CARING FOR AIDS PATIENTS IN A RURAL HOSPITAL SETTING: NURSES' PERSPECTIVES

NHLANHLA DENNIS ZULU

Student no: 200202337

Mini-dissertation submitted in partial fulfillment of the requirements for the degree of Masters in Health Promotion
School of Psychology

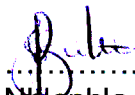## UNIVERSITY OF KWAZULU-NATAL

March 2009

Supervisor: Prof. Anna Meyer-Weitz

DECLARATION

Submitted in partial fulfillment of the requirements for the degree of Masters in Health Promotion, in the Graduate Programme in the School of Psychology, University of KwaZulu-Natal, Durban, South Africa.

I declare that this dissertation is my own work. All citations, references and borrowed texts have been duly acknowledged. It is being submitted for the degree of Masters in Health Promotion in the Faculty of Humanities, Development and Social Science, University of KwaZulu-Natal, Durban, South Africa. None of the present work has been submitted previously for any degree or examination in any other University.

....

Nhlanhla Dennis Zulu

12 March 2009

ACRONYMS

AACN	American Association for Critical-Care Nurses
AIDS	Acquired immune-deficiency syndrome
ART	Anti-Retroviral Therapy
ARV	Antiretroviral
DOH	Department of Health
DOT	Directly Observed Therapy
HAART	Highly Active antiretroviral therapy
HIV	Human immunodeficiency virus
HRC	Human Research Council
MDR	Multi-drug resistant
MRC	Medical Research Council
NDOH	National Department of Health
PLWA	People Living with HIV/AIDS
TB	Tuberculosis
UNAIDS	United Nations Joint Programme on AIDS
USAID	United States Agency for International Development
VCT	Voluntary counseling and testing
WHO	World Health Organization

ABSTRACT

The aim of the study was to explore nurses' experiences, attitudes and perceptions regarding the care of patients with the Acquired Immunodeficiency Syndrome (AIDS) before and after the introduction of Anti-Retroviral Therapy (ART) in a rural KwaZulu-Natal hospital.. A secondary aim was to investigate psychosocial stressors that nurses experience and the support they receive in this regard.

A qualitative study was conducted and three focus group discussions were conducted before the introduction of ART and five individual interviews were used for in-depth exploration of the health care workers' perceptions of caring for AIDS patients after the introduction of ART. Special attention was paid to nurses' experiences with AIDS patient care and with attention to stress and coping.

The AACN Synergy Model was used as a broad theoretical framework for the study to guide the exploration regarding the influence of both nurse and patient characteristics influence the care process within a rural South African context.

The findings suggested that before the introduction of ARV-therapy most patients had limited knowledge and understanding of HIV/AIDS disease and its processes. They and other significant others who could be a family member or even friends were marginally involved in the care process. Voluntary Counseling and Testing (VCT) seemed to impact negatively on this situation, and patients were not willing to test and disclose their status to health workers. The knowledge around HIV/AIDS among nurses seemed to be inadequate due to the lack of support and training. They reported being inadequately equipped to deal effectively with caring for their AIDS patients.

After the introduction of ARV-therapy, greater involvement of patients on ARV treatment was noted. The participation of significant others in patient

management also improved possibly due to their involvement as treatment associates, a requirement of the ART programme. However, the nurses still reported inadequate knowledge not only around AIDS in general but also pertaining ART as well as in the provision of psychosocial support to their patients.

The study also revealed that the Synergy Model for patient care, which compares the patient characteristics to nurse competencies can be used to gain insight into patient care and its demands. This model has also suggested weaknesses in nurses' training that need attention. Nurses are expected to use insight into patients needs to improve their competencies to meet the challenges of AIDS patient care and to fulfill their mandate as the key stakeholders on patient care. Lazarus and Folkman's (1984) views on stress and coping were useful in identifying the nurses' coping strategies.

The study highlighted specific areas in need of intervention. Formal and informal teaching for both nurses and the patients on HIV and AIDS management needs to be introduced. Patients and families' involvement in decision making and HIV/AIDS disease management should be expanded. HIV counseling and all its components, which are pre- and post-counseling as well as on-going disease management counseling needs to be re-evaluated. There is a need to advocate for a more patient orientated counseling rather than test orientated counseling. Psychosocial support to nurses should be a priority to help them cope with their stressful AIDS caring work. Advocacy for a worker friendly Employee Assistance Program (EAP) should be encouraged by the

managers of the institution. Intra-disciplinary and inter-disciplinary

communication needs to be improved through innovative strategies. The

address of the AIDS stigma within the healthcare system remains a priority and

this aspect needs to be incorporated at different levels i.e. basic training, in

counseling and within the psychosocial support efforts directed at nurses.

TABLE OF CONTENTS

CONTENTS	PAGE

CHAPTER 1

1.1 Introduction

Sub-Sahara Africa including South Africa is experiencing the highest HIV/AIDS burden in the world, with a 35% HIV-infection rate and 38% of AIDS deaths during 2007 (UNAIDS 2008). The current estimated national HIV/AIDS prevalence rate in South Africa alone is 28%, calculated from the antenatal survey study on pregnant women (South African Department of Health, 2008). It is estimated that 10.8% of all South Africans over the age of two years are currently living with HIV, of which 16.5% is from the province of KwaZulu-Natal (Shisana, Rehle, Simbayi et al., 2005). In KwaZulu-Natal, the province with the highest antenatal prevalence rate in South Africa, 37.4 % are HIV-infected (South African Department of Health, 2008).

HIV and AIDS have not only changed the pattern of disease by increasing the number of terminally ill patients globally. It has also changed the lives of healthcare workers who have to deal with this epidemic on a daily basis. AIDS care means witnessing suffering, experiencing unresolved grief from connection with the dying patient or relative, increasing work demands and declining team spirit (Sherman, 2000). To conceptualize the increased workload for healthcare workers this epidemic has brought, one has to look at the 56.9% increase in the reported deaths between 1997 and 2002 (Department of Health, 2006).

In 2004 Anti-Retroviral Treatment (ART) became available in South African public hospitals, by this time it was estimated that 5.5 million people were infected with the HIV and 1million of these needed ART (Ojikutu, Makadzange & Gaolathe, 2008). Prior to that a lack of political will and slow pace of ART provision to the public had culminated to a series of legal confrontations between the South African government and civil society.

In response to these challenges, the South Africa Department of Health (DoH) has embarked on a massive rollout of the largest Antiretroviral Treatment (ART) program in the world. Access to ART has improved drastically over the past few years, creating some hope in the face of a devastating AIDS epidemic (WHO, 2004). In rolling out this ambitious ART initiative, a large number of properly trained healthcare workers are necessary for its success (UNAIDS 2005). However, it is a concern when one looks at the high turnover of nursing staff resulting in inadequately staffed healthcare facilities, especially in the rural areas (Jaffar et al, 2005). There were 291 754 people who were on ART from the public sector in SA in 2006, this number increased to 428 91 in 2007 (WHO, 2008), while the HIV epidemic is currently credited for 1000 new infection daily, 900 deaths daily, (Kapp, 2006). Recent media reports have highlighted the slow rollout of the ARV-therapy due to limited budgets and unqualified staff.

Within the South African context, the AIDS epidemic is increasing the vulnerability of the health care system. This is because AIDS is not the only issue healthcare workers have to deal with. Service changes associated with day-night shifts, major staff shortages especially in rural areas and poor organizational atmosphere are some of the job related stressors resulting in stress and burnout among health workers (Fagin, 1996). In a study of the staffing trends of the Northern KwaZulu-Natal Hospitals, an area in which this study was conducted, it was reported that for the hospitals, 30% of nursing posts remain consistently vacant, while 20% of the medical and paramedical posts were vacant all the time. The mean number of days taken off work per worker increased from 41.8 days in 1998 to 60 days in 2001 and staff turnover due to health workers' death, increased from 0.38% to 4% (Unger, Welz and Haran, 2002). Furthermore, this study pointed out the problems of absenteeism, poor performance, under achievement and low self-esteem among health workers in the public sector. Similar findings were found in an American study investigating work-related stress and occupational burnout in AIDS caregivers (Gueritault-Chalvin, Kalichman, Demi and Peterson, 2000) and in a more

recent South African study on nurses' perceptions regarding HIV/AIDS in a public hospital (Smit, 2005). The situation has worsened since then, as a significant number of healthcare workers have left the public sector due to poor payment and difficult working conditions. A substantial number of South African nurses are being actively recruited by Western countries as better payment and working conditions are highly attractive. It has been reported that 29% of S.A. Public Health sector posts were vacant in 2006, of these 42 000 were nursing posts. This problem is compounded by the fact that the South African Nursing Council (SANC) reported that a total number of registered nurses grew by only 3.7% only between 2000 and 2003 (HIV & AIDS and STI: National Strategic plan, 2007-2011).

This high nursing staff turnover and the decrease in newly trained health workers remain a major financial burden for institutions and contribute to increased patient length-of-stay rate in hospitals, as well as increased patient mortality (Barden, 2003). Because of the inability of the public health care sector to deal with the patient load due to inadequate nursing staff, many patients are being sent home prematurely. In addition, nurses are also dying of HIV/AIDS related conditions like the rest of their communities. It was estimated that 15.7% of health care workers are HIV infected (Shisana et al, 2002). In addition, the working conditions including workload on the remaining nurses are compounded by increasing number of patient admissions and the health care demands of the terminally ill AIDS patients, despite the availability of ARV-treatment. This implies that quality healthcare service is denied to some patients. Despite this, it should be noted that healthcare services should not be conditional on the hospital context, but should be viewed as an absolute obligation of the Departments of Health (McCann, 1999).

It can be argued that the introduction of Highly Active Antiretroviral Therapy (HAART) has modified the disease from a highly morbid disease to a manageable chronic illness (Parry, Steward, Wright, and McLeod, 2004). This

being the case, it is therefore expected that the load of terminally ill patients to hospitals should be decreasing, but there are no local studies confirm or dispute this development. It can also be argued that if Voluntary Counseling and Testing (VCT) is a measure of behavioral change, one may assume that HAART will address the high rates of stigma and encourage people to come forward, for care and support where AIDS risk reduction is likely to be addressed (Jaffer, Govender, Garrib, Welz, Grosskurth, Smith, Whittle and Bennish, 2005).

It has been suggested that patient characteristics, together with compatible nurse characteristics would lead to improved patient care (Curley, 1998). Therefore the type of care AIDS patients is likely to receive will depend largely on the patients and how they are viewed by the nursing staff (Jennings-Dozier, 1999). The American Association for Critical Care Nurses (AACN) Synergy Model of patient care suggests a comprehensive and holistic framework to promote positive patient outcomes (Curley, 1998). In this model it is postulated that if nurses, the patient and the family act in mutually engaging ways, or in synergy, positive outcomes for patients are promoted. Practices are thus linked to outcomes. The belief is that positive patient results will occur when patient characteristics and nurse characteristics work in mutually enhancing ways and that positive results will occur if a nurse demonstrates the competencies in relation to patients' needs (Curley, 1998). While patient characteristics direct nursing practice, nursing characteristics are important to patients and strongly influence the level of care that patients will receive. The patient characteristics identified in the model are related to their illness presentation, their level of participation in care and in decision making, as well as their available emotional and financial resources. Nurse characteristics are linked to their work competencies, namely their ability to integrate their knowledge, experience, and skills in a caring, collaborative and patient centered approach necessary to promote optimum patient outcomes.

As ARV-therapy is not accessible to all people in need of ARV's, it is expected that as the epidemic gains momentum, nurses are expected to care for an increasing number of patients who are admitted to hospitals due to complications related to AIDS. In order to ensure quality care for AIDS patients and adequate support for nurses, it is important to first understand nurses' experiences of caring for AIDS patients. It should be noted that the experiences and strategies of nurses who work in the AIDS wards may assist the clinicians, educators and policy makers in supporting the nurses, improving caring potential and promoting the quality of care offered to patients with AIDS (Sherman, 2000). In this regard nurses' own clinical and care competencies as well their perceptions of AIDS patients' characteristics were explored.

1.2 Aim and Objectives of the study

1.2.1 AIM.

To explore nurses' experiences, attitudes and perceptions regarding AIDS care, as well as to investigate the influence of psychosocial support and the influence of the introduction of Anti-Retroviral Therapy, in caring for AIDS patients in a rural KwaZulu-Natal hospital.

1.2.2 OBJECTIVES.

- To explore nurses' attitudes towards AIDS patients.
- To investigate nurses' perceptions regarding their competency to care for AIDS patients
- To investigate existing psycho-social support for nurses caring for AIDS patients.
- To investigate the influence of Anti-Retroviral Therapy (ART) on nurses' experiences.

1.3 Ethical considerations

The permission to conduct the study has been granted by the local Hospital authorities and formal consent was obtained from the Department of Health, the office of the Director-General for KwaZulu-Natal Provincial Health. Ethical clearance for the study was also granted by the Ethics Committee of the University of KwaZulu-Natal. Signed informed consent was obtained from the participants.

1.4 Conclusion

This study will investigate the extent of the impact of HIV and AIDS on AIDS patient care as perceived by the nurses. It will explore how the HIV/AIDS disease influences the patient and the patient and nurse relationships regarding care. Lastly the study will attempt to understand whether the introduction of Anti-Retroviral Therapy (ART) has influenced AIDS patient care.

In the next chapter, literature specific to the South African context, with demographic information relating to the South African healthcare system, and related issues, will be presented. The theoretical framework, the American Association for Critical Care Nurses (AACN) Synergy Model, which explains the reciprocal influence of patient and nurse characteristics on patient care, will be discussed.

CHAPTER 2

LITERATURE REVIEW

2.1. INTRODUCTION (HIV/AIDS IN SOUTH AFRICA)

South Africa's HIV/AIDS epidemic is one of the world's fastest spreading and
most devastating on the human population. It was estimated that 5.7 million
people are currently infected with HIV/AIDS in South Africa (UNAIDS, 2008;
WHO, 2008). The antenatal survey conducted by the South African Department
of Health, estimated that 28% of pregnant women in South Africa were living
with HIV in 2007, 37.4 % of which is from KwaZulu-Natal (South African
Department of Health, 2008). According to the South African National HIV
Prevalence, HIV Incidence, Behavior and Communication Survey (Shisana et
al., 2005), the national prevalence was 10.8% of all South Africans over the age
of two; amongst the group aged 15-49, the HIV prevalence was more than
double the national statistic at 24.6%. Increased incidence of HIV infection
resulted in a projected 539,204 new infections in 2005. In 2005, it was reported
that 320,000 South Africans died from AIDS-related illnesses (Statistics SA,
2005). The similar scenario was painted by Dorrington et al, with mid-2006 HIV
and AIDS indicators of 11.2% prevalence, total number of people infected 5.4
million, people on ARV treatment 200 000 and those ill with AIDS 599 000
(Dorrington, Bradshaw, Johnson and Daniel, 2006). The number of people on
ARV-therapy in 2007 had increased to 428 951 (WHO, 2008). With no tangible
indication of decline, the South African HIV/AIDS epidemic is recognized as an
epidemic of extraordinary dimensions requiring an extraordinary response from
both politicians and civil society, as the impact has grave consequences at a
personal and institutional level and in particular on the health care system.

2.2. HIV/AIDS AND THE SOUTH AFRICAN HEALTHCARE SYSTEM

The South African Department of Health has been under increasing pressure to
deal effectively with the HIV/AIDS pandemic at the prevention and care level.

The response has been largely shaped by the available, though limited financial and human resources at their disposal. The South African Nursing Council, 2006 reported that the total number of registered nurses grew by 3.7% over the previous 3 years, but still 42 000 nursing post remained vacant in 2006. The number of nurses employed in 2003 was 155 484 giving a nurse/population ratio of 343:100 000 that is acceptable within the WHO minimum requirement of 200:100 000 (Hall & Erasmus, 2003). Despite this acceptable nurse/population ratio, there is a shortage of staff due to the poor distribution between private and public sectors and between urban and rural areas. The rural hospitals are in most instances adversely affected by the unequal distribution of human resources. (Hall & Erasmus, 2003; Unger, Welz & Haran, 2001). This is always blamed on limited financial resources.

The heavy HIV/AIDS burden in the country affects both the supply and demand of health care. This is primarily due to high demand of care required for patients suffering from AIDS related conditions, the mortality of AIDS patients and the high HIV infection rates of providers themselves. (Olivier & Dykeman, 2003; Sherman, 2000; Smit, 2006). A survey of 512 public sector workers done in four provinces showed that 16.3% of public sector workers were HIV-infected (Shisana et al, 2002). Similarly an HIV-prevalence study conducted at Helen Joseph and Coronation Hospitals showed that 13.7% of the 644 nurses were infected with HIV and 19% had AIDS-defining CD4 cell counts (DoH HIV & AIDS and STI Strategic Plan 2007-2011). The consequences of this will contribute to a high percentage of absenteeism or even worse, a high presence of ill workers who are unlikely to provide a good quality service (Fagin, 1996). This further implies an increased workload, levels of stress and negative impact on the morale of health care workers. This was also supported by a study among African nurses indicating that the stress factors experienced by nursing staff is limited human resources and health system factors like inadequate or shortage of equipment and medicines (Ngwezi, 1998). Poor interpersonal

relationships between the nursing staff and their superiors were also found to be a major stressor (Ngwezi, 1998).

A study on the prevalence of HIV and AIDS-related conditions on the adult patients in medical wards of a tertiary Hospital in Durban presented a bleak picture. Of the 507 patients studied, 54% were infected with HIV of which 84% had AIDS (Colvin, Dawood, Mullick, Lalloo and Kleinschmidt, 2001). Statistics South Africa, 2006 agreed with this by reporting an increase in total deaths by 87% between 1997-2005, 40% of these deaths are believed to be HIV-related (Dorrington, Johnson, Bradshaw, & Daniel, 2006)

South Africa has started the largest ARV program in the world, despite this the country is behind in supplying ARVs. About 65 000 people of the projected 5 5000 total will need ARV in two year's time in 2011 (Dorrington et al., 2006). Presently less than 500 000 people are receiving ARV's (WHO, 2008). A far greater number of people will thus have to be enrolled in the ARV program, resulting in further strain on an already inadequate health system (Jaffar, Govender, Garrib, Welz, Grosskurth, Smith et al., 2005; Unger et al, 2002). This is likely to compromise the quality of care.

2.2.1. Nurses' Knowledge

Nurses' attitudes varied about HIV/AIDS and seem to be dependent on social influences, personal experiences and their level of knowledge regarding HIV/AIDS (Van Wissen & Woodman, 1994). The attitudes of nurses concerning AIDS care have been found to be positively related to their behavioral intention to provide quality AIDS care (Fusilier, Harrison and Worley, 1996). This relationship seems even more important if the nurses hold conservative views about HIV/AIDS. It was suggested that an attempt should be made to modify nurses' attitudes and behavioral intentions through intensive AIDS education programs (Fusilier, Harrison and Worley, 1996). Recent studies support the notion that continuing education is vital for the delivery of quality HIV/AIDS care (Smit, 2005; Sherman, 2000; McCann, & Sharkey, 1998). Support is required at

all levels in terms of human and financial resources or the working environment (Smit, 2005; Sherman, 2000; Fusilier et al.,1996).

2.2.2. AIDS Stigma

Stigma is defined as an attribute that discredit and diminishes someone's stature in such a way that he or she is discriminated against at an individual or social level (Skinner, 2004). Researchers have identified four components of the stigma concept. These include distinguishing and labeling differences, associating human differences with negative attributes, separating the "us" from "them", and a loss of status and discrimination (Skinner & Mfecane, 2004).

AIDS stigma and discrimination is generally viewed as a counter productive epidemic on HIV/AIDS management (Holzemer & Uys, 2004; Skinner & Mfecane, 2004; Stein, 2003). The primary impact of the AIDS stigma is to drive the disease out of the public arena, which plays a significant role in the development and maintenance of the HIV epidemic. Stigma also limits individuals' access to HIV/AIDS treatment, by delaying testing and access to care (Dworzanowski, 2002). It also isolates the infected person by limiting the possibilities of disclosure, thus preventing adequate support from the family and friends (Skinner & Mfecane, 2004).

South Africa had its own stigma related discrimination, the media highlighted some of these, like the murder of Gugu Dlamini for openly declaring her positive HIV status (Baleta as sited in Skinner,2004). There was also a wide spread discrimination against learners who are HIV positive at certain institutions of learning (Sapa, 2002). Its is not surprising that in a Soweto study of patients on ARV treatment, it was found that 38% of the patients had not divulged their HIV status to their current sexual partners and this was attributed to fear of stigma and discrimination (Nachega, Lehman, Hlatshwayo, Mothopeng, Chaisson and Karsteadt, 2005).

10

Stigma is blamed for strengthening and endorsing the existing inequalities of class, race, gender and sexuality (Parker & Aggleton, 2002). Holzmer and Uys (2004) argue that unless stigma is conquered, the HIV/AIDS epidemic will not be defeated. Since HIV-related stigma is associated with stress and can interfere with coping and HIV disease management, it needs to be managed (Chesney & Smith, 1999). Thus how one manages the stigma directed at them largely depends on coping mechanisms that are available to deal with stress caused by the stigma at that time.

2.2.3. Stress and Coping

Work on stress started gaining momentum in early 1930's, when the experience of stress was linked to disease causation. Baum (1990) described stress as a negative experience accompanied by predictable biochemical, physiological, cognitive, and behavioral changes that are directed either towards altering the stressful event or accommodating it (Baum, 1990).

This was seen in the early research work done by Walter Cannon in the 1930's, he proposed that when an organism perceives a threat, the body is rapidly aroused and motivated via sympathetic nervous and endocrine system. The physiological response mobilizes the organism to attack the threat or flee, the fight-flight response (Taylor,1990). Cannon concluded that the stress can be harmful to an individual because it disrupts emotional and physiological functioning and can cause medical problems over time. Other researchers sited in Taylor are Mahl, (1952) who revealed that prolonged exposure to anxiety-producing conditions causes peptic ulcers due to excessive hydrochloric acid production and Selye, (1974) who argued that excessive exposure to stress causes burnout as seen in his General Adaptation Syndrome (Taylor,1990).

Selye's General Adaptation Syndrome, consist of 3 phases, the first phase is alarm, and the organism becomes mobilized to meet the threat. Second phase is the resistance, the organism makes efforts to cope with the threat. Third phase is exhaustion, which occurs if the organism fails to overcome the threat

and depletes its physiological resources in the process. (Selye as cited in Taylor, 1990).

The main work on psychological effects of stress was done by Lazarus and his co-workers. Lazarus (1968) maintains that when individuals are confronted with a new or changing environment, they would first engage in a primary appraisal process, which determines the meaning of the event (as harmful, threatening or challenging). Stress is the result of this process (Lazarus, 1968). The primary process of appraisal initiates the secondary appraisal process which determines whether the coping abilities and resources are sufficient to overcome the threat or the challenge posed by the event (Lazarus and Folkman, 1984). *This is shown in Figure 1. Below.*

Figure 1: Lazarus's Transactional Model of Stress (1984).

Primary appraisal
Is the event positive, neutral or negative in its implications? If negative, to what extent is it presently harmful, threatening for the future and potentially challenging?

Potential stressor
(External event)

Stress physiological, cognitive, emotional, and behavioral responses

Secondary appraisal
Are coping abilities and resources sufficient to overcome the harm, threat or challenge posed by the event?

Herbet and Cohen (1993) found that exposure to long term stressful events was significantly related to poor immune system functioning, thus the inability to recover quickly from a stressful event may be a marker for the cumulative damage that stress has caused (Herbet & Cohen, 1993). There is also considerable evidence that stress at work can contribute to cardiovascular disease (Repetti, 1993).

Previous studies have shown that while burnout is common among healthcare workers who nurse chronic patients, it is more intense on those working with AIDS patients (Gueritault-Chalvin, Kalichman, Demi and Peterson, 2000). The principal stress-producing concerns among AIDS healthcare workers are safety measures and the prevention of occupational infections (Gueritault-Chalvin et al, 2000; Sherman, 2000).The coping style nurses used was found to be an important determinant of burnout among nurses in Australia (Bennet, Kelaher and Ross, 1993). This suggests that adequate support is needed for healthcare workers to develop appropriate coping mechanisms.

Researchers agree that when coping is appropriate, the stress may be minimal. (Taylor, 1999; Lazarus and Folkman,1984). Coping is the process of managing demands (external & internal) that are appraised as taxing or exceeding the resources of the person (Lazarus & Folkman, 1984). There are two types of coping strategies, the problem-solving efforts and emotion-focused coping (Lazarus & Folkman, 1984). Problem-solving efforts are attempts to do something constructive about the stressful conditions that are harming, threatening or challenging an individual. Thus for work related stress, more problem solving effort may be necessary, e.g. in work overload. On other hand, emotion-focused coping involves efforts to regulate emotions experienced because of the stressful events. Thus for health related stress, more emotion focus coping may be used, e.g. in terminally ill patients. But according to Lazarus & Folkman, (1987) people use both forms of coping in almost all encountered stressful events (Lazarus & Folkman, 1987).

13

Both personal coping (talking to friends and family, crying or eating more) and professional support (informal counseling or formal counseling) were seen to be important in reducing stress among nurses experiencing high work stress (Hope, Kelleher and O'Connor, 1998).

2.2.4. Psychological Support for Nurses

In an attempt to support healthcare workers in South Africa, the Employee Assistance Programme (EAP) is based on two legislations, namely the Constitution of the Republic of South Africa (Act No. 108 of 1996) and the Occupational Health and Safety Act (Act No. 85 of 1993). The Employee Assistance Programme (EAP) was introduced to South African Public service as an employment-based programme which is derived from the White Paper on Transforming Public Service Delivery, notice no. 1459 of 1997 (Department of Public Service and Administration, 1997b). It stipulates that the wellbeing of the employees need to be accounted for, thus EAP provides assistance to employees with substance abuse problems or any other social problems including HIV/AIDS and work related stress which are affecting their work performance (Matlhape, 2001). The EAP as funded by the employer, is directed at the systematic, organized and continued provision of counseling, advice and assistance to employees and their families to deal with work-related problems and problems from external sources (Andrea & David, 2003; Hopkins, 2003; Berridge, Cooper, Highley-Marchington, 1997). High levels of ethics and professionalism are essential for the success of the program. If employees feel that their problems are not safe within the EAP they will stop using the service (Maiden, 1997).

2.3. PATIENT-CENTERED CARE

Quality patient care has been linked with patient centered care which in turn has yielded positive patient outcomes (Holman & Lorig, 2000). However, some studies have demonstrated inconsistencies between positive physical and

14

psychological outcomes and patient centeredness (Michie, Miles & Weinman, 2003). Mead and Bower (2000) concluded that despite some inconclusive results, that there is adequate support for patient-centered medicine and improved health outcomes. The interpretation of patient-centeredness is varied and it seems that the concept has created more confusion than direction (Van Dulmen, 2003). Patient-centeredness can be viewed as an antithesis to the previously doctor-centered approach by allowing greater patient participation and to extend a narrow disease focus to that of the patient in total (Van Dulmen, 2003). In most instances patient-centeredness are related to the facilitation of an active involvement of patients in the consultative and disease management process, as well as the ability of health workers to elicit and discuss patients' views. For patients with chronic illnesses of a more unmanageable or degenerative course, positive patient outcomes might depend more on health care workers' ability to elicit patients' perspectives (Van Dulmen, 2003) and to adapt care accordingly.

All this however, requires a receptive and responsive patient and not all patients have the desire to participate in their own care. Furthermore, AIDS management is a risky business and this risk must be communicated to the patient in a manner that will encourage patient-caregiver trust (Paling, 2003). The relationship based on trust however requires a high level of competence and high level of caring. For the majority of public health patients in South Africa, treatment and care is seen as a health worker responsibility and health workers on the other hand very seldom involve patients actively in their own care.

The level of care given to patient can be compared to the level of competence of the service provider, the higher the caring and the higher the competence of the provider, the better the trust that is generated. (See Figure 2. below).

Figure 2: Competence and caring in relation to building trust. (Spence, 2003).

2.4. THEORETICAL FRAMEWORK

The Synergy Model of patient care (1998) developed by American Association of Critical-Care Nurses was used only as a broad framework to understand patient care. Synergy is a new concept that occurs when the nurses, the patient and the family act in mutually engaging ways to promote positive outcomes for patients. The AACN Synergy Model for Patient Care links practice and outcomes. The belief is that positive patient results will occur when patient characteristics and nurse characteristics work in mutually enhancing ways and that these positive results will be found if a nurse demonstrates the competencies in relation to patients' needs (Curley,1998)

The AACN Synergy Model for Patient Care makes the patient characteristics the main focus of the nursing practice. The nursing characteristics are important to patients, as there are patient characteristics to nurse. These characteristics are also influence by the system where this patient/nurse interaction occurs.

(See Figure 3. below).

Figure 3: AACN SYNERGY MODEL OF PATIENT CARE

Functional changes;
behavioral changes;
trust; ratings; satisfaction;
comfort; quality of life
Patient

Physiological
changes;
presence or
absence of
complications;
extent to which care
or treatment
objectives
were attained

Nurses'
competencies

Patients'
characteristics

System

Recidivism;
costs/resource
utilization

Nurse
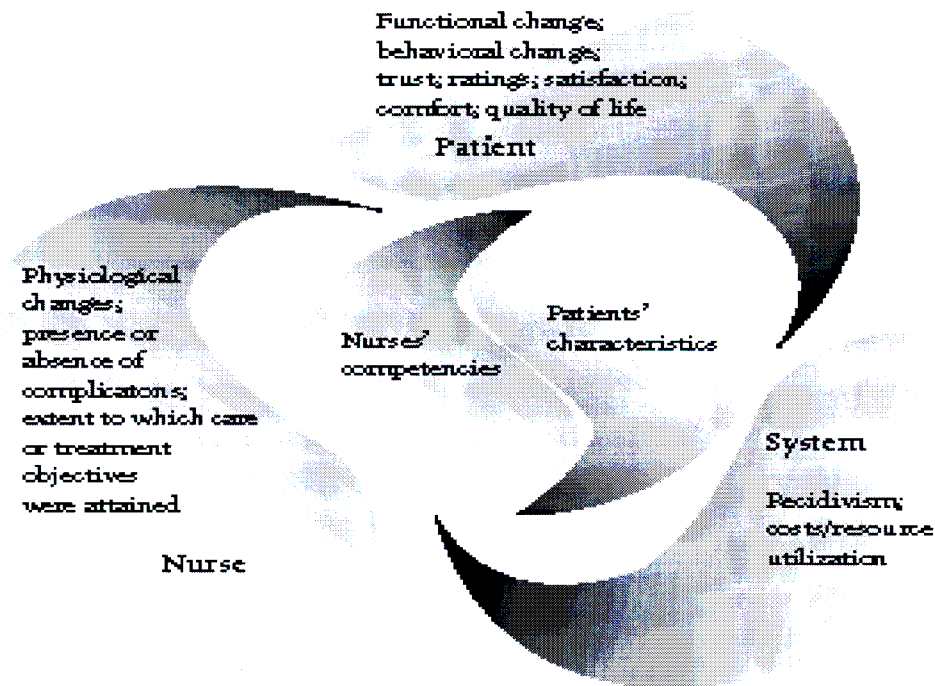
Figure 2: The AACN Synergy Model for Patient Care (Critical Care, 1998)

Table 1: Patient Characteristics

Characteristics	Details	Level 1	Level 3	Level 5
Stability	The ability to maintain a steady-state equilibrium	Minimally stable clinically	Moderately stable	Highly stable
Complexity	The intricate entanglement of two or more systems, like family & therapies.	Highly complex systems	Moderately complex	Minimally complex
Vulnerability	Susceptibility to actual or potential stressors that may adversely affect patient outcomes	Highly vulnerable	Moderately vulnerable	Minimally Vulnerable
Resiliency	The capacity to return to a restorative level of functioning using compensatory coping mechanisms, the ability to bounce back quickly after an insult.	Minimally resilient	Moderately resilient	Highly resilient

17

Characteristics	Details	Level 1	Level 3	Level 5
Predictability	Characteristics that allows one to expect a certain course of illness	Not predictable	Moderately predictable	Highly predictable
Resource Availability	Extend of resources, that technical, fiscal, personal, psychological, social which the patient, family and the community brings to the situation.	Few resources	Moderate resources	Many resources
Participation in care	Extent to which the patient and family engages in aspects of care	No participation	Moderate level of participation	Full participation
Participation in decision-making	Extent to which the patient and family engages in decision-making	No participation	Moderate level of participation	Full participation

Table 2: Nurse Characteristics

Competencies	Details	Level 1	Level 3	Level 5
Clinical judgment	Clinical reasoning includes clinical decision making, critical thinking, and grasp of global situation, acquired through the process of integrating formal and experiential knowledge.	Competent	Excellent	Expect level
Advocacy/moral agency	Working on another's behalf and representing the concerns of the patient, family and community, serving as a moral agent in identifying and helping to resolve ethical and clinical concerns within the clinical setting	Competent	Excellent	Expect level
Caring practices	The collection of nursing activities that are responsive to the uniqueness of the patient and family and that create a compassionate and therapeutic environment, with the aim of promoting comfort and preventing suffering. These caring behaviors include, vigilance, engagement and responsiveness.	Competent	Excellent	Expect level

Competencies	Details	Level 1	Level 3	Level 5
Collaboration	Working with others, like patients, families and healthcare provider, in a way that promotes and encourages each person's contributions toward achieving optimal and realistic patient goals. Collaboration involves intra- & inter-disciplinary work with all colleagues.	Competent	Excellent	Expect level
Systems thinking	The body of knowledge and tools that allows the nurse to appreciate the care environment from a perspective that recognizes the holistic interrelationship that exists within and across healthcare systems.	Competent	Excellent	Expect level
Response to diversity	The sensitivity to recognize, appreciates, and incorporates differences into the provision of care. Differences may include, but are not limited to, individuality, cultural differences, spiritual beliefs, gender, race, ethnicity, disability, family relationship, lifestyle, socioeconomic status, age values, and beliefs involving patients, families and members of the healthcare team.	Competent	Excellent	Expect level
Clinical inquiry or innovator/evaluator	The ongoing process of questioning and evaluating practice, providing informed practice and innovating through research and experiential learning. The nurse engages in clinical knowledge development to promote the best patient outcomes.	Competent	Excellent	Expect level
Facilitator of learning or patient/family educator	The ability to facilitate patient and family learning.	Competent	Excellent	Expect level

2.4.1. Patient Characteristics as explained by Curley (1998)

The patient characteristics identified in the model are resiliency, vulnerability, stability, complexity, resource availability, participation in care, participation in decision making, and predictability

These are characteristics with which the patients may present during some course of their illness. All patients have similar needs and experiences that occur during different phases of illness and, logically, the sicker patients have the higher levels of need.

The characteristics are measured in levels one to five, level one is low and level five is high.

Resiliency

Resiliency is defined as the capacity to return to a restorative level of functioning by using compensatory coping mechanisms. A patient with low levels of resiliency might be one whose compensatory mechanisms have failed, who may already have damaged his organs from environmental influences over an extended period, e.g. from chronic smoking. A patient with high levels of resiliency is able to maintain a response. In HIV infection early diagnosis can lead to high level of resiliency, lower levels may be associated with late presentation and late diagnosis.

Stability

Stability is defined as the ability to maintain a steady-state equilibrium. A level one patient is minimally stable, is unresponsive to treatment, and is at high risk of dying. A level five patient is highly stable and responds well to treatment.

Late stages of HIV infection (AIDS) is minimally stable and response to therapy is not guaranteed, for this reason aggressive management of opportunistic infections is desirable.

Complexity

Complexity is defined as the complex relationship of two or more systems, such as body, family, and therapy. A level one patient would have complex family dynamics or atypical type of presentation that you haven't seen before. A patient who is in level five in terms of complexity is someone who is very straightforward, has an uncomplicated presentation, and has routine family dynamics. Critical illness can cause high emotional needs. If the patient's family is not supportive during the time of critical illness, the patient will be very complex and have physical and psychological stressors. HIV/AIDS has influenced the presentation of disease and made the process of diagnosis more complex.

Resource Availability

Resource availability is defined as the extent of resources that the patient, family, or community bring to a situation. A level one patient with a low level of resource availability would be someone who has no knowledge or skill to deal with the situation, or patient with limited financial resources. A level five patient has extensive knowledge and skills, has financial resources readily available, and has strong social systems. HIV/AIDS is the disease of the marginalized communities, most people are from poor backgrounds and families bring minimal/no resources to the situation.

Participation in Care

Participation in care is defined as the extent to which the patient and family engage in care. A level one patient and family would be unwilling or unable to participate in care, whereas a level five patient and family would be fully able to participate in care. Level five families would like to be involved in patient care, so they feel less hopeless, less helpless and to make the situation more tolerable for them. If they want to help, give them simple things to do such as assisting with feeding and oral toilet.

Participation in Decision Making

Participation in decision making is defined as the extent to which the patient and family engage in decision making. A level one patient or family would have no capacity for decision making and would need someone to make decisions for them. A level five patient or family can make decisions themselves. If the family is willing to participate, the transition from critical illness to being discharged home and the time spent in the hospital are easier. Most traditional family structures have been destroyed by apartheid era economic activities such as migrant labour and population resettlement as well as by the recent process of urbanisation. In many cases there are no families to rely on.

Predictability

Predictability is defined as a characteristic that allows one to expect certain events or a course of illness. A level one patient is one who is uncertain or an uncommon patient. The patient doesn't follow a critical pathway or there is no pathway developed for the patient's condition. A level five patient follows usual and expected courses, follows a critical pathway, and cooperates with the therapeutic regime. While opportunistic infection and complications compound the picture in AIDS patient, the course of illness is straight forward and it leads to death eventually.

2.4.2. Nurse Characteristics as explained by Curley (1998).

Nursing care reflects the integration of knowledge, experience, and skills, which are all needed to take care of patients and to promote optimum patient outcomes. The AACN Synergy Model for Patient Care focuses on the unique characteristics and contributions of nursing, but it also emphasizes the professional role of nursing in relation to patient care.

Clinical Judgment

The clinical judgment is defined as clinical reasoning that includes clinical decision making, critical thinking, and a global grasp of the care situation, as

well as nursing skills acquired through a process of integrating formal and experiential knowledge. All of these characteristics are important to promote holistic care. Level one nurses will collect baseline level data, follow standing protocols and will be uncomfortable deviating from that sequence. They are able to match the formal knowledge learned in school with clinical events experienced on the unit in helping to make a decision about what a patient needs. Level five nurses are going to look at the bigger picture. They will collect data, make clinical decisions based on an immediate grasp of the whole picture, and will be able to decide on the appropriate interventions, based on the big picture, not just on one or two events or signs. They will use past experiences to help anticipate problems. With HIV/AIDS, every patient who shows signs of opportunistic infection will be referred to VTC and screened for Tuberculosis.

Clinical Inquiry

Clinical inquiry is defined as the ongoing process of questioning and evaluating practice and providing informed practice, and creating practice changes through research utilization and experiential learning. Level one nurses will follow standards and guidelines, implement clinical changes based on research practices developed by others, recognize clinical changes and needs of the patient, know that the patient is in trouble, and know when they need to get help. Level five nurses will improve or deviate from a standard; individualize care based on the needs of the patient and families; evaluate current practices based on patients' responses, review of the literature, research utilization, and education; and acquire the knowledge and skills they need to provide that clinical practice and solve clinical problems. Different presentations of the HIV requires these skills of level five nurses in order to individualize care giving as required.

Facilitator of learning

Facilitator of learning is defined as someone with the ability to help patients, nursing staff, physicians, and other healthcare disciplines learn, both formally

and informally. Level one nurses will follow planned educational programs, see education as being independent of patient care, and provide teaching to the patient without considering what the patient is going through at the same time or without seeking to understand. Level five nurses will modify and develop educational programs, integrate education throughout the course of patient care, and evaluate the understanding of that education through patients' behavior.

Collaboration

Collaboration is defined as working with others, including medical personnel, families, and other healthcare providers, in a way that promotes and encourages each person's contributions toward achieving optimal, realistic patient goals. Collaboration involves intra- and interdisciplinary work with colleagues. Level one nurses are willing to be taught and mentored. They will participate in team meetings or discussions and might attend a family meeting. Level one nurses may not be aware that they need to initiate a family meeting with the physician, social worker or counselor, but they know that attending such a meeting lends support. Level five nurses seek opportunities to teach and mentor; facilitate active involvement in contributions of others, such as a social worker; and recruit resources to promote optimal patient outcomes. Level five nurses might initiate a family meeting if the family decides to withdraw or withhold support. This is the level of collaboration necessary for the Rollout of Anti-Retroviral treatment program.

Systems Thinking

Systems thinking is defined as a pool of knowledge and tools that allow the nurse to manage whatever environmental and system resources that exist for the patient, family, and staff within or across healthcare and non healthcare systems. Level one nurses will use a limited range of strategies, have a limited outlook, and do not see the big picture.

Advocacy and Moral Agency

Advocacy and moral agency is defined as working on someone's behalf and representing the concerns of patients, families, and/or nursing staff and serving as a moral agent in identifying and resolving ethical and clinical concerns within and outside the clinical setting. Level one nurses work on behalf of the patient, knowing that there are ethical conflicts and issues that may arise. They will represent the patient when the patient can't represent himself. Level five nurses will work on behalf of the patient, family, and community; will advocate from a patient's and family's perspective; and will suspend some rules for the patient and family benefit, to drive the moral and ethical decisions.

Caring Practices

Caring practices is defined as a collection of nursing activities that create a compassionate, supportive, and therapeutic environment with patients and staff. The aim is to promote comfort, heal, and prevent unnecessary suffering. Level one nurses will focus on customary needs, can't anticipate future needs, will base care on standards and policies and protocols, and will probably accept death as an unavoidable outcome. Level five nurses have perceptive awareness, can anticipate patient and family changes and needs, and start processes to ensure patient and family comfort and that the concerns surrounding issues of death can be met with dignity.

Response to Diversity

Response to diversity is defined as the sensitivity to recognize, appreciate, and incorporate differences into the provision of care. Differences may include individuality, cultural differences, spiritual beliefs, gender, race, ethnicity, disability, family relationship, lifestyle, socioeconomic status, age, values, and alternative medicine involving patient's families and members of the healthcare team. Level one nurses will assess cultural diversity and will provide care based on their own cultural beliefs. Level five nurses will respond to and anticipate

differences in patients' cultural differences and plan their care to accommodate for those differences.

Outcomes

Nurses have their own ideas about which outcomes are important, but the outcome for the patient is what matters most. Outcomes are whatever the patient says they are. Some of our care is driven by which outcomes we want for the patient, and some outcomes are derived from the healthcare system. Some of the outcomes for the patient are functional change, behavioral change, trust, satisfaction, comfort, and quality of life. How do the patients perceive their quality of life? How do the patients perceive their change in function? ARV treatment does influence the quality of life and is expected to impact on nursing outcomes.

Trust is a big issue. We must think about trust issues. Some of the outcomes for a nurse are physiologic changes, such as the presence or absence of complications or the extent to which the treatment objectives were attained. Outcomes for the healthcare system, costs, and resource utilization are all part of healthcare outcomes.

2.5 CONCLUSION

This chapter looked at the South African AIDS epidemic and how it affects patient/nurse relationship. Patient care and the factors that influence stress and coping were explored in order to better understand AIDS patient care within the South African context. In the next chapter the methodology employed for the study will be discussed.

CHAPTER 3

RESEARCH METHODOLOGY

3.1. Introduction

This chapter describes the research design, the methods used to collect the data from the focus groups discussions and later from individual in-depth interviews, regarding nurses' experience in caring for AIDS patients pre-introduction of ARV treatment as well as after the introduction of ARV treatment in the rural health care setting.

3.2. Background to the study site

This qualitative study was conducted at a District Hospital, in a deep rural setting in northern KwaZulu-Natal that is struggling with inadequate infrastructure and poor patient accessibility. The hospital is experiencing difficulties in staff recruitment and maintenance due to its locality and lack of staff accommodation. The hospital admits an average of 400 patients, it had a combined nurse-to-patient ratio of 1:10, but if this is broken down to professional nurse-to-patient ratio (which exclude nursing assistance and student nurses) the ratio was 1:24. This is way above the 1:4 ratio seen in the private hospitals and 1:18 ratio that was reported at Chris Hani Baragwanath hospital. The setting was chosen because of the high incidence of HIV and AIDS in the area.

3.3. Research Design

A qualitative research design was used for the study. Focus group discussions were used with healthcare workers before the introduction of ART and then in-depth individual interviews were used for the follow-up phase with these healthcare workers after ART was introduced in the health care facility.

The use of focus group discussions was viewed as an appropriate method to explore the nurses' experiences in caring for AIDS patients. A focus group is described as being able to generate qualitative data through a discussion-based interview (Millward, 1995). It allows the researcher to get closer to participants' understanding and perspectives on the different issues of interest. Focus groups processes rely on the way in which people interact and communicate with each other. A general advantage of a focus group discussion is that it gives a collective opinion on issues under discussion and not individual information (Kreuger, 1994; Millward, 1995). This method provides an ideal forum for capturing and analyzing information about community resources and practices, especially in the face of crises like the AIDS epidemic (Millward, 1995).

In-depth individual interviews were used to explore nurses' perceptions relating to AIDS care after the introduction of ARV-therapy. In-depth interviews are normally used by health care researchers, with participants to create meaning of the events, to explore perceptions and find out experiences related to health and healthcare (DiCicco-Bloom & Crabtree, 2006).

3.3.1. Sampling

Sampling itself is the strategy of selecting a smaller section of the population that will accurately represent the patterns of the target population as a whole (Babbie & Mouton, 2002). Convenience sampling was used, and described as targeting a particular group of people. In this case the nurses, who are caring for people with HIV/AIDS. It should be noted that a limitation of convenience sampling is its lack of representativeness. It is possible that the type of people who might be available for the sample might be different from those that are representative of the population and thus introduce some bias (Babbie & Mouton, 2002).

The participants for the focus groups were selected on the basis of their experience in caring for AIDS patients. For an optimal focus group discussion it

is advisable to have a homogeneous group. However it was not possible to separate the groups in terms of their formal qualifications, but they were considered to have enough in common to constitute a relatively homogenous group. Group members should at least have some common characteristics to facilitate the sharing of experiences e.g. caring for AIDS patients (Krueger, 1988; Parker & Tritter, 2006). For the discussions a sample consisting twelve (n=12) nurses caring for the terminally ill at the rural hospital was invited to participate in the study. The participants were nurses who have been working in the medical wards for at least one year and who have been involved in nursing patients with HIV/AIDS. Five of these twelve nurses were professional nurses while seven were registered as enrolled nurses. They have an average of ten years experience working in the medical wards where most of the HIV and AIDS related conditions were treated. They were divided into three focus groups each group consisting of four participants to enable them to fit the discussion into their work responsibilities.

A year later, after the introduction of ART at the hospital, the nurses who participated in the focus group discussions were invited to participate in the in-depth individual interviews to explore possible changes that might have occurred after the introduction of ART in the health care setting. It should be noted that only five of these nurses could be invited as they were the only participants available from the previous groups. From the original sample, three nurses had left the institution, while four had died. The follow-up of participants is often difficult and unsuccessful. It has been stated that while returning to respondents for follow-up is not uncommon in qualitative research, it can be fraud with difficulty as people and circumstances change over time (Bloor et al., 2001 as cited in Parker & Tritter, 2006).

3.3.2. Research Instruments

For both the focus group discussion and the in-depth interviews, interview schedules (Appendix 3 and 4) were used to guide the discussion and

explorations. The interview schedules were developed from understandings obtains from the literature review and the theoretical framework of the study. The topics of interest were explored through open-ended questions and extensive probing was used to elicit specific information or to expand on participants responses.

In the focus group discussions the following topics were explored:
Patient characteristics as perceived by the nurses in relation to HIV were explored in terms of:

- Establishing the type of patients that nurses care for (i.e. who are they and at what stage of illness are they).
- Patients' understandings of their illness.
- Patient and family role in decision making regarding patient care.
- Family involvement and support in patient care.

Nurse characteristics were explored in terms of:

- Nurses' knowledge, attitudes and beliefs about HIV and AIDS.
- Nurses' training regarding HIV and AIDS.
- Patient care, especially AIDS care.
- Stressors and coping mechanisms nurses use as AIDS care workers.

For the in-depth interviews post-introduction of ARV treatment the five nurses (n=5) who were available after one year and who had participated in one of the focus group discussions were subjected to in-depth individual interviews. The same questions asked in the focus groups discussions were repeated and the following issues were added to explore the situation further.

- The impact of the HIV epidemic on nursing care at this rural institution.
- Specific pressures placed on nurses due to the AIDS epidemic.
- Pressures affecting the quality of healthcare provision.

30

- The role that the introduction of anti-retroviral treatment played in Healthcare provision.
- Changes that occurred regarding nurses' attitudes towards patients after the introduction of antiretroviral treatment.
- Changes in patient willingness to be tested and to disclose their status.
- HIV training, and in particular ARV-therapy.

3.4. Procedures and Data collection.

After permission for the study was obtained from the Department of Health and the University Ethics Committee (Appendix 5), written Informed consents were sought from all twelve voluntary participants after they were assured of confidentiality and their right should they choose not to participate. Permission was also asked to record the interview. Group confidentiality was sought for the focus group discussions. Three focus group discussions were held in the hospital premises and conducted in isiZulu, the preferred language of the participants lasting about an hour. The interview schedule as previously discussed was used to facilitate the discussion. The nurses' knowledge, their skills, their attitudes towards patients, experiences in caring, and their coping strategies were explored. Each group discussion was moderated by the researcher and as Krueger (1988) suggested had to improvise comments and questions within the framework set by the interview guidelines. The data collected was then translated from Zulu to English by the researcher.

Twelve months after the introduction of ARV treatment at the hospital setting, follow-up in-depth individual interviews were conducted with a few of the participants. The same ethical procedures were adhered to namely voluntary participation, the right to withdraw and confidentiality. Both focus group discussions and individual interviews generated qualitative data in the form of transcripts produced from audiotapes and written notes. The transcription and translation into English was done directly from the audiotapes and written notes produced the necessary textual data. No data editing occurred during the transcription process. .

3.5. Data analysis.

Qualitative content analysis was conducted. Content analysis has both mechanical and interpretative components. The mechanical aspect involves physical organizing and subdividing of the data into categories while the interpretative component involves determining which categories are meaningful in terms of the questions being asked (Millward, 1995). The qualitative emphasis is on meaning rather than quantification (Babbie & Mouton, 2002; Millward, 1995). Mechanical and interpretive content analysis, which involves physically organizing the data into categories while deciding on the meaningfulness of each category in relation to the question asked was done on data collected from both focus groups and in-depth interviews. From these categories meaningful codes were developed (Millward, 1995).

Code classification was done using the research questions as a guide. Additional conceptual codes arose from a closer examination of the whole data set. An overview grid was made for the data collected from the focus groups, this grid tabulated code on one axis and the focus group identifier on the other axis. These provided a descriptive overview of the data (Millward, 1995). This process allowed for the coding of the material into analytic distinct segments that were examined for interpretation and when drawing conclusions (Ritchie & Spencer, 1992). This was done with consideration of the complex task to interpret qualitative data (Millward, 1995). The categories and codes were discussed with the supervisor and where differences occurred these were clarified.

3.6 Conclusion

Three focus group interviews, before ART was introduced, and five individual interviews was used one year later, after ART introduction, to gain a better understanding and insight into how nurses perceive and cope with AIDS care. This period was expected to be sufficient to result to significant changes in nurses' experiences in caring for the AIDS patients.

CHAPTER 4

FINDINGS

4.1. INTRODUCTION

The data analysis was done on both the findings of the focus group discussions pertaining to the period before the introduction of the ARV-treatment program in the researched hospital and the in-depth individual interviews done after its introduction. Different themes emerged from the patient characteristics and nurse characteristics to influence patient care. The section concludes with stressors nurses experience and the coping strategies they employ in this regard.

4.2. PATIENT CHARACTERISTICS

4.2.1. Patients' illness presentation.

At pre anti-retroviral treatment, the nurses in the discussions described their patients' illness presentation similarly. Most of them indicated that their patients often presented with various opportunistic infections, wasting, poor nutritional status and other systemic complications such as tuberculosis. Despite the obvious diagnosis of AIDS, they were often faced with a complex situation where a significant number of patients refused to be tested for HIV so as to exclude evidence of HIV-infection. This led to some ambiguity in the caring process as patients were treated and cared for as AIDS patients without a definite AIDS diagnosis.

Participant:

> "...there are only a few patients where the doctors write RVD (retroviral disease), but for most patients we conclude by mere looking at the obvious opportunistic infections".

However, this situation seems to have changed after the introduction of ARV treatment where more patients seemed more open to talk about their disease.

Nurses reported that there is an increase in the number of patients getting tested and starting on treatment.

All participants explained that patients' illness presentations impacted on the level of care required. It was described it as "*very demanding*" because of the patient load, the required aggressive treatment regime and the fact that most of the patients are bed-ridden and imminent death is anticipated.

Participant:

> " .. *if one looks at the demand by the type of patients being attended to and the staff situation as well as their work experience, one will realize that we have a massive problem.* "

The demanding nature of patient care in terms of the above, remain challenging even after the introduction of ARV treatment as seen in the post introduction of ARV treatment interviews. Participants argued that while more patients are ready for testing, the amount of work has not changed but that the quality of care has deteriorated. One participant pointed out that "*personally, I think that the quality has gone down*". She further explained that she would have had no problem in being admitted to this institution in the past, but now she will be reluctant to be admitted to this institution due to the level of care available.

4.2.2. Participation in care and decision making

At the pre-ART phase, the nurses in the focus group discussions explained that patients and their families were passive participants in the disease management process. They indicated that there is no encouragement from their side for patients to participate in their own care.

Participant:

> "…*we just discharge the patients and are happy that the patient is out of our hands*".

Patient's involvement in care and decision making was also seen as being "*hampered by the low literacy levels* "among most of their patients. The nurses

explained that this impact on the patients' understanding of illness and in particular of AIDS, and the possible complications associated with the disease progression. Participants also thought that counseling or health education would not be effective in changing traditional conceptualizations with regards to viewing illness as being a result of being *"poisoned and bewitched, while they are having obvious signs associated with AIDS"*

The introduction of ARV-treatment seems to be changing some patients' behaviour as patients on ARV-treatment are given "preferential" treatment by the medical staff as opposed to those who are refusing to be tested. That was seen in the increased frequency with which the doctors wanted to evaluate their admitted patients on ARV treatment. Furthermore, patients on ARV's are also *"granted the privilege"* of keeping their tablets with them and are fully involved in administering their own treatment regime. The health workers were also of the opinion that in most instances these patients knew more about the ARV treatment than the nurses who take care of them. This is seen as a consequence of inadequate training of nurses about HIV/AIDS in general and ARV therapy in particular.

Participant:

> *"In most instances these patients know more about the ARV treatment than the nurses who take care of them. Unfortunately there is still no proper bedside teaching for the nurses regarding HIV/AIDS/ARV therapy".*

4.2.3. Emotional and financial resources

At pre ARV treatment discussions, the nurses were of the opinion that the noticeable absence of family support for the patients makes *"the picture even bleaker"*. They ascribed this lack of interest or support to the prevailing stigmatization of people with HIV/AIDS. Participants were of the view that the emphasis on confidentiality of the HIV status exacerbated the level of AIDS stigma and discrimination that exists in communities.

Participant:

> "Most patients want to keep this confidential, thus fewer families are involved, the problem is this - confidentiality issue, it makes broader involvement impossible".

This suggested that the adherence to strict confidentiality by the health care sector may result in *"families were being kept in the dark"* as patients might be reluctant to disclose their HIV status to their families. This made broader family involvement in patient care impossible as nurses could not involve families unless patients were willing to disclose their HIV status. This results in patients not being able to receive the necessary emotional support from their loved ones.

Participant:

> "...there *is also no teaching or counseling directed to relatives of the patients"*.

As mentioned previously, participants at the pos- ART initiation period reported improvement in this area as more patients are getting tested and commence treatment. Since they are encouraged to have a family member who will be responsible to assist with their treatment, disclosure seems no longer to be an obstacle. An increasing number of patients were also more open and ready to talk about their HIV-infection.

Participant:

"More patients are ready to talk about their disease. There are an increase number of them getting tested and starting treatment, they are encouraged to have family members to assist with treatment, so disclosure is no longer so difficult".

The majority of the patients were described as poor, with little or no economic resources and with no medical aid insurance. Poverty was seen by the nurses

as impacting negatively on both HIV-patients' prognosis and on HIV/AIDS prevention initiatives at both pre-ART and pos-ART times.

Participants:

> " A typical AIDS patients on presentation is neglected, malnourished with AIDS defining signs, these patients are poor and rely on government for treatment".

Because of poverty, patients' access to healthcare is limited to the public health care sector only. Poverty was seen as impacting directly on the nutritional status of the patients as proper and adequate nutrition is important in the management of HIV and AIDS. It was understood from the nurses that patients take responsibility for getting social grants to enable them to cope financially.

Participant:

> "...we do not do anything regarding the diet and nutrition ourselves, most discharged patients depend on social grants".

When participants were asked whether patient characteristics had changed since the introduction of ARV treatment, they pointed out that nothing had changed in terms of the type of patients they see but that the number of patients is increasing. They explained that an influx of patients at the health facility is experienced because of a greater number of people seeking VCT and more and more patients are willing to be admitted to the wards.

Participant:

> "...more patients are ready to for testing these days, and nurses' attitude towards patients with HIV/AIDS have improved".

4.3. NURSE CHARACTERISTICS

4.3.1. Knowledge and skills including clinical inquiry and judgment

All focus groups pointed out that although HIV and AIDS training should occur, there is no inclusive formal HIV/AIDS training program in place. These nurses

explained that they follow *"clinical management standing orders"*, and can not deviate from the protocol, let alone improving it.

Participant:

> "We *treat all patients the same"*.

This means that they are not in a position to use their experience to anticipate problems and influence patient care. Other than routine patient care as prescribed by the medical practitioners, there was no teaching, no protocols and there was no special knowledge specifically directed to nurses for the management of AIDS patients in the wards. This practice seems to be the status quo even after the introduction of ARV-treatment.

Participant:

> *"There are no specific protocols relating to AIDS patients alone, we treat all patients the same"*

Participant:

> *"...even now we have no bedside teaching about AIDS, no about any disease for that matter, doctors are very busy and have no time for teaching"*.

Elements of frustration and unhappiness were noted when participants claimed that, *"certain individuals are attending all the HIV-related courses but somehow are not directly involved with the day-to-day management of the patient"*. They also do not report back on what they have learned. This seems to reflect a limited collaboration among different stakeholders within the health care setting.

Participant:

> *"There is no feedback among staff members alone, there is no formal teaching from HIV/AIDS nurses to patients nor to fellow staff members, despite the workshops they are attending"*.

All groups agreed that they were lacking in basic HIV/AIDS and related knowledge and most have not received specific training pertaining to HIV/AIDS.

Participants:

> "We have no formal trainings, in fact regarding counseling the community
> caregivers are much better than us".

However, most of the health workers could explain HIV/AIDS-related signs and
symptoms, had some knowledge regarding HIV-transmission modes and
understood how HIV-testing was done. Nevertheless, there was also a
significant number of nurses who were not sure about HIV-modes of
transmission, signs and symptoms and how testing was done.

Participant:

> "...at times we feel that we may be infected easily by being in contact
> with these patients".

Insufficient knowledge about ARV treatment in general, and in managing
patients on ARV-therapy have been reported by the health workers after the
introduction of ART.

Participants:

> "...there is a lack of planned teaching regarding HIV/AIDS for ward
> nurses, most information we have is in bits and pieces that we get from
> the colleagues, from orders during the ward round and mostly from the
> news papers".

It was a general opinion that nurses needs more training regarding ARV
treatment if they are expected to advise patients properly, about treatment and
complications.

Participant:

> "Those patients on ART come with their special treatment and because
> they know more about their treatment than we nurses do, we let them
> self-administer the treatment. The patient on ART knows exactly what is
> wrong with them and is more helpful regarding their management. The

most difficult patients are those whom you suspect to be positive and at
times know it but do not want to accept any treatment relating to HIV."

This highlights the need to provide HIV/AIDS training to all nurses, in order to avoid the embarrassing situation where the receiver of care knows more than the service provider.

Participant:

"We think that DoH should facilitate in-service training which involves all health workers in HIV/AIDS management & HIV counseling within each institution, so that we will know what is happening and how to handle most problems".

ARV treatment was viewed positively because it has extended life for some patients for whom the staff and relatives have lost hope.

Participant:

"... ARV treatment is good, it has extended life for some patients for whom the staff and relatives have lost hope".

There were also not a significant number of patients who died after commencing ARV treatment, this was viewed as a *"sign that the treatment is working".*

However, the nurses' hope for the reduced hospital admissions because of ARV treatment was in vain. It seems that despite ARV-therapy availability, *"more and more patients still come to the hospital to die"*. Health workers argued that it might be due to patients still not willing to test and acknowledge AIDS at the early stages. But still, the staff hoped that more people will get tested and start early on treatment in order to reduce terminally ill admissions.

Participants:*"The staff hope more people will get tested and start on ARV-therapy in order to reduce terminally ill admissions, since there have not been a significant number of patients dying on ARV-therapy".*

In commenting on the quality of care, the participants were of the opinion that the quality of clinical inquiry and judgment had deteriorated post-ARV time due to limited experienced nurses and lack of training. As noted above, one participant said that previously she would not have had a problem to be admitted to this institution, but now would refuse admission, especially if her illness required intensive care.

The participants in this study at both pre-ARV and post-ARV times seemed not to be in control of the whole nursing process; they tend to follow the instructions passively without any clinical decision making, critical thinking or global grasp of the situation as per their acquired skills. This factor together with an abnormally high staff turnover caused by death of the colleagues and staff transfers to other institutions, creates a situation described by the participants as *"a situation where people cannot learn much".*

In the individual interviews post-ART introduction, nurses felt that comparing today's nurses with those of few years ago would be unfair due to changed circumstances and contexts that provide little support to younger nurses.
Participant:

> *"Today's nurses are thrown into the deep end without being properly prepared. There is no time for preparation, there are not enough experience nurses or doctors for that matter to prepare them".*

Some changes have been noted since the introduction of ARV-therapy as patient health outcomes have been positively influenced. Patients on ARV-therapy have someone who is involved in their treatment as part of their support system. This has become a prerequisite for access to ARV-treatment in the public health sector. However, the nurses felt that the HIV/AIDS epidemic has

impacted negatively on patient care overall as a number of experienced staff have left the hospital or have died because of AIDS e.g. *"we are not running short of staff but also running short of experienced nurses"*.

4.3.2 Caring practices, advocacy and moral agency

This section deals with issues affecting access to care by the patient as well as the physical and psychosocial aspect of care delivered to the individual patient. Access to quality care seemed to be compromised by a poor staff-patient ratio, overworked staff and inadequately trained staff.

Participant:

> *"Nursing is not what it used to be, these days we are overworked, underpaid and short staffed, these problems affect our work"*.

Nurses mentioned in the focus group discussions (pre ARV) that their institution seems generally reluctant to admit patients with AIDS and is thus eager to discharge those whom they have been forced to admit.

Participants:

> *"Once the patient has tested positive to HIV, the patient is not likely to be admitted at Out Patients Department, if he does, he is likely to be discharged the next day as long as he is fully conscious"*.

The nurses said they have no influence on admission policy and the length of stay regarding AIDS-patients, as this is a prerogative of the medical staff and hospital management. However, hospital admission of AIDS patients seemed to have improved for those patients who were attending the ARV-clinic, and probably because most of them were admitted via the ARV-clinic.

Participant:

> *"Most ARV patients are admitted via ARV clinic and are known to the doctors"*.

With regards to the physical aspects of care, specifically related to medication, pain control medication for admitted AIDS patients, seems to be done at the

discretion of "*certain medical staff*"; there was no standard protocol regarding pain management at the terminal stages of illness.

Participant:

> "*It is not uncommon to find patients with over-the-counter pain tablets, though some doctors do prescribe something stronger for pain management but the rest do not*".

Nurses reported that there was a tendency for essential stock to run out when it is most needed.

Participant:

> "*I would like to add that some bed sores may be caused by us here at the hospital, you find the patient lying in the pool of urine and diarrhea longer than necessary because we are running short of linen savers due to poor stock supplies. This seems to be a chronic problem in this institution*".

Most families are generally not involved in patient care, nor are they encouraged to, and the nurses do not seem to be willing to actively advocate for patient care.

Participant:

> "*Families are not involved in any manner, we discharge the patients and are happy that the patients are out of our hands*".

In terms of patient psychosocial support and the counseling the nurses gave, general feelings existed among the health workers that patient counseling is an area where nurses can not advocate for their patients as expected. One participant explained that they are not involved with the patient counseling, and hardly knew what was happening.

Participant:

> "*All what we saw are emotionally disturbed patients after counseling*"

This alerted them that something was wrong with the VCT, but they would keep their distance from the patient because they seem to feel excluded.

Participant:

> "... When we suspect something is wrong, we keep our distance from the patient because we are not involved".

This was done in respect for the patients' privacy, but a general opinion was that patient counseling within the institution was problematic. This opinion stems from the observation that for most patients *"their condition seems to worsen after counseling both physically and emotionally"*.

Participant:

> *"Some patients stop eating, some stop communicating. They get a lot of anxiety after the blood has been taken for HIV testing".*

Some health workers further explained that they and patients are unhappy with the way counseling is done, but that they are not able to offer short term solutions to the problem at present.

Participant:

> *"...a lot of patients are unhappy with the way counseling is done. It needs to be evaluated and the lay counselors be assisted depending on evaluation results".*

It was suggested that counseling services should be evaluated and that the lay counselors should be assisted in accordance with the evaluation results. The nurses believed that the existing patient counseling has also failed to change people's beliefs around illness as resulting from being poisoned and/or bewitched.

Participant:

> *"...we also think counseling is not effective in removing people from old beliefs of being poisoned and bewitched while they have HIV/AIDS".*

The current patient counseling and spiritual support services are limited due to the lack of training offered to the nurses in the wards. Irrespective of the fact that they work with patients with HIV or AIDS on a daily basis, they have not received any training at all in AIDS counseling.

Participant:

> "There is a lot of problems regarding HIV counseling, I think it creates more problems than benefits when its done the way it is done outside the wards, without involving us".

4.4 STRESSORS AND COPING

The majority of the stressors mentioned by the health workers are related to the HIV/AIDS pandemic, ranging from workload to inadequate resources to deal with the different dimensions of HIV/AIDS, to fear of becoming infected within the health care setting. During the focus group discussions, the high work load brought about by an exodus of staff from the health services or because of AIDS-related staff deaths, were considered as prominent stressors.

Participant:

> "...with abnormally high staff turnover, this create a situation where people can not learn much and if look at the demand by the type of patients, staff situation and experience one realize that we have a massive problem".

Despite the fact that ARV-therapy has extended the life of some patients and brought hope to hospital staff and families that had previously felt helpless, most stressors remained and in fact new stressors seemed to have emerged because of the availability of ARV-therapy i.e. inadequate knowledge and skills pertaining to ARV-treatment management. Another ARV-related stressor was the fact that healthcare workers do not take advantage of the availability of ARV treatment for themselves.

45

Participant:

> "I wish more nurses would test and take advantage of the availability of ARV treatment, since we have a significant number of staff members who have died with no proper diagnosis and treatment, because they are still scared to take an HIV test."

The participants expressed appreciation that the government acknowledged their workload and is employing community caregivers to help them with basic patient care within the hospital. It was however pointed out that they still need to mentor and supervise these community caregivers, thus adding to their existing workload. While the hospital management has reported to have tried to fill most of the vacant positions, this has not had the desired effect as inexperienced staff was employed and as one participant said, *"now we are not running short of staff but we are running short of experienced nurses".*

Participants reported that a range of strategies were used to cope with the stressors they experienced. Most nurses resort to religion when faced with the possibility of being infected with HIV. It was explained that they *"just pray and hope nothing will happen"* to them. Other strategies include having a good, fulfilling meal before commencing duty, and engaging in *"self-talk"* to encourage themselves to get through their duties for the day.

Participant:

> "We think you need a full stomach before you go on duty at the medical wards, you also need to talk to your inner-self to accept the fact that you are allocated to these medical wards and for the risk involved, you have to protect yourself".

A significant number of nurses indicated that when they are no longer able to cope with the work in "these wards", (implying wards with AIDS-patients), they simply transfer to other wards. Health workers also indicated that some of their friends have opted for transfer to other institutions. This seems to be done

without further engagement of the management regarding working conditions that they consider to be unbearable.

4.5. CONCLUSION

The data analysis showed that there were some changes in both patient characteristics and nurse competencies following the introduction of ARV-treatment. These changes had an impact on patient care as experienced by the nurses.

CHAPTER 5

DISCUSSION

5.1. INTRODUCTION

This study fills a gap in the current literature as it investigated two stages of AIDS patient care, before the introduction of ARV-treatment and a year after the introduction of ARV-treatment. The findings are discussed in terms of the aims and objectives of the study with consideration of the synergy model directed at a better understanding of patient care in terms of the reciprocal influence of both patients and nurses on institutional care. Attention was also given to stressors experienced by nurses and the coping strategies they employ.

In comparing the data from the focus group discussions before the introduction of ARV treatment to the individual in-depth interviews post ARV introduction, it appeared that some changes had occurred in both patient characteristics and in patient care. Most of these changes were attributed to the accessibility to ARV-therapy through the dedicated ARV-clinic within the hospital. The changes observed are discussed and recommendations are made with regards to patient care issues as emerged from the data.

5.2. PATIENT CHARACTERISTICS

5.2.1. Patients' illness presentation

In terms of the synergy model most patients nursed by the participants had low levels of "*Resilience and Stability*" due to the fact that they generally present at advance stages of the AIDS disease trajectory. As reported in the literature, the late clinical presentation with advance complications such as TB seems to be the most common presentation (Colvin, Dawood, Mullick, Lalloo & Kleinschimdt, 2001). This is however of concern that this occurred despite the fact that more patients are being tested for HIV since the introduction of ART. Hall (2004) argued that since AIDS patients take longer to recover and demand more time

and energy from nurses, it is important to encourage early consultation which will reduce the amount of nursing care needed. The care demand by AIDS patients in the study remain high and therefore the need for early HIV-testing which accompanied timely care and support needs to be a priority (Abdool Karim et al, 2008). The high demand placed on the health workers were reported to reduce the quality of care that is delivered to patients. Similar results were found elsewhere as well as an increase in absenteeism among nurses because of increased workload (Shisana, Hall, Maluleke, Stoker, Colvin, Chauveau, Botha, Gumede, Fomundan, Shaik, Rohle, Udjo & Grissdquist, 2002). The fact that the nurses indicated that they request transfers to different wards when they feel overwhelmed by the nature of their work and workload, imply a high turnover rate of nurses involved in AIDS care that may compromise knowledge and skills development necessary for the delivery of quality care in this regard. Access to quality care has been reported to be influenced by staff availability and staff training, often compromised by overwork and poor planning (Hall, 2004).

While the quality of care for all patients is important, it is suggested by the data that different components as suggested by the AIDS quality care model is necessary for AIDS quality care. This model was tested on two Gauteng Hospices, it showed that access to care, physical as well as psychosocial support is central to the quality of AIDS care (Dworzanowski, 2002).

From the data it is clear that AIDS stigma and discrimination still play a role in limiting early detection and access to care as reported elsewhere (Holzemer & Uys, 2004; Skinner & Mfecane, 2004; Dworzanowski, 2002). Self-stigma also emerged from the data in that health workers and some patients were not willing to disclose their HIV-status despite disease progression. In a study by Abdool Karim et al. (2008) self-stigma limited access to care as clients felt ashamed to access ART in a rural setting where people know each other and is also aware of where ART-services are offered. It will therefore be important to

address issues of stigma which limit PLWA from accessing the necessary help (Abdool Karim et al, 2008; Hall, 2004; Holzemer & Uys, 2004; Skinner & Mfecane, 2004). It is assumed that effective interventions might encourage people to come forward to test and thus allow for the introduction of anti-retroviral therapy (ART) once it is required (Jaffer et al, 2005). It is important that focus in knowledge around HIV/AIDS transmission should continue relentlessly to combat stigma (Abdool Karim et al., 2008). Similarly, Castro and Farmer (2005) has argued that in countries of generalized epidemics, improved AIDS knowledge might assist to decrease AIDS stigma.

The initiation of ARV-treatment had failed to decrease the nurses' workload, this was seen in the increasing numbers of patients admitted with AIDS. This was a deviation from what was expected, where the ARV treatment is supposed to modify the HIV/AIDS disease from a highly morbid disease to a manageable chronic illness (Parry, Steward, Wright & McLeod, 2004).

5.2.2. Patient participation in care

In the pre-ARV period most families were found to be passive participants in the disease management process. It has been found that low involvement of families in patient care is linked to the stigma attached to AIDS which seemed to have resulted in many HIV-infected people being deserted by their families and friends (Skinner & Mfecane, 2004). For the nurses in this study the contributing factor to poor patient involvement in decision making was attributed to low literacy levels among patients. It is possible that the low levels of literacy is linked to the view that AIDS is a result of witchcraft or bewitchment which in turn impact on patients seeking help from the formal health care sector sooner (Golooba-Mutebi & Tollman, 2008). It has been found that the illness representation of patients influence the way in which they will cope with the symptoms and their health care seeking behaviour (Meyer-Weitz, Reddy, Weijts, Van den Borne & Kok, 1998). The need for improved health education

and counseling by health workers in particular should continue relentlessly to enable more people to seek VCT-services and to seek care and support timeously.

The introduction of ARV treatment and the requirement for patients on the treatment program to disclose their status to at least one treatment "buddy", who could be a friend or family member has paved the way for greater participation of families and friends in the care of PLWA. The treatment buddy program is a program that encourages the patient who would assist with treatment and psychosocial support, it is based mostly on trust and is open to both family and friends chosen by the patients. This approach seems to benefit the patients by easing the burden of disclosure, access treatment and psychosocial support to address some of the issues raised in previous stigma research (Dworzanowski, 2002). .

While the nurses in the first focus group discussions indicated that they treat all patients the same, they indicated that patients on ARV treatment received "preferential" treatment from the medical staff. This is in contrast to the expectation that nurses should give quality care to all patients regardless of their illness and how they choose to cope with it. Their interpretation of preferential treatment is possibly due to the increased attention that is needed for the monitoring of the patients on ART (Jaffar et al, 2005; UNAIDS, 2004).

Further more, the positive view of patients on ARV-treatment could possibly be related to the fact that they were actively involved in their own treatment management because of the intensive training and counseling they received regarding their disease process and ARV- therapy. Because AIDS patients on ARV treatment are challenged by chronic disease and chronic medication with its side effects, the understanding of their prognosis and the ARV- treatment regime is important for treatment adherence (Corless, Nicholas, Davis, Dolan, & McGibbonC, 2005). The competence of patients in this regard allow for greater

participation in shared decision making regarding their illness, a component often argued to increase quality of care and patient satisfaction (Doble & Curley, Hessim-Laband & Shaw, 2000; Curley, 1998). On the other hand, these empowered patients seemed to have "*exposed*" the weaknesses of the health care institution in ensuring well-trained and competent healthcare professionals. This is reiterated by nurses' indication of their lack of training in ARV and therefore lack of knowledge about ART. This compromised the care givers in a context where their patients had a better understanding of ART than themselves. The importance of adequate training and continuous in-service training in the management of ART is essential. It is also a first step in achieving the National Department of Health's vision of greater access of treatment and support to those in need of ART (Jaffar et al, 2005). Recent media reports of patients dying before they are able to access ART have put the spotlight again on access to ART, especially for people in rural areas.

5.2.3 Emotional and financial resources

The emotional and financial resources among the predominantly rural patients seemed scarce and are also closely linked to AIDS stigma. In a study by Hall (2004) it was also noted that most patients were poor and their access to healthcare was limited to public health care institutions. It should also be noted that poverty and poor nutrition may impact negatively on HIV/AIDS prevention and treatment initiatives (Farmer, Leandre, Mukhenjee & Claude, 2001). However, family mobilization and empowerment can release some of the necessary resources no matter how small they may be. It should be noted that the resources patients need could be physical, economical, knowledge based and spiritual (Mahlungu et al., 2004; Smit, 2005).

In the pre- ARV treatment period, stigmatization was sited as one of the causes of lack of family support, that was seen as a product of strict confidentiality prevailing then. This is in agreement with Dworzanowski (2002) who argues that stigma can compromise access to care by limiting possibilities of disclosure

thus delaying testing and treatment initiation (Holzemer & Uys, 2004; Skinner & Mfecane, 2004; Dworzanowski, 2002).

During the pre-ART phase nurses could not involve any family members unless the patients were willing to disclose their status but after the introduction of ART the data suggested greater involvement of patients and their families. Similarly, Jaffer et al. (2005) found that with increased access to ARV-treatment, nurses and patients' attitude towards the disease changed, that more patients were getting tested and were willing to disclose their status to treatment buddies and to start their Anti-retroviral therapy (ART).

Nurses reported that patients on ARV treatment in this study showed openness about their condition and treatment management, that was in agreement with Jaffer et al (2005) who argued that HAART is expected to encourage people to come forward to address issues of AIDS risk reduction and care (Jaffer et al, 2005).

5.3. NURSE CHARACTERISTICS

5.3.1. Knowledge, skills and practices

The nursing care at both pre-ARV and post-ARV period did not seem to be patient specific. This is possibly a reflection of the general lack of knowledge about AIDS in general and specifically about AIDS patient management (McCann & Sharkely, 1998). Healthcare workers should be able to engage in a high level of clinical inquiry i.e. the ongoing process of questioning and evaluating the practices for informed practice for the delivery of high quality care (Kaplow, 1999). The nurses seemed not to be in a position to use their knowledge and experience to anticipate problems and influence patient care, as suggested by the Synergy model of patient care (Curley, 1989). They seemed not to have engaged with their practices at this higher level. As this is expected to come with knowledge and experience, the health workers', especially nurses'

lack of training in terms of formal clinical patient management seem to contribute to their lack of engagement also mentioned by others (McCann & Sharkely, 1998).

The shortage of skilled and experienced staff who have left the healthcare institution and those who have died because of AIDS, seem to be a problem experienced else where as well. A survey by Shisana et al., (2002) on HIV/AIDS' impact on health workers reported similar findings.

These circumstances contribute to high staff turnovers that is not conducive to teaching and learning as nurses themselves acknowledge that the quality of care has deteriorated. Jaffar et al, (2005) reported similar findings. It was argued that better training and job incentives should be offered in order to keep health workers, especially in the rural areas (Hall, 2004). In-service training programmes to improve nurses' level of knowledge and skills are also sited by other researchers as a tool to improve AIDS care (Van Wissen & Woodman, 1994; Fusilier, Harrison & Worley, 1996).

It should be noted that a shortage of knowledgeable and motivated staff will have a telling effect on the South African ARV-rollout program if we consider the UNAIDS recommendations which required first, numbers of properly trained staff of healthcare workers as a prerequisite for rolling out a successful ART initiative (UNAIDS, 2005). Despite the difficulties nurses experienced with regards to ART, they were in agreement with previous research findings that the ARV-treatment was a good program as it could extend the lifespan and improve patients' quality of life (Parry et al, 2004)

Furthermore, inadequate knowledge about HIV and related skills among nurses was found to compromise the quality of the interpersonal nurse-patient relationship. The nurses' relationship with others i.e. colleagues and the management seemed functional and can be described as a passive distant

relationship which did not go beyond clinical task at hand as presented by the patients' illness. This relationship was seen by the participant as limiting to skills transfer among staff. Negative interpersonal relationships between health workers seemed to be related to work overload and incompetence (Hall, 2004).

5.3.2. Psycho-social resources, support and counseling

Perceived counseling outcomes do not live up to the high expectations at all times, both in terms of patients being able to understand the disease process and to accept their status. The health workers seemed not to have any insight into the counseling that was offered to their patients in the hospital by the AIDS counselors. They further questioned the quality of the counseling patients received and argued strongly for a thorough evaluation of the counseling process and a revision of the strategy to make it more patient as well as nurse friendly. The questioning of the quality of AIDS counseling is probably due to the fact that AIDS counseling in South Africa is generally conducted by lay counselors who have received only a basic training. They may therefore not be adequately equipped to offer the counseling patients and their families need (Hutchinson & Mahlalela, 2006). It was suggested that the quality of interaction between these counselors and the patients has at times limited the acceptability of the counseling and diminished the likelihood of the post-test counseling (Coovadia, 2000, as cited in Hutchinson & Mahlalela, 2006).

The lack of counseling skills reported on by the nurses suggests that nurses feel inadequately prepared to deal with the in-depth and complex counseling tasks required by PLWA. They also rightfully recommended that counseling skills should become part of the basic patient management training. This recommendation is generally supported as it is viewed to provide the necessary skills training and support the nurses need in caring for AIDS patients (Smit, 2005; Ncama & Uys, 2003). This suggests that the lack of resources add to stressors experienced.

5.3.3 Stressors and coping

The participants in the study experienced various stressors from a high workload to a lack of knowledge and skills reflected in feelings of inadequacy (McCann & Sharkey, 1998). Interestingly, the fear of contagion as reported on by Sherman (2000) was not raised as one of the major stressors, despite mentioning that some of their colleagues died of AIDS related diseases. It is unclear whether this is because of them practicing universal precaution procedures.

The death of health workers is of great concern as it may be related to a resistance to test, disclose their status and to access the available ARV-treatment. Future research is needed as to why the nurses have not accessed ARV therapy from the health care system in which they work. It is possibly due to prevailing levels of AIDS stigma. However, there seem to be limited insight into nurse's access to ART.

With regards to coping with their stressors, the nurses resort to pray and self-talk to deal with stress (Sherman, 2000). The nurses also resort to eating as a strategy to cope, a practice that can lead to obesity. Obesity can predispose them to complications, like premature death, increased mortality related to diabetes, obesity-related cancers and to hypertensive diseases (Haslam, 2008). Self-fulfillment as cited by Smit (2005) as a reason for most nurses to carry on nursing AIDS patients, did not seem to play a role in this hospital study.

From the study it was learned that adequate support both from colleagues and the hospital management was lacking. It is interesting to note that the nurses did not attempt to improve their working conditions but opted to be transferred to other wards and later to other institutions when they could not bear it any longer. The lack of engagement with the hospital management regarding their working conditions could be reflective of general feelings of helplessness in changing the current health care systems in which they operate. Similar findings

were reported on by Hall (2004), in a study done on health workers in public institutions. Furthermore, the lack of institutional integration and support is further reflected in that very few nurses were aware of the benefits of the Employee Assistance Program (EAP). This initiative needs to be marketed to health workers in order for them to benefit from its psychosocial support, necessary for coping with the demands of work (Matlhape, 2001). It is also possible that through this programme the workers, including health workers can advocate for an improved psychosocial working environment (Andrea & Davids, 2003).

5.4 LIMITATIONS OF THE STUDY

While this study provides some insight into care giving of AIDS patients, this qualitative study only represents the views of a small group of health workers from the rural hospital and may not be generalized to urban hospitals with better infrastructure. The position of the researcher as a part-time medical officer in the same institution could have biased the data obtained despite an awareness and sensitivity to the influence of the researcher. On the other hand, the openness in which the participants talked about their experiences questioned whether this compromised the data quality. Having the nurses' perception only was also a limitation of this study, it is recommended that in follow-up studies the patients' perspective be included. The psychosocial support issues would also need further exploration.

5.5 CONCLUSION AND RECOMMENDATIONS

The findings suggested that before the introduction of ARV-therapy most patients had limited knowledge and understanding of HIV/AIDS disease and its processes. VCT often worsen the situation, thus less patients were willing to test and disclose. The significant other, who could be a family member or friend's participation in a patient care was very limited. AIDS knowledge among nurses was also inadequate, due to the lack of support and training.

After the introduction of ARV-therapy, better involvement of patients in their care through the ARV clinic was seen. The participation of significant other in patient management also improved, due to their involvement as treatment associates. Nurse were still lacking on knowledge and psychosocial support. The study revealed that the Synergy Model for patient care, which compares the patient characteristics to nurse competencies, can be used to gain insight into patient care and its demands. This model has also suggested weaknesses in nurses' training that need attention. Nurses are expected to use insight into patients needs to improve their competencies to meet the challenges of AIDS patient care and to fulfill their mandate as the key stakeholders on patient care. Lazarus and Folkman's (1984) views on stress and coping were useful in identifying the nurses' coping strategies.

The following recommendations arise from the study

- Bedside teaching, i.e. informal teaching for both nurses and the patients on HIV and AIDS management needs to be introduced.

- Patients and families' involvement in decision making and HIV/AIDS disease management should be expanded.

- HIV counseling and all its components, which are pre- and post-counseling as well as on-going disease management counseling needs to be re-evaluated. There is a need to advocate for a more patient orientated counseling rather than the test orientated counseling.

- Psychosocial support to nurses should be a priority in coping with their stressful AIDS caring work.

- Advocacy for a worker friendly Employee Assistance Program (EAP) should be encouraged by the managers of the institution.

- Intra-disciplinary and inter-disciplinary communication needs to be improved through innovative strategies.

- The address of the AIDS stigma within the healthcare system remains a priority and this aspect needs to be incorporated at different levels i.e. basic training, in counseling and within the psychosocial support efforts directed at nurses.

REFERENCES

Abdool Karim, Q., Meyer-Weitz, A., Mboyi, L., Carrara, H., Mahlase, G.,
Frohlich J.A. & Abdool Karim, S.S. (2008). The influence of AIDS stigma
and discrimination and social cohesion on HIV testing and willingness to
disclose HIV in rural KwaZulu-Natal, South Africa. *Global Public Health*,
3 (4), 1-15.

Babbie, E., & Mouton, J. (2002). *The practice of social research.* Cape Town:
Oxford University Press.

Basson, C.J., & van der Merwe, T. (1994). Occupational stress and coping in a
sample of student nurses, *Curationis,* 17 (4), 35-43.

Benatar, S.R. (2004). Health Care Reform and the Crisis of HIV and AIDS in
South Africa, The New England Journal of Medicine: 81-92. Retrieved
February 20, 2007 from http://www.nejm.org

Cartwright, S., & Cooper, C.L. (1997). *Managing Workplace Stress.* London:
Sage Publications Inc.

Castro, A. & Farmer, P. (2005). Understanding and Addressing AIDS-related
stigma, Anthropological theory to clinical practice in Haiti. *American
Journal of Public Health,* 95, 53-59.

Clarke, E. (2000). The private sector. Retrieved June 10, 2004 from
http://www.hst.org.za.

Colllins, K., Onwuegbuzie, A.J., & Jiao, Q.G. (2006). Prevalence of
Mixed-methods sampling designs in social science sesearch. *Evaluation
and Research in Education,* 19 (2), 83-101.

Colvin, M., Dawood, S., Mullick, S., Lalloo, U., & Kleinschmidt, I. (2001).
Prevalence of HIV and HIV related disease on the adult medical wards of
a tertiary Hospital in Durban, South Africa, *International Journal of STD
and AIDS,* 12, 386-389.

Constitution of the Republic of South Africa, Act no 108 of 1996.

Cooper, C.L., Dewe, P.J., & O'Drisoll, M.P. (2001). *Organizational Stress: A*

Review and Critique of Theory, Research, and Applications. California: Sage publications Inc.

Curley, M.A.Q. (1998). Patient –nurse synergy: Optimizing patients' outcomes. *American Journal of Critical Health Care, 7,* 64-72.

Department of Health, 2006. National HIV and Syphilis Prevalence Survey. South Africa 2005. Retrieved February 20, 2007 from http://www.doh.gov.za/docs/hiv-syphilis-f.html

Department of Health, 2008. National HIV and Syphilis Prevalence Survey South Africa 2007. Retrieved February 20, 2009 from http://www.doh.gov.za/docs/hiv-syphilis-f.html

DiCicco-Bloom, B., & Crabtree, B. (2006). The qualitative research interview. *Medical Education,* 40, 314-321.

Doble, R.K., Curley, M.A.Q., Hessim-Laband, E., Marino, B.L., & Shaw, S.M. (2000). The Synergy Model in practice: Using the Synergy Model to link nursing care to diagnosis-related groups. *Critical Care Nurse,* 20, 86-92.

Dorrington, R. E., Johnson, L.F., Bradshaw, D., and Daniel, T. (2006). *The demographic impact of HIV/AIDS in South Africa: National and provincial indicators for 2006.* Cape Town: Centre for Actuarial Research,Medical Research Council and Actuarial Society of South Africa.

Dworzanowski, B. (2002). Caring for people dying of AIDS: Lessons learnt from hospices. *Society in transition,* 33 (3), 420-431.

Farmer, P., Leandre, F., Mukherjee, J.S., Claude, M.S., Nevil, P., Smith-Fawzi, M.C., Koenig, S.P., Castro, A., Becerra, M.C., Sachs, J., Attaran, A., Kim, J.Y. (2001). Community-based approaches to HIV treatment in resource-poor settings. *The Lancet,* 358: 404-409.

Fransman, D., McCulloch, M., Lavies, D., & Hussey, G. (2000). Doctors' attitudes to the care of children with HIV in South Africa. *AIDS Care,* 12 (1), 89-96.

Fusilier, M.R., Harrison, M., & Worley, J.K. (1996). Nurses' attitudes and behavioral intentions concerning AIDS care. *Journal of Business and Psychology,* 11(2), 275-285.

60

Gueritault-Chalvin, V., Kalichman, S.C.,Demi, A. & Peterson, J.L. (2000). Work-related stress and occupational burnout in AIDS caregivers: test of a coping model with nurses providing AIDS care. *AIDS Care*, 12 (2), 149-161.

Hall E.J. (November 2004). Nursing attrition and the work environment in South African health facilities, *Curationis*, 28-36.

Hall, E.,& Erasmus, J. (2003). Medical practitioners and nurses. In Human Resources development review, education, employment and skills in South Africa. Human Research Council, Cape Town: HSRC Press.

Haslam, D. (July 2008). An introduction to obesity: Update. *The Journal of Continuing Education for General Practitioners*, 40-44.

Holman, H., & Lorig, K. (2000). Patients as partners in managing chronic disease. *British Medical Journal*, 230, 526-527.

Holzemer, W.L. & Uys, L. (2004). Managing AIDS Stigma. *Journal of Social Aspects of HIV/AIDS*. 1(3),165-174.

Hope, A., Kelleher, C.C., & O'Connor, M. (1998). Lifestyle practices and the health promoting environment of hospital nurses. *Journal of Advance Nursing*, 28 (2): 438-447

Hutchinson, P.L., & Mahlalela, X. (2006). Utilization of voluntary counseling and testing services in the Eastern Cape, South Africa. *AIDS Care*, 18(5), 446-455.

Jaffar, S., Govender,T., Garrib, A., Welz,T., Grosskurth, H., Smith P.G. Whittle, H., & Bennish, M.L. (2005). Antiretroviral treatment in resource-poor settings: public health research priorities. *Tropical Medicine and International Health*, 10(4), 295-299)

Jenning-Dozier, K. (1999). Predicting intentions to obtain a Pap smear among African American and Latina women: Testing the Theory of Planned Behaviour. *Nursing Research*, 48 (4), 198-205.

Kamppainen, J.K., Dubbert, P.M., & McWiliams, P. (1996). Effect of group

discussion and guided patient care experience on nurses' attitudes towards care of patients with AIDS. *Journal of Advance Nursing,* 24, 296-302.

Kaplow, R. (2004). Applying the Synergy Model to Nursing Education. *Critical Care Nurse,* 22(3), 77-81.

Krueger, R.A. (1988). Focus groups: A practical guide for applied research. London: Sage Publications

Lazarus,R.S., & Folkman,S (1984). *Stress, appraisal and coping.* New York: Spring publishing company.

Mahlungulu, S.N. and Uys,L.R. (2004). Spirituality in nursing: An analysis of the concept. *Curationis,* 27(2),15-26.

Manning, M.R., Jackson, C.N., & Fusilier, M.R. (1996). Occupational stress, social support, and the cost of Health care. *Academy of Management Journal,* 39 (3), 738-750.

Marelich, W.D., & Murphy, D.A. (2003). Effects of empowerment among HIV-positive women on the patient-provider relationship. *AIDS Care,*15 (4), 475-481.

McCann, T.V. (1999). Reluctance amongst nurses and doctors to care for and treat patients with HIV/AIDS. *AIDS Care,* 11 (3), 355-359.

McCann, T.V. & Sharkey, R.J.(1998). Educational intervention with international nurses and changes in knowledge, attitudes and willingness to provide care to patients with HIV/AIDS. *Journal of Advance Nursing,* 27, 267-273.

Meyer-Weitz, A., Reddy, P., Weijts, W., Van Den Borne, B. & Kok, G. (1998). The socio-cultural contexts of sexually transmitted diseases in South Africa: Implications for Health Education Programmes. *AIDS CARE,* 10, 1, S39-S55.

Michie, S., Miles, J., & Weinman, J. (2003). Patient-centredness in chronic illness: what is it and does it matter? *Patient Education and Counseling,* 51,197-206.

Millward, L.J., (1995). The focus Group, in G.M. Breakwell, S. Hammond &

C. Fife-Schaw (1st Ed), *Research Methods in Psychology,* (274-292).
London: Sage Publications Inc.

Mitchell, G.C.,Freels, S., Creticos, M., Oltean, A., & Douglas, R. (2007).
Preliminary findings of an intervention integrating modified directly
observed therapy and risk reduction counseling. *AIDS Care,* 19(4), 561-
564.

Mullen, J.E. (2002). The Synergy Model in Practice: The Synergy Model as a
Framework for Nursing Rounds. *Critical Care Nurse,* 22(6), 66-68.

Ncama, B.P., & Uys, L.R. (2003). Exploring the fear of contracting HIV/AIDS
among trauma nurses in the province of Kwazulu-Natal. *Curationis,* 11-
18.

Neuman, W.L. (1997). Social research methods: Qualitative and quantitative
approaches, 3rd ed. Boston: Allyn and Bacon.

Ngwezi, A.A. (1998). Work stress in a group of black nurses. Ph.D dissertation,
University of Pretoria, South Africa. Retrieved June 10, 2005 from
ProQuest at
http://proquest.umi.com/pqdweb?did=729841101&sid=2&Fmt=2&clientId
=57186&RQT=309&VName=PQD.

Nicholas PK, Kirksey KM, Corless IB, and Kemppainen J (2005). Lipodystrophy
and quality of life in HIV: symptom management issues.*Applied nursing
research : ANR* 18(1), 55-8.

Ojikutu, Makadzange & Gaolathe, 2008 Bisola Ojikutu, A. Tariro Makadzange,
Tendani Gaolathe. (2008) Scaling up ART treatment capacity: Lessons
learned from South Africa, Zimbabwe, and Botswana

Olivier, C., & Dykerman, M. (2003). Challenges to HIV service provision: the
commonalities for nurses and social workers. *AIDS Care,* 15(5), 649-
663

Paling, J. (2003). Strategies to help patient understand the risks. *British
Medical Journal,* 327, 45-748.

Parry, M.F., Stewart, J., Wright, P. & McLeod, G.X. (2004). Collaborative

management of HIV infection in the community: an effort to improve the
quality of HIV care. *AIDS Care,* 16(6), 690-699.

Parker, A., & Tritter, J. (2006). Focus group method and methodology: Current
practice and recent debate. *International Journal of Research & Method
in Education,* 29(1), 23-37.

Ritchie, J. & Spencer, L. (1992). Qualitative data analysis for applied policy
research. In: A. Bulmer (Ed.). *Quantity and Quality in Social Research.*
London: Routledge.

Sherman, D.W. (2000). Experiences of AIDS-dedicated nurses in alleviating the
stress if AIDS caregiving. *Journal of Advance Nursing,* 31(6), 1501-1508.

Shisana (2005). South African National HIV Prevalence, HIV Incidence:
Behaviour and Communication Survey, 2005. Retrieved June 10, 2006
from
http://www.hsrcpress.co.za/download.asp?filename=2134_00_hiv_preval
ence%7E07122005114531AM.pdf

Shisana, O., Hall, E., Maluleke, K.R., Stoker, D.J., Schwabe, C., Colvin, M.,
Chauveau, J., Botha, C., Gumede, T., Fumundam, H., Shaikh, N., Rehle,
T., Udjo, E., & Gisselquist, D. (2000). The impact of HIV/AIDS on the
Health Sector. Available online: Retrieved June 10, 2005 from
http://www.hsrcpublishers.ac.za

Shisana O, Rehle T, Simbayi L, Parker W, Zuma K, Bhana A, Connolly C,
Jooste S, Pillay V (eds). (2005). South African National HIV Prevalence,
HIV Incidence, Behaviour and Communication Survey. Pretoria, HSRC.

Shisana, Hall, Maluleke, Stoker, Colvin, Chauveau, Botha, Gumede,
Fomundan, Shaik, Rohle, Udjo & Grissdquist, 2002

Skinner, D. & Mfekane, S. (2004). Stigma, discrimination and the implications
for people living withHIV/AIDS in South Africa. Journal of Social Aspects
of HIV/AIDS, 1(3), 157-164.

Smit, R. (2005). HIV/AIDS and the workplace: perceptions of nurses in a public
hospital in South Africa. *Journal of Advance Nursing,* 51 (1): 22-29.

Soto, T.A., & Pillen, M.B. (2004). Literature review: For the HIV/AIDS treatment adherence, Health outcomes and cost study group. *AIDS Care, 16*, 43-55.

Statistics South Africa. 2006. P0309.3 – Mortality and causes of death in South Africa: Finding from death notification 2003, 2004. Retrieved February 20, 2007 from http://www.statssa.gov.za/Publications/download.asp?PPN=P0309.3&SCH=3659.

Stuart, R., & Behets, F. (2006). AIDS Care and Treatment in Sub-Saharan Africa: Implementation Ethics, *Hasting Center Report,*: 23-31.

Taylor, S.E. (1999). *Health Psychology* (4th Ed), Singapore: McGraw-Hill Inc.

Turner, H.A., Pearlin, L.I., & Mullan, J.T. (1998). Sources and Determinants of Social Support for Caregivers of persons with AIDS. *Journal of Health and Social Behavior, 39*, 137-151.

UNAIDS (2004). 2004 Report on the Global HIV/AIDS Epidemic: 4th Global Report, Geneva, UNAIDS.

UNAIDS/WHO, 2005 AIDS Epidemic Update: Special report on HIV Prevention: Geneva, UNAIDS.

Unger, A., Welz, T., & Haran, D. (2002). The Impact of HIV/AIDS on Health Care Staff at a Rural South African Hospital,1990-2001. *AIDS Research Institute.* Retrieve July 14, 2005 from http:www.//ari.ucsf.edu.

Van Wissen, K., & Woodman, K. (1994). Nurses' attitudes and concerns to HIV/AIDS: A Focus Group Approach. *Journal of Advance Nursing, 20*, 1141-1147.

World Health Organisation (2004). *World Health report 2004: Changing istory*, Geneva, WHO.

World Health Organisation (2008). *Epidemiological Fact Sheet on HIV and AIDS: Core data on epidemiology and response South Africa* (September 2008). Geneva, WHO

APPENDIX 1
INFORMED CONSENT FORM

My name is Dr. N.D. Zulu. I am doing a research study entitled: **Caring for AIDS patients, the strategies for improved care**. The study is the requirement for a Masters degree in Health Promotion.
My address is Box 73, Nkandla, 3855 and telephone is 035 8330946 should you have any questions.

Thank you, for agreeing to take part in the study. Before we start I would like to emphasize that:

-your participation is entirely voluntary;

-you are free to refuse to answer any question;

-you are free to withdraw at any time.

The discussion-interview will be kept strictly confidential and will be available only to members of the research team. Excerpts from the discussion-interview/individual results may be part of the final research report, but under no circumstances will your name or any identifying characteristics be included in the report.
Please sign this form to show that I have read the contents to you.
………………………………………………………(signed)
………………………………………………………(printed)
………………………………………………………(date)
Please send a report on the results of the project:

         YES   NO   (circle)

Address for those requesting a research report.

………………………………………………………

APPENDIX 2

INTERVIEW SCHEDULES

Caring for AIDS patients in a rural setting: Nurses' perspectives

A) Pre-ARV Interview guide

Section A (demographics)

Age:

Gender:

Qualification:

Year qualified:

Time working in the medical wards:

Section B (open-ended question)

(Patient characteristics)

I would like to learn from you about the AIDS patients you care for. So, I am going to ask you to tell me about them.

Describe a typical AIDS patient that you care for?

To probe the following:

- physical conditions: general prognosis, opportunistic infections, how they cope and how they respond to treatment, their risk of dying
- patients' understanding of their illness
- psychological state (cope, feelings)
- Family support and care
- Community support and care
- Financial support they have (own, family, community)
- Involvement of the patient and family in care
- Participation in decision making regarding care (patient, family)

(Nurse Characteristics)

I would also like to know about you as a nurse and also about you as a person.

Knowledge: establish knowledge about-

- Explain the different types of HIV antibody tests
- What do you understand by transmission of HIV infection by body fluids
- How long does HIV stays infective after death of the infected person
- Clinical presentation, can it tell you about patient status and stage
- What do you understand about Sero-conversion
- Any formal training in counseling
- What would you do if you were to get exposed to HIV infection

Training: To probe about-

- basic training and ongoing training (reading, information, research)
- adequacy of training in regards to care for AIDS patients
- training needs in caring for AIDS patients
- the health care system in which you care for AIDS patients

Patient care: To probe about-

- existing protocols for caring of AIDS patients (relevance, appropriateness, helpfulness, suggestions for change)
- Collaboration with others in the management of AIDS patients (nurses, doctors, social workers, psychologist, traditional healer, community members, family etc.)
- Ideas about the best way of caring for AIDS patients
- Most difficult issues in caring for AIDS patients

Beliefs/values:

- Their own feelings towards people with HIV and AIDS patients (sexuality, safer sex – condom use, monogamy, male-female gender power issues)
- Confidentiality
- Would you treat AIDS patients differently from others
- Describe the best outcome for AIDS patients

Coping:

- Support in the workplace, at home and from the community

- Stressors in the workplace and at home that impact on care for AIDS patients.
- How do you cope with these stressors?
- Ideas about how nurses can be helped to cope better in caring for AIDS patients.

B) Post-ARV Interview guide

Section A (demographics)

Age:

Gender:

Qualification:

Year qualified:

Time working in the medical wards:

Section B (open-ended question)

(Patient characteristics)

I would like to learn from you about the AIDS patients you care for. So, I am going to ask you to tell me about them.

Describe a typical AIDS patient that you care for?

To probe the following:

- physical conditions: general prognosis, opportunistic infections, how they cope and how they respond to treatment, their risk of dying
- patients' understanding of their illness
- psychological state (cope, feelings)
- Family support and care
- Community support and care
- Financial support they have (own, family, community)
- Involvement of the patient and family in care
- Participation in decision making regarding care (patient, family)

(Nurse Characteristics)

I would also like to know about you as a nurse and also about you as a person.

Knowledge: establish knowledge about-

- Explain the different types of HIV antibody tests
- What do you understand by transmission of HIV infection by body fluids
- How long does HIV stays infective after death of the infected person
- Clinical presentation, can it tell you about patient status and stage
- What do you understand about Sero-conversion
- Any formal training in counseling
- What would you do if you were to get exposed to HIV infection

Training: To probe about-

- basic training and ongoing training (reading, information, research)
- adequacy of training in regards to care for AIDS patients
- training needs in caring for AIDS patients
- the health care system in which you care for AIDS patients

Patient care: To probe about-

- existing protocols for caring of AIDS patients (relevance, appropriateness, helpfulness, suggestions for change)
- Collaboration with others in the management of AIDS patients (nurses, doctors, social workers, psychologist, traditional healer, community members, family etc.)
- Ideas about the best way of caring for AIDS patients
- Most difficult issues in caring for AIDS patients

Beliefs/values:

- Their own feelings towards people with HIV and AIDS patients (sexuality, safer sex – condom use, monogamy, male-female gender power issues)
- Confidentiality
- Would you treat AIDS patients differently from others
- Describe the best outcome for AIDS patients

Coping:

- Support in the workplace, at home and from the community

- Stressors in the workplace and at home that impact on care for AIDS patients.
- How do you cope with these stressors?
- Ideas about how nurses can be helped to cope better in caring for AIDS patients.

Additional questions

- What is the impact of HIV epidemic on healthcare workers at this rural Institution?
- What are the specific pressures placed on nurses?
- How are these affecting the quality of healthcare provided ?
- What role has the introduction of ART played in healthcare provision ?
- How has ART changed the nurses' attitudes and experiences ?
- Has the patient characteristics changed since the introduction of ART?
- Disclosure and confidentiality, how are they affected by introduction of ART?
- Is there any ART training for nurses, what is their perception regarding ARV Treatment?
- How accessible is the treatment ?

APPENDIX 3

EXCERPTS FROM FOCUS GROUP DISCUSSIONS

Are you happy with the type of care you give to AIDS patients.

No, because we are running short of equipments or essential materials
are out of stock all the time. At times we know what should be done but
cannot do anything because of these shortages.

(Like What)

Things like aprons, gloves and even patient screens. At times even when
the screen is there but we cannot put them up because there is no
space.

Facilities to wash and bath patient are not good at all.

There is an overflow of patients in these wards and understaffing on top
of this. The nurses themselves are ill and they are also dying like
everyone else.

On the point of equipment we are negligent there, look at section 2; the 4
spoons are shared among 50-60 patients, some of these patients have
AIDS, and there is a possibility of infecting other patients.

**What do you say on the issue that AIDS is not transmitted through using
the same utensils.**

No, no we would not like to believe that, at least we need to be careful.

I would like to add that some bedsores are caused by us here at the
Hospital, you find the patient lying on the pool of diarrhea & urine longer
than necessary because we are running short of linen savers due to poor
stock supplies. This seems to be a chronic problem in this institution.

How is the cooperation with other structures/Disciplines?

It is not guaranteed, that is all what we can say.

Are you happy with the knowledge available to you regarding HIV/AIDS.

We think we are lacking in the formal HIV/AIDS training, certain individuals are attending all the courses but somehow they are not directly involved with day-to-day management of the patient. They also do not report back on what they have learned.

Other supportive resources, how available are they?

There is some support generally, but there is always a situation where most materials/stock we need in patient care is out of stock. There is also that lack of knowledge among us which make us not to identify the essentials that may be necessary in time.

(What do you mean).

At times we feel that we may be infected easily by being in contact with these patients.

Do your patients have insight to their disease process.

The problem here is illiteracy, which act as a barrier to communicating the disease concept. We also think Counseling is not effective in removing people from old beliefs of being poisoned and bewitched while they have HIV/AIDS.

Is there any formal teaching among staff and patients regarding HIV/AIDS.

There is a nursing sister who is responsible for teaching, but this teaching is directed to patients who are undergoing counseling only. We as the staff who spend most of the time with these patients we do not get any teaching.

Here there is no coordination between what is done by the nurses who deal with HIV/AIDS patients at Crisis Centre (counseling) and what we do in the wards.

There is no feedback among staff alone, there is no formal teaching from HIV/AIDS nurses to patients in general or to fellow staff members, despite the workshops they are attending.

Counseling & Testing

We only see patients coming back with hardened attitudes after counseling or worsening of health conditions after counseling, what was said and the way forward remain the secrecy of the counselors and the patient.

The only feedback we get is when the patient has refused to be tested. The problem we are not involved with the patient counseling, we hardly know what is said there at the Crisis Centre. All what we see is emotionally disturbed patient after counseling and then we suspect that there is something wrong with the result, but we keep our distance from the patient because we are not involved.

Do you involve families & patients in AIDS management?

Most patients wants to keep this confidential, no families are involved in, except in PTB where families & communities get involved, the problem is this Confidentiality issue, it makes broader involvement impossible.

How & what do you think should be done regarding counseling?

We think it should be inclusive, even before bloods are taken, the families and the responsible nurse should be involved and something must be done with Confidentiality because we believe a lot of people die prematurely from fear and stress than from AIDS.

AIDS need to be projected as any other disease to reduce stigma and stress on the patients who are already affected, the family needs to be involved early on in the disease course.

How is your work viewed by the community?

The community does not fully appreciate our service and they think nurses are lazy, not appreciating how much effort we are put on managing these patients. The families themselves are afraid to be exposed to infections.

Even some nurses, due to lack of knowledge believe they would get infected by being in contact with the patient, some nurses still do not understand how this disease is transmitted.

What do you want to suggest regarding HIV/AIDS teaching?

We think that DOH should facilitate in-service training which involves all health workers in HIV/AIDS management & HIV counseling within each institution, so that we will know what is happening and how to handle most problems. All patients who are in hospital should be taught about HIV and how to prevent it & manage it. The community should also be involved in these discussions to reduce HIV stigma and denial.

How do you deal with the possibility of being infected?

We just hope and pray that nothing happen to us and we try to be careful as much as we can.

The problem is how to deal with patients most are coughing because they also have PTB, most of the staff generally shies away from these patients and those who are forced to attend them are not so friendly. The patients also see that they are not fully acceptable at the Hospital, so they are rushed through and quickly discharged home.

Cooperation/Team work among different groups of health workers.

There is no cooperation among health workers and the community, while the community has a tendency to dump their sick relatives at the Hospital, the nurses tends to neglect the patients when they are over-stressed

type of patients, staff situation and experience you realize that we have a massive problem.

APPENDIX 4
EXCERPTS FROM INDIVIDUAL IN-DEPTH INTERVIEWS

Participant background: The participant is a 41 year old registered nurse, she has been working in this institution since 1991. She is back from sick leave, this is the second long sick leave within a year, since she was diagnosed with tuberculosis. First time, she nearly died because she has systemic TB which is difficult to diagnose as oppose to PTB. She thinks her infection is occupation related. She says coming back to work makes her sick, the sight of other more sick patients depresses her, but she has no alternative she has to work since she still has young children.

On patient characteristics

HIV is a problematic disease, I believe almost all young patients we admit have something to do with HIV infection. Early admissions show opportunistic disease picture, but that's not very common, the common picture is that of late admission with severe infections including TB (MDR & XDR). The patients usually have been seen in several hospitals and will not remember whether he was ever tested for HIV. In most cases he knows his diagnosis, but he and or his relatives do not want to accept the possibility of HIV/AIDS.

HIV has destroyed families, we cannot expect much from them because in most cases there is more than one member of the family who are sick. In one instant three members of the same family were admitted at the same time and one of them died and was buried while the last one who eventually also died was still in hospital. While there is a lot of work pressure on the nurses I think there is even more pressure on the relatives, you can see it in their faces when they come to visit the terminally ill AIDS patients.

With all the teaching at schools, radio, newspapers, clinics etc there seems to be not much change in our work situation, in fact we see more terminally ill patients than at any time before.

The good thing is that now we have the ARV Clinic, this has brought about more patients being tested and more people being free to talk about HIV/AIDS. We have not seen a decrease in the workload. A number of our ward patients ask to be considered for the HIV clinic at a very late stage of infection, in most cases they die while they are still being prepared for the treatment program.

On the impact of the HIV epidemic on healthcare workers at this rural hospital.

She still feels that the HIV/AIDS epidemic has negatively impacted on the staffing. A number of experienced staff have left the hospital or died. The management has tried to replace most of the staff that has left & fill the vacancies that have always been there, but " now we are not running short of staff but we are running short of experienced nurses".

On the specific pressures placed on nurses by workload.

She thinks comparing today with five yrs ago would be unfair, today's nurses are thrown into the deep end without being properly prepared. There is no time for preparation, there are not enough experience nurses or doctors for that matter to prepare them.

The government has realized the workload on the nurses, recently they have employed the services of the community caregivers to help the nurses with basic patient care within the institution. The nurses have to mentor and supervise these community caregivers.

On how the quality of healthcare provided has been affected.

Personally, she thinks the quality has gone down, while she would have no problem to be admitted to this institution in the past, now she would not accept to be admitted there, especially if her illness is a serious one.

On the role played the introduction of ARV-treatment in healthcare provision.

More patients are ready for testing these days. The amount of work has not changed but nurses' attitudes towards patients with HIV/AIDS have improved.

On how the introduction of ARV-therapy changed the nurses attitudes & experiences.

You can now find nurses encouraging patients and staff to go for testing, instead of discouraging them.

The changes in patient characteristics since the introduction of ARV treatment.

Patients on ARV treatment are also given a preferential treatment by the medical staff as opposed to those who have refused testing. We see this by the increase frequency the doctors want to see patients on ARV treatment if they are admitted. They also have the privilege of keeping their tablets with them and are fully involved in administering their treatment regime. In most instances these patients know more about the ARV treatment than the nurses who take care of them. Unfortunately there is still no proper bedside teaching for the nurses regarding HIV/AIDS/ARV therapy.

Disclosure and Confidentiality, how are they affected by the introduction of ARV- treatment.

More patients are ready to talk about their disease. There are an increase number of them getting tested and starting treatment. Since they are encourage having a family member who will be responsible to assist with treatment, disclosure is no longer so difficult.

On ARV training for nurses, and their perceptions regarding ARV-treatment.

She thinks nurses' needs more training regarding ARV treatment if they expected to advise the patients properly, on treatment & complications. Unfortunately there is still no proper bedside teaching for the nurses regarding HIV/AIDS/ARV therapy.

She thinks ARV treatment is good, it has extended life for some patients for whom the staff and relatives have lost hope. The nurses have hoped that the introduction of ARV treatment will reduce hospital admissions but it has not happened, it seems more and more patients still come to hospital to die. It may due to the recent TB-XDR or just AIDS. The staff hope more people will get tested and start on treatment in order to reduce terminally ill admissions. There have not been a significant number of patients dying on ARV treatment, this may be the sign that the treatment is working.

On accessibility to ARV-treatment.

Accessibility is still a problem. Since the ARV treatment clinic was open here, this institution is receiving patients who come from other regions where their hospital/clinics have not started on the treatment program. The ARV clinic needs to increase the patient intake because some patient still die while waiting for blood tests or counseling classes before they can be admitted to ARV treatment.

Beliefs/values

More and more young women are infected because they get engaged in sexual activities at an early age, in most cases with adult men. That's why we more and more school children giving birth at maternity and younger girls dying in early twenties. Confidentiality is still an issue especially with staff patients who do not want their status to be known. They tend to seek help later than the patient they are looking after. With

ART the outcome have improved for those patients who get tested and start on treatment, but it has not changed for those patients who are in denial, they ultimately die a painful death. I believe there is exploitation of a girl child by elderly males which brings about increase in HIV infection. There seem to be a distinction between HIV negative patients, suspected HIV positive but not tested and HIV positive patients on ART. All HIV patients, I feel are somehow discriminated against when it comes to ward rounds and treatment orders, my colleagues can disagree if they want to. The HIV pos on ART are somehow treated better than the suspected chronically ill with no proper diagnosis. Patients on ART are at least seen daily by the doctor to monitor their treatment, which is not the case with the others.

On coping with work demands

Nursing is not what is used to be, a well respected profession that you would be proud of. These days we are overworked, underpaid and while there is a shortage of nurses but still our jobs are not guaranteed. This shows lack of support from the government and the management. These problems affect our work. Somehow as nurses we try to support each other in order to keep these hospitals running. The major problem is not worrying about getting infected, but is being always tired due to heavy workload. For this work you need to be healthy and take some time off to be away from sick people.

We need more nurses in SA who will be trained and paid accordingly. They need to be respected and their service be sincerely appreciated, not only when it suites the authorities. E.g. during certain campaigns etc.

On HIV/AIDS knowledge

The participant thinks she has enough information now about HIV/AIDS, which she did not have until she got TB infection. Because they were suspecting that she could be HIV positive, she was subjected to

counseling and testing. She thinks there is so much information that is known by patients that has undergone counseling and most of the information does not filter down to ward nurses. This is due to lack of planned teaching regarding HIV/AIDS for ward nurses, most information they have is bit and pieces that they get from the colleagues, orders during the ward round and mostly from the news papers. She argued that the workload leaves no space for independent reading, may be if all nurses can undergo pre-test counseling to acquire the same information as patients and fill the gaps of information that exist, this could bring them to the same level with their HIV/AIDS patients in terms of knowledge.

On Testing for HIV

Not many of her colleagues would opt for testing even when they are ill, this may be due to internal stigmatization, while people pretend to be supportive when you ill, they also divulge your illness to the broader public. So there is no rush among nurses to go for testing.

There is an increase in number of patients who agree to test since the ART clinic was started. This may be due to that patients now have an alternative to focus on should their results test positive. The general refusal of fellow nurses to test even after accidentally prick themselves with needles at work is risky, but nurses are a stress and overworked community, we do not want to overburden ourselves with knowing our status.

(Why)

We deal with very ill AIDS patients on daily basis, if you know that you are healthy but HIV positive, the sight of the patients will always remind you that, one of these days you will be in the same position.

On ARV-therapy

If she had tested positive to HIV this nurse says she would not have came back to work here, because she would have been sicker emotionally even though she has improved a lot on treatment. She would not be able to face the patients mostly and colleagues when she is on the other side of the treatment program.

On workload

She thinks the workload is increasing, may be due to more people coming up to testing clinics and more nurses who are leaving not replaced. ART have increased the numbers coming to hospital instead of reducing them, that's what is seen. *"The type of illness we see have not changed in terms of the picture, we still see very ill young women and men dying in agony. Most people are admitted at the late stages of illness because we can not admit them earlier beds are full (with marked emaciation, generalized body sores, bed sores, chronic diarrheas, severe PTB etc)"*

On staff support

When I started here, they use to be teams (teamwork) during the time the Germans (German & missionary doctors), now every individual nurse does her own thing with very little or no commitment to the ward team, these days I always feel as a member of a group not a team member.

(Why)

The team goes an extra mile to assist each other in order to make their work less stressful, but I do not blame the nurses, the work conditions have taken out the passion and the pride of being a nurse. This is also due to the fact that no one respects the nurses these days, from the government to the community we serve.

APPENDIX 5

DOCUMENTS PERTAINING TO STUDY APPROVAL

RESEARCH OFFICE (FRANCIS STOCK BUILDING)
HOWARD COLLEGE
TELEPHONE NO.: 031 – 2603587

29 SEPTEMBER 2004

MR. ND. ZULU
PSYCHOLOGY

Dear Mr. Zulu

ETHICAL CLEARANCE

I wish to confirm that ethical clearance has been granted for the following project but language in informed consent to be simplified:

"Caring for AIDS patients, strategies for improved care"

Yours faithfully

MS. PHUMELELE XIMBA
(FOR) MANAGER: RESEARCH OFFICE

PS: The following general condition is applicable to all projects that have been granted ethical clearance:

THE RELEVANT AUTHORITIES SHOULD BE CONTACTED IN ORDER TO OBTAIN THE NECESSARY APPROVAL SHOULD THE RESEARCH INVOLVE UTILIZATION OF SPACE AND/OR FACILITIES AT OTHER INSTITUTIONS/ORGANISATIONS. WHERE QUESTIONNAIRES ARE USED IN THE PROJECT, THE RESEARCHER SHOULD ENSURE THAT THE QUESTIONNAIRE INCLUDES A SECTION AT THE END WHICH SHOULD BE COMPLETED BY THE PARTICIPANT (PRIOR TO THE COMPLETION OF THE QUESTIONNAIRE) INDICATING THAT HE/SHE WAS INFORMED OF THE NATURE AND PURPOSE OF THE PROJECT AND THAT THE INFORMATION GIVEN WILL BE KEPT CONFIDENTIAL.

cc. Director of School
cc. Supervisor

DR. N.D. ZULU
BOX 73
NKANDLA
3855
TEL/FAX. 035 8330946
DATE: 8/12/2004

24 WILFRED STREET
MELMOTH
3835
TEL. 035 5407619

Attention: Ms N. Sithole

Province of KwaZulu-Natal
Health Services
P/Bag 9051
P.M.Burg
3200

Dear Ms Sithole

RE: APPLICATION TO CONDUCT RESEARCH ON NURSES CARING FOR AIDS PATIENTS AND STRATEGIES TO IMPROVE CARE. (REF:9/2/3R)

Kindly receive the approval letter from the UKN Research Ethics Committee. I have also included the Interview Schedule Questions (open-ended questions) which will guide the data collection on focus groups.

Yours faithfully
N.D. Zulu

NKANDLA HOSPITAL

"COMMITMENT TO EXCELLENCE"

☎ (035) 8330012
FAX: (035) 8330049
E-MAIL H020436@dohho.kzntl.gov.za

PRIVATE BAG : X 102
NKANDLA
3855
RSA

Enquiries:	Date:	Reference:
Imibuzo: MS Lindner	05/01/2005	
Navrae:	Datum:	Verwysing:

Dr. N.D. Zulu
P. O. Box 73
Nkandla
3855

Dear Dr. Zulu,
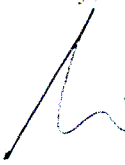
APPLICATION TO CONDUCT RESEARCH ON NURSES CARING FOR AIDS PATIENTS AND STRATEGIES FOR IMPROVED CARE

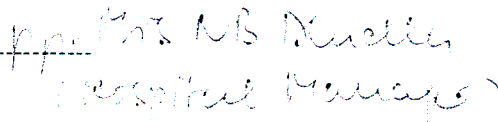Your request to conduct research in the context of your post-graduate studies refers.

Kindly be advised that authority is granted for you to conduct research on **nurses caring for AIDS patients and strategies for improved care at Nkandla Hospital,** provided the following is agreed to:

- The staff and patients are not inconvenienced and service delivery not affected.

- Confidentiality is highly maintained

- The Department is acknowledged.

- The Department and Nkandla Hospital both receive a copy of the report on completion.

With our best wishes for a successful research.
Yours faithfully,

DR. MS LINDNER
MEDICAL MANAGER
NKANDLA HOSPITAL

REFERENCE : 9/2/3/R
ENQUIRIES : Ms N Sithole
EXTENSION : 3123

Dr N D Zulu
Box 73
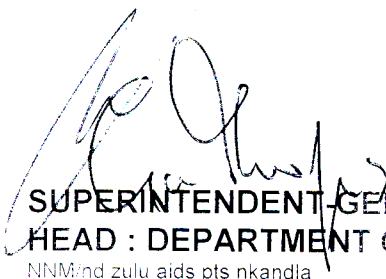**NKANDLA**
  55

Dear Dr Zulu

APPICATION TO CONDUCT RESEARCH ON NURSES CARING FOR AIDS PATIENTS AND STRATEGIES FOR IMPROVED CARE

Your facsimile received on 05 November 2004 refers.

Kindly be advised that authority is granted for you to conduct research on **nurses caring for AIDS patients and strategies for improved care at Nkandla Hospital**, provided that the following is agreed to:

(a)   Prior approval is obtained from Head of the relevant institution;

(b)   Confidentiality is HIGHLY maintained;

(c)   The Department is acknowledged;

(d)   The Department receives a copy of the report on completion; and

(e)   The staff and patients are not inconvenienced and service delivery not affected.

Yours faithfully

23.12.04

SUPERINTENDENT-GENERAL
HEAD : DEPARTMENT OF HEALTH
NNM/nd zulu aids pts nkandla

10.1 Interview schedule.

TITLE: Caring for AIDS patients -strategies for improved care.

Section A (demography)

Age:
Gender:
Qualification:
Year qualified:
Time working in the medical wards:

Section B (open-ended question)

(Patient characteristics)

I would like to learn from you about the AIDS patients you care for. So, I am going to ask you to tell me about them.

Describe a typical AIDS patient that you care for?
To probe the following:
- physical conditions: general prognosis, opportunistic infections, how they cope and how they respond to treatment, their risk of dying
- patients' understanding of their illness
- psychological state (cope, feelings)
- Family support and care
- Community support and care
- Financial support they have (own, family, community)
- Involvement of the patient and family in care
- Participation in decision making regarding care (patient, family)

(Nurse characteristics)

I would also like to know about you as a nurse and also about you as a person.

Knowledge: establish knowledge about-
- Explain the different types of HIV antibody tests
- What do you understand by transmission of HIV infection by body fluids
- How long does HIV stays infective after death of the infected person
- Clinical presentation, can it tell you about patient status and stage
- What do you understand about Sero-conversion
- Any formal training in counseling
- What would you do if you were to get exposed to HIV infection

Training: To probe about-
- basic training and ongoing training (reading, information, research)
- adequacy of training in regards to care for AIDS patients
- training needs in caring for AIDS patients
- the health care system in which you care for AIDS patients

Patient care: To probe about-
- existing protocols for caring of AIDS patients (relevance, appropriateness, helpfulness, suggestions for change)
- collaboration with others in the management of AIDS patients (nurses, doctors, social workers, psychologist, traditional healer, community members, family etc.)
- Ideas about the best way of caring for AIDS patients
- Most difficult issues in caring for AIDS patients

Beliefs/values:
- Their own feelings towards people with HIV and AIDS patients (sexuality, safer sex — condom use, monogamy, male-female gender power issues)
- Confidentiality
- Would you treat AIDS patients differently from others
- Describe the best outcome for AIDS patients

Coping:
- Support in the workplace, at home and from the community
- Stressors in the workplace and at home that impact on care for AIDS patients.
- How do you cope with these stressors?
- Ideas about how nurses can be helped to cope better in caring for AIDS patients.