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**AN EXPLORATORY STUDY OF THE  
PSYCHOLOGICAL IMPACT OF HIV/AIDS  
PATIENTS ON THE COUNSELLOR**

by

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**DECLARATION**

I hereby declare that an exploratory study on the psychological impact of HIV/Aids patients on the counsellor is my own work and that all the sources that I have used or cited have been indicated and acknowledged by means of complete references.

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M. K. HLALELE

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## **ABSTRACT**

This study presents the narratives of four female counsellors who were at the time of the research study working as counsellors at the Neurological clinic in Kalafong hospital. This dissertation explores the psychological effects and experiences of working with HIV/Aids patients on the counsellor. The definitions of different kinds of counsellors are discussed. The literature on the psychological impact of working with HIV/Aids patients is generally discussed.

This research study uses the qualitative method as a research approach. The process of inquiry that directs this research falls within a narrative framework, and the study also uses participants' stories to elicit common themes. Central themes that emerged relate mainly to participants' unique psychological effects and experiences of working with HIV/Aids patients. Some of the counselling issues that captured the attention of the researcher were counter-transference, coping with work stress, high level of perceived expectations, psychological responses to HIV-positive results, emotional workers and boundary between private and professional life. The participants experience other manifestations of distress, for example depression, anger, guilt and loneliness.

The reflections on the themes are discussed, together with the impact of the research process on both the participant and researcher are explored. Finally, some of the discourses around the psychological effects and experiences of working with HIV/Aids patients that may inform participants' stories and the researcher are explored.

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## **CHAPTER 1**

### **INTRODUCTION**

In South Africa a large of number of community-based intervention programmes have been established in order to address the ever-increasing number of people who are infected or affected directly or indirectly by the HIV/Aids pandemic. While the disease keeps ravaging the bodies, lives, and social networks of their patients, committed counsellors continue the counselling work in helping patients achieve more satisfying and fulfilling lives. The majority of patients who receive counselling after the HIV diagnosis do better emotionally, maintain better clinical follow-ups and present with less psychological symptoms such as denial, depression, anger, blame, social isolation, stress, and other HIV/Aids-related mental illnesses than those who do not get them.

This dissertation is written with the aim of understanding the psychological effects of working with HIV/Aids patients on the counsellor. It is within this context that the text aims to raise an awareness of psychological effects which counsellors experience in the execution of the counselling services with HIV/Aids patients. The aims of this research study will be elaborated upon later in this chapter.

Knox and Friedrich (1994) perceived that the more the South African people are adversely affected or infected by HIV/Aids, the more the counsellors' overall psychological functioning will be threatened. Being HIV positive makes a tremendous impact both on the medical, psychological, social, spiritual, educational and economic life of the infected person, his or her affected others and health professionals, as well as the community as a whole. All this places a tremendous burden on the shoulders of, in particular, counsellors who need to offer HIV infected or affected individuals and their significant others complete and dedicated services which exceeds the customary bounds of conventional medical care and treatment (Van Dyk, 2001). He provided a clear explanation of the counsellor working in the field of HIV/Aids as the comprehensive caregiver, educator and adviser in the diverse cultural and social contexts.

The researcher assumed that there are numerous definitions of a counsellor depending on the understanding and perception of an individual. According to the researcher's (my personal definition) understanding of the definition, a counsellor is professionally competent in assessing, diagnosing, and intervening in other people's life problems in order to alleviate or contain or facilitate their desirable psychological adjustment, growth, well-being and maturity. These counsellors are required to complete a two-year MA comprehensive training programme from the university and must comply with the minimum standards set by the Health Professions Council of South Africa (counselling psychologist). There are other counsellors who are registered as HIV/Aids counsellors, and who are involved with the individual counselling of individuals. These counsellors are only required to complete a special

training programme from the community-base organisation and comply with the minimum standards set by the Department of Health, HIV/STDs Directorate (volunteer counsellors).

All these counsellors need to maintain current competencies and in their areas of practice through continuing professional development, consultation, and other procedures to ensure high standards of professional competence for the public. For the purpose of this study, an exploration will be done on one professional counsellor and three volunteer counsellors who voluntarily offered to participate in the research after the researcher had clearly explained to them the nature and motive of the study (a course requirement), as well as the risks, obligations, and limitations.

## **1.1. BACKGROUND**

The disease known as acquired immune deficiency syndrome, or Aids, has been recognised for more than ten years. During this time it has been more intensively researched and studied than any other disease in the history of humankind. It seems likely that while medical and scientific research will continue to make progress from the 1980s, it is the psychosocial, behavioural and economic research into the disease, which will become increasingly important (Whiteside & Sunter, 2000). Disease such as human immunodeficiency virus, or HIV, profoundly affects the psychological, cultural, and political aspects of communities and countries. This worldwide pandemic has enormous implications of health and psychological well being of individuals, their families' structures, and community structures, as well as health

professionals, for the delivery of psychosocial and medical services, and responses by government sectors. Never before in the history of the human race has one disease presented so many challenges and brought about so many unanticipated changes (Kirkpatrick, 1988).

The present statistics in South Africa by Prins and Van Niekerk (cited in Van Niekerk & Prins, 2001, pp 12-14); tell one story about the demographic impact of the HIV/Aids. The vast majority of people with HIV/Aids are young, in their 20s to 40s, and this has multiple implications about the psychological impact of this epidemic on the extended family structures and caregivers (both formal and informal), as well as on lost years of the country's economic productivity. Moreover, HIV/Aids infection shows an increasing number of cases of heterosexual transmission, especially among young women, which might suggest that HIV/Aids disease now has a strong foothold in multiple populations (Hoffman, 1996).

Demand for HIV/Aids counselling services is increasing in developing countries, but there have been few previous research studies that describe counsellors' psychological experiences of and the effects of working with HIV/Aids-related patients in developing countries. One of the most powerful ways to address the psychological aspects of this disease is through psychological counselling interventions, such as giving professionally competent opinion or information, pre-and post-test counselling, group counselling, consultation about future actions, management of psychological symptoms and HIV/Aids-related mental illnesses, as well as other practical issues

beyond therapeutic boundaries, that are continually executed by the counsellors, who are in the process being affected directly or indirectly, emotionally and psychologically.

Selwyn (cited in Hoffman, 1996) has concluded that positive behaviour change in patients with HIV/Aids could be possible through comprehensive and ongoing counselling services that are often by the counsellors. This is valuable because as HIV/Aids disease progression occurs, patients, families, and friends, as well as counsellors are also undergoing major psychological changes in numerous aspects of their lives, other than their health status. On the part of the counsellors, as stated by Wicks (1997), the heavy workload, multiple deaths and routine after-effects of dealing with a variety of HIV/Aids patients, who often display various frightening symptoms, becomes a horrible, terrifying and overwhelming experience for them. Therefore, it is crucial that more research be encouraged in the field to help counsellors learn to cope with their work experiences and the psychological consequences thereof. This will also help everyone concerned, like significant others, friends, and the community at large, to become more caring and compassionate about those who have not been able to escape the experiences and consequences of being affected or infected by the HIV/Aids.

HIV/Aids counselling work challenges counsellors in almost the same ways that it has challenged the HIV/Aids patients. Both counsellors and HIV/Aids patients tend to experience similar reactions to the multiple problems presented by the disease and the

many challenges they face psychologically. For example, sexuality and sexual practices, drug practices, declining health and overall functioning, anticipatory grief, spirituality, and death and dying are common concerns of both counsellors and HIV/Aids patients who are infected or affected by the disease. Whiteside & Sunter (2000) suggest that work with HIV/Aids patients often creates more frequent negative deep thoughts than amongst health professionals working with other types of presenting problems, such as getting depressed, crying, alcohol abuse, marital and relationship problems, emotional numbness and eventually experiencing burnout. Although it is not unusual to work with patients who present with concerns in one or more of these areas, what is unique about HIV/Aids patients is that many of these issues need to be assessed and addressed with a degree of urgency and extraneous problems which do not typically require direct clinical intervention. For example, many of the HIV/Aids patients' concerns in South Africa focus more on practical issues such as unemployment, shortage of food, transport fares and disability grants than on real medical and psychological needs, and this could be attributed to the unfamiliarity of counselling as a profession in the face of the incurability of the HIV/Aids disease. In other words, many of the patients expect counsellors to deal with these practical issues and concerns than with the deep-rooted, general emotional tension that is constantly blocked by rigid psychological defences.

The researcher has also found, from his personal experience at the Neurological clinic in Kalafong hospital, that the clinic's counsellors use therapeutic strategies and techniques based on the person-centred approach of Carl Rogers. This therapeutic approach seemed not to be very effective especially when counsellors fail to take the

cultural and philosophical differences of patients into account. To illustrate this, what the researcher has found with his HIV/Aids patients was that problems are often dictated by what had already been addressed. For instance, HIV/Aids patients seemed to be resistant and reluctant in recognising their own feelings and emotions. They tend to focus on their physical complaints and often terminate therapy prematurely after a few sessions because they cannot see counselling as the solution since it cannot provide the expected outcomes to their problems, which is healing.

Havens (cited in Wicks, 1997) envisaged that past ways of responding to stressors in the form of reflecting to feelings often appeared to have little or nothing to do with current ways of responding. This could also be attributed to the unfamiliarity of the western healing ways of addressing the patients' problems that are foreign to the non-westernised African population. This disequilibrium is common in the field of working with HIV/Aids patients, and it is frequently carried over into counsellors' therapeutic work, as Beuster (cited in van Dyk, 2001) has mentioned, that ignoring a patient's cultural background not only leads to incongruence and misunderstanding, but it could also be anti-therapeutic and harmful. Nichols (1996) highlighted that special effort has to be made on the part of HIV/Aids trainers to explain and help counsellors understand the relevance of the cultural implications within the helping relationship. The counsellors' successes, resilience and job satisfaction depend on receiving regular positive feedbacks, motivation, and emotional support from patients, employers, supervisors and the community at large.

There also seems to be little literature available, as stated by Harrison (2001), to help HIV/Aids counsellors in assessing and understanding the enormity of what was actually happening to the HIV/Aids patients and to help connect with them so that they could intervene effectively in more helpful ways. This could also be an overwhelming experience to the counsellors since they would not only be focusing on their tasks at hand, but also on their feelings of uncertainty, inadequacy and stress triggered by working with a variety of HIV/Aids patients.

## **1.2. AIMS OF THE RESEARCH**

This research study is about the psychological impact of working with HIV/Aids patients on the counsellor (whether a male or female counsellor). In particular, this research study attempts to explore the psychological effects of the HIV/Aids counsellors working with HIV/Aids patients at the Neurological clinic in Kalafong hospital.

As has already been indicated above, research on the psychological impact of the HIV/Aids counsellor is scarce. According to Lippmann (cited in Hoffman, 1996), it is important to find out whether the psychological effects of working with HIV/Aids patients on the counsellor are transient or enduring. The researcher thus wanted to investigate whether persisting distress was a main feature of the narratives of the counsellors working with HIV/Aids patients. This study aims at exploring the narratives of participants, against the backdrop of their past and present lived experiences of working with HIV/Aids patients, in relation to their construction of

their social worlds. How has their working with HIV/Aids patients affected their social interactions at their homes, work, and with their peers, friends, as well as within their community?

For these and other reasons, a dissertation addressing the psychological experiences and effects unique to counsellors working with HIV/Aids patients is long overdue. This dissertation represents an attempt to fill this gap and might also be of interest to counsellors seeking a more in-depth understanding of how to prevent burnout and take care of themselves in the face of HIV/Aids morbidity and mortality. Burnout is the end product of intense, repressed emotional, physical and psychological experiences that accumulate over time (Hoffman, 1996). This concept becomes relevant as a forethought cautionary measure inherent to the counsellors' routine, exceptionally draining, work. The information gathered from this research study could be useful in helping counsellors take precautionary measures, to better supervise and support counsellors and thereby improve counselling services. The other purpose of this research study is to make a small contribution towards the empowerment of counsellors so that they can make a meaningful difference in the lives of others and plant a tree of hope and health.

The researcher's target audiences are volunteer counsellors who provide counselling services to HIV/Aids patients in the clinic and hospital settings. Since the phenomenon of the psychological impact of working with HIV/Aids patients on counsellors has received little research interest in South Africa, Chapter two include mostly international studies. The sustainability and psychological wellness of the

counsellors working with HIV/Aids patients seems to be somewhat neglected, particularly in African and South African research studies.

The process of inquiry informed by the narrative epistemology is discussed in Chapter three. Chapter four examines the central thematic analysis of the individual interviews and focus group discussions. At the end of this chapter a summary of the findings of the study is included in an effort to further elucidate these themes and the implications thereof. Chapter five includes the reflections on the themes and on the research process, with particular focus on the participants and researcher, as well as the discourses that are embedded within the narratives.

### 1.3 CONCLUSION

In summary, this dissertation's objective is to explore participants' narratives of their lives and to gain an understanding of the possible psychological effects and experiences of working with HIV/Aids patients, as well as to gain an understanding of any restorying that the research process might have prompted.

The following chapter contains a review of the literature on the psychological effects and experiences of working with HIV/Aids patients on counsellors, as well as on other health professionals.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### 2.1 INTRODUCTION

**Loss of a loved one or person one has established a relationship with has been acknowledged throughout history as one of the most profound life experiences...during protracted, life-threatening illness family members and counsellors accompany them on a journey through deterioration, multiple losses, and dying.**

**Hoffman, (1996, p. 179)**

There is a striking lack of literature on counsellors' experiences in working with HIV/Aids patients, especially in describing the psychological impact on counsellors. Most of the reading materials cited are reviews of quantitative and, to a much lesser extent, qualitative research, and the majority of the research studies or reviews was done outside South Africa. Most of the research studies used quantitative methodology, for example surveys, and scarcely follows up with qualitative in-depth interviews. Yet, large-scale research has been vital to establish the incidence, severity, stability, consequences, antecedents, gender differences et cetera, associated with HIV/Aids patients, but very little has been mentioned about counsellors' experiences and the effects of working with HIV/Aids patients.

As Ross & Altmaier (1994) have mention, the demographic incidences of HIV/Aids, reduction strategies, medical and neurocognitive aspects of the disease, unsafe sex and drug use, the patients' specific psychosocial concerns and appropriate intervention techniques have clearly received a wide attention. They also suggest that the research emphasis should now shift to investigating the therapeutic implications for counsellors, emotional reactions and coping, changes in life roles, death and dying, risk reduction and spirituality, as well as training and support needs of counsellors. Since most of the literature reviews used in this chapter are from abroad, most of the intervention strategies, ingrained views, typical goals and desired outcomes, counselling experiences and effects may or may not be applicable to South Africa.

The research presented here represents a conscious effort to provide a relatively comprehensive overview of the psychological effects and experiences of working with HIV/Aids patients on the counsellor.

## 2.2- THE IMPACT OF HIV/AIDS ON COUNSELLING

Counsellors are often forgotten when the psychological reactions of HIV/Aids considered. Frank and Frank (quoted in Hoffman, 1996) describe counselling as an interpersonal and intra-psychic process in which the development of the counsellor-patient relationship is central to the therapeutic impact. They explain that the interpersonal aspects of the relationship focus on the interplay between the counsellor and patient. For example, as patients with HIV/Aids becomes symptomatic, both the

patient and the counsellor may react in a number of ways, such as becoming more anxious, that might affect the boundaries or structure of the relationship. Tunnell (cited in Wicks, 1997) acknowledges that intra-psychic processes, which often reflect core personality dynamics, might also be expressed through transference and counter-transference.

Hoffman (1996) states that it is important to understand how HIV/Aids disease differs from other illnesses and the implications these differences have for counsellors. He elucidates that counselling a patient with HIV/Aids is unique both because of the characteristics of the disease as well as the psychological issues that accompany the disease process. According to Folkman, Friedman, Des Jarlais, and Sterk (cited in Hoffman, 1996), HIV/Aids characteristics, including the unpredictability of the disease, uncontrollability of the symptoms, and debilitating or disfiguring effects create stress for counsellors. By these standards of judging, HIV/Aids is one of the most stressful diseases. Counsellors of patients with HIV/Aids disease often find themselves going an extra mile in assisting with daily living activities such as shopping, running errands, and transportation to appointments (Stein & Steinberg, 1997).

Several psychological aspects of this disease create a unique situation for many counsellors (Ross & Seeger, 1988). These psychological aspects include the stigma associated with this disease, fear of contagion or becoming infected, the young age of most who are receiving care and of those providing care, and the fact that many counsellors themselves are infected with the same disease. These aspects associated

with HIV/Aids disease may also lead to depression, anger and isolation not only for the HIV-positive patient, but to the counsellors as well (Hoffman, 1996).

Young counsellors might also suffer from what Walsh & Bibace (1990) refer to as the “opportunity costs” of counselling - that means interference with establishing a career, developing deep and stable relationships, and entering the social and political life of the community. These costs represent disruptions in important developmental tasks in their lives, and on acceleration into adult life. Since they have already experienced multiple losses in their workplace, they might as well have to face spiritual and existential questions that their contemporaries may not face for decades (Harrison, Smit and Myer (2001). Hooper (2000) supports that it typically represents an “off-time” event in the lives of the young counsellors since it disrupts the natural flow and rhythm of the generations. In this study, the participants’ developmental stages ranged between late adolescent to middle adulthood.

These concerns were attributed to the counsellors' aversion and fears to the HIV/Aids disease, patients, and lifestyles. For example, they tend to over-identify with patients their own age and with similar life-styles, over-estimate the risk of HIV/Aids transmission through accidental needle sticks or may say that they would ask for a transfer if assigned to a heavy load of cases. Whiteside & Sunter (2000) note that this awareness might suggest a pervasive anxiety, rather than aversion, around the issues that are stimulated by this disease. They feel that counsellors often experience fear of the unknown, fear of contagion and fear of facing their own mortality.

### 2.3 COMMON THEMES IN THE COUNSELLING EXPERIENCE

Realizing that the researcher 's counselling experience of working with HIV/Aids patients at the neurological clinic at Kalafong and Natalspruit hospitals respectively often arouses almost similar compelling experiences and themes sparked the researcher's interest in this topic. The researcher began to realise how consciously and unconsciously he has constructed a narrative that was informed by his own experiences as a lay counsellor at Kalafong hospital. My personal experience at the hospital taught me that counselling patients with HIV/Aids disease is challenging and rewarding, but also often stressful, threatening and anxiety provoking. Dzuguda (2000) found that what is most fulfilling and rewarding for most counsellors is the achievement of behaviour change as the primary benefit of the job.

Several significant themes which run through the researcher' personal and his colleagues' experiences, as well as the literature consulted, (e.g. Hoffman, 1996; Van

Dyk, 2001; Wicks, 1997; Whiteside & Sunter, 2000), are as follows; (1) feelings of helplessness and ineffectiveness in the face of disease progression; (2) emotions associated with stigmatisation by others for doing this type of work, as well as one's own internalised homophobia and attitude towards patients with HIV/Aids disease; (3) fear of contagion; (4) coping with inadequate medical and social resources to assist patients with HIV/Aids disease; (5) profound feelings of grief and loss; (6) emotional reactions to repeated exposure to death and dying; and (7) feeling emotionally overwhelmed and isolated.

In addition to HIV/Aids counsellors' obligations in the counselling relationship (providing information, protecting confidentiality and being non-judgemental), Miller (1991) found that the counsellors felt pressure to provide this information and be good role models in their communities. Other additional stresses that are found common to counselling experience are related to external (economic and political) conditions, 'spillover' of HIV/Aids issues from their personal lives and providing counselling in their workplace (Ross & Altmaier, 1994). Socio-political and economic factors have an important bearing on the psychological well being of counsellors. The increasing levels of unemployment contribute to rob South African people of a sense of purpose and hope for the future; hence many of them resorted to volunteer their services in community-based organisations that offer HIV/Aids counselling services. Kalinski (quoted in Taylor-Brown & Garcia, 1995) acknowledges that deprived economic circumstances lead to other social ills including prostitution, child and sexual abuse and violence that make people (including counsellors) psychologically more vulnerable, increasing the cycle of helplessness and despair.

## 2.4 SPECIAL ISSUES OF HIV/AIDS PATIENTS

It seems necessary to discuss special issues for HIV/Aids patients since counsellors often feel overstretched and overwhelmed by their demands despite having no clear framework for the future. As stated by Visagie (1999) in his research study on working with HIV/Aids patients, he envisaged that counsellors working with HIV-infected people must first struggle to understand their involvement with people who they know will otherwise die. He mentioned that the social stigma of HIV/Aids and the complexity of the illness and associated regimes could further complicate the struggle to work from a truly psychological perspective. Counsellors must also titrate their own level of involvement, making therapeutic decisions that take into account the HIV/Aids patient's health and their own willingness to step beyond the boundaries of the counselling session. For instance, how much of an advocate will the counsellor be for HIV/Aids patients with medical staff, how flexible could the counsellor be in terms of rescheduling appointments, will the counsellor visit patients at the hospice or their homes, and will he or she attend memorial services or funerals when the patients die? All these difficult and overwhelming questions are expected to be resolved by the counsellors according to their own personal levels of comfort (Lie & Biswalo, 2000).

Counselling HIV/Aids patients, from the researcher's experience, often reflects the progression of the HIV illness, developing in stages that address concerns only relevant at that point of the disease. This might be traced to patients that regularly

come to the hospital to get both medical and psychological treatment, while it was difficult to keep track of those patients seldom show up and only when they have health or other complications. Lie & Biswalo (2000) highlights that counsellors must also constantly adjust their expectations to the fluctuating needs of the HIV/Aids patients-one week they might be too ill to attend, the next week they might feel strong and vigorous and then again become weak. It is also expected by HIV/Aids patients for counsellors to explore and understand their own reactions to these issues to prevent their counter-transference from interfering with treatment. Johnsons and Johnsons (cited in Wicks, 1997) emphasise that there must be a continuous learning process in which counsellors seek to understand the meaning of events in HIV/Aids patients' lives, evaluating the source of patients' behaviour while simultaneously being aware of their own counter-transference.

Stein & Steinberg (1997) reiterate that the psychological effects of the disease could not be understood without some knowledge of the HIV/Aids disease itself and an understanding of medical and societal reactions to the disease. As a counsellor, Hooper (2000) mentions, that one can only work with these issues through the process of working to understand the meaning each patient attributes to illness and treatment. This work is a dynamic process rooted in developing an understanding of the patient's character as well as understanding his/her personal and cultural history (Anderson, 2000; Wicks, 1997).

According to Potgieter, Roos, Preez (2001), supported that counsellors' work with HIV/Aids patients often overlaps in their personal affairs, and are expected to deal with the difficulties associated with their own future planning, employment concerns, decisions about pregnancy and child rearing, feelings of guilt and anger, fantasies of fleeing, fear of abandonment, and fear of intimacy in the context of potential loss. These issues must be understood as multiply determined, considering the patients' HIV/Aids illness and their personalities, as well as conflicts and concerns that preceded their diagnosis. How counsellors cope with the disease is a function of long-standing character styles (Visagie, 1999).

## 2.5 DEATH AND DYING

Death and dying, as reality and as metaphor, especially fear of suffering while dying, are topics of significance in the counselling of all terminally ill patients, and the psychological experience and impact inherent in the job to be carried over to the counsellors. Harrison et al (2001) propound that working closely with those preoccupied with death reminds people about their own vulnerability. They indicated that the counsellors' difficulty facing their own mortality could lead to denial and may cause the counsellor to be deaf to latent death content or might, conversely, result in them becoming overly sympathetic and intrusive with patients.

Van Dyk (1993) find that counsellors' own fears could be evoked as they become close to the HIV/Aids patients. He further stated that unresolved issues in the counsellor's life might also be stimulated by the intensity of this work, such as grief

over unresolved previous losses of significant others. Boyer and Hoffman (cited in Hoffman, 1996) have paralleled death and dying to the termination process in counselling. The termination process has been shown to be a significant predictor of counsellor's later feelings of anxiety and depression during the end phase of counselling - when the patient and counsellor are saying good-bye. Terminations also created more anxiety for counsellors when they perceived that the patient was sensitive to loss and was experiencing other losses of friends and family members. Stein & Steinberg (1997) acknowledge that the counsellors are experiencing, as they are working with terminally ill patients, both loss and the anticipation of loss, helplessness, anger and guilt as they provide care to these patients. They defined anticipatory grief as a psychological reaction to impending death frequently experienced by the person who is dying and by the partner, family and other carers. This could take place during any long debilitating illness of a terminal nature.

These research results highlighted by Van Dyk (1993) supports the view of Anderson (2000) that both counsellor and patient loss variables affect the termination process. He said that it is likely that these same types of counsellor and patient loss variables also affect terminal work with patients with HIV/Aids. Perry, Fishman, Jacobsberg, and Frances (cited in Hoffman, 1996) highlight that many counsellors have experienced multiple HIV/Aids related deaths among patients. They said that counsellors often struggle to cope with the experiences of loss; as HIV/Aids patients' health decline, the counsellors are expected to adapt their expectations, and when patients die counsellors must cope with their own grief. Kirkpatrick (1988) claimed that counsellors must not forget that the death of HIV/Aids patients are more often

than not intent upon mourning their own passing as they, indeed, are preparing to mourn others.

## 2.6 COUNSELLORS' PERSPECTIVES ON THE EXPERIENCE OF PROVIDING COUNSELLING

The researcher's own journey and interest in working with HIV/Aids patients, was when his close friend died of AIDS. His death has really touched him on a deep level and that the researcher, besides having to comply with his academic requirements, found it compelling to understand more about the experiences of working with HIV/Aids patients. Although his interest originated from this experience, the researcher was constantly exposed to getting the perspectives of others on their experiences of providing counselling to HIV/Aids patients. During several debriefing sessions the researcher had attended with other counsellors while at the Neurological clinic in Kalafong and Natalspruit hospitals, most of his colleagues expressed counselling work as rewarding and fulfilling, while others described it as difficult, mentally tiring, emotionally demanding and stressful because of the suffering, stigmatisation and incurable nature of the disease. They reported that counselling HIV/Aids patients provided considerable satisfaction in terms of providing comfort, support, education and helping significant others. Harrison et al (2001) find that the enormity of what HIV/Aids means in the life of the HIV/Aids patients is overwhelming that often the counsellors' struggles, losses, and grief are overlooked.

According to Van Dyk (1993), work with HIV/Aids patients created anxiety, interference with non-work activities, and frequent negative ruminations, such as worrying about the transmission of the disease. Loss of loved ones or patients one already built a rapport with are acknowledged by the researcher's personal experience as one of the most profound life experiences. Lie & Biswalo (2000) found that during the protracted life threatening illness family members, including the counsellor, accompany loved ones or patients on a journey through deterioration, multiple losses and dying.

Horstman and McKusick (cited in Hoffman, 1996) report that many counsellors frequently used forms of coping that could be viewed as negative, such as getting depressed (34%), crying (21%), and alcohol abuse (13%), as well as more positive forms of coping, such as seeking support and teaching others about HIV/Aids disease. They also concluded that counsellors' stress was a function of the proportion of the counsellors' work devotion to patients with HIV/Aids disease than the number of years working with this population. Ross and Seeger (cited in Hoffman, 1996) looked at levels of stress, rewards, and coping mechanisms in a sample of counsellors caring for patients with HIV/Aids. High stress and overwork was reported by the sample. They report that the greatest stressors in HIV/Aids counselling were the youth of the patients, neurological aspects of the disease, and dying patients. Baltimore (quoted in Lie & Biswalo, 2000) discovered that some characteristics of HIV/Aids counsellors might to a greater extent withstand the influence exerted by stress levels.

Harrison et al (2001) found that many patients with HIV/Aids and their counsellors were highly informed and motivated regarding treatment, which created high levels of

scrutiny of the care they offered. They said that it is likely that they cope with anxiety and uncertainty through educating themselves and seeking the best possible treatment. Thus, scrutinising might create challenges for counsellors, although it often reflects anxiety rather than a lack of confidence in the counsellors.

Stein and Steinberg (1997), from their research work of counsellors in Barangwanath hospital, in Soweto, were struck by how often counsellors reveal their aversion to this disease and the HIV/Aids patients. For example, they find that counsellors tend to overestimate the risk of HIV/Aids transmission through accidental needle sticks or may say that they would ask for a transfer if assigned too heavy workloads of cases with HIV/Aids patients. Perhaps what this finding or awareness suggests is a pervasive anxiety, rather than an aversion, around the issues that are stimulated by the disease. Dunkel and Hatfield (cited in Hoffman, 1996) note that counsellors might experience fear of the unknown, fear of contagion, fear of facing their own mortality and, at times, over-identification with patients with HIV/Aids. In addition, this level of emotional engagement with the HIV/Aids will stimulate many issues; such as feeling helpless at being unable to halt disease progression or losing a patient to whom one is attached. Murphy and Perry (cited in Hoffman, 1996) poignantly describe HIV/Aids counsellors as hidden grievers ” who have lived and died a little with each dying patient for whom they have cared” (p.454)

## 2.7 CONCEPTUALISATION OF BURNOUT

Since burnout is correlated with stress, and difficult to conceptualise, there is some evidence discovered by Land and Harangody (cited in Hoffman, 1996) that working with HIV/Aids patients causes it. The researcher has therefore found it essential to discuss the formation of burnout that is conceived through the constant exposure to a stressful work situation. This particularly occurs through the continuous engagement of counsellors with HIV/Aids patients that often leave them emotionally vulnerable. Researchers such as Miller (1991) and Stein & Steinberg (1997) reviewed that counsellors described many symptoms of work stress that could be closely linked to burnout, such as physical exhaustion, lingering somatic complaints, proneness to frustration and anger, marital and relationship problems, emotional numbness, and depression. Kaplan (1996) found that these symptoms could be exacerbated by the counsellors' concerns attributed in part to fears about HIV/Aids transmissions, treating the terminally ill, over-identification with patients' HIV/Aids related illnesses or that of their children's age with similar lifestyles, and concerns about being ostracised for working with this population.

Pine and Maslach (cited in van Dyk, 2001) define burnout as a syndrome of physical and emotional exhaustion, involving the development of a negative self-concept, negative job attitudes, and loss of concern and feelings for patients. They envisage that burnout among counsellors caring for HIV/Aids patients manifests itself in a wide variety of signs and symptoms, such as;

- loss of interest in and commitment to work and lack of job satisfaction
- failure to observe punctuality and neglect of duties
- feelings of inadequacy, helplessness and guilt
- a loss of confidence and diminished self-esteem
- a tendency to withdraw both from clients and from colleagues

- a loss of sensitivity in dealing with patients, referring to them in a dehumanised or purely impersonal way (which may include sick humour)
- avoidance of clients or limiting the time spent with them, that is, in the form of frequent and earlier than necessary referral of clients to other health care professionals
- indifference to the suffering of others, experiencing boredom with clients, and seeing all of them as being alike
- a loss of quality in performance of work, that is, they often work harder, but accomplish less
- irritability, tension, tearfulness, loss of concentration, sleeplessness, depression and feelings of distress
- chronic exhaustion, nightmares and physical weakness
- vulnerability to all kinds of illnesses and psychomotor symptoms
- deteriorating relationships with colleagues and friends, tensions and distress in personal life; difficulties in getting on with people
- an increased use of alcohol or drugs in order to cope at work or at home
- a decision to leave the job or profession as the only last option

Pearlman and Saakvitne (quoted in Dzuguda, 2000) argue that burnout might be permanent, but that it is modifiable when addressed actively. They further argue that burnout causes disconnection from one's usual experience of oneself, that is, it causes alienation from oneself, which might lead one into rethinking one's basic beliefs about identity and self-worth.

## 2.8 CONCLUSION

The researcher believes that a limitation of the existing research literature on the experiences and effects of counsellors working with HIV/Aids patients is the inadequate attention given to the well being of counsellors. It was also found that counsellors often experience many of the common issues as the HIV/Aids patients; such as stigmatisation by others, worry about transmission of the virus, physical and emotional exhaustion, a sense of helplessness and loss, feeling overwhelmed and feeling isolated. The question as to whether these psychological effects are transient or enduring has also not received enough research attention, particularly in Africa and South Africa.

Counselling patients dying from HIV/Aids demands a great deal from a counsellor. In most times, such counselling involves young counsellors in the prime of their life. Each counselling process is different and the counsellor's role varies according to the needs and demands of each counselling scenario. Despite this, the needs of counsellors have typically not been examined through research or addressed through relevant education, supervisions or counselling interventions.

There is no doubt that HIV/Aids disease, if no effective treatment or cure is found, will continue to ravage and affect many hundreds of thousands of people every year. These HIV/Aids patients will continue to desperately require the services of counsellors who are well prepared to help them, and, in turn, to help themselves (Dzuguda, 2000). The following chapter deals with the research methodology that

describes the narrative journey between the researcher and participants about their stories and experiences of working with HIV/Aids patients.

## **CHAPTER 3**

### **THE PROCESS OF ENQUIRY**

#### **3.1 INTRODUCTION**

This chapter locates the process of enquiry within a narrative epistemology, which seeks to describe the journey in which the participants and the researcher encountered each other and conversed together their stories and experiences of working with HIV/Aids patients. Many researchers have welcomed this narrative approach as a way through which people make sense of their lived experiences. Anderson and Goolishian (1988) propound that the researcher would have achieved his primary aim by facilitating in participants to co-create new narratives that would eventually dissolve their problems and in which the researcher becomes the manager of these conversations. Gergen (1994) mentions that narratives help in demystifying and simplifying life problems. He proceeded that narratives organise affect, and create identity and social connection.

White and Epston (1990) emphasize that people are rich in lived experiences, which could be used to establish a rich and fertile soil for the generation or re-generation of alternative stories. They mentioned that in trying to make sense of life, people organise their own experiences of events in sequence across time in an effort to have a better understanding of themselves and the world around them. They paid particular attention to how people organise their lives around specific meanings and how in so

doing they inadvertently contribute to their survival. The researcher thus assumed that the participants would be able to make a sense of meaning and continuity in their lives by telling their stories and experiences.

The participants will be anonymously introduced, and then the context of the interviews and the process of inquiry will be presented, followed by a discussion on the narrative analysis that occurred during and after the collection of data.

### 3.2 PARADIGM OF THE RESEARCHER

This research study used the qualitative method as a research approach. Qualitative approach focuses on description, interpretation, concepts, definitions and characteristics unlike quantitative approach, which is concerned of numbers and measurements (Kvale, 1996). The qualitative, interpretative paradigm was adopted for this study for several reasons. This approach is sensitive to context, and will therefore allow the researcher to retain some contextual reality with regard to the research area. This approach is deemed necessary in this study because of the limited research based on qualitative methodology, that is, much of the research done is based on a quantitative paradigm. Each individual participant has a unique background and history, which will ultimately have some bearing on individual's interpretations of needs (Neuman, 1997). Also, Guba and Lincoln (cited in Silverman, 2001) advocate the adoption of this paradigm, as it takes into account, the social experiences and individual needs.

The epistemology that directs this research falls within a narrative framework. Smith (1995) point out that in order for Psychology to be able to conceive itself as truly committed to a narrative paradigm, it needs to find new methods which are more appropriate to the questions it now wants to ask and to the settings in which it wants to ask them. A narrative approach as the chosen paradigm in terms of its broad propositions informs the way the researcher views the social world during this time in which the psychological well-being of the counsellors receive little or no attention at all. The implications of this for the chosen research methodology-or, rather, the process of inquiry- are reflected in three areas, being the nature of reality, the self, and the nature of knowledge.

Given that “reality” is socially constructed, in interaction with others; that the “self” is a multiplicity of forms of human relatedness rather than a single entity; and that knowledge is a process of social collaboration found within interpretive traditions, it seems that the focus now shifts away from objective facts to language and interpretations (Gergen, 1994). Hermans (1992) explains the multifaceted view of the self in that it is based on the notion that people told each other stories and listened to stories in all cultures at all times. In so doing people arrived at an understanding and ordering of the world and the self. He pointed out that the self has the ability to move from one position to the other in accordance with changes in the situation and over time. Rowan (cited in Hermans, 1992) explains that there is a growing recognition of the multifaceted, dynamic and narrative nature of reality and self, which also suggest that alternative stories and positions could provide more extensive information about the self, with its narrative and dialogical character. This approach promises to open up worlds that were previously closed by cultural limitations.

The present interest in stories, or narratives about people's lives reflects the move to narrative knowledge away from notions of objective reality. This move could as well extend from the individual subject to the linguistic construction of reality, not as spoken by unique selves, but rather language structures speaking through persons. Narrative is a form that provides a sense of "lived time" (Bruner, 1990, p.12). People gain a sense of coherence and continuity in their lives by means of retelling their experiences, which means that they connect past, present and predicted future experiences in developing their accounts of their lives (White & Epston, 1990).

Knowledge often occurs from the conversations (narrative, language) that take place between people (inter-relational) in a context of gathering information for a certain purpose. Silverman (2001), in exploring his vision of the qualitative research, proposes an interview as the "construction site of knowledge"(p. 42). The interview context is an interpersonal one, and thus influences the meanings of the interviews statements. Finally, the interwoven, interrelated nature of knowledge is acknowledged: "Knowledge is neither inside a person nor outside in the world, but exists in the relationship between person and world" (Rosenwald & Ochberg, 1992, p.5).

### 3.3 OBJECTIVES OF THE RESEARCH

The objective of this study is to find out how counselling HIV/Aids patients affect counsellors psychologically in their personal and professional lives and how they cope with this. The intent of this research is to obtain a holistic picture of the subject

of study with emphasis on portraying the everyday experiences of individuals by observing and interviewing them (Frankel & Wallen, 1990).

This research is a narrative study. The aim is twofold: firstly, to explore the narratives of the participants, and secondly, to reflect on the research process and its impact on participants as well as the researcher. The narrative exploration seeks to describe the narrative construction of the participants' lives at the time of the interviews with regard to their past and present working experiences with HIV/Aids patients. This study is about listening to the participants' narratives regarding their experiences, with particular focus on the psychological impact of working with HIV/Aids patients. How does their construction of their experiences inform their relationships with others? Are they silent about their experiences, and if so, what is the effect of this silence? What are the subtle manifestations of persisting distress outside of clinical syndromes such as depression and anxiety? The persisting distress outside clinical syndrome and its subtle manifestations is discussed in chapter four and five.

The reflection on the research process stems from the view that no research is neutral, as stated by Thayser (2001), and is an attempt to understand what impact the interviewing process has had on the lives of the participants and the researcher. What transformation process has been initiated in the lives of the participants and the researcher? The researcher hopes that this research will in some way be of benefit to participants by providing a means for self-reflection and an opportunity to retell their narratives. This is what White (1998) terms "the retellings of definitional ceremony" in which people's preferred claims about their lives and their identities are authenticated, and have the effect of pushing forward the themes that arise, that is,

they contribute to options for action in people's lives that would not otherwise be available to them. He also mentions that definitional ceremony is "moving" all participants in a way that it contributes to options for them to become other than who they were. This is about being moved in the sense of being transported, in other words in the sense of being changed or being elsewhere in life on account of this participation in the research process.

### 3.4 THE PROCESS OF INQUIRY

The process of inquiry and representation, which involved finding the participants, gathering data through interviews and focus group meetings, the recording of the data, the analysis thereof, and the reflections are all covered in this section.

#### 3.4.1 The Role of the Researcher

The researcher will draw on his first-hand experiences with the setting, informants, and documents or texts to interpret the data. The researcher's contribution to the setting can be useful and positive. His reflections and perceptions on the research study would obviously be shaped by his personal experiences. The researcher will be fully involved, and cannot ask for openness from the participants without being open and sincere himself. Empathy, sensitivity, humour and sincerity are necessary qualities of the researcher in qualitative interviewing (Rubin & Rubin, 1995).

According to Anderson and Goolishian (1988), the researcher has to play a particular role in order to facilitate a conversation or dialogue. They explained that the role of the researcher should be to create a space that maximizes the opportunity for dialogical communication between self and self, and between self and others. Penn (1991) argues that in the space provided, a person must perceive himself/herself as being heard, and in finding his/her own voice, discovering that he/she has been living his/her life less by his/her own experiences than according to other people's description of his/her experiences. The space referred here is that of reflection and introspection. In being heard, the person finds validation in a new story to replace the invalidation of his or her experiences that other people's description of him or her implied.

As a participant observer, as mentioned by Real (quoted in Anderson & Goolishian, 1988), the researcher is in the same egalitarian and non-hierarchical position as the other members of, co-operating, and attempting to understand and to work within other counsellors' meaning systems. His other position is that of collaboration, and is one of mutuality, modesty and respect for and about people and their ideas. The participants' ideas, stories and narratives are the only tool to keep the researcher and the participants open and flexible to the development of meaning and understanding.

Real (quoted in Anderson & Goolishian, 1988) conceptualises the researcher's role as that of multiple engagement, which stresses both the facilitative and participatory role of the researcher in the process of change through conversations. This role requires

creating a space for and facilitating a conversation such that it remains in the domain of dialogue. In such a process, the opportunity for communication regarding problems is maximized, new descriptions arise, new meanings are generated and therefore, new social organisation will occur around the different narratives.

White and Epston (1990) highlight that therapists are most likely to find themselves listening to stories that their clients tell and trying to discern the central underlying story that reflects the client's life. They refer to this as dealing in one way or the other with either autobiography or a biography. The therapist might see himself collecting life narratives, autobiographical accounts told in the person's own words. This could be an effective tool that enables people to understand their lives and make meaning out of them. The researcher believes that it could also be keeping a record or document about one's life, which could be kept across time.

#### 3.4.2 Setting the Scene

The initial baseline responsibility for the researcher was to obtain an informed consent from the prospective research participants and relevant authorities at Neurological clinic in Kalafong hospital. An appropriate consultation was done in which the Departmental head of Psychology at Vista University had written a formal letter to the clinic's management as an accepted ethical standard protocol that has to be observed in every conduct of research. The researcher then obtained an approval from the clinic's legally authorised person prior to conducting research and proper explanation was provided to obtain the participants' consent.

All the discussions and interviews were conducted during September and October 2003. Since the researcher was doing his internship far away from the research setting he had to take two weeks leave and make time, as well as making special arrangements with participants during the weekends to keep the research process moving forward. The interviews with the participants were tape-recorded and were conducted predominantly with a mixture of Northern and Southern Sotho languages. These languages were used most often in the conversations entered into because the participants and the researcher find them easier and comfortable to relate their stories. This approach, that the researcher could pay attention to the symbols and metaphors with which people describe their worlds only if he/she has an understanding of the language that the participants use, was encouraged by Schurtz (1967). Although only themes were extracted from the recorded discussions, it was a difficult and absorbing task taking into cognisance that English is not the researcher's first language.

The focus group lasted from 90-120 minutes, whereas individual interviews ranged from thirty minutes to one hour. Some incentives involved in an attempt to encourage participants to avail themselves to the interviews and discussions conducted, or otherwise they might either have chosen not to be present or find the interviews insignificant for them to attend, perhaps because the previous researchers had already spoiled them. The number of individual interviews conducted for each participant was at once, and focus group discussions took place four times.

3.4.3 Finding the Participants

“Samples” are traditionally selected from target populations. “Individual subjects”, assumed to be representative of and capable of speaking reliably and validly for the larger population, are selected from the target population (Holstein & Gubrium, 1995). The requirements for participation in this research study were voluntary, and simply that the individual should be working with HIV/Aids patients as a counsellor at Neurological clinic at Kalafong hospital, irrespective of their age, gender, experience, qualification, language, culture, religion, marital status, or any other basis. These counsellors were expected by the clinic management to function on the following levels:

- individual counselling and case work that takes place daily with individual adults and children.
- couple, family and group counselling that occurs on certain days in which patients are provided with an opportunity to share core issues, problems or experiences.
- community development projects that seek to extend a hand of healing around certain issues into the wider community.

In qualitative research, Willis (cited in Holstein & Gubrium, 1995) argues that the selection of interview participants represents an orientation to people as much as it is the sampling of a population. He indicates that in selecting few individuals as opposed to large representatives of populations, suggest that individuals, in principle, are equally worthy despite individual differences and therefore have worthwhile stories to narrate.

Counsellors recruited to participate in this research project were as follows; one professional counsellor (counselling psychologist) and three trained volunteer counsellors. All were women, the former was in her middle forties and the latter were in their twenties and early thirties. There were still other counsellors who choose not to participate in the study. They are currently working with HIV/Aids patients at the Neurological Clinic on the campus of a Kalafong public hospital, in the vicinity of the previously disadvantaged Black township of Attridgeville, near Pretoria, the capital city of South Africa. The professional counsellor is employed full-time and acts as a supervisor to volunteer counsellors, who all receive once per month group supervisions from an external supervisor. Their group supervision meetings included case discussions and difficulties encountered in their work with HIV/Aids patients.

Finding the participants for this research was carried out with a different strategy in mind, that is, to make a commitment of giving them some incentives in the form of buying them “lunch boxes” every time we meet in a focus group and a “can of cool drink” during individual interviews. It was indeed a very expensive exercise undertaken. This was necessary because of the precedence that was set by the researchers in the past, fortunately happened during my presence (the researcher) as a lay counsellor, who offered incentives to prospective participants that served as a prerequisite for participation in their research work.

Participants were requested to identify venues where our meetings would normally take place, particularly those that will be more convenient for them, with less distractions. Preference for choosing venues was awarded to them in an attempt to reduce the travelling expenses, which meant, the researcher would normally go to

them, of course, per appointments. Participants were then undertaken on a journey, first through individual interviews and then group discussions, asked questions that would lead them to tell their own experiences and stories of their lived world. They reported seeing between five to eight patients per day. Among the participants, two had a relative who had died of HIV/Aids related diseases, and indicated that they had been unable to discuss HIV/Aids topics with their family members because of the intense suffering that has already tormented them.

Fortunately, the participants had started to show their eagerness to talk about their concerns from the beginning of the research process, as Holstein and Gubrium (1995) mentions that, the participants must be willing to talk and to widely represent the range of points of views of others not selected in the research process. All of them participated in the individual interviews and then followed by focus group discussions, which took place two to three times a week and sometimes even on weekends but this only happened on arrangement basis, especially in the case where it was not possible to meet due to unforeseen circumstances.

The focus group and interviews were unstructured with open questions, and elaboration on brief responses or vague expressions was encouraged. The research participants have chosen to remain anonymous. All of them were female counsellors, as stated earlier, who spontaneously expressed their concern about the sexual behaviours of their partners and often felt unable to discuss HIV/Aids issues with them. They said that they needed confidential support to help them cope and deal with their personal sexual life, as well as the anxieties created by the job itself. They somehow felt convinced that their participation in the research process might help

them express their agitated feelings and thus facilitate in understanding themselves better. Penn (1991) contends that the research participants could be transformed by their journeys, not only by acquiring new knowledge but also potentially by the process of self-reflection that such journeys could initiate in them.

#### 3.4.4 Conversations with Participants - Narratives as Data

The data gathering part of the process of inquiry involved two phases, namely, the first phase consisted of unstructured interviews with individual participants and followed by a focus group in which all participants took part (second phase). The phased approach was intended to create an opportunity to fulfil the aims of exploring the narratives of participants and providing a space for reflections upon the process (Silverman, 2001). The researcher's view of the conversations as based on language and its implications is an important factor in this study. The narrative framework of discourse as formative informs it, defining frameworks, shaping the way we understand our world (Becvar & Becvar, 2000). Apart from the fact that my view has resulted from ongoing conversations, it has led the researcher to wonder about the discourses that go through them, and a brief review of some of these discourse in which participants stories are embedded is undertaken in chapter five.

The researcher, also as a facilitator and a participant, was fully involved, and therefore it became difficult, if not impossible for him, to observe the interactionist rule of being neutral. However, Penn (1991), states that neutrality in qualitative research is probably not a legitimate way of achieving the researcher's goal. In other words, the researcher cannot ask for openness from the participants without being open, free and

sincere himself. The researcher believes that the narratives as told by him or to him by the participants served as a window through which he sees himself, as White (1995) sees the interaction between the researcher and participants as having a reciprocal influence on one another. He argues that this story retelling can initiate a reverse process whereby a person could rescue himself or herself in the understanding of his roles and provide a platform of healing that was previously construed as formal self-misunderstanding and self mis-representation. Through these tellings and retellings, many alternative themes or counter-plots of people's lives are thickened, and the stories of people's lives become linked through these themes, and through the values, purposes, and commitments expressed in them.

Another use of the interview followed up by the group discussion in the narrative framework is described by Bruner (1990). This author describes his life story research with a family. He said that the family members were interviewed independently and individually, and then, a year later, were brought together in a discussion session. In the course of the elapsed year, Bruner's preliminary analyses of the family members' individual autobiographies produced a dominant theme, common to all members, which was then discussed at the joint meeting.

#### 3.4.4.1 **First Phase: *Unstructured Individual Interviews***

The unstructured interviews used during the individual interview phase were based on open-ended questions, and elaboration on expressions made was encouraged. With an unstructured format, Rubin and Rubin (1995) indicate that the researcher suggests the subject for discussion and has few specific questions in mind, but process will direct

itself as it unfolds. This method was used because it gave both the researcher and the participants much more flexibility, that is, the researcher was able to follow up particularly interesting avenues that emerged in the interviews and at the same time the participants were able to give a full picture of their experiences (Smith, 1995). If there were issues that were important to the participants that the researcher had overlooked or not thought about, then the participants would just openly, without any restrictions, go ahead to talk about them, while on the other hand would provide the researcher with the opportunity to explore more on some common issues of interest.

This permissive listening attitude showed by the researcher enabled the participants to speak freely and openly, and to talk as much as they could about their important issues and experiences in as far as their lives in relation to their work situation was concerned. Bruner (1986) acknowledges that by patient waiting, the researcher permits the participant to take the lead in saying what she desires to express and simultaneously be responsive to every mood, feeling or attitude expressed. The researcher would thereafter make efforts to follow up on issues that indicated negative or agitated feelings from what the participants had expressed. This corresponds to what Holstein and Gubrium (1995) have stipulated, that an interview is a naturally occurring occasion for articulating one's personal experiences. They maintain that it is a useful mode of systemic social enquiry because of its ability to incite the production of meanings that address issues relating to particular research concerns. Pool (cited in Holstein & Gubrium, 1995) supports that the participants' stock of knowledge could shift around in the course of the interview in relation to the role taken by the expected responses. He explained that rather than searching for the relevant, best and the most

authentic point, the aim is to systematically activate different ways of knowing, even if the participants reveal diverse and contradictory information.

Geertz (1973) further states that qualitative interviewing requires listening carefully enough to hear the meta-communications, that is, meanings behind the meanings, interpretations and understandings that give shape to the world of the participants.

The depth, detail and richness we seek in interviews are what Rubin and Rubin (1995) refers to as thick description that is rooted in the participants' first-hand experiences.

These descriptions form the material that the researcher gathers up, synthesize and analyse as part of hearing the meaning of data. Bruner (1986) reiterates that talking about problems, painful experiences or unresolved emotions could be very hard and demanding.

#### 3.4.4.2 **Second Phase: *The Focus Group***

The individual interviews and the group discussions were alternating in days and weeks in-between depending on the availability of the participants. There were some days and weeks which passed the researcher not being able to meet the participants, perhaps because either of work or personal commitments. The researcher believed that this variety provided him, as well as the participants, with the opportunity to plan ahead and space for self-reflection. The focus group was chosen in preference to a support group because it would provide an opportunity for the participants to share their experiences and thoughts while maintaining their own identity as individuals who are undergoing a common ordeal. Roberts (cited in Penn, 1991) acknowledges that joining together as professional helpers speaking the same language and sharing

common experiences could provide a context for change. He views professional helpers as tourists travelling on a journey, with patients as helpers.

Focus groups, according to Rubin and Rubin (1995), are increasingly used to bring people together who have experienced similar situations and problems, and are aimed at creating the opportunity for the emergence of new dimensions and nuances previously unconsidered by the individuals. They also maintain that focus groups create a professional environment where the participants are the experts of their situations, and the researcher moderates, or facilitates the conversations. Greenbaum (1998) acknowledges further that the homogeneity of participants contributes towards a greater degree of compatibility and a higher quality of discussions.

Throughout the focus group discussions, the researcher had a number of general questions and topics to cover, which the researcher had prepared beforehand, but the precise order was not fixed and was allowed to develop as a result of the exchange with the participants. For instance, there were questions such 'Does anyone care about the enormous implications for the health and psychological well-being of counsellors, and the sustainable delivery of counselling services'? 'What does counselling offer that other forms of care support are not offering? The discussions also had an advantage of allowing both the researcher and participants to explore the meanings of questions and responses, and misunderstandings were clarified and rectified. The researcher would ask deliberately open questions to the group as a whole so as to encourage the participants to share their stories and experiences with one another. An example of a question asked was as follows; 'How does the experiences of terminally ill or dying HIV/Aids patients affect counsellors? Neuman (1997) acknowledges that

group discussions provide an opportunity for the researcher to observe social interactions and dialogue.

### 3.5 DATA COLLECTION

Data collection, according to Rubin and Rubin (1995), attends to capturing the discursive interactional meaning-making process with which qualitative interviewing is concerned. They pointed out that the interview is conceptualised as recording for future analysis in the related interactional details of how the interview was accomplished. Chase (cited in Holstein & Gubrium, 1995) indicates that the researcher's questions incite responses that reveal the meaning-making process in relation to research objectives. He asserts that qualitative researchers agree that the questions we ask make a difference to the quality of the information we collect. The qualitative interview is more of a conversational agenda than a procedural directive, and questions should be phrased in everyday language with intent to ask participants' about their own experiences, thoughts, and feelings in order to gather data thick enough to shed light on life's problems.

The narratives that transpired during individual interviewing and the focus group meetings were tape-recorded. Permission to do so was sought, and given by all the participants, none of whom expressed any concern about being recorded. With and without the actual recordings, the researcher also recorded notes of the circumstances surrounding the interviews and discussions, to provide details of the contents to which the conversations might have been addressed (Holstein & Gubrium, 1995).

Rubin and Rubin (1995) point out that there are some variations in the degree to which the researcher directs the conversational agenda. In collecting data, with an unstructured format, the above-mentioned researchers suggest the subject for discussion but have few but specific questions in mind. They introduce the topic and guide the discussion by asking open-ended questions specific on the particular theme. All the above-mentioned techniques and strategies were used in this research study.

### 3.6 NARRATIVE ANALYSIS

The central themes that were covered in the individual interviews and focus group discussions were extracted from the wealth of narratives tape-recorded and notes taken. These themes were then discussed with reference to the literature review that had been studied before the interviews and discussions. Holstein and Gubrium (1995) acknowledged that analysing narratives in qualitative research is scientific and somewhat more artful than conventional. This does not suggest that analysis is rigorous, but that narratives require more attention and sensitivity to both the process and substance. They explain that a method that is commonly used in the analysis of data from both in-depth interviews and group discussions is called a content analysis method, which involves summarising and classifying data within a thematic framework. This framework provides a structure in the interpretation of qualitative research data so that it is based around emerging themes and concepts.

Once the researcher had identified particular phenomena in the data, explained Punch (1998), he or she would then group his or her concepts (perceptions or experiences) around them. This done to reduce the massive volume of information with which the

researcher has to work. The process of grouping these concepts that seem to pertain to the same phenomena is called categorising. Categories have conceptual power because they are able to pull together around them other groups of concepts or subcategories. Lieblich (1998) points out that it is not a simple matter to find the balance between too many categories and a few broad categories. Many categories result in rich variation, but the subtleties require careful sorting. Few categories may be easier to use but perhaps will not do justice to the complexity of the narratives. However, the themes that emerged from the stories told on various mediums of instructions relate to the subtle aspects of social interactions. These guidelines were followed in this research study.

Qualitative interview data are analysed to show the dynamic interrelatedness of what and hows. The participants' responses are considered in a way that they assemble aspects of reality and collaboration with the researcher. Data will often come with storied characteristics, as in unstructured interviews, where the participants gave narrative responses to the researcher's questions. Silverman (2001) envisages that narrative analysis gives a uniquely rich and subtle understanding of life situations and the story often is a feasible way of collecting data just because it is such a common device in everyday interaction. In this respect, narrative analysis overlaps with discourse analysis, in that it involves all forms of communication, including talk and conversation in response to the social world in everyday practices.

### 3.7 ETHICS

Ethical issues in research in general relate to the consequences of the research, the obtaining of informed consent, the protection of confidentiality of the participants, and the effects of both the participants' and researcher's role in the research study (Silverman, 2001).

The consequences of the research relate to the question as to whether the research will enhance knowledge and awareness around the topic, and the impact the study will have on the efficiency and performance of both the participants and researcher in their future work with HIV/Aids patients. The participants were informed about the nature and motive of the research study. They were informed that they are free to participate or to decline to participate or withdraw from the research. They were also informed of the potential consequences that might be expected to influence their willingness to participate (such as risks, discomfort, adverse effects, or limitations on confidentiality).

It was the latter that gave rise to concern, in that the opportunity was created for the participants to freely and openly talk about their overwhelming negative emotions that could trigger past, forgotten painful and stressful experiences, and this process would ensure addressing depressed feelings in a safe environment. In addition, the professional counsellor agreed to make therapeutic support available for any participant who might seem to be negatively affected. At the conclusion of the focus group discussions, an offer was made to continue with the meetings in the future as

they have declared them helpful and as a significant source of clarifications, insights and emotional support.

Each participant was a willing volunteer, and consented to be involved in both the interview and the focus group. Informed consent to conduct the study was obtained from the legally authorised person at the Neurological clinic in Kalafong hospital and from the participants involved. The researcher had used the languages that were reasonably understandable to research participants. Prior agreement was reached with the legally authorised person and prospective participants that the researcher would take the responsibility to highlight recommendations arising from the research process. Incentives were offered voluntarily by the researcher as his strategy to attract participation in the research project, and also a sign of appreciation and acknowledgement for participants' valued and valuable contributions. The participants have chosen to remain anonymous and that principle was by all means respected throughout the research process.

### 3.8 CONCLUSION

This chapter sets out the procedures followed in the process of enquiry in the research process. The selected participants, who contributed a great deal to this research, are anonymously mentioned in the next chapter, which deals with the results of the study. Individual interviews and focus group discussions are the two main data-gathering methods in qualitative research that were used. The next chapter will focus on discussions of the themes that emerged during the individual interviews and focus group discussions

## **CHAPTER 4**

### **THEMES FROM THE INDIVIDUAL INTERVIEWS AND FOCUS GROUP DISCUSSIONS**

#### **4.1 INTRODUCTION**

This chapter describes the central themes that emerged from the experiences and stories narrated by the participants and the researcher himself on working with HIV/Aids patients. In the discussion of the central themes, there is a high probability that the dynamics and uniqueness of each participant's telling of stories might be lost or missed, but some hints would be sparingly mentioned to provide a clearer picture of the participants' feelings during the course of the individual interviews and focus group discussions.

The themes that emerged from the narratives were identified through familiarisation with transcripts. The researcher sees all the themes as interconnected and will attempt to provide some insight into each topic by converting them into themes and describing them in this chapter. It must also be noted that most of the themes covered during the individual interviews and focus group discussions were identified in the literature review (in chapter two) prior to the interactions with the participants. The researcher at a later stage, discovered that some of the participants' narratives were found to be similar to some of the ideas already discussed in the literature review. The integration between the participants' narratives and aspects of the literature will be illustrated in the next chapter.

The researcher was concerned about losing the uniqueness of each participant's story in the interviews and discussions, but nonetheless tried very hard to extract some of the participants' accounts for verbatim quotations in an attempt to display the range of views, attitudes or behaviours described by the participants. Although the participants had many common experiences, their constructions of working with HIV/Aids patients and its effects were different. The researcher also experienced each participant as being quite different from the others. For the sake of protecting the participants' identities, their names will not be revealed, that is, they will be referred to as follows; "one" or "other" or "another" or "some participants", or some indication will be provided in brackets, for example, "volunteer" or "professional counsellor".

## 4.2 CENTRAL THEMES FROM THE INDIVIDUAL INTERVIEWS

### 4.2.1 Experiences of being an HIV/Aids counsellor

One of the most important themes that frequently emerged from the individual interviews was 'experiences of being an HIV/Aids counsellor' at the HIV/Aids clinic in Kalafong hospital. The participants seemed to have attached different meanings to their designation of being HIV/Aids counsellors. What they mentioned about being a counsellor was that apart from being remunerated, meeting new people everyday and gaining new experiences, they were able to help people solve their own problems. Some participants said it was interesting to watch some of them (both counsellors and HIV/Aids patients) changing for the better. Other participants indicated that to be an HIV/Aids counsellor was a privilege and a responsibility that should not be taken

lightly because it could mean life or death to a deeply depressed HIV/Aids patient who had just received the HIV-positive results.

Being a counsellor, there are things that are fulfilling and motivating, and those that are limiting, discouraging and demoralising. Participants spoke of patients' behaviour change as the primary reward of their job. They saw it as their role to facilitate behaviour change. They found it very discouraging when patients did not reduce their risk behaviours, and this was sometimes even seen as their work failures as counsellors. This could also mean that participants tend to take responsibility for their patients' behaviours and this places a lot of pressure on themselves as counsellors.

One counsellor said:

I like it most when I talk to and plan with the patient. And then the patient comes back and says 'OK'. I have brought my partner. And then you are talking to the partner. Or when he comes again and then he says 'My partner {and I} now have changed'. I like it when there is change and when he reduces the risk.

As far as HIV/Aids is concerned, said the other participant, when I'm able to help somebody calm down over the trauma of knowing that they are HIV-positive and have them accept the situation and to live positively, I feel good. But it can also be sad; when you tell somebody they are HIV-positive. You tell them how to live with it in order to avoid re-infections. It really puts one to the state of weakness when they come back, saying that they have not done anything about it, and for that matter, they have not even used one condom since then.

Another participant said that some of her patients, after going through their first counselling session, “would not come to the next session”. She commented:

Then, the message will be continually coming across one’s head that the patient is still not using the condoms, he is still having unprotected sex. You feel down. I feel down in my heart that I have done almost zero work.

The professional counsellor then mentioned:

I like being a counsellor because I can give service to people. When patients appreciate it, it is sort of motivating to me. If somebody appreciates what you do, then it really raises your morale”.

One counsellor said:

Being a counsellor has helped me to understand myself better. And then, apart from that, it has also helped me in how to relate with my spouse, because now I find it easier to discuss HIV/Aids issues with him. I have become freer in talking about sex, even to my children. But now since I’ve started counselling, I think they have a choice between abstaining from sex or have sex using the safety measures.

#### 4.2.2 Manifestations of Distress

The researcher found it appropriate to ask participants more about the psychological effects of working with HIV/Aids patients, since one participant was seen taking antidepressants during one of the individual interviews. It was accidentally discovered that she was suffering from depression since she started working as a counsellor, and in fact was in the grip of a depressive episode when we first met. However, she

indicated that she had been using the medication for two years now and was afraid that she might become addicted since she could no longer survive without taking it. She was using the medication called ‘Cipramil’, antidepressants. Other participants mentioned having feelings of depression, stress, suicide ideation, eating disorders and anxiety ever since they had started working with HIV/Aids patients.

One participant reported that she might have probably inherited her depression from her father or mother, since both of them had experienced depression, but did not exclude the fact that her job circumstances might have contributed largely to her current condition. Another participant related that she had experienced a ‘slight depression or something like stress’ some time ago after she woke up in the morning. She commented:

I really felt tired because I had numerous sleep disturbances at night. I didn’t want to get out of bed, I didn’t want to see anybody, I didn’t want to eat breakfast, and I really had no motivation at all to go to work.

There were two participants who acknowledged the fact that they often feel isolated and overwhelmed by feelings of isolation and aloneness, accompanied with a sense of worthlessness and emotional numbness. Another participant raised a concern of experiencing a regular loss of appetite, insomnia, fatigue and suicide ideation. The researcher observed that the isolation and loneliness inferred or overtly stated by the participants were still experienced in their lives in spite of the family support, intimate relationships and friends at their disposal.

One participant said that after she had received news that her father had died of a heart attack, she was terribly distressed even though she never knew him in her life. She started experiencing a loss of appetite, recurring headaches and did not sleep well for a couple of days as a result. She realised later, after having discussed the matter with the supervisor, that her environmental stress levels were undoubtedly substantial, that is, it was difficult to separate clearly her current stress from her long-standing personality problems and a long-term difficult work situation. She said that the supervisor did explain to her that the more stress one experiences, the more likely one is to break down either physically or psychologically, especially in the type of work they are doing where they have to carry other people's problems with them on daily basis.

#### 4.2.3 Counter-transference

There seems to be no other counselling issue that the researcher could think of other than working with HIV/Aids patients that requires so much from the counsellors in so many ways. Professional counsellor acknowledged that there are enormous demands that are constantly placed on one's energies as well as on one's professional skills and resources, possibly resulting in feeling overwhelmed that often leads to unmanaged counter-transference. She mentioned that the counsellors' inability to divorce personal values from the counselling process were perhaps the counsellors' greatest limitation.

She further indicated that counsellors were aware of the importance of being neutral and listening to patients' stories without prejudice and said repeatedly that their job was not to judge patients, but to express empathy and exercise unconditional positive

regard. She provided a testimony that there were instances where the counsellors would ask the patients “How many sexual partners have you slept with in your life”? They would unconsciously experience emotional reactions to ways of living that were familiar or unfamiliar or that seemed unacceptable or negative. Many of them, she said, had reported that they had difficulty working with patients who continued to engage in risky behaviours and this could also indicate taking responsibility for the patients’ behaviours.

Although there is no evidence that participants used evaluating language in the counselling sessions, their language in the individual interviews reflected negative judgements of patients’ behaviours. Sexual risk behaviour was described by one of the participants with statements such as “the lack of morals in society that put people at risk, bad behaviours are what generally resulting in people getting infected or patients having loose sexual lives”. Another participant described HIV/Aids patients as “unfaithful, going astray, having indiscriminate sex, behaving so terrible and intentionally spreading the disease to others because they do not want to die alone”. There also seemed to be an element of counter-transference on the part of the participants because they appeared to play out their internal conflicts towards the HIV/Aids patients and thus failing to stay neutral, as their work required of them.

One participant described; “Unmarried sexual partners as not real couples, not true couples but false couples”. She spoke of them as “difficult to counsel and just wasting our time since there is no long-term commitment”. The researcher found that the participants had mentioned some judgmental statements that were against men, which reflected some stereotypical gender roles since the participant herself was at the

moment experiencing an unhappy relationship, as stated later by her during the individual interview. She projected that men are “generally and naturally promiscuous, immoral by nature, and like dominating women”. The researcher noted to himself that all these remarks and criticisms might indicate signs of frustration, failure and anxiety, which could have stemmed from within the participants after many unsuccessful attempts of trying to address the infidelity problem in their own families.

#### 4.2.4 Coping with work stress

Participants’ work stress might have been worsened by the perception of loss of control over their work roles. Examples include the high flow of patients, changes in their job duties or workload related to administration work like updating and compiling files, as well as the writing of process notes.

They reported that they use both formal and informal procedures to reduce and cope with work stress. A formal procedure used was an external supervisor (a counselling psychologist) who volunteered her services to the clinic employees and normally undertook scheduled two hourly supervision sessions only once a month. Her commitment could be attributed to her passion to counselling work even though she was unpaid for rendering her most needed services.

One participant exclaimed:

It is helpful. It is helpful because maybe you are missing something and the supervisor can be in the position to help you, correct the way you are doing it, so as to improve. She can give you suggestions for improvement. When the

counsellor is seen in the context of giving advice and information, there is too much pressure on us. It is the most difficult part of the formal supervision when we most often see ourselves as inadequate, even though the supervisor had given us numerous assurances that we are not expected to be perfect.

Some participants mentioned that their informal means of reducing stress included talking with other counsellors between sessions, and sharing cases with other counsellors outside the supervision meetings. They suggested that work stress could be further reduced by reducing the number of patients each counsellor see per day and by providing additional educational opportunities for counsellors. The researcher suggested to them that they could also use counsellors' group therapy and could get together and share some of the common problems they encounter during the day. This interesting information originated from the researcher's experience acquired while doing his internship at Natalspruit hospital with the Khululeka Aids group. This could also imply forming the counsellors' own support group and strengthening their working relationships that could possibly extend to a personal level and otherwise.

#### 4.3 CENTRAL THEMES FROM THE FOCUS GROUP DISCUSSIONS

##### 4.3.1 High level of perceived expectations

Participants thought that they were perceived in the community as highly knowledgeable individuals who could provide solutions to all problems and know more about a wide variety of topics in addition to HIV/Aids, such as family planning and social services. This high level of perceived expectation came up constantly in the

focus group discussions and seemed to have put a lot of pressure on the counsellors to perform and place them in the expert role. One participant commented; “for instance, this is what the man in the street sees and thinks about the counsellor as somebody with a lot of knowledge”.

Participants spoke about patients who come to the counselling sessions expecting the counsellors to solve all their problems. They believed that this expectation made it even more difficult for counsellors to let go of the role of the problem-solver. Patients were perceived to think that the counsellor was going to automatically take away all their problems, or that the counsellor would provide them with all the answers to their problems. One participant made a loud outcry; “they do not know that the answers to their problems lie within themselves, we are only helping them to sort out their own problems”. The clinic’s referral resources include the hospital personnel (clerks, secretaries, guards and so on), and various health professionals (medical doctors, dentists, physicians, gynaecologists, social workers, and so on) from inside and outside the hospital setting. This could mean that the patients might be obtaining different messages from numerous health personnel, which could have possibly created some expectations for patients even before they get to the HIV/Aids clinic.

Another participant expressed, “I think when they come to us and if they really came to be counselled or get advice, they say to themselves ‘just advice me about what to do’, Doctor”. They said their usual response would be that they do not give advice, but they are only helping them to cope with the problem so that they could lead more satisfying lives even though they are still HIV positive. Participants commented that from the observations of their patients this response did not seem to convince the

patients very much since they would start being sceptical of whether “you will be able to help them or just wasting their time”. This could mean that the counsellors to some extent might experience feelings of helplessness since they could not ‘cure’ the patient as their primary responsibility according to the traditional healing processes.

Other participants in the group mentioned that many patients from the surrounding communities of Atteridgeville come to the clinic with expectations beyond receiving counselling services and antibody testing. They described patients “as expecting to be ‘helped’, ‘saved’ or ‘rescued’ from the HIV/Aids disease”. They wondered if these expectations stemmed from patients’ prior relationships with other non-governmental organisations in their communities or perhaps because they do not precisely know the work of counsellors. Since they are working in a hospital environment, patients come expecting more than just counselling and testing, but also injections as well as medication to go home with, as the medical doctors normally do. Another participant commented, “They (HIV/Aids patients) often come and ask what else are you going to give us?”

This might suggest that HIV/Aids patients would want something tangible that would give them some hope, like getting medication that will sustain their health or belief that they may be healed. The researcher noted:

Since the names of other health professionals are unfamiliar particularly to the uneducated Black population (especially those who originate from the rural areas), every health provider working in the hospital settings is referred to as a ‘Doctor’.

This implies that the names of other health professionals such as psychologists, gynaecologists, optometrists physicians and so on, are either unfamiliar or difficult to pronounce by most of these patients or perhaps could be the terminology used by the educated, middle class group.

#### 4.3.2 Work stress

Participants described a number of different sources of work stress; external conditions, the structure of their jobs and their actual job duties.

**External conditions.** On the most distant level from their workplace, the participants reported being stressed by factors external to their employment duties and the research study. The factors mentioned by the participants included the peak hours' traffic congestions (mornings and afternoons), township noise, unreliable and inconvenient public transport, undesirable home environments and unstable economic conditions in the country. The researcher noted that all these factors might be inherent to the unique historical background of this country's context and important to consider in assessing the overall stress that counsellors experience. Another participant related that one stressful aspect of working with HIV/Aids patients that could be annoying is "the patronizing reaction of others to finding that this is the type of work you do". Another participant added that one of her neighbours had said; "I don't know how you can work with these people". These were the comments used by the participants to illustrate the negative impact of working with HIV/Aids patients from the community around them.

Some of them indicated that because of the current high level of unemployment, their disadvantaged backgrounds and the limited options available to them, they had grabbed this opportunity primarily to get some income and working experience, and be able to support their unemployed immediate families. The word ‘grabbed’ was used to show the extent of their desperate need for employment. Some of the participants also commented on the difficulty of getting hold of transport fares to get to work because they are struggling to make ends meet in their families. Another participant said; “We are getting peanuts, we are earning very less as compared to people who are working in less strenuous circumstances, but who are going home with fat cheques”. Some of the participants got this job because one of their relatives had been working in the hospital and obtained it through them (nepotism) or it could be through their volunteering efforts. The researcher found that all of the counsellors were hired on a voluntary basis, and that there was no structured selection procedure in place.

**Job structure.** Participants reported experiencing stress related to the structure of their job, which include long working hours, meagre salaries, high case loads, an absence of compensations and benefits for overtime and other risks inherent to their work, and strained relationships with some co-workers. The researcher inferred that the counsellors’ relationships could have been strained by personal conflicts that occurred outside their work since they are staying in the same township that could have carried over to their working relationship. They described their workload as heavy and unpredictable since each counsellor is seeing approximately between 12 to 16 patients per day, from Mondays to Friday. They reported feeling tired and working under constant pressure, as one participant has put it like this; “especially when we

are supposed to compile counselling process notes, attending impromptu meetings and the emergencies, taking terminally ill patients to the hospice, doing ward rounds and so on and on...it is a long list of daily work chores". The researcher perceived that these responsibilities should require highly trained workers who are well paid and on the contrary, it could seem dangerously unethical to expect such demanding efforts from lay and poorly paid workers.

One participant commented as follows:

Probably, we could avoid burnout by seeing fewer patients per day. But as far as our programme is concerned we do not have control over that. The patients keep on flowing into the clinic, even if we have devised some means to consult them during specific hours and days, nothing seems not to have changed. The more the clients come, the better it is for the project, but totally not good for the counsellors' health and wellness. There are times when we leave the hospital; we feel that we are worn out, and that we are being overworked. And it becomes more overwhelming in the case when you are the mother, wife, and domestic worker in your own home.

**Job duties.** Participants described some specific job duties as particularly stressful. Although some of them had mentioned a fear of clients, such as physical assault and getting infected, the professional counsellor indicated:

In the history of this hospital and from the cases that were officially reported, the infection rate is dramatically very low. The only infection that I've heard of have last occurred six years ago to one medical doctor, but since then not even one patient have done harm to a health care provider in any way.

Other participants expressed their overall fear of not knowing enough and being unable to answer the patients' questions about HIV/Aids transmission or other related topics.

One participant mentioned:

We get to know our patients over a long period of time and it is not easy to cope with sudden deaths from overdoses or to see our patients' physical health deteriorating and eventually resulting into deaths. Some of us are not always strong or consistent in our responses.

There seemed to be some feelings of helplessness and inadequacy experienced by the counsellors that is explicitly evident in the participants' utterances.

#### 4.3.3 Psychological responses to HIV-positive test results

Giving positive test results was also described as stressful by most of the participants:

You also, as a counsellor, it takes a lot from you when you are supposed to give out those positive results. Bearing in mind that you are not the one who has personally neither took nor tested the blood of the patient. You are asking yourself first this question 'Are you sure you are giving the right result?'

There is a lot of emotion in that moment, it could be mild in you but more intense within the patient; you can imagine how you feel when you are in the position of giving a positive test result. It is like the act of judging, as similar to the act of pronouncing a death sentence by the court or as inflicted by God for the punishment of sinners.

These utterances could be an indication of judgement by the counsellors that could be stemming from their feelings of helplessness and anxiety.

All participants agreed that couple counselling was a very stressful situation, particularly regarding the issue of disclosing the test result. In addition to the interpersonal stresses of couple counselling, there are also ethical issues related to disclosing test results to the couple as it is practised particularly at Kalafong hospital. One participant said it is the rule to ensure that each member of the couple receives his/her test results individually and separately from the other member and then be encouraged to share their results when they were together in the counselling session. Participants felt somehow constrained by the confidentiality principle from giving out the test results when both couple members were present, particularly in the case when one is positive and the other is negative. Another participant exclaimed:

Counselling a couple is very difficult. Not every person is able to talk in front of his/her partner that he/she is HIV-positive. So it takes a lot of thinking and emotional energy from the counsellor to facilitate the passing of this information from one partner to the next, be heartily accepted.

The participants raised their concern of having a moral responsibility of giving the test results to the patients, but were worried that the infected patients might not disclose these results to their partners. They reiterated that many counsellors are often sceptical about the possible negative consequences of giving an HIV-positive test results to patients. One participant remarked:

How will I feel if one patient I've revealed the HIV-positive results decide to commit suicide, and only to find afterwards that the deceased was not HIV-positive after the post-mortem had been conducted?

Consciously or unconsciously, the participants were concerned about the negative consequences of disclosing HIV-positive results to patients and the feelings of guilt and blame that accompany the patients' loss of hope in their lives.

Participants indicated that the patient's disclosure of their test results to their partner(s) in the counselling session, or their promise to disclose upon returning home, was seen as central to the success of the counselling encounter. Thus, they expressed that they normally put a lot of pressure on themselves to 'succeed' in this regard. Another participant exclaimed, "If I do not succeed in convincing her to tell her partner, I always feel down, stressed, inadequate, and helpless". This could also indicate participants were again taking the responsibility for patients.

#### 4.3.4 Reactions of Participants to different Types of Patients

The researcher observed that the procedure counsellors normally follow in consulting HIV/Aids patients is that patients are normally coded into 'different types' in terms of the problems they have brought to the clinic, so that they could be systematically allocated to specific counsellors who have appropriate knowledge of, and competence in, the areas underlying such work, including specialised knowledge concerning specific patients. Patients 'typologies' had, according to the professional counsellor, important implications as they determined counsellors' implicit expectations, approaches and styles about which patients are more likely to change, and this could

also be seen as bringing some flexibility for counsellors to choose the types of HIV/Aids patients they feel comfortable to work with depending on their personal circumstances. For instance, counsellors could decide during specific weeks or days whether or not to:

- work with HIV/Aids patients who present with complex family situations;
- disclose HIV test results to patients;
- work with patients with psychiatric illnesses; or
- facilitate obtaining social grants for patients.

These options could be seen as having brought some adaptable measures and a sense of relief into the work of counsellors in choosing the types of patients one feels to work with depending on their current situations. On the other hand, this could also be seen as a deficiency since it meant that counsellors would be able to manipulate the system as they wish in terms working with the same types of patients longer than necessary and at the same time, overburdening other counsellors. One participant said:

These arrangements serve to signify whether or not certain patients would return for HIV testing after they have received pre-test counselling or after blood has been drawn from them. For example, patients who were ‘just curious’ about the services we deliver or those that were being pressured by their parents or collateral others to come to the HIV/Aids clinic were most unlikely to return for test results.

They claimed that these types of patients somehow discourage them because they started to have feelings of self-doubt and doubts about the quality of the services they rendered to the public.

When the researcher asked them, "Which types of patients are easiest and which types are most difficult?", another participant answered; "We normally reverted to two dimensions; that is, we prefer to work with those who spontaneously open up rather than with those who are resistant or reluctant to speak (including those who are still in denial about their risk and having the potential to either infect or be infected). We also like to work more with those who are honest than those who seem restrained to tell the truth about their circumstances and risk behaviours". They reported that they also found it difficult to work with patients who were reluctant to disclose their HIV status to others. One of them said:

Well, the best patients for me to work with as a counsellor are the ones that are free and open to talk about their ordeal. The ones who will tell you the truth, they are at least honest with themselves and their feelings, and one feels motivated to help such patients. If they tell you lies, it becomes more difficult since one has to do a lot of thinking and hard work, and to start digging up. It really consumes a lot of time for others.

They related:

Some HIV/Aids patients would just 'stop in' periodically to greet us but not to receive counselling services, and that normally raises many questions about their motives because they are usually patients that one had previously seen in counselling and didn't turn up for the following sessions.

They indicated that some patients arrive late for sessions as a result of a number of reasons that are beyond their control, such as, they might need to rely on others or public transportation. Another participant said: "There are times when one's work

commitment could not just allow you to see those patients even if you truly want to see them”.

#### 4.3.5 Emotional workers

All participants felt that their job, although rewarding, was difficult, mentally tiring and emotionally demanding. They described themselves as ‘emotional workers’ because they are constantly emotionally involved in their work with HIV/Aids patients. While participants were aware that these overwhelming duties and responsibilities are inappropriate and sometimes counterproductive, they resiliently continued to work with the magnitude of the patients’ problems.

One participant explained:

Emotional labour includes the type of work we do in comforting emotionally stressed patients, helping the patients to feel comfortable, raise their level of functioning so that we could lead satisfying lives while they are HIV-positive.

In their routine work with HIV/Aids patients, participants mentioned that they also discussed emotionally charged issues with patients such as sex behaviours, relationships and disclosure of HIV status. Another participant said:

Sometimes, it happens that you see ten patients in one day who are all crying, shocked and stressed out after receiving HIV-positive results or those who are still in denial and could not come into terms with the results or those who are constantly blaming the partner for committing infidelity.

They pointed out that their daily work with tearful patients had turned them 'emotionally blunt' to an extent that the patients even think that they are not human because they are not emotionally touched by other people's unfortunate circumstances and this could suggest having reached a moment of emotional depletion (burnout). They also indicated that even in the event of the death of their significant others or during burials where every member of their families is severely affected, it becomes difficult for them to express their emotions like other people normally do, even if they desire. Another participant said that one of her family members was surprised to see that she was the only person who was not crying. She remarked that her male relative even commented that "she has no feelings and her job has made her 'a hard nut to crack' ". This reaction suggests that the counsellors' daily routine emotional work with HIV/Aids patients had made them more vulnerable to feelings of being overburdened, stressed and helpless, as well as to experiencing blunt or inappropriate emotion, which could eventually lead to possible physical and emotional burnout.

#### 4.3.6 Participants' coping mechanisms

Participants acknowledged the importance of family support. One of them said her husband help her cope by being there for her and by trying to understand what is going on through her work and life. She indicated:

I normally use my husband as my support system to listen to strange cases that had personally affected and frightened me, and would immediately get better after I had coughed it out to him. She said, ...and so I think that a supportive family is very, very important.

One other way of coping that the group mentioned, was that “we often laugh about our experiences, we laugh about almost everything, and by so doing we are in a way able to minimise the negative impact of our work by reducing it to a laughing matter”. They acknowledged that this ‘laugh up one’s sleeve’ also works especially when they are in a group, but when they are on their own there isn’t that natural, exciting laughter.

The participants indicated that what they also do to cope with the cases that stress them is to drink alcohol, take antibiotics that help them to sleep right through the night without any sleep disturbances, keeping themselves occupied with other things, or preparing supper so as to divert their attention from thinking about their work matters. The researcher noted that their reactions to stress or possible depression are often accompanied by the use of a variety of defence mechanisms. In all these cases the counsellors ‘feed’ themselves to make up symbolically for the day’s undesirable experiences. He further observed to the participants that although these behaviours do make the individual feel better for some time, unfortunately they might lead to other serious problems.

#### 4.3.7 Boundary between private and professional life

Most of the participants reported that the HIV/Aids pandemic had directly affected them because they have friends, relatives and neighbours who are infected by the disease. Other participants reported that this proximity of the disease in their personal lives had played a role in their motivation to work as HIV counsellors because they felt that they had to make a difference in the lives of other people. Two participants

saw it as their obligation to provide services to the community (altruistic tendencies) while others described their involvement as helping themselves to deal with the losses they suffered through the deaths of their loved ones. Another participant mentioned; “No one in my family has ever been infected by disease, but I don’t think that it will never happen to me, it has affected everyone of us”.

They mentioned that their communication with their partners and family members about HIV/Aids and sex had improved tremendously and that they now feel more comfortable to talk about it, unlike before they became HIV/Aids counsellors. One participant (a married counsellor) expressed that her work with HIV/Aids patients had made her reflect on her own vulnerability to HIV/Aids disease in her private life - mostly as a result of her husbands’ suspected promiscuous behaviour. She commented; “I realise that I am at risk just as my patients are. And it would be a shame for me to keep telling patients about condoms or maybe I already have HIV, who knows”.

A lack of ignorance among family members seemed to be a common feature. Another participant exclaimed:

My close relative is currently suffering from the disease, their family members refuse to talk about it openly. No one is allowed to disclose this matter outside the family. It is a family secret. I’m quite sure that they are afraid of being stigmatised. They are spending a lot of money on expensive, private hospitals so that no one could know them.

The researcher discovered that for some participants, HIV/Aids had often spilled over from their professional life into their personal life. This reality of the participants’

work obligation having proceeded beyond the supposed limit could lead to feeling overburdened, increased life stress and eventually burnout.

They reported having acted as HIV/Aids educators for their immediate families, relatives and friends. Another participant mentioned that ‘charity begins at home’, describing how it is appropriate for counsellors to be a resource to friends, relatives and their families of origin. They related that becoming a counsellor had increased their self-understanding, improved their ability to resolve their own problems and helped them to become less judgemental of others and yet this was in some instances a contradiction of what they had reported elsewhere. It appears evident that it is difficult for these counsellors to establish a boundary between their private and professional life, perhaps because the disease had affected them in every sphere of their lives.

#### 4.4 A SUMMARY OF THE INTERVIEWS AND DISCUSSIONS

By interviewing participants the researcher was able to gain insight into the nature and process of counselling, how the participants perceived their own roles, what it was that they saw as the effective elements of counselling, and the work related psychological distresses that participants experience. It also seemed that counsellors had placed very high expectations on themselves, that is, they always wanted to achieve success in every patients’ life situations and circumstances, and take responsibility for them. Despite their feelings of inadequacy, they had to provide quality service to the patients. They also felt pressurised to be regarded as good role

models in their communities and in their other aspects of their lives. They described ways in which being a counsellor had psychologically affected (both positively and negatively) their personal lives, lifestyles and relationships, including the expectation that they would provide HIV/Aids education and counselling for family and friends. While these participants found their work very stressful and emotionally draining, lack of alternative resources for improving their knowledge and skills might be regarded as additional stressors. Coping with stress was a theme that came up constantly in the individual interviews and focus group discussions.

The interview and discussion findings indicate that participants understood and implemented the client-centred counselling model and that the model was feasible and acceptable, especially for an individualised risk-reduction plan. Participants' complaints about their caseload might reflect the desire for more control over and autonomy in intervention procedures. All of the participants acknowledged that their jobs were difficult and stressful. Part of this stress resulted from the nature of the work itself, and another part from the additional stresses of being overstretched beyond the boundary of the therapeutic work. They also related a concern about the external inconveniences and economic conditions that increased their level of strain and worry about travelling to work and in supporting their families.

Despite the many work stressors that they discussed, the participants were forced to get through these circumstances of need, able to persevere and continue to work throughout, with the low salary earnings that made it difficult for them to make ends meet in their own families. This might be attributed to the current undesirable economic conditions that limited alternative employment opportunities. The

participants seemed to be vulnerable to potential burnout of working under constant stress, that is, the participants' vulnerability could be mainly attributed to work-related stress. Participants' sustainability and resilience (used as a personality characteristic) despite their undesirable working conditions, could reflect the success of the mentioned combination of coping mechanisms, such as laughing, ongoing formal and informal supervisions as well as alcohol abuse (negative coping mechanism as a sign of not coping). They reported that the numbers of patients they were required to see per day, the nature of the problems presented and the patients' unreasonable expectations placed on the counsellors, often stressed them.

Participants reported that their employers expect them to perform well at all times in their work. Their apparent performance at work and quantity of work seemed to be more significant to the employers than the psychological well being of the counsellors. It is evidenced that participants really needed alternative indicators of job performance and frequent feedback and encouragement from the supervisors as well, which they did not get.

In terms of the structure of their supervision, participants felt the need to have individual supervision sessions so that they may be able to discuss personal difficult cases, which they could not discuss in the midst of other counsellors. The reason given for that was to create a safe environment for them so that they could freely and openly ventilate their agitated emotions without feeling ashamed or shy of being witnessed by the other counsellors in group supervisions. They also expressed a wish to have at least weekly individual supervision sessions and would feel more comfortable to have a permanent external supervisor who is accessible but not directly

responsible for evaluating the counsellors' job performance since this could lead to a loss of objectivity. The situation remained unaltered, as indicated by the participants, during the research process.

Participants also reported that they sometimes felt inadequate, that is, they felt that they did not know enough to answer patients' questions or to help them with their specific situations. In these circumstances, they expressed a need to attend regular workshops that would keep them informed and abreast with the latest developments and research findings.

Participants mentioned that an important role of the counsellor is not to judge the patients. While they did not describe their interactions with patients as judging, they did hold judgemental attitudes and reactions toward certain types of patients. In many cases during both the individual interviews and group discussions, judgemental statements and counter-transference directed towards patients were related to the counsellors' moral, religious or stereotypical gender views.

During the course of the individual interviews and group discussions the researcher felt suspicious and anxious that some of the participants might withdraw prematurely from the research process, since some of them did not show up for the appointments, and had to be phoned and persuaded to come. Sometimes, others had to be collected from their places of residence in order to attend both the individual interviews and group discussions because they would often claim not having transport fares.

#### 4.5 CONCLUSION

Participants related that their jobs were both rewarding and fulfilling, but stressful. These counsellors who participated in the study became an important source of information about the process of counselling, including the psychological impact of being a counsellor and their clear concern about the lack of training opportunities and support needs for counsellors working with HIV/Aids patients who are constantly under demanding circumstances.

However, there was often a religious or moralistic emphasis in participants' descriptions of patients' situations and behaviours in the research interviews and focus group discussions. Although there is no indication that participants used judging language in their counselling sessions with patients, their language in the research interviews reflected negative judgements on patients' behaviour.

The next chapter briefly reflects upon the themes presented here, deals with the reflections of the themes and research process, and looks at the discourses in which the participants' stories are embedded.

## **CHAPTER 5**

### **REFLECTIONS ON THE RESEARCH PROCESS AND THE DISCOURSES THAT SPEAK THROUGH THEMES**

#### **5.1 INTRODUCTION**

Chapter four set out in detail the themes that emerged during the research process. It concluded with a first level of reflection, in which a summary of the individual interviews and focus group discussions was drawn. By interviewing and discussing with the participants, the researcher was able to gain insight into the nature and process of HIV/Aids counselling engaged in by the participants. The chapter also looked at how the counsellors perceived their own role, what the counsellors had seen working for them, and the various elements of counselling process engaged in by the participants, as well as the work related stresses that these counsellors experience.

These themes that were subjectively selected from the individual interviews and focus group discussions by the researcher and highlighted in Chapter four, will receive further consideration in an attempt to make them clearer and understandable in relation to the literature review in Chapter two, as well as to other literature that could be found relevant to the findings. This chapter will reflect only some of the main themes stipulated in the last chapter, since a considerable number of them from the individual interviews and focus group discussions deal with almost the same subject and thus are interconnected and have many overlapping features. The researcher has

found this exercise very difficult to do because the subtlety of the participants' individual psychological effects and experiences were not easy to clearly identify, that is, they could only be inferred on from the participants' narratives.

Follow-up questions, which were found to constitute two key inquiries on the research process, will also be given attention. The first was what each participant, through both the individual interview and the focus group discussion, thought her individual effects and experiences were. The second was what impact the research process has had on each of them. These reflections are discussed, together with the impact of the research process on the researcher.

Finally, this chapter will also look at some of the discourses in which the participants' stories-and possibly the researcher's lenses- are embedded. A narrative approach as discussed in Chapter three proposes that people live their lives according to stories or narratives that are embedded within the available discourse. In this sense, it is the stories people tell themselves, and others, about their lives, which help them to make sense of their experiences.

## **5.2 REFLECTIONS ON THE THEMES**

### **5.2.1 Being an HIV/Aids Counsellor**

All participants found that working with HIV/Aids patients as a counsellor is an intense working experience. Being a HIV/Aids counsellor, inferred the researcher, involves a number of related activities and responsibilities, such as attentive listening, information absorption, message clarification, hypothesis generation and being there

for others. All these require intense energy, both mental and emotional, from the counsellor. Beyond these largely intellectual activities is the emotional experience of counselling and caring for another enough to be affected by that person's emotions and therefore running the risk of becoming debilitated as the counsellor. Patterson & Eisenberg (1983) acknowledge that counselling HIV/Aids patients involves a much higher level of intensity than other forms of counselling, and might leave counsellors mentally and emotionally depleted; yet still thinking about what was discussed.

The researcher was struck by how other participants reveal their fear of the disease, the patients, and their life-styles. For example, participants were more concerned about treating the terminally ill, the risk of HIV transmission through accidental needle sticks, over-identification with patients their own age and identification with patients with similar lifestyles. Others remarked, "We better leave our work if assigned to a heavy load of terminally ill patients". Most of the participants, especially the inexperienced and young ones, expressed being fearful of working with terminally ill patients or fearful of death. Usually this fear is kept private and fosters a sense of shame about one's own irrationality and vulnerability (Wicks, 1997).

Cushman (cited in Goodkin, 1990) highlights that much of fear could be alleviated beforehand by the giving of relevant information, accurate feedback, and reassurances in order to minimise uncertainty on the part of the counsellors, especially with regard to the transmission of the disease and dying. Bandura (1990) proposes that both outcome expectations and self-efficacy expectations be considered when developing a programme for the counsellors to manage the risk of HIV/Aids infection. He devised a programme that provides information about HIV/Aids and its causes. The

programme also teaches specific behaviours, including how to clean intravenous needles used for drugs and how to take care of oneself when working with HIV/Aids patients. It might be necessary to conduct awareness workshops so as to constantly alert counsellors of the mixed emotions that go along with working with HIV/Aids patients.

Some participants noted that working with HIV/Aids patients provided considerable satisfaction in terms of providing comfort, support, education, and helping significant others. No participants stated that they had experienced less stress when counselling HIV/Aids patients. Notably, all of them felt that HIV disease was very stressful because of the stigmatisation, suffering, and incurable nature of the disease.

A question was asked by the participants; “If, as counsellors, we find that the patients do not change or follow our advice, how do we deal with this disappointment, frustration and concern?” When the patient does not show any demonstrable change, this inevitably creates a sense of failure and inadequacy, and raises our anxiety levels, both in terms of the risk of the patients acquiring or transmitting infection and also by the fact that we may start to question our own abilities as counsellors”. Participants’ frustration and concern seem to be valid and create an ethical dilemma in terms of transmitting infection to others and patients’ confidentiality. Yet the researcher believes that this issue worries and concerns participants because it threatens that which is at the very core of the counselling relationship of trust.

### 5.2.2 Manifestations of distress

This cluster looked at depression, withdrawal, guilt, loneliness, anger, loss of memory and other manifestations of such as feelings of anxiety, emotional numbness, suicide ideation, eating disorders, and stress, as well as other physical complaints. All these sub-categories of distress gave rise to experiences that were common to some of the participants. Some participants suffered from depression, possibly influenced by a genetic disposition. A sense of worthlessness, fatigue and emotional numbness were considered to be the symptoms of depression, and were experienced by most participants. Insomnia, guilt, isolation and anger seemed to be common experiences that all participants narrated.

In a study examining depression in physicians working with HIV/Aids patients, Ross and Seeger (1988) concluded that the physicians' depression was less a function of years spent working with these patients than of concentrated (percentage of time per week) exposure. This meant that the amount of time per week spent with HIV/Aids patients was correlated with depression and overwork. This might suggest that an important contributor to depression is also experiencing difficulties emotionally and physically even outside the intense working situation, particularly in instances where the counsellor has other commitments outside his or her work.

Goodkin (1990) mentions that the most common reactions to counsellors working with HIV/Aids patients is reactive depression, that means, it could be a normal reaction to loss, adverse circumstances, helplessness in changing the situation, and how much effort any change requires. He states that depression may occur periodically in response to interacting with patients that reminds the counsellor of the past and same debilitating conditions that the deceased patients have suffered.

Lamson (cited in Kubler-Ross, 1970) adds that depression is also characterised by a withdrawal from previously rewarding activities, neglect of friends that one used to spend quality time with and developing a tendency to be aloof or isolated from other family members because the person feels overwhelmed in the company of others. These symptoms could contribute to feelings of vulnerability, guilt, and low self-esteem.

Anger could be one of the more difficult reactions that counsellors have to deal with when working with HIV/Aids patients. Gillman (1991) points out that anger that is not expressed could be turned inwards and, eventually, its cumulative effect could lead to depression.

### 5.2.3 Counter-transference

Some participants experienced reactions in the context of the counselling relationship that do not fit the definition of unconditional positive regard. The researcher noted that these counter-transferential reactions directed towards the HIV/Aids patients have been occurring unconsciously, and sometimes consciously within an interpersonal activity. Their expressions were based on the observations of their colleagues' reactions towards patients and awareness raised during supervisions. Yet all of these emotional reactions, said Hoffman (1996), whether counter-transferential or not, are important and meaningful for the counsellors to examine in order that they could optimise their clinical work. These reactions could also be put in use to deepen the understanding of the interaction between the patient and counsellor.

Sontag (quoted in Wicks, 1997) remarks:

Counter-transference reactions might revolve around negative feelings about behaviours patients might have engaged in to become infected such as sex with hundreds or thousands of partners, anonymous sex, prostitution, and injecting drug use (p161).

One participant asked a confrontational question to a patient as follows; “How many sexual partners have you slept with in your life?” Others reported having difficulty in working with patients who continue to engage in risky behaviours.

One participant’s unresolved emotional issues with her partner had been reflected in her conversations about ‘unmarried sexual couples’. To illustrate her negative reactions she unleashed a strong attack against men; “Men are generally and naturally promiscuous, immoral by nature, or like dominating women”. Counsellors’ internal reactions need to be attended to, understood, and managed so that they serve, rather than impede, their therapeutic work (May, 1980).

#### 5.2.4 Coping with work stress

As has been noted earlier in the introduction, some themes contain overlapping features and are somehow interconnected with each other. The researcher has thus decided to concurrently summarise the reflections of work stress and participants’ coping mechanisms under this heading.

Some participants obviously used some forms of coping that are particularly destructive and not helpful, whereas others behaved impulsively and compulsively. They often dealt with work stress through overindulging themselves in behaviours

that would make them feel better for a time, but that would unfortunately lead them to other problems as well. The researcher found that some participants frequently used ways of coping that could be viewed as extreme reactions, such as getting depressed, crying, going on buying sprees, anorexic tendencies and abusing alcohol, whereas others used more positive forms of coping, such as seeking support and teaching others about HIV/Aids.

Participants described the peer support group and family support as helpful to manage their work stresses and frustrations, as well as in dealing with the social aspects of the disease, such as fear, deaths, stigmatisation, shame, and anger. These support systems helped the participants cope better and, at least, instilled a sense of hope and control in their lives. Murphy and Perry (cited in Hoffman, 1996) indicate that support structures might be highly cost-effective in the long run, especially if they boost morale, and help the staff to cope with stressful work. Fears of contagion and about the counsellors' own safety often emerged, particularly to participants who were new and inexperienced in their exposure to HIV/Aids work. These fears, if unresolved, could create an inappropriate distance between counsellors and patients (Adler & Beckett, 1989).

Dealing with death and dying issues were the aspects most often mentioned by all the participants as being difficult to handle. As a result, patients' deaths were rarely acknowledged in an open public manner, even when they were experienced on a daily basis. Witnessing physical and mental debilitation occurring in patients was often cited as a reaction that was difficult for counsellors. Seeing this happen to a patient may also cause the counsellor to feel guilty about his or her own good health. Gillman

(1991) highlights that a dying patient might trigger feelings of helplessness and hopelessness to health professionals in general because the traditional basic training of health professionals emphasise “cure” as the only acceptable outcome of their intervention. This perception could negatively influence inexperienced counsellors.

Times (cited in George, 1988) highlights that what is sufficient and acceptable support for one counsellor might not be so for another. The type of support that normally worked for each of the participants was obviously a very personal thing, but he proposed that it is not something that should be left to the counsellors to sort out without the organisational backing. Cadwell (1994) suggested that counsellors might also cope by distancing themselves from the reality of the situation by using a variety of defence mechanisms. This could mean that counsellors would risk becoming insensitive and cold towards their patients. Alternatively, they might become over-involved with patients, and eventually find they cannot cope, and decide to leave their job.

Another possibility, if work creates severe emotional strain, is for support structures to be set up depending on the financial muscle available, and work to be organised in a way that strain involved is taken into account. Ross and Seeger (1988) found that the counsellors’ personal characteristics such as potency, resilience and mastery might also be used to determine how much a counsellor could be affected by the work stress. The fact that the participants had been working with HIV/Aids patients for some time, and were still showing some willingness and interest to learn more in the HIV/Aids field, bears testimony to their strength and potential to continue working despite the inherent difficulties.

However, Kassy (cited in Cadwell, 1994) finds that if the counsellors are overstretched for too long, the quality of their work inevitably suffers and might eventually decline. In one of the few controlled studies conducted by Lippmann (1993) on working with HIV/Aids patients, found that the majority of research respondents acknowledged that work with HIV/Aids patients created more anxiety, more interference with non-work activities, and more frequent negative ruminations, such as worrying about contagion. Stein and Steinberg (1997) stipulate that the counsellor's stress might be reduced and their effectiveness and retention improved by (1) allowing work flexibility; (2) providing supportive, non-evaluative supervision; (3) offering alternatives to client behaviour change as the indication of counsellor performance; (4) acknowledging and educating about 'emotional labour' in counselling; (5) providing frequent information updates and intensive training; and (6) encouraging counsellor participation in the development of research initiatives.

#### 5.2.5 High level of perceived expectation

All participants indicated that they faced significant challenges in working with HIV/Aids-infected patients, as well their significant others. Moylan & Jureidini (cited in Patterson & Eisenberg 1983) highlight that counsellors in an AIDS unit often receive powerful, primitive projections from the terminally ill patients that they could make everything right and whose power is envied and feared. One participant in this study provided an illustration of how the community around them perceive them as "somebody with a lot of knowledge". These projective identifications are produced imaginatively in the minds of the participants. HIV/Aids work has been defined by

Walsh & Bibace (1990) as “an attack on the self”, that is, it resonates powerfully from the patients to the counsellors by means of projective identification.

Although the participants provided substantial services to HIV/Aids-infected patients, they were often insufficiently prepared; a phenomenon especially pronounced when serving populations of different cultures (Taylor-Brown & Garcia, 1995). To obtain adequate preparation, they suggest that counsellors must possess knowledge adequate to address the unique needs of HIV/Aids-affected populations. Inadequate preparation may result not only in reduced quality of services to HIV/Aids patients and their families, but might also lead to counsellors’ feelings of inadequacy, self-doubt, frustration, job stress and dissatisfaction, as well as burnout (Ross & Seeger, 1988).

Most of the participants reported that they spend much of their time responding to a variety of crises, feeling drawn in many directions, thinking about how to “fix “ things, or feeling overwhelmed. In other words, they were often reacting in an anxious manner to whatever momentary challenges faced them. Stein & Steinberg (1997) state that, most often, just as counsellors had moved forward with an issue, something new and urgent would occur and counsellors would be expected to respond instantly and effectively.

The other aspect mentioned by the participants involved HIV/Aids patients who come with expectations beyond receiving counselling services. One participant from this study mentioned; “What else are you going to give us?” Participants felt that they were expected to fulfil the role of the good-enough parent, the one, said Judd (quoted in Ross & Seeger, 1988), who reflects back to the child its sense of uniqueness and

aliveness, and who can function as a protective filter of otherwise unendurable experiences. This attitude could also be attributed to the legacy of the past and policies of the previous apartheid régime, which rendered mental health services unavailable, inaccessible and unaffordable to non-white population groups. Mental health services were selective, favouring the white, urban, wealthy and medically insured clientele, as stated in the previous chapter. Preventative, primary and community health services (including psychological services) were unknown to the non-white groups and grossly neglected due to inappropriate emphasis on highly technological, curative, institution-based and doctor-oriented services (Freeman & Pillay, 1997). The effects of this mentality will take some decades before it can be eroded in the minds of the less educated and often rural class populations.

#### 5.2.6 Psychological responses to HIV-positive test results

All participants agreed that giving out HIV-positive test results to patients was very stressful, especially during couple counselling. They also indicated that being able to convince the couple members to eventually accept their HIV-positive status without any subsequent conflict was seen as central to the success of the counselling encounter. The participants questioned the validity of the test results since they were not the ones who were responsible for drawing and testing the blood samples, but were compelled by work obligations to disclose the HIV test results. There seems to be some limitations involved in this procedure in the sense that, those who did not perform the technical functions in the laboratories unfortunately reveal the results. The participants' perceptions seemed to be short-sighted and unreasonable since the test results have to be disclosed by people who are competent to assess and contain a relatively serious forms of distress.

On several occasions during the individual interviews and focus group discussions, participants discussed their fears of getting HIV/Aids through casual contact, even though they knew how the disease is transmitted. The researcher discovered that there was an underlying anxiety that needed to be acknowledged and examined in a manner that is non-threatening. It became evident that the participants' daily contact with HIV/Aids patients created feelings of anger, guilt, loss of hope, and lack of motivation. Participants were also encouraged to talk about their agitated feelings that were discussed in the context of participants' self-care and establishing their boundaries and limits.

Death and dying were frequent messages that patients who had just been diagnosed as HIV-positive receive. As with all treatments of terminally ill patients, counsellors working with HIV-infected people must struggle to understand their involvement with people who they know will die (Wicks, 1997). He proposes that the counsellor and patient must be able to understand the value of clarifying and working through issues despite having no clear framework for the future.

#### 5.2.7 Reactions of Participants to different Types of Patients

It is common for counsellors to be expected to cope 'professionally' with their emotions arising from working with the different types of HIV/Aids patients. This might mean that they are expected to hide their emotions, however upset, angry or

frustrated they might feel. Gillman (1991) acknowledges that HIV/Aids work might be particularly stressful for counsellors, because it means repeatedly facing different HIV/Aids patients presenting with various kinds of ill health, suffering and deaths, particularly of young people. It might involve working and coping over time with several deaths in one or more families at the same time, for instance, the deaths of young children and their parents, and with the grief of their relatives. This could really become an overwhelming task that counsellors are confronted with in executing their daily work routines since the patients often carry unique, different challenges with them.

Participants related that although counselling couples is more difficult than individual counselling, they felt that it was more likely to result in lasting behaviour change. This was reflected in Allen (1992) and Kamenga (1993)'s research findings (cited in van Dyk, 2001) when they supported the effectiveness of couple counselling in promoting behaviour change. Some participants reported feeling overwhelmed by couples in the counselling sessions. Van der Straten (1995) mentioned in his recent study the distresses that go along with working with HIV-positive patients, particularly when one partner refuses to disclose his or her status to another. He recommended that counsellors must be trained to work with these couples, including having up-to-date information about HIV transmission, ethical implications and the impact of disclosing the HIV status to another partner.

Given the personal and social consequences of HIV infection, educational programmes need to be comprehensive and skill based, and need to demonstrate effectiveness in both increasing counsellors' knowledge and improving the quality of

care regardless of patients' situations. Earlier research conducted by Knox & Friedrich (1994) has demonstrated the need to increase counsellors' comfort and willingness to work with the HIV/Aids patient population.

#### 5.2.8 Emotional workers

All participants felt that their work was difficult and stressful, but they enjoyed the rewarding, collaborative role they experienced with their patients. Cadwell (1994) supports that HIV/Aids patient' gains and movement toward autonomy, individuation, intimacy, and important life roles should be seen as a positive feedback, sources of pleasure and could be intrinsically rewarding to counsellors. In contrast, the patients at an advanced disease stage might become increasingly dependent, both psychologically and physically, and thus stimulate reactions from the counsellors as their role would move from a collaborative role to more of a care-taking role. Participants expressed their disinclination in that role.

One participant acknowledged that seeing dying and terminally ill young patients every day became so difficult for her to handle emotionally that she overslept and experienced nightmares. Perry (cited in Cadwell 1994) stipulates that this experience does not reflect an indifference or devaluing the practice of working with HIV/Aids patients, but rather, it reflects the struggle many counsellors face when what they envisioned in their work with HIV/Aids patients is threatened too often or when they find that they cannot emotionally cope with or escape the demands of their work situation. Some participants described feeling "an overwhelming sense of numbness, isolation, shame and sympathy".

All participants reported that HIV/Aids work is mentally tiring and emotionally draining. Miller (1991) acknowledges that many counsellors working with HIV/Aids patients often present with many symptoms of burnout such as physical exhaustion, lingering somatic complaints, proneness to frustration and anger, increased alcohol use, marital and relationship problems, emotional numbness, and depression. In addition, this level of emotional engagement with the disease often stimulate many issues, such as the counsellor feeling helpless about having failed to improve the HIV/Aids patients' condition or stop the disease progression or losing a patient to whom one was attached to. Mbuya (2000) indicates that these feelings of hopelessness and helplessness, on the other hand, might bring people much closer together, but it could also be extremely demanding and might lead to feelings of failure and inadequacy, or to resentment, anger and hostility. He recommends that all those caring for people with HIV/Aids, such as family, friends, and professional caregivers might need extra support themselves to cope with the emotional trauma of the disease. Hostman and Kusick (cited in Hoffman, 1996) call this phenomenon a "helper helplessness syndrome" which is caused by feelings of helplessness, depression, and anxiety.

#### 5.2.9 Boundary between private and professional life

All the participants agreed that HIV/Aids work had spilled over to their personal lives. Lie & Biswalo (1994) indicate that counsellors need to set limits or boundaries of acceptable behaviour for themselves and their work, an awareness that these boundaries will be tested in their work, and sensitivity to the feelings that boundaries could evoke in themselves and the patients. For some participants, HIV/Aids was not only the focus of their professional life, but was present in their personal life as well.

Nichols (1996) acknowledges that experiencing HIV/Aids as an unremitting thrust of one's professional or personal life could lead to feeling overburdened and experiencing burnout.

All participants noted that the ever-changing status of HIV/Aids patients alone demands that boundaries must constantly change with their needs. The researcher also agreed that setting boundaries with HIV/Aids patients might seem foolish and selfish, especially when the nature of the work requires continuous intervention and flexibility. Brody (quoted in Wicks, 1997) points out that counsellors must also titrate their own level of involvement, making clinical decisions that take into account the patient's health, at the same time consider their own conscience and willingness to step beyond the boundaries of the counselling session.

Participants agreed that too often they see, especially in 'new counsellors who have just come on board, a tendency to be afraid to set limits and boundaries with their patients and normally get their fingers burnt and then back off and become cynical and distrustful afterwards'. According to Prins and Van Niekerk (2001) a boundary setting, as indicated in last chapter, is the foundation of a professional approach to counselling work and should be seen as keeping the counsellor as safe and as intact as possible, which literally means keeping a limiting or restraining line.

### 5.3 REFLECTION ON THE RESEARCH PROCESS

#### 5.3.1 Impact on Participants

The participants' active involvement in the individual interviews and focus group discussions seemed to have made a profound impact on them. The researcher inferred that it would seem impossible for the participants to remain unaffected or somewhat unchanged during or after the research process. Being involved in the interviews and discussions where the participants undertook the process of making their internal stories known to others, seemed to have led participants to understand themselves better and to reach deeper levels of awareness. In narrative terms, this process could be seen as re-authoring. As a re-authoring conversation (White, 1998) evolved, participants were invited to link events of their lives in sequences through time according to a theme under discussion. However, in this activity, participants were assisted to reflect by means of questions focusing on the more neglected events of their lives - the unique outcomes or exceptions - and were encouraged to take these into alternative story lines. In other words, the researcher had in a way, through questions and reflections, encouraged participants to describe the alternative stories of their lives that are relevant to addressing their concerns, predicaments and problems that are at hand.

There are two aspects that the researcher wishes to explore in relation to the participants' growing awareness. The first is to consider participants' developing understanding and awareness of their reactions and the generation of new meanings by reviewing their experiences. The second is to draw attention to the significant differences between the participants. While they were involved in a process of drawing out their commonalities or the sameness of their experiences, they described different ways of experiencing their work and of being affected by their constant emotional engagement with HIV/Aids patients. In these reflections there are many

discoveries, realisations, conclusions, learnings, problem-solving practices, and so on, which become richly described. This contributes very significantly to a person's sense of being acknowledged, which provides a basis for them to develop specifics about how they might go forward in their lives (White & Epston, 1990).

About two weeks after the research process was completed, providing some space for participants to reflect on the research process, the researcher paid an approved visit at the hospital. Fortunately, it was during lunchtime and the researcher received an unexpectedly warm welcome from the participants. Only three of them were present on duty and were all requested by the researcher if they could share the same table together, and to his astonishment no hesitancy was experienced from them, perhaps because this could have been facilitated by the relationship of trust established during the interviews and discussions. Thereafter, the conversations with the participants spontaneously continued at the secluded table for one hour while they were eating. The mediums of conversations used were in both Northern and Southern Sotho, and were tape-recorded. The responses obtained from the participants were in relation to the question that was asked by the researcher, phrased along this line "Now that you have had a chance to digest the interviews and discussions, what impact, either positive or negative, do you think the research process had on you? Has it changed the way you see yourself now?" The spontaneity and favourable reception on the part of the participants and researcher could be attributed to an intimate relationship of trust and easiness that might have been successfully established in the reciprocal action entered into during the research process.

One participant (professional counsellor) answered, “I think it is important to continue these types of conversations because they help us to explore our experiences, attitudes, feelings and reactions toward our work”.

Another participant said, “It made me to know myself better. I discovered myself. This process has really helped to regain my self-confidence. I’m no longer having self-doubts or looking down on my capabilities or myself”.

A volunteer counsellor brought a sense of fear but immediately connected it to her resilience: “Hmm (long pause) I don’t know, it is a very complicated thing. I was easily intimidated by terminally ill patients, but now I realised that my reactions resulted from my past experience” (loss of her sister through Aids).

There were also some concerns raised by the participants about their job duties and structure: these were related to feelings of inadequacy and a lack of support and benefits, low salaries, heavy workload and absence of compensation schemes. They had expressed their feelings of helplessness, giving up and frustration since these concerns were brought to the attention of the management on several occasions, but nothing seemed to have been done about them. There seemed to be general concern among the participants over a lack of opportunity for self-development and self-growth in terms of receiving updated information or attending workshops so as to equip the counsellors adequately to comprehensively address the challenges that confront them.

Another participant spoke of becoming more aware in her execution of her duties and of gaining more insight into her experiences. She did not describe the behaviours she wanted to change, but her willingness to disclose more of her understanding of the

effects had become evident. She was able to openly articulate her fear of the contagion and hesitancy of discussing issues of sexuality, loss and dying.

One participant showed her willingness to acknowledge her confusion about knowing how to handle the effects of, and an awareness that she had to stop locating the blame within her, when the patient had failed to adhere to the treatment or stopped using safety measures (condoms). She indicated that it was difficult for her to acknowledge her feelings of anger, guilt and helplessness and would go to the tavern after work to drink herself out while the memories would still be fresh in her head.

Reflecting upon her developing awareness, one participant showed that she might have mastered expressing empathy towards clients, but at same time knowing how to distance the experience from herself and giving back the responsibility to the patients. She also mentioned wishing to be able, hence forward, to acknowledge her emotions.

Another participant, whose sister had since died from the disease, noted that the process had made her aware of her willingness to become an HIV/Aids counsellor or helping others with the disease as her defence mechanism of attempting to make up for the loss she had suffered (sublimation). She spoke of an awareness of her pain helping her to empathise with others.

Participants received varying levels of support on a continuum from little to substantial. One of the participants received support and help from her husband. Another participant mentioned she could only rely on her friends for support, but feared being criticised for working with HIV/Aids patients. One participant found her

parents to be emotionally unavailable to her, and she therefore had to cope alone at home. All of them reported a sense of relief and a feeling of being empowered by their participation in the research process.

### 5.3.2 Impact on Researcher

There were many instances during the research process when the researcher was overwhelmed by the generosity and willingness showed by the participants. Even though incentives were made available by the researcher as a motivation to buy the participants' availability to be present during the interviews and discussions, the value attached to the incentives gradually dissipated and the conversational process itself became a dominating factor towards the end. This attitude was illustrated when the researcher paid a visit to the hospital during the 'reflection period' when one of the participants offered to buy "a meal and cool drink" for the researcher, and offered a suggestion to continue the conversation meetings.

Since the researcher was one of the lay counsellors at the hospital (research setting) a year before conducting this research study, and was still involved with HIV/Aids patients in Natalspruit hospital where he was doing his internship, many things that were discussed during the research process resonated and became more visible to the researcher. Some of the contributions made during the research process, for instance, during the individual interviews and group discussions, were useful and motivated the researcher to execute his work with more confidence and more courage.

Through the process the researcher became more aware and understood himself better, as well as his own reactions to the multiple problems presented by the disease. The researcher realised afterwards that the interview and discussion meetings served as a support system for all of us and a safe platform to express one's agitated feelings, concerns and grievances. These meetings actually helped the researcher and the participants to refuel themselves as a means of sustaining or increasing a strong feeling to continue with their work with HIV/Aids patients. These encounters have truly shaped the researcher's views of what is important to explore and understand in the therapeutic relationship, and taught the researcher of the value of discussing potentially difficult issues, such as sexuality, stigma, loss and dying.

These reflections have, to some extent, implications for the researcher's future work as a therapist. The researcher will make it his responsibility to influence and mobilise his future colleagues in putting efficient coping mechanisms and support systems in place that will enhance their quality of life and sustainability.

#### 5.4 REFLECTION ON SOME OF THE DISCOURSES THAT COULD UNDERPIN THE NARRATIVES

The researcher believed that the discourses in which the narratives are embedded somehow contribute to the effects and experiences of the participants (and the researcher), particularly looking at the different conversations, which seem to run through the narratives. A narrative approach holds that no story can fully represent “lived experience” and this is partly because people have a tendency to select only those aspects of experience that fit their dominant stories, as mentioned in chapter three (White & Epston, 1990). Dominant stories means stories that richly describe the preferred accounts of a person’s identity and knowledge of life. Holstein & Gubrium (1995) defines a discourse as a social framework, frame of intelligibility or social process that has a powerful shaping influence over “what” sort of life events are storied, and “how” they are storied. As Rosenwald and Ochberg (1992) put it; “explanations individuals offer of their lives are inevitably shaped by the prevailing norms of discourse within which they operate ... social influence shapes not only public action but also private self-understanding”(p.5).

Some of the discourses around the experiences of working with HIV/Aids patients noted by the researcher are discussed. Morgan (cited in Hoffman, 1996) believes that some discourses perpetuate the problem, whereas the constructive and non-constructive ones could as well solve problems, or dis-solve them. All the participants had expressed to some degree a resistance to working with terminally ill patients and negative attitudes about death and dying. Participants mentioned that they were confronted daily with the “incurability paradox”. Terminally ill patients are by definition not curable, yet medical personnel are trained to cure, and feel effective only by restoring the patients to health. The failure to achieve a sense of mastery over the disease is a constant source of narcissistic injury (Maloney & Gillman, 1988).

This feeling of failure is often accompanied by experiencing feelings of inadequacy and helplessness. Participants' main concerns which they put forth were the lack of appraisals and additional training and of course, that the lack of adequate knowledge about issues relevant to HIV/Aids might contribute to the participants' discomfort in working with HIV/Aids patients. It seemed that their work focused more on responding to the patients' needs rather than in helping them achieve a more satisfying and fulfilling life. In other words, it appeared that they were trained to be reactive to meet the psychosocial needs of HIV/Aids patients, rather than being proactive. This could be another reason why the participants often felt that they were constantly responding to crises, which could result in a high degree of job stress and stagnation.

There were also other expressions in participants' conversations that indicated having directed their anger and guilt inwards. Some participants saw inadequate support structures and lack of coping skills as part of their problem. Another said she had been compulsively going on a shopping spree around malls, buying unnecessary items in an attempt to please herself inside. The participants also seemed to be overwhelmed by making themselves "Jacks of all trades" because they appeared to be providing all the services needed by the HIV/Aids patients. They have to do the pre-test and post-test counselling, disclosure of the test results, forming support groups, to do placements in available shelters and hospices, filling in disability grant forms, monitoring patients' health status and their adherence to medication, offering spiritual and religious support and attending to dying patients and their bereavements. The array of services and types of expertise and support that are needed at various points

of the disease progression suggest that one counsellor cannot serve all of the needs of the HIV-positive individual patient. Stein & Steinberg (1997) said:

Indeed, not even the best team of “experts” could provide for all of the needs of the HIV/Aids patients. Rather, ensuring “safe passage” involves not only medical and psychological care, but the care of significant others and the community (p.237).

Participants’ identification with their HIV/Aids patients seemed to be another source of vulnerability that was embedded in the conversations. Wicks (1997) envisaged that the rejection and stigmatisation of HIV/Aids patients seemed to have been well documented and has also appeared to have extended to those institutions and individuals caring for patients deemed fearful and unworthy. Participants also seem to be working with patients suffering not only from the effects of acute trauma (the illness requiring hospitalisation), but also of chronic stress trauma of a terminal illness. In the same note, counsellors working with these very ill patients could also be multiply and repeatedly traumatised, noted Cohen & Abramowitz (quoted in Whiteside & Sunter, 2000).

Although working with HIV/Aids patient as a counsellor has often been seen by many people as frightening and challenging experiences, Lifton (1999) has found that these experiences also provide unique opportunities for broadening psychological practice and for bridging the gaps in the therapeutic models. These experiences also allow counsellors to use their innovative skills and bring relevant contributions to HIV/Aids patient care, as well as participating more productively as partners in the health system. As patterns of practice in psychology are changing, with more opportunities

emerging in the counselling work with HIV/Aids patients, and as the medical system emphasizes primary care, psychologists could get more involved in the HIV/Aids projects in an effort to develop new and expanded roles in health care.

## 5.5 CONCLUSION

This chapter reflected upon the themes that emerged in the previous chapter. In addition, it discussed the impact of the research process on the participants. It described as well, the impact on the researcher. A brief review was undertaken of the discourses embedded within the narratives of the participants, in the context of the research, and the researcher's discourse, in which the interpretations are embedded, is considered.

It is clear from the above discussion that little attention is given by health authorities and researchers to counsellors' well being, who provide the most significant services to those who are infected and affected by HIV/Aids. Because all counsellors will probably encounter patients with HIV/Aids in their daily work routines, it is crucial that regular counsellor education programmes adequately prepare counsellors to address the issues of these patients. It is hoped that this research undertaking, based on the counsellors' lived working experiences, is contained with sound knowledge and meaningful experiences that will enhance the learning opportunities of many counsellors in practice.

**SPECIFIC RECOMMENDATIONS BASED ON PARTICIPANTS' CONCERNS  
AND ISSUES RAISED**

1 Continued training

The findings of this research suggest that lack of continued training and knowledge about issues relevant to HIV/Aids is one of the concerns raised by the participants, and may account why many of the counsellors are experiencing discomfort working with HIV/Aids patients. It is also helpful to examine the training needs of counsellors who are extensively involved in working with HIV/Aids patients. Therefore, continued training is important to adequately prepare counsellors to address most of the HIV/Aids-related concerns.

2 Case consultation team (regular supervisions)

It might be helpful if the clinic authorities could seek consultations or supervision with an experienced, permanent professional who will be easily accessible to the counsellors, especially for counsellors who are new and inexperienced in working with HIV/Aids-related concerns and issues. It might also be essential to collaborate with other professionals who are involved in the patients' care. The array of services and types of expertise and support that are needed at various points in the disease progression suggest that one provider cannot serve all of the needs of the individual patient.

### 3 Referral System

It might be essential to establish a sound referral system that is community-based and that can be more accessible to the infected/affected communities so as to reduce the heavy workloads and long working hours. Indigenous or community resources, including peer leaders as well as existing agencies and institutions, can be utilised in addressing other important needs of the community and help the hospital in planning and implementing interventions. Interventions are more effective when counsellors and others work in partnership with community leaders.

### 4 Research on caregivers

Caregivers, whether formal or informal, are often forgotten when the psychosocial impact of the disease is considered, and more research on them needs to be encouraged if their most needed services are to be sustained. Despite this, the needs of caregivers have typically not been widely examined through research or addressed through counselling interventions. In addition, much of the existing research done is based on quantitative, rather than qualitative methodology, which may not be the best or only way to learn about some psychological aspects, needs, concerns and issues of HIV/Aids and about other populations concerned, since the psychological aspects are often neglected in research.

### 5. Therapeutic Work

From the researcher's experience at both Kalafong and Natalspruit hospitals, he found that the ability to switch treatment modalities as dictated by changes in the individual or family's needs is important. He also discovered that a reframing technique is effective in what counsellors could offer to the HIV/Aids patients. In using reframing patients would be helped to affirm the circumstances that contributed to their current situation, and facilitate their acceptance as well as discussing possible options available to adequately address the traumatic situation from a position of coping rather than helplessness. This process might leave HIV/Aids patient feeling much better and empowered. He believes that healing could occur through the therapeutic relationship. This type of healing is based not on 'curing', but rather on the power of sharing the patients' narratives.

A willingness and flexibility on the part of counsellors to address concrete service needs of HIV/Aids patients as they arise is essential. The rescheduling of time and missed appointments is important. Finally, sensitivity to language and cultural differences of patients is of utmost significance and their understanding provides the foundation of effective treatment.

A quotation by Chesney (in Hoffman, 1996) describes some of the diseases' trends as follows:

Many should not expect HIV/Aids to be the last pandemic. The conditions that created this pandemic have the potential to perpetuate others. Because of this, we can use HIV/Aids to help prepare for future epidemics. Our response to HIV/Aids can serve as a template for responding to other health crises. Will HIV/Aids adequately prepare us to respond effectively to other health

challenges? Will we have learned effective strategies that prevent the spread of disease? Will we have learned psychological interventions that alleviate the distress of those who are infected and significant others, as well as those who ensure that these services are delivered, whatever the costs. Most important, will we have learned to view all those affected in a more compassionate way that reflects that we are all in this together; that what happens to others also affects us all (p. 281).

The researcher hopes that this piece of research work will serve as an inspiration and encouragement to other counsellors to meaningfully appreciate and confront their own grief as well as to understand their own psychological effects and experiences of working with HIV/Aids patients.

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