

**THE EXPERIENCES OF PEOPLE LIVING WITH HIV-AIDS WITH  
REGARD TO THE COMPREHENSIVE ANTIRETROVIRAL THERAPY  
MANAGEMENT RECEIVED FROM REGISTERED NURSES AT  
SELECTED PUBLIC PRIMARY HEALTHCARE CLINICS IN NELSON  
MANDELA BAY**

by

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## **ABSTRACT**

Currently South Africa has the highest number of persons living with HIV-AIDS (PLWAs) in the world. Focus-group discussions conducted by Moon (2005:3) in the Eastern Cape indicated that people may not want to get tested for HIV or to access antiretroviral therapy (ART) for fear of disclosure of their HIV-positive status and of stigmatization. These findings prompted the researcher to conduct a study in this field. The objectives of this study are to explore and describe the experiences of PLWAs with regard to the comprehensive ART management received from registered nurses at selected public primary healthcare clinics in Nelson Mandela Bay; and to develop guidelines for registered nurses that could facilitate them in rendering appropriate comprehensive ART management.

The research study is based on a qualitative, explorative, descriptive, phenomenological and contextual research design. The research population comprised of HIV-positive patients who received treatment at the selected public primary healthcare clinics. Criterion-based, purposive sampling was used to select participants for the interviews. Ten in-depth unstructured interviews were conducted. Data was then transcribed and coded. One central theme identified the fact that PLWAs experienced both positive and negative experiences at the clinics. The main findings of this research included evidence of various forms of stigma experienced by the PLWAs; distrust of the lay health counselors; but also that PLWAs were generally well-treated and satisfied with the service they had received.

Broad guidelines for registered nurses was formulated that could facilitate them in rendering appropriate comprehensive ART management. The study concludes with recommendations made with regards to the areas of nursing practice, education and research. Throughout the study the researcher abided by the ethical considerations.

The aspects of trustworthiness implemented in this study, included dependability, credibility, transferability and confirmability (Holloway & Wheeler, 2002:354).

## **KEYWORDS**

Human Immunodeficiency Virus (HIV)

Acquired Immune Deficiency Syndrome (AIDS)

Antiretroviral therapy (ART) clinic

Person living with HIV-AIDS (PLWA)

Comprehensive ART management

Stigmatisation

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# CHAPTER 1

## OVERVIEW OF THE STUDY

### 1.1 INTRODUCTION

Interventions to mitigate the impact of the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) in South Africa are imperative because South Africa is currently having the highest number of persons living with HIV of any country in the world. By the end of 2007, the National Annual Anonymous Antenatal survey conducted on pregnant women estimated a total of 5.54 million individuals in South Africa to be living with HIV infection (<http://www.doh.gov.za/docs/reports/2006/hiv-syphilis>, 30/07/2008). More than 23% of the adult population is infected with HIV; and the prevalence is predicted to rise to more than 25% by 2010. Furthermore, the Eastern Cape HIV-prevalence figures reflected in the findings of the 2007 Annual Anonymous Antenatal survey indicated a rate of 28% (National 29.1%). HIV-prevalence amongst men is estimated at 85% of the total figure. In 2007 the Nelson Mandela Bay HIV-prevalence amongst pregnant women reflected a rate of 31,9%, the highest in the Eastern Cape (<http://www.doh.gov.za/docs/reports/2006/hiv-syphilis>, 30/07/2008).

In November 2004 the South African Cabinet approved the “Operational Plan for Comprehensive HIV-AIDS Care, Management and Treatment for South Africa”, which was developed by the National Department of Health (DOH, 2004:1). The latter Operational Plan was necessary because HIV infection typically progresses from a prolonged asymptomatic stage during which the person’s well-being can be maintained, until a stage is reached at which ARTs become a critical part of the care and treatment strategy (DOH, 2003:54). The development of an effective programme to provide Antiretroviral therapy (ARTs) is a critical

component of the larger comprehensive plan to care for people living with HIV-AIDS (PLWAs). People infected with HIV should be provided with a continuum of care and support services that respond to their changing needs over the course of their infection (DOH, 2003:54).

Antiretroviral therapy (ART) services have been incorporated into the local district hospitals and certain public primary healthcare clinics in order to make ART services more widely accessible to the community members who are in need of such services. Antiretroviral services, like other primary healthcare services, such as preventive, diagnostic, therapeutic and rehabilitative services, are provided free of charge to community members who cannot afford medical insurance (DOH, 2004:1). When a stage is reached at which ARTs are required to maintain the PLWAs health, medication should be made available and accessible through a co-ordinated programme across all levels of the public healthcare system involving primary healthcare clinics, community healthcare centres, district hospitals, and regional and tertiary healthcare institutions (DOH, 2003:54). Prior to a patient commencing ARTs a first screening visit is required, which occurs 2-4 weeks before starting antiretroviral therapy. This is followed by a second visit to the healthcare centre a month later. Once the patient satisfies the treatment criteria, ARTs may be commenced, after which the patient is required to visit the ART centre initially on a monthly basis in order to maintain the treatment chain (DOH, 2004:1).

The HIV-AIDS care and treatment programme is intended to integrate care and treatment with prevention efforts such as voluntary counselling and testing (VCT), prevention of mother-to-child-transmission (PMTCT), and Tuberculosis control. All South Africans should be able to access the full array of interventions and services available to address HIV-AIDS within the context of a continuum of care (DOH, 2003:54).

The Operational Plan for Comprehensive HIV-AIDS Care, Management and

Treatment is guided by certain fundamental principles, such as quality of care, universal care and equitable implementation, strengthening the national healthcare system, providing a comprehensive continuum of care and treatment, a sustainable care and treatment programme and promotion of individual treatment choice. (DOH, 2003:16-22). The quality of care principle includes making a proper diagnosis, counselling, treatment of opportunistic infections, preventive and supportive strategies and antiretroviral drugs for the management of AIDS. However, the improper use of these drugs can hasten the development of drug-resistant strains of the virus, thus undermining effective treatment and posing public health risks. Accordingly, care and treatment protocols need to be based on international best practices with the necessary extensive training and certification of healthcare professionals to support the ART treatment programme (DOH, 2003:16-17).

The Operational Plan provides for extensive investments in monitoring and research in order to improve the quality of care for all South Africans undergoing care and treatment. Universal access to equal care for both urban and rural areas is a target. The principle of strengthening the national healthcare system includes plans to upgrade public hospitals; to make significant additions to human resource capacity; and to provide incentives to recruit and retain healthcare professionals. Comprehensive care and treatment of HIV-AIDS needs to be delivered in an integrated manner within a coherent overarching public policy framework. The Operational Plan makes provision for ongoing medical services to provide treatment for opportunistic infections and when necessary, antiretroviral treatment to arrest the progression to full-blown AIDS (DOH, 2003:20). A sustainable care and treatment programme as mentioned in the Plan entails commitment to providing care and treatment for patients over a long period of time. Once patients are on the comprehensive treatment and care programme, the treatment must be sustained. The programme must therefore be cost-effective, efficient and uncompromising in quality (DOH, 2003:21). South Africans living with HIV-AIDS are encouraged to make their own informed

choices about the types of treatment they wish to seek. Potential clients must be informed about all the care and treatment options provided to them through the comprehensive package of care (DOH, 2003:22).

The HIV-AIDS public primary healthcare clinics are nurse-led clinics with registered nurses trained in the provision of ART treatment. The registered nurses form part of a multidisciplinary team along with the doctor, psychologist and pharmacist, whom together assess the readiness of the patient for ARTs. The registered nurse is responsible for issuing maintenance treatment to the patient and for the monitoring of any adverse side-effects as a result of the ART treatment in the patient who would then be referred to the doctor (Stuart, 2008:4).

A critical factor in the provision of improved treatment for HIV-infected individuals includes the psychological phenomenon and the reduction of stigma associated with being at risk and living with HIV-AIDS (DOH, 2003:213). The link between HIV-AIDS stigma and health is well documented and profound. Because of the severity of the African epidemic, HIV-AIDS research is now being focused on Africa. Lorentzen and Morris (2003, in Deacon, 2005:viii) maintain that HIV-AIDS-related stigma in Sub-Saharan Africa presents a serious challenge to the understanding, alleviation and prevention of HIV.

Research indicates that once PLWAs enter the healthcare system, they run the risk of receiving inadequate care because of being stigmatised by healthcare providers. It has also been shown that stigma can interfere with adherence to ART because patients may choose to miss doses rather than take them in the presence of others (Chesney & Smith, 1999:1169; Muyinda, Seeley, Pickering & Barton, 1997:143; Sangiwa, 2001, in HDN, 2001:20). Since healthcare providers and family members are often stigmatised due to their close contact with PLWAs, this further jeopardises the care given to AIDS patients. Stigma can also increase the stress levels of PLWAs, which may negatively affect the course of the disease. Many internalise the stigmatising messages from society and blame

themselves for their condition. They may end up feeling profoundly isolated (Chesney & Smith, 1999:1169).

As part of a pilot project in the Eastern Cape to ascertain how antiretroviral roll-out would influence people's perceptions of PLWAs, Dr Martha Moon, an Associate Professor at the Virginia Commonwealth University (VCU) School of Nursing, Richmond, Virginia, USA, and colleagues from Rhodes University and the Nelson Mandela Metropolitan University (NMMU) in the Eastern Cape, conducted seven focus-group discussions with various target groups from October to November 2004. In July 2005 individual interviews were conducted with eight nursing staff members, namely Nursing Service Managers and registered nurses in selected public healthcare clinics in the Nelson Mandela Bay. Stigma and discrimination among registered nurses towards PLWAs were identified as major impediments to HIV-AIDS testing and treatment. The lack of confidentiality and identified unprofessional conduct of nurses resulted in people not wanting to get tested for HIV or to access ART for fear of disclosure and stigmatisation (Moon, 2005:3).

Much research has been done on the problem of stigma, but the work of Goffman (1963:3) has been widely credited with conceptualising and creating a framework for the study of stigma. He describes stigma as an “attribute that is deeply discrediting within a particular social interaction”. His explanation of stigma focuses on the public’s attitude toward a person who possesses an attribute that falls short of societal expectations. The person with the attribute is “reduced in our minds from a whole and usual person to a tainted, discounted one”. Goffman (1963:4) mentions three different types of stigma: firstly, abominations of the body (physical deformities); next are blemishes of individual character perceived as weak will, domineering or unnatural passions, rigid beliefs and dishonesty (for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts and radical political behaviour). Finally there are the tribal stigmas of race, nation and religion



(stigma that can be transmitted through lineages).

Goffman (1963:3) notes that diseases associated with the highest degree of stigma share the following common attributes:

- The person with the disease is seen as responsible for having the illness.
- The disease is progressive and incurable.
- The disease is not well understood among the public.
- The symptoms cannot be concealed.

Human Immunodeficiency Virus (HIV) infection fits this profile since it carries a high level of stigmatisation (Herek, 1999:1102). Herzlick and Pierret (1985, in Muyinda et al, 1997:143) states that once illnesses acquire a popular imagery of being scourges, they stop being seen in terms of individual misfortune and instead represent menacing forms of collective adversity which threaten the whole community. Sontag (1989, in Muyinda et al, 1997:143) states that AIDS provides a good example of such illnesses because of its association with sex, the lengthy incubation period giving a sense of it spreading underground, and because it is fatal. Sontag (1989, in Muyinda et al, 1997:143) has pointed to the similarity between cancer and AIDS as stigmatising conditions which may elicit fear and avoidance rather than sympathy.

With stigmatising illnesses, “disreputability and even evil” may adhere to the person so afflicted (Freund, 1991, in Alonzo & Reynolds, 1995:305) and, as noted by Goffman (1963, in Alonzo & Reynolds 1995:305), to his family and friends in the form of a courtesy stigma which is explained as that which is extended to others due their close association with the HIV-infected person. Conrad (1986, in Alonzo & Reynolds 1995:305) further suggests that stigmatising illnesses are connected to deviant behaviour either by producing it, as in the case of epilepsy or mental illness, or being a product of it, as in the case of sexually transmitted diseases such as genital herpes or gonorrhoea. Thus, some individuals stigmatised by illness are devalued, shunned or otherwise lessened in

their life chances because of the illness they have, or are suspected of having, and this discredits their claim to be “moral characters” and one of “us” (Goffman, 1963, in Alonzo & Reynolds, 1995:305).

Stein (2003:9) maintains that blame and stigma have functions. They make us feel safe or less vulnerable to misfortune because, unlike the victim, we have done nothing to 'deserve' it. Stigma is therefore a psychological defence mechanism which serves to control anxiety in the face of danger. Moral stigma associated with HIV-AIDS functions to reinforce social norms around fidelity and family. Because HIV is sexually transmitted, it functions as a marker of promiscuity and other “deviant” sexual practices which threaten to disrupt family life (Stein, 2003:9). Preliminary research indicates growing resentment in Sub-Saharan Africa towards people living with HIV-AIDS because of the resources they expend within the household and within the public health and welfare system (Moon, 2002, in Stein, 2003:8).

On our continent a working definition for stigma and HIV-AIDS in Africa was developed in June 2001 and is specific to HIV-AIDS in Africa: “HIV-AIDS-related stigma is a real or perceived negative response to a person or persons by individuals, communities or society. It is characterised by rejection, denial, discrediting, disregarding, underrating and social distance. It frequently leads to discrimination and violation of human rights” (HDN, 2001:7).

In a review of issues and responses on stigma and HIV-AIDS in Africa at a conference in Dar-es-Salaam, Tanzania in 2001, France (2001, in HDN, 2001:18) presented a detailed summary of the findings from focus groups, interviews and an email discussion group as follows: AIDS stigma is found in all countries. Women, who are seen as transmitters of the virus, suffer more stigma than do men, who are perceived as unlucky. Children are also particularly vulnerable to stigma. It was found that AIDS was stigmatised because it was related to sex and promiscuity. The healthcare sector was identified as the place

where one was most likely to be stigmatised, followed by within the family.

When people are HIV-positive, but do not know it, they are more likely to put others at risk of infection, which further threatens public health. If antiretroviral therapy is available, a delay in diagnosis will delay getting the medicines that could be critical to long-term health. Furthermore, once people have learnt that they are HIV-positive, stigma often prevents them from disclosing their status to others, which cuts them off from critical sources of emotional support. Mothers who are HIV-positive and who know that breastfeeding increases the risk of mother-to-child transmission, may decide to continue breastfeeding their babies anyway, if they think this will conceal their HIV-status (Chesney & Smith, 1999:1163).

The internalisation of stigma or self-stigmatisation, involves accepting some of the negative social judgements of one's identity as HIV-positive. Perceived stigma is the stigma people expect from others should they be known to be HIV-positive (Bharat, Aggleton & Tyrer, 2001, in Deacon, 2005:31). Fife and Wright (2000, in Deacon, 2005:35) suggest that the individual's perception of stigma accounts for the significant differences seen in the impact of an illness on the self and influences responses to stigmatisation. Higher perceived stigma reduces the likelihood of disclosure of HIV-positive status and an unwillingness to present for voluntary counselling and testing (VCT) and treatment (Lichtenstein, 2003, in Deacon, 2005:35).

In a report on the analysis of HIV-AIDS stigma research, a project initiated by the Human Sciences Research Council (HSRC) in Cape Town, Deacon (2005:ix) refers to HIV-AIDS stigma as “negative things people believe about HIV-AIDS and people living with HIV-AIDS”; and to discrimination (enacted stigma) as “what people do to unfairly disadvantage people living with HIV-AIDS”.

In a qualitative study conducted recently in Kwa-Zulu Natal (Campbell, Foulis,

Maimane & Sibiyi, 2005:808), the researchers concluded that stigma serves as an effective form of “social psychological policing” by punishing those who have breached unequal power relations of gender, generation and ethnicity.

## **1.2 PROBLEM STATEMENT**

Data obtained from focus-group discussions conducted by Moon (2005:3) from October to November 2004 with healthcare providers rendering ART services revealed serious impediments of stigma and discrimination towards people living with HIV-AIDS. People are still afraid to come forward for testing or treatment for fear of being subjected to the judgemental attitudes of the nurses, while the prevalence of HIV in Nelson Mandela Bay continues to increase unabated.

The researcher, a professional nurse practitioner, then employed at the AIDS Training, Information and Counselling Centre (ATICC) of the Nelson Mandela Bay Municipality had personally encountered many incidents reflecting stigma and discrimination amongst peers with regard to how they counsel and handle their HIV-positive patients. In some instances incorrect information is provided by registered nurses to the public at large resulting in unfounded fears and the fuelling of myths about the spread and prevention of HIV-AIDS. The unprofessional conduct of registered nurses witnessed by the researcher, for example, not respecting the privacy and confidentiality of the client’s HIV-status, could be a major obstacle to the success of antiretroviral therapy access and adherence. Prompted by the findings of the focus-group discussions conducted by Moon (2005:3) and the researcher’s own experiences in the field, the researcher was interested in exploring the experiences of PLWAs with regard to the comprehensive ART management received from registered nurses at selected public primary healthcare clinics in Nelson Mandela Bay.

In order to establish the experiences of PLWAs in the selected primary healthcare clinics the following research questions would be posed:

*What are the experiences of people living with HIV-AIDS with regard to the comprehensive ART management received from registered nurses at selected public primary healthcare clinics in Nelson Mandela Bay?*

*What can be done to facilitate registered nurses in rendering appropriate comprehensive ART management to their patients?*

### **1.3 PURPOSE OF THE RESEARCH**

The main aim of the study is to explore and describe the experiences of PLWAs with regard to the comprehensive ART management received from registered nurses at selected public primary healthcare clinics in Nelson Mandela Bay. The findings of this research will be used to develop guidelines for registered nurses that could facilitate them in rendering appropriate comprehensive ART management to their patients.

### **1.4 RESEARCH OBJECTIVES**

The research objectives of this study are:

- to explore and describe the experiences of people living with HIV-AIDS with regard to the comprehensive ART management received from registered nurses at selected public primary healthcare clinics in Nelson Mandela Bay, and
- to develop guidelines for registered nurses that could facilitate them in rendering appropriate comprehensive ART management to their patients.

### **1.5 CLARIFICATION OF CONCEPTS**

The following concepts will now be clarified:

- **People living with HIV-AIDS**

The term “people living with HIV-AIDS” (PLWAs) refers to people who have tested positive for the HIV and are living with HIV-infection and/or full-blown AIDS (DOH, 2003:16).

- **Registered nurse**

According to the Nursing Act of South Africa (Act No. 50 of 1978), a registered nurse means a person registered as a nurse under section 16 (The Nursing Act, no. 50 of 1978). In this study “registered nurse” will refer to all registered nurses employed at the public primary healthcare clinics or provincial hospitals that have been accredited as antiretroviral therapy sites.

- **Public primary healthcare clinics**

In this research “public primary healthcare clinics” (DOH, 2003:54) will refer to clinics rendering ART comprehensive management in the public sector in Nelson Mandela Bay.

- **Comprehensive ART management**

Management of the patient with AIDS who requires ARTs is comprehensive in that it encompasses the prevention, treatment, care and support of the patient. Antiretroviral therapy prolongs and improves the quality of life of a person with HIV. The approach adopted by Government is that of a continuum of care integrated from primary to tertiary levels, and from pre-diagnosis to palliative care (DOH, 2004: Introduction).

- **Prevention** within care refers to integrating education and support messages for positive patients as an important part of the comprehensive care of PLWAs (Family Health International (FHI), 2007:133).
- **Treatment** involves making available medications for prophylaxis,

opportunistic infections and full-blown AIDS in order to control or delay the progression of HIV-infection in the individual (Synergy Project, 2000:7).

- **Care** involves services to stabilise and/or improve community and physical health of individuals infected and affected by HIV-AIDS (Synergy Project, 2000:7).
  
- **Support** involves interventions to stabilise and/or improve community and societal systems affected by the epidemic (Synergy Project, 2000:7).

- **Experience**

The term “experience” (Sykes, 1976:365) can be defined as: “Actual observation of, or practical acquaintance with, facts or events: knowledge or skill resulting from this; an event that affects one; fact or process of being so affected; to meet with, feel, undergo (treatment, fate, pleasure)”. The researcher wishes to explore and describe the experiences of PLWAs with regard to the comprehensive ART management received from registered nurses at selected primary healthcare clinics.

- **Guidelines**

Sykes (1976:477) defines a guideline as “a directing principle or standard”. The findings of this study will be used to develop guidelines that could facilitate registered nurses in rendering appropriate comprehensive ART management.

## **1.6 RESEARCH DESIGN AND METHODS**

A brief outline of the research design and methods that will be utilised in this study is described below.

### **1.6.1 Research Design**

A research design is a plan for conducting research that maximises control over factors that could hinder the validity of the eventual events (Mouton, 1996:27). In order to meet the aims and objectives of this study, the researcher will adopt a qualitative, exploratory, descriptive, phenomenological and contextual research design. A full description of this design will be presented in Chapter two.

### **1.6.2 Research Methods**

The research method which involves data collection and data analysis (Babbie & Mouton, 2001:104) will be divided into two phases:

#### **1.6.2.1 Phase One**

This phase will consist of data collection and data analysis and it will involve the exploration and description of PLWAs' experiences with regard to the comprehensive ART management received from registered nurses at selected primary healthcare clinics in Nelson Mandela Bay. The following sections comprise Phase One:

- **Research Population and Sampling Strategy**

For the purpose of this research the research population will be HIV-positive clients who receive treatment from the selected ART primary healthcare clinics in Nelson Mandela Bay. The researcher will make use of a criterion-based, purposive sampling procedure, the participants being selected for a specific purpose on which the researcher decides. According to LeCompte and Pressle (1993, in Holloway & Wheeler, 2002:122) purposive sampling is criterion-based or hand-picked. The sampling strategy will be discussed in detail in Chapter two.

- **Data-collection method**

The researcher will make use of in-depth interviews based upon a phenomenological approach, field notes and observation notes as a means of



data collection. According to Strydom (2002:278) qualitative studies usually employ unstructured or semi-structured interviews, also known as in-depth interviews. An in-depth discussion of the data- collection process will be given in Chapter two.

- **Data analysis**

Data will be analysed using Tesch's method, as described in Creswell (2003:192). Tesch proposes eight steps to consider in data analysis. Identified themes will then be formulated. This will be discussed in more detail in Chapter two of this study.

A pilot interview will be conducted and used for data analysis. In qualitative research the pilot study is usually informal and consists of the researcher determining whether the relevant data can be obtained from the participants. By testing the nature of the questions in a pilot interview the researcher is able to make modifications with a view to quality interviewing during the main study (Strydom & Delport, 2002:337). The pilot study will consist of a trial interview with one of the PLWAs at a selected primary healthcare clinic, from which the interview technique and questions can be assessed.

- **Literature Control**

The literature control will provide a framework as well as the benchmark for comparing the findings of the study and contrasting the results, themes or categories of this research with other findings (Compare Creswell, 1994:23). In this study literature pertaining to experiences of PLWAs will be applied to the results of the interviews.

### **1.6.2.2 Phase Two**

The information obtained from the data analysis and literature control will be used as a basis for describing broad guidelines for registered nurses that could

facilitate them in rendering appropriate comprehensive ART management to their patients.

### **1.7 MEASURES TO ENSURE TRUSTWORTHINESS AND AUTHENTICITY**

Authenticity will be achieved by the researcher by being fair to participants and gaining their acceptance throughout the study. Continued informed consent will be obtained. According to Holloway and Wheeler (2002:254), trustworthiness in qualitative research means methodological soundness and adequacy. The researcher will make judgements of trustworthiness possible through developing credibility, transferability, dependability and confirmability. Each of these aspects will be discussed in more detail in Chapter two.

### **1.8 ETHICAL CONSIDERATIONS**

Conducting research is an ethical enterprise, ethics being considered as 'a system of morals, rules of behaviour' (Struwig & Stead, 2001:66). Therefore, throughout the research, the rights of the individual not to be harmed, to give informed consent, voluntary participation, confidentiality, anonymity and justice are paramount and must be considered throughout the research (Holloway & Wheeler, 2002:39). As a registered nurse involved in a research study the researcher is responsible for assuring all participants of their above-mentioned rights by explaining the purpose of the study; and to ensure that none of the participants is deceived about the nature of the study (Creswell, 1998:132). Ethical considerations will be discussed comprehensively in Chapter two.

### **1.9 CHAPTER DIVISION**

The research study will be divided into four chapters of which the format will be:

Chapter 1: Overview of the study

Chapter 2: Research design and method

Chapter 3: Discussion of results and literature control

Chapter 4: Summary, conclusions, guidelines and recommendations.

### **1.10 CONCLUSION**

In this chapter the researcher gives a conceptualisation of selected public primary healthcare clinics in Nelson Mandela Bay offering comprehensive ART management to PLWAs. Due to the link between HIV-AIDS and stigma, an overview of literature on stigma and discrimination towards PLWAs is given. The problem statement and research objectives are stated within the context of the research and the research methodology is outlined and discussed.

# **CHAPTER 2**

## **RESEARCH METHODOLOGY**

### **2.1 INTRODUCTION**

The previous chapter presented an orientation to the research study. The research problem was identified and the purpose of the study and study objectives were introduced. The researcher wished to ascertain the experiences of people living with HIV-AIDS (PLWAs) with regard to the comprehensive ART management received from registered nurses at selected public primary healthcare clinics in Nelson Mandela Bay. In this chapter the research design and methods are discussed in more detail. Data was collected by means of in-depth interviews. Data analysis enabled themes to be identified and coded. Broad guidelines were constructed to facilitate registered nurses in rendering appropriate comprehensive ART management.

### **2.2 RESEARCH DESIGN**

Mouton (2002:107) defines a research design as a set of guidelines and instructions to be followed in addressing the research problem. The objective of the research design is to plan, structure and execute the relevant project in such a way that the validity of the findings is maximised. The researcher adopted a qualitative, exploratory, descriptive and contextual study design based on the phenomenological approach to data gathering. The research design will now be discussed.

#### **2.2.1 Qualitative Research**

Polit and Hungler (2001:466) define qualitative research as the investigation into a phenomenon, typically in an in-depth and holistic fashion, through the collection of rich narrative materials using a reflexive research design. Qualitative research

largely uses an inductive approach, reasoning from the specific to the general (Creswell, 2003:179). Burns and Grové (1999:388) further state that qualitative research is a systematic, participative approach used to describe life-experiences and give them meaning. The researcher therefore utilised this research design to gain an in-depth understanding of the experiences of the participants with regard to the comprehensive ART management received from registered nurses at the selected public primary healthcare clinics. The data obtained provided a wealth of information in understanding the aforementioned experiences of PLWAs. The latter information received assisted the researcher in constructing guidelines that could facilitate registered nurses in rendering appropriate comprehensive ART management to their patients.

### **2.2.2 Exploratory Research**

The aims of an exploratory study are to establish the facts, explore topics which are relatively unknown, formulate a problem, and develop a hypothesis for further study (Babbie & Mouton, 2001:79).

Babbie and Mouton (2001:79) further state that exploratory studies are done for the following reasons:

- to satisfy the researcher's curiosity and desire for better understanding of a topic,
- to test the feasibility of undertaking a more extensive study,
- to develop the methods to be employed in any subsequent study,
- to explicate the central concepts and constructs of a study,
- to determine priorities for future research and
- to develop new hypotheses about an existing phenomenon.

The researcher therefore selected this design because she intended to explore and describe the lived experiences of PLWAs attending selected primary healthcare clinics which provided insight into and understanding of their

experiences with regard to the comprehensive ART management received from registered nurses.

### **2.2.3 Descriptive Research**

Descriptive research is the description of a phenomenon in a real life situation. It provides an accurate account of characteristics of particular individuals, situations or groups. Through descriptive studies researchers discover new meanings, determine what exists, determine the frequency with which something occurs and categorise information (Burns & Grové, 1999:24). Its purpose is to provide a picture of a situation as it naturally occurs (Burns & Grové, 1999:192). A descriptive research design was selected so that the researcher could give a thick description of her research findings.

### **2.2.4 Contextual study**

According to Holloway and Wheeler (2002:11), contextual research describes the space and environment of interaction. This includes cultural and historical implications which are important for understanding the phenomenon being studied. The researcher gives a description of the reality, typical of a specific context in which the phenomenon occurs. The total context of the participants' lives will affect the findings of the study (Holloway & Wheeler, 2002:11). The context involves situating the object of the study or phenomenon of study within its immediate setting (Creswell, 1998:68).

In this study a contextual design is used to describe the experiences of PLWAs. This study was conducted in Nelson Mandela Bay which is one of the health districts in the Province of the Eastern Cape. The researcher collected data from eight of the nine accredited ART public primary healthcare clinics of Nelson Mandela Bay. The research study was contextual in nature as the participants were interviewed within the physical environment and cultural context in which they were treated. Most of the inhabitants in the area of research belong to the

Xhosa ethnic group and the Coloured population group, with the former group making up the majority of clients who attend the public healthcare services, including the ART clinics. The persons attending the clinics do not have medical insurance and are mainly from the lower socio-economic and unemployed sector. Two-thirds of people infected with HIV are women.

### **2.2.5 Phenomenological Approach**

This study is grounded in a phenomenological approach to inquiry, which is aimed at understanding and interpreting the meaning that the participants give to their everyday lives (Fouché, in de Vos, Strydom, Fouche & Delpont, 2002:73). This is achieved by following a naturalistic method of study and analysing the conversations and interactions between the researcher and the participants. Data is systematically collected and meanings, themes and general descriptions of experiences are analysed within a specific context (Fouché, in de Vos et al, 2002:73). In attempting to describe the lived experiences of PLWAs the researcher focussed on what was happening in their lives and how they were treated at the clinics.

The success of this research is thus dependent on having a phenomenological approach throughout the study. Through this approach the researcher aims to bring the 'human side' of the participants to the fore.

## **2.3 RESEARCH METHOD**

The research method, which involves data collection and data analysis, was divided into two phases.

### **2.3.1 Phase One: Exploration and description of participants' experiences with regard to the comprehensive ART management received from registered nurses at selected public primary healthcare clinics.**

This phase comprises the research population, sampling method, data-collection method and data analysis and literature control. Each of these will now be discussed.

#### **2.3.1.1 *Research population***

According to Polit and Hungler (2001:173), a research population is the entire aggregation of cases that meets a designated set of criteria. The research population for this study comprised all HIV-positive clients who were receiving comprehensive ART treatment from registered nurses at the selected primary healthcare clinics in Nelson Mandela Bay. Eight of the nine ART public healthcare clinics were included in the study.

#### **2.3.1.2 *Sampling***

Criterion-based, purposive sampling was used in the recruitment and preparation of research participants. For the in-depth interviews, participants were selected so as to maximise the richness of information obtained pertinent to the research questions. Brink (2006:141) and Polit and Hungler (2001:237) describe purposive sampling as a sampling method based on the researcher's judgement about subjects that are typical or representative of the phenomenon being studied in cases where the researcher is particularly knowledgeable about the problem. In such cases the researcher intentionally selects the participants she feels are suitable and requests them to participate. The advantage of purposive sampling is that it allows researchers to select the sample on the basis of their knowledge of the phenomenon being studied.

Eight sites were visited from the nine ART public healthcare clinics in Nelson



Mandela Bay. Participants were interviewed from each of the eight identified sites. The researcher went to the identified sites and approached clients as they came out of the ART consultation room and asked them whether they would be interested in participating in the research. This continued until ten clients who fitted the selection criteria and who gave written informed consent were found. The following selection criteria were utilised by the researcher for the selection of participants in the study, namely, the participant had to:

- be HIV positive and receiving ART at the clinic,
- have been attending the ART clinic for at least three months, irrespective of adherence factors,
- be able to communicate well in English and be able to express himself/herself clearly in order to avoid misinterpretations by the researcher and
- be a voluntary participant and have given written consent.

### **2.3.1.3 Data-collection method**

The researcher made use of phenomenological, in-depth interviews as a means of data collection. The in-depth interviews lasted 40-45 minutes. Holloway and Wheeler (2002:79) state that in-depth interviews have become the most common form of data collection in qualitative research. Interviews are personal and intimate, with an emphasis on depth, detail, vividness (intensity) and nuance (subtle difference in meaning) (Crabtree & Miller, 1999:93). According to Holloway and Wheeler (2002:81) unstructured interviews start with a general question in the broad area of study. The following broad question was posed to each participant:

*“Tell me about your experience of attending this ART clinic.”*

Probes and follow-up questions were also used for the participants. Interviewing

continued until data saturation was reached (Strauss & Corbin, 2002:292). Data saturation was reached after ten interviews.

The process of entry to the selected primary healthcare clinics by the researcher was made by contacting the Sister- in-Charge to inform her about the research and to enquire which days of the week would be best to find most PLWAs attending the clinic for treatment and to arrange a private room in which to conduct the interview without interruptions. On arrival at the respective clinics the researcher approached the Sister-in-Charge to announce her presence and to present the letter of permission granted by the Manager of the respective authority. The researcher was shown to the room which had been made available for the interviews to take place. At some clinics the room was private and quiet, but at others there was the occasional interruption and background noise due to renovations taking place at the clinic. The researcher went to wait outside the consulting rooms for patients to come out, whereupon she approached them to enquire whether they would be willing to participate in the research. Prior to conducting the interview the researcher spent some time introducing herself, to build rapport and to explain the purpose of the research and the process, stressing that participation was voluntary and confidential. The Participant Consent Form was signed and permission had been requested from the participants prior to interviewing to use a tape-recorder to record the interviews (see Annexure A). The aforementioned was necessary to enable the researcher to record the exact words of the interview, inclusive of questions, so that she did not forget important answers and words. Using a tape-recorder also allowed the researcher to have eye contact with the participants and pay attention to what the participants said and did not say. The tape was dated, labelled and checked immediately before and after the interview to establish whether it was functioning properly in case the researcher had to re-do the interview.

#### **2.3.1.4 Field notes**

According to Polit and Hungler (2001:436), field notes are made by the researcher about observations that are made in the field. They help to supplement recorded interviews in that the physical setting and impressions made on the researcher by the participants are included in the field notes. Comprehensive, descriptive field notes were made after collecting information to make sense out of what had been observed.

In this study, several types of field notes were made during and shortly after interviews for cross-referencing with recorded interviews (Morse & Field, 1996:91). Relevant information that would not be on audio-tapes was noted and explained.

Field notes deepen the insight of the researcher into the life-world of the participants. Gestures and facial expressions were noted (Creswell, 1994:165). Once the participants repeated the same or similar information without giving new information, interviews were stopped because data became saturated (Streubert & Carpenter, 1999:124). A separate journal was kept by the researcher for documenting insights, reactions, questions and impressions during the interview sessions (Compare Tutty, Rothery & Grinnel, 1996:80). After the interview, field notes about the interview sessions were written and the researcher's impressions documented. Different types of field notes made by the researcher will be described in the following paragraphs.

- **Theoretical notes**

This term refers to the theories that emerge in the field during data collection and are clarified by the researcher during reviewing of the data. The researcher made suggestions that would link ideas and proposals and also record and develop new concepts out of the data or observations. As part of theoretical notes analytic memos are developed (Neuman, 2006:366).

- **Personal notes**

The researcher kept a section of the notes like a personal diary that recorded personal life events and her feelings, as personal feelings and emotions can become part of the data and cloud what a researcher sees and hears. The researcher kept separate all these personal notes to be used after the data had been collected. Personal notes serve three purposes: they serve as an outlet for the researcher, helping her to cope with stress; they serve as a source of data about personal reactions; and also act as a way to evaluate direct observations or inferences made when the data is re-read later after the interviews (Neuman, 2006:366).

- **Direct observation notes**

In this study the researcher utilised direct observational notes immediately after leaving the field. These notes were written in a chronological manner with the date, time and place on each entry. Field notes in this study serve as a detailed description of what the researcher heard and saw in concrete specific terms and as an exact record of particular words, phrases or reactions. The researcher wrote verbatim statements with double quotation marks to distinguish them from paraphrases and also recorded dialogue accessories like non-verbal communication, props, tone, speed, volume and gestures. On direct observation, the researcher records the sentences as they are, not rephrasing them; and describes information in detail and not as a summary (Neuman, 2006:365).

- **Jotted notes**

In the field the researcher jotted down short temporary memory-triggering words and phrases on a notepad. These were incorporated later in the discrete observational notes.

- **Methodological notes**

In this study the researcher kept methodological ideas in analytical notes to record plans, tactics, ethical and procedural decisions and self-criticism of tactics. In this study these methodological notes served as a guide during the researcher's recording of field notes (Neuman, 2006:365).

### ***2.3.1.5 Role of the Researcher***

A qualitative researcher is the primary instrument of data collection and analysis, rather than through inventories, questionnaires or machines, and implies openness on the part of the researcher with regard to examining new ideas (Creswell, 1994:145). A qualitative researcher functions in the capacity of a human instrument in an effort to explore how PLWAs experience comprehensive ART management received from registered nurses at the selected primary healthcare clinics. The research interview is an interpersonal situation, a conversation between two partners about a theme of mutual interest, a specific form of human interaction in which knowledge evolves through a dialogue. The interaction is neither as anonymous nor neutral as when a subject responds to a survey questionnaire, nor is it as personal and emotional as a therapeutic interview (Burns & Grove, 1997:80).

This means that the researcher utilised bracketing (Burns & Grove, in de Vos et al, 2002:337) by placing her knowledge and preconceived ideas about the phenomenon between brackets, and focusing her awareness and energy on the experiences of participants and the research process (intuiting). Bracketing implies that the researcher willingly laid aside what was known about the experience being studied to achieve an open context and to facilitate “seeing” all facets of the phenomenon. Intuiting, which is the process of actually “looking at” the phenomenon and developing insight into it, requires concentration and complete absorption in the experience being studied (Strydom & Delpont, 2002:337). In order to achieve meaningful bracketing and intuiting, continual

self-evaluation was a prerequisite for the researcher in order to avoid bias related to preconceived ideas and notions.

#### **2.3.1.6 Data analysis**

The recorded interviews were transcribed by an independent transcriber. A clean set of the transcribed interviews and instructions (see Annexure B) was given to an independent coder, experienced in the field of qualitative research. The researcher and the independent coder analysed the data independently, together with the field notes, to develop themes and categories. Coding was done according to Tesch (1990, in Creswell, 2003:192) to reduce the data into themes or categories. The method used consisted of the following steps:

- Get a sense of the whole. Read all the transcriptions carefully and make short notes.
- Pick one document at a time, go through it to try to make meaning of its contents and write notes in the margin.
- When this action has been completed for several documents, make a list of all the topics. Cluster similar ones together and form them into columns that can be arranged as major topics, unique topics and leftovers.
- Take the list and go back to the data. Abbreviate the topics as codes and write the codes next to the appropriate segments of the text to see whether new categories and codes emerge.
- Find the most descriptive wording for the topics and turn them into categories. Reduce the total list of categories by grouping topics that relate to one another. Lines could be drawn between categories to show interrelationships.
- Make a final decision on the abbreviation for each category and arrange these categories alphabetically.
- Assemble the data material belonging to each category in one place

and perform a preliminary analysis.

- Re-code existing data if necessary.

On completion of the coding, the researcher and the independent coder communicated to discuss themes and categories in order for consensus to be reached. Both the researcher and the independent coder agreed that data saturation had been reached and that there was no need for further interviews to be conducted. Thereafter the researcher discussed the themes and categories with the research supervisor and co-supervisor and agreement was reached. The themes and sub-themes and categories portrayed the storyline in a meaningful and descriptive way.

#### ***2.3.1.7 Pilot Study***

In qualitative research the pilot study is usually informal and consists of the researcher determining whether the relevant data can be obtained from the participants. By testing the nature of the questions in a pilot interview the researcher is able to make modifications with a view to quality interviewing during the main study (Strydom & Delpont, 2002:337).

Two pilot interviews were conducted by the researcher in order to assess whether the sequence and wording of the questions posed were understandable to the interviewees and within the framework of a phenomenological approach to the enquiry. Conducting a pilot interview enabled the researcher to assess whether the research questions generated the desired effect. It also served as an assessment tool for the researcher with regard to the technique of interviewing. The second pilot interview was used in the final 10 interviews.

#### ***2.3.1.8 Literature control***

After the data had been analysed a review of applicable literature was done. The purpose of a literature control is to place the findings within the context of what is

already known about the topic and verify the themes and sub-themes (Streubert & Carpenter, 1999:25). The literature control was done in order to illustrate the summary of the main ideas from previous studies and some of the problems and contra-indications found and how they related to the problems of this study. The literature control was only done after data analysis had been completed in order to avoid the researcher developing pre-conceived ideas about the problem under review. If no literature had been found to support statements, the researcher highlighted it during the discussion of results in chapter three of this study.

### **2.3.2 Phase Two: Developing guidelines**

Within this phase information obtained from the data analysis and literature control was used to construct guidelines for registered nurses that could facilitate them in rendering appropriate comprehensive ART management. The guidelines are discussed in chapter four of this study.

## **2.4 MEASURES TO ENSURE TRUSTWORTHINESS**

According to Holloway and Wheeler (2002:256), a study is authentic when the strategies used are appropriate for the true reporting of the participants' ideas, when the study is fair and when it helps participants and similar groups to understand their world and improve it. Authenticity will thus be achieved by the researcher by being fair to participants and gaining their acceptance throughout the study. According to Holloway and Wheeler (2002:254), trustworthiness in qualitative research means methodological soundness and adequacy. The researcher will make judgements of trustworthiness possible through developing the following:

### **2.4.1 Dependability**

Holloway and Wheeler (2002:254) quote Lincoln and Guba (1985, in Polit & Hungler, 2001:307) as using the term “dependability” instead of “reliability”. If the



findings of the study are to be dependable, they should be consistent and accurate. The context of this research is described in detail in order to account for any changes in the design created by an increased understanding of the phenomenon.

#### **2.4.2 Credibility**

Credibility corresponds to the notion of internal validity. This means that the participants must be able to recognise the meaning that they themselves give to a situation and the truth of the findings in their own social context. The researcher ensures that her findings are compatible with the perceptions of the participants (Holloway & Wheeler, 2002:255). Credibility in this study was ensured by utilising reflexivity, peer review and an independent coder.

#### **2.4.3 Transferability**

Holloway and Wheeler (2002:255) state that Lincoln and Guba (1985, in Polit & Hungler, 2001:307) use transferability instead of generalisability. This means that the findings of this research should be able to be transferred to similar situations or participants. The knowledge acquired in this study will be relevant in another, so that those who carry out the research in another context will be able to apply certain concepts originally developed in this research study (Holloway & Wheeler, 2002:255). In this study use was made of a dense description of the research process to ensure transferability of findings.

#### **2.4.4 Confirmability**

Lincoln and Guba (1985, in de Vos et al, 2002:352) use confirmability instead of objectivity and stress the need to ask whether the findings of the study could be confirmed by another. This again needs an audit or decision trail from which readers can trace the data to its sources. Readers are able to follow the path of the researcher and the way she arrived at the constructs, themes and their

interpretation. An independent coder and reflexivity were used to ensure trustworthiness. As previously mentioned, an independent coder was used to verify the identified categories and themes. The independent coder was handed a set of clean transcriptions with guidelines on how to analyse the data according to Tesch. A consensus discussion took place between the coder and the researcher to agree on themes and categories.

## **2.5 ETHICAL CONSIDERATIONS**

Ethical considerations have to be considered throughout the study to protect the participants from any form of harm. The health professions recognise that human life is very fragile and realise that those entrusted with the responsibility of rendering care need a guideline for action (Searle, 2000:97). Ethical codes for professions set the parameters of the responsibilities the nurse owes to her patients. Professional ethics are moral dimensions of attitude and behaviour based on values, judgement, responsibility and accountability that the practitioner takes into account when weighing up the consequences of his/her professional actions (Searle, 2000:97).

The following principles with their subsections as set out by Polit and Hungler (2001:130) were utilised as a guide throughout the research in order to protect the participants from any harm.

### **2.5.1 The Principle of Beneficence**

One of the most fundamental principles in research is that of beneficence which encompasses: *Above all, do no harm*. Beneficence consists of the following subsections:

- **Freedom from harm**

An ethical researcher must be prepared, at any time during the research, to terminate the research if there is reason to suspect that continuation would result

in undue stress to participants. Participants were reassured that they could withdraw from the study at any time if it became too emotionally distressing for them. It was thus important to develop a good rapport with the participants so that they would be encouraged to continue in the research study. All attempts were made to prevent any physical or emotional harm to the participants while sharing their experiences (Babbie & Mouton, 2001:522). The researcher was sensitive to the delicate issues experienced by the participants, who were promised counselling, should the need arise.

- **Freedom from exploitation**

Involvement in the research study did not place participants at a disadvantage or expose them to situations for which they had not been explicitly prepared (Polit & Hungler, 2001:130). Once the whole research process was explained to the patients they were no longer hesitant to share even their negative experiences with regard to the comprehensive ART management received from registered nurses with the researcher. Initially they may have feared that the researcher might reveal this information to her nursing colleagues and may also have feared being treated negatively by the registered nurses after their experiences had been revealed to the researcher. The researcher assured the participants that the information they gave would not be used against them in any way and would not be divulged to the registered nurses. The researcher applied the principle of freedom from harm to all the interviews conducted.

## **2.5.2 The Principle of Human dignity**

According to Polit and Hungler (2001:358), humans should be treated as autonomous agents, capable of controlling their own activities and destinies. The principle of human dignity consists of the following sections:

- **Right to self-determination**

The principle of self-determination was adhered to throughout the study. This

meant that the prospective participants had the right to decide voluntarily whether to participate in the study without the risk of incurring any penalties or prejudicial treatment. It also meant that the participants had the right to decide at any point to terminate their participation, to refuse to give information or to ask clarification about the purpose of the study or specific questions (Compare Polit & Hungler, 2001:133).

- **Right to full disclosure**

The researcher ensured the right to full disclosure by fully describing the nature of the study, likely risks and benefits and also allowing the participants' right to refuse participation (Polit & Hungler, 2001:133).

- **Informed consent**

Informed consent was obtained from every participant in this research study. Informed consent refers to the consent of participants to participate voluntarily in the research or decline participation, on the basis that they have adequate information regarding the research, are capable of comprehending the information and have the power of freedom of choice. The researcher documented the informed consent process by having participants sign a consent form. This form includes information about the study purpose, specific expectations regarding participation and voluntary nature of participation (Polit & Hungler, 2001:134).

In addition to consent that must be obtained from the patients, Brink (2006:46) states that the consent of research ethics committees within the health services is also necessary so that the researcher and the participants are protected. The researcher obtained written permission to conduct the study from the following departments to ensure that the relevant authorities were fully aware of the nature and purpose of the research:

- Human Ethics Committee of the Nelson Mandela Metropolitan University (see Annexure C).
- FRTI (Faculty Research, Technology and Innovation Committee) of the Nelson Mandela Metropolitan University (see Annexure D).
- Directorate of Health, Nelson Mandela Bay Municipality (see Annexure E).
- District Manager: District Office of Health (see Annexure F).

### **2.5.3 Principle of Justice**

This includes the following:

- **Right to fair treatment**

Participants have the right to fair and equitable treatment before, during and after their participation in the study. The fair treatment of participants in this study included the following aspects (Polit & Hungler, 2001:137):

- The fair and non-discriminatory selection of participants. In this research study participants were selected by purposive criterion-based sampling strategy.
- Non-prejudicial treatment was implemented to those participants who declined to participate. No participants withdrew from the study after agreeing to participate.
- All agreements made between the researcher and the participant as indicated in the participant consent form were honoured.
- Participants' access to appropriate professional assistance was assured if there was any physical or psychological damage.
- Debriefing was offered to share any information withheld before the study or to clarify issues that arose during the study.
- Sensitivity and respect for the beliefs, habits and lifestyles of people from different cultures was upheld. This is especially relevant in

South Africa with its 'rainbow' nation that comprises many cultural groups and the importance of respecting the participants' cultural beliefs and habits cannot be over-emphasised.

- Participants were treated courteously and tactfully at all times (Polit & Hungler, 2001:137).

- **Right to privacy**

According to Brink (2006:40), privacy is the freedom an individual has to determine the extent to which, and general circumstances under which, private information will be shared with, or withheld from, others. Individuals who agree to participate in research have a right to expect that the information collected from them will remain private. This can occur through:

- **Anonymity**

Anonymity refers to the act of keeping individuals nameless in relation to their participation in the research. No-one, including the researcher, should be able to link specific data to a specific person or institution (Brink, 2006:41). In order to ensure anonymity for participants who are HIV-positive, the researcher utilised the following mechanisms as outlined by Brink (2006:45) i.e. providing each participant with a number or code name, keeping the master list of participants and matching code numbers in separate locations, destroying the list of actual names and using code names when discussing data. Audiotapes will be kept in a safe place and will be destroyed after the research. Privacy will be ensured through confidentiality.

- **Confidentiality**

Confidentiality refers to the researcher's responsibility to protect all data gathered within the scope of the project from being divulged or made available to any other person. This means that the research

data should never be shared with outsiders. The participants were told before they gave consent to participate that the researcher intended to publish the results of the study. The participants were also informed that the researcher would do her best to ensure that personal characteristics will not be made known. A breach of confidentiality can occur when a researcher allows an unauthorised person to gain access to the raw data of a study or when the researcher accidentally or otherwise reveals the participants' identities in reporting her research (Brink, 2006:40).

## **2.6 CONCLUSION**

Chapter two described the research design, research method, trustworthiness and ethical considerations comprehensively. The research consists of two phases. During phase one individual depth interviews within a phenomenological approach were described as well as the data-collecting method. Data analysis followed, describing how themes were created and consensus sessions with an independent coder held afterwards. After data analysis, a literature control will be implemented to compare findings from data with existing data in literature. The first objective of the study is to explore and describe the experiences of PLWAs with regard to the comprehensive ART management received from registered nurses at selected public primary healthcare clinics in Nelson Mandela Bay. This objective will be reached through completion of phase one. Phase two consists of constructing guidelines for registered nurses that could facilitate them in rendering appropriate ART management.

The following chapter will discuss the identified themes and literature control.

## CHAPTER 3

### DISCUSSION OF DATA ANALYSIS AND LITERATURE CONTROL

*“AIDS is hard; hard on the patients who learn the grim news; hard on the healthcare workers who have only a limited armoury of therapies and no vaccine or cure in sight; hard on the scientists working at the edges of knowledge, always under the pressure of a major catastrophe affecting millions of people in virtually every land; hard on lawmakers struggling to bring the cumbersome, imperfect machinery of legal control to bear effectively on intimate personal behaviour, which must be modified quickly if the spread of the epidemic is to be slowed. Prejudice and hatred, fuelled by fear, are always close at hand”* (Graubard, 1993, in Madru, 2003:47).

#### 3.1 INTRODUCTION

In chapter two, a full description of the research design and method was given. In this chapter the results that emanated from the in-depth interviews conducted with the research participants will be discussed in conjunction with a literature control that allows for the verification and contextualising of research findings.

#### 3.2 OPERATIONALISING OF DATA ANALYSIS AND LITERATURE CONTROL

Ten in-depth interviews, each lasting 40-45 minutes, were conducted. The ten participants interviewed all met the inclusion criteria for this research, namely that all participants:

- were HIV-positive and receiving ART at a selected public primary healthcare clinic for at least three months
- were able to communicate well in English and able to express themselves clearly in order to avoid misinterpretation by the researcher

An independent coder was utilised to assist with the data analysis and the



identification of the main theme and its sub-themes and categories. After discussions with the independent coder, supervisor and co-supervisor, consensus was reached on the main theme, its sub-themes and categories.

A literature control was implemented in order to:

- outline what was already known concerning the subject,
- identify if emergent themes from the research had been previously documented,
- identify the context in which the research topic was being explored and
- indicate where the results of this research study fitted into the bigger picture of the general body of scientific knowledge.

### **3.3 IDENTIFIED THEMES**

The concept “theme” refers to a subject of a topic or element which occurs frequently within the text (Rogers, 2005:454). Phenomenological themes may be understood as the structures of experience and are the process of insightful invention, discovery and disclosure of meaning (Rogers, 2005:455). One central theme, two sub-themes and their categories emerged from data analysis of the information obtained from the interviews and field notes. The following table represents the identified central theme, sub-themes and their categories.

**Table 3.1: Identified central theme, sub-themes and categories relating to the experiences of PLWAs with regard to the comprehensive ART management received from registered nurses at selected public primary healthcare clinics in Nelson Mandela Bay.**

| CENTRAL THEME   | SUB-THEMES AND CATEGORIES   |
|---|---|
| <p><b>PLWAs expressed diverse experiences when attending ART clinics.</b></p> | <p><b>Sub-theme 1:</b></p> <p>PLWAs had negative experiences when attending ART clinics.</p> <p>PLWAs experienced:</p> <p>1a) a lack of resources,</p> <p>1b) the long waits at the clinic as frustrating,</p> <p>1c) a lack of professionalism amongst some registered nurses,</p> <p>1d) various forms of discrimination and stigma at the clinics and</p> <p>1e) Lay health counselors as untrustworthy.</p> |
|   | <p><b>Sub-theme 2:</b></p> <p>PLWAs had positive experiences when attending ART clinics.</p> <p>PLWAs experienced:</p> <p>2a) confidentiality being maintained by registered nurses,</p> <p>2b) the registered nurses and doctors as caring and supportive,</p> <p>2c) other PLWAs as supportive and</p> <p>2d) the counseling and education provided as good.</p>  |

### **3.4 DISCUSSION OF THEMES AND LITERATURE CONTROL**

Generally the researcher observed that all participants who participated in this research study appeared to have reached a stage of openness in discussing their HIV-AIDS status and their treatment regimens with the registered nurses, doctors and also with other fellow-patients at the clinics. Of the ten participants interviewed, six were female; eight were black Africans and two were coloureds; three lived in townships in Uitenhage and seven lived in Port Elizabeth. Only two participants were employed. During the interviews some of the PLWAs indicated that they viewed their participation in this research as being the voice for their fellow PLWAs who were too sick and who were not willing to speak openly about their HIV-status. This is evident from the following quotes:

***“In my position I don't mind [being open], but not all of us will be [open] right, there are always people who are sick and don't want to be seen sick, you know, and at least they can ask us who's not minding sitting here...”***

***“...to talk for them also...”***

It is evident from the above discussion that the participants had reached some level of acceptance with regard to their HIV-status.

#### **3.4.1 Central Theme: PLWAS Expressed Diverse Experiences When Attending ART Clinics**

The main theme that emerged from the data analysis was the diverse experiences expressed by the participants which included both positive and negative experiences that ranged from, for example, fears of being stigmatised, discriminated against and rejected, to absolute satisfaction with the services. This is evident from the following quotations:

***“I was worried that I'm going to lose my job because they want me at the clinic every time...”***

***“At first I was shaky and not very sure. I thought what kind of people are they and if I'm coming, how will they treat me and all that, but when I came here to the clinic and saw what kind of people they are, and what I tell them when they ask questions and I answer, then I see they are nice people, so I can come with my problem.”***

According to France (2001, in HDN, 2001:18), the healthcare sector was identified as a place where one is most likely to be stigmatised. The discrimination reported by HIV-positive persons is similar to that experienced by cancer patients. The way an individual experienced life before being diagnosed with HIV changes and the individual tries to conform to a new lifestyle and new rules which are life-long and challenging. Learning that one is HIV-positive sets a new life course that will involve decisions ranging from disclosing sero-status to partners, family, friends and healthcare professionals, to entering and participating in care (Chesney & Smith, 1999:1165). The stigma associated with HIV-infection has been shown to lead to loss of family ties, friendship, employment and housing; dismissal from school; and denial of health and life insurance as well as healthcare. Stigma increases the stress levels of PLWAs, which can negatively affect the course of the disease (Chesney & Smith, 1999:1169).

Many of the participants indicated that they felt fearful initially about attending an ART clinic because of rumours that they had heard about how the registered nurses treated the patients, but experienced that this fear was usually not borne out in reality:

***“I was scared to come because people just say ‘Oh, sister so-and-so will chase you away’ - but I did come to that sister...with this problem...they did give me treatment here, that is why I like to come to this clinic.”***

***“The people they were telling me that the nurses treat the patients badly, but I discovered that I was in good hands actually.”***

Overall the participants indicated that they did not experience any problems with the staff at the ART clinics and that they felt pleased with the service that they received. However, it may be that patients have low expectations of healthcare in our clinics and therefore it would not be difficult for registered nurses to meet those expectations. Nonetheless, participants indicated that PWLAs sometimes came from afar to attend a specific clinic because the services there were experienced as being better than the clinic closer to them. The following quotes illustrate this:

***“... for the fact that they come from so far, they came here, that means they [the nurses] are treating us good...”***

***“I guarantee this place, not this place, the people that are working in this place you see, I guarantee them, I’ve got no problems, nothing, I come inside and I’m going back home with a nice clean heart...”***

There were some participants who indicated that the staff did have their faults:

***“...but they [the nurses] do have their mistakes...”***

***“Sometimes some of the sisters they can be so harsh towards the patients...not knowing the way to talk to the patients. I cannot say all of them. Some are ok. Some, it depends on their moods, you know, not all of them are polite.”***

The researcher found the findings of this research to be incongruent with an article in the Eastern Province Herald (Sonjica, 2006:5) that painted a very negative picture about patients’ visits to the clinics as “nightmares” because some registered nurses

were insensitive and unprofessional. The article in the local media stated that one of the PLWAs who was interviewed for the article indicated that the treatment received from clinics was “painful” (Sonjica, 2006:5).

Although PLWAs in this research also indicated that they had experienced some incidences of stigma from the registered nurses, these seemed not to be as negative as those portrayed in the media, but were present nonetheless. It may be possible that PLWAs told the newspaper reporters what they wanted to hear, and that in this research the PLWAs told the researcher a more realistic version of their experiences. On the other hand the participants may still have had some fears that the researcher would tell the registered nurses what they had said about them and thus would face victimisation. Some participants shared experiences of stigmatisation from fellow patients at the clinics, as expressed in the following quote:

***“...the people around they are walking and looking at you, ooh she's sick, she's staying on that side, they are HIV and AIDS peoples there, you know...”***

One of the negative experiences of participants interviewed in this research was that they feared the registered nurses' reactions to them coming for their supply of pills after their due date. It has been documented that once PLWAs enter the healthcare system, they may receive inadequate care because of being stigmatised by healthcare providers. For example, it has been shown that stigma can interfere with adherence to ART (Chesney & Smith, 1999:1169).

***“It's my first time I'm late for my tablets, so I'm worried the nurse say: why you come only now? It's my first time, but I'm still scared, ja...”***

Patients affected by their fear of the nursing staff have to try and overcome their experiences of pain, anxiety and doubt as to how they would be handled by the registered nurse, because their lives depend upon fetching and taking the treatment.

Other participants also described their fears of the registered nurses' reactions. The following PLWA indicated that she had never defaulted on her treatment; but now for the first time she was two days late and was very anxious about how the registered nurse would react to her:

***“The nurse she's going to shout at me, I'm just thinking to myself, but then I think I can make it, it's my first time to come late, I can't wait for the other month, I have to come now. I'm becoming very comfortable when I come in here because every time I come in here I haven't got a problem from my nurses who are attending, they are right, every time I come; but now today I'm scared because Monday I didn't come, that is my ONLY problem I've got in my life with this clinic, that's for today.”***

The researcher asked to speak to the above participant again, after her visit to the registered nurse to find out how the nurse had reacted to her coming two days late. On her return the patient was visibly relieved and smiling because the nurse was accepting and friendly. The nurse had been reassuring and had advised that she send her support person next time to fetch the pills in case she was not able to come herself.

Perhaps registered nurses are not aware of the impact of their reactions on their patients. This would need to be addressed in order to improve the relationship between registered nurse and patient since fear reactions are not conducive to therapeutic relationships. “Fear”, is defined in Chamber's Dictionary (Kirkpatrick, 1983:460) as “a painful emotion excited by danger; apprehension of danger or pain; anxiety or to be in doubt.” Fear is a normal reaction and can make people feel angry, depressed or aggressive which is something, that registered nurses need to be aware of in the way they handle their patients so that they do not drive them away. Fear of formal medical facilities may result in people turning to traditional healers as a psychologically more satisfying alternative and culturally it is perceived as more

acceptable for chronic sickness to be caused by imprecise external forces such as witchcraft rather than AIDS (Muyinda et al, 1997:145).

Attitudes held by healthcare workers toward persons with HIV and the way in which these attitudes are perceived will influence access and use of healthcare facilities (Knox & Dow, 1989; McDonnell, 1993, in Chesney & Smith, 1999:1167). Findings with HIV-positive people in focus-group discussions held in Grahamstown (Moon, 2005:3) noted problems which might slow down the testing for HIV and use of ARV's (antiretrovirals), including the unprofessional conduct of nurses (expressed as a lack of tact in dealing with patients); a lack of confidentiality in handling patient records (nurses are the worst violators of confidentiality followed by support groups); and discrimination by the clinics in the provision of ARVs (medical staff insist that patients must come from within the clinic's area of jurisdiction to get the services).

In many cases in the healthcare sector, stigma may not be the result of denial or of devaluing people with HIV-AIDS at all, but rather the result of valid or misguided fears of infection. This applies to both lay and professional people (Stein, 2003:11). In one survey in America conducted by Wallack (1989, in Chesney & Smith, 1999:1168) 87% of physicians and nurses reported experiencing more anxiety when treating AIDS patients than with treating other patient groups. Some physicians and nurses viewed HIV patients as responsible for their illness and deserving less sympathy than other patients, such as those with leukemia (Kelly, St. Laurence, Smith, Hood, & Cook, 1987, in Chesney & Smith, 1999:1168).

However, there is some international evidence to suggest that the HIV-AIDS stigma has diminished substantially over time (France, 2001; Moon, Mitchel & Sukati, 2002, in Stein, 2003:2). Thus far, however, South African research regarding HIV-AIDS stigma has been extremely limited and comparisons of stigma levels over time have been based largely on anecdotal evidence. Two quantitative HIV-AIDS surveys conducted in South Africa, which have included measures of stigma, have identified what appear to be relatively low levels of HIV-AIDS stigma in the general population.



The Nelson Mandela/HSRC Study of HIV-AIDS suggests that the majority of South Africans adopt attitudes of acceptance towards people living with AIDS (Shisana & Simbayi, 2002, in Stein, 2003:2).

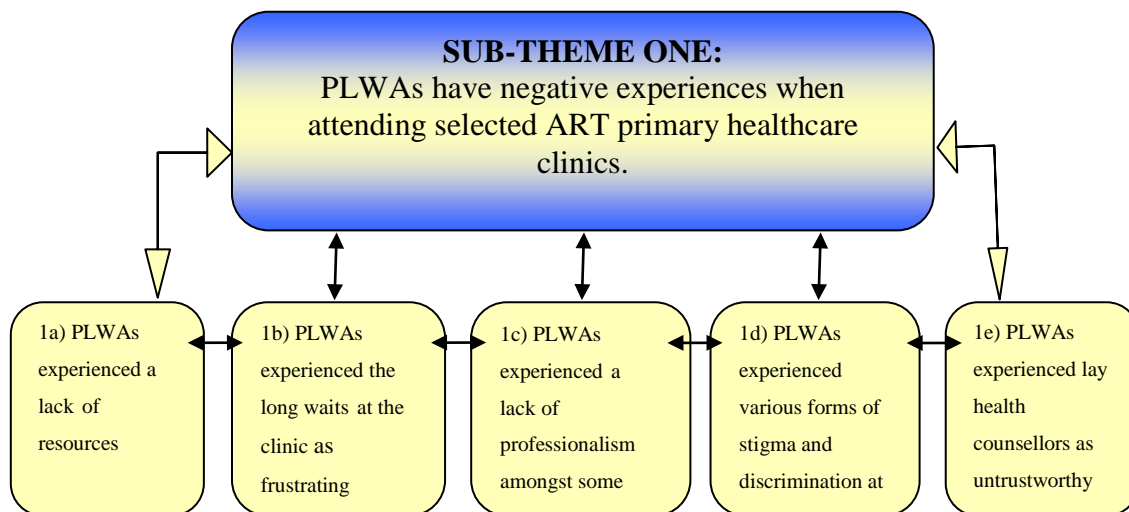
Perhaps this is reflected in the fact that all participants interviewed in this research were eager to relate especially the positive experiences they had at the clinics. The level of quality care and support provided by registered nurses needs to be acknowledged and encouraged, while negative experiences expressed as by participants in this research need to be addressed in order to ensure the best quality of care possible.

According to the Constitution of South Africa, the Batho Pele policy and Patients' Rights Charter (DOH, 2000:12) all patients have a right to complain about the healthcare service they receive. The patients' rights, responsibilities and procedure for complaints encourage patients' involvement in assessing the quality of healthcare they receive. Patient satisfaction is a measurement of quality healthcare (Bediako, Nel & Hiemstra, 2006:12).

#### **3.4.2 Sub-theme One: PLWAs had negative experiences when attending ART clinics**

The participants indicated that they had various negative experiences when they attended the ART clinics. These negative experiences related mainly to a lack of resources, the long waits at the clinic, lack of professionalism amongst some registered nurses, institutional discrimination and lay health counsellors being untrustworthy. Participants also mentioned that there was a lack of educational literature such as pamphlets available in the clinics.

A graphic representation of Sub-theme One and its categories is presented below.



**Figure 3.1 Diagrammatic representation of Sub-theme One on the negative experiences of PLWAs with regard to the comprehensive ART management received from registered nurses at selected public primary healthcare clinics in Nelson Mandela Bay.**

**1a) PLWAs experienced a lack of resources**

Resources such as manpower, facilities, supplies and funding can be sought from both within and beyond of the community; and the clinics and health services in general may be considered as resources for the community members, specifically health resources (Hitchcock, Schubert & Thomas, 2003:339). If the clinics are understaffed and/or under-resourced then the community members are likely to notice this and comment. Lack of resources in this instance would mean that healthcare in this particular sector is not able to meet the needs of those requiring assistance due to the lack of essential supplies, manpower and other aspects of service (Mellish, 1985:69).

The participants indicated that the resources which were lacking in the ART clinics

included human resources, physical resources and educational resources. This is evident from the following quotes and discussions:

***“Everything is good, there’s only one problem, the government must hire more staff because there’s only one lady here...not enough nurses, the delivery is slow.”***

The overall shortage of healthcare personnel is a chronic national and international healthcare problem affecting both the public and the private health sectors. A report from the World Health Organisation has warned that four million healthcare workers are needed to combat the “chronic shortage” around the world (Capazoria, 2006:10).

Former Eastern Cape Health MEC Goqwana's spokesperson, Kupelo, (2003:3) said hospitals and clinics in the province were accumulatively short-staffed by 1,989 professional registered nurses, excluding assistant nurses and managing personnel. He added that there were 7,742 nursing posts in the Eastern Cape, of which 5,753 were filled. Statistics South Africa (2006:10) reports a population per total qualified nurse ratio of 346:1 in the Eastern Cape Province. The national population per total qualified-nurse ratio ranges between 175:1 in Gauteng Province and 368:1 in Mpumalanga Province. A report by Capazoria (2006:1-2) on staff shortage in the Port Elizabeth Hospital Complex has stated that there are 743 vacant nursing posts and 72 vacancies for medical staff such as doctors.

The shortage of nursing staff can have far-reaching implications as indicated by research that is increasingly demonstrating that the level of staffing has an impact on patient outcomes such as mortality. The North Carolina Nurses' Association states that “Safe staffing reflects the maintenance of quality patient care, nurses' work lives and organisational outcomes. Safe staffing practice incorporates the complexity of nursing activities and intensities; varying levels of nurse preparation, competency and experience; contextual and technological environment of the facility; and available support and protection” (Geyer, 2006:3).

The participants in this research indicated that they experienced the lack of staff at the clinics resulting in slow delivery and lengthy waits. The participants expressed the opinion that the appointment of more registered nurses in the ART clinics would assist in expediting access to treatment and would reduce waiting time for patients:

***“If they can add a staff because sometimes there is one sister who helps us [at ART clinics], sometimes there are 2 sisters. If they can put 3 sisters here that can help us, it [the waiting] can be improved in that way.”***

***“There are only 4 nurses, maybe if there can be maybe, if there are 6 they can change things, you know, there’s too little nurses.”***

***“I think the government can bring some other nurses so we mustn’t sit the whole day here like that.”***

The participants also indicated that they experienced a need for more doctors at the ART clinics because the current arrangements did not meet their needs. They indicated that they were unable to consult with a doctor when they needed one because the doctors were only at the clinics on certain days. They also indicated that there should be more than one doctor at a time at a clinic:

***“And when we want to see a doctor, you come here and you want to see a doctor but you can’t get a doctor, they tell you that the doctor is not here today she will be in on Thursday, but you’re sick on Monday and they tell you that the doctor will be here on Thursday, so you have to wait because you don’t have money to go to the surgery, you want to go here because it’s free, to get a doctor here, but now we don’t get a doctor every day, you get a doctor once a week here.”***

***“They can organise more doctors here, there is only one doctor, if you are very sick you must wait, you must wait until the doctor come – at least there should be 2 or 3 doctors. The doctors are short.”***

One participant on the other hand indicated that he experienced no problems seeing the doctor and that the registered nurse had facilitated the visit:

***“If I ask the sister may I see the doctor, please, they say okay, then she does her thing, take my blood and weight and all that and then send me to the doctor, so there is nothing I can complain about.”***

From the experiences related by some of the participants it can be deduced that they are frustrated by not being able to see the doctor and by being referred back and forth between the registered nurse and the doctor, as is apparent from the following quotes:

***“The nurse said no, you must come tomorrow and then you must speak to that doctor first, so I did come yesterday, and the doctor said no, I must come today, that is why I am waiting here.”***

***“They [the nurses] know what they are doing, they know, but they must work hand in hand with the doctor, even if the doctor is not here the nurses should be able to help you, like I said before, I was once here they told me I must wait for the doctor [for a letter that he is sick and not working], and the doctor said “No, nurses have the right to do that.” So they must start working hand in hand.”***

It appears as if the registered nurses may be avoiding additional work such as writing letters, and may be referring patients due to an overwhelming workload. In South Africa healthcare professionals are already overburdened and tend to resist additional functions (Reeman & Pillay, 1997, in Freeman 2004:143). The shortage of staff

results in heavy workloads and long working hours for the staff and is a serious source of stress for the staff (Grobler, Warnich, Carrel, Elbert & Hatfield, 2002:440).

In research conducted by the Human Sciences Research Council (HSRC, 2003:72) on the impact of HIV-AIDS on healthcare workers in the health sector, it was found that half of the nurses in the study reported workload increases of at least 75% over the past year, which they attributed mainly to staff shortages, patient increases and more patients with HIV and related diseases. Changes to health structures to make provision for a system of comprehensive healthcare also resulted in extra work for many healthcare workers.

From the aforementioned direct quotes extracted from the raw data, it is clear that the participants experienced a shortage of staff at the clinics and that this affects the service delivery that they receive. Besides the lack of sufficient staff at the clinics, participants also expressed a shortage of available health literature resources in the clinics. The following quote illustrates this:

***“The pamphlets here are very rare. They must recognise, it is not all of us that have education about HIV, and if they think you are illiterate you can give the pamphlet to somebody to read to you, but uhh, pamphlets here are scarce. It is not everything that I know about HIV, there is something that maybe I don't know so by reading the pamphlet then I get more exposed to the dangers of HIV, so they must organise as much pamphlets as they can get.”***

***“On our side there are no pamphlets here.”***

The latter findings are incongruent with the core norms and standards for healthcare clinics, which states that there should be supplies of appropriate health learning materials in local languages. It states that culturally and linguistically appropriate patients' educational pamphlets should be available on different health issues for free

distribution. It requires that appropriate educational posters are posted on the wall for information and education of patients; and that educational videos are shown in those clinics with audio-visual equipment while patients are waiting for services (DOH, 2000:1-89). According to Doyle (2006:12), there should be a mission statement and 'brief' policy on health promotion that would make it easier to 'enforce' rules, so that every clinic could have an educational presentation to patients every day; that someone should take responsibility for the posters and pamphlets in every clinic; and that there should be regular workforce motivation meetings to increase morale and encourage one-on-one patient education.

In the public sector pamphlets and posters are received from the South African government's National Department of Health, HIV-AIDS Directorate, through an agency that has been awarded a tender for this purpose, for example, Khomanani. On enquiry it was found that the latest tender had not yet been awarded, resulting in a nation-wide shortage of literature since the end of 2006 and during most of 2007. According to Doyle (2006:12), supplies of educational materials on HIV, sexually transmitted infections (STIs) and tuberculosis (TB) were available from the AIDS Training, Information and Counselling Centre (ATICC) and were still found at all three clinics, though sometimes buried or hidden in the clinics. The most often requested languages for pamphlets in this area are Xhosa, followed by English and then Afrikaans.

The PLWAs interviewed by the researcher indicated that there was a lack of pamphlets and suggested that clinics should make these available because they could learn something from reading them. Literature should be available with information about ART treatment and adherence or about how to access grants, and should be offered to patients who are afraid they will not remember everything the registered nurse told them. Therefore it is important for registered nurses to ensure that adequate supplies of health education literature are available for patients in the clinic because some participants indicated that they could not remember everything that the registered nurses told them when they were sick:

***“I was worried, I must remember what I'm going to do, I must remember, and before I eat the treatment I forgot what you said before, so I was not remembering everything when I was sick, mmmm.”***

It may be possible that patients with advanced HIV disease may be forgetful due to the crossing of the virus into the brain. The HIV crosses the blood-brain barrier and enters the central nervous system (CNS). Many HIV-infected individuals may begin to show early signs of CNS involvement, including mild cognitive impairment, forgetfulness, decreased concentration and short-term memory loss. The counsellor may have difficulty discerning if these symptoms are caused by anxiety and depression or by advancing illness. In some individuals cognitive impairment and AIDS dementia are the first indications of deterioration (Kain, 1989:72). Healthcare professionals should be on the lookout for signs of CNS involvement.

Thus registered nurses should recognise the fragility of the emotional and psychological state of patients when giving health information and be prepared to repeat themselves when necessary. Pamphlets and other literature should be available for patients to take home with them to reinforce what they have been told at the clinic.

A lack of physical resources was also experienced as a problem by the patients. Some clinics are in need of repair and upgrading and are currently unable to handle the number of clients currently utilising these services. A few participants complained that the clinics were not consumer-friendly and that there was no shelter for them outside while they waited for the clinics to open, and it was worse for them when it was cold and raining. Combined with a compromised immune system PLWAs have the added stress of trying to stay warm in cold conditions, which puts them at further risk of ill health. They feel that something should get done about it:



***“...that is another problem, we don’t have shelters, we are supposed to have shelters, once it is raining or it is windy, we can go there.”***

***“Maybe they could organise something and then we must go and wait there, something like a hall, and then we must go and sit there until they open.”***

***“This place is too small.”***

It is evident from the aforementioned discussion that there appears to be inadequate physical resources available at the ARV clinics which could further challenge the health of PLWAs.

***1b) PLWAs experienced the long waits at the clinic as frustrating.***

The participants experienced the long waits at the clinic as frustrating and this evoked feelings of anger and helplessness. They related how they got up very early, some as early as 5 o'clock, to get to the clinic for their treatment at 07:30 because they had experienced how long the day could be and they therefore tried to miss the long queues by getting to the clinic first:

***“We came here as early as 5 o'clock, sometimes it is cold outside, it is raining, we must wait outside the gate, and they open and we just come in, maybe it is 7:30.”***

***“Whenever we come I know you can be bored by the queue; it is too long – sometimes they will start to work very late while you come early, early – you will be sitting there, waking up very early in the morning, sometimes they start late only 9:00 while you were queuing 5:00, people will be standing outside, we are sick.”***

The participants expressed the need to be helped promptly, especially those who were ill, and that they should not be made to wait so long:

***“You wait in long queues, you must sit in a queue here, they can’t take me. Sometimes me I’m sick, this lady come and say to me you must wait, first this old lady must come then you. I feel they must take the sick person first.”***

***“And the way they are handling other people who are very sick, like they can ask us, the one who came here first, to make the time for the people who are sick and then we can follow...but they don't do that, they do as we come here, they don't take the sick one first.”***

The researcher observed that the participants were frustrated at waiting so long and this evoked feelings of helplessness and despondency among participants. They accused the registered nurses of coming to work late, and then taking their time before they got started. The participants expressed unhappiness about this because they got tired and felt that they were not getting the prompt service that they expected to get:

***“...if you come here late it’s going to be a big problem, but if THEY [the registered nurses] came here late it’s not going to be a problem. We have to wait for them, we get here very early because we have all things to do. I have a baby of 10 months, so when I come here I expect them to come on time so that I can go home on time, but you don’t get that.”***

***“The services here are too slow, we are not getting good service because we come here at the early time, but we go home very late...you don’t get service at the time you expected.”***

***“Once we are inside we must wait until all the nurses come and we are served. We wait too long, even today I was here as early as 5:30...and the people are more, there is a lot of people here, but the treatment is good, the problem, they must do something about us.”***

***“I wish when you come here you mustn’t sit here a long time, yes, we get tired when we sit here.”***

In a study conducted on service-related barriers to VCT in South Africa, van Dyk and van Dyk (2003:4-9) state that the large patient turnover and low counsellor-to-patient ratio are causes for concern. For example, the average number of patients consulted for VCT at a rural district hospital in the Eastern Cape, is 6 per hour, averaging 10.4 minutes per client. Proper HIV-AIDS counselling is simply not possible under such circumstances. This lack of personnel and heavy client load causes long waiting periods for clients, who may not have the time to line up for hours to receive HIV counselling and testing.

In a study of factors influencing the utilisation of Prevention of mother-to-child transmission (PMTCT) services in the Eastern Cape by Peltzer, Skinner, Mfecane, Shisana, Nqeketo and Mosala (2005:38), it was found that all clients interviewed felt that the clinics were under-staffed leading to excessive waiting times, which were made worse by the cold, boring waiting rooms.

Besides the heavy client load, it seems the long queues and the noise outside the consulting rooms may affect the care that registered nurses provide, and they have to come out and ask the patients to stop arguing and to be quiet so that they can concentrate. Added to the noise and stress levels at certain clinics that the researcher visited, there were renovations underway with intermittent drilling and hammering. The researcher experienced the cramped conditions and noise levels in the waiting areas and could relate to the experiences of the patients, as well as with the registered nurses regarding the stressful conditions under which they had to render care. One participant related the following in this regard:

***“Look now they [patients] are always fighting about the queue, each and every day you find that the patients are shouting at each other sometimes about the queue. The nurses say they can’t concentrate.”***

The researcher observed that the patients were fed up and angry about the long waits at the ART clinics. The participants indicated that the registered nurses did not care about them waiting so long and that they were being 'slow' even if there were not many patients. The participants expressed their dissatisfaction about the registered nurses all going to tea or taking lunch breaks at the same time:

***“The thing that I don’t like, because sometimes the nurses, we come there around 6 or 7 o’clock and they come about half past 7 or that time, and then they are helping, but they are helping slow because sometimes they are going on tea and then they come back and then helping and helping and then they go to lunch. At the other side by observations, there are no people, the people are being helped, but we are still sitting here till 3 o’clock sometimes.”***

***“We are coming to the clinic at 7:00 and they come in at about 7:30, and at about 9:00 or 10:00 they all go on tea at one time, so we are going to sit for that 30 minutes doing nothing – at least if they can make alternate turns if the other 2 is going to tea, the other 2 must stay with the patients, when that 2 comes back, then the other 2 can go. That will be the best. The same applies at lunch time that 1 hour, they all go on lunches for 1 hour, we are sitting here getting drowsy on the chairs because we are doing nothing, but if they make alternate turns the others go and when the others come back then the others can go, that will be much better.”***

***“That’s the thing they don’t care about, because they are slow.”***

During the interviews conducted, participants expressed feelings of anger towards the registered nurses for being slow because the pills they were drinking made them hungry and then they had to go home to eat and then come back for their turn:

***“The nurses are slow because sometimes there are not many patients, just few patients, but they take a lot of time to help us. I don’t know why they are slow because they are slow. Sometimes there are 10 maximum people and they take a lot of time to help those people. Sometimes I go home without being helped and then come back in the afternoon.”***

***“It makes me not alright...angry because the pills that we are drinking make us to eat a lot, they make us hungry and then now we must go home and go and eat and then come back.”***

***“Sometimes I go home without being helped and then come back in the afternoon.”***

Some of the participants indicated that they considered leaving the ART clinic without receiving their treatment but realised that it would not be good for them to be without treatment:

***“...you come in the morning, you leaving late because it’s a big story, it’s a long story. I was starting to feel fed up and then to leave this, but then I say it’s my fault if I can leave, it’s me whose gonna suffer.”***

Clark (2004:20) advises HIV-positive women attending clinics to “Be prepared to wait. Even in the most efficient clinics, people may have long waits. Bring something to keep yourself occupied. Snacks are a good idea.”

Registered nurses need to explain to the patients that adequate counselling with

regard to adherence to ARTs cannot be rushed hence the reason for the long waits. There was only one participant who indicated that he did not wait long to be attended to by the registered nurse:

***“No, I don’t wait long here. When I come here I come fetch my tablets, my treatment, maybe I’m not going to see the doctor, I must just see the nurse, she must sign for me and then I must go to the dispensary to go fetch my tablets, so within an hour, cause I just wait, I can’t just force, I must wait in the queue and then when I’m finished there and others are finished and it’s my turn and then I go to the nurse.”***

It is clear from the aforementioned discussion that the participants in this research were frustrated about the long waits at the ART clinics.

**1c) *PLWAs experienced a lack of professionalism amongst some registered nurses.***

Nursing is a true profession, distinguished by its philosophy of care, its full-time commitment to well-being, its particular blend of knowledge and skills and its valuable service to the community (Curtin & Flaherty, 1982:92, in Botes, 1999:64). Ethics and ethical behaviour are vital to nursing since ethics are the foundation of committed service to humankind. When nurses practise in an ethical manner they should adhere to ethical principles like autonomy, beneficence, justice, veracity, fidelity, confidentiality and privacy (Botes, 1999:64). Through research done in South Africa by Botes (1999:66) on nursing ethics in a developing country, it was concluded from case studies that the ethical conduct of nurses did not meet the standards set by ethical principles; and in fact the case studies were reminiscent of “thriller movies”. Nursing Education in South Africa is amongst the best in the world and the ethical and legal framework of the practice of nursing is clearly defined but is not virtue-based. Virtues indicate the inherent characteristics of a person and imply that the

ethical values have been internalised to such an extent that they form part of the person's character. The person thus acts morally without the necessity of rules (Botes, 1999:67).

Mellish, Brink and Paton (2004:9) state that nursing is a helping profession because nurses care about and for human beings. The goal of nursing is to help persons to maintain their health so that they can function at an optimum level in their social roles. The domain of nursing includes promotion of health, maintenance and restoration of health, care of the sick and injured and care of the dying.

The participants in this research have expressed both positive and negative experiences at the hands of registered nurses at the ART clinics. Working with PLWAs on a daily basis may be a contributing factor to registered nurses not being constant in their approach to professional care of PLWAs. Professional healthcare workers believed that the quality of their work was negatively affected by their daily workload. Nurses interviewed at public clinics commented that, although the emphasis should be on holistic care, they could barely find time to attend to the physical health of patients and believed they were not offering an adequate standard of care; and that they also had to deal with grumpy patients (HSRC, 2003:73).

In a study on the image of the nursing profession in KwaZulu-Natal (Kunene, Nzimande & Ntuli, 2001:35-41) 24% of participants perceived nurses' attitudes as negative and besides poor communication and an unacceptable manner of approach, emphasised that patients were taken as "things" and not "people"; and that patients were treated with a lack of empathy and respect for human dignity. Smith (1992, in Kunene et al, 2001:35-41) state that when patients were asked to describe a good, ideal nurse, attitudes and feelings were more likely talked about rather than technical competence. Development and the image of the nursing profession depend on the attitude projected by each member of the profession.

The attitudes of nurses towards HIV-positive patients are described as predominantly

negative in several international studies (Allender, Senf, Bauman & Duffy; 1991; Baylor & McDaniel, 1996; Bliwise, Grade, Irish & Ficarotto, 1991, in Deetlefs, Greeff & Koen, 2003:24). In South Africa Metz and Malan (1988, in Deetlefs et al, 2003:24) found that negative attitudes of nurses towards HIV-positive patients occurred because of ignorance, the high mortality associated with the disease and the stigmatisation of persons with AIDS. Their negative attitudes cause reactions of fear, despondency, denial, blaming and unnecessary avoidance of HIV-positive patients (van Dyk, 1992, in Deetlefs et al, 2003:24). This may influence the quality of care rendered to HIV-positive patients negatively, while positive attitudes may improve the quality of care (Baylor et al, 1996, in Deetlefs et al, 2003:24).

The participants expressed fear of the registered nurses' unprofessional reactions when they reported to them that they had missed or were late for their tablets. One participant indicated that he would not report medication defaulting to a registered nurse again. These experiences are evident in the following quotes:

***“...an approach, if they can have an approach, some of them, not all of them, some they do have approach. Some even come here moody, that is why I say some have problems, they take their problems and come with them here, you understand. Some, their approach is not right, but some in order to find their approach and talk in a rough way so that the patient can listen it is better that way to be harsh – because some of the patients when you are not too harsh to them they relax, that is why they get sick so they must have sometimes that pressure.”***

***“They mustn’t shout at us, let’s say now I’m late for my tablets, if I come here and then she shouts at me and then you’d be scared to come and then I lose my tablets the whole month so I’m gonna be sick, so I’m scared that she’s gonna shout at me.”***



***“They just count your pills and maybe find that you didn't eat your pills like the way you supposed to eat them, okay, they shout at you. And then I come in: they say ‘No, no, no, no, wait, wait, wait. We are busy, this patient is not eating her pills, maybe you don't eat even your pills’.”***

***“I felt a bit scared because, hey, the nurse change her face now, hey, ok, I don't look in her eyes, I look on the floor, ok, Sister, I won't do it again, sorry sorry ...”***

***“I feel so little bit angry with the nurse today, and I, I, I shouldn't tell her this and that.”***

When asked if he would be afraid to tell the registered nurse about something next time, he said ***“Yes, yes, yes, yes, yes, yes! And I must stick it away!”***

One of the participants indicated that the registered nurse should be a bit harsh, so that patients will listen to her:

***“The one nurse, she is a bit snaaks [strange]. I know I'm wrong, so I don't blame the nurse, I'm wrong, she must do it because I give her a hard time...I must get a little bit scared.”***

Other examples of a lack of professionalism as expressed by participants include judgemental attitudes of registered nurses, categorising people and accusing patients of wanting disability grants:

***“They don't check us, they just tell us you don't eat your treatment. Not some of us, I know there are some of us who don't eat our treatment but not all of us... They say you're not going to take your pills because you like the disability grant and you want your CD***

***count to be low so you stop taking your pills. They accuse us of that so I asked them: 'why you don't you check that we are taking our pills'.***

***"I always hear the ARVs [patients] complaining. I never heard the ones who are positive who are not on ARVs complaining. I never heard, maybe they do shout at them, I don't know, but most of the people who are on this drug do get a disability grant, so that is a problem of the patients."***

Moon (2005:7) recorded findings regarding the disability grant during focus-group discussions with nurses in Grahamstown. Regarding the effects of HIV on the community, they stated that communities had been rendered dependent on government grants due to their prevailing HIV-AIDS status and that this had engendered rivalry between nurses and the community due to the requirements for these grants. In most cases those who turn out to be negative accuse nurses of denying them chances of getting government grants. In addition, some families are willing to care for the orphans in order to get government funding (Moon, 2005:7).

In research done on the image of the nursing profession as perceived by three communities in KwaZulu-Natal (Kunene et al, 2001:35-41) 26% of participants stated that they would be happy to see more commitment demonstrated, especially by the younger generation who were seen to be less committed than the 'older nurses'. For example, these participants highlighted that the 'younger nurses' had a tendency to discuss matters pertaining to their personal and social life instead of concentrating on the patient/clients' needs. Other reasons given for lack of commitment were rooted in inadequate facilities, equipment and personnel; and that the ideals of nursing were lost and nurses had developed a "carefree" attitude and were more job-oriented than patient/client oriented. The latter reasons for lack of commitment do not lay the blame on nurses *per se*. The authorities are responsible for the provision of health facilities and resources. Since lack of commitment was partly related to a lack of

these, it poses a challenge to the authorities (Kunene et al, 2001:35-41).

Participants experienced that some registered nurses came on duty late, and then socialised before they started working. This is viewed as a lack of commitment by the participants:

***“...they like to talk before they work you know, its good to work while you talk because the more you talk the more work will be done, but they came here and they talk and talk and talk, when it suits them they start. They talk to each other about their issues, their things at home, their things they did on the weekends and then they are getting late like that.”***

When the same participant approached the registered nurse who had come late, to indicate her limited time, she was rebuked and impatiently told to wait. These experiences can tarnish the image of nursing:

***“The one who is helping us with ARV treatment she come in quarter past 8 today so I asked her I've been here since 7 o'clock because I want to go home early, she said: no no no no, you wait, I'll be with you, wait. And then I wait, she comes out quarter to 9 to help us. She was joking inside with the other nurses. Yes, they can work and talk, they can do that at the same time, but they are just talking.”***

One participant noted that the clinic turned patients away after a certain hour. A lack of human resources and heavy workloads may be the reasons for the observation made by the participant who stated that after 09:00 the clinics did not take any more patients, unless it was an emergency:

***“At 09:00 they say they not taking any more patients, unless you are so sick that it's an emergency.”***

No other participants from any of the other clinics mentioned this, but anecdotal evidence suggests that this does occur at some facilities. The practice of turning patients away from a public healthcare facility within working hours is unacceptable. It amounts to denying the public access to healthcare and therefore requires further investigation.

**1d) PLWAs experienced various forms of discrimination and stigma at the clinics**

From the experiences related by nearly all the participants in this research, it is apparent that PLWAs experienced various forms of discrimination and stigma such as withholding treatment because of having a positive HIV-status or sometimes forcing them to use a contraceptive method. Some PLWAs indicated that they felt like “dirt” because of the manner in which they were being treated by some registered nurses. The aforementioned is illustrated in the following quotes:

***“Uhh, the nurses are quite good, but there is one time that I felt bad, I had some pimples on my buttocks and when I reported it to the sister she told me you are HIV-positive, as if it is right to grow these pimples. I am not going to do anything because you are not going to get better, you must grow pimples because you are HIV-positive. Oh, I was down...because it was my first time to get that sort of treatment. ...She didn't write anything to put on, like ointment or something to put on these pimples. She said you can't put on nothing, you can use calamine - she didn't even prescribe this calamine she was talking about. Then I went down the passage and I met another sister and I told her, she just shook her head and she wrote for me. That was my worst experience, as if when you are HIV you must get these funny things, you are not going to be treated for them, you must learn to get them and not be treated, you see, it wasn't right...”***

***“They put me on a birth control injection, I don’t have a boyfriend – I never worry about anything, my children are grown up already. I can just focus on my health now and they told me, you must take it, they forced me. I know myself when I know I am sexually active, and I am a grown up, I am 41 years old now, so I don’t need to be told how to look after myself. I don’t think it is right for them to force us to take a injection...She said you must, even above what I was telling – I don’t worry about boyfriends but she said no you must take – you must take – what if you fall pregnant now. And she did give it to me...On my return date I told her I am not going to take it again.”***

***“I felt down, as if I am a piece of dirt.”***

Research suggests that long-term survivors with HIV disease are actively involved in their care and work with their healthcare professionals in making treatment decisions (Remien, Rabkin, Williams, & Katoff, 1992, in Chesney & Smith, 1999:1169). In the KwaZulu-Natal study (Kunene et al, 2001:35-41) 44% of respondents did not participate in decision-making; yet all the respondents were adults who should have been allowed to exercise freedom of choice on those matters wherein they were capable of making their own decisions. Adults tend to avoid, resist or resent situations where they feel treated like children and being 'talked down to'. This may lead to a lack of adherence and attendance at clinics; and can account for attrition rates.

Another participant indicated that she felt like a “germ” because of the negative attitudes displayed by the registered nurses and the manner in which the registered nurse spoke to her colleague about her (the patient) in her presence:

***“On this side of the ART clinic, they are not stigmatising, but when I came here for the first time, that side where they took blood, the other nurse said to this nurse who is taking the blood, you must be aware***

***because last time we took blood from a patient and the blood like sprayed, so we must be aware for her blood because she is HI-positive...I felt sad...because there was nothing I could have done at that moment...The way that I felt is like someone with a germ or something, they can't touch me because they are afraid of the blood that can spray or they are afraid of someone that is HIV-positive. Like someone with a germ that is spreading fastly, or I am someone with a sickness that is spreading quickly just by touching..."***

The fear of contagion by nurses is an affective stress-coping response to illness. It is an anxious response to the perceived threat of catching the disease. Reutler and Northcott (1994, in Deetlefs et al, 2003:27) also mention that this might be a coping mechanism to make the risk of nursing HIV-positive patients more manageable. Meisenhelder and La Charite (1989, in Chamane & Kortenbout, 1997:43-45) state there are three behaviours that characterise this kind of fear: avoidance, taking extreme precautions and verbal expression of fear regarding the disease.

The above participant believed that the registered nurses involved in taking blood from her had learnt all about HIV-AIDS and should have known how HIV spreads and what precautions they had to follow, and that they should have known not to say such hurtful things in front of patients, as the participant explains below:

***"The nurse knows everything about HIV, she shouldn't have said that because she knows how it spreads and everything. She should have just said to the other nurse: wear gloves and that, because that is the precautions to wear gloves, but I thought she is a nurse and she's learned all about this. That shouldn't have come out of her mouth. Maybe if it came out of the mouth of a patient I would understand, because a patient doesn't know everything about HIV and AIDS. The nurses are taught every time about HIV and the precautions they must follow."***

A study done among nurses by Chamane and Kortenbout (1997:43) revealed marked fear of contracting the disease irrespective of the knowledge pattern and experience. This was aggravated by the fact that the disease was incurable at this juncture. Focus-group interviews in the above study revealed the fact that highly perceived fear was that of “knowing” that one had HIV-infection; and the nurses felt that people did not die of AIDS and its complications *per se* but died more from “knowing” and the depression associated with this incurable monster which further lowered their immunity. It was discovered that those were the reasons for taking extreme precautions, avoidance of challenging situations and verbalisation of fear. The nurses in the study felt that they needed to be comfortable with themselves so as to be able to care for other individuals.

According to literature (Ogden & Nyblade, 2005:31), consequences of stigma in the health sector are that HIV-positive people receive inferior care or are denied care altogether, as was admitted by a healthcare worker in Vietnam: “We absolutely never inject (HIV) infected persons. We just give them medicines...We also treat small children here, so we give (HIV) infected people no injections at all.” A person living with HIV in Ethiopia recounted the following experience: “I went to a dentist (and) told him I am HIV positive. When he heard this he told me that he cannot help me and asked me to leave his clinic.” Recent research on Sub-Saharan Africa has shown that although caregivers and medical professionals might be better educated about HIV-AIDS than the general population, they continue to stigmatise and discriminate against PLWAs, especially where there are limited resources for care (Deacon, 2005:62).

Researchers have found that experiences of stigma within the clinical setting influences an individual's access to medical care, and impairs the sharing of medical information. Stigma also obstructs the healthcare workers' ability to communicate with patients and potential to support people (Madru, 2003:39). A survey done in America with a sample of nine HIV-positive European American women showed that despite

expectations by the participants that people in the healthcare arena were more educated about HIV and should be more accepting of people with HIV-AIDS, the women found this not to be true. They also realised that acceptance by one provider at the site did not guarantee the same from others at the same site. Many healthcare providers reacted with disgust, disdain, and fear, with physicians often being the most vocal (Carr & Gramling, 2004:34).

A participant interviewed by the researcher related an experience with a doctor that was discriminatory and that she was obstructed from access to medical care due to her status:

***“Uhhmm, the doctor one time, I told her I got this problem, these spots on my feet and they are swollen...’she’ told me that there is nothing that can be done with these things because you are HIV. She is lying.”***

Institutional stigma refers to differential treatment within any broadly defined institutional setting that leads to a negative outcome for the PLWAs (Ogden & Nyblade, 2005:29). The main areas documented had to do with loss of or inability to secure livelihoods, housing, healthcare, and education. It also includes losing access to new or future opportunities because an HIV-test is required to qualify for a job, loan, scholarship or visa for travel; differential treatment within an institution that leads to poorer outcomes (for example, having to wait longer for health services); and the way those with HIV are depicted in the media. Abadia-Barrero and Castro (2006:1221) define institutional discrimination as including spheres where “legislation, regulations, policies and procedures can include discriminatory or anti-discrimination provisions and practices.” Non-institutional discrimination refers specifically to relations between individuals, within families and communities.

Institutional discrimination in this research is expressed by participants who describe having separate areas in the clinic and folders that look different. Separate facilities



and colour-coded folders serve to visibly mark a person as having HIV, exposing him or her to other forms of stigma. All participants believed that other patients at the clinic knew the purpose of the separate consulting rooms and therefore knew who were HIV-positive:

***“When we are sitting there on these chairs they know, I'm sure, that that space is for HIV, you know, they just look and walk.”***

***“We group together here - those people they come there, all those peoples sitting there are positive, some they go check whether they are positive or not.”***

***“...all the people they know this side, this side is the people who are positive.”***

***“...every people knows that we are sitting here we are positive...we pass through some people to go to this place.”***

***“People who come here they know that these chairs are for the people who are HIV-positive, you know, people know us where we are staying here...”***

Fawcet (2001, in van Dyk & van Dyk, 2003:4) states that a common practice in hospitals and clinics is to demarcate a special room for HIV counselling. This practice makes clients reluctant to go to these facilities because they are afraid that they will immediately be labelled as being HIV-positive.

Stein, (2005, in Deacon, 2005:77) commented that the design of the healthcare system and its treatment programmes affect the impact of stigma on access to treatment. Providing separate clinics for HIV-AIDS treatment forces PLWAs to disclose their status publicly by attending the clinic. This may function to reduce

stigma when people realise how widespread the problem is; but it could have less positive effects as well. Some people may not feel comfortable about coming to HIV-AIDS clinics for VCT and ARTs in the current stigmatising climate while other patients may resent the special status of PLWAs.

Participants suggested that the clinics should provide a place for the PLWAs to sit 'inside' and not on the bunks in the separate area, particularly for those who did not wish to be identified as HIV-positive. They also disliked having to go to three different consulting rooms or sharing a consulting room with other patients and would have preferred all procedures to be carried out in one room, where it would be more private and not be so obvious to everyone that they were on ARTs:

***“...so you don't have to go in 3 rooms when you are here to fetch ARVs, you have to do all these things, taking blood, taking blood pressure, your pills, you have to get in the one place, you know, so that the people outside cannot see the difference between our folders and their folders, you know, ja, and if they can find a place here, a big place so that we can get inside and not sitting outside on the bunks so that people can see us that we are here for ARVs.”***

***“It's not right, it's not nice, but I'm not worried about somebody knowing I'm HIV-positive, but it's not nice.”***

***“Like this one is going to write our folders and take our bloods, and this one will do another job, but in the same room not in different rooms, that's what made them to take our time a lot because you come in this room they check your blood pressure and they write in your folder and you go to another nurse, they take another 10 years to write in your folder, ask your problem, ask if you want to see a doctor or not, then you go to...office to get your treatment, that's another time. If they can do that in one room the service will be very***

**good.”**

Sometimes other patients make PLWAs feel discriminated against, for example, they are curious and ask about the PLWAs folders being different. Such remarks and comments constantly remind PLWAs about their status and make them feel different:

**“Another problem is that our folders are different from the other people and the people start asking questions that: why are our folders looking like that? And why we are going this side?”**

**“...having these 2 folders the others want to know: why man you have 2, and then we are all looking at each other and we just tell them, no man”, don't worry please about us man, just put your own one there...”**

One participant indicated that having a different folder was acceptable to him. However, up to the time of the interview he was unaware of what VCT meant; but still said he didn't mind:

**“So if you are going to see the doctor or going to TB, so then you must get a green card so, and when you come there where we get our treatment, as you can see it is VCT then they give us this card.”**

After explaining what VCT meant, he said **“Jaaa, but uhh...there is nothing wrong with this to me...it is acceptable to me.”**

Stigma can be verbal, directly (pointing fingers, insulting, taunting, or blaming), or more indirect (gossip and rumours) (Ogden & Nyblade, 2005:29). PLWAs feel discriminated against by being jeered at by other patients. One participant in this research said she felt empathy for new PLWAs who were exposed to being jeered at and attempted to help them accept their status:

***“...I told them, the ones who are new who's here to take ARVs, that guys, please accept who you are...”***

In work on eating disorders, Smart and Wegner (1999, in Deacon, 2005:34) argue that people who try to hide their status experience greater anxiety than those who reveal it; and the same may be true for PLWAs.

PLWAs are members of the same cultural, social and moral communities as many of their “stigmatisers” (Ogden & Nyblade, 2005:32). They ascribe to the same values and norms and so have the same ideas about the nature of HIV and what it means for people living with it. This phenomenon is referred to as “self-stigma” or “internalised stigma” and occurs when people living with HIV-AIDS impose stigmatising beliefs and actions on themselves. Nonetheless, they have to deal with being the object of the cruel, thoughtless and hurtful actions of others.

Literature suggests that levels of expected stigmatisation and discrimination affect the self-esteem and behaviour of PLWAs. Clark, Lindner, Armistead and Austin (2003, in Deacon, 2005:35) show that increased perceived stigma reduced the likelihood of disclosure of HIV-positive status in African-American women in the United States. Perceived levels of stigma may also have a negative effect on willingness to present for VCT and treatment (Lichtenstein, 2003, in Deacon, 2005:35). Some research also suggests that levels of stigma perceived by PLWAs tend to be higher than 'actual' levels of stigma (Green, 1995, and Green & Rademan, 1997, in Deacon, 2005: 35).

#### ***1e) PLWAs experienced lay health counsellors as untrustworthy***

The term “lay health counsellors” referred to in this study has been an initiative of National Government since 2004, when volunteers from the community were recruited as additional support in the ART programme. These lay health counsellors are part of a national programme including other categories of volunteers collectively know as Community Care Workers. The lay health counsellors' duties are to assist registered nurses with pre-and post-test counselling for VCT, including counselling for

drug readiness and adherence monitoring; to give client education on related topics; to initiate ART support groups; and to do home visits to support the ART programme. In the Nelson Mandela Bay area each of the nine ART treatment sites recruited volunteer lay health counsellors according to certain recommended guidelines and the volunteers would receive a stipend if the criteria for stipend eligibility was met, namely that they must-

- work 4 hours a day for 5 days or 80 hours per month,
- have completed the volunteer daily attendance register,
- be unemployed,
- not be in receipt of a stipend elsewhere,
- have signed a Volunteer Agreement and
- have completed basic counselling training.

In this research study the PLWAs interviewed indicated that they were not comfortable in sharing information with the volunteer lay health counsellors because they lived in the same community as the PLWAs who experienced them as untrustworthy and lacking in confidentiality ethics. Participants also indicated that they found that the lay health counsellors gossiped about them with the other members of the community. The aforementioned is evident from the following quote:

***“One day there was a volunteer here, she was the one who gossips...a volunteer working here in the area, I'm not getting along with her, she comes here and looks at my folder and then is going to the street and tell the people what's happening in your life. She's a lay health counsellor.”***

Healthcare workers should be very sensitive to the issue of confidentiality in Africa. Although it may seem that black African people usually share all their experiences with one another, normative regulations exist as to which kinds of information can be shared and with whom. Black African people are especially concerned about secrecy and confidentiality where AIDS is concerned, because they often fear rejection by the

community, and even death, if their HIV-status becomes general knowledge. As elaborated in a survey done by Lie and Biswalo (1994, in van Dyk, 2001:4) 98% of subjects indicated that secrecy and confidentiality were very important to them. Subjects pointed out that they would prefer to talk to somebody “who can keep a secret” about their HIV-status. Such people are usually trusted relatives, medical personnel, religious leaders and traditional healers.

Some of the participants expressed the fact that they experienced the volunteers as inquisitive and that they gossiped about the patients. Confidentiality and trust in the healthcare system are major public concerns; and everything possible should be done to overcome the barrier if VCT is to be a successful part of HIV care and prevention programmes. Van Dyk and van Dyk (2003:4) state that one of the major challenges for the South African health services is to change the image of its counsellors to that of people who can be trusted; and the importance of confidentiality must be emphasised in training programmes.

Community members may not always be able to distinguish between registered nurses and the lay health counsellors at the healthcare facilities they attend; and unethical behaviour by the latter could tarnish the image of the nursing profession. The negative remarks about lay health counsellors should be investigated and corrective action taken to address the issue.

The participants interviewed said that they did not trust the lay health counsellors to do follow-up visits at their homes because they lived in the same area as they did and they gossiped and were seen as making fun of them:

***“No, not them [lay health counsellors], because these counsellors are the ones’ who are living around our homes, you know, they see you sick and they go gossip around it.”***

***“No, I don't trust the lay health counsellors because they are making***

***fun of us.”***

The participants expressed the fact that they would like the registered nurses to do the home visits instead and appeared to be disappointed that the aforementioned did not happen. The participants indicated that the registered nurses did not seem to get time to do home visits or ask about PLWAs' living conditions at home or they did visits only occasionally:

***“The nurses, I do trust the nurses, if only they can do our follow ups to go out and visit our homes. I know they are busy but not every day, like once in this month: I'm going to visit 5 patients this month...you not going to tell me when you're coming home to visit me, you just come by surprise, just come and visit me maybe you find me not there and you ask my family what you were going to ask me.”***

***“The nurses here they don't ask how we are living at our home, that's the most of our problem.”***

***“Sometimes the nurse they will check us at our houses, they do that. I am very happy, they check that you are using your tablets regularly, that you are not doing something wrong.”***

The following participant indicated that registered nurses would not be regarded as entirely professional unless they did home visits as well:

***“They are professional, but they would be VERY professional if they can do what I am asking them to do, to go and visit our homes and see where we are staying and how we are living, they would be very professional, yes, [pause] so they are not properly professional now because of that, ok?” [Laughs].***

Regardless of support from lay health counsellors, it will be expected from registered nurses, who already carry a very heavy burden in this epidemic, to form the backbone of VCT and ART services. Lay health counsellors are not professional practitioners and may not possess the ethical values necessary for sustained moral conduct as is the requirement for registered nurses. An example of this as related by one participant, was the story of a volunteer who asked a fee from a patient to see the doctor. The patient was the participant's mother. When asked if she reported the incident, the participant said she feared being victimised at the clinic because she was afraid the lay health counsellors were friendly with the registered nurses and she believed they would treat her differently thereafter:

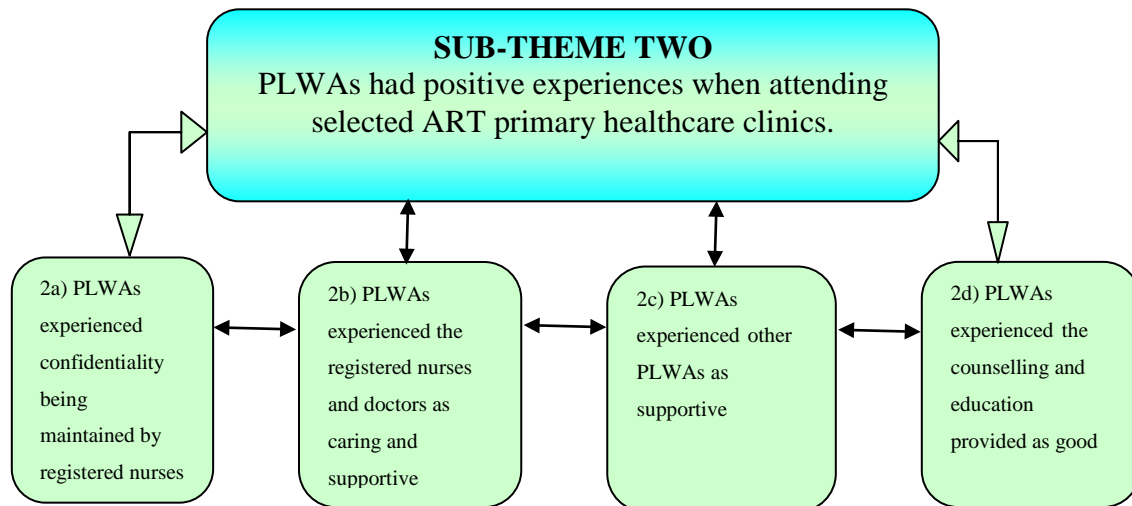
***“...you know there's a thing like that here in..., that you go to see a doctor but you have to pay the one who sent you to the doctor a R10 or R20 you know, things like that. It happened to my mother, she had to get R10 for the lady who sent her to the doctor so that she can fill in here in the list. It was one of those counselling volunteers... I never report it because once you report something you will be hated...it's not any use talking to the nurses because they talk nicely to the health workers working here as a volunteer, so they are going to tell them who says this, you know. Yes, and then you come here looking for service and you are not going to get any service...she tell the volunteer my name...it's me who done the wrong...”***

In an Eastern Cape study with PMTCT clients, Peltzer et al, (2005:38) found that participants viewed the lay health counsellors as useful, although there appeared to be uncertainty surrounding them. Many claimed not to have met lay health counsellors or to have heard of them. Those who did know about volunteers spoke highly of the services they provided. This is contradictory to findings in this research conducted in ART clinics in Nelson Mandela Bay.



### 3.4.3 Sub-theme Two: PLWAs had positive experiences when attending ART clinics.

Sub-theme Two and its categories is presented below:



**Figure 3.2: Diagrammatic Representation of Sub-theme Two on the positive experiences of PLWAs with regard to the comprehensive ART management received from registered nurses at selected public primary healthcare clinics in Nelson Mandela Bay.**

#### **2a) *PLWAs experienced confidentiality being maintained by registered nurses.***

Healthcare professionals are ethically and legally required to keep all information about their clients confidential. Any information about a patient's illness or treatment can only be given to another person with the patient's informed consent. The right of HIV-infected people to be treated fairly and confidentially should be recognised and accepted. If clients do not have the assurance that healthcare professionals will keep their diagnosis confidential, they might be too scared to go for treatment. Because people living with HIV-infection often face discrimination and prejudice, it is even

more essential to keep the information about their infection confidential (van Dyk & van Dyk, 2003:244).

Not one of the participants interviewed experienced a breach of confidentiality by a registered nurse. By the conciseness of their comments below it seems apparent that this is not an issue that causes them concern and they trust the registered nurses in this regard:

***“We experience that our status are being kept confidential.”***

***“I never had an experience that someone [registered nurses] not keeps confidentiality, no problem.”***

***“I never hear them [registered nurses] gossip about patients.”***

***“Uhh, it is only those who is working with us, it is not all of them - not the whole clinic knows about these things [HIV-status], no, it is only the nurses who is working with us.”***

Although this is encouraging for the nursing services in the Nelson Mandela Bay area, it does not seem to be the case elsewhere according to literature consulted. Literature regarding the issue of confidentiality states that public healthcare services, especially overburdened in Africa, generally fail to provide confidential treatment (Deacon, 2005:77). Patients are therefore effectively forced to disclose their status when using public healthcare services. This human rights problem is not receiving sufficient attention because of the emphasis on disclosure as being 'good for everybody' anyway (Stein, 2005, in Deacon, 2005:77). In South Africa the public health treatment programme requires PLWAs receiving ART treatment to disclose this to a 'treatment buddy' and to attend a special clinic. We need to find ways of securing confidentiality while promoting and supporting disclosure in both public and private health contexts (Stein, 2005, in Deacon, 2005:77).

In another research study conducted in South Africa by Deetlefs et al, (2003:26) on the attitudes of nurses towards HIV-positive patients, findings indicate that nurses see confidentiality as beneficial only to HIV-positive patients, but detrimental to the community; and it was said that in fact confidentiality should be abandoned. In contrast to this belief, a unique finding was that some of the nurses were of the opinion that ignorance about patients' HIV status facilitated the development of a relationship between the patient and the nurse and the reduction of discrimination. Patients who are HIV-positive are also considered to be dangerous (Berkowitz & Nuttal, 1996; Newton, 1995; Latman, Horton, Finney & Fenstermacher, 1996, in Deetlefs et al, 2003:26). The rights of the HIV-positive patients are considered to be in conflict with the rights of the nurse, as one nurse participant in the above research mentioned: "I have rights and the patients have rights; but I must consider my duty and pledge".

A PLWA interviewed at one of the ART clinics made an interesting comment about what a registered nurse said regarding confidentiality. The remark by the registered nurse is in line with the above quote in terms of the patient's rights being important and that registered nurses are doing their duty in this regard, albeit seemingly with a grudge:

***"...they [the registered nurses] never tell other people about our status, no, no, no, they always say to me when I ask them: hey, you always complain about your rights, so we [registered nurses] are doing what you want, we keep your status confidential. It's confidential, ok?"***

It appears that registered nurses may be maintaining confidentiality as a matter of duty, rather than out of a conviction for it. The PLWAs in this research appreciate that their rights are upheld in this regard. In a clinic situation, however, shared confidentiality is encouraged when clients share the information of their HIV-status with family members, loved ones, caregivers and trusted friends who are willing to

support them. Sadly, HIV-infected people are often rejected by their significant others because of the stigma that still surrounds the disease (Stein, 2005, in Deacon, 2005:77).

**2b) *PLWAs experienced the registered nurses and doctors as caring and supportive.***

The number of comments made by participants about the caring and supportive attitude of health staff exceeded the complaints received in this regard. This is encouraging since “Caring is nursing and nursing is caring” (Leininger, 1984, in Nelkin, Willis & Parris, 1991:119). A caring relationship with patients as defined by nursing entails a dynamic “turning toward the other”, the meeting of registered nurse and patient, through which the registered nurse enters and empathically shares the patient's situation and suffering. By being present with patients in this compassionate sense, and using herself, as well as her knowledge and skill, therapeutically, the registered nurse provides comfort and support to them and to their families; relieves their physical, emotional, and existential distress; promotes their developmental growth and change (and her own as well); and creates a climate in which healing, if not always cure, takes place. Perceptual awareness and discretionary judgement, devotion, trust, hope, courage, respect and something akin to love for the person who is one's patient are all elements of this ideal model of nursing care (Gaut, 1979, in Nelkin et al, 1991:125).

Participants taking part in this research were very eager to share with the researcher their positive experiences of care and support received from registered nurses and doctors. The following participant related how, on her first visit to the ART clinic, she was made to feel very welcome at the clinic by the staff:

***“When I came here I felt very welcomed the first day.”***

Consumers of public healthcare facilities are expected to attend a clinic which is closest to their place of residence. The participant quoted below wanted to attend

another clinic on the other side of town where she felt she would be happier than at the one closer to her. On her attendance at the clinic of her choice, the staff did not turn her away as she had expected. She found them to be considerate, concerned and caring; and this made her feel welcome:

***“...they are so considerate, they even ask me if the bus fare's not going to be a problem for you, so I told them no, it is not going to be a problem with me, so they say, okay, if you got no problem with that, we have also got no problem with you - you see, so I was getting warm welcome.”***

The participants expressed praise for the registered nurses at the ART clinics where this research was conducted. The participants indicated that they felt uplifted and appreciated the way they were treated by most of the healthcare staff. They indicated that they experienced love, empathy and encouragement from the registered nurses who attended to them in a non-discriminatory way which made them feel happy and good when going home:

***“I experience love.”***

***“They are caring people.”***

***“...that nurse, the treatment that she gave me, she felt for me - she felt my pain - because I was even afraid to voice that I am HIV- positive.”***

***“I guarantee this place, the people that are working in this place you see, I guarantee them, I've got no problems, nothing, I come inside and I'm going back home with a nice clean heart.”***

***“I never had a nurse who is discriminating - I don't want to lie.”***

Participants also expressed their appreciation of the spiritual support that they received from some of the registered nurses at the ART clinics and indicated that the prayers in the morning made them feel good and it also indicated to them the staff's strong belief in God as their saviour:

***“I know every morning when you come here they have a small reading out of the Bible, maybe 2 or 3 hymns that we sing in the morning, and that is a very good idea...They actually teach us in the morning that they start their life with Jesus every single morning.”***

***“I love to come to this clinic, sometimes on Fridays in the mornings you get prayers. I can see their treatment is too good for me, I do not know other peoples, in my side is too good...I can say they treat me well”.***

Literature indicates that the religious convictions of nurses play a positive role in how they act towards HIV-positive patients. Sherman (1996, in Deetlefs et al, 2003:29) shows the relationship between spirituality and the willingness among nurses to care for HIV-positive patients. Nurses also ask God to protect them during the nursing of HIV-positive patients, and, according to Bailey and Clarke (1989, in Deetlefs et al, 2003:29), praying and reading from the Bible are active direct coping mechanisms used by nurses to relieve stress. Definitions of spirituality include the psychological concept of a search for meaning and hope. Emotions and spiritual needs can also interrelate on a clinical level: spirituality has been shown to be associated with decreased anxiety and depression (Clark, Drain & Malone, 2003:659). Weinstein ([www.4therapy.com/consumer/conditions/item.php?uniqueid=6960&category](http://www.4therapy.com/consumer/conditions/item.php?uniqueid=6960&category)) states that those who can turn to a “higher power” generally fare much better in dealing with their condition than “non-believers”.

Besides the emotional and spiritual support they received from the clinics, participants also expressed their appreciation of the food they received, such as bread and soup

or porridge, from some of the clinics or community centres close by. The participants indicated that the ARTs made them hungry, especially since they had left their homes early in the morning and had not had breakfast before they came. Some PLWAs indicated that they could not afford to buy food, that they left home too early to eat or were too weak to prepare it for themselves and therefore found the clinics to be considerate in this regard:

***“They are friendly, every one...If I am hungry they send me to the Community Centre next door - I can get some soup and bread - so that is why I have no complaints about them.”***

***“They will serve you those buns, and people they make us soup, you know, because sometimes you feel weak.”***

***“There's always porridge, sometimes if you forget they tell you there's the porridge.”***

***“...when you come here in the morning uhh, we are given a cup of soup, so they are considering that maybe we left early at home and didn't eat so we get a cup of soup, we drink the soup nice and thick.”***

The participants expressed that they experienced being in good hands at the clinics. One participant related how she was afraid and shaky at first to come to the clinic; but after meeting the staff, felt at home and accepted there, in the same way that her mother made her feel. The participants felt that the staff addressed them with respect and treated them well:

***“At first I was shaky and not very sure...but when I came here to the clinic and saw what kind of people they are, when they ask questions and I answer, then I see they are nice people so I can come with my problems...I feel like at home, like when I come to my mother with a***

***problem like that.”***

***“...inside this clinic the peoples they've got good hands, open hands and a good smile for me, and the nurses are also talking nicely, they don't shout or anything or talk rude or anything. If I'm wrong and she's got something to tell me: come outside and she talk to me one side, not in front of the other peoples and she talk nicely and I'm glad for that and I'm happy.”***

***“The way they are treating us right now, they are treating us well and nice.”***

***“The nurse she handle me well now. Now I'm feeling much better.”***

One participant indicated that she was very impressed with the Sister-in-Charge at the clinic because she opened the gates to the clinic herself instead of delegating it to a subordinate:

***“...actually the Sister in Charge, she was the one this morning who opened the doors for us - now just think about that - the person in charge - she can give her keys to the people and say okay, open the doors for me please, but no, she go and open the gate self.”***

The participants expressed appreciation for being made to feel privileged and special by registered nurses and doctors at the ART clinics. They indicated that they felt as if they received preferential treatment and indicated that the latter made them feel happy:

***“The sister here treat the HIV-people as very special people.”***

***“It is a privilege for us as HI-persons that uhh the sisters, the doctors,***



***everyone cares about us - to me I am very happy for that.”***

***“Sometimes you come here, it is raining and then this Mr ... he stay in ... it is not far from me, and he say you can wait for me here, when I am going on lunch I can drop you on my way. I know it is not just for me they do it - I hear and see.”***

***“We as HIV-positive persons, the doctor will see us first. That makes me feel very happy.”***

The participants also expressed their appreciation for the treatment that they received from the registered nurses at the ART clinics. They indicated that the registered nurses were caring and followed the necessary procedures for checking readiness for ARTs. The participants said that they were happy with the treatment that they received and the way they were handled. The above sentiments are clear from the following statements:

***“...they want to check me if I am ready to use the ARV tablets...they find me I have got the TB, they treat the TB first then after 3 months they said I must come here at this place and then they check the blood and CD4 count...and that is why I started my treatment here, but it was very nice for me.”***

***“...it's like it's good when they check our blood pressures, I like it.”***

***“If they were careless they would just take it from me - okay, she is HIV-positive and she tested in 2004, let me just write down - they won't bother to test me again, you see, if they were careless.”***

Other participants shared how they were adequately treated for opportunistic infections which they had suffered from, from time to time. They also indicated that

they experienced receiving the necessary attention and care that they needed and that the required medicines were readily available when prescribed:

***“If I said something, ne, I get flu or something I don't understand, I come here and tell them, they give me medicine for that.”***

***“Sometimes I come here maybe with chest or sometimes my ears, and so: Sister, I haven't got medicines, just check in my ears, and then she checks them, takes that thing and put in my ears and then afterwards put in my file and say, okay, you can go to the dispensary, or sometimes...they will get the stuff for me. So that is why I can't complain about them.”***

***“I get the attention that I want because if I say I've got my chest problem , anything I want and say, maybe because I'm always conscious of my body, anything that I ask I am complaining about, they have got medication for that thing, you understand.”***

One participant expressed her appreciation for the compassion demonstrated by one of the registered nurses in indicating to the participant that she was prepared to give her medication to her relative if she (the participant) was too sick and therefore unable to collect the medication personally:

***“...you must come even if you are sick, then we can see, shame she's very sick, so next time if you sick we know you sick, so you can send someone to fetch your tablets.”***

From the quotes included in the above sub-theme it is clear that these experiences made the PLWAs feel like respected human beings, which is every patient's right, regardless of who he/she is; and such positive behaviour by staff needs to be applauded.

**2c) PLWAs experienced other PLWAs as supportive**

One of the participants interviewed expressed her experience of feeling loved when she was at the clinic; and indicated that other PLWAs and the nurses enjoyed it when she tried to make them happy. The participant also indicated that she experienced it as beneficial to speak about her HIV-positive status because it made her feel better and less stressed. The researcher observed that this particular participant was very talkative and jocular and she indicated to the researcher that one should strive towards leading a normal life by developing a positive attitude to life:

***“It's because I met people who are also HIV-positive here and there's some of the people are being happy when I'm here. They become happy when I'm here because they know I love to talk, I make them laugh, I talk about everything, and even the nurses they know me. So I feel something I get, you know even if I go home angry like I'm kept here in the room...I make that thing go away because if you keep it inside it's going to eat you. You don't have to stress yourself when you are HIV-positive you have to lead a normal life like everyone else, you know, don't take everything seriously, it's going to eat you up.”***

The participants indicated that they experienced the support received from their fellow PWLAs as positive because it gave them hope and they also experienced mutual gain by providing emotional support to one another while waiting to be attended to by the registered nurses. Some of the participants even indicated that they would like to assist the registered nurses with the counselling of other PWLAs, especially those who might still be in the denial stage so that they could hopefully accept their HIV-positive status. The participants also indicated to the researcher that they experienced the counselling received from or given to their fellow PLWAs as therapeutic:

***“Another patient was called to give faith in me, to give me faith excuse me, then uhh, he explained about his ordeal, his CD count***

***was 95, so below mine, so when he talked to me, this patient, I felt no, I am not alone and if he could make it I can also make it, so that is the help that I got from them here.”***

***“I support somebody if they tell me oooh, I'm sick I'm sick, I don't know what's wrong, then I support them. Sometimes somebody who sits near me support me also.”***

***“...and sometimes maybe if they can organise some sort of workshops, people with HIV just gathering, talking, maybe just so that we are not alone you see and maybe when...talking about our experiences, some other HIV-patients are still in that denial stage, so when you gather together and talking and uhmm...all of us has got the same HIV, they can feel better and they can accept the disease more easily.”***

Kain (1989:72) states that an important component of treating the HIV-infected individual involves referring the client to a supportive group experience. This has been shown to be effective in countering isolation, providing education and decreasing risky behaviour. If possible, it is more effective to offer separate groups for individuals who are affected differently by the virus. Spector and Conklin (1987, in Kain, 1989:72) advised that asymptomatic HIV-positive people not be mixed with people with AIDS because the presence of individuals with an advanced illness often intensifies the fears of others, motivating them to drop out of the group early. Those who remained in the group had a greater rate of staying on treatment because dropping out of the group could mean a return to risky behaviour. Other authors also reported that the psycho-educational group experience was effective in dealing with reducing behaviour that could pass the virus on to others as well as providing a powerful format for confronting other forms of self-destructive behaviour. The group experience may be the only haven a client or significant other has that provides acceptance, safety and reassurance while dispelling the blame and guilt often

associated with AIDS.

The participants expressed an interest in support groups; but indicated that the support group should meet at the clinic and not at an outside venue because they feared that the support groups might be attended by individuals who were curious to see who was HIV-positive so that they could go out and gossip about the PLWAs in the community. The participants indicated that they experienced the PWLAs as trustworthy because they were all in the same boat:

***“Yes [to support groups], but this time not outside because the problem with the outside support groups, there are some people who are not HIV they just coming to look who is going to come, who is going to say what, but when you are doing it here in the clinic we are all coming for treatment then we know we are, we are all HIV, all singing one song, you see.”***

***“...and you know there are these support groups in our areas, I never joined that, I never liked that because you go to the support group, you know that they say they are not HIV-positive you know, how can you say I'm HIV-positive when there's no-one else here that's HIV-positive, how can you be sure I'm going to tell there about my status, how can you be sure they are not going to tell the other people, you know, ja, and then my support group is my family, they are very supportive you know, and I'm happy about that...but not all of us get that supportive families you know, that's why I'm having a problem that the nurses have to ask us how are we staying at our home, you know, to make us to tell our stories.”***

The participants indicated that whilst waiting to be attended to they learned from one another about diets and health matters related to HIV-AIDS. The aforementioned is evident from the following direct quotes from the raw data:

***“It's nice when you sit there and they're [patients] talking there by the chairs and sometimes about dieting, you don't know, they talk about what must you eat here, you must eat vegetables, and some other things that people don't know, they talk about everything that help you, the garlic and the juices like that, the vegetables, they talking about the health there by the chairs.”***

***“...the patients, when they get a chance, they talking and talking and talking, you get something when you sit there by the chairs.”***

The aforementioned discussion indicates a need for support groups at the clinics even though the participants indicated that they experienced the support received from one another as positive.

**2d) *PLWAs experienced the counselling and education provided as good.***

All participants interviewed indicated that they experienced the counselling and education received from the lay health counsellors and registered nurses as positive and non-judgemental. The participants indicated that they were not forced to undertake VCT but were rather advised to wait until they were ready to undertake the latter. The majority of the participants indicated that they felt that the information received at the counselling sessions was useful, thus empowering them in making relevant decisions about their health and future.

***“When you've got a problem they are not judgemental, they listen to your problem and give you advices and then when you come next time they ask you is the problem solved.”***

***“There are volunteers, they come out and they talk to us: it is dangerous, you must use a condom when you got a boyfriend, they tell us about this, so when you come here to the clinic, you get something while you are here.”***

***“...so they encouraged me not to take alcohol, you must talk to somebody. They also gave me their phone numbers anytime when I feel down I can call them, even if they are out of duty, I even got their phone numbers, I feel weepy at night, I am so stressed and want to talk to somebody, I just call them about my problem now, my personal problem, not the treatment problem you see, that is how they encourage me.”***

***“They ask from you: are you ready? [to have the VCT test done]. If you are not ready, please don't take a chance, not today, come another day...we don't force you, we don't force anyone.”***

***“...and then the results came HIV-positive and I feel I get mixed up in my head and now I want to cry and she console me...”***

Van Dyk and van Dyk (2003:6) conducted research with subjects on their previous experiences with HIV counselling and testing and found that the experiences were mostly favourable and described their counsellors as being professional, compassionate, supportive and informative. Participants also felt that the structured situation of a counselling session helped them to think about the results and its consequences and to make informed decisions. Participants generally appreciated a positive and hopeful attitude. Unfavourable experiences with counsellors included a lack of knowledge, experience, skills, depth and sensitivity (van Dyk & van Dyk, 2003:7).

Peltzer et al, (2005:38), in a study conducted on PMTCT services, found that almost 100% of women felt the counselling received was excellent and that they received adequate information on all aspects of PMTCT. Many would have liked more time with the counsellor. More than 90% felt that the staff was friendly. Earlier research and observation seemed generally to support these positive attitudes and that the majority of the counsellors had the necessary repertoire of skills (Maluleke, 2003, in

Peltzer et al, 2005:38).

The participants experienced the counselling with regard to death and dying as particularly encouraging because it allayed their fears and anxieties, thus giving hope for a longer life:

***“She explained everything, if you are HIV-positive that doesn't mean you are dying...don't listen to the person telling you everything, just listen here what we are telling you.”***

***“...she say, don't worry, you are a human being like the others, don't take your facts wrong like you are nothing now on earth, no, that is not the end.”***

***“...I didn't lie down and think that I'm gonna be sick, I mustn't think about that I'm going to die and so on. That's what I get from the counsellors here: don't tell yourself that.”***

***“...if I don't care what she say to me I won't come right, I'm going to die...so I must just take the care of what she say and what the doctor say. I must do all that, doing what they tell me, you see, musn't do my own thing.”***

It could be that counselling for a positive attitude to life is easier for those who are on ARTs than for others because of the hope they now have for an extended lifespan because of the treatment. Studies show that the mental health situation of PLWAs changes quite dramatically when ART is available. With longer life and hope for PLWAs the despondency and depression associated with impending death and bereavement may be lifted (Rotherham-Boris, Lee, Gwadz & Draitin, 2003, in Freeman, 2004:139). Kalichman, Graham, Webster and Austin (2003, in Freeman, 2004:139) found that people who were not on ARTs had a greater level of depression



and deeper pessimistic attitudes than those on treatment. Those on ARTs now tend to focus on uncertainty around their future and anxiety about forming future relationships, disclosure and the demoralisation related to the side-effects of the disease and its treatment. Emphasis should be given to these issues during ART counselling.

The effort to provide counselling to the HIV-positive client calls upon our most human traits and can challenge our own feelings about our sexuality and mortality. The counsellor must convey a hopeful, positive and caring attitude that in itself can be healing without minimising the real and painful struggles the client has to endure. Life is a fragile existence that can be lost at any moment. For the HIV-positive client, the struggle centres around how to live life deeply and with meaning in the here-and-now while preparing for an uncertain future. As counsellors it is our responsibility to prevent this virus from destroying self-respect (Kain, 1989:73). The diagnosis of HIV-infection or AIDS evokes severe emotional reactions such as shock, anger, feelings of guilt, self-reproach, anxiety, depression, suicidal thoughts, obsessiveness and denial (van Dyk, 2001:81). HIV-infected people are particularly fearful about being isolated, stigmatised and rejected. Apart from physical care, one of the most important tasks of the nurse is to provide psychological and social support to infected people, to be there for her patients, to listen to their problems and to support their self-determination.

### **3.5 CONCLUSION**

This chapter focused on the discussion of the results that emanated from the data-collection phases and the process of data analysis of the study. The experiences of PLWAs attending selected public primary healthcare clinics were described in detail, based on data generated from ten in-depth phenomenological interviews. Both positive and negative experiences of the PLWAs emerged clearly from the interviews and were described in this chapter under specific identified themes. Research findings were placed within the context of the broader body of scientific knowledge as

found in literature. Broad guidelines for registered nurses that could facilitate them in rendering appropriate comprehensive ART management to PLWAs, as well as limitations of the study and recommendations will be dealt with in chapter four.

## **CHAPTER 4**

# **SUMMARY, CONCLUSIONS, GUIDELINES AND RECOMMENDATIONS**

### **4.1 INTRODUCTION**

In the introductory chapter an overview of the study was presented and the problem statement was described. Chapter two covered the research design and method. In Chapter three data was gathered and analysed into themes. The themes identified reflected the experiences of PLWAs with regard to the comprehensive ART management received from registered nurses at selected public primary healthcare clinics in Nelson Mandela Bay. In this chapter those experiences as reflected in the themes and the transcribed interviews form the baseline for the development of broad guidelines for registered nurses that could facilitate them in rendering appropriate comprehensive ART management to their patients. The guidelines together with the researcher's recommendations will be brought to the attention of the management of the relevant authorities involved and shared with the registered nurses at the primary healthcare clinics. In addition to the guidelines and recommendations, this chapter also includes the summary of findings, limitations and the conclusion of the study.

### **4.2 SUMMARY AND CONCLUSIONS OF RESEARCH FINDINGS**

During the research process, PLWAs who formed the target population were interviewed and voiced their experiences to the researcher with regard to the comprehensive ART management received from registered nurses at selected primary healthcare clinics in Nelson Mandela Bay. Information-rich data was generated by the unstructured, in-depth individual interviews. The data was analysed and reported on under one central theme and two associated sub-themes and their categories (see Table 3.1).

One central theme emerged, namely that PLWAs expressed diverse experiences

when attending the selected ART primary healthcare clinics, which included both positive and negative experiences ranging from fears of being stigmatised and rejected and feeling like a “germ” or “dirt”, to absolute satisfaction with the services they received. Mostly their fear was a result of rumours that they had heard about how registered nurses treated the patients, but the PLWAs interviewed had not experienced this in reality. However, the negative experiences must be taken note of and addressed where possible.

In sub-theme one, the focus was on negative experiences of PLWAs when they attended the primary healthcare clinics. These negative feelings related mainly to a lack of resources in the clinics, namely human, physical and educational. Most PLWAs complained about the shortage of registered nurses and doctors, which made the delivery of services slow and resulted in registered nurses being overburdened which seemed to affect their attitudes towards their patients. Some PLWAs accused a few registered nurses of having an unprofessional conduct and lack concern for their patients. The PLWAs experienced this as a lack of respect and this made them fearful of reporting problems. Institutional discrimination was identified as having separate areas in the clinic and folders that looked different, thus exposing them to stigma by staff and patients. Lay health counsellors were cited as untrustworthy because they gossiped and did not uphold confidentiality. No experiences of a breach of confidentiality by registered nurses were expressed by the participants. The PLWAs indicated that they would like to have a shelter outside when waiting for the clinic to open, and once inside the clinic, to have waiting space that was not in the passage where everyone could see them. They would like to have support groups and workshops, as well as literature and educational talks to reinforce all the information that the registered nurses had given them.

Sub-theme two highlighted the positive experiences of PLWAs when they attended the primary healthcare clinics. It was obvious to the researcher that the PLWAs interviewed had reached a stage of openness in discussing their HIV-AIDS status with the registered nurses and doctors as well as with other PLWAs. They were

willing and enthusiastic when sharing both their positive and negative experiences with the researcher.

Positive experiences expressed by PLWAs recorded that the registered nurses made them feel “like a person” and that they trust the registered nurses and believe that the nurses “know what they are doing”. Most PLWAs feel they are still alive because of the treatment they receive at the clinics and were grateful for that. This may be why they are generally very accepting of the circumstances at the clinics. All the PLWAs interviewed expressed their appreciation of the registered nurses. Most said they were made to feel welcome, and described the registered nurses as “nice people”, encouraging, considerate, empathetic, caring, friendly, understanding, and non-judgemental. The PLWAs interviewed were generally comfortable and happy with the services they received.

Based on the rich data obtained through the interviews and the researcher’s experience, the information was used as the main departure point from which to formulate the broad guidelines for registered nurses that could facilitate them in rendering appropriate comprehensive ART management.

In view of the above summary of research findings, it can therefore be concluded that the research objectives have been achieved, namely to explore and describe the experiences of PLWAs with regard to the comprehensive ART management received from registered nurses at selected public primary healthcare clinics in Nelson Mandela Bay, and to develop broad guidelines for registered nurses that could facilitate them in rendering appropriate comprehensive ART management, which is discussed below.

### **4.3 BROAD GUIDELINES FOR REGISTERED NURSES THAT COULD FACILITATE THEM IN RENDERING APPROPRIATE COMPREHENSIVE ART MANAGEMENT.**

By describing the lived experiences of PLWAs attending selected public primary healthcare clinics, gained through the research interviews, a clear picture emerged of how they are managed at these clinics. Their experiences were related in this study in their own words.

The main focus of this study has been on the lived experiences of PLWAs with regard to the comprehensive ART management received from registered nurses at selected primary healthcare clinics. Accordingly the proposed broad guidelines have been constructed utilising the following sources:

- Research findings
- Relevant literature, including Department of Health guidelines
- The experiences of the researcher
- Discussions with relevant experts familiar with this field.

The proposed guidelines, rationale and operational implications for each guideline are presented below.

**Table 4.1: Broad guidelines for registered nurses that could facilitate them in rendering appropriate comprehensive ART management**

| <b>Principal guidelines</b>   | <b>Sub-guidelines</b>  |
|---|--|
| <b>1. Create a therapeutic environment conducive to facilitate the rendering of appropriate comprehensive ART</b> | <ul style="list-style-type: none"> <li>• Promote an improved physical environment for PLWAs.</li> <li>• Promote a therapeutic psychological environment for PLWAs.</li> <li>• Prevent stigma and discrimination of PLWAs.</li> </ul> |

| Principal guidelines   | Sub-guidelines   |
|--|--|
| management.  |  |
| <b>2. Ensure that all aspects of comprehensive ART management are integrated when rendering ART services to PLWAs.</b>               | <ul style="list-style-type: none"> <li>• Integrate prevention and education messages for HIV-positive patients.</li> <li>• Uphold the patient's right to access to treatment.</li> <li>• Integrate care and support services when rendering ART management.</li> </ul> |
| <b>3. Identify and enhance areas for the training and support of Lay health counsellors (LHCs) to ensure confidentiality ethics.</b> | <ul style="list-style-type: none"> <li>• Build the capacity of LHCs under their supervision.</li> <li>• Ensure support for LHCs.</li> <li>• Act as role-models for LHCs.</li> </ul>  |

#### **4.3.1 PRINCIPAL GUIDELINE 1: CREATE A THERAPEUTIC ENVIRONMENT CONDUCIVE TO FACILITATE THE RENDERING OF APPROPRIATE COMPREHENSIVE ART MANAGEMENT.**

In order for registered nurses to render appropriate comprehensive ART management to their patients, it is necessary to create a working environment that is conducive to rendering such management.

##### ***Rationale***

The creation of a therapeutic environment that addresses physical and psychological dimensions would result in more satisfied patients; improved utilization of the clinics; and could enhance the ART adherence of patients. The registered nurse is accountable to the employer for reporting any unfavourable conditions which could impact on the quality of care rendered to patients (Mellish, 1985:140).

Participants in this research expressed negative experiences regarding the environment at the ART primary healthcare clinics therefore it is important to improve the therapeutic environment.

### ***Operational implications***

The operational implications include:

- **Registered nurses could promote an improved physical environment for PLWAs by:**
  - Embarking on a joint project with staff and the patients to improve the physical environment.
  - Ensuring adequate ablution and hand-washing facilities, with a pure source of drinking water for PLWAs.
  - Ensuring adequate natural lighting and ventilation in the waiting room.
  - Ensuring adequate seating arrangements for PLWAs so as to ensure that there are sufficient chairs and that sick patients do not spend hours standing and waiting for their consultation.
  - Ensuring that the waiting room is not boring and that it is more stimulating in terms of the adequate availability of literature in the form of educational pamphlets and posters as well as audio-visual equipment to show educational videos.
  - Ensuring that a staff member is allocated to change the posters and literature regularly in order to cover a variety of salient health topics and present health educational talks to PLWAs on:
    - The prevention of new transmissions of HIV
    - The prevention of re-infection
    - The prevention of other sexually transmitted infections (STIs)
    - Making informed decisions about health choices including contraception and pregnancy
    - Living a healthy lifestyle
    - The importance of adherence to ARTs (FHI, 2007:134).



- Negotiate for a sheltered area outside, where patients can wait for the clinic to open, irrespective of the prevailing weather conditions.
- **Registered nurses should promote a therapeutic psychological environment by:**
  - Being courteous and respectful at all times
  - Showing empathy to their patients
  - Offering innovative ways to help patients to remember information and treatment instructions that they give.
  - Recognising possible Central nervous system (CNS) involvement in PLWAs and be prepared to repeat themselves when giving health education and counseling.
  - Arranging for follow-up home-visits to assess the patient's situation by utilising a community support system or home-based care (HBC) organization.
  - Initiating and running support groups at the clinic as requested by participants in order to reduce the possibility of being stigmatized if held in the community.
  - Offering spiritual counseling and support in a manner which is sensitive to the religious diversity in the community, without being ethnocentric or offending other beliefs held by PLWAs (FHI, 2007:133).
  - Teaching staff at the clinics values clarification including the importance of the patients' human rights.
  - Revisiting the importance of implementing the Batho Pele (People First) Principles and the Patients' Rights Charter (Kunene et al, 2001:40).
- **Registered nurses should prevent stigma and discrimination of PLWAs by:**
  - Utilising the same colour for folders and cards as used by other patients attending the clinic for other healthcare services.
  - Not segregating PLWAs to sit in a passage in full view of other patients.

- Instituting practical and attitudinal HIV-related training for all healthcare workers to enhance the awareness and impact of stigma and discrimination on PLWAs (UNAIDS, 2001:48).
- Offering workshops for PLWAs on coping skills and assertiveness in order to avoid feelings of being subjected to fear and blame.
- Involving PLWAs in decision-making through all phases of healthcare delivery, from needs assessment, planning and implementing healthcare programmes, to monitoring and evaluation (Kunene et al, 2001:40).

#### **4.3.2. PRINCIPAL GUIDELINE 2: ENSURE THAT ALL ASPECTS OF COMPREHENSIVE ART MANAGEMENT ARE INTEGRATED WHEN RENDERING ART MANAGEMENT.**

The rationale and operational implications for the abovementioned principle guideline will be discussed below.

##### ***Rationale***

Integrating comprehensive ART management in terms of prevention, treatment, care and support will render an improved service to PLWAs and will promote quality care and more equitable implementation of services (DOH, 2004:17).

##### ***Operational implications***

The operational implications include:

- **Registered nurses should integrate prevention and education messages for HIV-positive patients by:**
  - Establishing a peer network system that can be utilized to disseminate ART information at workplaces, churches, schools and youth centers, and at police and military institutions to facilitate and promote awareness of ART services, eligibility criteria for ARTs and access to ART services in the community (Ritzenthaler, 2005:36).

- Ensuring greater involvement of PLWAs (GIPA) as trained expert patients for the provision of healthcare services such as health promotion and prevention, home-based care, adherence support and treatment literacy activities and psychosocial support (WHO, 2008:49).
  - Providing adequate access to condoms and demonstrating their proper use/disposal.
  
- **Registered nurses should uphold the patient's right to access to treatment by:**
  - Offering ART services at the clinic at a time outside of the normal working hours, for example, the so-called 1-4 shift-work, with half the staff off duty in the afternoon and returning from 4-7 pm, for those patients who find it difficult to visit the clinics during office hours.
  - Allowing patients to attend a clinic of their choice if they have adequate means of transport to get there.
  - Advocating that staff ratios take into consideration the literacy and cognitive levels of understanding of the clients, so that the allocation of staff and doctors can take place accordingly (Kunene et al, 2001:40).
  - Ensuring the availability of medical practitioners by extending the services to include the services of private doctors.
  - Ensuring that the tea and lunch breaks of staff are staggered so that the steady flow of patients does not stop.
  
- **Registered nurses should integrate care and support services when rendering ART management by:**
  - Providing the following basic HIV-related care and support services for persons diagnosed HIV-positive:
    - Education, psychosocial and peer support for the management of HIV
    - Periodic clinical assessment and clinical staging
    - Management and treatment of common opportunistic infections
    - Provision of Co-trimoxazole prophylaxis

- Tuberculosis screening and treatment when indicated; preventive therapy, when appropriate
- Malaria prevention and treatment, where appropriate
- Management and treatment of STI cases
- Palliative care and symptom management
- Advice and support on other prevention interventions, such as safe drinking water
- Nutrition advice
- Infant feeding counseling
- Antiretroviral treatment and adherence.
- Advocating for Task-shifting (WHO, 2008:2) by which some healthcare tasks are delegated to competent lower-trained healthcare workers or lay health counselors in order to meet the growing demand for services. This may involve reviewing local laws and regulations (WHO, 2007:33).

#### **4.3.3 PRINCIPAL GUIDELINE 3: IDENTIFY AND ENHANCE AREAS FOR THE TRAINING AND SUPPORT OF LAY HEALTH COUNSELORS TO ENSURE CONFIDENTIALITY ETHICS.**

The rationale and operational implications will be discussed below.

##### ***Rationale***

Lay health counselors (LHCs) may not have formal education or experience in the medical field, nor understand the importance of work ethics and confidentiality. Confidentiality is of utmost importance for building trust with patients. LHCs need capacity and support in order to ensure that they provide the best possible care.

##### ***Operational implications***

The operational implications include:

- **Registered nurses should build the capacity of LHCs under their supervision by:**
  - Revisiting the recruitment selection criteria; roles and responsibilities; and adequate remuneration and incentives of LHCs, in collaboration with local and provincial health authorities.
  - Ensuring that LHCs wear a clear distinguishing device or uniform with 'Lay Health Counselor' printed on it in order that patients and the community can easily differentiate them from professional healthcare workers.
  - Ensuring that LHCs attend a compulsory annual training and in-service education sessions for the expansion of knowledge, to include ethical values training and the rights of patients in terms of confidentiality.
  - Ensuring that LHCs understand the clause that they sign on maintaining confidentiality.
  
- **Registered nurses should ensure support for LHCs by:**
  - Arranging for adequate structured and regular debriefing sessions for LHCs.
  - Handling breaches of confidentiality by means of counseling the official involved and organizing education for the affected clinic (Knigge, 2004, in Siyam'kela, 2004:17).
  
- **Registered nurses should ensure that they act as role-models for LHCs by:**
  - Showing positive attitudes towards HIV-positive patients both in their verbal and non-verbal behaviour.
  - Equipping themselves on matters such as effective communication; mutual acceptance and support; interpersonal skills; effective conflict management and problem-solving, and to impart these skills to LHCs through role-plays.

#### **4.4 LIMITATIONS OF THE STUDY**

- It is recognised with all qualitative studies that the limited sample size and the

specific nature of the sample and research context means that generalisations are not possible.

- The researcher experienced a paucity of information related specifically to the experiences of PLWAs with regard to the comprehensive ART management received from registered nurses at ART public primary healthcare clinics.

## **4.5 RECOMMENDATIONS**

In the light of the research findings and indicated limitations the following recommendations for nursing practice, education and research were formulated:

### **4.5.1 Recommendations for nursing practice**

The following recommendations are proposed for nursing practice:

- Local government and District healthcare personnel need to be made aware of the findings of this study through dissemination of the results.
- Guidelines need to be made available to all public primary healthcare clinic managers in the Municipal area.
- The guidelines in this study should be included at in-service education sessions for registered nurses, and registered nurses should be encouraged to utilise the guidelines in their nursing practice.
- Guidelines need to be further refined to develop an individual programme for registered nurses in their clinic settings.
- The provision of healthcare services that are “friendly” to PLWAs including VCT and prevention, treatment, care and support services, need to be scaled up.

- Communication, interaction and listening to patients should be facilitated through reviewing the staffing patterns in line with patient numbers and patient acuity so that time for emotional support is also calculated when determining staffing needs.

#### **4.5.2 Recommendations for nursing education**

The following recommendations are proposed for nursing education:

- Ensure that the application of the code of ethics and professional conduct taught in the professional training curricula is internalised by all nursing students. This can be achieved through the utilisation of an interactive teaching strategy, for example role-play.
- Practical and attitudinal HIV-related training for all healthcare workers and volunteers should be encouraged.
- In-service education courses and workshops need to be developed to enhance the stigma-reducing skills of healthcare workers and volunteers working with PLWAs who are on ARTs.

#### **4.5.3 Recommendations for nursing research**

The following recommendations are proposed for nursing research:

- The conduction of a quantitative research study using the survey method to determine the extent of stigmatisation of PLWAs.
- A study could be done to determine the effectiveness and impact of the implementation of the guidelines generated from this study.

#### **4.6 CONCLUSION**

This study provides insight into the lived experiences of PLWAs with regard to the comprehensive ART management received from registered nurses at selected public primary healthcare clinics in Nelson Mandela Bay. Findings of the study were used as a foundation upon which broad guidelines were developed for registered nurses that could facilitate them in rendering appropriate comprehensive ART management to their patients.

People working on the “frontlines” of HIV-AIDS care and prevention have both a responsibility and a unique opportunity to be role models within their professions and workplaces. Their professional codes of ethics and conduct, social and professional authority and their ability to be educators in their communities, all place them under an ethical obligation to be “change agents” for the rights of PLWAs and to promote the utilisation and accessibility of ART services. Unfortunately experience shows that healthcare institutions and individuals sometimes behave in a discriminatory and stigmatising way against PLWAs despite their professional codes (UNAIDS, 2001:47).



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**ANNEXURE A**

# **PARTICIPANT CONSENT FORM**

## NELSON MANDELA METROPOLITAN UNIVERSITY

### **INFORMATION AND INFORMED CONSENT FORM**

(Please delete any information not applicable to your project and complete/expand as deemed appropriate)

|  |   |                |
|--|---|----------------|
| <b>Title of the research project</b>   | The experiences of people living with HIV-AIDS with regard to comprehensive antiretroviral therapy management received from registered nurses at selected public primary health care clinics in Nelson Mandela Bay. |                |
| <b>Reference number</b>  | Student number: 177082100   |                |
| Principal investigator   | Dawne Shirley Jackson   |                |
| <b>Address</b>   | 8 Vine Street<br>Uitenhage  |                |
| Postal Code  | 6229  |                |
| <b>Contact telephone number</b><br>(private numbers not advisable)   | (Work) 041 4532233 (Cell) 084 570 7170  |                |
| <b>A. DECLARATION BY OR ON BEHALF OF PARTICIPANT</b><br>(Person legally competent to give consent on behalf of the participant)  |   | <b>Initial</b> |
| I, the participant and the undersigned<br>(full names)<br>I.D. number of the participant<br>Address (of participant)   |   |                |
| <b>A.1 I HEREBY CONFIRM AS FOLLOWS:</b>  |   |                |
| 1. I, the participant, was invited to participate in the above-mentioned research project that is being undertaken by Dawne Jackson of the Department of Nursing Science in the Faculty of Health Sciences of the Nelson Mandela |   |                |

|  |  |
|--|--|
| Metropolitan University.   |  |
| <p><b>2. The following aspects have been explained to me, the participant:</b></p> <p><b>2.1 Aim:</b> The investigator is undertaking this study to obtain information regarding the experiences of people living with HIV-AIDS with regard to comprehensive ART management received from registered nurses at selected public PHC clinics in NMB.</p> <p>The information will be used to develop guidelines for registered nurses that will facilitate them in rendering appropriate comprehensive antiretroviral management.</p> |  |
| <p><b>2.2 Procedures:</b> I understand that interviews will be used to collect the data for the study.</p>   |  |
| <p><b>2.3 Risks:</b> There are no real risks involved in the research study. The researcher will ensure that the participants are not subjected to any harm.</p>   |  |
| <p><b>2.4 Possible benefits:</b> As a result of my participation in this study I will contribute towards the development of guidelines for registered nurses that will facilitate them in rendering appropriate comprehensive antiretroviral management.</p>   |  |
| <p><b>2.5 Confidentiality:</b> My identity will not be revealed in any discussion, description or scientific publications by the investigators.</p>  |  |
| <p><b>2.6 Access to findings:</b> Any new information/or benefit that develops during the course of the study will be shared as follows: a copy of the research findings will be made available at ATICC (AIDS Training, Information and Counselling Centre) for all members of the community and registered nurses to read.</p>   |  |
| <p><b>2.7 Voluntary participation/refusal/discontinuation:</b></p>   |  |

|  |  |
|--|--|
| <p>My participation is voluntary</p> <p>YES</p> <p>NO</p> <p>My decision whether or not to participate will in no way affect my present or future care/employment/lifestyle</p> <p>TRUE</p> <p>FALSE</p>   |  |
| <p>3. The information above was explained to me/the participant by Dawne Jackson in</p> <p>Afrikaans</p> <p>English</p> <p>Xhosa</p> <p>Other</p> <p>and I am in command of this language/it was satisfactorily translated to me by (name of translator)</p> <p>I was given the opportunity to ask questions and all these questions were answered satisfactorily.</p> |  |
| <p>4.No pressure was exerted on me to consent to participation and I understand that I may withdraw at any stage without penalisation.</p>   |  |
| <p>5. Participation in this study will not result in any additional cost to myself.</p>  |  |

A.2 I HEREBY VOLUNTARILY CONSENT TO PARTICIPATE IN THE ABOVE-MENTIONED PROJECT

Signed/confirmed at

on 2006

Signature or right thumb print of participant

Signature of witness

Full name of witness

B. STATEMENT BY OR ON BEHALF OF INVESTIGATOR(S)

I, **Dawne Shirley Jackson** declare that

- I have explained the information given in this document to

(name of patient/participant)

**and/or his/her representative**

(name of representative)

- he/she was encouraged and given ample time to ask me any questions;

- this conversation was conducted in

Afrikaans

English

Xhosa

Other

and no translator was used / this conversation was translated into

(language) by

- I have detached Section D and handed it to the participant

YES

NO

Signed/confirmed at

on

2006

Signature of interviewer

Signature of witness

Full name of witness

C. DECLARATION BY TRANSLATOR

I,

**I.D. number**

**Qualifications and/or**

**Current employment**

confirm that I

translated the contents of this document from English into:

**(indicate the relevant language) to the participant/the participant's representative;**

(name)

- also translated the questions posed by

(name)

as well as the answers given by the investigator/representative; and

- conveyed a factually correct version of what was related to me.

Signed/confirmed at

on 2006

I hereby declare that all information acquired by me for the purposes of this study will be kept confidential

Signature or right thumb print of translator

Signature of witness

Full name of witness

#### D. IMPORTANT MESSAGE TO PATIENT/REPRESENTATIVE OF PARTICIPANT

Dear participant/representative of the participant

Thank you for your/the participant's participation in this study. Should, at any time during the study:

- an emergency arise as a result of the research, or
- you require any further information with regard to the study, or



the following occur:

(indicate any circumstances which should be reported to the investigator)

Kindly contact Dawne Jackson

at telephone number 041- 4532233 or 084 570 7170

(it must be a number where help will be available on a 24 hour basis, if the research project warrants it)

**ANNEXURE B**

**LETTER: INDEPENDENT CODING  
INSTRUCTIONS**

15 January 2007

Mrs Gail Klopper  
Programme Manager  
M.A. Health and Management  
P.O. Box 77000  
Nelson Mandela Metropolitan University  
PORT ELIZABETH  
6031

Dear Mrs Klopper,

### **INDEPENDENT CODING DETAILS**

Thank you for agreeing to do my independent coding. Attached please find a clean set of transcriptions of the ten interviews to be analysed.

Please use Tesch's method as listed below for coding the interviews::

- Get a sense of the whole. Read all the transcriptions carefully and make short notes.
- Pick one document at a time, go through it to try to make meaning of its contents and write notes in the margin.
- When this action has been completed for several documents, make a list of all the topics. Cluster similar ones together and form them into columns that can be arranged as major topics, unique topics and leftovers.
- Take the list and go back to the data. Abbreviate the topics as codes and write the codes next to the appropriate segments of the text to see whether new categories and codes emerge.
- Find the most descriptive wording for the topics and turn them into categories. Reduce the total list of categories by grouping topics that

relate to one another. Lines could be drawn between categories to show interrelationships.

- Make a final decision on the abbreviation for each category and arrange these categories alphabetically.
- Assemble the data material belonging to each category in one place and perform a preliminary analysis.
- Re-code existing data if necessary.

Thank you once again.

Yours faithfully

DAWNE JACKSON

Mobile: 0845707170

**ANNEXURE C**

**CONSENT FROM THE HUMAN  
ETHICS COMMITTEE**



**Nelson Mandela  
Metropolitan  
University**

*for tomorrow*

**Chairperson of the Research Ethics Committee (Human)**

**NMMU**

Tel . +27 (0)41 504-2499 Fax. +27 (0)41 504-2770  
Rosa.DuRandt@nmmu.ac.za

• PO Box 77000 • Nelson Mandela Metropolitan University  
• Port Elizabeth • 6031 • South Africa • www.nmmu.ac.za

Ref: N 01/11/03/07 [H06HA-034/Approval]

Contact person: Mrs U Spies

12 September 2006

Ms D Jackson  
8 Vine Street  
UITENHAGE  
6229

Dear Ms Jackson

**THE EXPERIENCES OF PEOPLE LIVING WITH HIV/AIDS REGARDING STIGMATISATION AT  
ANTIRETROVIRAL THERAPY CLINICS**

Your above-entitled application for ethics approval served at the August 2006 ordinary meeting of the Research Ethics Committee (Human).

The Committee approved the above-mentioned application.

Please inform your co-investigators of the outcome. We wish you well with the project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Rosa DuRandt'.

**Prof R du Randt**  
**Chairperson: Research Ethics Committee (Human)**

cc: Department of Research Management  
Faculty Officer, Faculty of Health Sciences

**ANNEXURE D**

**CONSENT FROM FACULTY OF  
HEALTH SCIENCES**



**Nelson Mandela  
Metropolitan  
University**

*for tomorrow*

• PO Box 77002 • Nelson Mandela Metropolitan University  
• Port Elizabeth • 6031 • South Africa • www.nmmu.ac.za

Summerstrand South  
Faculty of Health Sciences  
Tel. +27 (0)41 504 2121 Fax. +27 (0)41 504 2854  
ga.lehbel@nmmu.ac.za

Ref: 177082100

Contact person: Ms G Ehbel

Date: 19 September 2006

Address:

Ms DS Jackson  
8 Vine Street  
UITENHAGE  
5229

Dear Ms Jackson

**FINAL RESEARCH PROPOSAL: MCUR**

Congratulations on a well prepared final research proposal. Please be advised that your final research proposal was approved by Faculty Management subject to the following suggestions/recommendations being made to the satisfaction of your Supervisor:

- (i) That it was suggested that the title be amended as follows: "STIGMATISATION EXPERIENCES OF PEOPLE LIVING WITH HIV/AIDS AT ANTIRETROVIRAL THERAPY CLINICS";
- (ii) that it was recommended that keywords be added below the Abstract;
- (iii) that it was recommended that the inclusion criteria of the participants on page 12, be more clearly specified;
- (iv) that grammar and consistency in tense usage be corrected throughout the report;
- (v) that this proposal needed to be submitted to the Human Ethics Committee as it differed from the previous research proposal;
- (vi) that the Reference List be refined by using the Harvard Method of referencing.

Yours sincerely

**OFFICE OF THE DEAN  
FACULTY OF HEALTH SCIENCES**

GEH:Horchael@nmmu.ac.za



**ANNEXURE E**

**LETTER OF PERMISSION FROM  
MANAGEMENT OF  
INSTITUTION ONE**

09 October 2006

Ms Dawne Jackson (NMMU Student Number: 177082100)  
8 Vine Street  
UITENHAGE  
6229

Dear Ms Jackson

**RESEARCH PROPOSAL FOR PERMISSION: THE EXPERIENCES OF PEOPLE LIVING WITH HIV/AIDS REGARDING STIGMATISATION AT ANTIRETROVIRAL THERAPY CLINICS**

In response to your application for permission to conduct your Masters level research study at facilities within the Nelson Mandela Metropolitan Municipality (NMMM) and in terms of your research ethics approval dated 12 September 2006 (NO: N 01/11/03/07 [H06HA-034/Approval]), permission is hereby granted with the following proviso:

There should be no negative impact on existing health service delivery operations as well as the normal operations of ATICC. All required data should be collected by the Researcher or a designated fieldworker (whose name should be forwarded to the relevant Sub District Manager prior to data collection).

This letter should be presented when visiting the selected clinic facility or when interacting with any of the three Sub District Managers listed below:

|                                    |   |
|------------------------------------|---|
| Sub District A - Mrs Anne Mkosana  | Telephone 508 7425 (Cell: 079 490 0670) |
| Sub District B - Mrs Sarah Forbes  | Telephone 9941228 (Cell: 079 490 0674)  |
| Sub District C - Mrs Nola Monteith | Telephone 508 7424 (Cell: 079 490 0742) |

The Nelson Mandela Metropolitan Municipality, as part of the research site will expect a copy of the final research report when the study is completed. If the duration of the research period is required to be extended, the NMMM should be informed accordingly.

We would like to take this opportunity to wish you well for your research study.

Yours truly,  
  
**BUSINESS UNIT HEALTH**  
**DR IBRAHIM HOOSAIN**  
9/12/2011

**ANNEXURE F**

**LETTER OF PERMISSION FROM  
MANAGEMENT OF  
INSTITUTION TWO**

**DEPARTMENT OF HEALTH, PROVINCE OF THE EASTERN CAPE**

**Office of the Nelson Mandela Bay Health District Manager**



*Ikamva eliyaqambileyo!*

**Enquiries** : LTV Oliver

**Our** :

**Reference**

**Telephone** : 041-391-8100

**Your** :

**Reference**

**Facsimile** : 041-374-5766

**Date** : 10 October 2006

**E-mail** : [tommy.oliver@impilo.ecprov.gov.za](mailto:tommy.oliver@impilo.ecprov.gov.za)

The Manager / To Whom It May Concern

Provincial PHC Facility

Metro Health District

### **Request to Conduct Interviews with Patients**

This is to inform you that Mrs Dawne Jackson has requested permission to interview people living with HIV/AIDS and who are currently on our ART programme.

This permission is hereby granted, provided that:

- The interviews are conducted in such a way that it will adhere to all the prerequisite ethical and legal considerations.
- The interviews are conducted in such a manner that it does not interfere with the normal functioning of the clinics.

- It would most probably be advisable to make an appointment with the Facility Manager, before visiting the facility.

You are thus requested to support Mrs Jackson by allowing her to approach potential participants to this study.

Your kind cooperation in this regard will be appreciated.

A handwritten signature in black ink, appearing to read "D. River.", is positioned above the typed name. The signature is fluid and cursive.

**DISTRICT MANAGER: PROVINCIAL HEALTH**

**ANNEXURE G**

**TRANSCRIPTION OF INTERVIEW**

The experiences of PLWAs with regard to comprehensive ART management received from registered nurses at selected public primary health care clinics in NMB.

Participant number three, interviewed on 13 November 2006

Interviewer: Dawne Jackson

INTERVIEWER:

Tell me about your experience of attending this ART clinic.

PARTICIPANT:

I experience love. The nurses and the doctors they are doing their best jobs but they are not doing proper jobs like we expected. We experience that our status are being kept confidential, but people who come here they know that these chairs are for the people who are HIV-positive, you know, people know us where we are staying here, and people [pause], like for me, I'm not scared about talking about my status and I'm not scared of my confidentiality, like I'm proud of myself and I'm not scared of being HIV-positive because I don't know of the colour of it, I'm not scared of it, okay; and the nurses, the services here are too slow we are not getting good service because we come here at the early time but we go home very late, because I'm supposed to take my treatment at 9 o'clock. I get here on 7 o'clock and maybe I didn't bring my treatment with me so I came here early so that I can get the service and go home before 9 o'clock so I can drink them but none of that happens here. You get here at 7 o'clock, you get service past 10 or to 11. You don't get service at the time you expected. And the way they are handling people who are sick; like me, I'm not sick you know, there are other people who are very sick, like they can ask us - the one who came here first - to make the time for the people who are sick and then we can follow. The people who are sick become first, then we become the next ones, but they don't do that, they do as we come here, they take the first one, then the 2nd one and the 3rd one, they don't take the sick one first. They just deal with the one who

gets here first. And when we want to see a doctor, you come here and you want to see a doctor but you can't get a doctor, they tell you that the doctor is not here today she will be in on Thursday, but you're sick on Monday and they tell you that the doctor will be here on Thursday, so you have to wait because you don't have the money to go to the surgery, you want to go here because its free, to get a doctor here, but now we don't get a doctor every day, you get a doctor once a week here.

PAUSE.

PARTICIPANT:

Another problem is that our folders are different from the other people and the people start asking questions that: why are our folders looking like that? And why we are going this side?

PAUSE

PARTICIPANT:

So that's our problem. And we don't get something to eat here, we are not looking for something special, maybe some soup every day. They did promise us they were going to do that but they did never. It was last year when I started my treatment. I started on 1 January last year, yes, they promised us they are going to look for sponsors for us, the ARV-peoples, and they are going to cook us soup and they are going to find us blankets because we are [did not complete sentence]. I get help at home, but not all of us are having help, maybe sometimes you tell your parents you are HIV-positive and they kick you out, ok; and the nurses here they don't ask how we are living at our home, that's the most of our problem. They don't ask us how we are living at our home, like try to counsel the situation at home. They don't ask you if you are poor or if you want something you are short about; what do you want , you know, our goals, we do have our goals even this time when we are HIV-positive. Like me, I was doing



Standard 10 in 2001 and then I left school in the middle, I didn't finish it and then in 2002 I get tested and then I found out I was HIV-positive so I was always getting sick, getting sick. Since the time I started ARVs, I never get sick again, from last year I've never been sick, only a fever or a headache. I never get sick like a illness, so now I have a dream of going back to school but they don't ask us what we feel, you know, we want to be asked what we feel, when we eat day to day treatment, because that's not a good thing to eat pills each and every day of your life, but that's not a good thing - but they don't care and they don't ask us what we feel, because some of them did need help. Maybe we're living with your little sister and you don't have someone to care for you, when you are sick they're going to wash you. They don't even visit us at home to see where we are living, what kind of a life we are living when we are still [pause] and it's like it's good when they check our blood pressures. I like it. What I want them to do now it's to check if each and every one of us do take our treatment regularly, they don't check us, they just tell us you don't eat your treatment! You don't eat your treatment! But we do eat our treatment. Not some of us I know there are some of us who don't eat our treatment, but not all of us. At 9 o'clock I'm eating my treatment regularly but they keep on telling us if someone is not eating their treatment - they going to tell you the same thing you are not eating your treatment. I've been asking them to give us this test of checking what our treatment is doing to our CD4 count, checking our treatment regularly, or because some of us do not get a disability grant and then they tell us you are going to get disability grant when your CD count is low, so to make a CD count low what are you going to do? You're not going to take your pills because you like the disability grant and you want your CD count to be low so, you stop taking your pills. They accuse us of that so I asked them that: why you don't check that we are taking our pills. They say they are going to do that, don't have a problem, we are going to do that, and then I asked them, like most people are drinking we were taught before we eat these drugs you don't have to drink alcohol but some of us do drink alcohol and they think about it like it's fine, you don't have to get sick when you drink Hunter's Dry sweet, the alcohol that is sweet, not the strong

one, but when I was told that: if you eat these drugs you have to stop taking alcohol and use condoms, you don't get sick and then I tried that and I didn't get sick and then I asked them why they are not going to check our bloods if you are drinking alcohol so that they can see who's drinking and who's not drinking, not accuse all of us for doing someone's problem.

## PAUSE

And like, you know, I'm a talkative person, they know and they like me and I like them, you know. They treat me alright sometimes, and sometimes, its like the problem would be you came here late and it's going to be a big problem, but if THEY came here late it's not going to be a problem. We have to wait for them, we get here very early because we have all the things to do. I have a baby of 10 months so when I come here I expect to come on time so that I can go home on time, but you don't get that, you come here and you stay by those chairs, and the people around they are walking and looking at you - ooh she's sick, she's staying on that side, they are HIV and AIDS people there you know. Sometimes they ask because they are curious: why your folders are looking like this, and then I'm not scared I told them, no, we are HIV-people, we are here to take our ARVs and I told them the one's who are new who's here to take ARVs that: guys, please accept who you are, it's not going to go away just being quiet about it, it's going to stay there with you and it's going to eat you, just talk and tell people how you feel, and the sisters like me, they don't see me as I am because I'm not a naughty one, I'm a right person, I talk about HIV but some days they said to me: yooo, you like having fun with all the people who are sick. No, I'm not like that you know, I'm trying, when a sick person is here, I'm trying to talk to her so that she can forget about this HIV thing and be here and be a human being , be a person, but they always tell me: no, you are a naughty girl, you are making fun of people. I'm not doing that, if each and every thing is.... I'm not doing that I'm just talking about my status to every one every day, even if you don't know me I will tell you, if you ask me I'm going to tell you, jaa, my name and my status and

then some of the people say: no, you are lying, there's nothing like that. Because of you, that's the way I am, I'm open and my family are supportive, but not all of us get that supportive families you know, that's why I'm having a problem that the nurses have to ask us how are we staying at our homes, you know, to make us to tell our stories.

INTERVIEWER:

Okay, you've said many things. I would just like to go back to some of the things you've said to make sure I've understood properly. You said initially that you experience love when you come here. Can you just explain to me how you feel that love, what makes you feel loved?

PARTICIPANT:

It's because I met people who are also HIV-positive here and there's some of the people are being happy when I'm here. They become happy when I'm here because they know I love to talk, I make them laugh, I talk about everything, and even the nurses they know me. So I feel something I get, you know even if I go home angry like I'm kept here in the room and I was angry I come here and I tell them: ooo, today my mother shouted at me about something else like when I told them about my knee, you know, I make that thing go away because if you keep it inside it's going to eat you. You don't have to stress yourself when you are HIV-positive you have to lead a normal life like everyone else, you know, don't take everything seriously it's going to eat you up.

INTERVIEWER:

You feel accepted when you come here?

PARTICIPANT:

Yes, when I come here because they understand the position I'm in, some of them are also HIV-positive so they understand where I'm coming from and I like to give them advices: don't do that, do this, okay, or someone says I've got a

headache I'm having something wrong, I'm sick here, then there's something you do that you're not supposed to do. Stop doing that and do this and you'll be very well, you know, yes.

INTERVIEWER:

Okay, you also said you have to sit on chairs that are separate from the others.

PARTICIPANT:

Yes

INTERVIEWER:

How does that make you feel?

PARTICIPANT:

In my position I don't mind but not all of us will be right, there are always people who are sick and don't want to be seen sick, you know, and at least they can ask us who's not minding sitting here, or who's minding, so they can take those ones inside and leave us who don't mind outside, you know. That's a good point. But they just left us there, they don't care they just stand back and they call you by names [emphasized] okay, so people are coming and going you see, there's no room that we can sit that no-one can see us, we sit there in the passage and the passage is for everyone, everyone comes and goes and can see that those people sitting there are HIV-positive.

INTERVIEWER:

And you said the nurses are slow.

PARTICIPANT:

Yes

INTERVIEWER:

Do you think it's because they are overworked or what do you mean by slow?

PARTICIPANT:

They are slow, they like to shout, to talk, gossiping maybe, they like to talk before they work you know, it's good to work while you talk because the more you talk the more work will be done, but they came here and they talk and talk and talk, when it suits them they start. They talk to each other about their issues, their things at home, their things they did on the weekends and then they are getting late like that. They get here at 7 o'clock maybe half 7 but they are supposed to open at 8 o'clock. They told us you come here at 7 then we're here, we know each and every day it opens at 8 o'clock but here we're told to come at 7 so we came at 7. For example the one who is helping us with ARV treatment, she came in quarter past 8 today so I asked her I've been here since 7 o'clock because I want to go home very early: she said no, no, no, no, you wait, I'll be with you, wait. And then I wait, she comes out quarter to 9 and help us.

INTERVIEWER:

And what was she doing in the meantime?

PARTICIPANT:

She was joking inside with the other nurses.

INTERVIEWER:

So that makes them slow because they're not getting their work done?

PARTICIPANT:

Yes, they can work and talk, they can do that at the same time, but they are just talking.

INTERVIEWER:

You said 'gossiping', do you think they gossip about patients?

PARTICIPANT:

I never hear them gossip about patients. One day there was a volunteer here, she was the one. I came here, there was a crowd, there was something wrong and then I asked her what's happening. Then next month when I came here the service was different, the service was not the same as last month and then I asked why. They told me no, we want you to come in with your own folders, so that you can come here and you bring your own folders to us and then we will check, we will have our folders, the one we are using here so that because some of us are pregnant, they know about you. A volunteer working here in the area, I'm not getting along with her she comes here and looks at my folder and then is going to the street and tell the people about what's happening in your life. There is a patient whose got a bad situation, she's a friend of mine, she came to me and I told her don't stress about that. She's also HIV-positive but she's not eating ARVs, she is going to the clinic, don't worry we are going to be strong, she's going to be weak because she laughed about you. She's a lay health counsellor. And they decide that those who are counselling are not going to counsel the people who knows them you know if she lives in this area she can't counsel the people who are living in her area, they decide on that, but I asked them why they are not asking us first what are we going to do or how do we feel about this. So that they ask the people who are HIV who can come with the solution, it's us who knows how to be treated, who knows what they want. They don't do that , you just come here next month and you find the things different then you come the other month and you find things different again, they change everything every month you come here monthly you found we're supposed to be here, but now you are there. In this month you are supposed to be helped by this one but now its a different one, like it's good for them to change them but they have to ask us how do we feel about that idea, you know.

INTERVIEWER:

You also said they talk to you generally and they scold you and say you didn't eat your pills even if it wasn't you, do that they talk to everybody like that?

PARTICIPANT:

Yes, if I come in they told me you don't eat your pills, they are not even sure about that, you know, they just count your pills and maybe find that you didn't eat your pills like the way you supposed to eat them okay, they shout at you, and then I come in: they say: no, no, no, no, wait, wait, wait, because we are busy this patient is not eating her pills, maybe you don't eat even your pills, so that's why I ask if they could have some machine to check our bloods you know, they do take our CD4 count it's good but they don't know if we are eating our ARVs regularly they have to know that we eating them, they have to care that we are eating, but to me it doesn't seem like they care, its like they say: you don't eat your pills, it's you who's going to get sick, I don't care. It's like that here. They're supposed to do a follow up and find out that you are not eating your pills, they need to ask you why, they need to go, like, we have our home phone numbers here, we have our cell numbers here, they need to phone around and find out why didn't you come on your date why, didn't you eat your pills regularly or ask your mother what time is your daughter supposed to eat her pills to be serious because coming here, you pregnant, you take your drugs, you go home, you sit at home, no-one's watching you, no-one cares about you, maybe your mother whose supposed to tell you to remind you about your tablets is not here and then you forgot, some of us are sick, some of us are getting sick by the gate you know, we forget things, we put the thing there and then we don't remember it so it's their job to follow up on us you know, not only give us the next date and the pills only, and to call around our families and find out, ask questions, like me, I have a sister who's living in PE I asked her what would you say when B calls you about why I didn't come for my treatment, she said why you ask me that? No, I'm just concerned that the things that are supposed to be happening are not happening. No, I will tell her I will ask you why she didn't come because we know the next date and you know what time you have to eat your pills so the problem is that at the time you will not know why you didn't come or maybe you are sick, we will take blood, we know the reactions, okay she's there in the hospital, if I don't know I will tell you I don't know, I will make a follow up to that,

you know. That's something they're suppose to do, to call our homes and find out what we are doing. And then there are some of us who are working, not all of us are working, then not call me, to call my mother and ask her how her daughter is doing, how am I or something like that.

INTERVIEWER:

Would you expect the nurse to follow up or would it be okay if the lay health counsellor follows up on you?

PARTICIPANT:

The nurses

INTERVIEWER:

Would you not like the lay health counsellor to follow up on you?

PARTICIPANT:

No, not them because those counsellors are the ones who are living around our homes, you know, they see you sick and they go gossip around it.

INTERVIEWER:

Have you experienced that?

PARTICIPANT:

Yeess, of course, and you know there are these support groups in our areas, I never joined that, I never liked that because you go to the support group you know that they say they are not HIV-positive you know, how can you say I'm HIV-positive when there's no-one else here that's HIV-positive, how can you be sure I'm going to tell there about my status, how can you be sure they are not going to tell the other people, you know, ja, and then my support group is my family they are very supportive you know, and I'm happy about that.



INTERVIEWER:

So you don't trust the support groups?

PARTICIPANT:

No, I don't trust them.

INTERVIEWER:

You don't trust the lay health counsellors either?

PARTICIPANT:

No, I don't because they are making fun of us. The nurses, I do trust the nurses if only they can do our follow ups to go out and visit our homes. I know they are busy but not every day, like once in this month I'm going to visit 5 patients this month of November. I know there are lots of us this month, go and visit 5 patients, you not going to tell me when you're coming home to visit me, you just come by surprise just come and visit me maybe you find me not there and you ask my family what you were going to ask me.

INTERVIEWER:

So you wouldn't mind if you get a surprise visit from the nurse?

PARTICIPANT:

No I wouldn't mind, me, I wouldn't mind, I don't know about the other patients, but me I wouldn't mind, I would really like, I want that, I want my family to see me, I do talk about the nurses so I would want my family to see what I meant when I talk about them, I do talk about them, I do, very, very much.

PAUSE

INTERVIEWER:

Okay, my second question is; tell me more about the treatment you receive from the registered nurses, in the sense of how you are handled.

PARTICIPANT:

The treatment, ja it's good, I never get sick, I started ARVs last year in July. I never get sick, like sick when you don't leave your bed, you don't eat, you don't have an appetite, you are sick like that, I never get that sick. I only get a fever or headache, I never complain about anything else here and its, like good man, because at the point of I'm not getting sick , I'm getting better you know, its good.

INTERVIEWER:

Earlier you said they call you naughty, does that offend you?

PARTICIPANT:

No [laughs] no, I'm not naughty. I told them I'm not naughty, ask the person who I'm talking to she will tell you: no she's not naughty she's just joking and she just makes us feel like - oh yes, they love it, I love to talk to people especially who are HIV-positive I like it. I wish, like us who are sick, can also be asked to counsel the people who are sick, not to take people who have no experience of what she's talking about. Even if you've been educated about counselling you never feel the pain, you never been hurt, you never feel the pain, you've never been what its like to be HIV-positive you know, yes.

INTERVIEWER:

You mentioned that sometimes you feel angry, what do they do to make you angry?

PARTICIPANT:

Sometimes you come here you expected to be taken blood and they tell you: oh no, no, not this month, next month. They need to explain to us you know, this is

our bodies, they need to explain to us. From when I started eating ARVs I was told we are going to take blood every 3 months we are going to check your CD4 count but now they changed things, now but they never stated to us, they need to check, to tell us that they were thinking about, how about we extend the month, we take it after 6 months or after 9 months, they just do that without asking us how we feel you know, because there's a problem of - we are looking for disability grants and then you're scared to go to the doctors for the disability grant because your CD count is high so we want to do the CD 4 count very quick so that you can go to the doctor, you come here and they say: no you can't do a CD4 count, we are going to do a CD4 count every 9th month you have to wait for that and then you do the CD4 count and they tell you you can't see the doctor with that, you can see the doctor for other things like complaining about how you feel but you can't see the doctor for the grant. That's the problem of the patients because you can't eat ARVs when you have no food on the table you know. And what I started to say, some of us don't have homes, you tell your parent you're HIV-positive they kick you out some of us you know, and you find out when you are sleeping alone that you are HIV-positive and then you are scared to go home because they are going to tell you you are coming home because you are sick you are going to die so some people do get a disability grant and its taken away so it's not easy when your disability grant is taken away, to go back home, they are going to tell you: you are not getting your disability grant, now you come back to us, what do you want us to do with you because you are going to die anyway, you know something like that. They need to explain to us you don't have to come here for disability grant you know, or Monday maybe the doctor will be here for disability grant, not to shout at us, they do shout at us: No no no, don't talk to the doctor about disability grant. You are trying to ask how are we not going to need disability grant: no no no, don't mention disability grant to the doctor [angry voice] just complain about your sickness or something like that.

INTERVIEWER:

And that doesn't make you feel good.

PARTICIPANT:

No, it's happened to other of the patients, you know those ones that are still sitting there are having that problem you know, so I had to tell you that story you know. What I'm saying I've never had a problem like that I was very helped when I was making out my disability grant at that time because it was Dr [name] that was here and then it was very easy. I got my form for disability grant and I bring it here and they tell me she's here then I came in to do it, but I was not lucky about permanent, they give me 12 months, so now it's taken away, but I'm not in a rush to renew it, I'm just going to take it, I'm not getting any money, what I'm going to do you know, I just want to stay and see how people around me are going to react when I'm not getting disability grant. Maybe sometimes at home you get support because you are getting money, you know there are families who are like that, so I just want to check now if now that I'm not getting a disability grant how they are going to treat me, my family. I just want to be supported, not to support myself you know.

INTERVIEWER:

Tell me, do you think the nurses that shout at you also shout at other patients as well or do they mainly shout at patients who are on ARVs, what do you think?

PARTICIPANT:

I never heard a patient who couldn't, not yet eat ARVs complaining, I always hear the ARVs complaining. I never heard the ones who are positive who are not on ARVs complaining. I never heard, maybe they do shout at them, I don't know, but most of the people who are on this drug do get a disability grant so that is a problem of the patients: How did they get it, how did they get that? So you know how we think, we can think negatively, we can think positively you know. Maybe they bribe or they go straight, you know there's a thing like that, here, in [name of centre], there is the thing that you go to see a doctor but you have to pay the one

who sent you to the doctor a R10 or R20 you know, things like that.

INTERVIEWER:

Do you have experience of that?

PARTICIPANT:

Yeess [emphasized]

INTERVIEWER:

Tell me more, did it happen to you?

PARTICIPANT:

No, it happened to my mother, she was here doing it but she had to get R10 for the lady who sent her to the doctor so that she can fill in here in the list.

INTERVIEWER:

Was it a nurse?

PARTICIPANT:

No, no, it was one of those counselling volunteers.

INTERVIEWER:

Did you report it?

PARTICIPANT:

I never report it because once you report something you will be hated, I don't like to be hated you know, I don't want people to judge me, like I'm honest so I keep quiet but we are talking that is wrong, that is wrong or we want to talk but we don't know where to go to talk to, you know, some people to help us, to hear us, about what is our problem.

INTERVIEWER:

You don't feel it's any use talking to the nurses?

PARTICIPANT:

No, it's not any use talking to the nurses because they talk nicely to the health workers working here as a volunteer you know, so they are going to tell them who says this you know.

PAUSE

INTERVIEWER:

You mean then that you feel they might treat you differently?

PARTICIPANT:

Yes, and then you come here looking for service and you are not going to get any service

or maybe you don't know the directions or the way to where you're going so you're looking for directions, she's going to stand there and look at you and not answer you. Sometimes you don't have a chance to come here yourself to fetch your treatment so you send your sister to fetch them so your sister doesn't know the directions and then she come in here to fetch the treatment, she tell the volunteer my name, she recognise my name and not help her, you know, but it's me who done the wrong, it's not my sister, but she will take that to her.

INTERVIEWER:

Is this a Lay health counsellor volunteer who talks like this?

PARTICIPANT:

Yes, people are very wrong here, that's why I always say people who are counselling us they have to know the way we feel not just to counsel us and tell us what to do and not to do.

INTERVIEWER:

Tell me more, do the nurses also talk to you like that?

PARTICIPANT:

Um, they never tell other people about our status, they always, no, no, no, they always say to me when I ask them: hey, you always complain about your rights, so we are doing what you want, we keep your status confidential, it's a confidentiality okay. Some patients don't like people who go for their folders, they like to ask me to help them to look for other peoples folders, so some people don't like that, to see you have their folder, so they stopped that. I told them that some people don't like it when you ask me to look for their folder, do that yourself, so they do it again.

SILENCE

INTERVIEWER:

Do you have any other examples of how the nurses are behaving in a professional or in a non-professional way?

PARTICIPANT:

They are professional, but they would be very professional if they can do what I am asking them to do, to go and visit our homes and see where we are staying and how we are living, they would be very professional, yes, so they are not properly professional now because of that, okay. [Laughs].

PAUSE

INTERVIEWER:

Then my last question to you is: tell me how can the way you are handled at the clinic be improved?

PARTICIPANT:

Okay, about the time we get here, that can be improved. When we get here at 7 o'clock, that by past 7 we get service so you don't have to stay here longer and you don't have to go in 3 rooms when you are here to fetch ARVs, you have to do all those things, taking blood taking blood pressure, your pills, you have to get in the one place, you know, so that the people outside cannot see the difference between our folders and their folders, you know, ja, and if they can find a place here at (name of centre), a big place so that we can get inside and not sitting outside on the bunks so that people can see us that we are here for ARVs.

PAUSE

INTERVIEWER:

You mentioned some other things like helping the sick people first.

PARTICIPANT:

Yes, they can do that, it's going to work, they help the sick people first and then they help the ones who are not sick last, you know.

INTERVIEWER:

And you mentioned the folders that look different.

PARTICIPANT:

Yes, and the folders, like I don't mind exactly about our folders. There are people who asked why are our folders are not the same as theirs. This is my folder, this one is the same as everyone's who was here for blood pressure, sugar diabetes, everything looks like this one, but the one we are given there to go and see [name] so that she can give our treatment is very different.

INTERVIEWER:

Is (name) a nurse?



PARTICIPANT:

She is a pharmacist. So the one is very different, so that is what the people ask: why are these folders not the same as ours?

INTERVIEWER:

You would like your folder not to look different then?

PARTICIPANT:

Yes, I would like that.

INTERVIEWER:

You also mentioned that they promised to give you maybe some soup.

PARTICIPANT:

Yes, they did promise us but they never did, they could give to those who are needy because there are a lot of us who are very poor, to organise us some groceries you know. What I'm saying there's a small place in PE called Walmer, I was asked there why we are not getting groceries, because there each and every person who is HIV-positive is getting a monthly grocery and they told me that I must raise that issue here and then I didn't know where to go here and raise the issue and then I keep quiet but the people who are asking why you are not getting the proper service because we are HIV-positive we are hungry, we are eating ARVs we can't eat ARVs without eating, why don't you get some grocery monthly each and every month, you get your grocery, like maybe some people don't want to be seen, they know our addresses, like organise something for us. They can tell us we found something for you and you are going to get your groceries and then they are going to ask us how are we going to give you your groceries you know, you come with an idea, maybe can you please deliver, make deliveries to our homes because of the transport, we can come here and fetch it we don't mind I live a long way, I come with a car to get here. I pay R5 to get here and R5 to get back home. I don't mind because I'm known I'm here to

get helped.

PAUSE

INTERVIEWER:

Any other examples you can think of about how you are handled at the clinic that can be improved?

PARTICIPANT:

As I was saying they have to check us if we are eating our ARVs properly and if we are not drinking alcohol. I really would like that to be happening because I can see people. I ask myself why you people are getting sick when you are on ARVs, while me I never get sick you know. So I ask them there is something you are doing you are not supposed to do on your stress and they told me we do drink but not a lot of drinks you know, that's the problem. If you stop drinking you'll never get sick. Stop drinking, stop smoking and you'll be good healthy. When you come here the patient is sick, so they should ask how did you get here, who are you with, if the patient tells them I am here alone ask the patient for any family contact numbers so that they can contact the family and ask if there is someone who is available and can come here you know, if you are sick you are not going to answer all the nurses questions, so someone in the family has to be here with you when you are sick. It's their job, the nurses, to call our homes and find the person available to come here with us.

INTERVIEWER:

Do you feel there are not enough nurses, is that why they are not following up on the patients, what do you think?

PARTICIPANT:

There are only 4 nurses, maybe if there can be maybe, if there are 6 they can change things you know, there's too little nurses, like this one is going to write

our folders and take our bloods and this one will do another job, but in the same room not in a different rooms that's what made them to take our time a lot because you come in this room they check your blood pressure and they write in your folder and you go to another nurse, they take another 10 years to write in your folder, ask your problem, ask if you want to see a doctor or not, that's then you go to [name] office to get your treatment, that's another time, if they can do that in one room the service will be very good.

INTERVIEWER:

Anything else you can think of that you've forgotten that you want to tell me?

PARTICIPANT:

I don't think so, I have your number I can call you.

INTERVIEWER:

Yes, you can call me and we can continue our conversation.

PARTICIPANT:

Yes, okay.

INTERVIEWER:

Good, thank you very much for sharing all your feelings and your experiences with me.

PARTICIPANT:

Okay, thanks.

END

**ANNEXURE H**

**LETTER OF REQUEST FOR  
PERMISSION TO CONDUCT A  
RESEARCH STUDY AT INSTITUTION  
ONE**

3 August 2006

Dr E. Hoosain  
Acting Business Unit Manager: Health  
Nelson Mandela Metropolitan Municipality

Dear Dr Hoosain,

**A REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY: THE EXPERIENCES OF PEOPLE LIVING WITH HIV-AIDS AT ANTIRETROVIRAL THERAPY CLINICS IN THE EASTERN CAPE**

I hereby request permission to conduct the above research at ART (Antiretroviral therapy) clinics under your jurisdiction.

I am registered for the degree Magister Curationis in Primary Health Care with the Department of Nursing Science, Faculty of Health Sciences, at the NMMU (Nelson Mandela Metropolitan University), Port Elizabeth. The study is being conducted under the supervision of Mrs E. Ricks and Dr J. von der Marwitz at the University.

The aim of the study is to explore and describe the experiences of people living with HIV-AIDS (PLWAs) regarding stigmatisation. The information will be used to develop guidelines for registered nurses at clinics regarding the prevention or decrease of stigma towards PLWAs.

The research will be based on a qualitative, exploratory, descriptive, phenomenological and contextual research design. In-depth interviews will be conducted with 10 clients as the method of data collection.

Permission is requested to enter the premises of the clinics to approach potential participants as they leave the ART consultation room, when they will be asked whether they are willing to participate in the study. The study will adhere to all the prerequisite ethical and legal considerations.

A copy of the draft proposal is included for your perusal. Please feel free to contact either of my supervisors if you have any ethical or other concerns related to the study. Mrs Ricks: telephone 084 800 1283, or email, [esmeralda.ricks@nmmu.ac.za](mailto:esmeralda.ricks@nmmu.ac.za) or Dr von der Marwitz: telephone 082 463 6825, or email, [jill.vondermarwitz@nmmu.ac.za](mailto:jill.vondermarwitz@nmmu.ac.za).

Thanking you  
Yours faithfully

Dawne S. Jackson  
Cell: 084 570 7170  
Email: [dawndave@absamail.co.za](mailto:dawndave@absamail.co.za)

**ANNEXURE I**

**LETTER OF REQUEST FOR  
PERMISSION TO CONDUCT A  
RESEARCH STUDY AT INSTITUTION  
TWO**

6 October 2006

Mr T. Oliver  
District Manager  
Department of Health  
Nelson Mandela Bay

Dear Mr Oliver,

**A REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY: THE EXPERIENCES OF PEOPLE LIVING WITH HIV-AIDS AT ANTIRETROVIRAL THERAPY CLINICS IN THE EASTERN CAPE**

I hereby request permission to conduct the above research at ART (Antiretroviral therapy) clinics under your jurisdiction.

I am registered for the degree Magister Curationis in Primary Health Care with the Department of Nursing Science, Faculty of Health Sciences, at the NMMU (Nelson Mandela Metropolitan University), Port Elizabeth. The study is being conducted under the supervision of Mrs E. Ricks and Dr J. von der Marwitz at the University.

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The research will be based on a qualitative, exploratory; descriptive, phenomenological and contextual research design. In-depth interviews will be conducted with 10 clients as the method of data collection.



Permission is requested to enter the premises of the clinics to approach potential participants as they leave the ART consultation room, when they will be asked whether they are willing to participate in the study. The study will adhere to all the prerequisite ethical and legal considerations.

Attached please find a letter from the NMMU Research Ethics Committee (Human), dated 12 September 2006, stating that my proposal has been approved by the Committee.

A copy of the proposal is included for your perusal.

Please feel free to contact either of my supervisors if you have any ethical or other concerns related to the study.

Mrs ricks: telephone 084 800 1283, or email, [esmeralda.ricks@nmmu.ac.za](mailto:esmeralda.ricks@nmmu.ac.za) or  
Dr von der Marwitz: telephone 082 463 6825, or email, [jill.vondermarwitz@nmmu.ac.za](mailto:jill.vondermarwitz@nmmu.ac.za)

Thanking you  
Yours faithfully

Dawne S. Jackson  
Cell: 084 570 7170  
Email: [dawndave@absamail.co.za](mailto:dawndave@absamail.co.za)

**ANNEXURE J**

**LETTER TO CERTIFY EDITING**

200 Fodyce Rd  
Walker  
6070  
14th May 2009

To Whom it may concern

This is to certify that I edited and proofread  
Dawn Jackson's dissertation.

Yours faithfully

RA Batcherlor  
(Mrs) R. A. Batcherlor  
(tel) 041-581-1231