*“I can only understand love through what Jesus did on the cross when his life was substituted for the sin of humanity”*

Three sub-categories emerged from this category:

- Loving is difficult
- Loving oneself facilitated loving others
- Forgiving oneself facilitated forgiving others

### **Sub-category 1: Loving is difficult**

Some participants reported that, accepting and loving people who infected them was difficult because some of them were raped, while others, because of their lifestyle, did not know who infected them. Still others, because of the environment in which they grew, did not know about love. Loving in this case was difficult or probably confusing.

The following quotations illustrate this sub-category:

*“I do not know the person who infected me; if you know the person, it is easy to forgive and love, but if you do not know you are in the middle.”*

*“As a child, I was raped by my own brother so many times and when I grew up I thought my mother did not love me because she did not protect me.”*

Participants expressed a strong connection between the ability to love and trust, signifying that without trust, love was impossible. The following quotes are illustrative:

*“Love for me is difficult because I do not trust anyone; and if I do not trust anyone, it is difficult to love.”*

*“I did not grow up in a loving environment and I don't know about it.”*

### **Sub-category 2: Loving oneself facilitated loving others**

Participants expressed that although they experience love from family members, they need to extend love to others and this can only be possible when you are able to accept and love yourself. This was expressed as the major factor to loving others. The following quotes are illustrative:

*“The biggest love that one can ever have is to be able to love yourself and understand that you are precious.”*

*“If you do not love yourself, you are not going to be able to love someone else.”*

### **Sub-category 3: Forgiving oneself facilitated forgiving others**

For many participants, forgiving oneself was an issue, especially for those who self reported that they became HIV positive through living their lives recklessly. There was an expression of the feeling of guilt in many instances because they blamed themselves for becoming infected. In such instances, forgiving, accepting and loving themselves were prerequisites to forgiving and loving others. The following quotations are illustrative:

*“I don’t blame anyone for my infection; I blame myself for being reckless with my life.”*

Participants who reported as blaming themselves for the infection said that they do not hold a grudge against the person who they suppose infected them. The following quotes are illustrative:

*“I never held a grudge against anyone, not even the person that I supposed infected me because at some point in my life, I was careless in the way that was going to lead to HIV infection anyway; even if it had not been that person, I would have probably been infected still; so I never held a grudge against anyone, not even the person that infected me.”*

Respondents who reported reckless living struggled to forgive themselves. Once they have forgiven and accepted themselves, they were better able to forgive and to love others. However, there was a general agreement that when you forgave, you stopped condemning yourself or the other person because you could understand that some actions were taken prematurely or out of ignorance. The following quotes are illustrative:

*“In the past, I struggled to forgive myself for the way I lived my life.”*

*“When God forgives me, he forgets about the past, so why should I carry guilt around like a burden?”*

Some participants believed that they need to move on with their lives instead of getting stuck with the thought of the person that infected them because they were unable to undo the past. The following quotes illustrate this thought:

*“I don’t have a grudge against that person because it has already happened.”*

*“The person who infected me said he did not know that he had the infection; it just happened to him so I had to forgive him.”*

*“I forgive because I love the person just like the way I love myself.”*

#### **4.4.4.2 Category 2: Spirituality facilitated forgiveness.**

Participants expressed diverse opinions about forgiveness. For some study participants, forgiveness was a Divine act. That is, only God could enable them to forgive whereas by themselves they were unable to forgive. This was true especially for those who became

infected as the result of rape. In these cases, forgiveness was closely related to one's past experience. The following quotes are illustrative:

*"Forgiveness does not come easily; one has to pray about it."*

*"I cannot forgive my brother; it is possible with God, but it is impossible with me."*

*"I did not know that there was anything called forgiveness until my husband was killed; I nearly died until I forgave those who killed him, although I did not know them."*

Two sub-categories emerged from this category

- Unforgiveness affects the unforgiving person
- Forgiveness facilitates peace of mind

#### **Sub-category 1: Unforgiveness affected the unforgiving person**

Participants described unforgiveness as carrying an unnecessary load or a burden that affects the unforgiving person. The following quotes are illustrative:

*"Unforgiveness does not only harm the person that you have to forgive, but you harm yourself by not forgiving."*

*"I cannot stay with something against someone for a long time; if I do, that thing will kill me."*

#### **Sub-category 2: Forgiveness facilitated peace of mind**

Participants believed that they needed to forgive others in order to be at peace with themselves. They believed that whenever they met a person who they had not forgiven,

they would experience emotional struggle and mental tension. However, when they forgave, there was peace.

*“Personally, when I forgive, I can feel very light and there is a sense of peace all over me.”*

*“My belief in God helps me to make peace with the people who offend me.”*

*“It is not easy to forgive the person who hurt your feelings, but when you forgive, you can experience peace with yourself as well as with the person you forgave.”*

*“When you forgive, you change your mind about the person and the situation, and you take it positively, causing your feelings about the person and the situation to change as well.”*

#### **4.4.4.3 Category 3: Spirituality facilitated connectedness.**

Participants reported that connectedness was significant in their lives. They understood the word in terms of physical and spiritual connectedness. There was a need to be connected to the self, to God and also to other people. The following quotes illustrate this sub-theme:

*“I like to get connected to my kids and with my father by being there for them.”*

*“I connect with other people too, because when I am not connected, I can feel lonely.”*

Participants believe that when you are physically connecting with people, you are able to convey messages to them. You are able to discuss issues and arrive at a common understanding. The following quotes are illustrative:

*“I can connect with other people and try to tell them something, and although they may not want to listen to me, I have to connect with them and try to make them to understand me.”*

At the spiritual level, participants reported that they connected with themselves and with God. Self connection was reported as being achieved through self talk. For example, one participant reported that she usually connects to the HIV in her body through talking to herself as illustrated in the following quotes:

*“You have to connect to yourself first; connecting to yourself, but how”?*

*“You can do this by talking to your HIV status.”*

Self connection was also reported as being achieved through being alone in a quiet place.

The following quotes are illustrative:

*“Talking about connectedness, you really need to be in a quiet environment; you sometimes need to be by yourself alone and talk to yourself.”*

Connection with God was reported as very important in the lives of people living with HIV /AIDS. For many participants, this was achieved through prayer. The following quotes are illustrative:

*"I always pray to connect with my God."*

*"I want to stay connected to my God through prayer everyday."*

Three sub-categories emerged from the sub-theme:

- Connecting with the self facilitates understanding of oneself and connecting with others
- Connecting with God promotes wellness
- Connecting with others facilitates interaction

**Sub-Category 1: Connecting with the self facilitated understanding of oneself and connecting with others**

Participants viewed connecting with the self as vital to understanding oneself and others. They believed that many questions regarding humanity are left unanswered because people are unwilling to be alone and connect with themselves. They connected to themselves by being in a quiet place and sorting things out from within. The following quotations are illustrative of this category:

*"I need to understand myself before I can understand others."*

*"You have to talk to yourself first in order to be able to talk to others."*

*"Connecting with myself helps me to realize that I have personal issues in my life that I need to deal with."*

*"I always connect with myself and talk to my HIV status."*

Participants believed that they have spiritual needs that they need to fulfil, and without being alone one is unable to attend to one's spiritual needs. The following quotes are illustrative:

*"It is nice to have friends all around, but your spiritual needs are not fed by your friends; you need to be the feeder of your own spirit."*

*"Sometimes you need that tranquillity to be within yourself and to think about yourself."*

*"I think that the human spirit is always on call, but does not always respond to crowded places; you sometimes need to be alone by yourself, thinking through issues and before you know it you can have the solution." "If we will always be making noise and having fun, we will never get to the point that we want to get in life."*

*"You need time just with yourself."*

Participants believed that people need to have a balance in life. Being alone served as a balance between the physical and the spiritual. The following quotes are illustrative:

*"Connecting with oneself gives you a balance in life."*

*"I need to connect with myself in order to understand what is going on within my body."*

Generally, participants believed that connecting with the self involves a connection that transcends the self. They believed that when they connect with themselves in a quiet place, they experience the presence of God. The following quotes are illustrative:

*“Connecting with myself is helpful in determining whether I am still connected to my God or not.”*

*“When you connect to yourself, you are able to rise above and forgive people who offend you because you have a clear understanding of yourself that your offenders do not see; people only look at the physical body.”*

*“When I am alone and meditating, the Holy Spirit shows me things that I have got to put right with God and when I do these things, there is a chain of connection between us.”*

### **Sub-category 2: Connecting with God promoted wellness**

Participants reported that Connecting with God was experienced through prayer or some kind of ritual. It was important to all participants, despite their religious affiliations. For all participants, it was reported that this aspect of connectedness promotes wellness and enabled them to transcend challenges and kept them well. The following quotes are illustrative.

*“For me, it does not matter what you believe; it could be God or your ancestors; the mere fact that you actually believe in something is a great comfort.”*

*“Connecting to your Higher Power enables you to transcend what ever barriers that people might actually put before you.”*

*“The most important thing in everything I do is asking God to help me and he is helping me.”*

Because connecting with God promotes wellness, participants reported that this connection became particularly important after a person was diagnosed with the infection. Several participants reported that they never really prayed until HIV/AIDS came along, and those who previously prayed intensified their prayers after they contracted the infection. The following quotes are illustrative:

*“Before my illness, I was not connected to God, but now, I choose to live another life; that is to attend and become a full member of a Church.”*

*“The most important thing in my life now is to remain connected to my God.”*

*“I need to connect with God always because I am very young with this infection, so that I will not fall sick.”*

### **Sub-category 3: Connecting with others facilitated interaction**

Connecting with other people was also reported as vital to participants because people need each other. Physical connection provided an alternative to loneliness. They connected with other people by physically being there, through the telephone, or through the internet. They felt that connectedness helped them to feel alive because people are meant for each other. The following quotes are illustrative.

*“When I connect with other people, I can help them and they can help me as well.”*

*“Connection with others helps you to feel strong and safe.”*

*“I am fortunate I come from a close and loving family because my family doesn't leave me alone.”*

*“I talk with my elder sister on a regular daily basis and I talk to my other sisters as well; I never really feel disconnected.”*

*“I don’t have many friends, but I have one lady friend who creates external connections for me.”*

*“I have a very close internet connection through which I receive daily Bible readings.”*

Participants believed that connecting with other people in the support group provided them with opportunities for discussing their common problems, and identifying the needs of others and helping them when they can. The following quotes are illustrative:

*“Although we have families, this support group provides connection for many of us; we can get some information that others do not get.”*

*“When I was tested positive I became confused, but this support group has helped me to be connected with others who are also infected and we share information with each other.”*

#### **4.4.5 Sub-theme 5: Spirituality provided protection**

Protection from HIV-related diseases and death was expressed as a common concern for all study participants. Although not openly stated, the protective role of spirituality was implied by each participant throughout the interview process. In fact, many participants reported that they became spiritual (praying more or respecting the elders) after their HIV diagnoses. Participants believed that it was only God or the

ancestors that could protect them from all impending danger. The following quotes are illustrative:

*“I think I have to pray so much to God for protection because I lost some of my friends and my life is not improving.”*

*“I want to live, but when death comes, I cannot control it; personally I cannot protect myself, God protects me.”*

*“I believe in the ancestors and I also believe in God because the ancestors are believed to be your family members who die, so I believe in them because they are able to protect you and God is also able to guide and protect you on the other side.”*

Protection was not only experienced from HIV-related illness or death, it was also experienced from fear and crime as illustrated by the following quote:

*I believe in God because he protects me, even when I walk alone on the way.” “ I am not afraid because I know that I have God.”*

*“Whenever I wake up in the morning, I pray and thank God for providing me with security because the criminals are making us afraid at night, but what can we do, we have to continue to pray and carry on with our lives.”*

Protection from harm was closely related to one’s own choice that is one’s decision to respect the elders. The following quote is illustrative:

*“I always make sure that in whatever I do, I don’t disrespect the elders because respecting the elders and believing in God are the ways through which we can extend our days on the Earth”*

#### **4.5 Theme 3: Beliefs about the cause, prevention and cure of HIV/AIDS**

Participants expressed diverse beliefs about the cause of HIV/AIDS. Some study participants believed that the infection was as ordinary as tuberculosis, hypertension or any of the other ordinary illnesses. Others also believed that it was God’s plan, God’s warning sign, a blessing and a fulfilment of Biblical prophecies. The following quotes are illustrative of this theme:

*“For me, HIV/AIDS is an ordinary sickness just like tuberculosis, pneumonia, and the other illnesses.”*

*“As for me, HIV/AIDS is God’s way of saying something to humanity.”*

Five sub-themes emerging from this theme are:

- HIV/AIDS is ordinary
- HIV/AIDS is God’s plan
- HIV/AIDS is God’s warning sign
- HIV/AIDS is a blessing
- HIV/AIDS is a fulfilment of Biblical prophecies

##### **4.5.1 Sub-theme 1: HIV/AIDS is ordinary**

Participants believed that HIV/AIDS is not a curse or punishment from God. Instead, it is ordinary just like leprosy, tuberculosis, pneumonia and the other illnesses. They reported

that before the cure of tuberculosis was discovered, many people lost their lives by it just like it is with HIV/AIDS and its cure will come some day later. The following quotes are illustrative:

*“I don’t believe that God gave us AIDS as a curse or something like that; if it is a curse, then we brought it upon ourselves.”*

Those participants, who believed that HIV/AIDS is ordinary, also believed that its prevention is also ordinary and simple as wearing of condoms and having a healthy lifestyle that includes good nutrition and exercise.

*“People need to protect themselves from the infection by wearing condoms and having a healthy lifestyle.”*

*“I think people need to practice safe sex in order to remain well.”*

*“People need to exercise regularly in order to remain fit.”*

*“I can say it is an ordinary sickness and one day the cure will be discovered.”*

Concerning the cure, those who believed that the infection was ordinary reported that they also believed that the cure will be discovered in the same way the cure for all the other illnesses was discovered as illustrated below:

*“HIV/AIDS is not a curse because in the old days, tuberculosis and leprosy were some of the sicknesses that didn’t have cures, but now there are cures for them.”*

#### **4.5.2 Sub-theme 2: HIV/AIDS is God's plan**

Participants believed that HIV/AIDS is God's plan through which He is demonstrating His power to humanity. There was an agreement among participants that God is so powerful, but he chooses not to use all of his power. That is why he has put HIV/AIDS in place in order to bring people back to him because He loves people very much. The following quotes are illustrative:

*"God does not set out to hurt people, but then certain things have to be done for people to come to him."*

*"God has a bigger plan than we can even fathom right now, for example, a domestic worker has to get into an accident so that her child can be eventually adopted by somebody else who can afford a better education for her child, so that he/she can probably grow up to become a minister of the country; but had that child been raised by her own parents, he/she would have probably ended up out of school because of lack of financial resources."*

*"We always cry from the pain that is immediate, but there are far reaching plans."*

Some participants expressed the belief that HIV/AIDS was not due to witchcraft or a punishment from God, but instead they reported that it was God's plan to accomplish his purpose, as illustrated in the following quotations:

*"I cannot say HIV/AIDS is due to witchcraft or a punishment from God."*

*“HIV/AIDS is not a curse, it is just God’s plan; and God’s plans always work perfectly because there is a plan and a purpose in everything that happens.”*

There was an agreement that some of God’s plans can be revealed to humanity, but sometimes some of these plans he chooses not to reveal. The following quote is illustrative:

*“We are human beings and God was generous to us by offering us brains and everything else in order to figure out things and think for ourselves; we need to question some of the things, but there are certain things that we can never really know because they are for the glory of God.”*

Because some participants believed that HIV/AIDS is God’s plan to turn people from evil, they also believed that its prevention is only through abstinence and faithfulness in marriage. The following quotes are illustrative:

*“In my opinion, HIV/AIDS can only be prevented through faithfulness in marriage; I do not think condoms can prevent it.”*

*“I believe that if people are faithful to one another in their relationships, the infection could be prevented.”*

*“In addition, I think people could abstain from sex when they are not married; there is time for everything, and if your time has not yet come, abstain from sex.”*

Those participants, who believed that the infection can be prevented through faithfulness in marriage, also believed that only God can cure it. However, they believed that before the cure can come, people have to first change their ways of living. The following quotes are illustrative:

*“God can forgive, but he cannot look at the evil that man does and he cannot hold himself back when people start to do evil such like these”*

*“People need to change from their evil ways then God will bring the cure.”*

#### **4.5.3 Sub-theme 3: HIV/AIDS is God’s warning**

Other participants also believed that HIV/AIDS is God’s warning to mankind because he is tired of the way people are living. They believed that according to the Bible, the same things for which God destroyed Sodom and Gomorrah are happening around us today. They believed that God is warning people to repent. The following quotes are illustrative:

*“When I look at HIV/AIDS, I think it is a wake up call from God because he is tired of the way people are living.”*

*“The same thing that happened to Sodom and Gomorrah in the Bible are happening; for example, look at what is happening today, if people are sleeping with animals, do you think AIDS is going to stop?”*

Participants also believed that the prevention of HIV/AIDS is possible through abstinence and faithfulness in marriage, but only God can cure it. This can only be achieved when

people turn from their evil practices. Because participants believed that God brought about the infection in demand for behaviour change in humanity, God will also bring about the cure when this behaviour change is achieved. The following quotes are illustrative:

*“But if it was possible for all of us to stop evil, then I think AIDS will also stop when we ask God to stop it.”*

*“It would be like as the Bible says in the II Chronicles 7:14, if my people who are called by my name will humble themselves and pray and seek my face and turn from their wicked ways, then I will hear from Heaven and forgive and heal them and heal their land; this is what I think will cure AIDS.”*

*“One day, I believe that the cure for the infection will come from God.”*

#### **4.5.4 Sub-theme 4: HIV/AIDS is a blessing**

Some participants believed that HIV/AIDS was not a curse, but a blessing from God in that it made them to come to God and it also brought about a positive change in their lifestyles. The following quotes are illustrative:

*“I don’t think HIV/AIDS is a curse, but it is a blessing.”*

*“Maybe God is angry with us and is saying all these rotten people will come to me with the disease; I think God is blessing us through HIV/AIDS to bring us back to him.”*

*“It took AIDS to make people to realize that God is against the lives they were living, so it is a blessing.”*

*“But for me, HIV is a blessing in many ways because I think it was the one aggressive thing that led me to coming to God; it had to be something aggressive.”*

One participant expressed that HIV/AIDS is bringing sanity to humanity through the changes that are reported in the lifestyles of many of her friends that are living with the infection, as illustrated by the following quote:

*“AIDS is bringing sanity to humanity.”*

Because some participants believed that HIV/AIDS was a blessing by bringing them to God, they also expressed the belief that God will cure them as illustrated below:

*“I believe that very soon God will cure me from this disease.”*

#### **4.5.5 Sub-theme 5: HIV/AIDS is the fulfilment of Biblical prophecies**

Participants believed that the fact that there has no cure for HIV/AIDS proves that it is the end of time, and God was warning humanity about this. They believed that the Biblical prophesy as recorded in the book of Revelation was being fulfilled. The following quotes are illustrative:

*“I believe that we are in the last days.”*

*“The Bible says that in the last days there will be terrible diseases and everything will go wrong.”*

*“HIV/AIDS is the sign that God is fulfilling prophesy.”*

*“Because it is written in the Bible, I can say God is doing something like this.”*

Those participants who believed that HIV/AIDS was a fulfilment of Biblical prophecies also reported that it is possible to prevent oneself from the infection, but its cure depends on God as illustrated below:

*“It is possible to prevent the HIV/AIDS, but only God can cure it.”*

#### **4.6: Theme 4: Benefit of belief in helping people living with HIV/AIDS to cope with the infection**

Participants expressed one major benefit of their spiritual belief that plays a significant role in helping them to cope with the infection. All participants believed that their spiritual belief promoted a restoration of relationship with God or the ancestors as well as with others. Restoration of relationship was facilitated through forgiveness of others and asking for the same. The following is illustrative of this theme:

*“Through my belief, I know that if I don’t forgive someone who has offended me, God will not forgive me as well; so I am obliged to forgive others just as I know I am forgiven by God.”*

One sub-theme emerged from this theme:

- Spiritual belief promoted restoration of relationship

##### **4.6.1: Sub-theme 1: Spiritual belief promoted restoration of relationship**

There was an agreement among participants that a restored relationship with God or the ancestors placed them at a peace level where general wellness becomes possible. When they forgive others, their relationships were restored and they could qualify to also ask

God for forgiveness and receive it, thus restoring the relationship between them and God.

The following quotes are illustrative:

*“I cannot keep on asking God to do things for me when I have my own issues to deal with like forgiving people and loving people; When I do not do that, there is a wall of separation between me and God because I have to be clean before I start to pray.”*

*“If there are bumps and humps in your life and you think that God will hear you without forgiving that person, you are just wasting your time.”*

*“I don’t usually forgive, but I do forgive because God says if I do not forgive, He will not forgive me.”*

One category emerged for this sub-theme:

- Restored relationship promotes healing

#### **4.6.1.1 Category 1: Restored relationship promoted healing**

Participants believe that holding onto unforgiveness makes people sick emotionally, spiritually as well as physically, but when you are willing to forgive, your relationship is restored and you can be healed in different dimensions of life.

*“When you carry unforgiveness around, you have got a load on your shoulders and when you forgive, you feel healed.”*

*When I forgive, I feel very light, I can feel free and there is a sense of peace all over me.”*

*“The Bible says when we ask God to forgive us, there is no condemnation for those in Christ Jesus and you are healed from emotional condemnation from your past actions.”*

They believed that once the relationship with God was restored, they could pray for their needs and He could hear them and provide their immediate needs. One of such needs could be relief from physical symptoms of illnesses. The following quotes are illustrative:

*“For the past two weeks, I had sexually transmitted infections and I became very discouraged; although I went to see the doctor, I started praying and crying on God to help me because I did not want to die and leave my kids”. Like a miracle, the STI went away.”*

Once the relationship with God is restored, participants reported that you are empowered by God from within to fight HIV/AIDS and overcome its difficulties. The following quotes are illustrative:

*There is nothing that HIV can throw on me that I cannot fight, because I've got God on my inside.”*

*“Last week, when I got sick, I just took two days off duty and stayed at home and the only medication that I took was to read God's word.”*

*“So for me, that's all that I will ever take and that's all that I need to take because I am totally convinced that there is God and soon I will test negative.”*

One sub-category emerged from this category:

- Restoration of relationship provides hope

### **Sub-category 1: Restoration of relationship provided hope**

Participants reported that a restored relationship with God and their fellow human beings provided the hope they needed to carry on with their lives despite the difficulties associated with the infection. They felt hopeful especially regarding their future because their faith in God reassures them that there will be a good future. Many of them spend quality time praying because they were hopeful that God always hears and answers them.

The following quotes are illustrative:

*“The first day that I tested positive, I was so confused, but after I cried and prayed to God, I felt that comfort and hope.”*

*“Praying can help me to manage and cope with the daily worries.”*

*“What I can say is that believing in God and praying to him can feel like you are talking to someone and you can feel the comfort and hope from being in his presence.”*

*“When you are alone in your room, you can just pray, especially when you have a problem.” “God is always there and you can feel that he is able to heal you.”*

## **4.7 Conclusion**

The data collected from twenty (25) study participants were presented. Data were obtained through four focus-group interviews and six individual one-on-one interviews facilitated by the interview schedule that was prepared for the study. Each participant

described their own spirituality and provided their definitions of spirituality. General themes identified from this sample group included a definition of spirituality, the role of spirituality in the lives of people living with HIV/AIDS, the different beliefs about the cause, prevention and cure of HIV/AIDS and the benefits of spiritual beliefs in helping people living with HIV/AIDS to cope with the infection.

Participants described themselves as spiritual, and defined spirituality as a personal relationship with God or higher power that facilitates love, forgiveness and connectedness; taking precaution, respecting the elders and believing in God for everything. Spirituality was expressed through prayer, meditation, reading the Bible and helping others. Spirituality played helpful roles in the lives of people living with HIV/AIDS. Basically, it provided strengths for people living with HIV/AIDS to carry on with life, provided hope for the future, facilitated interpersonal relationships and provided protection from imminent fear.

Participants expressed five major beliefs about the cause of HIV/AIDS. Some study participants believed that the infection was ordinary and its prevention was as ordinary as wearing of condoms and observing a healthy lifestyle. Furthermore, they believed that the cure would be discovered just as the cure of other illnesses was discovered. Others believed that it was God's plan, God's warning sign, a blessing and the fulfilment of Biblical prophecies. The latter believed that the infection could be prevented through sexual abstinence and faithfulness in marriage. One major benefit of participants' spiritual belief that plays a significant role in helping them to cope with the infection was

a restoration of relationship with God or the ancestors as well as with others. Restoration of relationship was facilitated through forgiveness of the self, God, others, and asking God and others for the same. Connectedness and love for the self, God and others can be possible only through forgiveness.

## **CHAPTER FIVE: DISCUSSION OF RESULTS, SUMMARY AND RECOMMENDATIONS**

### **5.1 Introduction**

This chapter highlights the major research findings as presented in the preceding chapter, in relation to relevant literature and the conceptual framework that directed the study. Also presented in this chapter are recommendations based on findings of the study. The researcher was interested in exploring the role of spirituality in the lives of people living with HIV/AIDS. The study was also aimed at exploring the different beliefs held by the PLWHA about the cause, prevention and cure of HIV/AIDS and the benefit of these beliefs in helping them cope with the infection.

The conceptual framework that guided this study is a modification of the Cognitive-Behavioural Spirituality model developed by Randy Neid. According to Neid (2000), the Cognitive-Behavioural Spiritual framework explains spirituality as a function of beliefs, values, behaviours and experiences in which beliefs give rise to values, which inform our behaviours, resulting in an experiential impact upon the spiritual belief system. The variables in the conceptual framework are the Ultimate Reality/God/Higher Power, love, forgiveness and connectedness.

The discussion will therefore be centred on the four major themes of the study:

- Definition of spirituality
- The role of spirituality in the life of people living with HIV/AIDS

- Beliefs about the cause, prevention and cure of HIV/AIDS
- Benefits of spiritual belief in helping people living with HIV/AIDS to cope with the infection.

## **5.2 Discussion of definition of spirituality in relation to literature**

The participants described themselves as spiritual, although most of them expressed difficulty in providing a definition for spirituality because they said that the word was difficult to define, since it means different things to different people. However, there was a general agreement that spirituality was a personal relationship with God or a higher power that facilitates love, forgiveness and connectedness; taking precaution, respecting the elders and believing in God for everything. The definitions of spirituality provided by study participants were reflective of the diverse definitions of spirituality found in current nursing literature such as the definitions given by Neid (2000) who defined spirituality as a cognitive/mental relationship with the Transcendent Being (or whatever is considered Ultimate) informed by one's belief or value system, that promotes well-being and a sense of meaning and purpose for the person; Thorpe & Barsky (2001) defined it as an inner guidance toward one's life purpose (reflecting one's values and beliefs); Aldridge (2001), on the other hand, defined spirituality as the search for the divine and the achievement of unity; and Skokan & Bader (2000) defined it as an integral dimension of human life and an essential factor in health and well-being.

The definition given by Kretzshmar (1995) in her discussion on the prerequisite for reconstruction of South Africa showed how vital the spirituality of individuals are to the

development and reconstruction of the country. Kretzchmar (1995) stated that “a holistic spirituality seeks to integrate rather than separate the various dimensions of human existence; adding, that we are created to be in relationship with the rest of the created order, each other and God (p. 64)”. Kretzchmar (1995) further stated that “in the most generous sense, spirituality has to do with how we experience ourselves in relation to what we designate as the source of ultimate power and meaning in life, and how we live out this relationship” (p. 65). This statement agrees with the study because it was found that people need a relationship with a higher power in the same way that they need a relationship with other people.

Ronaldson (1999) defined spirituality as “that which lies at the core of each person’s being, an essential dimension which brings meaning to life (p. 1)”. Spirituality is understood broadly as a relationship with God, however as perceived by the person, and in relationship with other people. It is often defined as one’s experience of meaning and purpose in life- a sense of connectedness with people and things in the world (Martsof, 1997). Laukhuf & Werner (1998) have argued that although all people have spiritual desires and a need to fulfill them, they feel this especially when they are ill because it brings them three benefits: hope, strength, and emotional support. As the result of meaningful spiritual experiences, the person will often have a sense of peaceful satisfaction with life and satisfaction even with the illness. In the same way, this study found that a good relationship with oneself, the higher power and with others gives the person a sense of inner peace and hope.

Spirituality was described as a phenomenon that is expressed in different ways. The most common expression of spirituality used by participants was prayer which was reported by all of them, although some used other forms of expressions like meditation, reading the Bible and helping others. Almost any action or creative process that connects your deepest and innermost self with the larger world in a positive, life-enhancing way can be a spiritual expression. In her research on the sacred in everyday through spiritual expression, Johnson (2002) found that the most commonly used expressions reported by the participants were prayer, meditation, contemplation, silence, singing, learning, dreaming and dream interpretation, reading, writing, creating, spiritual rituals or initiations, and attuning to the life cycles of living, dying, death and resurrection.

The helpful role played by prayer is being increasingly seen as an appropriate therapeutic strategy (Canda, 1990; Bullis and Harrigan, 1992; Bullis, 1996). Prayer can be silent; it can be short, mantra-like recitations or community shared prayer (Bullis and Harrigan, 1992). Despite the controversial nature of this technique, Bhagwan (2002) found that God's power is invited directly into situations of pain, injustice or disorder through its use. Kasiram (1998) expressed that when all else has failed, humankind may benefit from the helpfulness of prayer because it not only brings relief, but the expectation of a new understanding or a change of consciousness. In this study, the same was found to be true for participants who reported that through prayer, they were strengthened physically and emotionally to carry on with their lives.

Ritual and symbol are inherent in essentially every spiritual tradition. Scripture reading, prayer, meditation, Holy Communion, ceremonial rites, and other spiritual exercises

embody spirituality (Hodge, 2000). Regular engagement in such practices has been widely associated with positive outcomes whether performed in a community context or individually (Levin, 1994; Pagament, 1997; Perry, 1998; Worthington, Kuru, McCullough & Sandage, 1996). The modern propagator of cognitive therapy, and perhaps the harshest contemporary critic of devout spirituality (Hodge, 2000), has stated that the Bible has probably enabled more people to make more extensive and intensive personality and behavioral changes than all professional therapist combined. In this study, it was found that constantly reading the Bible, especially in areas related to healing, brought relief from some physical symptoms of sufferers.

The practice of private and public rituals serves to ease anxiety and dread, defeat loneliness, promote a sense of security, and establishes a sense of being loved and appreciated (Levin, 1994). Brock (1990) has suggested that rituals foster these traits by “re-enacting” the individual’s relationship with the Ultimate. Thus, rituals become a “sacred short-hand” for talking about and experiencing the presence of a transcendent Power. The same was found to be true for the study participants who reported that they experienced the presence of God through prayer, meditation, reading the Bible and helping others.

Although rituals foster a wide array of positive outcomes (Levin, 1994; Worthington et al., 1996), they may be most efficacious in facilitating mental health (Jacobs, 1992). They are also an important dimension of resiliency and a primary method of coping (Pagament, 1997; Perry, 1998). In this study, it was found that practicing forgiveness toward those who offend helped participants to move forward with their lives.

### **5.3 Discussion of the Role of Spirituality**

It was found that spirituality played important roles in the lives of people living with HIV/AIDS. Participants reported that it was through their spiritual expressions, that their higher power provided them with strengths to deal with stigma and discrimination, to live positively with the infection and to have hope for the future. Spirituality also provided strength that facilitated interpersonal relationships, and provided protection for participants.

#### **5.3.1 Dealing with stigma and discrimination**

Living with HIV/AIDS was reported as challenging by the participants in this study. The challenges were related to coping with the shock and social stigma that surround a diagnosis. Participants expressed different ways in dealing with stigma. Some participants expressed that they did not reveal their HIV-status to many people, but only told a few people who were close to them. It was found that many participants were involved in self-care, personal, family, and social roles. In support of this statement, Grimes and Cole (1996) found that for people living with HIV/AIDS, the ability to function in daily activities and roles can be particularly impacted when they are stigmatized and discriminated against. In addition, the stigma and discrimination associated with HIV and AIDS can create an atmosphere of fear whereby many people become more afraid of the stigma and discrimination than the disease itself. The Congress of South African Trade Union (COSATU, 2000) argued that sometimes those who publicly announced that they were HIV-positive were seen as a threat and a danger. They reported the tragic case of a KwaZulu-Natal woman, who was murdered after

disclosing that she was HIV-positive. There are numerous examples of people being beaten for their status (COSATU, 2000). Excerpts from the statement on AIDS by Bishops of Chad (in UNAIDS, 2003) urged Christian communities, associations and movements to support each other in faith, in prayer and action, adding that “let us therefore train ourselves to give love that goes beyond all frontiers in order to make each man and woman experience more happiness and freedom”(p. 1). The same was found to be true in this study as evident by the constant prayer that was made by most participants. Through prayer, God helped participants to overcome stigma and discrimination.

### **5.3.2 Positive living with HIV/AIDS**

Positive living promotes healing for people living with HIV/AIDS (McIntyre, 2003). Healing does not necessarily mean cure of disease, but healing the mind and transforming the body to realize its full potential, joy and purpose which includes learning about the influence that thoughts have on life and health, from breakdown to breakthrough. Thus McIntyre (2003) found that healing does not come from what one can provide for oneself, but it is provided in connectedness to others. However, this was not the case with the results of the study. Although participants were aware about the influence that their thoughts have on their lives and health, it was found that the strength to live positively with HIV/AIDS came from positive self-talk and determination. The result is in line with Uys and Middleton (2004) who considered positive self-talk as a positive promoter strategy of health because it is action oriented in fighting the condition back from within. Positive self-talk is one of the early interventions used in mental health to avert relapse (Uys & Middleton, 2004). Miller (1992) in Middleton (2005) identified determination

and goal accomplishment as ways in which people with schizophrenia can be inspired to carry on with their lives.

### **5.3.3 Inspiring hope**

This study proved that a belief in God reassured participants that there is a way out of the infection; this helped them to face the future with confidence. A trust in God also transcended the worries associated with the infection. This argument is in line with Mellors, Riley, & Erlen, (1997) who found that hope enables persons living with HIV/AIDS to self-transcend by developing characteristics that expands one's boundaries of the self in order to take on broader life perspectives, activities and purposes that can help a person to discover or make meaning of one's life. Faced with the irreversible fact of illness, people living with HIV/AIDS are able to transform this information from despair to challenge, from psychological crisis to personal growth, from a death sentence to a new meaning and look forward to a better future (Mellors et al., 1997). In this study, many participants have made significant changes in their lives as the result of HIV/AIDS. For example, the participants who reported that they once lived their lives recklessly have changed their behaviour as the result of the infection.

Murdaugh (1998) found that hope enables people living with HIV/AIDS to achieve a balance in life, enabling them to refuse to let the clinical aspects of AIDS take control of their daily lives and define how they view themselves, or others view them as individuals (Bedell, 1999). Freehling (1996) noticed that maintaining hope and faith in God seemed that those who are ill are able to accept the negativity of pain and suffering and to

transform it into something positive. Patients who relied on hope as a healing instrument became more focused, authentic, genuine, and accepting of their fate, while giving evidence of having a power which may even enable them and their physicians to cause the regression of life-threatening illnesses, such as cancer (Freehling, 1996). The same was found to be true in this study because patients did not consider HIV/AIDS as a death sentence, but they hope that they will live despite its difficulties.

Hope may be closely linked to spirituality. Gaskins & Forte (1995) provided some insight into the themes which define hope for people who have chronic illnesses. Three of the most common themes defining hope were spirituality, relations with others and having one's health. The same was also found to be true in the study. The common themes describing hope for the participants were belief and trust in God, in oneself and in others. In their study on the clinical assessment of hope, Farran, Wilken & Popovich (1992) noticed that hope is an expectation about attaining some desired goal in the future, a necessary condition for action, a subjective state that can influence realities to come, and knowledge that as human beings we can somehow manage our internal and external realities. They identified four central attributes of an acronym of hope: H-health, O-others, P-purpose, and E-engaging process (Farran et al., 1992).

Hope in its mature form becomes a sense of certainty about the coherent nature of human life and acceptance of one's lifestyle as worthwhile, but within the perspectives of health and well-being, hope may seem to be a fragile reality. It involves the person's concept of their reason for being, and if spirituality is explored by individuals as they define their life's meaning, then hope keeps them engaging in the process (Farran et al. 1992). In the

same way, in this study, hope was found to be related to the participant's desire to achieve a goal in life.

#### **5.3.4 Spirituality facilitated relationship with God/Ultimate Reality, the self and others**

Interpersonal relationship seemed very important in the lives of study participants, especially a relationship with God or the Ultimate Reality. They believed that amidst the challenges posed by HIV and AIDS, spirituality enabled them to establish and maintain interpersonal relationships with themselves, God and others, thereby giving them peace of mind, which eventually lead to a sense of general wellness. Daniels (2003) found that a relationship with the Ultimate Reality is spiritual, cognitive/mental, and it is direct and personal. Walsh and Vaughan (1993) found it to be a mystical transpersonal experience in which the sense of identity of self extends (transcends) the individual or personal to encompass wider aspects of humankind, life, psyche or cosmos. Daniels (2003) suggested that one basic characteristic of God/Ultimate Reality was His Fundamental Human Meaning, that is, it has a profound effect on human life, imbuing it with a sense of purpose and significance. Interpersonal relationship facilitated love, forgiveness and connectedness as discussed in the following paragraphs:

##### **5.3.4.1 Spirituality facilitated love**

Love was found to be very important in the lives of people living with HIV/AIDS, but due to personal experiences, many participants reported of their inability to love other people. For many of them, love was mainly limited within very few family members, but there was a general agreement that only God can help people to love each other because

He is the one that loves people unconditionally. Knowing that one is loved unconditionally by God, that a caring Transcendent Being is working all things together for one's good, and that one's life has eternal significance, can yield optimism, self-confidence and a sense of purpose for an individual (Ellison, 1993; Sethi & Seligman, 1993). Barton (1998) found that the greatest thing one can be proud of is love that is shared and it is or should be unconditional. There was a general agreement among the study participants that love originates from the Ultimate Reality in order to unite humankind by drawing the whole being homeward under the guidance of love.

Underhill (1995) also found that the business and method of mysticism is love. Love and union with the Ultimate Reality is based on the urge to escape from the sense of isolated selfhood and the achievement of peace through a closer participation with the nature of the Ultimate Reality. However, participants believed that love does not stand alone, it exists alongside forgiveness. That is, in order to establish and maintain a relationship of love, one has to always be willing to forgive and then God will enable you to love.

#### **5.3.4.2 Spirituality facilitated forgiveness**

Diverse opinions were expressed about forgiveness. For some study participants, forgiveness was a Divine act. That is, only God could enable them to forgive whereas by themselves they were unable to forgive. This was true especially for those who became infected as the result of rape. In this case, forgiveness was closely related to one's past experience. However, they described unforgiveness as carrying an unnecessary load or a burden that affects the unforgiving person. They also believed that they needed to forgive

others in order to be at peace with themselves, because whenever they met a person who they had not forgiven, they would experience emotional struggle and mental tension.

The impact of forgiveness may boost health. In a survey of 1, 500 people suffering from serious chronic illnesses, Krause, a researcher at the University of Michigan's School of Public Health, (in Christian Science Monitor, 2004) found that people who forgive easily enjoy greater psychological well-being and have less depression. In a further argument, Christian Science Monitor (2004) suggested that the healing power of forgiveness has been around for a while and it has benefit both for those who practice it toward others or for themselves, and those who are on the receiving end of forgiveness. Forgiveness is something almost anyone can do to lessen mental darkness and increase wellness because through it, a forgiven person is perceived in his/her true nature-guiltless, loved and unconditionally accepted by the forgiver and God (Christian Science Monitor, 2004), thus moving healing forward. The statement agrees with the findings of the study because it was found that when you forgive, you change your mind about the forgiven person and the situation and you look at the person and the situation positively.

Kersting (2003) noted in therapeutic settings, several techniques that include forgiveness protocols and use of Biblical text are used in order to reinforce healthy mental and emotional habits and to change the punitive God images of clients. Spiritually guided forgiveness protocols are used to help clients deal with emotional problems that resulted from harm inflicted by friends or family members, enabling them to "let go" of unhealthy anger and move past an abusive situation without justifying the abuse (Kersting, 2003).

Mahlungulu (2001) stated that forgiveness is an internal process that encourages a person to objectively look at the old wounds or scars to perceive them as they are and to bring inner healing in spite of the scars; it is dealing with the reality of the past and not suppressing it. The process of forgiving begins with oneself as Ross (1998) said; we can find inner peace only when we realize that we must change ourselves rather than the people who have hurt us. In the same way the study found that forgiveness facilitated inner peace because it enabled participants to forgive and accept themselves and others, thereby qualifying them to receive God's forgiveness.

Dossey (1993) noticed how men and women who practiced forgiveness manifested great faith in God through prayer, thus acknowledging that the Supreme Being was an active presence in their lives. In about 15 to 20 percent of cases, there is advanced healing when such patients and others have prayed for divine assistance (Dossey, 1993). In this study, forgiveness was found to be the variable that promotes love and connectedness with God, the self and with others. Without being forgiven by God, the self and others, one was unable to love or connect with God, the self or others. In order to love and connect with God, one must be able to forgive God for the things that one has been blaming Him for, although they were not His fault. One must be able to ask God to forgive him/her for blaming Him. This type of forgiveness places the person in the position to connect and experience the love of God because God is all love. In the same way, without forgiveness, one is unable to connect with God.

#### **5.3.4.3 Spirituality facilitated connectedness**

Connectedness was found to be significant in the lives of participants. The word was understood in terms of physical and spiritual connectedness. It was found that participants needed to be connected to the self, to God and also to other people. Connection with God was reported as very important in the lives of people living with HIV /AIDS. For many participants, this was achieved through prayer. Similarly, Jacobs (1992) found that the interactive process of prayer serves to reinforce the sense of connection to others as well as to the Divine. This sense of bonding facilitates a cathartic response through which painful emotions can be brought to consciousness, and relieved or expressed, which in turn fosters wellness. A corporate example is provided by the Plains Ojibway who, at regular intervals, gather to publicly confess their sins in the presence of Spirits. Anxiety and isolation are reduced as the tribe acknowledges, expresses and resolves their sins, and associated sense of shame and guilt, within a social milieu of attachment and connection to their significant others (Jacobs, 1992). In the same way study participants believed that connecting with the self involves a connection that transcends the self, during which they experienced the presence of God and received peace of mind.

Connecting with the self was vital to understanding oneself. Connecting to the self promotes self introspection. A deep introspective exploration of the self which is a necessary behaviour modification is actively encouraged in many spiritual traditions (Goldstein, 1995). Self-reflection is an integral part of healing (Thorpe & Barsky, 2001). It results from both personal and professional stimuli and signifies the need for change so

that healing can begin. For example, John Calvin (in Hodge, 2000) opened his influential “Institutes of the Christian Religion” by stating “without knowledge of self there is no knowledge of God.” Indeed, spiritual direction, in which one attempts to develop a deeper relationship with the higher power, shares many of the same aspects of self-exploration as found in traditional psychotherapy (Ganje-Fling & McCarthy, 1991). In the same way, within Christianity, those traditions that are influenced by Roman Catholic spirituality are aware that knowledge of the self leads to a process that is similar to ego supportive and ego modification interventions (Goldstein, 1995). Ego supportive interventions, strengthening adaptive behaviour and building up ego deficits are associated with developing one’s self as an individual created in the image of God. Since the self is an irreplaceable, unique being of inestimable worth due to its status as God’s image bearer, its functioning is to be enhanced so that it may achieve its full, God-designed potential (Hodge, 2000). In mental health, self introspection enables care-givers to explore their limitations and prejudices and deal with them in order to safeguard themselves against care givers’ beliefs imposition to those for whom they provide care (Eckroth-Bucher, 2001). Participants also believed that connecting with the self helps you to understand yourself and others. They believed that many questions regarding humanity are left unanswered because people are unwilling to be alone and connect with themselves. They connected to themselves by being in a quiet place and sorting things out from within and usually, the answers do come.

Physical connection was found to be vital to participants as well because it provided an alternative to loneliness. Physical connectedness helped them to feel alive because people

are meant for each other. In the same way, an individual's spirituality is informed by a community of individuals who share similar phenomenological experiences (Hodge, 2000). This may occur indirectly through books and other written material, or more directly by physical meetings in faith communities, small groups, church gatherings, etc. In all cases, a sense of connectedness and support may be engendered (Ellison & Levin, 1998). The same results were found in this study; physical connection was achieved by being there, through telephone and through the internet as well as in the support group.

Physical connectedness or group membership has at least two beneficial aspects (Hodge, 2000): First, there is a realization that one is not alone. In other words, people's sense of isolation is ameliorated by knowing that they are participants with others. Secondly, individuals receive confirmation that their conduct and perceptions concerning daily events and community affairs are reasonable and appropriate. They are affirmed that their lives have coherence and meaning (Ellison & George, 1994). The study results are similar to the above statement. Participants believed that connecting with other people in the support group provided them with opportunities for discussing their common problems, and identifying the needs of others and helping them when they could.

Connectedness implies oneness meaning that all things are interrelated and every one of us has a connection to one another, the earth, the universe and the Ultimate Reality (Todeschi, 2004). Since there is only one Ultimate Reality, the source of all that exists, the universe must be composed of only one force. Connectedness is a force of good and not of evil, although due to freewill, some individuals are able to direct the force into

selfish purposes and desires, creating “evil” in the process (Todeschi, 2004). In the same way, this study found that it was impossible to connect with the Ultimate Reality when one has personal issues like unforgiveness and hatred. One has to be forgiving and loving others in order to connect with Him.

### **5.3.5 Spirituality provided protection**

Spirituality was found to provide protection from HIV-related diseases and death. Although not openly stated, the protective role of spirituality was implied by each participant throughout the interview process. In fact, many participants self reported that they became more spiritual (praying more or respecting the elders more) after their HIV diagnoses. Participants believed that it was only God or the ancestors that could protect them from illnesses and death. Belief systems, in conjunction with the faith that animates them have demonstrated both protective and curative properties (Propst., 1996).

As individuals seek to develop their relationship with the Ultimate Reality, there are behavioural stipulations that are incorporated into daily living (Perry, 1998). These lifestyle choices may be protective because they relate most directly to decreased rates of morbidity, mortality and alcohol, tobacco and other drug usage (Levin, 1994; Strawbridge, Cohen, Shema & Kaplan, 1997). This was not the case with the results of this study because participants believed that through prayer or respecting the elders, God or the ancestors provided direct protection from HIV-related illnesses as well as from death.

In other studies, spirituality in the form of social support facilitates a number of protective outcomes, particularly within the purview of physical and mental health (Ellison & George, 1994; Ellison & Levin, 1998). For example, participation in faith communities resulted in less susceptibility to the common cold and greater longevity (Kark et al., 1996). Additionally, resiliency and coping ability are associated with higher levels of social support (Cohen, Doyle, Skoner, Rabin & Gwaltney, 1997). This was similar to the results of this study as evidenced by the fact that many study participants have had the infection for over ten years.

## **5.4 Beliefs about the cause, prevention and cure of HIV/AIDS**

### **5.4.1 Beliefs about the cause of HIV/AIDS**

The participants expressed diverse beliefs about the cause of HIV/AIDS. Some of them believed that it was not a curse, but an ordinary disease. Others believed it was God's plan, God's warning sign, a blessing, and a fulfilment of Biblical prophecies. These statements agree with the different types of beliefs found in the literature. For example, Walker et al. (2004) found that the way we understand AIDS are often informed and answered by our belief systems or worldviews. Our belief systems are shaped by many factors, including our cultural, religious and ethnic background, our family and personal history, our gender and our economic circumstances. Belief systems impact directly on how we understand health and respond to illness. Some individuals and communities understand disease to be caused by magical and spiritual forces, others draw on scientific reasoning and many apply both models (Walker et al., 2004).

The South African society is characterised by cultural diversity, complexity and difference, which is reflected in the many ways that health and disease are understood (Fadiman, 1997). There are many health-care systems in this country, each rooted in its own worldview and each with its own explanation about HIV/AIDS. Heald (2002) recorded that a study of a government AIDS message in Botswana showed that local, traditional explanations for the transmission of HIV/AIDS do exist. Some of them are rooted in Tswana beliefs and indigenous medicine. Others are based on Christian beliefs. Some people believe that AIDS is a punishment sent by God due to unnatural things like homosexuality, Satanist cults who practise cannibalism, ritual murders, bestiality and other kinds of evil. The above suggestions are similar to the findings of this research because some participants believed that HIV/AIDS is God's warning to mankind because he is tired of the way people are living. They believed that according to the Bible, the same things for which God destroyed Sodom and Gomorrah are happening around us today. However, HIV/AIDS was not found to be a curse, instead, it was found to be a blessing.

Heald (2002) also found that in Botswana a common belief among many sangomas is that AIDS was a new manifestation of an old disease that has emerged because people (particularly young women) have rejected or abandoned their cultural or traditional practices. The sangomas believe that there is no AIDS, and if there is, then it is made by makgoa (whites) because of the many things that they recommend to be used: the pills, the injection, condoms, and the coil. He also found that AIDS was due to a loss of culture and contamination through exposure to modern (Western) devices such as condoms.

Other beliefs suggest that AIDS is caused by “tonono” (the result of sleeping with a woman who is menstruating); AIDS is meagre (germs) which has been spread by the government through condoms (Heald, 2002); he also found that traditional healers in South Africa explain HIV/AIDS in a similar way.

A study of traditional healer’s knowledge and understanding of the cause of HIV/AIDS in Gauteng and Mpumalanga demonstrated that they were well informed about the biomedical explanations of the transmission and causes of HIV/AIDS (Thornton, 2002). However, most healers interviewed blamed HIV/AIDS on “dirty blood” and believed that it was transmitted either through sexual permissiveness or “ritual pollution”. The idea of ‘dirty blood’ is that when two people sleep together and the other party’s blood is dirty, he can infect the other (Thornton, 2002). This demonstrates just how powerful the epidemic is in creating controversy and debate, confusion and ambiguity (Stadler, 2003). The scientific community considers questions about the causes and solutions to HIV and AIDS to be relatively clear. However, people from all kinds of groups, cultures and religions have a whole series of different views, values and beliefs about the infection. In the same way, the study found diverse beliefs about the cause of HIV/AIDS, although the majority of the participants blamed God for its cause.

Despite the different views about the infection, HIV/AIDS is becoming meaningful to many people (Stadler, 2003). Many people in Africa believe in the power of witchcraft and attest to its effects on daily lives. A study of religion and perceptions of HIV/AIDS in Tanzania found that in the case of a chronic or a deadly illness, the individual suffering is

associated with spiritual forces, witchcraft or malevolent ancestors (Dilger, 2001). The AIDS epidemic is well suited to interpretation through the paradigm of witchcraft because it is mysterious, elusive, difficult to understand and constantly changing. In this study, HIV/AIDS was found to be meaningful to participants who believed that HIV/AIDS is God's plans through which He is demonstrating His power to humanity. There was an agreement that God is so powerful, but he chooses not to use all of his power. That is why he has put HIV/AIDS in place in order to bring people back to him because He loves people very much.

In her study, Stadler (2003) referred to HIV/AIDS as a "crisis of meaning", which she said is revealed by the way in which local villagers talk about AIDS in South African lowveld. She noted that although local villagers are able to recite in parrot fashion the ABCs of AIDS prevention, there is much confusion about it due to unanswered questions about who to blame, why the infection affects some people and not others. Bate (2003) expressed that the main reason that there is controversy about AIDS which does not apply to other sicknesses is that HIV/AIDS has become something that affects many different aspects of our human life. It has become a matter of life and death, of sickness and health, of medicines and no medicines, of jobs and unemployment, of wealth and poverty, of politics and power, of spirits and witches, of sin and evil and of ethics and morality.

Some other participants also believed that HIV/AIDS was not a curse, but a blessing from God in that it made them to come to God and it is also bringing about positive changes and sanity to humanity through the changes that are reported in the lifestyles of many people. Research shows that there is a core of opinion which accepts that suffering and

pain are a part of a larger life experience, and that they can have meaning for the patient, their friends and caregivers (Aldridge, 2000). However, the emphasis is placed upon the person's concept of God, sources of strength and hope, and their belief system. In a related study, Tsevat, Sherman, McElwee, Mandell, Simbartl Sonnenberg & Fowler, (1999) found that patients interviewed indicated that their life with HIV was better than it was before they contracted the infection, and the factors that contributed to their health values were spirituality, concern and love for their children.

Because HIV/AIDS is illusive and mysterious, many people blame God for its cause. Dyk (2001) provided four answers to questions about why people may think that God allowed AIDS. This explanation is in line with the Judeo-Christian framework:

- Sickness and death came into the world because of sin (Genesis 6:3). However, this does not mean that one can attribute specific illnesses to specific sins. For those Christians and Jews who think in terms of so called 'rigid wisdom', sin and illness are closely connected because sin always causes sorrow (e.g. disease). This perception, according to Dyk (2001) should be rejected in the strongest terms because 'bad' people do not become ill more than 'good' people. This is consistent with the results of the study because some participants believed that HIV/AIDS is not a punishment for sin, but God's plan to bring them back to Him.
- The purpose of illness (or any suffering) is not to punish us for sin, but to test our faith and to make us better people. Suffering sometimes enables us to purify ourselves and grow spiritually. This is consistent with the results of the study

because participants believed that HIV/AIDS has brought about behavioral changes in their lives and for some of them, there was a need for something as drastic as HIV/AIDS to bring them back to God.

- Because of limited insight and knowledge as human beings, we cannot make any sense of suffering. Although we accept that suffering may not be intended as punishment, we might believe that it fits into God's purposes and intentions in some mysterious way, although we often do not know exactly what God's purposes and intentions may be. This is also consistent with the result of the study because some participants said that HIV/AIDS was meaningful.
- A fourth answer emphasizes the fact that it was God's intention to give humans freewill. Life is therefore a challenge that is presented to humans. The challenge is that human beings should try to make the best of their lives without too much interference from God (Dyk, 2001). This is in line with the result of the study because participants said that although they had freewill, they knew that God was in control of their lives.

Other authors think that in Traditional Africa, the cause of a disease is either attributed to natural agents, witchcraft or the displeasure of the ancestors (Uys & Middleton. 2004). However, in this research it was found that the majority of the participants believed that HIV/AIDS was God's plan.

The obvious injustice of the infection, in addition to being incurable, primarily affects the most vulnerable – the poor, the youth and the “blameless”- fuels suspicions of witchcraft (Ashforth, 2002). In Soweto, Johannesburg, research showed that there are a number of popular beliefs about HIV/AIDS and witchcraft. The popular form of witchcraft to which HIV/AIDS is attributed is *isidliso* (a range of symptoms leading to a slow wasting illness) commonly known as “poison” or “African Poison”. Often placed in food, *isidliso* will harm or kill only the intended victim. Other results of this study range from bad luck (divorce, unemployment, unpopularity, family dissension) to sickness and even death. Thus, *isidliso* is greatly feared (Ashforth, 2002).

#### **5.4.2 Beliefs about the prevention of HIV/AIDS**

Participants expressed three major beliefs about the prevention of HIV/AIDS: The infection can be prevented through condom use, through abstinence and through faithfulness in marriage.

##### **5.4.2.1 Prevention through the use of condoms**

The participants, who believed that HIV/AIDS is an ordinary illness, also believed that its prevention is through the use of condoms. Jackson (2002) suggested that the most certain ways to prevent HIV acquisition through sex are not having sex or staying faithful to one uninfected lifelong monogamous partner, but consistent condom use reduces infection risk substantially. However, she further suggested that strategies to provide condoms and promote their use are quite compatible with promoting abstinence and fidelity, and both should be accepted as elements of overall strategies to slow the spread of HIV. This is

consistent with the findings of the study because some of the study participants also believe that condom use and having a healthy lifestyle that includes good nutrition and exercise can prevent the spread of the infection.

Despite much research, there is no vaccine that will prevent HIV infection (Dipentima, Dowhen & Dowshen, 2005). Only the avoidance of risky behaviors can do this. Among teens and adults, HIV transmission is almost always the result of sexual contact with an infected person or sharing contaminated needles. Infection can be prevented by never sharing needles, and abstaining, or not having oral, vaginal, or anal sex. Risk can be substantially reduced by always using latex condoms, avoiding direct contact with blood, semen, vaginal fluids, and breast milk of an infected person.

Although condom use is believed to reduce the risk of HIV-infection, most Churches have different opinions about its use. The Roman Catholic leaders in Africa have pledged to step up their involvement in the fight against the continent's AIDS pandemic, but steadfastly refused to endorse the use of condoms in the fight (Sylla, 2003). "The Church says one must be faithful in marriage and save oneself for marriage, adding, we cannot say to people, to our youth, to all those who want to use condoms: 'Go ahead, use them' and thus cave in to the current trend". This is consistent with the findings of the study because some study participants did not endorse condom use because they said that sex is only permitted in marriage.

Although sub-Saharan Africa is the hardest hit by AIDS, being the home to more than two-thirds of those infected with HIV or full-blown AIDS worldwide, nevertheless, the Churches cannot condone the use of condoms. Sylla (2003) highlighted two of the

reasons for the Church's position: "Using condoms as a means of preventing AIDS can only lead to sexual promiscuity" and "Condoms facilitate sexual licentiousness".

The emphasis in all public health messages on HIV/AIDS is the practice of safe sex through using condoms. Although some religious groups see this as an invitation to promiscuity, others view its use with suspicion for other reasons. In Botswana and South Africa some people actually blame condoms for the spread of HIV/AIDS (Walker et al., 2004). For example, the lubricant on condoms can be seen to cause vaginal discharges – often interpreted as a sign of ill health. Also, in communities where good health is seen to depend on the appropriate exchange of body fluids, condoms are seen as a barrier to maintaining health and warding off illness (Walker et al., 2004). On the other hand, many people think that HIV/AIDS and other STIs are the result of breaking long-standing cultural taboos (Heald, 2002).

#### **5.4.2.2 Prevention through abstinence**

On the other hand, the participants who believed that HIV/AIDS is God's plan to turn people from evil also believed that its prevention is only through abstinence and faithfulness in marriage and not through condom use. In support of the statement above, Scorgie (2002) found that while the act of refusing sex and of asserting the desire to abstain may be difficult (owing to immense peer pressure to become sexually active and to the general persistence of boys in their 'love proposals'), abstaining is also a potentially self-affirming exercise. For teenage girls, faced with the challenges, reward and dangers of impending adulthood (at a time when the very chances of arriving at that stage appear to be increasingly precarious) this act may be one of the few ways in which

they are able to extend a measure of control over their lives (Scorgie, 2002). Other authors endorse virginity-testing as a way forward for young girls. Walker et al. (2004) says that to dismiss virginity-testing as a conservative backlash is to ignore and reject the ways in which ordinary people make sense of the AIDS epidemic, which may serve to reinforce the old divides between white and black, between Western and African, between science and magic. Stopping HIV/AIDS and treating those who are already positive means dismantling old fault-lines and developing strategies of inclusion (Scorgie, 2002).

The HIV/AIDS prevention campaigns which only follow the biomedical line have messages that 'tell just one story', when there are other voices to be heard (Heald 2002). Indigenous knowledge systems provide an alternative way of making sense of life-threatening conditions such as HIV/AIDS. Heald (2002) found that many people think HIV/AIDS and other STIs are the result of breaking long-standing taboos. Modern society and modern ways of behaving are also blamed for the spread of HIV/AIDS. Encouraging people to adhere to traditional practices can be a way of prevention. The return to virginity-testing in Kwazulu-Natal is one example of this (Heald, 2002).

Bate (2003) in similar argument wrote that the issues around HIV/AIDS reveals the real truths, beliefs and values of our society. Thus preventing AIDS must be in line with our spiritual beliefs. This statement is in line with the results of the study because some participants believed that the infection is God's way of demanding behavioural change from humanity. That is, some participants stated that those who are not married should abstain from sex until they are married.

### **5.4.2.3 Prevention through faithfulness in marriage**

This study also found that HIV/AIDS can only be prevented through faithfulness in marriage and not the use of condoms. Bernier (2001) speaking about the Catholic Church, HIV/AIDS and condoms said that even if condoms are 100% effective in preventing the infection, the Church is discouraging unmarried people from engaging in premarital sex, because what is at stake is not only your health, but the good of children, the sanctity of marriage, your own spiritual welfare, etc. This is because of HIV/AIDS, but also because of many values: preserving the body and sex until marriage is indicated. Some participants believed that unmarried people should wait until they are married before they can engage in sexual relationships.

In 2001 the South African Bishops' Conference (South Africa, Botswana & Swaziland) in Pretoria, released a statement about the promotion of condom use to combat HIV/AIDS (Malcolm, 2001). The release stated that condom use was an "immoral and misguided weapon against the disease". The reasons given was that "condoms may even be one of the main reasons for the spread of the infection; apart from the possibility of condoms being faulty, or wrongfully used, they contribute to the breaking down of self control and mutual trust". The statement further emphasized that "condoms do not guarantee protection against the infection, as they change the beautiful act of love into a selfish search for pleasure, while rejecting responsibility"; concluding, "abstain and be faithful in the human Christian way of overcoming HIV/AIDS".

In the Ugandan Government's ABC HIV/AIDS prevention program, the "C" is a sensitive issue among many religious communities. While most faith-based groups in Uganda do

not condemn the government strategy of condoms, they also do not openly condone the promotion of condoms for HIV prevention. They tend to reject condom use because condoms provide a means for people to have sex outside of marriage (Farrell, 2004). Among its arguments against the use of condoms, the Catholic Church in Uganda focuses on the fact that condoms are not 100% effective in preventing HIV transmission. Echoing Vatican opinions, several priests interviewed by the author claim that the pores on a condom are larger than the HIV virus, so the condom cannot protect against its transmission (Farrell, 2004).

The Catholic Church is renowned world-wide for its stringent position against the use of all contraceptives. The rationale behind this is that people should only engage in sex within marriage and with the intent of procreating. Thus, the Church argues that as long as a person restricts sex to marriage, there is no need for condoms. "No one has ever died of abstinence," explained a Catholic community organization coordinator (Hogle, 2000)

### **5.4.3 Belief about the cure of HIV/AIDS**

#### **5.4.3.1 An ordinary cure**

Those who believed that the infection was ordinary also reported that they believed that its cure will be discovered through research in the same way the cure for all the other illnesses was discovered. The medical treatment for HIV ranges from prevention and treatment of the opportunistic infections (OIs), to treatment that directly targets the virus itself: antiretroviral (ARV) therapy, or ART. These medications work best when people are well nourished, not over-stressed or over-tired, and are able to have a positive attitude toward life. The whole well-being of the person, spiritual, psychosocial and material is

important, not just physical or medical treatment (Jackson, 2002). The goal of this treatment is focused on finding ways to control the condition and, in particular, to reduce the concentration of HIV within the body in order to minimise the effect of the infection. Although the current ARVs therapies are effective in reducing HIV concentration in the blood, they are problematic since they are toxic to the body and are also not effective if the treatment is not taken following exact guidelines as to quantities and times of medication (DiPentima et al., 2005). In the same way many study participants reported they were afraid to resume ARVs because of its side effect, although some of them were being prepared to resume the treatment during data collection.

There have been two major advances in the treatment of HIV/AIDS over the last 20 years. One is the development of drugs that inhibit the virus's growth, preventing or delaying the onset of AIDS and allowing people living with HIV to remain free of symptoms longer. The other is the development of medications that have proven very important in reducing the transmission of the virus from an HIV-infected mother to her child. However, there is no known cure for HIV or AIDS (DiPentima et al., 2005). Participants were also aware that there is no cure for the infection, but are optimistic that the cure will be discovered by researchers. The search goes on for a vaccine that might prevent HIV infection. But even if such a vaccine is developed, it is likely years away. That's why prevention of HIV remains of worldwide importance today because there is no cure.

#### **5.4.3.2 Belief about a “God cure”**

Some participants also believed that the prevention of HIV/AIDS is possible through abstinence and faithfulness in marriage, but only God can cure it. However, this can only be achieved when people turn from their evil practices. Because participants believed that God brought about the infection in demand for behaviour change in humanity, they reported that God will also bring about the cure when this behaviour change is achieved. Talking about evil practices and behavioural change, Bate (2003) described AIDS as a sickness which thrives on social chaos like drunkenness, lawlessness and licentiousness. When a society degenerates into social chaos the cultural, moral and religious restraints on killing, rape, violence and respect are gradually eroded. It is in such a context that prostitution may become the only means of survival. In such a context, men may feel that the rape of a child to be cleansed of the virus is a good path of action to take.

#### **5.4.3.3 Belief about a “virgin cure”**

The myth of the “Virgin Cure” has a rich and diverse history stretching back to 16th century Europe, and more prominently to be found in 19th century Victorian England, where, in spite of the emphasis on morality and family values, there existed a widespread belief, that sexual intercourse with a virgin was a cure for syphilis, gonorrhoea, and other sexually transmitted diseases (STDs) like HIV/AIDS (Earl-Taylor, 2002). In the Eastern Cape of South Africa, when a significant outbreak of STD's was spread by troops returning home from overseas after World War Two (WWII), the Virgin Cure was widely sought among the population (Earl-Taylor, 2002). Encompassed in the current belief system of both prevention/cure of HIV/AIDS is the notion that an intact hymen, and the smaller amount of vaginal secretions in young girls, prevents transmission of the disease

through sexual intercourse. As previously posited, experts agree to disagree on the root causes of the shocking incidence of child rape (Earl-Taylor, 2002). This is consistent with the evil described by participants in this study.

In the Markinor Survey (2005), a total of 3 500 South African adults (16 years and older) are randomly selected and interviewed during April and May each year. This year, the study was focused on awareness, knowledge, beliefs and opinions about HIV/AIDS in South Africa. It was found that a sizable group (16%) believed that HIV/AIDS could be cured by Western medicine or doctors; that traditional herbal remedies could protect a person from contracting HIV/AIDS (14%); or that HIV/Aids could be cured by traditional healers (12%). In the same way, this study revealed diverse beliefs about the cure for HIV/AIDS.

#### **5.4.3.4 Other beliefs about the cure of HIV/AIDS**

The Barzakh Foundation (1999), an Islamic social organization located in Jakarta, has opened a worldwide service to cure HIV/AIDS patients using the Sufi Healing method. The Sufi healing method is an Islamic healing method using Divine spiritual power that has been practiced exclusively by the Sufis for centuries. The basic principle in Sufi Healing is that the True Healer is God Himself, the Sufis only act as mediators. The physical healing methods of the Sufis was derived first from the Holy Qur'an, and second from the traditions and actions of the Prophet Muhammad (peace be upon him) (Barzakh Foundation, 1999). In the same way participants believed that only God can cure the disease.

Bate (2002) stated that in medical science, the remedy for the illness, i.e. “headache” is “two aspirin”. In Zulu, the remedy for umukhuhlane (headache/flu) is umuthi (medication). In the Catholic and Pentecostal Churches, the remedy for “possession by evil spirits” is prayer or “casting out demons” (Bate, 2002). In Christianity, the remedy for sin is asking God for forgiveness and repenting of one’s sin. In the same way, participants believed that through repentance and changing one’s behaviour, God will bring about or reveal the cure for the infection.

### **5.5 Benefit of spiritual belief in helping people living with HIV/AIDS to cope with the infection**

The benefit of the spiritual belief that helped participants to cope with the infection was the achievement of inner peace. Inner peace was achieved through restoration of relationships with God or the ancestors, as well as with others. This was facilitated through forgiveness of others and asking for the same through the use of different spiritual expressions. The most commonly used spiritual expression reported was prayer, through which participants asked God to forgive them. Forgiveness helped them to love and connect with themselves, the Higher Power and with others. There was an agreement among participants that a restored relationship with God or the ancestors as well as with others placed them at a level of peace, where general wellness became possible. As recorded in Mahlangu (2001) inner peace is one concept which is a clear consequence of a dynamic relationship with God. The Oxford English dictionary defines peace as a quiet tranquillity, a mental calmness or serenity (Fowler & Fowler, 1990). This kind of

peace does not come naturally; it only comes as a result of God's direct intervention in the affairs of humanity (Amenta, 1997).

Luskin (2002) argued that inner peace is experienced through forgiveness, and it is the understanding that can be felt in the present moment. However, this does not mean forgetting or denying that painful things occurred, but it is the powerful assertion that bad things will not ruin your today even though they may have spoiled your past. (Luskin, 2002, p.7). This statement agrees with the result of this study as evidenced by the fact that many participants forgave those who infected them in order to have inner peace and move on with their lives. Some participants forgave themselves for their past lives and others had to ask God to forgive them for wrong doings. Once forgiveness had taken place participants experienced inner peace. On the other hand, when they forgive others, their relationships were restored and they could qualify to also ask God for forgiveness and receive it. Some participants believed that once they were forgiven by God, they qualified to ask Him to heal them and He did.

Studies have looked at the differences between people who are more or less forgiving. They found that, overall; there were less reported incidence of physical illness in those people who were more forgiving. Specifically, people who were deeply hurt by a parent, friend, or romantic partner and forgave the betrayal, had better blood pressure, healthy muscle tension, better immune response, and improved cardiovascular, muscular, and nervous system functioning than others who had not forgiven ( Luskin, 2002; Enright, 2002).

Also, research has found that forgiveness results in less psychological pain, reduced stress, and increases in self-confidence, compassion, quality of life, and hope (Enright, 2002). These are in line with the results of the research because some participants reported that they experienced mental tension and emotional disturbance when they held onto unforgiveness. Without forgiveness, participants could not love or connect with the higher power or with other people.

In order to experience peace of mind, one has to acknowledge that the relationship with the Ultimate Reality is based on love, and is maintained through connectedness and forgiveness (Underhill, 1997). The ultimate goal of a relationship with the Ultimate reality is the good of humanity (Todeschi, 2004). There are common bonds (the bonds of love, forgiveness, connectedness and peace) that all should share as collective humanity, regardless of the name by which we call the Ultimate Reality or the religion on earth that we feel drawn to, because there is but one Creator, one Source of life and one Law. This is concept of "oneness". However, the relationship with the Ultimate Reality has boundaries which can be crossed by humanity through the negative use of the freewill (evil, sin) given to all (Todeschi, 2004). The nature of the Ultimate Reality is good, and evil violates this good nature, resulting in a relationship breakdown. This relationship breakdown can lead to lack of peace, illnesses (mental, physical and emotional), diseases, death, disasters, and all kinds of evil.

Everything that is valuable in life can be expressed in terms of relationships (World Council of Churches, 2004). There are relationships within the Trinity (God the Father, God the Son & God the Holy Spirit); between God and creation, both its human and non-

human aspects; among human beings; and between human beings and the natural world. The life of the Holy Trinity moves in relationships among Father, Son and Holy Spirit, and characteristically all that God does in and with creation is also fashioned in the processes of relationships. Thus when God created the world (cf. Gen. 1:3), He did not let it *go*. That is, He did not let the world survive on its own. Instead, at every moment the triune God initiates and maintains relationship with every part and particle of it. In the same way, participants believed that humans were made to be in relationship with each other and with God. Without relationship, there is a sense of isolation because no man is an island.

Because man was made to be in relationship with the Ultimate Reality for the good of humanity, a broken down relationship produces bad results. In Romans 6:23, it is recorded: for the wages of sin is death, but the gift of God is eternal life through Jesus Christ our Lord. The increase in evil of humanity is the cause of sicknesses and diseases. Moses said in (Exodus 15:26) that if you listen carefully to the voice of the Lord your God and do what is right in His eyes; if you pay attention to His commands and keep all His decrees, I will not bring on you any of the diseases that I brought on the Egyptians, for I am the Lord who heals you. God's nature is to heal (World Council of Churches, 2004). However, this can only be possible when there is peace between God and man in a restored relationship with Him. Similarly, the study found that because man was made for relationship, unforgiveness makes people sick emotionally, spiritually as well as physically, but when you are willing to forgive, the relationship is restored and one can be healed in different dimensions of life, thereby promoting peace. Because humans are beings-in-relation, forgiveness enables this relationship to continue, but a refusal to

forgive brings it to an end (World Council of Churches, 2004). In the same way, participants believed that there was a need for humanity to be forgiven by God so that the relationship with Him can continue and to be at peace with Him. For all have sinned and fall short of the glory of God (Romans 3:23). This calls for repentance, by which the relationship between God and human beings is maintained. Restoration of relationship precedes human repentance and it is in repenting that the existence of forgiveness is discovered (World Council of Churches, 2004).

Participants believed that once the relationship with God was restored, they could pray for their needs and He could hear them and provide their immediate needs. One of such needs was relief from physical symptoms of illnesses. Bate (2003) suggested that healing and health are the same. Health may include notions of salvation, as in the Christian faith, or enlightenment as in eastern religions or of a good life lived in harmonious relation with others as in African traditional culture. It may include notions of correct human social living as in the Marxist, Christian, Muslim, and Western systems. It may also include a moral or ethical system which allows people to live in peace, mutual trust and respect rather than in social chaos (Bate, 2003). This statement is in line with the results of the research because participants believed that a restored relationship is crucial to love and connectedness, without which there was lack of inner peace, constant isolation and hatred.

A restored relationship with God and their fellow human beings provided participants with the hope to carry on with their lives despite the difficulties associated with the infection. They felt hopeful especially regarding their future because their faith in God

reassures them that there will be a good future. Many of them spend quality time praying because they were hopeful that God always hears and answers them. Prayer that yields results comes from a forgiven, loving, connected and righteous heart just as it is written in the Bible (James 5:16b), the effective prayer of the righteous man avails much. In addition, the prayer that yields results is prayed from a heart full of faith which comes from a forgiven person's heart (Hebrews 11:6). Without faith, it is difficult to please God; if you have faith as small as a mustard seed, you will tell this mountain be removed and cast thyself into the sea and it will obey you (Mark 11:19-20). Once the relationship with God is restored, participants reported that you are empowered by God through the Holy Spirit from within to fight HIV/AIDS and overcome its difficulties.

Forgiveness and ways of cleansing the mind and body are basic to all religions. By encouraging people to engage in purification rituals, to meditate and to restructure the remainder of their lives, one may be preparing the self for peace and a restoration of relationship with the Ultimate Reality or preparing the self for life after death (Dyk, 2001).

## **5.6 Recommendations**

Adaptation of a universal definition for spirituality is imperative. As suggested by many nursing scholars, definition of the term must be broad and inclusive (Narayanasamy, 1999; O'Brien, 1999; Sellers, 2001). Rather than getting stuck on rhetorical terms, it would be wise to capture the essence or intent of spirituality. This study has revealed several roles of spirituality that require further investigation and testing. The role of spirituality needs to be tested for its practicality in clinical practice and in education. The

components of spirituality (love, forgiveness and connectedness) need to be tested in reality in different clinical settings within the South African context. A larger sample may be appropriate in subsequent studies to strengthen the validity and reliability of the findings utilizing quantitative research methods to find out from nurses, patients, religious leaders, teachers and others, and get their opinions about the role of spirituality in the lives of people living with HIV/AIDS.

Quantitative research would be appropriate in testing and measuring the specific areas of spiritual expressions (prayer, meditation and reading the Bible) and finding the relationships between them. On the other hand, certain aspects of spirituality can be measured only through qualitative research. The researcher therefore recommends that in particular, the role of forgiveness and restoration of relationship with the higher power in curing HIV/AIDS be tested in reality and validated.

In her study, Mahlunqulu (2001) recorded that most nurses in her study reported that they were never taught how to provide spiritual care during their educational programs. They reported that only when they were in actual practice did they realize that they needed to care for the spiritual aspects of patients and their families. Nurses are not taught how to deal with sensitive spiritual issues. Although nursing defines a person as a spiritual being, students are not taught how to evaluate this dimension of a person. There is therefore a need to incorporate this aspect of care-giving in nursing education. Nurses need to rise up and develop themselves in this aspect of patients' care so that they are able to recognize

spiritual needs whenever they arise and deal with them. Spirituality should be an integral part of the nursing curriculum.

Restoration of relationship with the Ultimate Reality was found to be the way forward for the HIV/AIDS dilemma. Therefore, nurses should be provided with the knowledge that they need on how to guide people living with HIV/AIDS in the process of restoring their relationships with whomever they may refer to as their higher power. The continuous increase of AIDS tells us that there is a need to change the way in which we have handled its management. Spirituality is the way forward, let's embrace it.

This research has vital implications for policy makers. If national as well as international health organizations must deal effectively with the HIV/AIDS situation, there is an urgent need for them to include in their policies the role of spirituality in the management of the infection. Training should also be provided for those that will implement these policies. Everyone should be included in this endeavour: religious leaders, governmental and non-governmental organizations, individual and families.

### **5.7 Limitations**

The major limitation of this study is that the results cannot be transferred to other settings or groups because of the methodology used and due to the sample size (25). Polit and Hungler (1997) state that the results found in a study where purposive sampling was used are difficult to generalise to the entire population.

## **5.8 Conclusion**

The study aimed at exploring the role of spirituality in the lives of people living with HIV/AIDS. It was guided by the following questions:

- What is spirituality?
- What is the role of spirituality in the life of people living with HIV/AIDS?
- How do people living with HIV/AIDS describe their beliefs about the cause, prevention and cure of the infection?
- How does spiritual belief help people living with HIV/AIDS cope with the infection?

The theoretical framework that guided this study was the Cognitive-Behaviour Model of Spirituality by Randy Neil. The framework explains spirituality as a function of beliefs, values, behaviours and experiences. The findings of this study have revealed the role that spirituality plays in the lives of people living with HIV/AIDS and the different beliefs that these people have about the cause, prevention and the cure of the infection, and the benefit of spiritual beliefs in helping them to cope with the infection.

The conceptual definition used in this study is in conformity with the definitions provided by the study participants. The major concepts that were developed were basically related to the participants' understanding of the role of spirituality in the life of people living with HIV/AIDS. In this study, spirituality was defined as the relationship with the transcendent being/higher power, with the self and others that facilitated love for God, the self and for others; forgiveness by God, by self and by others; and connectedness to the self, to God and to others.

Spirituality was found to play helpful roles in the lives of people living with HIV/AIDS: It provided participants with strength to deal with stigma and discrimination and helped them to live positively with the infection. It also provided hope for the future, facilitated interpersonal relationships with the higher power, the self and with others, and provided protection from death and HIV-related problems.

Different beliefs were expressed about the cause, prevention and cure of HIV/AIDS: It was found not to be a curse from God, but an ordinary illness. Others believed that the illness was God's plan to bring humanity back to Him, while others believed that it was a blessing. The study found that HIV/AIDS could be prevented through the continuous use of condoms, faithfulness in marriage and abstinence, but its cure could only come from God after the accomplishment of the purpose for which He allowed the infection. However, some study participants believed that the cure would be discovered through research.

The benefit of the spiritual belief that helped participants to cope with the infection was the achievement of inner peace which was achieved through restoration of relationships with God or the ancestors, as well as with others through forgiveness of others and asking for the same through the use of spiritual expressions. Forgiveness helped them to love and connect with themselves, the Higher Power and with others. There was an agreement among participants that a restored relationship with God or the ancestors as well as with others placed them at a level of peace, where general wellness became possible.

Repentance was found to be crucial to the restoration of relationship between humanity and God without which one is unable to experience inner peace and God's forgiveness.

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**ANNEXURE A:**

**COPIES OF LETTERS REQUESTING  
PERMISSION TO CONDUCT RESEARCH**

University of KwaZulu-Natal  
School of Nursing  
Howard College Campus  
Durban, 4041

January 24<sup>th</sup>, 2005

Department of Health  
Province of KwaZulu-Natal  
Private Bag 9051  
Pietermaritzburg

Dear Sir/Madame:

**REQUEST FOR PERMISSION TO CONDUCT A NURSING RESEARCH**

My name is Meiko Josephine Dolo. I am currently studying at the above mentioned institution pursuing a Master's Degree in Mental Health Nursing, and this research is undertaken in partial fulfillment of this degree.

The title of my research is: **THE ROLE OF SPIRITUALITY IN THE LIFE OF PEOPLE LIVING WITH HIV/AIDS**. The purpose of this study is to explore the role of spirituality in the lives of people living with HIV/AIDS, which is aimed at exploring the different spiritual beliefs held by this group of people and the importance of these beliefs in helping them to live with HIV and AIDS.

The researcher therefore requests permission to collect data in focus groups and on one-on-one basis from people living with HIV/AIDS in support group at Philani Clinic, King Edward VIII Hospital. The study will focus on the adults (18 years and above) who can understand and communicate well in the Zulu and English languages. Although the

researcher does not speak Zulu, she is going to have a second person that understands and speaks the Zulu language very well.

This research has been cleared by the Research Ethics Committee at the above mentioned University. Participants for the study will be given a letter each with information regarding the nature and purpose of the study and they will be asked to sign a consent form. They will also be assured that confidentiality will be respected and their names will not appear anywhere in the research report.

Enclosed are the research proposal summary and the interview guide for participants, including a copy of a clearance from the Research Ethics Committee of the University of KwaZulu-Natal. Your support in this regard is highly appreciated.

Faithfully yours,

  
Meiko J. Dolo

Master's Student



THE SOUTH AFRICAN CENTRE  
FOR EVIDENCE-BASED NURSING & MIDWIFERY



THE JOANNA BRIGGS INSTITUTE



UNIVERSITY OF  
KWAZULU-NATAL

February 14, 2005

The Medical Superintendent  
King Edward Hospital  
P.O. Box 281  
Durban, 4000

Dear Sir/Madame:

#### **REQUEST FOR PERMISSION TO COLLECT DATA**

My name is Meiko Josephine Dolo. I am currently studying at the above mentioned institution pursuing a Master's Degree in Mental Health Nursing, and this research is undertaken in partial fulfilment of this degree.

The title of my research is: **THE ROLE OF SPIRITUALITY IN THE LIFE OF PEOPLE LIVING WITH HIV/AIDS**. The purpose of this study is to explore the role of spirituality in the lives of people living with HIV/AIDS, which is aimed at exploring the different spiritual beliefs held by this group of people and the importance of these beliefs in helping them to live with HIV and AIDS.

The researcher therefore requests permission to collect data in focus groups discussion and on one-on-one basis from people living with HIV/AIDS in the support group at Philani Clinic, King Edward Hospital. Your institution has been chosen because it is recognised as one of the outstanding health centres that provide hope to

#### **School of Nursing, Howard College Campus**

Postal Address: Durban, 4041, South Africa

Telephone: +27 (0)31 260 2499

Facsimile: +27 (0)31 260 1543

Email:

Website: [www.ukzn.ac.za](http://www.ukzn.ac.za)

Founding Campuses:

Edgewood

Howard College

Medical School

Pietermaritzburg

Westville

people living with this condition. The study will focus on the adults (18 years and above) who can understand and communicate well in the Zulu and/or English languages. Although the researcher does not speak Zulu, she is going to have a second person that understands and speaks the Zulu language very well.

This research has been cleared by the Research Ethics Committee at the above mentioned University. Participants for this study will be given a letter each with information regarding the nature and the purpose of the study, and they will be asked to sign a consent form. They will also be assured that confidentiality will be respected and their names will not appear anywhere in the research report.

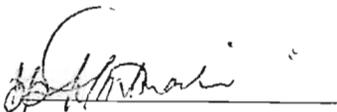
Enclosed are the research proposal summary and the interview guide for participants, including a copy of a clearance from the Research Ethics Committee of the University of KwaZulu-Natal. Also enclosed is a copy of the letter of permission given me by the Department of Health of the Province of KwaZulu-Natal. Your support in this regard is highly appreciated.

Yours faithfully,



Meiko J. Dolo

Master's Student



Dr. Sarah Mahlunqulu

Research Supervisor

**ANNEXURE B:**

**LETTERS OF PERMISSION TO CONDUCT  
RESEARCH**



# DEPARTMENT OF HEALTH

PROVINCE OF KWAZULU-NATAL

SPECIAL SUPPORT SERVICES

Natalia, 330 Longmarket Street, Pietermaritzburg, 3201  
Private Bag X9051, Pietermaritzburg, 3200  
Tel.: 033 395 2542, Fax.: 033 845 0312

ENQUIRIES : Miss NP Beeton  
EXTENSION : 2542  
REFERENCE : 9/2/3/R

Meiko J. Dolo  
Nursing Department  
University of KwaZulu-Natal  
**DURBAN**  
4041

Dear Ms Dolo

## REQUEST TO CONDUCT RESEARCH ON THE ROLE OF SPIRITUALITY IN THE LIVES OF PEOPLE LIVING WITH HIV/AIDS AT PHILANI CLINIC, KING EDWARD HOSPITAL, DURBAN

Your letter dated 24 January 2005 refers.

Please be advised that authority is granted for you to conduct a research regarding the role of spirituality in the lives of people living with HIV/AIDS at Philani Clinic, provided that:

- (a) Prior approval is obtained from the Heads of the relevant Institutions;
- (b) Confidentiality is maintained
- (c) The Department is acknowledged;
- (d) The Department receives a copy of the report on completion; and
- (e) The staff of the hospital are not disturbed and/or inconvenienced in their work and that patient care is not compromised.

Yours sincerely

  
SUPERINTENDENT GENERAL  
HEAD: DEPARTMENT OF HEALTH  
NPB/meiko j dolo research

04.02.05





# KING EDWARD VIII HOSPITAL

Postal Address: Private Bag , Dalbridge, 4014. • Telephone: 031 3603853 • Fax: 031 2061457 •

Enquiries: Mr. A.J Seekola  
Reference: KE 2/7/1 (5/2005)  
Research Programming  
15 February 2005

**Meiko J Dolo**  
School of Nursing  
Howard College Campus  
DURBAN  
4041

Fax No. 260 2499

## **Request to conduct research at King Edward VIII Hospital**

*Protocol: The Role of Spirituality in the Life of People Living with HIV/Aids.*

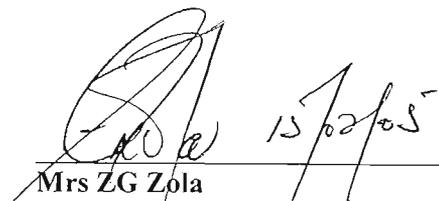
Your application received on the 14 February 2005 is approved.

Please ensure the following:

- That King Edward VIII Hospital receives full acknowledgement in the study on all publications and reports and also kindly present a copy of the publication or report on completion.
- Before commencement:
  - \*Discuss your research project with our relevant Directorate Managers.
  - \*Sign an indemnity form at Room 8, Hospital Manager's Complex, Admin Block..

The Management of King Edward VIII Hospital reserves the right to terminate the permission for the study should circumstances so dictate.

Yours Sincerely



Mrs ZG Zola

Acting Hospital Manager.

cc All Directorate Managers. A&E/ Critical Care/ General Surgery/ Internal Medicine/  
O&G/ Orthopaedics/ Paediatrics/ Radiology/ Specialty Services/ Theatre.

Noted  AM

**ANNEXURE C:**

**ETHICAL CLEARANCE FROM UNIVERSITY  
OF KWAZULU-NATAL**



UNIVERSITY OF  
KWAZULU-NATAL

**RESEARCH ETHICS COMMITTEE**

Student: Meiko JOSEPHINE DOLO

Student No: 203514805 Qualification: \_\_\_\_\_

Research Title: The role of Spirituality in the life of people living with HIV/AIDS

A. The proposal meets the professional code of ethics of the Researcher:

YES  NO

B. The proposal also meets the following ethical requirements:

	YES	NO
1. Provision has been made to obtain informed consent of the participants.	✓	
2. Potential psychological and physical risks have been considered and minimised.	✓	
3. Provision has been made to avoid undue intrusion with regard to participants and community.	✓	
4. Rights of participants will be safe-guarded in relation to:		
4.1 Measures for the protection of anonymity and the maintenance of confidentiality.	✓	
4.2 Access to research information and findings.	✓	
4.3 Termination of involvement without compromise.	✓	
4.4 Misleading promises regarding benefits of the research.	✓	

Signature of Student: [Signature] Date: 18/11/04

Signature of Supervisor: [Signature] Date: 23/11/04

Signature of Head of School: [Signature] Date: 24/11/04

Signature of Chairperson of the Committee: [Signature] Date: 25/11/04

**Faculty of Community & Development Disciplines**

Postal Address: Durban 4041, South Africa

Telephone: +27 (0)31 260 3139

Facsimile: +27 (0)31 260 2458

Email: khonyid@ukzn.ac.za

Website: www.ukzn.ac.za

**ANNEXURE D:**

**LETTER WRITTEN TO PARTICIPANTS  
REQUESTING PERMISSION**

University of KwaZulu-Natal  
School of Nursing  
Howard College Campus  
Durban, 4041

February 14, 2005

Members of Support Group  
Philani Clinic  
King Edward VIII Hospital  
P.O. Box 281  
Durban, 4000

Dear Sir/Madame;

**REF: REQUEST TO PARTICIPATE IN RESEARCH STUDIES**

My name is Meiko Josephine Dolo. I am currently studying at the above mentioned institution pursuing a Master's Degree in Mental Health Nursing, and this research is undertaken in partial fulfillment of this degree.

The title of my research is **THE ROLE OF SPIRITUALITY IN THE LIFE OF PEOPLE LIVING WITH HIV/AIDS**. The purpose of this study is to explore the role of spiritual beliefs in the lives of people living with HIV/AIDS and the importance of these beliefs in helping them to live with the infection.

I therefore request your participation in this research study by permitting me to interview you in group discussions and individually. Each interview will last for about thirty (30) minutes. I also request your permission to tape record the interviews. Participation is voluntary and you have the right to withdraw from the interview at any time.

Confidentiality will be respected and your name will not be mentioned anywhere in the completed document.

Your participation in this regard is highly appreciated.

Very truly yours,

  
Meiko J. Dolo

**Permission from participants**

I would like to participate in the above research. I understand that this is voluntary.

**Signature of participants:**

**ANNEXURE E:**  
**DATA COLLECTION TOOL**

## APPENDIX 1: DATA COLLECTION TOOL

### Questionnaire-1

#### Section A: Demographic Data

Question 1: Age: -----

Question 2: Gender: Male/Female

Question 3: What is your marital status? (Tick that answers that apply to you).

Married	
Single	
Separated	
Divorced	
Widow	
Live with spouse	

Question 4: What is your level of education? -----

Primary	
Secondary	
Matric	
Tertiary	
Other specify	

Question 5: What is your religious affiliation? -----

Christian	
Muslim	
Hindu	
Buddhist	
Ancestral Worship	
No Religion	

Question 6: How do you express your spiritual beliefs/Form of worship? -----

Prayer	
Reading Bible	
Meditation	
Helping others	

## **Section B. The role of spirituality**

**Question 8:** How can you describe your own spirituality?

**Question 9:** How can you describe the role of spirituality in your life?

- a. In performing daily activities?
- b. On your perspectives about the future?
- c. In overcoming the difficulties related to HIV/AIDS?

Probes: (stigma, side effects of ARV)

**Question 10:** What is the meaning of love to you?

- a: What is the role of spirituality in helping you understand love?
- b: How do you experience love in your life?

Probe: How does spirituality help you to love the person who infected you?

**Question 11:** What is the meaning of forgiveness to you?

- a: What does forgiveness do in your life?
- b: How does spirituality helps you to experience forgiveness in your life?

Probe: How does spirituality helps you to forgive the person who infected you?

**Question 12:** What is the meaning of connectedness to you?

- a. What does connectedness do in your life?
- b. How does spirituality help you to experience connectedness in your life?

Probe: How spirituality helps you to get connected to others?

## **Section C: Belief system**

**Question 13:** What are your beliefs about the cause, prevention and cure HIV/AIDS?

## **Section C: Benefit of spiritual belief**

**Question 14:** How does your belief help you to cope with HIV-related problems/difficulties?