

NURSING IN TRANSITION: NEGOTIATING THE EXPERIENCE

**AN EXPLORATION OF THE IMPACT OF THE AIDS PANDEMIC ON THE SUBJECTIVE
WORK EXPERIENCES OF PERI-URBAN NURSES**

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ABSTRACT

A substantial amount of international research exists examining the impact of HIV/AIDS on health care workers. However, the impact of HIV/AIDS on nursing staff in South Africa has been relatively neglected. The primary objective of this study was to examine the impact of the AIDS pandemic on the subjective work experiences of peri-urban nurses in South Africa. The study explored the relationship between external changes in the nurses' working environment and their internal psychological responses for negotiating this change.

A focus group of eight nurses was conducted, followed by indepth individual interviews with three group members. A grounded theory method was utilised to process and analyse the data. The research showed that nurses experience two forms of change. It was suggested that nurses respond to external changes in a manner designed to maximise their control and sense of meaning in an unpredictable environment. This accommodation involves the restoration of an internal psychological equilibrium through a process of balancing positive and negative experiences. The attainment of such an acceptable equilibrium may allow for diminished stress, increased satisfaction or fulfilment and the validation of personal and professional significance.

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CHAPTER 1: INTRODUCTION

1.1 Motivation for the study

The Acquired Immune Deficiency Syndrome (AIDS) and the Human Immune Deficiency Virus (HIV) are responsible for social, cultural and economic upheaval throughout the world. In South Africa, a country with an escalating prevalence rate of infection in the population, the implications of this pandemic should not be underestimated.

A substantial amount of international research exists, examining the impact of HIV/AIDS on health care workers. However, the impact of HIV/AIDS on nursing staff in South Africa has been relatively neglected. There is a need for research exploring in what way the experiences of nurses internationally are similar or different to those of South African nurses. Furthermore, as the cultural and socio-economic contexts of South Africa are unique, research is required to reflect the specific concerns of South African health care workers. At present much of the South African research in the field of AIDS is focussed on the rights and needs of the infected patient. While this is extremely valuable, there is a gap in our knowledge of how health care workers are being affected by the pandemic. Unless the needs and concerns of these workers are explored and acted upon, the health care system will lose dedicated staff whose care and expertise is vital in addressing the vast patient numbers effected by the pandemic.

In this study, the researcher's personal experience in Hospice work and interest in the field of professional nursing was influential in determining the field to be studied. It was through training, supervising and supporting professional nurses working in the field of AIDS that an awareness of the challenges they face arose. Hospice, as an organisation, makes provision for constant support and training of its staff members. This expertise resulted in the Hospice at which the researcher was employed being frequently requested to intervene in other organisations and institutions which did not routinely offer such supportive services. The researcher therefore became involved in a networking arrangement, offering support to nurses working in the hospital and community clinic systems of a peri-urban region of the Eastern Cape. Working with these nurses provided a glimpse of the profound impact that the AIDS pandemic has had on their experience of themselves as professionals. It was therefore decided to pursue a research question which examined the impact of AIDS on nurses, raising awareness of both the difficulties and

successes of these remarkable women. Such findings could serve to inform training practices and promote the need for regular support structures within hospitals and community clinics.

This study then, was an investigation of how peri-urban nurses negotiate the changes in their work, necessitated by the AIDS pandemic. Using theoretical sampling, eight nurses were approached to attend a focus group interview. The focus group was conducted to explore the various aspects, both positive and negative, of working with AIDS patients. Three of the group participants were then selected for indepth individual interviews. All participants were asked open-ended questions about their experiences including, "What are the positive and negative aspects of working in this area?" and "What differentiates this area from others?". The focus group and interviews were tape recorded and transcribed. A grounded theory method was utilised to process and analyse the data collected.

Using the concepts of grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990) a qualitative analysis of the data identified a number of similar conceptual categories. Common links and themes from both the focus group and the sets of interviews influenced the emergent theory.

The research showed that nurses experience two forms of change, the first having brought about the second. Firstly, there are changes in the nature of the work that they have to perform and secondly, the nurses themselves have changed to accommodate the new circumstances they face. This accommodation is required in order to restore an internal psychological equilibrium which is disrupted by the changes in their work. It is accomplished through a process of balancing positive and negative experiences until an acceptable equilibrium is reached.

1.2 The structure of the thesis

In chapter 2 the context for the research project is established through a literature review, culminating in the research question. In chapter 3 the methodology of the study is outlined. Included in this is a discussion of the qualitative paradigm and the grounded theory method. The processes of sampling, data collection, data ordering and analysis are discussed in detail, with reference to both theory and application in the study.

Chapter 4 is a presentation of the results of the research, which incorporates the beginnings of interpretation of the data. The final synthesis, interpretation and discussion of the data is found

in chapter 5. This split is deliberate in order to emphasize the emergent theory. The concluding chapter contains reflections on the research process and explores the contribution of the study, as well as its strengths and weaknesses. Finally, possibilities for further research are mentioned.

CHAPTER 2: CONTEXT AND LITERATURE REVIEW

2.1 Introduction

The HIV/ AIDS pandemic is recognised as a crisis for much of the developing world. In South Africa, an estimated 4.2 million people are said to be HIV positive (Whiteside & Sunter, 2000). Information is abundant about what the consequences will be, predicting declines in life expectancy, changing population structures, growing numbers of parentless children and an escalating demand for health services (Whiteside & Sunter, 2000). Increasingly, people are becoming ill, and clinics and hospitals are overwhelmed (Vasani, 1999). Significant alteration in the existing health care system will be required to meet the demands which the pandemic brings (UNAIDS, 2000).

2.2 The challenge to health care systems

People with HIV/AIDS have a range of health care needs. Most HIV-related conditions can be managed effectively at the primary health care level, where basic treatments can improve the quality and length of life. However, as the disease progresses, demand changes. Patients need care for both acute, treatable problems and terminal conditions (Barnett & Whiteside, 2002). Increased demand comes from young adults, who are not normally users of health care services. In one relatively well-resourced South African province it was estimated that HIV/AIDS alone will more than double the required number of hospital beds between the years 1997 and 2006 (Barnett & Whiteside, 2002). Clearly the scale of this projected demand is problematic as the health sector is already struggling to provide for basic medical needs.

Barnett and Whiteside (2002) warn that due to the dynamic nature of the pandemic the impact will be felt in waves. Firstly there are the HIV infections, then the AIDS cases, thirdly the deaths and finally the consequences. They predict that “whatever we face today in Southern Africa, it will be worse over the next few decades” (p. 28). HIV/AIDS compromises the capacity for health care through its direct and indirect impact on the people who provide the services (Whiteside & Sunter, 2000).

There is a growing burden on the health care system, and on the professionals within it who

provide the services. At present the focus of the limited resources is on providing for the needs of the patients and their families and most health organisations have not been structured to provide support for staff who are experiencing the death of patients on a daily basis. The AIDS pandemic has sparked off new fields for specialization and research but in many ways, the health care providers have been left behind (Harley, 2000). Much research, both local and international, has focussed on the medical and psychological needs of the patient. Limited attention has been paid to the experience of professional nurses working within this field. Unless the needs and concerns of nurses are explored and acted upon, patients will continue to lose dedicated staff who are vital to quality health care.

2.3 Stress in nursing

The existence of occupational stress in the health professions is not in dispute and is extensively supported in the literature (Bailey & Clarke, 1989; Bennett, Miller & Ross, 1995; Ngwezi, 1997; Sherr, 1995; van Dyk, 1993). Bailey and Clarke (1989) suggest that nurses in particular experience excessive stress. Not only is the physical nature of their work taxing, but in addition, 80% of their time is estimated to be spent interacting with patients and their relatives. They pursue their argument by stating that, "one can hardly pick up a nursing journal, or even read a newspaper article about nursing, without finding the word 'stress' used liberally" (Bailey & Clarke, 1989, p.xi).

Ngwezi (1997) researched work stress in a group of African nurses working in South Africa's health care system. The study focussed on general hospital nursing, stress responses of nurses and their coping strategies. The research confirmed international findings that nursing is a challenging and stressful profession. In particular, Ngwezi (1997) found that hospital work environments are highly stressful and expose staff members to extremely demanding roles. It was suggested that situational factors, managerial styles, the limited scope for promotion, poor working conditions and salaries were key features in making nursing stressful.

Much of the understanding about work stress and its impact on health care providers has come from the burgeoning literature on burnout, perhaps mainly because health care has been seen from the beginning of burnout research as the rightful domain of such work (Maslach & Schaufeli, 1993). The reason for the focus on these professions was that they were seen as occupations

where the goal is to provide aid and service to people in need, and which can therefore be characterized by emotional and interpersonal stressors (Maslach, Schaufeli & Leiter, 2001). According to Maslach et al.(2001), exhaustion, cynicism and inefficacy can result from chronic interpersonal and emotional stressors in the workplace. Burnout then is the term for a stress reaction to work related pressures which results in such symptoms. It is suggested that there are situational and individual characteristics involved in experiencing work life as positive or negative (Burke, 1988).

Maslach et al.(2001) have identified that professional nursing incorporates all the categories of situational factors which are likely to increase the chance of work related stress. Firstly, *job characteristics*, such as high work loads and qualitative job demands (for example, the severity of patients' problems) are a regular feature in nursing. Secondly, stressful *occupational characteristics* for nurses include frequent contact with patients with stressful problems and needs, compounded by limited resources to assist such patients. The expectation that nurses should restrict and control their emotions in response to patients' situations is a further occupational characteristic contributing to stress. Such emotional factors have also been identified by Zapf, Seifert, Schmutte and Mertini (2001) who have found that these factors account for increased levels of stress and even burnout, over and above other job stressors. In particular, in the medical arena, such stress is manifest as a marked decrease in efficacy, with a slight increase in cynicism and exhaustion. Lastly, *organisational characteristics* impact on the work experience of nurses. Because organisations exist in a social context, social, cultural and economic issues may effect them, bringing about change in working conditions and value systems within these organisations (Maslach et al., 2001). A current example of this is the impact of AIDS, a social dilemma, on the South African health system. As organisations within this system try to respond to the pandemic, much of the burden of implementing the change and providing the necessary services falls on the nursing staff who hold the infrastructure together.

2.4 AIDS/HIV care as a speciality

Nursing then contains many factors conducive to work stress. Within the nursing field, the area of terminal care and AIDS nursing is particularly loaded with these stressors. Many of the difficulties experienced generally in nursing are compounded in the exacting and demanding work

of palliative care (Mc Grath, Yates, Clinton & Hart, 1999). Palliative medicine is an approach for treating active, progressive, incurable disease. It aims to treat symptoms as they arise, but due to the incurable nature of the illness, it is unable to address and cure the underlying condition (Sanei, 1998). Palliative nursing is both a rewarding and an emotionally draining specialization (Mc Grath et al., 1999). In Hayter's (1999) study of community nursing sisters working with AIDS patients in the North of England, 66% of respondents scored as moderate or high burnout cases, indicating that the nature of the work is very stressful. Similar findings are present in the research of Catalan, Burgess, Pergami, Hulme, Gazzard and Phillips (1996) who showed that the stress of AIDS and cancer nursing contributed to abnormal levels of emotional exhaustion, depersonalization, and concerns about personal accomplishment. Several other writers highlighted through their studies the uniquely stressful nature of nursing in this area of medicine (Gueritault-Chalvin, Kalichman, Demi & Peterson, 2000; Kelly & St Lawrence, 1988; Kübler-Ross, 1969; van Dyk, 2001).

In their examination of general stress among health care providers, several authors have explored the question of whether specific AIDS related concerns increase the likelihood of work stress and even burnout for staff (Bennett et al, 1995; Bennett, Kelaher & Ross, 1994; Mc Grath et al., 1999; Miller, 2000; Sherr, 1995). There seems to be some controversy over whether HIV/AIDS care providers experience unique stresses. Miller (2000) reports research which suggests that unique characteristics of HIV/AIDS care include secondary stigmatisation from working with a stigmatising disease, identification with patients who may have the same sexual orientation and experiences as the health care provider, the absence of a cure and the inevitable fatal outcome, the intensity of the pandemic with its high numbers, fear of being infected with HIV in the work place and finally, the constant exposure to death and dying. Other research suggests that the burdens faced by HIV/AIDS health care providers are not yet proven to be unique. However, the recognition given to the potential for staff stress by the media, patients and health staff groups probably is unique (Miller, 2000). From the outset of the pandemic, the stresses in HIV/AIDS work were compounded by the high profile and often contradictory media attention that the pandemic attracted. This was due in part to the public stigma and fear associated with myths about methods of contraction of the disease (Miller, 2000).

These findings outline areas of concern similar to other types of terminal nursing and also dimensions which appear to be specific to the area of AIDS/HIV work. Much of this work is still

in its infancy and relates purely to a First World context. However the insights gleaned are briefly discussed below.

2.5 The experience of HIV/AIDS work

As well as its effect on the health care delivery system, AIDS has had a profound effect on the practice of medicine (Eldridge & St Lawrence, 1995). AIDS care incorporates general terminal care as well as other specific factors which make it a unique area of work. The literature supports the argument that AIDS has both introduced new challenges and exacerbated old problems for health professionals. However, it also highlights that with these difficulties come opportunities for staff development, personal fulfilment and job satisfaction (Bennett et al, 1994; Eldridge & St Lawrence, 1995; Miller, 2000). These various professional issues are outlined below.

The absence of cure: Research in three Australian HIV/AIDS units revealed that death and issues surrounding the death of patients were the greatest cause of concern for all health care providers. Several issues that were difficult or stressful were identified (Bennett, 1995), the first being the current lack of cure for AIDS. This is linked to the expectation that patients will be cured and restored to health by medical personnel. Nurses, accustomed to curing their patients, become taxed by their inability to provide substantial remedies to patients in the last stages of their disease. A sense of futility is often experienced by staff treating terminal patients (Eldridge & St Lawrence, 1995; Mc Grath et al., 1999). Often the nurse is only able to provide reassurance, emotional support and compassion which may not seem adequate in the face of such suffering. Health care providers may become frustrated by their inability to restore health to their AIDS patients (Kelly & St Lawrence, 1988). At present, health care providers in First World countries can treat opportunistic infections, slow progression of the underlying disease and offer palliative care, but cure is not an option (Eldridge & St Lawrence, 1995). However, in developing countries options for slowing disease progression are difficult to obtain and certainly not available to the majority of patients. This clearly suggests that a change of focus from cure to palliation is required if working in this area of nursing (Bennett, 1995).

Multiple deaths and workload: A second aspect relates to the number of deaths and responsibility for death. The workload may be very demanding and health care providers often experience

stress because of the large numbers of patients with HIV and AIDS (van Dyk, 2001). In the African context, frustration over lack of space and privacy in their work was also noted, due to the inadequate resources and large numbers (UNAIDS, 2000).

Constantly watching large numbers of young people in the prime of life wasting away can carry a heavy emotional toll for nurses (Kelly & St Lawrence, 1988). Indeed, this is a key feature in making the emotional strain associated with AIDS work different from other terminal illnesses (Kleiber, Enzmann & Gusy, 1995). Not only is AIDS concentrated in young adults, but the deaths are often lingering and painful (Eldridge & St Lawrence, 1995). The high death rate in AIDS patients can result in repetitive grief reactions in nurses, with little time to grieve before the next patient death. Piemme and Bolle (1990) warn that nurses working in AIDS face bereavement overload. Contact with constant patient deaths can lead to health care workers assuming responsibility for patient lives and losing sight of the numerous extemporaneous factors that affect the patient in addition to medical treatment.

A number of studies have explored the influences on health care providers of the time that they have worked in the area of AIDS. Stress, burnout and grief are all more likely to be reported after a longer period of time in this area of work (Bennett, 1995; Bennett et al., 1994, Catalan et al., 1996; Eldridge & Lawrence, 1995; Miller, 2000). The higher the percentage of time spent in contact with AIDS patients, the more likely the experience of psychological distress. It therefore appears that intensity rather than chronicity of work contributes to AIDS health care provider stress (Bennett, 1995). It has been suggested that the critical cutoff point for avoiding psychological distress is to spend less than 60% of the working week in the context of HIV-1 infection (Miller, 2000). If staff are to spend long hours or the majority of their work time caring for people with AIDS, they need to be prepared for the emotional impact of frequent deaths (Bennett, 1995).

The nature of the disease: A further area of concern involves the nature of deaths suffered by patients and the dilemmas of palliation versus aggressive therapy. The nature of the deaths was considered by nurses to frequently be more difficult than even the loss of young patients. Watching patients struggle with changes in body image, disfigurement and pain is very stressful for staff. Health care providers do not only have to contend with the ultimate loss of their patients

through death. They must also negotiate the multiple losses associated with patient care, such as witnessing their patients losing weight, vitality, health, friends and living standards. All of these losses impact on the nurses who support them through these situations (Bennett, 1995).

In addition to this, health care providers also suffer stress, frustration and conflict surrounding the decisions made about death. They are generally ill-equipped to deal with some of the ethical dilemmas posed by HIV and AIDS (AIDS Brief, 2000). At times it becomes difficult to know what is in the best interests of the patient, and difficult decisions about quality versus quantity of life may have to be addressed (Farsides, 1995).

Fear of contagion: Fear of HIV infection and AIDS are important predictors of staff stress and may impact on the way in which nurses and other health care providers respond to people with HIV related diseases (Essien, Ross, Ezedinachi & Meremikwu, 2000). Despite much information to the contrary, many health care providers fear the risk of contagion even though the chances of infection are exceptionally low if standard body fluid precautions are followed (AIDS Brief, 2000; Eldridge & St Lawrence, 1995; UNAIDS, 2000). Even when staff have been exposed to HIV- infected blood through needlestick injuries and other accidental on-the-job exposures, only 0.5% subsequently seroconverted. However, research identified higher levels of fears as the amount of contact with AIDS patients increased (Link, Feingold, Charap, Freeman & Shelov, 1987). Kelly and St Lawrence (1988) point out that there seems to be a gap between cognitive knowledge of risk and personal attitudes and anxieties, resulting in stress and fear.

Grief and loss: According to Bennett (1995) the influence of grief and bereavement on health care providers has received relatively scant attention. There are possible, yet unclear links and interactions between the experience of stress, burnout, loss and grief in the area of AIDS health care which requires further investigation (Bennett, 1995). A number of variables are discussed below which may contribute to the relationship between grief and stress.

A strong predictor of the impact of a patient's death on a health care provider is the strength of the bond held with the deceased person. The nature of AIDS-related illnesses often involves repeated contact between patients and the nurses who care for them. Due to this, a health care provider may spend more cumulative time with one patient than the average spent with a single

patient in many other areas of health care (Bennett, 1995). Nurses become closely involved with intimate aspects of their patients' lives. Furthermore, the holistic model of care that many international health systems now utilise sees nurses involved in the management of psycho-social as well as physical aspects of the patients' care. This increases the emotional attachment of nurses to their patients (Mc Grath et al., 1999). For many AIDS patients, their families are less available for support than terminal patients with other diseases. The health care providers become very important to the AIDS patients as they form a surrogate family. This further exacerbates the nurses grief when the patient dies (Bennett, 1995).

The length of time that a nurse has known a patient also helps to sanction the grieving associated with their loss. If the nurse has had a long-term relationship with the patient grieving is seen as legitimate. Bennett (1995) cites Doka, who introduced the concept of disenfranchised grief to assist the understanding of a loss that is not socially sanctioned. This refers to situations where a person does not have a clear, socially recognized right, role or capacity to grieve. The disenfranchised griever suffers a loss but has little or no opportunity to mourn publicly. The population of health care providers working in the area of AIDS often experience grief that is disenfranchised.

Over-identification: The degree to which health care providers identify with their patients has been shown to relate to the intensity with which they experience grief and burnout. On self-report questionnaires, nurses who experienced higher levels of grief were those who reported higher identification with people with AIDS (Bennett, 1995). This is explained as being due in part to a reduced ability to separate themselves from their work and over-involvement with patients. Conversely however, it has also been shown that positive work experiences are influenced by having close, empathic relationships with patients and may even buffer against burnout (Bennett et al., 1994). It could be argued that greater identification reflects greater personal engagement and satisfaction with work, reducing the likelihood of burnout. An additional dynamic of personal identification with the suffering of people with AIDS was also noted as a stress. It is recognised that health care providers may themselves be infected with HIV and thus be observing first hand how they too will become sick and die (Eldridge & St Lawrence, 1995; van Dyk, 2001).

In areas where many HIV positive patients are homosexual, over-identification can have both negative and positive consequences when health care providers are themselves homosexual. The contribution made by staff of the same sexual orientation can be very valuable, as they are not judgmental of the patient's lifestyle and can understand many of the issues with which the patient must grapple (Kalichman, 1998). This meaningful involvement may contribute to the health care provider experiencing the work as rewarding because of the contribution they can make. However, the negative side is that there is stress involved in caring for people whose high risk lifestyle is one's own.

While international literature still promotes the homosexual aspects of HIV/AIDS, the scenario is very different in the South African context. Here it is mainly a heterosexual disease, with only a small portion of patients being from the gay community (Whiteside & Sunter, 2000). It can therefore be argued that any health care provider who engages in high risk sexual behaviour may over-identify with patients as they remind him or her about the possibility of their own HIV positive status.

Powerlessness: A recurrent area of concern for nurses in the literature is that of powerlessness. Nurses report feeling helpless in the face of incurable disease and death, and may experience symptoms of depression, anxiety, hopelessness and general feelings of inadequacy in response to this (Bennett, 1995). Powerlessness and inadequacy are also experienced by health care providers when they are unable to meet the needs of patients. Setting professional boundaries is often difficult, particularly when patients are so desperate. This can be even harder in African communities since the extended family system means that a person is rarely a stranger in a village or community. The likelihood of a nurse or caregiver being from the same clan is often high. This makes limit setting on professional lines more complicated (van Dyk, 2001).

For the majority of AIDS sufferers in Africa financial hardship exacerbates their conditions. The message of positive living and healthy eating is inappropriate in environments where bringing any food to the home is a struggle. Nurses are faced with the extreme poverty of their patients and a lack of resources to eliminate the need (van Dyk, 2001). So too is the terrible plight of children a significant stressor for health professionals. How to care for or talk to the children who are left behind after a parent dies poses dilemmas, particular with limited resources available (van Dyk, 2001). All these situations leave nurses feeling very powerless.

Burnout: Miller (2000) explains that work stress is an individually based, affect laden experience associated with stressors which are subjectively perceived. A stressful work situation is one in which a person's coping resources are not well matched to the level of demand that is placed on them, or where there are constraints placed on coping, such as a lack of social support. The result is that the person will have negative emotions which chronically diminish well-being. Various factors have been identified that contribute to stress in the work place. These include changes in workload or type of work, increased or decreased responsibility and conflict with superiors or colleagues (Miller, 2000).

Job satisfaction is the result of appraising one's work in terms of the needs and values one has, and the possibilities for meeting these. These may include work that is mentally challenging, personally interesting or that provides rewards which fit with the persons aspirations. Work conditions which promote effectiveness or work that contributes to high personal self-esteem are also important (Miller, 2000). Work becomes dissatisfying if one or more of these conditions are not met. People require, at the very least, a balance between positive and negative aspects of their work in order to avoid burnout. This state of equilibrium facilitates coping. Clearly, a more optimal state would be where positive work aspects exceed the negative. However, if this is not possible striving for balance will suffice (Miller, 2000).

Burnout among health care providers working with patients with HIV/AIDS is well documented (Eldridge & St Lawrence, 1995; Catalan et al., 1996; Maslach et al., 2001; Miller, 2000; Ngwezi, 1997; van Dyk, 2001). The burnout syndrome includes symptoms of physical and emotional exhaustion from the chronic stress of care provision. Other symptoms include the development of negative self-concept, negative job attitudes and loss of concern and feelings for patients (Maslach & Ozer, 1995). Much of the stress that nurses experience is inherent in the nature of the work that they perform. They witness daily the effects of an incurable disease which kills mostly young people and causes terrible suffering (van Dyk, 1993).

Eldridge and St Lawrence (1995) suggest that there is a need to look at both the individual health care worker and at health care systems when trying to understand causes of burnout. They believe that the role of the institutional level is under researched and that problems within these structures are fundamental in causing work related stress.

Professional uncertainty: Professional adequacy may be challenged in a variety of ways. AIDS forces health care providers to re-examine and readjust values and beliefs acquired early in their medical training. Beliefs such as that medical science can cure most diseases and that the role of the health care provider is to cure, have to be reassessed. If these values are not revisited then staff may perceive the deaths of young productive adult patients as personal failures (Eldridge & St Lawrence, 1995). Miller (2000) reports that health care providers may experience conflict between traditional health work goals and the consequences they have for some patients. This is particularly the case when new treatment opportunities arise and are clamoured for by an increasingly anxious population, only to then fail or make patients more sick. Health care providers may experience feelings of uncertainty about what they should be offering patients as they grapple with the question of whether they are prolonging life or prolonging death.

Training and developing new skills: Medical training is changing in response to AIDS. In certain areas concern has been expressed that too much emphasis will be placed on the disease as teaching hospitals become inundated with AIDS patients. The fear is that training professionals will get limited exposure to other conditions because of the enormity of the pandemic (Eldridge & St Lawrence, 1995). A related issue is the demand on health care providers to remain abreast of emerging information about a new and complex disease, that requires complicated medical interventions and current information on diagnosis and care. As a result, health care providers like nurses may find themselves providing services for which they feel untrained, inadequately informed and uncomfortable. Nurses also face patient needs for which they may feel unsuited, such as psychosocial support, counselling, and being confronted with difficult topics such as sexuality (Eldridge & St Lawrence, 1995; van Dyk, 2001). Interestingly, in an attempt to address directly which issues of care gave the greatest stress for HIV /AIDS health care providers, Scottish nurses and physicians were investigated and asked what they thought were the unique demands of HIV/AIDS care (Miller, 2000). Overall the most demanding aspect reported of their work was working with families of people with HIV and providing psychosocial support.

Disclosure: Secrecy and fear of disclosure among people with AIDS, makes the nurses' task of caring for AIDS patients very difficult. If they are required to keep the HIV positive diagnosis a secret, accessing appropriate medical help can be difficult or impossible. Nurses cannot educate

and equip family members if they cannot tell them that the patient has AIDS, and so the nurse carries the responsibility alone. It is also impossible for the nurse to prepare the family for the patient's death if the AIDS diagnosis is a secret (van Dyk, 2001). A further dilemma is that while required to keep HIV status confidential, nurses are sometimes aware that the patient is putting others at risk by repeatedly having unprotected sex (AIDS Brief, 2000). This raises concerns about whose rights are to be protected.

According to Kalichman (1998) people affected by stigmatized medical conditions, often hide their diagnoses from others, especially when symptoms are not visible. The social context of AIDS creates an environment of shame and secrecy that fosters concealment of a HIV positive test result. The reasons for doing so vary: some individuals fear rejection, others wish to avoid pity or want to protect their loved ones from the emotional pain and embarrassment they anticipate. Still others have concerns about discrimination if their status becomes known. For certain individuals, concealing their HIV positive status may be part of an effort to maintain as much normalcy as possible in their life (Kalichman, 1998). For the patient, choosing not to communicate their HIV condition to medical professionals and family can result in their not receiving adequate or appropriate medical assistance and support. Health care providers involved with such patients can experience much frustration in trying to afford them the best possible care. In Kay's (2000) paper the controversial issue of confidentiality was raised, querying whose rights are being protected by the rigidity with which it is maintained in African countries. It was suggested that the rights of HIV negative people and health care providers are being overlooked as emphasis is placed only on the needs of HIV positive individuals. And, as mentioned above, even the patients do not always benefit from concealing their diagnoses. Ganasinghe (2000) supports this, suggesting that the accountability of health care providers needs to be balanced by equal accountability and attitude change from people with HIV/AIDS, in order to protect the interests of both groups.

Working with stigmatized groups: Health care providers have their own beliefs and values. Working in the field of AIDS/ HIV can bring them face to face with their own prejudices due to the prevalence of HIV infection within already stigmatized populations. In the USA, as it spread, the disease became localized in the populations of gay men, intravenous drug users, the urban poor, and racial and cultural minorities (Eldridge & St Lawrence, 1995). As a result, in some

cases attitudes expressed by health care providers toward patients with HIV or AIDS extend from preexisting prejudices. Patients may be held responsible for their illness in ways that individuals with other chronic and fatal illnesses are not (Eldridge & St Lawrence, 1995). In South Africa the stigma is mostly derived from the fact that AIDS is a sexually transmitted disease. Here, the most prevalent mode of HIV transmission is heterosexual intercourse (Barnett & Whiteside, 2002). Thus nurses may hold patients accountable for contracting the virus, assuming promiscuity, which is socially frowned upon. While such attitudes are clearly detrimental to the patient's well-being, they may also evoke stress for staff who resent providing care to people they feel could have avoided their condition.

The stigma associated with HIV and AIDS stigmatizes both infected individuals and uninfected people working in the field. The secondary stigma can have a powerful effect on the health care provider's status with family, friends and the public at large. Health care providers may be deprived of much needed support if they become ostracised by their family and professional peers who are uncomfortable with the disease or the life-styles of AIDS patients (Kelly & Lawrence, 1988; van Dyk, 2001). However, other studies have shown that there can be social rewards attached to working in this arena. Health care providers are often admired and supported by friends and other professionals for performing work which is perceived to be hard and gruelling. This recognition is a factor in perceiving the work as valuable and in coping well with stress (Catalan et al., 1996).

Risks for staff in developing countries: The potential for occupational stress in AIDS/HIV health care providers can be expected to increase in the near future, particularly for those in the developing countries (Bennett et al., 1995). Among the reasons for this are that the numbers of people with recognised HIV and AIDS are rising rapidly, there are more frequent deaths and overwork is increasing. Sadly, as numbers increase, so resources are decreasing, adding to the stress of nurses who are trying to assist.

In many parts of the developing world whole communities are increasingly becoming riddled with HIV and AIDS. This means that health care providers are unable to find distance from the disease. Further stressors include that the patient presenting characteristics are altering, with the "patient" increasingly being the whole family, groups and communities of orphans (UNAIDS, 2000). Lastly, many overt psychological pressures are being increasingly recognised as important in care

and management of people with HIV and AIDS. In areas where resources for such needs are not available the burden may fall on staff not fully equipped to provide these services.

Additional work related frustrations for health care providers mentioned in the UNAIDS (2000) report included not receiving the necessary support from superiors, having to work in isolation, training, skills and preparation for the work are often inadequate and limited resources restrict the extent of the services they can provide. It was also felt that as the people in the forefront of the pandemic, directly providing services to patients, their opinions and innovative ideas should receive more attention.

Personal growth and reward: Lastly, while research provides many indications that health care providers find dealing with death extremely challenging and difficult, there are also indications that work in the area of AIDS/HIV is an opportunity for personal growth. In Bennett's (1995) study, nurses reported that they gained understanding of people's capacity for dignity, a sense of the community spirit that can be found through this disease and reassurance of the human tendency to hope. While nurses provide patients with support, many report receiving support and friendship from their patients, as well as learning valuable lessons from them. The positive aspects of AIDS care, such as intellectual stimulation, challenge and personal growth were also identified in other research in this area (Bennett, 1995; Demmer, 2002; Miller, 2000). It is of interest to note that in Hayter's (1999) study, many of the stressors considered to contribute to the presentation of burnout were paradoxically also found to be factors which made the work meaningful to the research subjects. These included working with patients for long periods of time and forming close, emotional bonds. Overall, most studies suggests that there are positive and negative dimensions of AIDS care and that the balance between these different facets of the work environment determines the degree of staff stress (Bennett et al., 1994).

2.6 Responding to the experience of AIDS/HIV work

Coping and adaptation: While working in this field may be fulfilling and many health care providers have responded with sensitivity and compassion, they may still require assistance in handling the stress and fears created by caring for AIDS patients if they are to adapt and cope. Acknowledging the stressful nature of work in the AIDS/ HIV field is the first step to implementing measures to counter the effects of stress. Doing so legitimizes the feelings of

distress rather than seeing them as signs of personal weakness or a lack of professionalism (van Dyk, 1993).

Stressful work requires some form of adaptation. Seven stages of adaptation are identified by Kavenaugh (1973) as shock, disorganization, volatile emotions, guilt, loss and loneliness, relief and re-establishment. Shock and disorganization result from health care providers seeing increasing numbers of patients dying when they have been trained to cure and indeed want to see people getting better. Volatile emotions occur periodically for many nurses during their work in terminal care. Part of coping effectively with such feelings is being in a supportive work environment which understands the importance of emotional expression (van Dyk, 2001). Years of conditioning may have taught nurses that outward displays of emotion are unacceptable, resulting in them suppressing their true feelings. This makes it difficult for others to extend help and support as they may be left unaware of the distress their colleague is experiencing (Bennett, 1995).

Understanding and dealing with the guilt is the third stage. The death of a patient can cause nurses to discredit the care they provided and to question if everything possible was done. Learning to deal with feelings of guilt is important and has considerable effect on the quality of future care provided (Bennett, 1995). At times feelings of guilt may be used to address feelings of helplessness. Finding themselves culpable of some oversight gives a false sense of responsibility and belief that there is something that health care providers can do in the face of death (Price & Murphy, 1984).

The stage of loneliness comes when the reality of the loss is unavoidable. Should the loneliness persist, the risk of burnout increases and it may be a signal for taking time away from work. However, a supportive work environment can facilitate an adaptation to the stress. Health care providers who cope with these stages may experience a strong sense of achievement at having adapted to the stress. As Bennett (1995) aptly states, these stages not only afford understanding of the positive outcomes of adapting to the stressful work, but they also alert us to variables which can contribute to maladaptation, such as unresolved guilt and retention of emotion.

Various authors have recommended ways of managing stress and perceiving the role it plays in the work experience. An alternative view of the "purpose" of burnout is provided by Price and

Murphy (1984). They offer a view of burnout as a coping response, in part, to loss. They consider burnout to involve considerable loss for the health care provider, as it entails loss of an aspect of the self, which may include disillusionment, loss of motivation for creative involvement and withdrawal from emotional engagement with patients and colleagues. Burnout then is an indicator of underlying problems, which once identified, through the symptoms, can be addressed.

A recommended method for managing stress is cultivating an internal locus of control to reduce internal stressors associated with working in AIDS care (Bennett, 1995). It is advocated that health care workers be taught coping skills which involve personal agency rather than relying on external factors to reduce stress. Such a style of coping involves believing that they can make a difference for their patients, rather than having a pessimistic attitude. This shift allows health care providers to perceive their actions as important and healing, even when they do not lead to cure (Bennett, 1995).

Other suggestions by Bennett (1995) to enhance health care provider's coping is to actively change the focus of care in AIDS from a traditional cure-based approach to a psycho-social achievement model. The incurable nature of the disease makes it appropriate to emphasize psycho-social interventions rather than cure. These interventions increase the dying individual's psychological comfort and are extremely valuable. Focussing on these psycho-social "successes" may act as an antidote to burnout (Bennett, 1995). Self-awareness and realistic expectations of self are identified by van Dyk (2001) as fundamental to coping with work stress. Setting attainable goals for work with patients requires a recognition that in the context of AIDS the emphasis needs to be on caring and not on curing. There is also a need for clarity about the limits of responsibility so that nurses do not impose unfair expectations of themselves.

Relaxation, healthy eating and plenty of rest are recommended for health care providers. Awareness of the need for self care is vital to managing the stresses of working in the field of AIDS. So too is the use of available support systems. It is recommended that if such resources do not exist, nurses should establish their own, either formally or informally (van Dyk, 2001). However, it was also noted that while support groups in particular can be very valuable, secrecy and non-disclosure can make attaining much needed support very difficult, especially in communities where secrecy is the norm (van Dyk, 2001).



Adequate training for the tasks involved in AIDS care is a buffer to stress. Knowledge is empowering and does much to alleviate anxiety and uncertainty in health care providers. Working as part of a multi-disciplinary team is also an effective way of protecting nurses from undue stress because it spreads the burden of care and responsibility and accesses a variety of knowledge and expertise (Brown, Schultz, Forsberg, King, Kocik & Butler, 2000).

2.7 Implications for South African nurses

The magnitude of the impact of AIDS on Third World countries has necessitated a shift in the palliative care paradigm to one that is more all-encompassing. It has become necessary to broaden the definition and scope of palliative care to include a much broader set of interventions, from initial diagnosis to the last stages of the illness, rather than concentrating only on the terminal stages of disease (Sanei, 1998). One implication of this for nursing professionals is that even those who have not chosen to work in a palliative modality are now required to do so.

In addition to this, since the advent of the AIDS pandemic in South Africa, there has been a shift away from pure primary health care nursing in clinics (Tutani, 2000) to a focus that includes terminal and palliative care. The demand for care has become too great for institutions specialized in terminal and palliative care, forcing clinics and hospitals with a more primary health or curative focus to become involved. Nurses who chose to work in these environments because of the curative and preventative nature of the work, are now forced to face the challenge of working with the seriously ill and dying. A pertinent example of this is that specialist hospitals such as those for Tuberculosis (TB) now have large portions of their patients diagnosed as HIV positive. These patients frequently die of TB, due to complications imposed by the Human Immune Deficiency Virus. Prior to the AIDS pandemic, TB was an illness for which the prognosis was extremely good (Cronje, 2000). In this way the pandemic has brought pressure to bear on health care providers by forcing a change from their accustomed curative approach, to palliative nursing, for which they are ill equipped. The involuntary nature of this shift in nursing focus may add an additional dimension to the experience of palliative nursing in the field of AIDS.

While the experience of AIDS care nursing is well described in the international literature, little attention has been given to this in South African research. The South African context has its own unique dynamics which in combination with the extent of the pandemic contribute to nurses'

experiences of both stress and fulfilment. In particular, the South African setting of peri-urban nursing sees staff facing numerous challenges unique to a Third World environment. This study therefore proposes that there is a need to explore the subjective perceptions of nursing sisters in a peri-urban area of the Eastern Cape, regarding their experience of the transition from curative to palliative nursing, necessitated by the AIDS pandemic.

CHAPTER 3: METHODOLOGY

3.1 Aims of the research

The overall aim of this research project was to explore, through a qualitative methodology, how peri-urban nursing sisters experience working in the field of HIV and AIDS. The study is based on the premise that understanding of this experience can be gleaned from speaking with a sample of such nurses and analysing their self-reports. The way in which they describe their work experience, their personal responses to their profession and the issues which they choose to highlight provide insight into the world of their work environment. The research hoped to find among the participants varying perspectives on their work experience, as well as a variety of ways of perceiving and addressing pertinent issues. It was hoped that this project would provide a body of research that could encourage and aid the understanding of how nursing sisters are experiencing the AIDS pandemic as it directly impacts on them. The possibility exists that this research, of limited scope, may lead to further research in this field that will promote awareness of nurses needs and their significant contribution to addressing the enormity of the pandemic that the world, and more specifically, our country is facing.

3.2 Research question

In an attempt to meet the aims outlined above, the following research question was asked:
How has the transition from curative to palliative medicine, necessitated by the AIDS pandemic, impacted on peri-urban nursing sisters' subjective experience of nursing?

3.3 The research methodology

3.3.1 The research paradigm

This is a qualitative study using two methods of data collection. According to Cresswell (1998) "qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem." (p.15). It is conducted in a natural setting where the researcher is an instrument of data collection, gathering information in the form of words or pictures and analysing them inductively with a focus on the meaning they have for the participants. The process is then written up and the researcher builds a complex, holistic picture of the experience of those chosen for study (Cresswell, 1998).

A qualitative approach is indicated when a process needs to be explored. It is also useful where

variables are not easily identified and theories are not yet available to explain the behaviour of the participants under study. A qualitative study also allows for the provision of a detailed view of the topic and enables individuals to be studied in their natural setting. This approach was also chosen because of the role of the researcher in this paradigm. In qualitative research the possibility exists for the researcher to be seen as an active learner in the process, who can then tell the story of the participants, rather than an “expert” who passes judgment (Cresswell, 1998).

A qualitative approach is appropriate to this particular enquiry because the study aims to explore the reported experience of subjects (Kelly, 1999). Throughout the study the focus will be on subjects’ personal interpretations of their work experiences.

3.3.2 The grounded theory method

In order to embrace unique themes which may be present in the data, a grounded theory approach will be used. Neuman (1997) states that “the purpose of grounded theory is to build a theory that is faithful to the evidence” (p. 334). Grounded theory, developed by Glaser and Strauss, has also been called the constant comparative method (Hueser, 1999). It is a qualitative research technique which uses an inductive approach guided by a set of procedures, in order to explore a particular phenomenon (Strauss & Corbin, 1990). The theory which emerges from this method of untiring comparison between categories, is grounded in the data, which then supports the existence of the theory.

Glaser and Strauss (1967) first proposed the method as a way for undertaking social research. According to them, the unique goals and strategies of grounded theory were a valuable alternative to the prevailing empiricism of the time. They believed in a pragmatic approach where “the theory must fit the situation being researched, and work when put into use” (1969, p.3) and therefore saw the value of their method as being its ability to fit the different social problems being researched and providing a wider application than traditional empirical methods.

Since Glaser and Strauss’ initial writing, grounded theory has evolved, resulting in the emergence of various forms of the method. The different forms seem to agree on the basic tenets of the theory but differ on issues of implementation and practice. However, it would be fair to say that

for all versions the concept of constant comparison remains important (Hueser,1999).

There are five steps to the emergence of theory according to the grounded theory method (Pandit, 1996). These steps are research design; data collection; data ordering; data analysis and the literature review. A discussion of the first and last steps is provided below, while the remaining three will be elaborated on further into the chapter.

The research design is the first step towards the emergence of a grounded theory. The research project first begins to take form when the researcher finds an area of social process which warrants exploration (Pandit, 1996). This is the beginning of the formation of a research design and a sample and methodology are identified as appropriate to the area of study. Further focussing of the questions to be asked allows the study to become defined (Strauss & Corbin, 1990).

In this study, the researcher's personal experience in Hospice work and interest in the field of professional nursing was influential in determining the field to be studied. Through formal and informal conversations with professionals working in these areas, certain possibilities for research emerged. The questions giving rise to this study were formulated in respect of these discussions.

The last step Pandit (1996) details is the literature review. It warrants attention at this point in the methodology simply because this is an unusual position in comparison to other research approaches. In traditional research methods the literature review is a fundamental aspect of the initial phase of the research. An extensive search of the existing literature pertaining to the topic is used to inform and guide the hypothesis and questions being asked. However, the grounded theory method utilises literature resources differently (Strauss & Corbin, 1990). With this approach, the researcher does not know ahead of time what areas will become relevant, because the method dictates that the themes and issues be allowed to emerge as the data is collected. Therefore, doing a detailed literature review in grounded theory is difficult and it is recommended that the difficulty be overcome by becoming familiar with the broad area of study (Glaser & Strauss, 1967; Strauss & Corbin, 1990). It follows then that a narrow focussed literature review was not attempted in the early stages of this research process because this may have resulted in the researcher exploring the area of study with pre-established hypotheses and knowledge which

could potentially impact on the theory (Dey, 1999). Any researcher will naturally enter into their research with a particular frame of reference which sets the parameters of interest, but this needs to be acknowledged and suspended in order to allow themes to emerge from the data. This then ensures that the theory is “grounded” in the data (Cresswell, 1998). Furthermore, the absence of an extensive literature review prior to data collection makes certain that literature is not given a position of privilege when compared to data (Dick, 2000; Strauss & Corbin, 1990). Rather, any available literature is treated as data and in some cases may be analysed together with any other data collection, thereby becoming an integral part of the data collection and analytical procedure (Dick, 2000). This process of interweaving the emergent theory with existing literature is valuable in enhancing the internal validity, generalisability and the theoretical level of the theory being created, particularly as the emerging theory is often based on a very limited sample (Pandit, 1996). The process of literature analysis continues until the point of theoretical saturation is reached.

3.4 The participants

When the aim of the research is to develop theory rather than to estimate population parameters theoretical sampling is best employed (Fife-Shaw, 1995). For a grounded theory study, the researcher chooses participants based on their ability to contribute to an evolving theory. This is termed theoretical sampling, a subcategory of purposive sampling (Cresswell, 1998). It is a common sampling method in qualitative research where statistical inference is not needed. The advantage of this method is that the participants are chosen from people most likely to give the greatest insight into the research question. However, it is important to note the disadvantage that it is possible to end up not utilising people who might contradict the emerging theory (Fife-Shaw, 1995).

In line with the above, in this project a theoretical sample was used as people were approached who best represented the group whose experience was being explored (Strydom & De Vos, 1998). Since the aim of the study is to explore the experience of nurses working in the field of HIV/AIDS, key organisations and institutions in this work were targeted. The respondents for the focus group were selected with the assistance of members from the HAST [HIV/AIDS, Sexually transmitted diseases and Tuberculosis] Committee which is co-ordinated by the District Health Office in the Makana Region. It was established that there would be two participants from the local government hospital, two participants from the Tuberculosis hospital, two from the

municipal clinics, a Hospice representative and a representative from the psychiatric hospital. Once the target institutions were decided on, the researcher approached the matrons in charge and requested their permission to conduct research with some of their staff. The purpose of the project was explained, as well as the need for confidentiality and voluntary participation. Once permission was given, the matrons identified staff members who they felt could contribute to the study. These nurses were then telephonically approached by the researcher and invited to attend the focus group. In assessing their willingness to participate, issues of confidentiality, voluntary participation and the time commitment involved were clarified. If willing to participate, the date and time of the focus group was provided and transportation requirements established. At the beginning of the focus group, each participant was asked to sign a consent form [Appendix A] detailing their willingness to participate, right to confidentiality and their right to withdraw from the study at any time. The form also highlighted the possibility that some participants would be approached for further interviews after the group meeting had been analysed.

The subjects for indepth interviews were selected from the professional nurses who attended the focus group. This was again based on their ability to contribute to the study by providing more detailed information than that gleaned during the focus group.

All 8 participants were qualified professional nurses and 7 had furthered their qualifications and become nursing sisters. Their ages ranged from early thirties to mid-fifties, and all had been in the nursing field for over seven years. All focus group participants were female, one was English speaking and the remainder spoke Xhosa as their home language. However, as all were proficient in English, the group was conducted in this medium. For the interviews, all three participants were from a Xhosa background and had been nursing for between 10 and 25 years.

3.5 Data collection method

The research project had two phases to data collection. The first phase of the research project took the form of two preliminary interviews to pilot the project conceptually and to ensure that an appropriate psychological register could be attained. In the second phase, data was collected by two methods, namely a focus group and semi-structured indepth interviews with selected members of the group.

In a grounded theory study, data may be collected in a variety of ways such as focus groups, interviews, relevant literature, documentation and observations (Dey, 2000). For this study the option of a focus group followed by interviews was chosen as it was thought to reveal the most

amount of data for a small scale project. The questions asked in both the focus group and the interviews were designed to be open and general, to let the respondent direct the course of the interview. After the initial stage of data collection, a Grounded Theory approach requires that further data collection is based on what has already emerged from the data (Dey 2000). This is labelled “theoretical sampling” by Glaser and Strauss (1967) and is a flexible, dialectical process which is based on the understanding that comparative and variably rich data will be obtained through further data collection.

3.5.1 The focus group

Millward (1995) defines a focus group as a discussion based interview that produces qualitative data for the researcher. Focus groups aim to gain clarity about participants understanding and perspectives on various issues. They are valuable when the interaction among participants is likely to yield the best information and when participants are similar and cooperative with each other (Cresswell, 1998). While focus groups may be used as the main method of data collection in studies, they are most frequently used as an adjunct to other methods, being deliberately chosen to complement, prepare for or extend other forms of gathering data (Bloor, Frankland, Thomas & Robson, 2001). In this enquiry the focus group was valuable in establishing key areas of work experience for nurses, which were then elaborated on in the interviews. In the focus group eight nurses were asked about their current experience of working in the field of HIV/ AIDS. Using a semi-structured focus group schedule the participants were requested to discuss the challenges and rewards they thought their work situation presented, as well as any changes they felt there had been in their work experience over the last 5 years. The group also explored their perceptions of the reasons for the changes they had experienced. The focus group lasted for between 2 hours and was videoed and audio-taped to facilitate analysis of the data.

3.5.2 Indepth individual interviews

The purpose of the qualitative research interview is to “obtain descriptions of the lived world of the interviewees with respect to interpretations of the meaning of the described phenomena” (Kvale, 1996, p.30). What is aimed for is an interpretations of the meaning of central themes in the life world of the subject. The interviewer registers and interprets the meaning of what is said, as well as the manner in which it is said (Kvale, 1996).

Interviews play a central role in the data collection in a grounded theory study. Cresswell (1998)

recommends the identification of interviewees based on purposeful sampling procedures. This is followed by an assessment of the type of interview which is most practical and which will provide the most useful information to answer the research question. In this study semi-structured interviews were used. These involve the implementation of preformatted questions that are asked in a systematic and consistent manner that also makes provision for the interviewer to digress and pursue new avenues introduced by the interviewee. This freedom to digress allows the interviewer to elaborate on the answers given by the interviewee, and make unscheduled probes into answers that may need clarification or more detail (Seidman, 1991).

The areas that were focussed on in the interviews stemmed from key issues raised in the focus group, such as challenges and rewards of the field of HIV/AIDS nursing. After identifying themes evident from the focus group discussion, the indepth interviews were conducted with three of the participants from the focus group. Those nurses who had contributed most freely in the focus group were targeted for further interviews as it was hypothesised that the most information would be gained from them. For each initial interview a semi-structured interview schedule, based on information from the focus group, was used. The purpose of these interviews was to expand on, and clarify, some of the themes which emerged from the focus group discussion and to incorporate additional individual perspectives which did not emerge in the group setting. Each participant was interviewed twice, with the interviews lasting 1 hour each and being audio-taped. The initial interview was analysed and used to facilitate exploration in the final interview.

3.6 Data processing

The data was processed by transcribing the focus group and individual interviews and then analysing the data using a Grounded Theory approach. The research project makes use of the grounded theory techniques of coding, constant comparison and integrative diagramming (Strauss, 1987). Notes and observations made during the group and interviews were used as supplementary data. The focus group transcription was done prior to the conducting of the interviews, and was used to construct an interview guide.

The process of reading through the data to establish the overall processes being communicated is called data ordering and sets the scene for a detailed analysis. Here, the researcher also organises the most significant incidents or happenings into some form of order. This ensures that data analysis is facilitated and that the basic social processes are clear and can be methodically

examined (Pandit, 1996).

The initial coding of the data is accomplished by examining each line of text, or even each word. Everyday practical knowledge as well as the theoretical knowledge the analyst brings to the study influences the process of coding (Van Vlaenderen, 1999). Coding is based on a concept-indicator model that involves the constant comparisons of indicator to indicator. Indicators, which are words taken from the text, are chosen according to their relevance to the analysis. The indicators are compared with each other (constant comparison) and this forces the analyst into “confronting similarities, differences and degrees of consistency of meaning among indicators” (Strauss, 1987, p. 25). The method of constant comparison entails the constant questioning of gaps, oversights and discrepancies (Van Vlaenderen, 1999). Indicators that are similar are coded into conceptual categories. The categories are then examined to ensure the indicators fit best into the categories they have been placed into. Indicators are moved around and category labels are changed until “the codes are verified and saturated, yielding nothing new” (Strauss, 1987, p. 25).

The final stage involves diagramming the results of the coding process. This entails presenting the coded categories in a diagram format (Strauss, 1987). More detail of these processes is provided below.

3.7 Analytical procedure

Grounded Theory uses set procedures which must be rigorously and meticulously followed to analyse the data. Using this method, three types of coding were employed to analyse the transcribed data from the focus group and interviews. The four sets of data were comprised of the transcriptions from the focus group and the three participants interviewed. The set considered to provide the greatest amount and richness of data was prioritised for analysis. The other three sets were rank ordered according to the amount and detail of data they provided. In total all four data sets were analysed in detail, with the less detailed sets confirming and elaborating on emerging themes in the more substantial sets.

The data sets were individually analysed and then contrasted with the next data set, and their respective similarities and differences used to understand the properties and dimensions of the emerging categories (Pandit, 1996). This process was repeated until all sets had been examined and compared with all other sets. Dick (2000, p.13) provides a useful diagram to understand this process, which has been reproduced below:

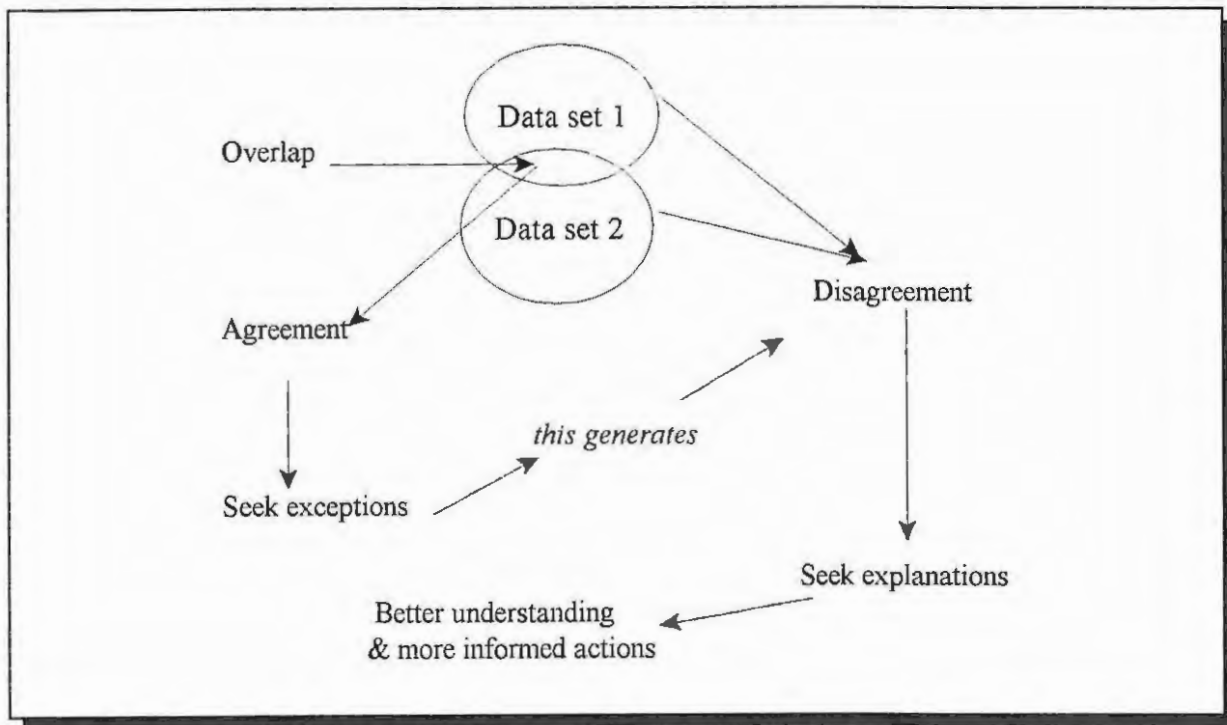


Figure 1. The Grounded Theory Process; reproduced from Dick (2000, p.13).

The analysis following a Grounded Theory approach consists of open, axial and selective coding and was conducted as follows:

- Initially a process of open coding was employed where the data was examined and themes were coded into categories (Dey, 2000). Open coding facilitates the naming and categorizing of phenomena in the data, breaking it down into parts which can then be compared to other parts for similarities or differences (De Vos & van Zyl, 1998). A theme was any specific issue that was expressed within the data. The themes, once labelled, were grouped together via a process of constant comparison, to form categories. The transcripts were examined and the text was divided into what information fitted Positive work experiences, Negative work experiences and Change experiences. These three categories emerged from the focus group as the categories which the nurses used in describing their work experience. Fragments of the text were then placed into categories under the three headings [see Appendix B]. The focus group transcript was the first to be addressed. This allowed the researcher to broadly organise the nurses reports and to identify further, more detailed areas of work experiences. Doing this not only allowed for a better understanding of the information gathered but also identified areas for further exploration in the

individual interviews still to be conducted.

- The themes were then observed to identify ways in which they related to each other. These related themes were grouped to form categories [see Appendix C]. Following Dey (2000) the emphasis was on categories that were “analytic and sensitising rather than representational” (p. 8) ensuring that diverse and varied happenings were drawn out and not just common themes.
- Theoretically, axial coding follows the process of open coding, although in reality they may occur interchangeably (Strauss & Corbin, 1990). Axial coding is used for interconnecting the categories (Cresswell, 1998) and allows the formation of initial hypotheses about the possible relationships between categories and subcategories (Hueser, 1999). This coding method requires the researcher to examine the categories in detail so that relationships and dimensions can be highlighted and explained. For the purpose of this study Strauss and Corbin’s (1990) flexible paradigm model was used to examine each category according to the context, causal conditions and actions or interactions used to manage the phenomenon. Intervening conditions such as cultural norms and resources were also identified, as well as strategies taken as consequences of these conditions. The outcome of the axial coding was that it provided detailed definition of the categories initially established by the open coding stage.
- Finally selective coding was used where the core categories were identified and systematically related to the other categories, constantly validating the relationships and filling in other categories which needed to be refined or developed (De Vos & van Zyl, 1998). This process of relating the categories to the core category forms the basis of the grounded theory which emerged. Selective coding builds a narrative about the relationships between categories, resulting in a discursive set of theoretical propositions (Cresswell, 1998) which explains and integrates the categories and their relationships which have emerged from the earlier analytical steps (Strauss & Corbin, 1990).
- The analysis of data and theoretical sampling stops when theoretical saturation has been reached. This occurs when the concepts in the data no longer reveal any new categories, properties or relationships (Glaser & Strauss, 1967). The research process ends as no further information, related to the created narrative is expected from additional data collection (Dey, 2000).

3.8 Ethical considerations

Consideration was given to ethical principles in all aspects of this study. Confidentiality and anonymity of participants was maintained throughout the research process. The right to decline to participate or withdraw from the study at any time was emphasised verbally for each participant at the time of signing the consent form. In addition, it was arranged that verbal feedback would be provided to all participants at the conclusion of the research. A brief written report, adhering strictly to the agreed participant confidentiality would be made available to the HAST meeting and other relevant institutions, on request.

3.9 Internal and external validity

In qualitative research there is an acknowledgement that interpretation is always present and that the findings are not judged against a universal truth. Instead here, validity is about the researcher attempting to reflect as closely as possible the experience of the participants of the study. What is produced then is not a generalizable, objective theory, but a theory grounded in the experiences of eight women. Validity is enhanced by the researcher making explicit the process of interpretation of the data.

In an attempt to ensure that the research was internally and externally valid, triangulation, in the form of two methods of data collection and analysis was used. Informant verification was also employed to ensure that the data has been interpreted in a way that reflects the reality of the participants. This allows for an explicit clarification of the researcher's bias, while ensuring that the interpretation offered is viable (Banister, Burman, Parker, Taylor & Tindall, 1994). The verification of many of the emerging categories and themes by the existing literature was also used to validate the research process.

CHAPTER 4: RESULTS

The nature of qualitative research is such that a split between results and interpretative discussion is often neither possible nor desired. The intermingling of results and discussion most aptly reflects the research process. With this in mind, the current chapter contains both results and some interpretative comments. A concluding synthesis of the discussion is provided in chapter 5. This allows the reader to first view the emerging patterns and then to consider the researcher's suggestions of how they interrelate.

From the data it is apparent that change is a key aspect of the nurses current work experiences. Nurses perceive multiple changes which they believe are a direct result of the AIDS pandemic.

When we started there were not a lot of people that came in being sick. But oh! With the AIDS and HIV now, people and things have really changed. They are changing so fast!

The pervasiveness of the pandemic ensures that nobody in the health profession can escape the impact, and nurses repeatedly emphasised this point in statements such as,

Like things are changing now. It's been in (*name of ward*), even the private patients, they do have it. It's everywhere. It affects everybody.

The challenge that AIDS has imposed on health professionals cannot be underestimated. The unpredictable nature of the disease and its rapid spread has meant that health care has had to accommodate new types of care with little time to adapt. Again this is demonstrated by comments such as, "It was a change of everything that I used to do."

The data analysis revealed that the change nurses are experiencing takes two forms. Firstly there are changes in the nature of the work they are performing. Secondly, there are changes in the nurses themselves in terms of what they feel and how they negotiate the changes. The results presented in this chapter provide a synthesis of these two forms of change and are diagrammatically represented in Figure 2.

The overlapping of certain themes within the results reflects the research process. The repetition has been retained as it serves to provide the reader with a sense of how strongly the themes emerge. It also highlights that with each repetition a new facet is added, culminating in a richer understanding of the concept under discussion.

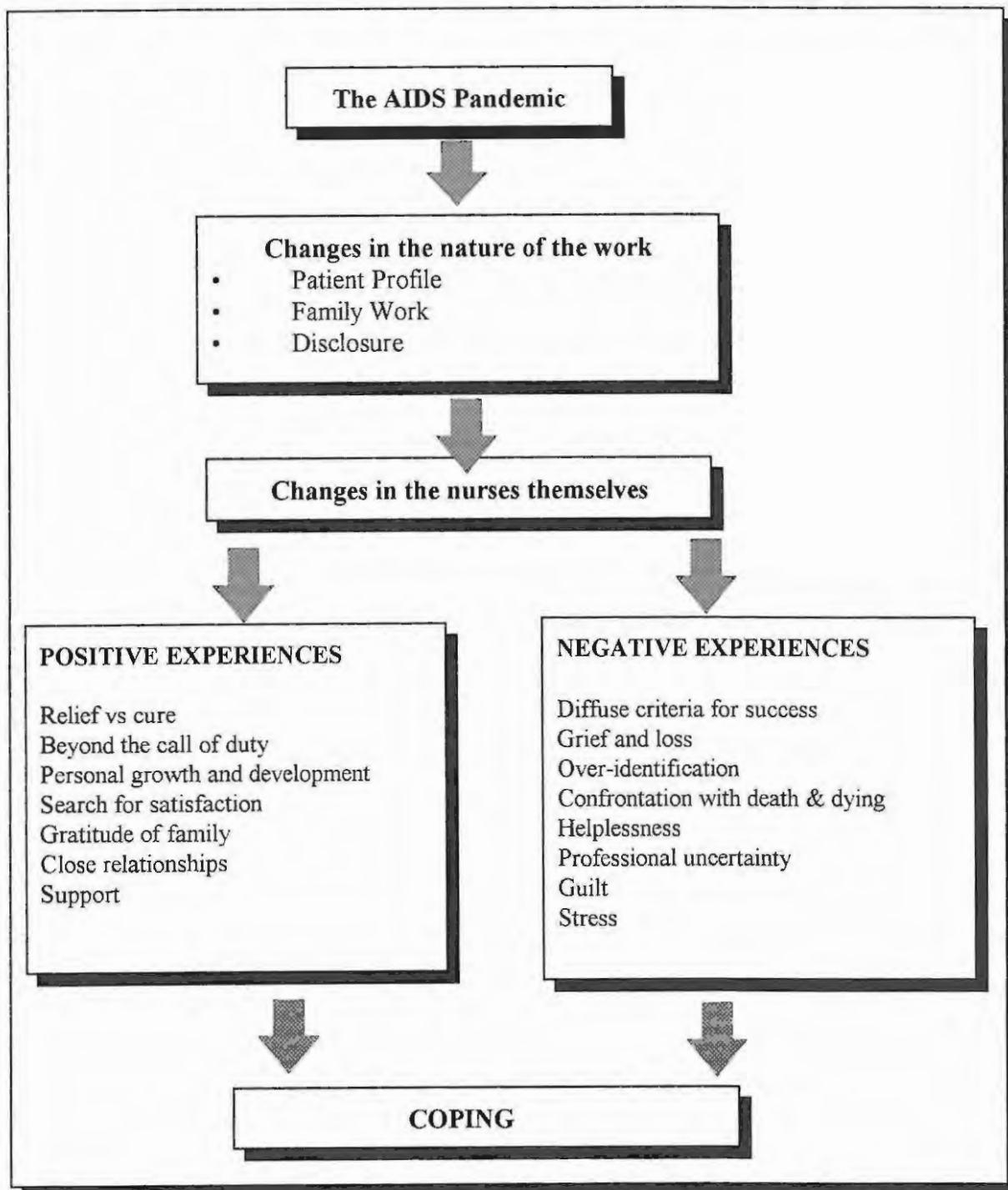


Figure 2. Nurses experience of change in the nature of their work and in themselves as they respond to the change.

4.1 Changes in the nature of work

4.1.1 Patient profile

The data reveals that the nurses perceive the profile of patients to have changed over the past five years. They spoke about the numbers of patients being different and that the definition of who

the “client” is has changed. The age of patients has shifted and the nature of the conditions requiring treatment is also different, being more complicated and severe than in the past. Furthermore, an increase in the number of terminal cases that nurses carry has necessitated a shift in the type of nursing that these patients require. Nursing then has seen a change in focus from that to which the participants were accustomed. These areas will be explored in detail below.

Number of patients and workload: Nurses report an increase both in the numbers of patients testing HIV positive and in the number of patients now regularly attending municipal and hospital clinics because of HIV and AIDS related illnesses.

So the pile was getting bigger, at the same time, more people were being diagnosed.

It was explained that as the pandemic progresses and patients move from HIV to AIDS, so the demand on health services is increasing. Nurses perceive this shift already, as indicated by the following statement:

And people are coming regularly to the clinic now. These were coming once in three or four months, but you can treat them better two or three times a month. So they.. we are really, we see the same person monthly. The same faces. It’s because they are getting sicker and sicker.

The client redefined: The AIDS pandemic’s devastating impact on both those infected and their loved ones has necessitated a broadening of the definition of who the “client” is. Nurses now find that they are providing services not just to the patient alone, but to his or her entire family system. Such services take the form of both physical and psycho-social interventions.

In light of the redefined “client” mentioned above, nurses have found that their caseloads are extremely large.

It’s quite a lot because of all the clients, as we also extend care to the family, for clients with AIDS and HIV.

Caring for both the patient and their family means several new “clients” for every one HIV positive patient. Added to this is that when a patient dies, the family continues to require support, so there is no decrease in work for the nurse. They still call on her, throughout their grieving process, and sometimes even beyond this due to having experienced contact with her as a valuable support. As one nurse stated, “I can’t get rid of the families. I’ve got to be with them too.”

Age of patients: A change that has been very difficult for nurses is the shift in the ages of patients

for whom they are caring. With the AIDS pandemic it is the younger patients who are dying and who are testing HIV positive. A nursing sister described her experience of the age group of patients infected as,

More especially in the late teens, up to the late thirties. The parents are burying their children and grandchildren, and that is very stressful.

All nurses commented on this shift. They stated that while it was never easy to have a patient die, geriatric patient deaths were more tolerable because the person had had their chance in life. The death of young adults, teenagers and children was heartrending.

Type of disease: Of the patients utilizing health care services there is a marked increase in the number who are HIV positive and who have full blown AIDS. Nurses also identified changes in the types of diseases that they are having to treat, which they link to the presence of HIV and AIDS.

Really we are seeing a lot of things that we have not seen before, in the last five years. You are seeing now the impact of AIDS and HIV. I'm sure then it was only HIV. Now it's in stages of AIDS and we are seeing the diseases that we only read about.

In particular, they noted that diseases which had been eradicated due to medical progress are once again being seen in AIDS patients, whose immune systems make them susceptible to infections.

And we are seeing the diseases that people used to have, but that they don't have anymore because of medical advances. You know? Because of their immune systems.

Furthermore, diseases are being made more complicated in the presence of HIV and AIDS, and more difficult to treat. Even problems which were common, now present in new, more extreme forms. This makes them difficult to diagnosis and frequently, resistant to the usual treatments.

Anyway, we are not treating the same thing. If it's the ringworm, we just treat the ringworm. But now.....the ringworm that you are treating is not the same that you saw five years ago.

Severity of illnesses: Nurses are now seeing an increasing number of patients suffering from serious conditions, which are HIV/AIDS related.

Very much it has changed. People I nursed were not as sick as they are now... It was very rare to nurse a really young person who was very sick ... as it is now...

In particular nurses in municipal clinics, identify this as a marked change as before the AIDS pandemic they dealt mainly with minor ailments. They also reiterated how illnesses which should

be curable become complex when the patient is infected with HIV.

It is TB, but it's now always AIDS related... if it was just plain TB, with the treatment for six months the patient is cured. But the patients take such a long time now to recover and they have all sorts of illnesses in between, and now you don't have to concentrate on TB now, you are more caring for people who are sick and dying.

Hospital nurses described a similar change. They now see more seriously ill patients, most of whom are curable.

AIDS deaths: Nurses reported that they see more patients dying of AIDS now than five years ago. The enormity of the impact of AIDS is clear in the following statement:

Five years ago you never thought you would be seeing people dying like this. We are burying people on a weekly basis.

Type of nursing: A shift in the focus of nursing was identified by all participants in that they see a greater part of their work now being with patients who are seriously ill or dying. The most marked experience of a shift was presented by those nurses who work in the municipal clinics. They explained that at first, municipal clinics were only supposed to offer preventative and primary health care, such as immunisations, family planning and antenatal advice. All illnesses requiring treatment were sent to the hospital. Then approximately 10 years ago, policy changed and it was decided to make health care more accessible to the people. So clinics began to provide curative services which involved diagnosing, treating and dispensing medicine. Two of the participants had been integrally involved in this change explaining, "before if someone was sick, they never came to the clinics". If the first shift was from a preventative to a curative nursing focus, then AIDS has necessitated another shift. Nurses are now involved in terminal care to a far greater extent than before. There is now a more palliative focus to nursing, where only the patient's symptoms are treated because the underlying disease is incurable. Both community clinic nursing and general hospital nursing have had to include more palliation in their focus.

I had to change when I came to the community but it's more palliative. That was never here before.

4.1.2 Disclosure

Nurses find that the issue of confidentiality and disclosure of a patient's HIV positive status seems to dominate and influence their work with patients with HIV and AIDS. The normal patient confidentiality adhered to by all health professionals has become a complicated and controversial

issue when working in this field of nursing. What is different is that disclosure of their HIV positive status is greatly feared by the patients, due to the very real possibility of ostracism by the family and community. This has made patients wary of all levels of disclosure and reluctant to permit even health professionals to know their HIV positive status.

Confidentiality and the enormous emphasis placed on patients' rights imposes restrictions and pressure on the health professionals. While none of the nurses at any time denied patients a right to privacy, they find that the regulations and informal uproar around HIV disclosure is different to that assigned to any other medical condition. With other serious conditions, it is accepted that medical professionals will disclose a diagnosis to the team treating the patient. The absence of social stigma makes this a less emotionally laden occurrence. However, with HIV this is not the case. Nurses perceive the issue of disclosure, with its restrictions and pitfalls to have changed the nature of nursing. They identify several ways in which this has occurred, which are discussed below.

Legal issues: Nurses explained that as the current law stands, patients have the right to decide whether or not they are going to disclose their HIV positive status to family. Provision is made for nurses to disclose a patient's status to other medical professionals in order to facilitate the treatment of the patient. Such disclosure is legally permitted, even without the patient's verbal or written consent, if it is considered to be in the patient's best interests. However, in reality, patients resist this and can then become hostile to nurses if they discover that she has disclosed. Therefore, while a nurse is on sure legal ground if she discloses to a colleague, there are broader implications to doing this. Social sanctioning is as powerful a threat as legal action for the nurses, and they fear being labelled by the community as "gossips" and the criticism that may ensue if they are accused of disclosing when a patient did not want them to.

All health professionals must have the patient's consent if they wish to inform the family or patient's sexual partner about a positive diagnosis of HIV. However, if they are aware that a patient is deliberately infecting an unsuspecting partner they are able to inform the partner. But as one nurse indicated, doing this can seriously damage a trusting relationship with the patient: "You are able to tell that partner but it's a difficult one because we don't want to be policing people". However, with the patient's permission, written or verbal, the nurses indicated that they

can inform the partner about the patient's HIV status after the patient's death.

Therefore, both legal and social sanctions ensure that ultimately the patient has the final say about disclosure. This means that regardless of whether it is in the best interest of the patient, the nurse is bound by confidentiality.

HIV is not notifiable... no one is forced to tell. You cannot tell, if she says, 'I don't want anybody to know' then you've got to listen to that...or you are liable for legal action.... You can really lose your job if you start divulging. So you keep those secrets.

Consequences of breaches: Nurses emphasised their acute awareness of the penalties of being accused, falsely or otherwise, of breaching confidentiality. The fear of being accused of disclosing has serious consequences for the nurses. As indicated below in the discussion on working with the families of patients, one nurse had been called to a disciplinary hearing after the family had falsely accused her of revealing a patient's diagnosis. She commented,

So I nearly lost my job. So I hate this confidentiality.

Apart from formal discipline and job loss as penalties, nurses also have to contend with social ostracisation and gossip if they are accused of disclosing that a patient is HIV positive or has AIDS. What is vitally important with regard to this is that nurses perceive the risk of being falsely accused as far greater than being accused for having actually disclosed.

Because I told her that according to the policy we're supposed to send the results down to your nearest clinic. And she said, 'Please Sister, don't send down the results' and I said I would not. So now, maybe one time they [*the clinic*] might actually hear about it somewhere, she will say it was that hospital Sister who told. Yet you are not the one.

The feared consequences of confidentiality breaches, actual or perceived, is one reason for nurses being reluctant to get involved in HIV testing and patient care.

I remember one patient, she did confide to someone else. She doesn't like that one now. Maybe she thinks she goes out and tells the others. That's what I don't like about it. If maybe you come and confide to me... the next day you don't trust me.

The knowledge that someone is HIV positive was seen as making the nurse a target. Once she holds this knowledge the threat of being identified as the one "who has told" hangs over her head.

She thinks she is telling other people about her. I don't like it because maybe you're creating enemies at the same time that you're making friends. Because others will think if the community knows about the diagnosis, it's you who has been spreading rumours. That's the bad side of being a counsellor.

Enforced collusion: Patients' unrealistic or well-grounded fears of disclosure impact on the manner in which the nurses perform their work. Nurses are constrained by these concerns and see themselves as forced to engaged in extreme secrecy. The nurses often spoke of feeling that they were caught in the middle between patients needs and the needs of the families as a result of the rigours of confidentiality.

And it was really a difficult time because (*she*) was HIV positive, her daughter was HIV positive, but the two of them didn't know about each other. She was hiding this and it was difficult for me ... you know I had to be in-between these two.

As the "client" now often includes the patient's family system too, keeping secrets about the diagnosis raises concerns about which part of the patient system to prioritise for care. Nurses know that all aspects of the system are suffering, but for different reasons.

Because sometimes you know, as a nurse, that this patient is suffering from this, but the parents are also suffering because they don't know what is wrong with their child. So you can't even give them a tip that she's suffering from this, so let's make this and that.

Furthermore, they also expressed a sense of being forced to collude with the patient, even when they disagreed with their choices, for fear of being accused of breaching confidentiality. At times nurses believed that the patient's health and well-being were being compromised by their not disclosing, but were forced to allow this.

So you are caught in the middle, you really don't know what to do. Actually you cannot tell him what is going on with his child because if the mother didn't tell you that you can, then you can't. So you just don't know what to say to him until the baby dies.

At other times they struggled with being unable to inform concerned family members, and even having to lie to divert suspicion.

And at times they are very sick, they are being brought by a family member and somebody who is really concerned and would love to know what is really happening.

One nurse told of a family where the parents were desperate to help their ailing daughter. They knew she attended the clinic regularly, and so when they could not persuade her to tell them what was wrong, they came with her to see the nurse. While faced with their obvious pain and concern for their child, the nurse was forced to maintain confidentiality because this was the patient's wish:

She [*the patient*] was just sitting on a couch and they were right in front of me. And she is trying to stand up straight and tell me something. While I am talking to the parents she is trying to relay a message to me and she just ... 'Mmmm' and moved the head. She is pleading with me not to tell them. Meanwhile I am trying to find words... what to say to them.

Such situations place a burden on the nurse, who while trying to care for her patients, is aware that others are suffering.

Maybe you are the one who is keeping the secret, you know, it is a strain on you.

Nurses constantly expressed the belief that in many cases, non-disclosure was not the best option for either the family or the patient.

Nurses also spoke of an additional dimension to enforced collusion, where the family of the patient is known to them, or even a close personal friend. Here, they are forced to withhold sensitive information from people they know and care about.

And the other thing, when you test or you know the results of somebody that you really know of. It's either you know the parents and then unfortunately for you, you have to test their child's blood. And you have a sort of have a relationship with the parents, but now you have to keep a secret. You know, they are your friends. They are your friends, but you cannot tell them what is happening to their child. And you really don't know, in that case, what to do.

The position is aptly summarised in the words of one participant:

Once you know that this patient is dying from this... our legs are bind [sic].

Sometimes the collusion reaches a point where nurses fear that they may be putting other lives at risk by maintaining secrecy. The patient's decision not to disclose to family members can potentially put the family at risk for contracting HIV. Once a patient becomes ill and is being nursed by family, the possibility of contact with body fluid exists. Family members with no knowledge of the diagnosis are unaware of what precautions to take to ensure that they are not infected and nurses are not always able to warn family, for fear of raising their suspicions.

And at times when a lot of them are affected within the same family you start asking yourself, 'Didn't they get infected while they were still busy with her?'
Then you don't know, did they get it through nursing her... which is possible.

It is well known that patients with HIV and AIDS are at risk for contracting opportunistic infections. Patients who do not inform their family of their condition cannot involve the family in ensuring that they avoid infections. Nurses must watch as patients put themselves at risk for illnesses which they could avoid by informing their family.

So you are not able to tell other family member that, 'Please take care, don't infect her' because it is a misconception that she is the only one who will infect them. Yet they are the sources of infection for her (*with other diseases*).

Another group who might be at risk because of non-disclosure is the sexual partners of patients who are HIV positive. Although, as mentioned, nurses can inform partners at risk, this does not often occur. Nurses agonise over decisions about whether to disclose or not. Most often they try to persuade their patients to disclose themselves. However, patients are even reluctant to start using condoms because they say that their partners will require a reason for the change.

Because they are not able to tell the partner now, ... you have to explain why you are using condoms. Instead they now decide, "Okay, I'm not going to explain, I will go on without.

Restrictions on intervention options: For the patient, the cost of disclosing is perceived to be very high, and so it is often avoided. Non-disclosure is a fear driven response which frequently does not allow for the best interests of the patient to be pursued. Quality medical care cannot always be provided when secrecy is the patient's priority. Nurses stated that they are sometimes unable to provide quality care as they cannot always easily consult colleagues or give the most appropriate treatments without raising suspicions. As a participant explained,

So, in your intervention you are limited because you have got to nurse this confidentially.

Legally consultation between colleagues is permitted but patients are often resistant. Some patients will resist a nurse requesting a second opinion even when reassured that their HIV status will not be mentioned. Thus, options for referral and treatment are restricted, sometimes resulting in the patient not receiving the best care available.

At the clinic, at times you've got a problem, or you are not sure of a diagnosis or what to give, you always consult your colleagues. Now you say, "Okay, can I tell her?" but with them at times that you cannot do. And the best treatment or the best advice you could get from your colleague you cannot.

When going on leave, nurses have tried to refer their patients to other colleagues for the duration of their time away. Not only would this ensure that patients receive treatment, but it also lightens the burden of being the only person involved in the patients care. Again however, confidentiality issues frequently intervene, with patients sometimes choosing to be without health care for that period rather than have another person know their diagnosis:

They don't even want you to tell your colleagues so that if you are not around at least they can get help because somebody else knows. Then you are the only one who knows this.

A key example of such dilemmas was describe when nurses are caring for young men who are HIV positive and have to go into the bush for initiation practices. One nurse explained how she requests permission from her patients to inform male nurses, involved in the initiation process, of

the patient's status. This is so they can be well cared for if there are any problems. However, more often than not, the patients refuse. What then occurs is that while in the bush the patients become ill. As tradition dictates that they cannot have contact with females during initiation, an ill patient has to secretly communicate with the nurse to request treatment:

And when he is there you get the letters because when they are in the bush they are not supposed to communicate with females. So now this is stuck with the little boys, the little boys bring you... it's like in jail, they write on those match boxes... then they tell you in those few lines, 'This is happening. Please help.' And you have to roll in some few tablets for him. I mean, that's not treatment!

For some nurses, there was concern about appropriate interventions being limited because of restrictions on record keeping. They find that administrative records are being adversely effected by patients' fears of disclosure. What emerged was that patients are often reluctant to have their diagnosis or treatments written down, as they worry that others may read this. This issue seemed to be more relevant to the community clinic situation where the patients retain their "health passport" themselves, taking it home where other family members might read the contents. Patients would sometimes beg nurses not to write in the passport because of this. However, nurses, who are obliged to record all procedures carried out and medications given, find themselves caught between administrative requirements and the need for confidentiality. They also fear that if treatments are not recorded, patients may be inappropriately handled by another professional who is unaware of the medications the patient currently uses. Hospital nurses did not report the same extent of difficulties with recording, as it was accepted that hospital files are generally only accessed by other medical staff. However, they had experienced incidents when patients had pleaded with them not to record that an HIV test was done, to avoid anyone asking the results.

She asked me, 'Please Sister, let this be between you and me. Nobody else must know about this.' But I don't know how to keep it a secret because I'm going to write it down on the charts. So it is not easy to keep it confidential.

Nurses believe another limitation on intervention is that by not disclosing, patients deny themselves access to the best possible medical care and support. Their silence also limits the nurse in her ability to give quality care. While all nurses fully appreciated the difficulty of telling someone that you are HIV positive, they felt strongly that patients who stubbornly refuse to allow the nurse to help them disclose frequently do themselves a disservice. They see these patients as not getting care and support, dying without preparing their families for their death, being

subjected to traditional healing methods by family who are unaware of the diagnosis, and putting themselves at risk for further infection through unsafe sex and proximity to disease. There is enormous frustration for the nurses in having to collude with this.

And when maybe the secrecy part is just not there, then patients are able to die in peace. Because they take the baggage with them. They die having not told even their own kids that they are suffering... Your own family and you leave them in the dark. And it is only a nurse who knows.

Several nurses expressed hope that the situation will change with time and that patients will be able to make peace with their condition and the implications that it has for them:

Maybe as time progresses and HIV being accepted and de-stigmatized, you will be able to communicate with the family, and the patient will be dying in peace, having been able to make a will, having been able to say what he wants to say to the family. And you will know that there is no secret between you and somebody who's really dying, and it ends there.

Finally, a tension between the nurses own traditional upbringing and the knowledge of western medicine was raised as a potential stressor. This is exacerbated by issues of non-disclosure. At times nurses experience conflict between allowing their patients to make use of traditional practices because they know that they are important to them, and not having the traditional medications interact with those prescribed by medical doctors. A nurse described how at times a patient will die, and when clearing out their possessions, nursing staff will discover bottles of Xhosa medicine stowed away. The nurse feels frustrated, as she is aware that these traditional treatments have possibly inhibited the other medications that the patient was given. However, as most of the respondents in the research were themselves Xhosa woman, they tread a fine line of respecting the beliefs of their patients and knowing their importance, while also understanding the greater possibilities offered by 'western' medicines.

It was also reported that an inability to disclose the diagnosis to patients' families often leaves the nurse in a position where she watches families incurring great expense for traditional remedies and ceremonies, knowing that a cure will not be forthcoming. Furthermore, non-disclosure of diagnosis to family members can result in the patient being subjected to harsh traditional medicines which worsen their physical condition, simply because the family are unaware of the nature of their illness. This is captured in the statement below:

The other thing that really worries me is when the people they don't know what is wrong with this person. So they do all these sort of things, going to witch doctors and follow his medicine which is going to make it worse for this client.

4.1.3. Family Work

As mentioned above, the nature of the “client” has been broadened to include the family of the patient with HIV and AIDS, as they are frequently also in need of intervention both physical and psychosocial. This psychosocial care, like that offered to the patient, takes the form of counselling, linking with resources, facilitating grant applications and providing information.

Becoming involved with the family of patients was unanimously identified as a change in work experience which nurses perceived to be linked to HIV/AIDS. Before HIV/AIDS they worked little with dying patients, and contact with family was minimal, because patients were treated, became healthy and returned to their homes.

You had really little contact with the family..... and that seems to be changing a lot now.

Now, with the vast number of seriously ill patients, families are becoming more actively involved, necessitating nurses interaction with them. Furthermore, what was repeatedly stated was that a nurse now works with a specific patient for a reasonably long period of time, as they move through HIV into AIDS and then die. Family members are often involved during this time, and have many of their own needs. They also continue to require the support of the nurse once the patient has died.

You don't have that relationship with the family, but this time you had to have a relationship. Especially now because our patients are very young.

While this interaction was seen as positive at times, it was usually described as a challenge to the nurse for reasons outlined below.

Criticism by family members: Having closer contact with the family of seriously ill patients made the nurses very aware of the expectations and criticisms of the relatives. Most felt that they were under constant scrutiny, which was exacerbated by non-disclosure of the nature of the illness by the patient. The sense of being criticised related to several areas of patient care:

Neglect: Nurses felt that family members were often critical of them, implying that they are not doing everything possible for the patient because they have not cured them or referred them to someone who can. This happens frequently, and is particularly difficult, where family do not know or understand that the patient is terminal, and expect the nurse to offer a cure.

The relatives, they feel like their relative is neglected. They ask, ‘Why can't you refer?’ and meanwhile you know that there's nothing much that can be done, nothing else that's

going to be done for them and you feel bad.

You don't know what to do especially when they are now standing here around you and you have to do your procedures while they are watching you.

Nurses expressed regret when such misunderstandings prevent them from providing appropriate care and preparation for families. Below, a nurse describes how she was criticised because of the family's lack of knowledge:

The grandparents never understood why we didn't do more, and the worst is that they still don't know that their daughter is HIV positive.

Traditional beliefs and superstitions: There are certain myths or superstitions about nurses which can contribute to making the work with terminal patients difficult. It was mentioned that certain groups of people believe that when a patient is terminal, nurses give injections which hasten the patient's death. Families who believe this are therefore very suspicious of any procedure which the nurse carries out, even when they are attempting to increase the patient's comfort.

It is quite difficult for us to attend a patient where there are relatives around. More so because we know that the traditional belief is that when a patient is about to die the nurses accelerate the death by giving those injections. So when you are resuscitating or giving the injections....they say that we are accelerating the dying of the patient. So now, when they are around then you feel something inside you when you are giving that thing, because you know what they are thinking.

Nurses expressed their frustration with such superstitions, saying that it leaves them feeling criticised and wary when working with their charges. It also raises anxiety as nurses are placed in conflict between what the patients need and the families expectations.

We know we are helping these patients, but you know that the relatives are thinking that all these nurses are just finishing off my mother!

Public criticism or gossip: The power of social sanctioning was an important theme to emerge in the data. Nurses described how, particularly around issues of disclosure, they felt at the mercy of the patients and their families, because gossip about misconduct, even if unfounded, had severe implications for them. It was explained that if a family member felt that a nurse had neglected a patient who died, it was possible that this would be stated at the patient's funeral and the nurse publically chastised. This could occur even if the accusations were without foundation. Even more harmful to the nurses are accusations by families about having disclosed a patient's HIV status. Again, families are frequently inaccurate in their accusations, but for their own reasons will pursue them nonetheless. The cost of this to the nurse is social humiliation, professional

embarrassment and the strong possibility of facing a disciplinary hearing and dismissal. The fact that there is excessive secrecy around people's diagnosis was seen as contributing to this problem, as families become suspicious and look for a scapegoat, which is frequently the nurse.

They'll go around and talk, maybe even preach about you at the funerals and you feel bad. Sometimes, maybe if they knew (*the diagnosis*) it will not go that far, they won't let it go that far.

Gratitude: A positive aspect of involvement with patient's families occurs when the family is able to appreciate the care that is being provided, even if a cure is not forthcoming. This is clearly best facilitated by the family being aware of the terminal nature of the diagnosis.

I feel that it is better when the family knows what's wrong with their loved ones. They then appreciate everything really.

Nurses are sometimes included in funeral rituals by the family of patient's whom they have nursed. This is seen as an important validation of the care the nurse has provided and the family's gratitude.

And even if they die, they (*the family*) come and report to me, some of the clients they want me to go to the funeral.... they want me to speak there.

Limited training or experience of "family care": Nurses found the need to work with patients and their families to be a marked change in their work experience. They spoke of not feeling adequately equipped to meet the family's psychosocial needs, having not had sufficient training in family care.

We work a lot more with the family than just with the patients. When I was trained that's not what we did.

We were never trained for family care. Even if this one dies you are left with the family. There's a child... you still have to take care of the family with the sick child.... you have to nurse and make follow-ups.

Difficulties were experienced with not knowing how to balance the needs of the family with those of the patient. Nurses expressed a marked sense of loyalty and responsibility to the families of their patients and wanted to know how best to assist them. However, again they felt that their training had not prepared them for this.

You really used to have very little contact with the family....but that seems to be changing a lot now. I know for us it's very different because we're involved with the families, because you've got to worry about everything that's going on for the family members as well as what's going on for the patient.

Disclosure and confidentiality issues: The impact of patients choosing not to disclose their HIV

positive status to the family was a theme which emerged in various forms throughout the research. What was evident in the context of family work is that the nurses experience high levels of stress as a result of non-disclosure by patients. As discussed, nurses felt trapped by the confidentiality legislation, which at times seems to limit their provision of quality care to patients. Below a nurse speaks of her frustration and sadness at not being able to provide this family with the full extent of care available to them:

Because she wouldn't tell them, we've not been able to prepare the family for her death at all. And for us that's a failure because it's supposed to be what we're supposed to be doing.

One nurse described how she had been targeted by a family when it became general knowledge that their relative had died of AIDS. The patient had in fact been disclosing her diagnosis herself, but the family chose to scapegoat the nurse who had cared for her, saying she had breached confidentiality. This nurse had to appear before a disciplinary hearing and almost lost her job.

There was a patient... this lady was known to be HIV positive, as she was telling everybody... I was trying to help her... I was always there for her. But I was the one who went to the disciplinary enquiry. The relatives say that I said of what this lady died.....The relative said that it was [me] who spread the gossip. They said it is [me] who knows that this lady is HIV positive.

Limited resources: Nurses described being left with needy families after a patient has died and feeling a keen sense of responsibility for the families' welfare because of the nurse's prior involvement with them.

We see it in the community and it is really difficult for us now. We are trying to help the family afterwards... when a person dies and what to do with the children? How to help them. There are more people who need food.

The magnitude of the pandemic is stretching resources to their limit and the Eastern Cape is particularly badly affected. The need for poverty relief and social services is especially great among children.

And it was worse now when you visit them, you get there and you find they have lots of orphans.....And then you go to start scratching and getting money for buying bread for this family.

The lack of appropriate resources to which patients can be referred for social and poverty relief has extended the role of the nurse. Many felt obliged to help their patients financially and to become involved in seeking social grants and assistance for them.

4.2 Changes in the nurses themselves

Nurses find themselves responding in new ways to the changes in the nature of their work, brought about by the AIDS pandemic. Sometimes the experiences are not entirely new, but are exacerbated or enhanced by their changing work environment. These responses are discussed below with respect to the changes in the nature of work outlined above, as well as some additional changes which relate to the more general work experience.

4.2.1 In response to the patient profile

Relief versus cure: Prior to an increased amount of work with dying patients, nurses found much of the satisfaction in their work through healing patients. Nurses identified that curing or healing was something that gave them a sense of accomplishment.

We want the people who are coming to hospital to go back to their relatives (*healthy*).
That is what we are preaching.

In the context of HIV and AIDS, cure is not yet possible. However, given the incurable nature of the illness, there seems to be a shift in nurses approaches to patient care. Instead of offering cure in terms of the total condition, nurses find fulfilment in other ways, thereby responding to the change in patient profile. For example, when it is possible to assist a patient overcome one of the opportunistic infections, nurses experience a sense of satisfaction. While all acknowledge a desire and preference to be involved in cure, most were able to find satisfaction in providing relief for patients. Such relief took the form of the alleviation of either physical or psychosocial discomfort, and may therefore involve palliation or counselling, among other interventions. Nurses conveyed this shift in approach in statements such as:

You know, if I can do a little bit for them, that's what counts.

Just to make them suffer less.

Beyond the call of duty: There were several indications from nurses that they experience a sense of achievement when they have acted beyond the call of duty for their patients. This again is a response to changes in the extent of patient need and suffering. Nurses increased their involvement by doing home visits to patients and providing food and monetary support from their own resources.

I would take them as part of my family. Some of them go to my house, I give them food, I give them jobs... I feel like at least I go beyond my duty as a nurse.

It would seem that by giving that extra attention to patients, nurses attempt to combat some of the helplessness that they experience in the face of terminal illness:

the patients will die but during their stay, while they are still alive I will do my best. So that when they die, there is no part of me that is really affected. I'll really know that I've done my best.

Personal growth and development: Generally, nurses seemed to find the challenges of their field to be positive experiences. One of their responses to the changing patient profile was to see it as an opportunity for personal growth and development. This appears to include both emotional and intellectual development. Nurses felt that their work broadened their knowledge of medicine and enhanced their diagnostic skills. This was linked particularly to the AIDS pandemic where nurses are now seeing complicated, serious conditions of which they had no prior experience. The following excerpts capture their positive attitudes:

I think it is beneficial because you are always up to date with everything.

But working in the community was very, very fulfilling because I learnt a lot.

You need to be broad minded because if this guy is coming in with AIDS... you can feel yourself there is something opening up inside, ne? Because if you are ordering an antibiotic for the HIV/AIDS patient who has a respiratory tract infection, it's not going to be the same as like the patient with a straight respiratory tract infection....so you must know everything.

There was generally a sense of enjoyment at being in a field where they were not specialised in the nature of the work they were doing. Although some nurses identified this as challenging at first, having come from more specialised hospitals and wards, all stated that the stimulation of "needing to do and know everything" was a positive experience.

The negative side of not being specialised is that one cannot avoid specific types of patients or work. This means that with the prevalence of HIV and AIDS today, all nurses have some degree of contact with the disease if they are involved in general nursing.

You do everything, and there is nothing that you can say 'I don't like this, I'd rather do this than that'.

What also emerged was that working in this arena, while hard, had given opportunities for emotional development and personal insight.

And the whole process, you learn a lot about yourself. You know you also learn about the mistakes you have done because throughout that depression period of mine I learnt a lot about myself and that I must set limits for myself. I mustn't try to do things I cannot

do and I must accept the situation that HIV is here.

Diffuse criteria for success: Despite their attempts to adapt, nurses who have focussed on healing as the ultimate goal of their profession still struggle to work with more seriously ill patients. The change in the patient profile has challenged their ideas of what constitutes “success” in nursing. Most nurses have found this difficult to engage with.

You are used to a patient getting better, now you ask yourself, ‘What is it that I’m supposed to be doing?’ You don’t get that fulfilment.

Although nurses have made a remarkable effort to respond to this shift in the nature of their work, it continues to be a source of stress. Suddenly they have found that the criteria for success are quite diffuse.

You can imagine from somebody who gets fulfilled hearing or seeing people moving around healthy, and now you’ve got a bunch of people that you know, ‘if she is healthy today, tomorrow she’s very sick and that other day she will be much better’ and then you see them deteriorating until they die.

Providing relief does not always feel adequate, as nurses prefer to see their patients recover completely:

I’m not used to nursing dying people. I’m used to seeing people getting better. And I am still battling with that today.

The potential exists for the nurse to see herself as not having done enough for her patients, because cure has not been achieved. Such responses may suggest a risk for burnout.

There was a time that I blamed myself. I took everything upon myself. I wanted to do a lot. I wanted to do miracles, yet I couldn’t. And I felt so bad about myself and about nursing as a whole.

Grief and Loss: In the face of young, terminal patients all the nurses expressed varying degrees of grief and loss.

It hurts if it’s a young person, it hurts very much....an older person you know at least he has had his chance in life. This one hasn’t.

In the experience of grief and loss, the issue of disclosure again rears its head. In the extract below, the patient was known to the nurse whose grief was exacerbated by the patient’s mother’s refusal to acknowledge that her daughter had AIDS. An overwhelming sense of loss was experienced by the nurse, not just because of the death of a loved young person, but because she felt unable to fully assist her because of the non-disclosure.

She wanted to tell me but I'm sure her mother said no.... and I cried and she cried, you know, there in that bed. And I felt so bad. And the mother was sitting there and I cried and you know, that experience is still hurting me. And she died.

Throughout the data the link between loss and helplessness was apparent. Many nurses expressed despair at doing all they could and yet not being able to prevent numerous deaths.

Over-identification with patients and their families: Being part of the same culture as many of their patients, nurses feel strongly for the family who is losing a young person, because they understand the cultural ramifications of the loss. It is understood that in their old age, parents will be cared for by their offspring. The death of large numbers of young people from AIDS has seen this support structure being gradually eroded. Nurses identify with the fears of the parents and the despair of dying children who know they will be unable to provide for their elderly parents. This can result in the nurse "carrying" the family's pain, as she over-identifies with their feelings as if they were her own.

It hurts you very much now she is going to die, she's leaving behind her parents or his parents... who were looking forward to him.... You know you make an investment in your family in our culture. You know later you are going to reap.

Working with patients dying from AIDS raises fears among nurses for the safety of themselves and their loved ones, as they over-identify with the patients and families for who they care. Some fears are quite general and unrelated to HIV alone. They are issues about mortality and fear of suffering a painful death:

Sometimes you look at yourself or your relative and say, 'I wonder how am I going to die?'

Other nurses experience identification with patients, patient's parents and family members, specifically relating to HIV and AIDS:

And what makes it more stressful is if you've got children. When you see a late teenage person...and they have relationships with teenagers you're always thinking 'Gosh, my children!' So you are not only stressed by the HIV status of the patient, ne? You are also stressed by the unknown HIV status of you own children.

A nurse described how working with her first young AIDS patient evoked enormous anxiety about the well-being of her own brother who was the same age as the patient. She found herself very emotional whenever she was with the patient, and finally phoned home and lectured her brother on the use of condoms and safer sex.

Confrontation with death and dying: Nurses clearly indicated that in their current work they have more contact with dying patients now than they did when they first started nursing. This contact forces a confrontation with issues relating to death and dying. Nurses expressed views that they had seen a change in their work environment because of AIDS, particularly in the last five years. They come into contact with terminal patients more frequently now and find this a difficult experience, as many of them still have a curative focus and wish to see patients becoming healthy.

We become happy if we have done something. We don't want to see people dying.

It is hard especially if you know that you are nursing someone that is not going to make it, but knowing that you have done everything for them, yet they are not going to make it.

There is a strong sense of helplessness for nurses when confronted with an increasingly number of patient deaths. Nurses spoke of how hard it was when first starting to work with AIDS patients, saying for example, "I used to feel very stressed. In my training I was never prepared or trained to look after dying people." When asked what was particularly difficult, responses focussed on the absence of a possibility of cure as indicated in the following example:

Seeing them not getting better... We are used to curing people and then seeing them getting better. But with these, you know they are not going to get better and ultimately they die.

Furthermore, the nature of the illnesses which AIDS patients contract, results in much suffering. This was illustrated by a nurse who expressed a wish that the uncontrollable and unpredictable nature of the disease could be eradicated:

Because they die such horrible deaths. And the problem with it is it doesn't present with one thing. It presents with all sorts of things. You cannot choose and say, 'No, I'm going to die of pneumonia' or 'I'm going to die of Kaposi's Sarcoma.'... It presents with diverse things.

Nurses responses dealt mostly in the present, but some expressed concerns about the future, particularly regarding the likely increase in patient numbers and the degree of suffering as more people die of AIDS. While the extent of the pandemic contributed to their current stress at work, it also made some fearful of the future. One nurse stated that she felt uncertain about whether she would be able to continue working in this field because she saw such suffering now, but she predicted that this would increase tenfold in the future. She explained that, "What I'm seeing now, it is the tip of the iceberg" stating that as more patients developed full-blown AIDS the numbers of deaths would escalate. She doubted her ability to cope with this.

In ten years time I so wish God can take me, so that I don't feel what is going to happen. Because I foresee that a lot of people are going to suffer in ten years to come and I don't want to be part and parcel of that..... If God wants me to be part of what I foresee then it will be fine. But my wish is that I don't want to see the suffering that is going to come out.

When exploring these fears, nurses who expressed concern about the future of the pandemic were asked what they envisioned it would be like in ten years. Responses indicated anxiety about the number of patients needing care and uncertainty about nurses' abilities to cope with the demands made on them by these patients.

What are we going to do? What are we going to offer them?

It's going to be stressful for people who have not been through this. People who have not been involved, it will be new to them. We at least, we have been seeing the progression of the disease.

One nurse identified the greatest threat as, "It is fear of the unknown" as she felt that the unpredictable nature of the pandemic made planning and coping so very difficult.

Lastly, the issue of notifying the family that a patient has died emerged. Nurses spoke of this as a difficult and emotionally taxing experience for them:

I had deaths of young people and notifying the family is not an easy thing. Sometimes you think you're going to control your emotions, but when they (*the family*) come, ooh! It is very hard.

4.2.2 In response to disclosure

Issues around confidentiality and disclosure impact on the nurse to a significant degree. While some nurses have found satisfaction at times in persuading a patient to disclose to good effect, the majority of the time disclosure issues impede work satisfaction. There is a sense of resignation in the nurses response to maintaining extreme confidentiality.

And now you could have done this and this. But, I cannot do it, my best, because they always limit you because of confidentiality.

In search of satisfaction: Some nurses found that they had reasonable success encouraging their patients to tell their family their diagnosis once they started to become seriously ill.

It's the way I talk to my clients to show them and to see that the family needs to know. Especially when they are in stage three or four.

Being able to facilitate patients disclosure of the illness to their families was identified as a significant source of fulfilment for nurses. One nurse spoke of how she was able to work with a

family, close to the death of the patient, encouraging them to share what was happening to them. The patient died soon after this. For the nurse it was a very precious memory:

What kept me on was her smile and that she told me that the burden she'd had on her shoulders was gone. She was so happy that I had taken it off, because she had told her mother.

However, most nurses spoke of situations where patients refused to disclose and the consequences this had for those providing for their care.

You feel less content because you know, somebody else could have helped. You feel, 'I could have done more'.

Helplessness: In the face of controversy over confidentiality issues nurses expressed an overwhelming sense of helplessness. With most of their other challenges, a positive resolution of some form was found. However, with disclosure nurses expressed anger, frustration and powerlessness in response. When working with families, the limits of confidentiality left nurses uncertain of how to speak to relatives without lying to them:

Meanwhile, I am trying to find the words... what to say to them.

Not being able to inform the family of the diagnosis restricts the care that nurses can offer, resulting in feelings of inadequacy:

I could not know how to deal with this family. I felt very helpless. Helpless that I could have done more, that these people should have been supporting each other.

There was also a sense of helplessness in the face of the threat of social sanctioning or job loss. The possibility of being blamed for breaching confidentiality, despite the facts, makes nurses wary of involving themselves in AIDS work. They feel that there is little they can do to protect themselves in the face of social sanctioning, stating "And you are left so helpless".

Lastly, helplessness is also related to the area of terminal care. Nurses feel powerless to heal and relieve their patients at times. When a patient insists on not disclosing, nurses cannot always effectively offer palliative options to them. It is with resignation that one nurse stated, "And sometimes you cannot help people."

Professional uncertainty: Maintaining rigid confidentiality affects nurses confidence and sense of competence. They fear asking for second opinions from colleagues yet are caught in a double bind because without this consultation they are uncertain how to treat the patient.

When you have got a problem with a client in the consulting room... let's say palpating an abdomen ne? You are not sure what you are actually feeling there... you always call the other person for a second opinion..... but now she's [*the patient*] always worried that you might say something about her status, you know what I mean. So now you are not sure.... You are feeling uncomfortable about calling the other Sister to assist you, but you are also feeling unsure... you are just, you are not winning.

At times nurses begin to doubt whether the profession is still where they want to be as illustrated by one nurses statement that, "I don't know how I feel about nursing, because wherever you go you meet with this HIV. It's just everywhere."

4.2.3 In response to family work

Gratitude of patients and families: Many nurses spoke of how the gratitude of patients or their families enhances the nurses sense of enjoyment and purpose in her work. One nurse spoke of a family who still send her a gift every birthday in gratitude for her care of their son. The fact that they hold her in such high regard is important to her, as well as the fact that she was able to provide care to their child. Other nurses spoke of how the families have continued to visit them even when the patient has died, because the family appreciated the nurses' role to such an extent and still enjoy support from her.

When I went to see the family, you know, they said, you know, that they were happy they had me as part of what was happening to their sister because it was easier for them to understand what was happening.... You know, those are the kind of things that make me happy and fulfilled. At least I've done my bit.

Nurses remind themselves of these moments and recall them when under stress in order to help them cope.

Guilt: Guilt is experienced by nurses when they have knowledge of the diagnosis and the family does not. This is most difficult when the family is a caring and involved one, who would manage the information sensitively in the interests of the patient. However, if the patient refuses to disclose, the nurse is powerless to include the family.

Because the guilt come when the family does not know. You are the only one who knows. You know what is happening but you cannot tell. I'm not used to not telling.

Going beyond duty: As mentioned before, going beyond the call of duty is a response of the nurse to the extreme needs of her "client" system. Nurses extend this care to the family as well as to their individual patients.

In the work we are doing we are not supposed to go out and do home visits. But sometimes there is a need that you really need to go, so I do.

But I do have that chance of going to them. Even if I go to them before I come to work and all my spare time....after work... even weekends I do visit them.... just to see how they are.

4.2.4 General responses to changes in the nature of work

Development of relationships with patients and families: An area which was highlighted by all nurses was that of forming trusting relationships with patients. This was seen both as a very positive and rewarding aspect of their work, and as a potential stress. Particularly in the field of HIV and AIDS, where patients are wary to disclose their status and trust others, being confided in held value for nurses. Nurses spend considerable amounts of time with these seriously ill patients, and so significant emotional bonds often develop between them.

And some of them... I build such a relationship with them that they are like my family. You know, you get so attached to them.

This allows the nurse to meet the patients psycho-social support needs when their physical needs are not reversible. Patients' confiding, is a very affirming experience for the nurses as it confirms the patient's trust in them and the nurses ability to form a close and safe relationship with her patients.

And she confided in me. She told me everything that was bothering her.

However, it was also recognised that there was sometimes a price to being the confidant, if patients later chose to accuse the nurse of disclosing their diagnosis. While close, trusting relationships with patients provided satisfaction to many nurses, they were also part of increasing the work loads and stress levels of nurses. In addition, the family's neediness can become burdensome to an already overloaded nurse:

What made me depressed was that the family was so dependent now on me.

And I also have a relationship, after even the patients have died, with the family.

It was also shown that being able to work with patients in such a way that they trust nurses to help them include and incorporate traditional treatments into the treatment regime, is a source of great satisfaction for nurses.

But I was happy for the fact that they had trusted me to tell when they wanted to go to the traditional healers.

It was recognised that there are several traditional healers who advertise that they have the means

to cure HIV and AIDS. Patients who are desperate for a cure wish to make use of all possible options. Nurses who have been trusted by their patients have been able to facilitate the patients' exploration, ensuring that they come to realise the need for 'western' treatments, without feeling that their traditions have been criticised.

Stress and support: A general need for more support, both in terms of emotional support and practical information about talking to terminal patients and their families, was raised.

That is what is really what is breaking us. Not being able to deal with this stress and you see yourself going down each day.

It was stated that there is no infrastructure for support in any of the work environments represented by the research participants. It was felt that their situations must become extreme before help is offered by employers. While only one nurse had displayed symptoms of burnout, all others had experience marked stress at times.

And what is frustrating is that you are on your own. There is nobody that you go to and tell her that I feel like crying, I'm really stressed.

A need to have the profession or work environment accept and acknowledge the degree of stress involved was identified as something that would be beneficial. One nurse explained how she had initially thought that she was weak because she experienced stress in the work.

That is how I used to feel. I thought something was wrong with me, that it was a weakness. It was something that I could not accept because it was like admitting that I'm not competent.

There was also discussion of the difficulty that nurses sometimes have in acknowledging their stress.

In training most of the nurses had been taught to control their emotions in front of patients and their families. What emerged is that while most of the nurses agree in principle that greater emotional expression is both healthy and even valuable to patients and family, there was still a sense that they perceive it as a weakness if they do become emotional in front of their patients. There is also a unspoken social status to "being strong" which many of the nurses saw as something they wished to aspire to. The image of a nurse as someone who "copes" and carries the burdens of others has a significant status, particularly in the African community. However, while affording a certain amount of social recognition it also imposes certain limitations on voicing one's own struggles and stressors:

Everybody sees you as somebody who's going to help. So that's what is stressing us.

Coping: Nurses spoke spontaneously of various ways in which they manage the stressful nature of the work that they do. Religious beliefs and prayer were mentioned by the majority of nurses as a fundamental way of coping. This includes praying to ask for guidance but also a general underlying belief that the difficult situations which occurred, were willed by a higher being. Recalling previous successes was utilised as a coping tool by several nurses, who explained that when they were having bad times they would remind themselves of occasions when they had "made a difference". In particular one nurse recalled incidents when she had been involved in life saving procedures. This helped her to manage her sadness when young patients were dying. Emotional expression was mentioned as a means of relieving stress. Nurses spoke about crying as, "it spills a little bit of something out, a little bit of stress out, to cry". Other means of expressing the emotions generated by work, included talking to spouses, close friends and colleagues about events in the day. The use of colleagues was considered by all nurses to be very important because it was felt that they could best understand what was being experienced. Also, sharing of work load with colleagues and referring patients to other sources for care was spoken of as a form of stress management.

It was a big number, but when everybody took over at each clinic, you know there was a nurse there, things got much better because I could refer patients.

Having interests outside of work, such as hobbies was considered important by one nurse. Another spoke of how crucial it is to take leave regularly, as this impacts on her ability to tolerate the stress. Four nurses had experience of utilising a formal support service such as a support group or professional counsellor, which they had found helpful.

What emerged from the entire data collection process was an overwhelmingly positive approach by the nurses to the work that they are doing. There was ready acknowledgement of the stressors, and particularly in those interviewed, much discussion about the situations that they found difficult. However, they constantly returned to areas of their work which gave them satisfaction, personal fulfilment, intellectual stimulation and a sense of purpose. This positive emphasis seemed to be fundamental to their coping ability. Nurses expressed positive feelings and experiences of their work when they spoke of its meaning for them as individuals, and their belief in the importance of the work that they were doing. Perceiving their work as personally

meaningful was integral to their coping.

I can't see myself not in the nursing field, in this profession, this helping profession...
making a difference.

CHAPTER 5: DISCUSSION

As mentioned in Chapter 4, the nature of qualitative research makes separation of results and interpretation extremely difficult, and indeed less useful than an integrated approach. Therefore, some discussion has already been provided in the previous chapter. What remains to be examined are ways in which the emerging data can be interrelated to further our understanding of the experiences of the nurses studied. This chapter offers some perspectives on the patterns apparent in the results and suggests reasons for the particular interplay of themes and ideas.

The dimensions of the pandemic experienced by the nurses are glaringly apparent in the results and are consistent with those reported in the literature. Nurses are more taxed in their work than before the AIDS pandemic (Vasani, 1999) and multiple stressors abound in the nature of the work they now perform (Bennett, 1995; Bennett et al., 1995; Hayter, 1999; Maslach et al, 2001; Miller, 2000; van Dyk, 2001). This discussion chooses to focus not on the external factors and their influence but on the internal psychological experiences of the nurses. The reason for this is twofold: Firstly, a focus on internal processes attains the necessary psychological register for a thesis in the area of clinical psychology. Secondly, as shown in the literature review, there is already an extensive body of research on the external experiences of nurses in this field. Therefore, a focus on their internal processes provides a new approach to understanding nurses experiences. A dynamic argument is put forward, which is both inferred from and validated by the data. However, it recognises a mutual influence between the external changes and the internal psychological shifts.

The focus of this discussion is on the dynamic process relationships between motives, strategies and consequences. For the purpose of analysis it is useful to isolate the various aspects for discussion. This is done for clearer understanding but it is understood that none of these aspects operate in isolation. The argument is illustrated diagrammatically in Figures 3 and 4.

5.1 Causal conditions and phenomenon

The research question aimed to explore the impact of AIDS and HIV on the work experiences of peri-urban nurses. Recurrent themes in the data indicate that change is the central phenomenon of their experience and that there are two aspects to this change. One is the change

in the external world, in terms of the nature of the work they are required to perform. The other is an internal change within the nurses themselves as they respond to and negotiate the psychological changes imposed by the first. This change is due to the AIDS pandemic, with all its associated challenges, and therefore AIDS is the causal condition in the emerging theory. The phenomenon under examination is the process of negotiating change.

5.2 Motives

People are intentional and purposeful in their actions. This remains so even when those actions are unconscious. The nurses' response to the changes in their external working world, is an internal purposeful adaptation process. Underlying the actions of the nurses are two pervasive motives whose influence can be seen in the focus of the strategies they employ and ultimately in the consequences produced. Firstly, there is a desire to gain control in a situation of disruption and unpredictability. Secondly, there is a drive towards finding or creating meaning within this situation. These motives mediate the psychological strategies of the nurses, as well as the context and intervening conditions which influence their internal processes.

5.3 Strategies

Nurses have experienced internal disruption as their external working world has changed. Human beings strive to maintain a degree of internal equilibrium in order to interact effectively in the world. When this is challenged, attempts are made to restore it, either to its original form or to another equally acceptable one. In doing this, the potential for personal growth exists, as the new state of being may be a more developed, mature state than that previously held. Conversely, so too could the new state be stable, but less developed than before, a regression to a less sophisticated but steady way of being.

The literature recommends various methods of addressing stress for nurses (Bennett, 1995; Brown et al., 2000; van Dyk, 2001). Some of these are practical techniques and others psychological processes for adaptation (Bennett, 1995; Kavenaugh, 1973; Miller, 2000), including the cultivation of an internal locus of control (Bennett, 1995). In the study, although nurses spoke of concrete activities which they use to manage the change, such as emotional expression, relaxation and hobbies, their strategies can also be understood on a more conceptual

level.

Nurses employ one major strategy with several sub-strategies in order to negotiate the external changes and manage the psychological impact. The term 'managing' is used deliberately as it implies active participation and not passive acceptance of the situation.

The major strategy used has been termed 'balancing'. This refers to the manner in which nurses actively seek to find positive experiences in their working lives which balance or compensate for the many negative situations which they are having to withstand. Maintaining this balance ensures the nurse a degree of internal equilibrium as they gain some sense of control within their internal psychological world or find meaning in the tasks that they have to perform. The term "psychological world" refers to the nurse's internalised experiences and perceptions which together influence the way she sees herself, the world and others.

When thinking of the process, it is useful to apply the metaphor of a seesaw, with positive experiences at one end and negative at the other. The seesaw can overbalance towards either side, or remain stable. When an imbalance threatens, nurses employ balancing strategies to ensure that a positive imbalance or, more frequently, a state of stability is regained.

One form of re-establishing balance has been termed 'accessing positives'. This is consistent with other studies and recommendations which discuss the value of focussing on successes in order to enhance health care providers' coping capacity (Bennett, 1995; Bennett et al., 1995). When accessing positives the nurses in this study may do one of two things to achieve the same goal. The first option is 'finding positives'. The nurses consciously choose to review their work history and current situations in ways which allow positive situations to be identified. This is the opposite to becoming overwhelmed by the distressing aspects of work so that the entire work experience is perceived negatively. An example of this would be how, while discussing the difficulties around death of numerous young patients, several nurses balanced this by telling stories about situations where they had been able to save lives or cure patients. Although none of these patients had AIDS or HIV, nurses used these incidents to curb some of the emotion generated by speaking and thinking about many patient losses. Nurses are active in searching for valuable, meaningful experiences which remind them that amidst the difficulties, there is hope and fulfilment. Some nurses stopped at this point, finding a simple awareness of the existence of positive features sufficient to restore balance to their internal worlds.

Others made use of the second option, 'emphasizing positives'. Here the nurses might recall an incident that has occurred which they perceive to be very positive. They remind themselves of this incident, which results in their feeling that they or their work are worthwhile and valuable. This recollection is managed in such a way that the positive incident is strongly emphasized over any negative situations that the nurse might be experiencing or recalling. In doing this, the positive is given sufficient 'weight' to balance the negative. This strategy was seen in both the content and in the process of nurses' responses. Nurses spoke of several difficult situations and then would often spontaneously insert a positive recollection, not always directly related to the negative ones they had been reporting. This occurred both in the focus group and in the individual interviews conducted. Of note is that the number of positive incidents did not have to equal or exceed the negative ones. Rather by adding and focussing on the positive the nurses righted some undefined balance for themselves, rendering the negative less powerful.

An example of this would be that while speaking of many situations where traditional ceremonies can impede patients' physical recovery, a nurse mentioned an incident where she was trusted enough by her patient to be informed of his intention to make use of a traditional healer. She was thus able to explain to him the possible consequences of this and support him as he decided to take the risk. Throughout her account of other difficulties, she repeatedly returned to this incident, stating how good it had left her feeling. The emphasis she placed on the event lightened the weight that the other difficult situations carried.

A further strategy for balancing is that of 'avoiding negatives'. Here the nurses respond in a manner opposite to that outlined above. Instead of focussing on the positive, they balance the experience by diminishing the focus on negative experiences. This is done either by minimizing the significance of the experience or by moving away from the emotional impact through physical or psychological distancing. While this may be considered by some to be an unhealthy response, in the context of such stressful work it is an appropriate method for negotiating the effects of the changed environment.

Comments such as, "but this is what nursing is about" can be seen as a means of minimising the significance of negative situations, by suggesting that they are to be expected and are therefore unimportant. Psychological distancing is seen in emotional withdrawal from patients (Kavanaugh, 1973; Maslach et al., 2001; Zaph et al., 2001) and setting limits on the extent of

emotional engagement with patients. Not all nurses reported becoming close to their patients, choosing instead to maintain clear professional limits on their interactions, as a protective measure against emotional pain. The literature supports the concept that greater grief and loss is felt by health care providers who have allowed themselves to engage meaningfully with patients (Bennett, 1995; Eldridge & St Lawrence, 1995; Mc Grath et al., 1999). Therefore, although avoiding this denies the nurse an opportunity for a rewarding encounter, it does provide protection from hurt and stress, and avoids disruption of the internal equilibrium.

Even burnout can be viewed as an avoidance strategy for keeping balance. This stance is similar to Price and Murphy's (1984) view of burnout as a coping mechanism. Although this is simplistic, such stress often results in absenteeism from work, thereby physically distancing the nurse from the causes of stress for a time. Symptoms of burnout, particularly when extreme, give the nurse 'permission' to withdraw from work difficulties. The display of these symptoms ensures that others are not critical of her for not doing her part, but instead are understanding of her need to withdraw. This strategy is not as effective as others but does not have to become maladaptive. The danger lies in if it is only the single strategy employed, or is used repeatedly.

What is achieved through avoiding negatives is a respite, time to recoup ragged coping mechanisms and re-evaluate personal needs and desires before continuing in the work, or possibly even deciding to leave it. Metaphorically the nurses are re-balancing the seesaw by removing some aspects of the negative pole or by denying them their full weight.

'Reframing' is the third strategy for creating balance. This refers to the ability to be open to the possibility of perceiving experiences in a new and more favourable light, or to find value in the experience as it stands. This willingness to consider alternative perspectives enables the nurses to take negative experiences and reframe them in ways that hold a more acceptable meaning for the nurse. An example of this is in the shift from curative medicine to palliation. Here, nurses struggle with no longer being able to offer their patients a cure. The literature also reveals this as a key area of stress for health care providers in the field of AIDS (Bennett, 1995; Eldridge & St Lawrence, 1995; Mc Grath et al., 1999). Their changing role as providers of cure and health can leave nurses feeling uncertain about what they have to contribute to patients. Reframing their role as relievers of discomfort would then have the value of re-establishing a sense of purpose to

their work. When offering cure, they are relieving discomfort, but they can also offer relief to dying patients, in the form of symptom and pain control. Those nurses able to make this reframing of their work are able to perceive their role in a positive light. They see themselves as caring rather than curing and do not diminish the value of this. Furthermore, when viewed from this perspective, caring is expanded to providing psychosocial support (Bennett et al., 1995; van Dyk, 2001).

Returning to the metaphor, the action of reframing shifts the negative from one side of the seesaw to the other, by altering the way in which it is perceived so that it can be experienced as positive. This takes the 'weight' from the negative side and allows equilibrium to be restored.

The final strategy for bringing about balance is 'acceptance'. It differs from reframing in that it does not attempt to change the perception of negative experiences, but rather serves to promote acceptance of them, thereby rendering them impotent. Metaphorically, it moves them from one pole of the seesaw to the centre, where they cannot influence the balance in any way. Acceptance is very different from resignation, which has connotations of passivity and hopelessness. Acceptance is a powerful stance, where the nurse gains internal control over a situation in which she has little external influence by deciding to acknowledge this reality. This acceptance makes way for adaptation to a new way of being. One of the nurses, in speaking of her experience of depression while working in this field commented that she had found it very difficult to accept the extreme changes brought about by AIDS. In particular, it was difficult to accept her own personal limitations in assisting the numerous patients who were under her care. She indicated that it was only when she was able to accept the reality, that she could start to set limits which ultimately reduced her stress level and made her a more effective nurse.

Accessing Positives:

- Finding positives
- Emphasizing positives

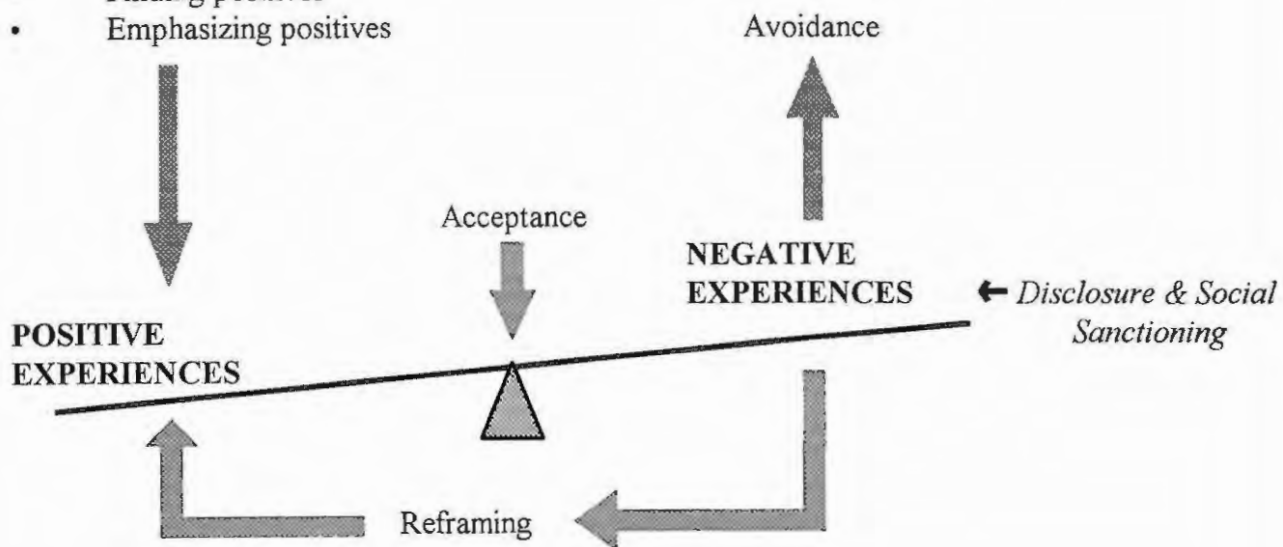


Figure 3. The strategies and metaphorical seesaw of internal psychological balancing

5.4 Consequences

Whatever the strategy, be it accessing positives, acceptance, avoiding negatives or reframing, the motivation appears to be the same. The coping dynamics aim to re-establish a sense of control and stability for the nurse who employs them, and to find meaning.

The AIDS pandemic has been responsible for much disruption, not least of which has been to disturb the internal equilibrium of coping for nurses. Plunged suddenly into a world of new and daunting challenges, their sense of trust in the predictability of their external and internal worlds has been shaken. New demands could not always be met by familiar responses and so new methods have had to be found. Losing control of their psychological world is closely intertwined with their sense of meaning. Regaining a belief in the value of the work that they perform is crucial to stability and internal equilibrium. The potential consequences of employing strategies with these motives as directors are threefold: Nurses may diminish their stress; they may achieve a personally acceptable work experience, namely either satisfaction or fulfilment; and they may validate their professional and personal worth.

The diminishing of the experience of stress refers to an internal process. Indeed the stressors in the external environment may remain unchanged, but the nurse's approach to them shifts as a result of balancing her experiences to gain control and meaning. This internal process is highly personalised, taking into account her individual personality, interests and beliefs. In the formation of this internalised sense of control and meaning, external factors may have influence, as the nurse does not exist in isolation. However, it is not the factors themselves but rather her perception and internalisation of these factors that ultimately constructs an inner world of resilience.

So too is the attainment of an acceptable work experience an internal process. For some nurses their work is simply a means of financing living. They perform to the best of their ability, but are not necessarily seeking personal growth through their employment. They are therefore more likely to desire mere satisfaction from work, for which it is sufficient to only accomplish what is required of them. Balancing strategies of avoiding negatives and acceptance may be used extensively by these nurses as they restore equilibrium but do not necessarily provide positive experiences. However, for other nurses in the study, their work is a vocation. They seek fulfilment through their balancing, a state where their work is not just done well but where it provides for them a deep-seated sense of personal accomplishment. They are more likely to utilize strategies which enhance the positive nature of the work, such as accessing positives and reframing.

The challenges of AIDS work can call into question the role of the nurse as she struggles to adjust to the limits of what she can provide for patients (Eldridge & St Lawrence, 1995; Miller, 2000). A final consequence of gaining control and meaning through balancing, is validation of the significance of nursing as a profession and a returned sense of worth for the nurses. Strategies such as acceptance, permit the establishment of realistic goals and expectations within the nurse, helping her to accept the limitations of herself and the profession. In so doing, she is able to more fully appreciate the contribution that she is able to make. Reframing provides alternative perspectives on roles and involvement that may previously have been seen as inadequate or outside of the role of the nurse. This also validates the services she offers her patients. Lastly, accessing positives, particularly those reframed, maintains a sense of hope and purpose for the nurse, as the significance of the work she performs becomes apparent.

When a difficult situation in the work context is experienced the nurses react by feeling stressed. This disrupts their sense of control over their psychological world and sense of meaning. In an attempt to restore internal equilibrium and return to a non-stressed state, certain strategies are employed. These strategies aim to reduce the effect of the external stressor. Successful accomplishment of this results in the nurse internalizing a new, more manageable perception of the stressor, as well as a personal sense of empowerment for having negotiated it effectively. This process may then be outwardly manifested as diminished stress, feelings of satisfaction or fulfilment in the work experience and, or validation of her professional and personal worth. What is so remarkable is the clear indication that most nurses have embraced the challenge of finding meaning and re-establishing their sense of control. They are indeed coping.

5.5 Disclosure

It is apparent that nurses are able to negotiate the difficulties imposed by the AIDS pandemic by using the strategies identified. Issues that challenge these mechanisms are disclosure and confidentiality, which appear prominently in the data. These issues and the problems they present will be discussed in more detail in this section.

Disclosure and confidentiality pose significant challenges to the nurses' ability to find meaning and gain control over their work experiences. Indeed when reviewing nurses' experience of disclosure, the metaphorical seesaw becomes increasingly difficult to balance. While a few nurses spoke of the satisfaction gained by helping a patient to disclose, most stories shared were decidedly negative in form. None of the balancing options already discussed seemed to help the nurses negotiate the dilemmas of disclosure. It would seem that the external influences which create problems relating to disclosure are very powerful. They prohibit the nurses' utilization of internal strategies through which they could create an outcome that is acceptable to them. Instead, nurses speak of being forced to collude with a situation they find damaging to themselves, the patients and the families they serve. There do not appear to be sufficient positive situations within the context of disclosure and confidentiality to allow for a balancing of the negative, resulting in the situation remaining intolerable. The data reveals how problems relating to disclosure pervade all areas of the nurses' work experience. This inability to assert some form of control, or find meaning sees nurses responding with resignation to matters of confidentiality. They express frustration, anger and helplessness as they speak of the restrictions it poses on them.

So the question must be asked, “What makes the issue of disclosure so powerful?”

The difficulties of maintaining secrecy around diagnosis are mentioned in other research, mainly from the perspective of the patient (Kalichman, 1998; van Dyk, 2001). International research, while acknowledging confidentiality as a concern in AIDS care, does not highlight it as a significant source of stress for health care providers. However, for this study in the South African context in which the nurses work, disclosure issues hold power. The impact of these issues should not be underestimated. Nurses find them impossible to reframe positively, nor are the issues avoidable as they emerge in every area of the nurses’ work. Indeed, nurses experience themselves as being constantly under the threat of exposure for contravening confidentiality requirements. In the majority of cases this fear is present even when they are aware that they have not done anything wrong. There is a double-bind for nurses in the confidentiality criteria. They appreciate that it protects the patient from discrimination, but they also see that it denies the patient access to quality medical and psychosocial care. Furthermore, the impact of the threat to nurses of being accused of disclosing without permission, sees them trying desperately to protect both themselves and the patient. They feel caught in the middle and lack the satisfaction of having provided appropriate services to the patients. Having the whole family as a ‘client’, which frequently occurs as patients become more ill, adds to the nurses’ dilemma of whose interests she is expected to protect, to the detriment of others. Nurses spoke of “doing their best” but this is little consolation as they continue to be pressured into providing inferior care in order to maintain secrecy. Attempts to reframe this as being ‘better than nothing’ do not provide satisfaction as this is unacceptable to most nurses. Indeed, there is a refusal to accept the situation which they view as unjust. The results of this situation are dire. There is frustration for the nurse, who may suffer feelings of incompetence and lowered confidence in her work, the patient receives inferior care, and the nurse may then be criticised for not doing everything possible. This evokes a cycle of further frustration for the nurse, a decreased sense of meaning and control and further inner turmoil.

Interestingly in this study, the only participant who did not experience such marked anxiety about disclosure was not an African nurse. Although the frustrations and limitations of patients not disclosing were a part of her daily work, the fear and threat of exposure as someone who has breached confidentiality was not present.

It has already been mentioned in chapter 2 that cultural and societal factors may have a role in how

easily patients are able to disclose their HIV positive status (UNAIDS, 2000; van Dyk, 2001). Strong taboos on discussing sexuality or on being perceived to be sexually active make the fear of societal sanction very real. The majority of nurses in this study were Xhosa women, members of a strongly collective culture where belonging and acceptance by the community is extremely important. Furthermore, as professional nurses they hold, by virtue of their education and expertise a position of status in their community. For them, it is suggested that societal sanctioning holds greater threat than for nurses from more individualistic cultural groups, or where nursing is not a well respected profession. The Xhosa nurses feared social sanctioning far more than the disciplinary process that would face a professional nurse if she were accused of a confidentiality breach. The latter involves the possibility of job loss, which is dire. But the former would involve ostracism from her community, and a sense that she had betrayed her people.

The role of social sanctioning and culture in the nurses' experience of their work in AIDS care warrants further exploration as it appears to be such a powerful influence. This, and other areas for further research will be discussed in the chapter that follows.

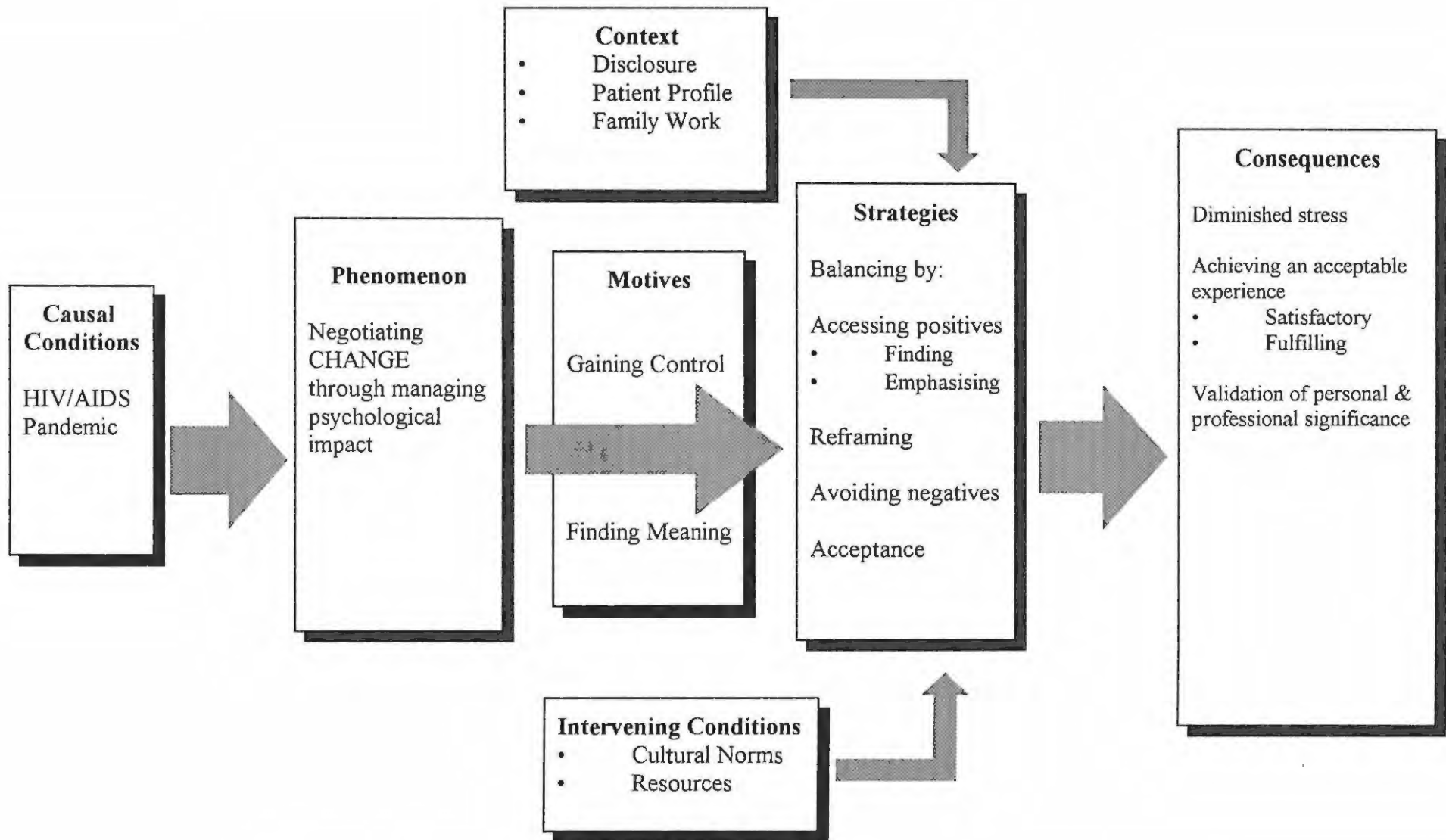


Figure 4. Theoretical model for negotiating change through managing psychological impact

CHAPTER 6: CONCLUSION

6.1 Reflections on the Study

This study was an investigation of how peri-urban nursing sisters negotiate the changes in their work, necessitated by the AIDS pandemic. A grounded theory method was utilised to process and analyse the data from a focus group and three indepth interviews. The research showed that nurses experience two forms of change, the first having brought about the second. Firstly, there are changes in the nature of the work that they have to perform and secondly, the nurses themselves have changed to accommodate the new circumstances they face. This accommodation is required in order to restore an internal psychological equilibrium which is disrupted by the changes in their work. It is accomplished through a process of balancing positive and negative experiences until an acceptable equilibrium is reached.

As mentioned in chapter 3, the literature review in grounded theory is initially used simply to familiarise the researcher with the field of study. It is only extensively pursued once the data has been collected and analysis has begun. Reflecting on this process, the value of such a method becomes apparent. In this study, the literature shows many similar issues to those which the participants expressed. However, as these were not yet accessed at the time of data collection, the literature can serve to validate the research findings.

The merit of grounded theory's design to allow the theory to emerge was seen in this study. Entering into the process, the researcher believed that there were certain key issues that were likely to emerge. Although no attempt was made to deliberately facilitate their emergence, it was an expectation within the researcher from the outset. Indeed the research question, "How has the transition from curative to palliative medicine, necessitated by the AIDS pandemic, impacted on peri-urban nursing sisters' subjective experience of nursing?" captured some of these expectations. It was anticipated that nurses would report being overwhelmed by the changes in their work and that they would strongly emphasise the curative to palliative nursing shift. It was also anticipated that the involuntary nature of the shift would be a contributing factor to their stress. So it was with surprise and appreciation that the researcher realised that this was in fact not the nurses experience. Rather, a pervasive sense of positiveness and a striving to find meaning and control emerged throughout the data. The research question was answered, in that information and

themes were gleaned about the nature of the nurses experience but this answer was not that which was initially hypothesized. The awareness of the researcher's place in the process is valuable because it also serves to validate the research conducted. It is apparent that although initial hypotheses existed and assisted in the formulation and design of the research, they were open and flexible to change as the nurses' experiences surfaced.

6.2 Contributions of the study

The AIDS pandemic and the effect that it has on the health system and health care providers, is a vital concern in South Africa where the prevalence of HIV is so very high. The role that nurses have in the pandemic is crucial and therefore research which aims to understand their experience is most relevant. This study has served to raise awareness of the stresses, challenges and triumphs of these nurses. It contributes an alternative perspective to much of the AIDS research done in South Africa, which tends to focus on the patients, and not on those who serve them.

The study has also built on existing research, which is largely international. Similarities have been identified between the experiences of nurses in international and local studies and in the participants of this research. It has been shown that many of the stresses are the same, but it also shows areas of difference. In particular, the influences of poverty, culture, limited resources, disclosure issues and the size of the pandemic have been identified as specific to a Developing World setting such as South African.

The study also offers a way of understanding how nurses negotiate an internal equilibrium in the context of change. A theory has been put forward, suggesting that a process of balancing is utilised by these nurses in order to regain control and meaning in their work. Furthermore, the study has raised the issue of the influence of disclosure on the work experience of peri-urban South African nurses. It has provided suggestions about why disclosure is so powerful, as well as a way of understanding the complications it brings.

6.3 Strengths and Weaknesses of the study

One of the ways in which qualitative research methods differ from quantitative approaches is in terms of representativeness. Since this is a small grounded theory study, with a sample which does not claim to be representative of a certain population, the results cannot be generalised. This can be seen as a weakness by researchers for whom general results are important. If

generalisation is desired an alternative method would need to be adopted to explore the research question. This is a small study, which needs to be expanded by further cycles of data collection and validation to reach saturation. However, this weakness is also a strength in that it provides a valuable beginning for further investigation. The study has produced a theory from the emerging data, but these findings need to be further validated by different research methods, including quantitative ones. In addition a more thorough survey of literature on 'coping' would be needed to expand the patterns in the data. This was not the focus of the research and was therefore not included in the scope of this study. However, given the nature of the theory that has emerged, it becomes necessary.

The focus group was a valuable data collection tool, not just from the perspective of validation but also because it created a forum in which multiple perspectives could emerge and be pursued in further indepth interviews. The researcher was able to establish rapport with the participants and thus a comfortable atmosphere contributed to the depth of material collected. The nurses were at ease and responded openly and honestly. This compensated, in part for the researcher's inexperience in conducting focus groups and lack of familiarity with the grounded theory method. The choice of a grounded theory methodology was valuable since it is well suited to investigating processes and motivations. This method of enquiry facilitates the emergence of the participants' experience, which is particularly important when it differs from that expected by the researcher, as occurred in this study.

The study has resulted in the development of a theory which provides a foundation for further theorizing and research. This is a strength in the research process, as it goes beyond discussion of results and offers a theoretical framework for understanding the nurses experiences and responses. A final strength of the study is that the theory which has emerged is considered to fit the data well, and suggests some important insights for the South African situation.

6.4 Suggestions for further research

As this was a very small scale exploratory study, larger more extensive research would be valuable to see if the findings could be generalised beyond the sample used here. Furthermore, similar issues could be explored in rural and urban nurses to see how their experiences and responses may be similar or different. It would also be useful to specifically explore cultural issues as they interact with the work experience. This is particularly with reference to the dilemma of

confidentiality as it would be interesting to work with nurses from diverse cultural groups, to establish the influence of culture on the degree of social sanctioning to which they are exposed.

In short, the success of this project lies largely in inspiring other researchers to pursue these issues at greater depth. Not only would this recognise the importance of the area of study, but it would further validate the significance of the experiences that nurses have in their pursuit of quality care for those suffering in the AIDS pandemic.

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APPENDIX A

PARTICIPANT CONSENT FORM

Dear Participant

My name is Lisa Brown. I am a Clinical Psychology Masters student at Rhodes University. As part of my course I am required to conduct a research project. I have chosen to explore the effect of the AIDS pandemic on the work experience of nursing sisters in the Grahamstown community.

In order to successfully complete this study I would like to run a focus group with several nursing sisters, such as yourself. During this group I will be asking your opinions about issues relating to the research question. The group will be videoed and audio taped.

After the focus group, I will also approach some of the participants for an individual interview, to gather more information for my research. These interviews will be audio taped.

If you are willing to participate in this study please fill in the underlying form:

I voluntarily consent to being part of this research project. I understand that I will be part of a focus group, which will be videoed and audio taped, and that I may be approached for additional interviews after the group session.

I understand that my name and personal details will not be included in the report, and that anonymity and confidentiality will be maintained by destroying the tapes and transcripts once the research is completed.

Signature

Date

APPENDIX B

The data was first organised into the most significant incidents or happenings. Several cycles of open coding were utilised to name and categorize the data. Initially, the transcripts were examined and the text was divided into information which fitted “Positive work experiences”, “Negative work experiences” and “Change experiences”. An example of this initial coding is presented below:

Example 1: Excerpt from the Focus Group (Initial coding)

Sr: You know the Sister that was counselling her was so surprised. She said she'd never visit her. I said, “Yes. She's ... she's just ... she's in front of me. I'm phoning. She's in my room and I'm coming back and I've written in the passport that she wants her results to be sent with her consent ...”

LJB: Ja.

Sr: “... to ... to ... to Joza where she is going to attend” She said, “Oh. That's ... that's wonderful.”

LJB: Mmmm ... ja ... that is great ... okay. One of the things I just want to pick up on is that there's been ... there's been mentioned now, of words like ... um ... ‘very sick’ ... um ... ‘dying’ ... ‘HIV/AIDS’ ... and so on. Um ... and then also ... the word ‘stress’ has been ... mentioned by a number of you. Um ... what ... what is the kind of ... are ... are you feeling stressed in your work. Not necessarily all the time but at times, and if so, what ... what are some of the things that are stressful?

Sr: Yes we do ... I do feel stressed. Especially, I am going to refer to my experience in the community. I used to feel very stressed. In ... in my training I was ... never ... prepared or ... trained to look after ... dying people.

LJB: Mmmm.

Sr: And ... uh ... it's nice with Hospice because you choose to be a Hospice nurse.

LJB: Mmmm.

Sr: But now we didn't choose to be ... Hospice nurses as I call it.

LJB: Ja.

Sr: And ... we were there on our own ... seeing them not ... getting better. We are used to curing people and then seeing them ... getting better. But with these ... you know they are not going to get better ...and ultimately they die. Having to deal with the family ... a family who does not know, at times, what is really going on.

LJB: Mmmm ... mmmm.

Sr: We have never been trained to ... for family care.

LJB: Ja.

Sr: And ... most patients who are infected ... they ... they keep on coming, and there are always more that are being diagnosed and ... um ... even if this one dies you are left with the family. There's a child ... you still have to take care of the family with the sick child.

LJB: Mmmm.

Sr: The family that is ... that you have got to nurse and to make it follow up. And what is frustrating is that you are on you are own.

LJB: Mmmm.

Sr: There is nobody that you go to and tell her that I feel like crying ... I'm really stressed..

LJB: Mmmm ... mmmm.

Sr: And ... not having those ... systems or structures that are there to ... to ... to cope with ... with ... with the type of patients that we are really nursing.

LJB: Mmmm ... mmmm.

Sr: It's really frustrating.

LJB: Ja ... ja.

Sr: So you realise that ... your work itself now ... is really frustrating.

Example 1: Coding Key

- Positive experiences
- Negative experiences
- Change experiences

APPENDIX C

A further process of coding identified the issues within each of these three broad categories. Axial coding was then used for interconnecting the categories. The initial hypotheses formed about the possible relationships between categories and subcategories were presented with examples in Chapter 4. Below is an example of the next phase of coding, using the same excerpt.

Example 2: Excerpt from the Focus Group (Second Cycle coding)

- Sr: You know the Sister that was counselling her was so surprised. She said she'd never visit her. I said, "Yes. She's ... she's just ... she's in front of me. I'm phoning. She's in my room and I'm coming back and I've written in the passport that she wants her results to be sent with her consent ..."
- LJB: Ja.
- Sr: "... to ... to ... to Joza where she is going to attend." She said, "Oh. That's ... that's wonderful."
- LJB: Mmmm ... ja ... that is great ... okay. One of the things I just want to pick up on is that there's been ... there's been mentioned now, of words like ... um ... 'very sick' ... um ... 'dying' ... 'HIV/AIDS' ... and so on. Um ... and then also ... the word 'stress' has been ... mentioned by a number of you. Um ... what ... what is the kind of ... are ... are you feeling stressed in your work. Not necessarily all the time but at times, and if so, what ... what are some of the things that are stressful?
- Sr: Yes we do ... I do feel stressed. Especially, I am going to refer to my experience in the community. I used to feel very stressed. In ... in my training I was ... never ... prepared or ... trained to look after ... dying people.
- LJB: Mmmm.
- Sr: And ... uh ... it's nice with Hospice because you choose to be a Hospice nurse.
- LJB: Mmmm.
- Sr: But now we didn't choose to be ... Hospice nurses as I call it.
- LJB: Ja.
- Sr: And ... we were there on our own ... seeing them not ... getting better. We are used to curing people and then seeing them ... getting better. But with these ... you know they are not going to get better ... and ultimately they die. Having to deal with the family ... a family who does not know, at times, what is really going on.
- LJB: Mmmm ... mmmm.
- Sr: We have never been trained to ... for family care.
- LJB: Ja.
- Sr: And ... most patients who are infected ... they ... they keep on coming, and there are always more that are being diagnosed and ... um ... even if this one dies you are left with the family. There's a child ... you still have to take care of the family with the sick child.
- LJB: Mmmm.
- Sr: The family that is ... that you have got to nurse and to make it follow up. And what is frustrating is that you are on you are own.
- LJB: Mmmm.
- Sr: There is nobody that you go to and tell her that I feel like crying ... I'm really stressed.
- LJB: Mmmm ... mmmm.

Sr: And ... not having those ... systems or structures that are there to ... to ... to cope with ... with ... with the type of patients that we are really nursing.

LJB: Mmmm ... mmmm.

Sr: It's really frustrating.

LJB: Ja ... ja.

Sr: So you realise that ... your work itself now ... is really frustrating.

Example 2: Coding Key

- Close relationships with patients [positive]
- Confrontation with death and dying [negative]
- Involuntary shift in work [negative/ change]
- Family Work [negative]
- Disclosure [negative]
- Stress/ support needs [negative]

